

## Quality of Life and Intellectual Disabilities: Implementing the POS Scale in a case study

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### Abstract

This paper sheds light on the combination between Quality of Life and Adulthood, focusing on the analysis of a case study. The considerations concerning the theoretical framework of reference, or the epistemological frame of the Quality of Life, allow to draw the more or less satisfactory perceptions on the life of an adult with intellectual disabilities, aiming to log regressions and improvements after a longitudinal trail that lasted two years.

**Keywords:** Quality of Life, Intellectual Disabilities, POS Scale, Case Study

### Introduction

In recent years the concept of Quality of Life was structured within the framework of social policies and educational projects, becoming the milestone for the planning of effective interventions and for organizing quality services (Schalock, Verdugo Alonso, 2006; Gomez *et al.*, 2013; Van Loon *et al.*, 2013).

The growing interest within studies in the field of special pedagogy lead to the in-depth investigation on the aspects of Quality of Life of people with disabilities, becoming, in this domain, one of the most investigated perspective in the field of intellectual disabilities (Schalock *et al.*, 2010; Simões & Santos, 2017; Scott & Haverkamp, 2018). In this direction, the scientific literature extends to the point of entering the dimension of ageing (Efklides *et al.*, 2006; Crespo *et al.*, 2012; Prieto-Flores *et al.*, 2012), education, (Faragher & Ommen, 2017), mental and physical health (Goksel Karatepe *et al.*, 2011) and, more recently, Quality of Life in the family (Boehm & Carter, 2019), stretching out as far as becoming a tangle of definitions and implemented measures of cross-cultural nature (Verdugo &

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Schalock, 2001; Jenaro *et al.*, 2005; Schalock *et al.*, 2005, 2008; Verdugo, Arias & Gómez, 2006; Verdugo, Gómez, Arias & Martin, 2006).

The starting point, shared by international scientists, is the report by Schalock *et al.* (2002), considered a «manifesto» (Giaconi, 2015, p. 14) of the construct of Quality of Life, as it proposes a multidimensional model applicable to the services for the person, allowing the professionals to use a common language and share the planning criteria. Schalock *et al.* (2002) specify «Quality of life might best be viewed as a sensitizing concept (rather than a definitive one) relevant to public policy determination; evaluation of services; and development of innovative local, national, and international programs» (Schalock *et al.*, 2002, p. 458). This direction avoids what Taylor (1994) defined «tyranny of the Quality of Life» to happen that is: «The more the concept is defined the more you register a loss of meaning (...) which prescribes lifestyles and limiting personal freedom and satisfaction» (Taylor, 1994, p. 264).

Based on these assumptions, the next paragraphs will introduce the theoretical framework of the Quality of Life, to measure and apply the construct in a case study. The involvement of the Anffas's structure of Macerata made possible to monitor chronologically the Quality of Life of an adult subject with intellectual disability. Her perception has been deduced using the tool called Personal Outcomes Scale. The scale was deployed in a first phase in 2017 and again, after two years, in 2019. The flow outlined by the Quality of Life perceived by the subject during the two years pushed our reflection toward conclusive observations focused on taking charge of adults with intellectual disabilities.

### Theoretical framework

In the effort to go beyond the debate concerning the nature of the factors affecting the welfare of the person, whether subjective (e.g. perception of well-being) or objective (e.g. elimination of poverty), the reflection on the Quality of Life is pushed towards the description and understanding of its essential dimensions. Specifically, the theoretical principles introduced by Schalock *et al.*, regarding *conceptualization*, *measurement*, and *application* (Brown, Keith & Schalock, 2005; Schalock, 2005; Verdugo *et al.*, 2005; Schalock, Gardner & Bradley, 2007) represent the scientific bases of the construct.

The *conceptualization* principle provided the foundation of Quality of Life, affirming that its multidimensionality includes: «positive values and life experiences; has the same concepts for all people; has both subjective and

objective components; and is enhanced by self-determination, resources, purpose in life, and a sense of belonging» (Schalock, Gardner, & Bradley, 2007, p. 3).

The model is composed of domains, indicators and descriptors that can be measured in three levels: personal, functional and social (Schalock, Verdugo Alonso, 2006; Giaconi, 2015). The main consensus in the international literature (Schalock, Parmenter, 2000; Schalock *et al.*, 2002) on the Quality of Life is recorded in the following fields: Emotional Well-being, Interpersonal Relationships, Material Well-being, Personal Development, Self-determination, Social Inclusion and Rights. All these domains represent the entire construct and, therefore, can be considered the most relevant dimensions in the lives of all people.

As affirmed by Schalock et al. (2016) Quality of Life is

*«a multidimensional phenomenon composed of core domains that constitute personal well-being. These domains are influenced by personal characteristics and environmental factors. One's Quality of Life is the product of these factors and can be impacted positively through quality enhancement strategies that encompass developing personal talents, maximizing personal involvement, providing individualized supports, and facilitating personal growth opportunities»* (Schalock *et al.*, 2016, pp. 4-5).

The indicators can be defined as «Perceptions, behaviours or conditions that reflect the Quality of Life of a person, real or perceived» (Schalock, Verdugo Alonso, 2006, p. 67). The following criteria must be met when choosing a marker, which can define a domain: validity, reliability, sensitivity, specificity and sustainability related to the person (i.e. various in terms of values and subjective perception) and with cultural sensitivity (Schalock, Verdugo Alonso, 2006). Finally, the construct is further operationalized through the identification of descriptors which are «the behaviours or observable situations relevant to the context of reference» (Giaconi, 2015, p. 23).

