Education Sciences & Society, 2/2022 ISSN 2038-9442, ISSNe 2284-015X

The Application of Quality of Life in Services for Persons with Intellectual and Developmental Disabilities: Lines of intervention in Spain and Italy

Catia Giaconi, Miguel Ángel Verdugo**, Noemi Del Bianco*, Laura E. Gómez***, Ilaria D'Angelo*, Robert L. Schalock*****

Abstract
The concept of quality of life (QOL) has become a measurable construct of great value to all people, including people with intellectual and developmental disabilities (IDD). In particular, the field of IDD is currently experiencing a paradigm shift related to beliefs, assumptions, policies, and practices concerning people with disabilities and their families and the place and role they play in society. This article starts by reconstructing the state of the art of the application of QOL in Social Services, reconstructing its research developments, operational declinations and influences in social policies in Spain and Italy.

Key words: Quality of life; Supports; Quality of life supports model; Developmental disabilities; Intellectual disability; Social Services

First submission: 01/09/2022, accepted: 16/11/2022

1. Introduction

Schools and services are called upon to design inclusive environments and educational opportunities (United Nations, 2006; World Health Organisation, 2001), which guarantee a better Quality of Life (QOL) for persons with disabilities (IDD) and their families.

---

* University of Macerata.
** INICO. Universidad de Salamanca.
*** Universidad de Oviedo.
**** Hastings College, University of Nebraska (United States).

Doi: 10.3280/ess2-2022oa14963

Indeed, enhancing one’s Quality of Life (QOL) is the prerequisite to guarantee the establishment of contexts, services and policies capable of ensuring the full and active participation of persons with IDD.

Starting from these considerations we will focus our attention on Quality of Life as a framework for the construction of inclusive design (Giaconi & Del Bianco, 2018). The importance of this reflection lies in systemic and ecological actions that require significant skills in terms of observation and reading of contexts, identification of barriers and facilitators in the design of individualised and personalised supports that can guarantee the participation of each person, taking into account the differences in available resources and opportunities.

The 2030 Agenda for Sustainable Development (ONU, 2015) has strongly called for the need to design environments that ensure that every person has access to institutions, resources and opportunities to live fully in society, respecting (and guaranteeing) present and future generations. The various types of intervention aimed at making educational contexts accessible are developed through an interdisciplinary design approach capable of interacting with the complexity that characterises today's living contexts.

This requires that attention is given to reasonable accommodation and supporting people with IDD with flexibility and consistency across different needs and inequalities. Improving one’s QOL requires understanding the epistemological model of QOL and applying QOL guidelines targeted to educational and instructional designs in different contexts. This we do in the following three sections of this article. We conclude the article by discussing the design of adult life pathways for people with IDD.

2. The Quality of Life Supports Model

The field of intellectual and developmental disabilities (IDD) is currently experiencing a paradigm shift relative to beliefs, assumptions, policies, and practices regarding people with disability and their families, and the place and role they play in society (Schalock et al., 2022). A basic component of this new paradigm incorporates the *Quality of Life Supports Model* (QOLSM; Gómez et al., 2021a, 2021b; Verdugo et al., 2021). This new paradigm, inclusing the QLSM, is replacing the historical paradigm that emphasized defectology, segregation, devaluation, and facility-based services with a community-based approach.

As explained by Gómez et al. (2021b), the QOLSM consolidates core values related to social-ecological model of disability; the capacity and potential of individuals to grow and develop (Nussbaum, 2011; Wehmeyer, 2013); the new disability rights paradigm created by the Convention on the Rights of Persons with Disabilities (United Nations, 2006) that emphasize legal, economic, social, and cultural rights (Claes et al., 2016; Esteban et al., 2021; Gómez et al., 2020, 2021b; Harpur, 2012; Lombardi et al., 2019; Mittler, 2015; Morales et al., 2021; Verdugo et al., 2012); the emphasis on context, self-determination, inclusion and equity (Morán et al., 2019; Schalock et al., 2020; Shogren et al., 2021; Vicente et al., 2019; Wehmeyer, 2020); the use of best practices and value-based outcomes-based evaluation (Gómez et al., 2012, 2022; Gómez & Verdugo, 2016; Schalock et al., 2011); and the commitment to address a person's support needs and foster opportunities to enhance individual functioning and personal well-being (Buntinx et al., 2018; Schalock et al., 2021a; Thompson et al., 2015, 2016).

The use of a conceptual and measurement framework such as the QOLSM provides a systematic approach to the evaluation process, providing an excellent opportunity for collaborative efforts among people with IDD, advocates, supports providers, relatives, researchers, and policy makers, keeping in mind a person-centered research approach that focuses on what is relevant to the person (Gómez et al., 2021b).