In this articulation, the concept of Quality of Life allows to identify «the meaningful markers of a life with quality» and «to target resources to maximize positive effects» (Schalock, Verdugo Alonso, 2006, p. 57). This also allows to identify, through different types of assessments, in addition to individual aspects and environmental situations, the systems of values and beliefs that play an important role in the life of everyone (Brown & Brown, 2009; Schalock, Gardner & Bradley, 2007).

The conceptualization component allows the *measurement* principle that offers a quantitative method of evaluation. The process of measuring a person's Quality of Life considers the degree to which people have life

experiences, taking into account «the domains that are often contributory to a person's life, the environmental contexts (including physical, social, and cultural), and both common and unique experiential occurrences» (Schalock, Gardner, & Bradley, 2007, p. 3). Therefore, measuring is essential to implement the concept of Quality of Life, because it unavoidably interferes with the results and, consequently, the educational choices related to the subject with disabilities. Specifically, the measuring of the Quality of Life does not rely only on the perspectives of the construct, but also on the ecological, holistic and personal perspectives, building a measurement model characterized by the assumption of several theoretical precautions. The latter include «material achievements, stability of human institutions, social ties and life opportunities» (Schalock, Verdugo Alonso, 2006, p. 256), and everything that acquires value for the single person. Principles and guidelines to be beared in mind to make valid measuring are multiple and should «have a clearly articulated use; (...) be a guide for personal, service, or policy enhancement rather than a classification of individuals, services, or systems» (Verdugo *et al.*, 2005, pp. 707-717).

Approaching the measurement of the Quality of Life is affected by a multiple methodology and a perspective capable to reflect the multidimensional model. Nevertheless, a general agreement exists at the present time, about the urgent need of investigating the best ways of measuring and evaluating the Quality of Life concept, lending special attention to both objective and subjective circumstances (Gómez *et al.*, 2007; Goodley, Armstrong, Sutherland, & Laurie, 2003; Schalock *et al.*, 2010; Verdugo *et al.*, 2010; Giaconi, 2015).

In conclusion, the Quality of Life *application* component is represented by a set of guidelines, indicated for people with disabilities and also for all providers of services and families with children/adult with disabilities. The application, strongly influenced by the conceptualization and measurement of the construct of the Quality of Life, includes aspects such as enhancing well-being across cultural contexts; forming the basis for interventions and supports; supporting evidence-based findings; and mandating its inclusion into all professional education and training protocols (Schalock, Gardner, & Bradley, 2007).

This contribution belongs to the theoretical framework proposed by Schalock et al. (2002), it recognizes the importance of the approach of Quality of Life in the *lifespan* perspective of people with intellectual disability. Our choice has been directed in this direction both for the recognition at the international level of the proposal and for the scientific validation that distinguishes the construct.

## Measurement and Application

Before entering the details of the analysis of the Quality of Life in our case study, we introduce briefly the methodology used. Our choice, to detect the Quality of Life of the person, fell on the instrument called Personal Outcomes Scale (POS) (Van Loon *et al.*, 2008). Specifically, to impact the field of intellectual disabilities, POS development has been guided by three trends: reframing quality; assessing personal outcomes based on a validated quality of life conceptual and measurement framework; and involving multiple stakeholders in the process of selecting relevant quality of life-related indicator items, administering the assessment instrument, and developing and using the final instrument and resulting data (van Loon, Van Hove, Schalock, & Claes, 2009).

The POS is based on a conceptual framework, which assumes the multidimensional character of the Quality of Life concept, and a measurement framework proposed by Schalock and colleagues (2002; 2006; 2010). Many international studies validated the scale to assess the Quality of Life of people with disabilities, intellectual disabilities and without disabilities (De Windt & Lannau, 2009; Van Havere, 2011; Van Hove *et al.*, 2011; Guàrdia-Olmos *et al.*, 2017). The instrument has been proved to have a satisfactory reliability and is therefore considered to be a valid way to measure an individual's Quality of Life.

The Italian version of the Scale has been adapted, elaborated and validated in accordance with the Italian context (Jenaro *et al.*, 2005; van Loon *et al.*, 2017) through a comparison with the authors of the original version and respecting the guidelines on the properties that a scale on the Quality of Life for people with intellectual disabilities should have (Schalock, Bonham, Marchand, 2000; Finlay, Lyons, 2001; Verdugo, Schalock, Keith, Stancliffe, 2005). The POS evaluate aims to assess Quality of Life in people with intellectual disability on the basis of three factors and eight domains validated in a series of cross-cultural studies: (1) Independence, composed of Personal Development and Self-determination; (2) Social Participation, which includes Interpersonal Relations, Social Inclusion and Rights; and (3) Well-being, which encompasses Emotional Well-being, Physical Well-being and Material Well-being (Jenaro *et al.*, 2005; Schalock *et al.*, 2005; Wang *et al.*, 2010).

The core domains of the Quality of Life refer to the POS: where each domain is composed of six items; for a total of 48. For example, in the domain "Emotional Well-being", there are items: 1. Do you feel secure/protected and at ease in the place where you spend most of the day (do you feel fine with the people with whom you spend most of the day)?; 2. Do you feel you are doing well in the things you do? (for example, in your job, drawing, doing

homework, a game, an exercise)?; 3. How often do you express to others that you love them, that you are fond of them, that they are important to you (for example, do you say or write it, or show it with kisses, hugs or caresses)?; 4. Are you a happy person?; 5. Are you satisfied/pleased of how things go in your life, i.e. you do not have particularly serious worries?; 6. Do you really trust the people who are important for you (for example, family, friends, staff of the frequented structure, i.e. operators)?.