In this way, the QOLSM unites WHAT is important (people's QOL) with HOW to achieve it (supports). As we detail in the next sections, both essential constructs on which the new paradigm is based – QOL and supports –, each in its own way, have been an important shock in the field of disability, giving rise in recent years to important advances in people with disabilities' lives, improvements in the organizations that provided them supports and changes in society's attitudes.

2.1. Quality of Life

The concept of QOL has evolved from being a generic expression related to sociological analysis to materializing in a measurable construct of great value for people with IDD. In the eighties and nineties of the last century, several researchers from different countries began practical applications of the QOL concept linked to deinstitutionalization experiences. The call for an increased emphasis on the QOL of people with IDD lead to the development of a set of guidelines regarding the concept of QOL and its measurement. These guidelines emphasized that the conceptualization and measurement of the QOL concept should: (a) focus on the abilities and capabilities of people with IDD; (b) involve a collaborative effort among stakeholders, including people with IDD; (c) recognize people with IDD and their families are the best judges of their QOL; (d) use multiple reliable and valid methods and multiple sources to assess or measure QOL.

At the beginning of the 21st century, Schalock et al. (2002) published a consensus document regarding principles underlying the conceptualization, measurement, and application of the QOL concept.

- *Conceptualization principles* were that QOL is multidimensional and influenced by personal and environmental factors and their interaction; has the same components for all people; has both subjective and objective components; and is enhanced by self-determination, resources, purpose in life, and a sense of belonging.
- *Measurement principles* were that measurement in QOL involves the degree to which people have life experiences that they value; reflects the domains that contribute to a full and interconnected life; considers the contexts of physical, social, and cultural environments that are important to people; and includes measures of experiences both common to all humans and those unique to individuals.
- *Application principles* were that QOL application enhances well-being within cultural contexts and should be evidence-based; and that QOL principles should be the basis for interventions and supports, and take a prominent place in professional education and training.

The efforts materialized in the international research of the two previous decades were synthetized in a multidimensional proposal known as the QOL model by Schalock and Verdugo (2002), in which QOL is composed of wight intercorrelated domains (i.e., emotional well-being, physical well-being, material well-being, self-determination, social inclusion, personal development, rights, interpersonal relationships). The QOL domains just referenced reflect the QOL concept's universal property, a clear focus on the individual, and application principles related to equity, inclusion, self-determination, empowerment, and valued outcomes. The domains also provide a framework for policy development, supports planning, and outcome evaluation. Thus, as a critical element of the QOLSM, QOL domains can be used to guide collective efforts and provide measurable indicators to test the QOLSP.

Since then, intensive and rigorous work has been carried out to develop QOL instruments by INICO at the University of Salamanca, which continues to this day. The scales developed have become an international reference for measuring QOL, and their application by professionals and social organizations has become widespread. Likewise, the application of the concept has made it possible to accompany and guide transformation processes of organizations towards inclusive goals and the exercise of the rights of people with IDD.

2.2. Supports

Since the introduction of the concept of supports in the definition of intellectual disability in 1992 (Luckasson et al., 1992), its implementation has impacted the field of IDD in numerous ways like: (a) the use of standardized support need scales (e.g., Stancliffe et al., 2016; Thompson et al., 2015, 2016); (b) the development of support standards (e.g., Buntinx et al., 2018); (c) the implementation of personal support plans that align an individual's support needs, personal goals, support strategies, and valued outcomes (e.g., Schalock et al., 2018a); and (d) the implementation of horizontally structured support teams that develop user-friendly support plans (e.g., Reinders & Schalock, 2014).

Systems of supports are a key component of the QOLSM. Support models, such as the QOLSM, focus on the fit between people and their environments, and approach disability as the expression of limitations in functioning within a social context. Support models posit further that: (a) disability is neither fixed nor dichotomized but rather flexible, depending on the person or family's strengths and limitations and the supports available within the environment; and (b) one can mitigate the effects of one's disability by designing interventions, services, and supports based on collaborative participation and an understanding of disability that comes from lived experience and knowledge (Amor et al., 2020; Baker et al., 2016; Schalock et al., 2018b, 2021a; Thompson et al., 2009, 2014).

According to Schalock et al. (2021a), systems of supports are a broad range of resources and strategies that prevent or mitigate a disability or its effects; promote the development, education, interests, and welfare of individuals with IDD or their families; and enhance individual or family functioning and well-being. Through the planning and delivery of a broad range of resources and strategies, they can also be used to guide the collective efforts regarding support provision, organization transformation, and systems change.