Each item on the POS is evaluated on a 3-point Likert-type Scale. Outcomes are obtained from every dimension. The sum of all of the scores from the six items is obtained using the following calculation: 3 = always, 2 = sometimes and 1 = rarely or never. After the dimensions of every factor are totalled, a final score is calculated for each factor (Guàrdia-Olmos *et al.*, 2017; van Loon *et al.*, 2017). The total score goes from 6 to 18, with a theoretical average of 12. The strategy of raw scores cannot be the criterium for the bases of evaluation of the Quality of Life for a person with intellectual disability. In fact, evaluation must be respectful of the values and aspirations of the subject. During the survey it is also possible to insert notes, comments and impressions that emerge in a free flow from the respondent. To give added meaning to the scores of a single individual it is necessary to evaluate the Quality of Life indexes from the intersection of the data of the total raw scores in the self-assessment scale (provided by the individual) with those coming from the hetero-evaluating scale (of a caregiver) (van Loon *et al.*, 2017).

The Scale administrators, who can be educators, psychologists, psychiatrists/neuropsychiatrists, social workers, must have attended a training regarding the theoretical model and proper administration of the scale (van Loon *et al.*, 2017).

The POS Scale turns out to be a very versatile tool that allows programming interventions focused on the person, providing a complete picture to make eventual organizational changes. The use of this methodology is to provide general information on the on-going Quality of Life of an individual, without becoming the criterium on which establish the evaluation of his/her Quality of Life.

### *Introducing the case*

This study is a case study for the interesting development of the experience conducted (Smith & Osborn, 2003; Zappella, 2018), in order to describe and analyse the Quality of Life perceived by an adult with disabilities. Specifically, we considered the case in the caregiving of the daily centre

Anffas of Macerata. The study evaluates the POS Scale (self-assessing) data submitted to a 46 years old female with minor intellectual-relational disabilities, a rare genetic syndrome and associated eating disorders. We bring to the centre of reflection and debate the uniqueness of the situation lived by the person, to organize its perceptions and analyse the data obtained. The administration of the scale and the output of data, allow to outline a full profile related to the Quality of Life of a person with disabilities, becoming, in an wide mode, a useful tool for all operators of services to the people, orienting the educational projects. The aim of administering the POS, which overcomes the formulation of a judgement, attempts to increase the understanding of the personal situation, with the intent of improving the care for the person and focusing on the possible attainable results. Therefore, the use of the scale investigates a complex situation, through a qualitative survey, allowing to go beyond the opinions of the administrations, to concentrate on the data obtained, able to understand a 'phenomenon' through the perceptions that the person attribute to their experiences.

*Methodological Procedure: administration of the scale*

Data was collected over a period of two years to monitor the evolutive trend of the Quality of Life of the adult with disabilities. Data collection, in 2017 and 2019, was done with direct interviews with the subject, for the completion of the POS Scale. The completion of all the items of the scale, in both years, was done with two sessions of about one hour each. The consistent duration follows the need of the subject to have her personal rhythm, and the longer time needed to understand the request and formulate the answer. The tendency of the subject to digress on personal stories was recorded in several occasions, for this reason we chose to open a room for expression beyond the contents required by the single items. We wanted to foster an open and trusting climate, to facilitate the expression of the thoughts and ideas of the subject with disabilities. The criteria used for the choice of the administer were: having spent a reasonably long time with the subject and having shared with the subject significant moments of her life. During the 2019 submission, the same procedure was implemented, however, the interviewer was changed. This choice responded the need to avoid the expectation, by the person, of answers that would be "expected".

*The data*

In 2017 the self-assessing POS Scale outlined a perception of the Quality

of Life of the person within a range of 10-18, specifically, the least satisfactory domain was the one of "Rights" (p. 10).

The subject answered negatively "Never" to these items: "Are you free to leave and come back from the house, apartment or structure where you live when you want?"; "Can you have a boyfriend or girlfriend, if you want?"; "Do you vote at the local or national elections?". These items caused the lowering of the perception of the person in this domain.

The domains of "Personal Development" and "Self-determination" reached the average threshold, both have the score 12. Often, in most of the items the answer was "Sometimes", as it happened to the questions concerning personal development: "Do you have a chance to put into practice how much you can do? To show that you can do certain things?"; "Do you use technological items like, computer, cell phone, DVD reader, sound system, I-Pod, microwave oven, washing machine?"; and in some of the items of self-determination: "Can you make choices?"; "Do you make choices if you are given the chance of choosing?".

"Social Inclusion" reached the score of 13. "Often" was stated in the items: "Do you talk (communicate) personally or by phone with the people next to you, do you visit them?"; "If you see the people from your town/quarter or neighbourhood, do you know them? How many of them?"; "Do you use the services in the place where you live or the opportunities of your area?". "Sometimes" was the answer for "Do the people from your town/quarter or neighbourhood do things for you like, invite you to their home for coffee or lunch, visit you, keep you company when alone, accompany you where you need to go?". "Rarely": "Do you help your neighbours (people of your area) when they need you?"; "Do you do activities with people from your town/quarter or neighbourhood like going shopping, eat out, go to shopping malls, go to fun places?".

The person perceived the domain "Physical Well-being" as satisfactory p. 14. To the question "How often do you practice physical exercise or sport?" the person answered "Often"; also, the item "Do you rest and relax enough and have some free time to relax or rest?" received a positive answer. The question "How is your health going? How do you physically feel?" had a lower result "Average"; "Do you eat healthily, i.e. eat healthy and varied foods, do not skip meals, eat at regular times and in adequate quantities?" obtains the answer "Sometimes".

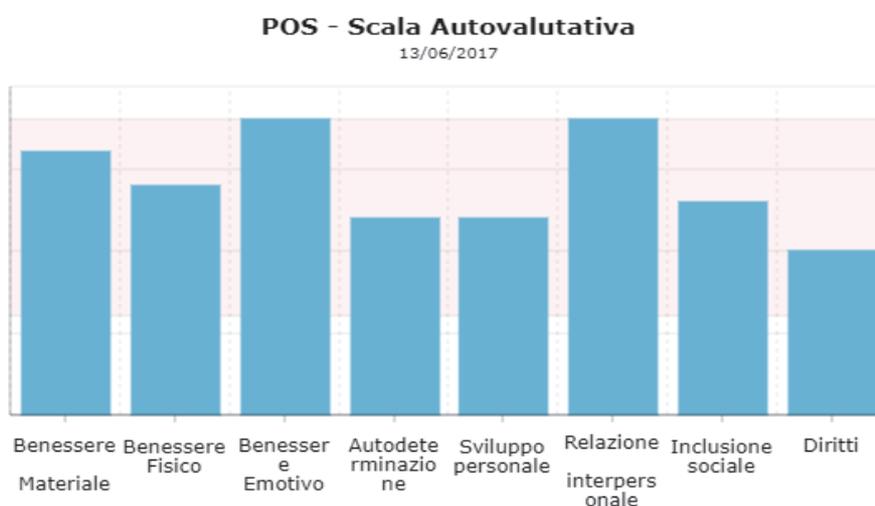
The domain "Material Well-being", reaching the score 16, takes a meaningful threshold of success. All items have a positive result, with the exception of "Do you have a paid job?", to which the subject answered "Never". This response is the only one that negatively affects the perception of the person in this domain.

“Emotional Well-being” and “Interpersonal Relationships” reach a score of 18, thus representing the domains that reached the highest threshold of perceived quality. All the items are satisfactory with positive answers.

Generally speaking, the profile of Quality of Life created allows to plot a trail that outlines a general picture that is satisfactory on the subject side. The flow realized is regular, with the highest peak reached in the domains “Emotional Well-being” and “Interpersonal Relationships”, while the lowest score was in “Rights”, which was nevertheless within the average range.

The following figures (1, 1.1) contain, with an histogram and a web, the profile of Quality of Life of our case in 2017.

Fig. 1 - Histogram. POS- Self-assessment. 13/06/2017 (see the English translation in the note)<sup>1</sup>



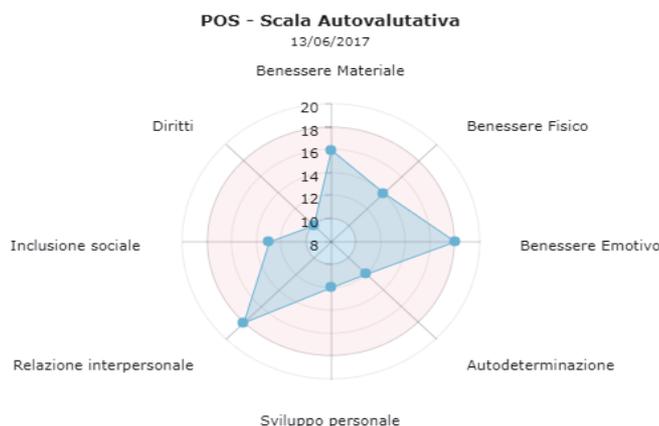
The profile of Quality of Life for 2019 shows an overall satisfactory picture for the person. In relation to the scores obtained, the submission of the scale shows a range within the average, from a lowest score of 10 to a highest of 18.

The domain “Rights” scores the lowest level of satisfaction by the subject. In fact, it scores 10, standing below the average (12), but still within the range (6-18). Denoting a low quality perception, the subject answered negatively to the items: “Are you free to leave and comeback from the house, apartment or structure where you live when you want?”; “If you want, can you have a

<sup>1</sup> *Benessere Materiale* “Material Well-being”; *Benessere Fisico* “Physical Well-being”; *Benessere Emotivo* “Emotional Well-being”; *Autodeterminazione* “Self-determination”; *Sviluppo Personale* “Personal Development”; *Relazioni Interpersonali* “Interpersonal Relationships”; *Inclusione Sociale* “Social Inclusion”; *Diritti* “Rights”.

pet?"; "Can you have a boyfriend or girlfriend, if you want?"; "Do you vote at the local or national elections?".

Fig. 1.1 - Web. POS- Self-assessment. 13/06/2017 (see the English translation in the note)<sup>2</sup>



The domain "Social Inclusion" score a total of 11: "Rarely" was the answer used for the item "Do you help your neighbours (people of your area) when they need you?"; the remaining items reach the frequency "Sometimes".

The score 13 is reached in the domain "Personal Development". All the items the frequency value "Sometimes", except the item: "Do you Have a chance to put into practice how much you can do?" whose answer was "Often". Overall the satisfaction degree is fair, standing above the average (12).

The domains "Material Well-being" and "Interpersonal Relationships" receive a total score of 16, showing a good degree of satisfaction for the person. The domain "Material Well-being" shows items with positive answers: "Always" is the most common statement. The only exception concerns the item: "Do you have a paid job?" to which the subject attributes "Never". For the domain "Interpersonal Relationships" the items that condition the perception of the subject negatively are: "How often do you participate to social activities with friends and acquaintances?"; "How often do you talk to your friends personally, by phone or write e-mails?" to which the person answers "Sometimes".