Application of the supports paradigm results in one's ability to assess the pattern and intensity of support needs and using this information for subgroup classification, aligning support needs to support strategies, and identifying and operationalizing systems of support elements (Gómez et al., 2021b). In this sense, AAIDD and INICO have also made an intensive work of development and adaptation of standardized assessment of support needs (e.g., Aguayo et al., 2019; Amor et al., 2021; Claes et al., 2009; Dizdarevic et al., 2020; Thompson et al., 2015, 2016; Verdugo et al., 2020).

3. QOL in Social Services: Research, Organizations Applications and Public Policy

3.1 The State of the Art in Spain

The advances of recent decades have had a huge impact in Spain in different scenarios and levels of the system, although there are still unresolved issues or that still need to be addressed with courage and determination (Verdugo, 2018). We are in the midst of a paradigm shift, which revolves around the abilities, potentialities, personal goals and rights of people with disabilities, and which has important implications, not only for our educational conceptions, but also for the science, politics,literature, economics, religion, and even our conceptions of the non-human world (Maslow, 1968).

At the *microsystem level*, in recent decades, it can be seen in Spanish society the outstanding advances in competence and specialization of many professionals and the advanced level of organization and political representation achieved by organizations, family members and committed professionals. However, the road has only just begun, as families must acquire a greater role in the lives of their children, and professionals must move towards a more community role, increasing their skills and interdisciplinary collaboration.

Over the last three decades, many professionals have benefited from postgraduate training and retraining opportunities that did not exist before in university settings, such as the master’s degrees on inclusion and QOL developed by INICO, which provide insight into the most current and innovative models, along with experiences most relevant national and international support organizations. In turn, support organizations have intensely and extensively promoted the learning of evaluation and intervention strategies from applied research and accredited professional experience (Lacasta, 2015; Tamarit, 2015). A clear example of the training received is the progressive application of support from a person-centered planning approach, which has resulted in better professional practices and better results for people with IDD.

A pending challenge is the transformation of the traditional professional role towards an approach more linked to inclusion in the community and less to exclusively person-centered responses within the center itself: professionals must support people with IDD by providing them with new opportunities and building social networks in their natural environment to facilitate inclusion and a meaningful life plan, with constant and renewable goals. For this, professional and social values (such as dignity, respect, equity, empowerment, self-determination, inclusion, rights) are fundamental that are identified with positive principles and rules of conduct, that represent great individual ethics towards people and that determine the good practices of professionals, organizations and public policies (Schalock et al., 2018c; Verdugo, 2011). Another pending task for professionals is to promote and apply evidence-based practices (Schalock et al., 2011, 2016, 2017; van Loon et al., 2013), as well as to increase the transmission of knowledge from experience, publishing what works and what does not work and promoting critical reflection.

For their part, relatives have been increasing their participation from the exclusive, traditional and permanent role of the mother to the effective activation of fathers and siblings. Relatives have played an important role in the development and consolidation of support organizations in Spain, but they have remained largely relegated in individual support programs and in decision-making on essential aspects for the future of their relatives. Today their voice about support needs and priorities is essential. So much so that public policies should regulate the participation of people with IDD and their families to guarantee their rights (Gómez et al., 2021b).

At the *mesosystem level*, together with the extensive growth of services and the consolidation of many Spanish organizations, there is also a commitment to the development of good practices, the transformation of the services offered and their quality. A clear exponent is the transformation process promoted by *Plena inclusion*, which proposes person-centered services centered, giving relevance to the role of full citizenship (Gómez et al., 2022), personalized support and opportunities for inclusion (Schalock et al., 2021b), while advising organizational change processes with a consulting network (Lacasta, 2015; Tamarit, 2015). However, there is still significant resistance from some organizations to progress towards a community model. The causes of this resistance are diverse: lack of appropriate information and training, insecurity and fear of change, lack of financial incentives from administrations, personal and organizational interests, comfort and apathy...

The strategy to overcome this situation of resistance to change is to promote a model focused on values, rights and the context (Gómez et al., 2022; Schalock et al., 2018c; Schalock & Verdugo, 2013, 2019; Shogren et al., 2021; Verdugo et al., 2012, 2017). The responsibility of professionals is essential, who must know the United Nations Convention on the Rights of Persons with Disabilities and the QOLSM, be well trained in evidence-based practices, act in accordance with an ethical code, exercise critical thinking and support people with IDD in achieving their vital project in their natural community environment (Schalock & Keith, 2016). In the same way, the commitment to quality systems (e.g., EFQM and ISO standards) together with the focus and values of the QOLSM constitute an important compass in Spain to maintain the north in the person and valued personal outcomes (Schalock et al., 2016; 2018c; Verdugo et al., 2017).