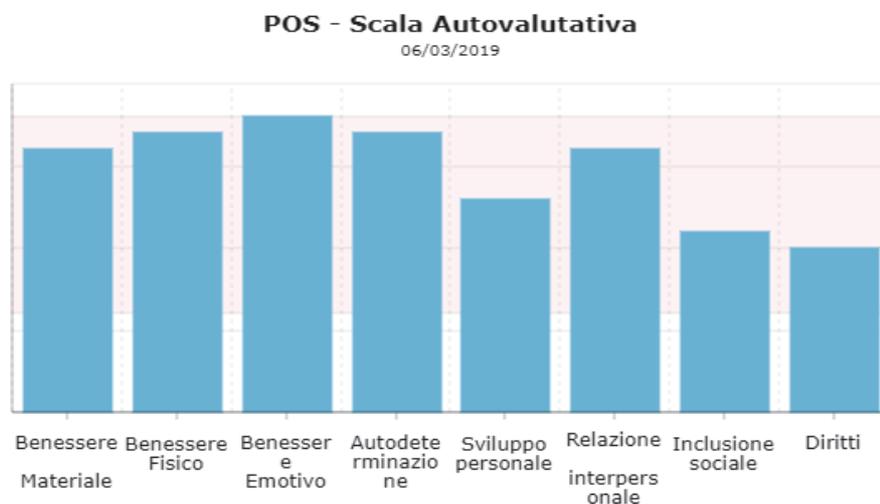
<sup>2</sup> *Benessere Materiale* "Material Well-being"; *Benessere Fisico* "Physical Well-being"; *Benessere Emotivo* "Emotional Well-being"; *Autodeterminazione* "Self-determination"; *Sviluppo Personale* "Personal Development"; *Relazioni Interpersonali* "Interpersonal Relationships"; *Inclusione Sociale* "Social Inclusion"; *Diritti* "Rights".

The score 17 is given to “Physical Well-being” and “Self-determination”. Both of them do not reach the highest score but prove a meaningful degree of satisfaction of the subjects for these items. Elaborating on these perceptions, “Self-determination” receives the frequency “Sometimes” on the item “Can you decide not to do something you have been asked to do?”; this is the only answer showing a minor degree of satisfaction. In the domain “Physical Well-being” the item receiving the frequency “Sometimes” is the following: “Are you worried about getting sick, being sick or experiencing pain?”, in this case too this is the only exception recorded.

The most satisfactory domain is “Emotional Well-being” with the highest degree of 18, which it receives in all the answers, that is “Always”.

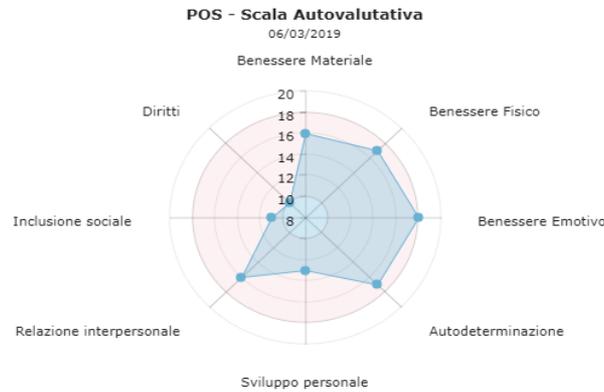
The scores obtained in each domain, which give rise to the evolution of the Quality of Life of the case considered, recorded in the year 2019, are shown in the histogram and web figures (2, 2.1), which follow. Generally speaking, the majority of the domains stand above the average range of 12. The Quality of Life profile obtained allows to outline an overall satisfactory picture for the person.

Fig. 2 - Histogram. POS- Self-assessing Scale. 06/03/2019 (see the English translation in the note)<sup>3</sup>



<sup>3</sup> *Benessere Materiale* “Material Well-being”; *Benessere Fisico* “Physical Well-being”; *Benessere Emotivo* “Emotional Well-being”; *Autodeterminazione* “Self-determination”; *Sviluppo Personale* “Personal Development”; *Relazioni Interpersonali* “Interpersonal Relationships”; *Inclusione Sociale* “Social Inclusion”; *Diritti* “Rights”.

Fig. 2.2 - Web. POS- Self-Assessing Scale. 06/03/2019 (see the English translation in the note)<sup>4</sup>



*Data discussion: the main issues that emerged*

The longitudinal research has allowed us to grasp the most significant changes and the dynamics that have occurred in the period of time studied. The case studied shows in two years a satisfactory perception of the subject’s own Quality of Life, which is always within the range 10-18. In the two-year period the most consistent improvements were in the following items, “Personal Development” (from 12 to 13 points), “Self-determination” (from 12 to 17 point) and “Physical Well-being” (from 14 to 17 points); the domains “Rights” (10 points) “Emotional Well-being” (18) and “Material Well-being” (16) were unchanged; while we recorded a regression in the domains concerning “Interpersonal Relations” (from 18 to 16 points) and “Social Inclusion” (from 13 to 11 points).

The elements and factors that led to an increase or decrease of the Quality of Life perceived by the subject are interesting. The first meaningful element is “Personal Development”. To the question “Do you Have a chance to put into practice how much you can do?”, in 2017, the subject declared “Sometimes”, reaching a more consistent frequency in 2019; specifically, the person affirms that she “Often” helps other people with disabilities in the day-care centre, especially in practice of dressing themselves. The mutual aid has been reinforced with the time by the team that gives care the person; since the

<sup>4</sup> *Benessere Materiale* “Material Well-being”; *Benessere Fisico* “Physical Well-being”; *Benessere Emotivo* “Emotional Well-being”; *Autodeterminazione* “Self-determination”; *Sviluppo Personale* “Personal Development”; *Relazioni Interpersonali* “Interpersonal Relationships”; *Inclusione Sociale* “Social Inclusion”; *Diritti* “Rights”.

subject showed in some cases uncertainty in her actions, the team preferred to value the potentialities of the person by giving positive feedbacks while she supported other people, rather than focusing on the difficulties or shortcomings.

The domain “Self-determination” recorded a significant increment over the time. In 2017, the subject answered “Sometimes” to the question “Do people take your decision seriously?”, but in 2019 she declared “Always”. It appears that in the past the family decided for her what to buy or to wear, while, now the subject explains that she is always given the opportunity to express her preferences concerning different aspects of her life and that now they are accepted in the family as important. Therefore, the maturation of the subject caused a different responsible attitude, characterized by an increased consideration of her choices.

Considering the domain “Physical Well-being” the growth has been considerable over the two years. The eating disorders, that mark the case, push family and the caregiving centre to pay more attention to the subject’s physical well-being. The main concern of the person, who expresses a deep awareness of her weight and her “obsession” with the food, relates with the diet, she admits: it is “difficult to resist temptations”, affirming that to resist them “I should not see them”. After two years, she affirms that she eats “Always” healthily, at regular times and appropriate quantities.

The domain of “Interpersonal Relationships” reached considerable peaks in 2017, but had a regression in 2019. To the question “How often do you participate to social events like going out, eating, going to parties, dining or dancing with friends or acquaintances?”, the person answered “Often” in 2017, and “Sometimes” in 2019. To “How often do you talk to your friends personally, by phone or write e-mails?”, likewise, in 2017 the subject answered “Often”, while in 2019 there was a regression, affirming “Sometimes”.

In the reconstruction of “Social Inclusion”, it emerges that the person had a qualitative decrease in the domain. In the questions “Do you talk (communicate) personally or by phone with the people next to you, do you visit them?”; “If you see the people from your town/quarter or neighbourhood, do you know them? How many of them?”; “Do you use the services in the place where you live or the opportunities of your area?” the answers present a meaningful passage from “Often” in 2017 to “Sometimes” in 2019.

By questioning the qualitative decrease of domains concerning relational contacts and social inclusion, additional words leaked by the subject manifestations that are leaked from the subject's additional words can manifest important meanings. “In the apartments building where I lived before the earthquake”, people used to do activities with her, meeting her and

spending important amounts of time. Later on, after the earthquake, the person and her family had to move house, due to this passage her friendships were compromised, manifesting attachment to past places, but also to the people who represented a constant relational point of reference for her.

The process of relocating the person, which in the specific case happened from one place to another together with the family, but which could be generalized as the passage from the familiar place to a residential structure or anyway to the insertion in alternative situations planned for the “After Us”, turns out to be for subjects with intellectual disabilities a difficult experience. As sustained by Giaconi (2015) «it is a leap that marks, sometimes, a detachment from the relational and community life place for the subject» (Giaconi, 2015, p. 75). The cause may lie in the fact that social inclusion is a complex dimension that is not fulfilled by the simple relocation of people (Schalock & Verdugo Alonso, 2006). When changes occur only at the level of residential and physical environment, the effect could be circumscribed within the new environment, detaching the subject from the surrounding relational context. Schalock e Verdugo Alonso declare that «it is necessary to provide learning opportunities in new conditions so that the person can become more competent and more independent within a broader social group (...)» (Schalock & Verdugo Alonso, 2006, p. 156). The “place” and the “time” in which the person is included, properly negotiated and shared with her, should always have an “educational” character, that is the new contexts should be able to provide relational opportunities and moments of personal fulfilment (Giaconi, 2015).

For these reasons, the knowledge of the paradigm of Quality of Life on its practical use, through the POS measurements, produced important question in Anffas’s structure already in 2017 which opened the doors to the possibility to rethink and re-organize the educational practices and the caregiving on the bases of the needs that emerged. Important considerations sprung up on the necessity to align the modes of action and the needs of the person with disabilities, in order to improve their living conditions. We therefore conclude that POS, for the changes and opportunities that it generated, apart from the general consensus it obtained with the team as a pertinent methodological tool, resulted very apt to measure the paradigm of the Quality of Life as a social construct and unifying them concerning the operational practices.

## Conclusions

Over the recent years, the scientific literature has stressed the crucial importance of the construct of the Quality of Life, also for people with

disabilities, as a guidance in making administrative and educational choices in the community practices. The introduction of such paradigm in the communities/centres for people with disabilities, allowed to make more explicit and aware the goals of the educational behaviour aimed to the well-being and the protection of the dignity. The identification of the significant predictors for a qualitative life, contributed greatly to the reorganization of the services, that have been moved into the promotion of a design focused on the person and an afterthought of the implementing programs in relation to the results obtained from the perceptions of the subject. In fact, the relevance that the assumption of Quality occupies in the life of everyone stresses on its concrete application, assuming, for those who act for the person with disabilities, the connotation of the goal to be pursued.

The reflections that rose during this research and the results obtained demonstrate the usefulness of the Quality of Life construct, articulated as: notions raising awareness about a qualitative life design; a construct capable of activating verifications on the situation and perception of the subject; point of reference to initiate practices aimed at a more dignified life. Having recorded the paradigm of the Quality of Life, using the POS Scale, allowed to safeguard the administration of the construct from fall in the dangerous practice of prescribing a lifestyle. The use of this specific tool has contributed to the construction of a complete and comprehensive vision about a life of quality characterizing a subject with disabilities. In fact, the considerations arisen could be generalized or presented in other subjects with disabilities, even in the awareness of the extreme subjectivity of each case.

The methodological adequacy of the scale is found in the quality of the data provided, related to the degree in which the examined person has lived meaningful life experiences, and in having provided reflections in different areas of reference. In fact, the POS has investigated, with validation and sensitivity, all the necessary domains needed for a dignified life, causing important considerations related to themes concerning the “Interpersonal Relationships” and “Social Inclusion” in adulthood.