At the *macrosystem level*, there is a great contradiction between the speech that is pronounced and the actions that must be carried out: we know that it is correct and profitable to identify with people with disabilities and their needs (they use and abuse their image), but the administrations do not act accordingly when it comes to providing resources and regulating appropriately with laws and regulations that encourage the changes that must be implemented. Those responsible for central and regional Spanish public policy tend to commit exclusively to changes in regulations, but rarely to real change in the streets (Turnbull & Stowe, 2017), leaving organizations and their professionals defenseless in their implementation. When programs, regulations or commitments are established, they must entail resources for their implementation and translation into concrete indicators that allow their evaluation, since another of the main shortcomings of the actions of the Spanish administrations is the lack of concern for evaluating the results of their actions. A basic requirement for the credibility of those responsible for public policy is the development of a culture of evaluation that contributes to improving the analytical rigor of advances in the well-being of people with IDD and their social inclusion (Rodríguez, 2015).

The time has come to demand a shift in general strategic planning, synchronizing the principles from which it is based (e.g., rights), the means available (e.g., supports) and the results that are pursued (e.g., QOL). From a holistic perspective focused on the QOLSM, a reference framework should be established that integrates and aligns the goals of public policy with valued personal outcomes (Gómez et al., 2022; Lombardi et al., 2019; Verdugo et al. al., 2012).

Finally, organizations and systems must make decisions so that the resources can go more and more directly to the families and people with IDD, as well as to involve other entities (e.g., unions, foundations, cultural associations, etc.) to manage and weave a natural network of support from society itself, without monopolizing the exclusive responsibility of providing support, since disability is a matter for the whole of society (Verdugo, 2018).

3.2 *Guidelines for the design of a Quality of Life: Italian overview*

Personal services in the Italian context move toward greater awareness about models of human functioning and the construct of supports (Cottini et al., 2008) or people to lead independent lives (Law 112/2016) and to improve their QOL (Giaconi, 2015), in line with international scientific references (Amor et al., 2020; Buntinx & Schalock, 2010; Buntinx et al., 2018; Esteban et al., 2021; Schalock & Verdugo, 2013).

Despite the growing awareness about the need to ensure that people with IDD have life projects oriented to QOL models, the focus of the scientific training communities remains on aspects related to the training of personal services professionals (Giaconi et al., 2022). The reflection still is both in terms of knowledge and use of QOL models and in terms of assessment procedures and guidelines for design that can take into consideration the person in different life contexts and throughout the life span.

In the area of research and training, in the Italian context, two focuses have been most investigated: evaluation procedures, with a focus on the adoption of triangulation methodologies that can ensure a timely starting design profile (D'Angelo, 2020; Del Bianco, 2019; Giaconi, 2015), and alignment practices (Giaconi, 2015). Assessment and alignment represent the most significant interest in personal services, since they can guide individualized educational planning, life projects and inclusive practices, as well as social, health and educational policies for people with disabilities, especially for people with IDD.

The QOL construct being sensitive to both synchronic and diachronic dimensions allows thinking actions from an ecological and longitudinal perspective (Giaconi, 2015). Therefore, the design work must be declined on alignment plans concerning three progressive levels: micro-level, meso-level and macro-level to increase well-being conditions.

At the microsystem level, alignment occurs in several stages. First, it enters into the merits of the construction of the Individualized Education Project for the person with disabilities, and second, it relates the Individualized Education Project to one's Individual (Interministerial Decree n. 328/2000). The microsystem level, in the Italian context, is realized through work conducted by multiple professionals and is embodied by taking into account the following steps: (1) taking charge; (2) assessment or initial evaluation; (3) ecological assessment[1]; (4) definition of general goals and specific objectives; (6) planning of supports[2]; (7) supports and support activities; (8) ongoing monitoring; (9) evaluation of outcomes. These steps enable the preparation of an individualized educational design that aligns the description of functioning profiles and perceived needs with supports that could increase the domains of QOL.

---

[1] The ecological balance sheet consists of a pattern of analysis of individual conditions of functioning that is used in the detection of outcomes and that guides an understanding of needs, supports referred to life domains.

[2] Supports are the resources and strategies that improve outcomes relevant to the person with disabilities (Schalock et al., 2002).

Specifically, the need is to respond to the continuity of educational planning from a longitudinal perspective to guarantee temporal continuity to the person's existential trajectory in the adult perspective. In this direction, Italian regulations call for the need to align the Individualized Educational Project with the Individual Project. To this end, the QOL construct is increasingly identified as a theoretical-practical framework capable of aligning the languages, practices and expectations of the professionals who draft the two documents, as well as caregivers and the person with disabilities.