To direct the projects of life, from the first taking charge of the subject under the sign of a better Quality of Life, means to carry out a constant work of reflection of the modalities and the practices, which are activated in the different contexts of reference, in order to operate towards an unequivocal direction. Starting from these assumptions, the considerations of the special pedagogy reached a moment of re-thinking in the planning of the direction of the life paths of the person with disabilities, where the paradigm of the Quality of Life represents the core capabilities that direct the entire walk of life of each person. Identifying information on the promotion and qualitative change of the lives of people with disabilities, means directing the design of

the existential path towards the development of participatory and collaborative programmes, aimed to achieve personal goals in an inclusive living environment in the community, where role, value and social function are attributed to the person (Striano, 2010; Balboni *et al.*, 2013; Ciani, 2017; Zappella, 2018). In this direction, the Quality of Life depends also on the services ability to create significant networks with families and professional roles that operate in the structures (Giaconi, 2012). «The perspective of the project of life requires to work within a network, or to work to create links and opportunities for communication between different entities (be they people, agencies and resources), that can converge towards a shared action» (Zappella, 2018, p. 209). As suggested in another work (Giaconi, Del Bianco, 2017) we want to underline that the structuring of potential paths is based on the needs of a specific person with disabilities, in relation to his/her reference contexts and in line with his/her life project.

## References

- Balboni G., Coscarelli A., Giunti G., & Schalock R.L. (2013). The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies. *Research in Developmental Disabilities*, 34(11): 4248-4254.
- Boehm T.L., & Carter E.W. (2019). Family Quality of Life and Its Correlates Among Parents of Children and Adults With Intellectual Disability. *American Journal on Intellectual and Developmental Disabilities*, 124(2): 99-115.
- Brown I., Brown R.I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6: 11-18.
- Brown I., Keith K.D., & Schalock R.L. (2005). Quality of life conceptualization, measurement, and application: Validation of SIRG-QOL consensus principles. *Journal of Intellectual Disabilities Research*, 48: 451.
- Crespo M., Bernaldo de Quiros M., Gomez M. M.; Hornillos C., (2012). Quality of Life of Nursing Home Residents with Dementia: A Comparison of Perspectives of Residents, Family, and Staff. *Gerontologist*, 52(1): 56-65.
- Ciani A. (2017). Progettare interventi e servizi educativi per il “dopo di noi”: educare all’autodeterminazione. *Studium Educationis*, XVIII(3): 149-150.
- De Windt E. & Lannau S. (2009). *Vergelijking van de Kwaliteit van Bestaan van mensen met een verstandelijke beperking met andere burgers uit de Zeeuwse samenleving* (Ongepubliceerde masterproef). België: Universiteit Gent.
- Efklides A., Varsami M., Mitadi I., Economidis D. (2006). Health Condition and Quality of Life in Older Adults: Adaptation of QOLIE-89. *Social Indicators Research*, 76(1): 35-53.

- Finlay W. M., & Lyons E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13(3): 319-335.
- Faragher R., Ommen M.V. (2017). Conceptualising Educational Quality of Life to Understand the School Experiences of Students With Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 14(1): 39-50.
- Giaconi C. (2012). *Nella comunità di Capodarco di Fermo: Dalle pratiche all'assetto pedagogico condiviso*. Roma: Armando.
- Giaconi C. (2015). *Qualità della vita e adulti con disabilità. Percorsi di ricerca e prospettive inclusive*. Milano: FrancoAngeli.
- Giaconi C., Del Bianco N. (2017). Paths and Technologies in the Life Project of People with Disabilities: International Perspectives and Educational Potential. *Research on Education and Media*, 10(2): 40-54.
- Goodley D., Armstrong D., Sutherland K., & Laurie L. (2003). Self-advocacy, learning difficulties, and the social model of disability. *Mental Retardation*, 43(3): 149-160.
- Goksel Karatepe A., Kaya T., Gunaydn R., Demirhan A., Ce P., Gedizlioglu M., (2011). Quality of Life in Patients with Multiple Sclerosis: The Impact of Depression, Fatigue, and Disability. *International Journal of Rehabilitation Research*, 34(4): 290-298.
- Gómez L.E., Verdugo M.A., & Arias B. (2007). *Validation of the eight-domain model of quality of life*. Presentation at the ISQOL Conference: International Society for Quality-of-Life Studies. San Diego, CA, December 6-8.
- Gómez L.E., Verdugo M.A., Arias B., Navas P., Schalock R.L. (2013). The development and use of provider profiles at the organization and systems level. *Evaluation and Program Planning*, 36: 80-87.
- Jenaro C., Verdugo M.A., Caballo C., Balboni G., Lachapelle Y., Otrebski W., Schalock R.L. (2005). Cross-cultural study of person-centred quality of life domains and indicators: a replication. *Journal of Intellectual Disability Research*, 49(10): 734-739.
- Guardia-Olmos J., Carbó-Carreté M., Peró-Cebollero M. & Giné C. (2017). Item response theory analysis applied to the Spanish version of the Personal Outcomes Scale. *Journal of Intellectual Disability Research*, 61(11): 1021-1033.
- Prieto-Flores M.E., Moreno-Jimenez A., Fernandez-Mayoralas G., Rojo-Perez F., Forjaz M.J., (2012), The Relative Contribution of Health Status and Quality of Life Domains in Subjective Health in Old Age. *Social Indicators Research*, 106(1): 27-39.
- Schalock R.L. (2005). Introduction and overview to the special issue on quality of life. *Journal of Intellectual Disability Research*, 49: 695-698.
- Schalock R.L., Bonham G. S., & Marchand C.B. (2000). Consumer based quality of life assessment: A path model of perceived satisfaction. *Evaluation and Program Planning*, 23: 77-88.
- Schalock R.L., Bonham G.S. & Verdugo M.A. (2008). The conceptualization and measurement of quality of life: implications for program planning and evaluation