At the *mesosystem* level, the first consideration should be the alignment between service principles and QOL domains. The principles that guide the service's purposes go to influence elements such as the structure of the service (spaces, number of employees and people accommodated, schedules), the training of professionals, and the activities and intervention strategies. When considered in conjunction with QOL domains allow for the verification of outcomes of improvement in both the person's intake and the service itself. Operationally, defining this perspective means, for example, taking adult services as a reference, guaranteeing personal spaces of privacy, such as private rooms that can be personalized with objects and photos, which allow for reconstructing a sense of history, present and future. A further exemplification concerns the design of activities, which should be aligned with "adult" ways of working that, in addition to taking into account mental age, are relevant to a life project that promotes the acquisition of an adult identity status (Ferrari et al., 2008; Giaconi, 2015; Ianes & Cramerotti, 2009).

At the *macrosystem* level, Italian legislation (328/2000) ensures that individuals and families are provided with an integrated system of interventions and social services in coherence with Articles 2, 3 and 38 of the Italian Constitution to guarantee: a higher QOL, equal opportunities, non-discrimination and citizenship rights by preventing, eliminating or reducing conditions of disability, need and individual and family hardship, resulting from income inadequacy, social difficulties and constraints of non-autonomy. Specifically, Law No. 328, stipulates in Article 18 that the government shall prepare a National Plan of Social Interventions and Services on a three-year basis. Regarding the structuring of services, the National Plan of Interventions and Social Services 2021-2023 emphasizes the importance of fostering a person-centered approach, which is an organizational approach that shows a comprehensive view of the person by placing his/her needs at the center. The starting point of any socio-educational intervention rests, therefore, on three pillars: the right to a life of dignity for each person, attention to the family context, and the enhancement and care of the living contexts (Caldin & Giaconi, 2021a, 2021b).

Briefly, the guidelines that are followed in the alignment procedures underlying the model-oriented design of QOL are the following (Giaconi, 2015):

- Alignment between the profiles of functioning and the domains of QOL, aimed at designing the necessary supports.
- Alignment between the individualized educational project and the context of reference, with the demands and activities specific to the life context, to design the supports necessary for the active participation of the person with disabilities, specifically with IDD.
- Alignment between national intervention policies and the expectations of the person with disabilities, the family and personal services professionals, to build shared planning that never loses sight of the expectations of the person, the true protagonist of their life project.

4. Conclusions and Future Perspectives

Human rights are the same for everyone, and exercising them is a responsibility of the whole society. What the UN Convention proposes is a mandatory roadmap not only to change norms and regulations but also to transform society. And to transform society we must begin by transforming support organizations, empowering people with IDD and their families, improving professional and organizational practices, and making a qualitative leap in the strategic planning of public policy.

To do this, the first step is to be aware of where we are from the historical evolutionary perspective of the paradigms that have inspired good practices. In the last century evolved from institutional practices towards services in the community. Currently, we are moving from services to individual support in the person’s natural environment.

The second step is to fully implement the QOLSM in the three levels of the system described, advancing in all of them, pursuing the alignment of the efforts made, changing the mental models and encouraging innovation and change, with prudence and security, but without rest. For this, we will need organizations and professionals with the courage to overcome inertia, politicians determined to provide solutions and provide resources, and collaborating researchers committed to improvement processes that provide instruments of evaluation, rigor and analysis in the processes of transformation. As for the training of professionals, specific disciplines attentive to the construction of professional skills in terms of knowledge of the principles, evaluation procedures and educational design focused on the domains of QOL have entered wholly into the undergraduate and postgraduate paths. The aim is to prepare professionals who will have to work in personal services precisely and punctually on the knowledge and application of the constructs of QOL and, therefore, to never lose sight of life projects of the right, even for people with IDD to verge on appropriate levels of QOL.

A final line of thought concerns the design of adult life pathways of people with IDD.

To support the transition into adulthood and overcoming the "After Us" difficulties (when the principal caregivers die or are no longer able to support the person with disabilities) (Giaconi, Socci, et al., 2020), policies and service professionals have to rethink a design that should be focused on “During Us” (start the implementation of adulthood pathway since the principal caregivers are still alive and able to successfully support the person with IDD).

The relevant literature (Gauthier-Boudreault et al., 2017; Lindahl et al., 2019) points out that the lack of systematic transition planning and the limited services for the social inclusion of young adults with disabilities are among the most looming educational needs. To achieve fruitful support for people with IDD and their families, we focus on the regulatory and organizational frameworks that direct the planning actions and the offers of support services to people with disabilities.