- in the field of intellectual disabilities. *Evaluation and Program Planning*, 31: 181-90.
- Schalock R.L., Brown R., Cummins R.A., Felce D., Matikka L., Keiyh K.D., Parmeter T. (2002). Conceptualization, Measurement, and Application of Quality of Life for Person With Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40(6): 457-470.
- Schalock R.L., Gardner J.F., & Bradley V.J. (2007). *Quality of life for people with intellectual and other developmental disabilities: Applications across individuals, organizations, communities, and systems*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock R.L., Keith K.D., Verdugo M.A., & Gómez L.E. (2010). Quality of life model development and use in the field of intellectual disability. In: Kober R. (Ed.). *Enhancing quality of life for people with intellectual disability: From theory to practice* (pp. 17-32). New York: Springer.
- Schalock R.L., & Verdugo M.A., (2002). *Handbook on Quality of Life for Human Service Practitioners*. Washington DC: American Association on Mental Retardation.
- Schalock R.L., & Verdugo M.A. (2006). *Manuale di qualità della vita. Modelli e pratiche di intervento*. Brescia: Vannini Editoria Scientifica.
- Schalock R. L., Verdugo M.A., Jenaro C., Wang M., Wehmeyer M., Jiancheng X., et al. (2005). A cross-cultural study of QOL indicators. *American Journal on Mental Retardation*, 110(4): 298-311.
- Schalock R.L., Verdugo M.A., Gomez L.E., & Reinders H.S. (2016). Moving Us Toward a Theory of Individual Quality of Life. *American Journal on Intellectual and Developmental Disabilities*, 121(1): 1-12.
- Schalock R.L. & Parmenter T. (2000). Preface. In *Quality Of Life: Its Conceptualization, Measurement, and Application, A Consensus Document*. IASSID: Washington.
- Scott H. M., & Haverkamp S. M. (2018). Comparisons of self and proxy report on health-related factors in people with intellectual disability. *British Journal of Learning Disabilities, Online Early*, 31(5): 927-936.
- Simões C. & Santos S. (2017). The Impact of Personal and Environmental Characteristics on Quality of Life of People with Intellectual Disability. *Applied Research in Quality of Life*, 12(2): 389-408.
- Smith J.A., & Osborn M. (2003). Interpretative phenomenological analysis. In: Smith J.A. (ed.). *Qualitative Psychology* (pp. 51-80). London: Sage.
- Striano M. (ed.) (2010). *Pratiche educative per l'inclusione sociale*. Milano: FrancoAngeli.
- Taylor S. J. (1994). In support of research on quality of life, but against QOL. In: Goode D. (ed.). *Quality of life for persons with disabilities: International perspective and issues* (pp. 260-265). Brookline, MA: Cambridge.
- Van Havere T. (2011). *Onderzoek naar kwaliteit van bestaan en onafhankelijke cliëntondersteuning bij gebruikers van ADO Icarus vzw en Zewopa vzw. Onderzoeksrapport*. Gent, België: Hogeschoo.

- Van Hove E., Vandeveldel S., Claes C., van Loon J., Verschelden G., & Van Hove G. (2011). Samenvatting 'behoefteonderzoek naar personen met een handicap en personen met een chronische ziekte in gent'. *Stad Gent*. Geraadpleegd via <http://www.gent.be>.
- van Loon J.H.M., Van Hove J., Schalock R.L., & Claes C. (2008). *Personal outcomes scale*. Gent, Stichting Arduin, Universiteit Gent.
- van Loon J., Van Hove G., Schalock R.L., & Claes C. (2009). *Personal Outcomes Scale: Administration and Standardization Manual*. Middelburg, the Netherlands, Stichting Arduin and Gent, Belgium, University of Gent.
- van Loon J.H.M. Gordon S.B., Peterson D.D., Schalock R.L., Claes C., Decramer A.E.M. (2013). The use of evidence-based outcomes in systems and organizations providing services and supports to persons with intellectual disability. *Evaluation and Program Planning*, 36(1): 80-87.
- van Loon J.H.M., van Hove G., Schalock R.L., Claes C. (2017). *POS-Personal Outcomes Scale*. Versione italiana. *Protocollo* (Adattamento italiano di A. Coscarelli e G. Balboni). Gussago, Brescia: Vannini Editoria Scientifica.
- Verdugo M.A., Arias B., & Gómez L.E. (2006). Escala integral de medición subjetiva y objetiva de la calidad de vida en personas con discapacidad intelectual. In: Verdugo M.A. (Dir.). *Como mejorar la calidad de vida de las personas con discapacidad. Instrumentos y estrategias de evaluación* (pp. 417-448). Salamanca: Amarú.
- Verdugo M.A., Gómez L. E., Arias B., & Martin J.C. (2006). *Validation of the eight domain model of quality of life*. Presentation at the symposium on quality of life outcomes: Their empirical development, verification, and use. International symposium on social inclusion, Montreal, CA, May 2-6.
- Verdugo M.A., Gómez L.E., Arias B., & Schalock R.L. (2010). The Integral Quality of Life Scale: Development, Validation, and Use. In Kober R. (Ed.). *Enhancing quality of life for people with intellectual disability: From theory to practice* (pp. 47-60). New York: Springer.
- Verdugo M.A., Schalock R.L., Keith K.D., & Stancliffe R.J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research*, 49: 707-717.
- Verdugo M.A., & Schalock R.L. (2001). *Cross-cultural survey of quality of life indicators*. Salamanca: Institute on Community Integration, Faculty of Psychology, University of Salamanca.
- Wang M., Schalock R.L., Verdugo M.A. & Jenaro C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. *American Journal of Intellectual and Developmental Disabilities*, 115: 218-233.
- Zappella E. (2018). Quality of life and professional orientation for people with intellectual disability: a case study in Lombardy. *Form@re - Open Journal per la formazione in rete*, 18(3): 207-219.