Supporting life projects oriented to the QOLSM model also means designing adulthood through experimental paths such as university career, employment, and independent living (D’Angelo, 2020; Del Bianco, 2021; Giaconi et al., 2018; Giaconi, Del Bianco et al., 2020).

In conclusion, based on these reflections, the orientation of practices and policies to the construct of QOL can prove to be the tool capable of fostering, at different levels, conjoint actions of co-responsibility and co-design.

Operating from the perspective of QOL, finally, allows planning to be directed to trajectories of adult life and quality in respect of the values of continuity and sharing, making it possible to build, outside the logic of emergency and welfare, unique and authentic life paths.

References

Aguayo V., Verdugo M. A., Arias V. B., Guillen V. M., & Amor A. M. (2019). Assessing support needs in children with intellectual disability and motor impairments: measurement invariance and group differences. *Journal of Intellectual Disability Research, 63*(12): 1413-1427. Doi: 10.1111/jir.12683.

Amor A. M., Fernandez M., Verdugo M.A., & Schalock R. L. (2020). Shaping the faces of the prism: Rights, supports, and quality of life for enhancing inclusion and opportunities in students with intellectual disability. *Czlowiek, Niepelnosprawnosc, Spoleczenstwo, 49*(3): 5-33. Doi: 10.5604/01.3001.0014.3573.

Amor A. M., Verdugo M. A., Arias B., Fernández M., & Aza A. (2021). Examining the suitability of the list of indicators describing age-related typical support needs. *International Journal of Environmental Research and Public Health, 18*: 764. Doi: 10.3390/ ijerph18020764.

Baker A., Salisbury B., & Collins D. (2016). Changing service delivery systems: An example from Community Living British Columbia. In R. L. Schalock and K.D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual disability* (pp. 149-166). American Association on Intellectual and Developmental Disabilities.

Buntinx W. H. E., Tu Tan I., & Aldenkamp A. P. (2018). Support values through the eyes of the patient: An exploratory study into long-term support for persons with refractory epilepsy. *Epilepsy and Behavior, 82*: 155-163. Doi: 10.1016/j.yebeh.2018.02.031.

Buntinx W. H. E., & Schalock R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(4), 283-294.

Caldin R., & Giaconi C. (2021a). *Disabilità e cicli di vita. Le famiglie tra seduttivi immaginari e plausibili realtà* [*Disability and lifecycles. Families between seductive imaginaries and plausible realities*]. Milano: FrancoAngeli.

Caldin R., & Giaconi C. (2021b). *Pedagogia Speciale, famiglie e territori. Sfide e prospettive* [*Special pedagogy, families and territories. Challenges and perspectives*]. Milano: FrancoAngeli.

Cottini L., Croce L., Fedeli D., & Leoni M. (2008). *La Supports Intensity Scale nel panorama riabilitativo italiano. Standardizzazione italiana e procedure psicometriche*.

Claes C., Van Hove G., Vandevelde S., van Loon J., & Schalock R. (2009). Evaluating the inter-respondent (consumer vs. staff) reliability and construct validity (SIS vs. Vineland) of the Supports Intensity Scale on a Dutch sample. *Journal of Intellectual Disability Research, 53*: 329-338.

Claes C., Vandenbussche H., & Lombardi L. (2016). Human rights and quality of life domains: Identifying cross-cultural indicators. In R. L. Schalock and K. D. Keith (Eds.), *Cross- cultural quality of life: Enhancing the lives of people with intellectual and developmental disabilities* (2nd Ed.) (pp. 167-174). American Association on Intellectual and Developmental Disabilities.

D'Angelo I. (2020). *Pedagogia speciale per i servizi alle persone con disabilità complesse* [*Special pedagogy for services to people with complex disabilities*]. Milano: FrancoAngeli.

Del Bianco N. (2019). *Autodeterminazione nelle persone con disabilità intellettive. Studi, ricerche e questioni di pedagogia speciale* [*Self-determination in people with intellectual disabilities. Studies, research, and issues in special education*]. Milano: FrancoAngeli.

Del Bianco N. (2021). Il Progetto Mongolfiera. Uno spazio e un tempo per diventare adulti. *L'integrazione scolastica e sociale*, *20*(3): 28-51.

Dizdarevic A., Ahmetovic Z., Malec D., Mujezinovic A., Ahmetovic M., Zilic F., & Mehmedinovic S. (2020). Analysis of Factor Validity of the Support Intensity Scale on Bosnian-Herzegovinian Sample. *Advances in Cognitive Psychology, 16*(2): 117.

Esteban L., Navas P., Verdugo M. Á., & Arias V. B. (2021). Community living, intellectual disability and extensive support needs: A rights-based approach to assessment and intervention. *International Journal of Environmental Research and Public Health, 18*(6), e3175. Doi: 10.3390/ijerph180631.

Ferrari L., Nota L., & Soresi S. (2008). Conceptions of work in Italian adults with intellectual disability. *Journal of Career Development*, *34*(4): 438-464.

Giaconi C. (2015). *Qualità della vita e adulti con disabilità. Percorsi di ricerca e prospettive inclusive* [*Quality of life and adults with disabilities. Research pathways and inclusive perspectives*]. Milano: FrancoAngeli.

Giaconi C., Capellini S. A., Del Bianco N., Taddei, A. &, D'Angelo I. (2018). Study Empowerment for inclusion. *Education Sciences and Society*, *9*(2): 166-183.

Giaconi C., & Del Bianco N. (2018). *In azione: Prove di inclusione*. Milano: FrancoAngeli.

Giaconi C., Del Bianco N., D'Angelo I., & Sarchet T. (2022). Famiglie con giovani con disabilità intellettiva profonda e multipla: crisi o rinascita?. *MeTis-Mondi educativi. Temi indagini suggestioni*, *12*(1): 178-195.

Giaconi C., Del Bianco N., D'Angelo I., & Kraus A. (2020). New perspectives for Inclusive University Teaching: EduPlan4Inclusion. *Education Sciences & Society*, *11*(1): 159-168.

Giaconi C., Socci C., Fidanza B., Del Bianco N., d'Angelo I., & Capellini S. A. (2020). Il Dopo di Noi: nuove alleanze tra pedagogia speciale ed economia per nuovi spazi di Qualità di Vita. *MeTis-Mondi educativi. Temi indagini suggestioni*, *10*(2): 274-291.

Giaconi C., Taddei A., & Del Bianco N. (2021). La formazione dell'insegnante specializzato: il "dossier" come interfaccia tra teorie, laboratori e tirocini [Specialized teacher training: the "dossier" as an interface between theories, workshops and internships]. In M. Stramaglia (Ed.), *Abitare il futuro. Politiche per la formazione* (pp. 71-80). PensaMultimedia.

Gomez L. E., Arias. B., Verdugo M.A., & Navas P. (2012). An outcomes-based assessment of quality of life in social services. *Social Indicators Research, 106*: 81-93. Doi: 10.1007/s11205-011-9794-9

Gomez L. E., Monsalve A., Moran L., Alcedo M. A., Lombardi M., & Schalock R. L. (2020). Measurable indicators of CRPD for people with intellectual and developmental disabilities within the framework of quality of life. *International Journal of Environmental Research and Public Health, 17,* 5123. Doi: 10.3390/ijerph1.

Gómez L. E., Morán L., Al-Halabí S., Swerts C., Verdugo M.A., & Schalock R.L. (2022). Quality of life and the International Convention on the Rights of Persons with Disabilities: Consensus indicators for assessment. *Psicothema, 34(2),* 182-191. Doi: 10.7334/psicothema2021.574 7145123.

Gómez L. E., Schalock R. L., & Verdugo M. A. (2021a). A new paradigm in the field of intellectual and developmental disabilities: Characteristics and evaluation. *Psicothema, 33*(1): 28-35. Doi: 10.7334/psicothema2020.385.

Gómez L. E., Schalock R. L., & Verdugo M. A. (2021b). A Quality of Life Supports Model: Six research-focused steps to evaluate the model and enhance research practices in the field of IDD. *Research in Developmental Disabilities, 119,* 104112. Doi: 10.1016/j.ridd.2021.104112.

Gómez L. E., & Verdugo M. A. (2016). Outcomes evaluation. In R. L. Schalock and K. D. Keith (Eds*.), Cross-cultural quality of life: Enhancing the lives of people with intellectual disability (2nd Ed.) (*pp. 71-80). American Association on Intellectual and Developmental Disabilities.

Harpur P. (2012). Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities. *Disability and Society, 27*: 1-14. Doi: 10.1080/09687599.2012.631794.

Ianes D., & Cramerotti S. (2009). *Il piano educativo individualizzato. Progetto di vita* (Vol. 1). Trento: Edizioni Erickson.

Lacasta J. J. (2015). FEAPS, 50 años de unión por las personas con discapacidad intelectual y por sus familias [FEAPS, 50 years of union for people with intellectual disabilities and their families]. *Siglo Cero, 46*(1): 41-65. Doi: 10.14201/scero20154614165.

Lombardi M., Vandenbussche H., Claes C., Schalock R. L., De Maeyer J., & Vandevelde S. (2019). The concept of quality of life as a framework for implementing the UNCRPD. *Journal of Policy and Practice in Intellectual Disabilities, 16*(3): 180-190. Doi: 10.1111/jppi.12279.

Luckasson R., Coulter D. L., Polloway E. A., Reiss S., Schalock R. L., Snell M. E., Spitalnik D. M., & Stark J. A. (1992). *Mental retardation: Definition, classification, and systems of supports (9th ed.).* American Association on Mental Retardation.

Maslow A. (1968). *Toward a psychology of being.* Van Nostrand.

Mittler P. (2015). The UN Convention on the Rights of Persons with Disabilities: Implementing a paradigm shift. *Journal of Policy and Practice in Intellectual Disabilities*, *12*: 79-89. Doi: 10.1111/jppi.12118.

Morales L., Morán L., & Gómez L.E. (2021). Evaluación de resultados personales relacionados con derechos en jóvenes con discapacidad intelectual y TEA [Assessment of rights-related personal outcomes in esar people with autism spectrum disorder and intellectual disability]. *Siglo Cero, 52*(3): 81-99.

Morán L., Gómez L. E., & Alcedo M.A. (2019). Inclusión social y autodeterminación: los retos en la calidad de vida de los jóvenes con autismo y discapacidad intelectual [Social esarroll and self-determination: the challenges in the quality of life of youth with autism and intellectual disability]. *Siglo Cero, 50*(3): 29-46. Doi: 10.14201/scero20195032946.

Nussbaum M. C. (2011). *Creating capabilities: The human development approach.* Belknap Press of Harvard University.

Reinders H. S., & Schalock R. L. (2014). How organizations can enhance the quality of life of their clients and assess their results: The concept of quality of life enhancement. *American Journal on Intellectual and Developmental Disabilities, 119:* 291-302. Doi: 10.1352/1944-7558-119.4.291.

Rodríguez G. (2015). Prólogo [Foreword]. In J. Calero, X. Fontcuberta, and A. García, *Manual práctico de evaluación para políticas públicas en el ámbito de la discapacidad* (pp. 9-12). CINCA.

Schalock R. L., Baker A., Claes C., Gonzalez J., Malatest R., van Loon J., Verdugo M. A., & Wesley G. (2018c). The use of quality of life scores for monitoring and reporting, quality improvement, and research. *Journal of Policy and Practice in Intellectual Disabilities, 15*(3): 176-182. Doi: 10.1111/jppi.12250.

Schalock R. L., Brown I., Brown R., Cummins R. A., Felce D., Matikka L., Keith K. D., & Parmenter T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disability: Report of an international panel of experts. *Mental Retardation, 40:* 457-470. Doi: 10.1352/1944-7558-119.4.291.

Schalock R. L., Gómez L. E., Verdugo M. A., & Claes, C. (2017). Evidence and evidence-based practices: Are we there yet?. *Intellectual and Developmental Disabilities, 55*: 112-119. Doi: 10.1352/1934-9556-55.2.112.

Schalock R. L., & Keith K. D. (2016*.), Cross-cultural quality of life: Enhancing the lives of persons with disability*. American Association on Intellectual and Developmental Disabilities.

Schalock R. L., Luckasson R., & Shogren K. A. (2020). Going beyond environment to context: Leveraging the power of context to produce change. *International Journal of Environmental Research and Public Health, 17*(6): 1885. Doi: 10.3390/ijerph17061885.

Schalock R. L., Luckasson R., & Tassé M. J. (2021a). *Intellectual disability: Definition, diagnosis, classification, and planning supports*. American Association on Intellectual and Developmental Disabilities.

Schalock R. L., Luckasson R., & Tassé M. J. (2021b). Ongoing transformation in the field of IDD: Taking action for future progress. *Intellectual & Developmental Disability, 59*(5): 380-391. Doi: 10.1352/1934-9556-59.5.380.

Schalock R. L., Luckasson R. L., Tassé M. J., & Shogren K.A. (2022). The IDD paradigm of shared citizenship: Its operationalization, application, evaluation, and shaping for tor the future. *Intellectual and Developmental Disabilities, 60*: 426-443. Doi: 10.1352/1934-9556-60.5.426.

Schalock R. L., Thompson J. R., & Tassé M. J. (2018b). *A systematic approach to personal support plans*. American Association on Intellectual and Developmental Disabilities.

Schalock R. L., & Verdugo M. A. (2002). *Handbook on quality of life for human service practitioners*. American Association on Mental Retardation.

Schalock R. L., & Verdugo M. A. (2013). The transformation of disabilities organizations. *Intellectual and Developmental Disabilities, 51*: 273-286. Doi: 10.1352/1934-9556-51.4.273.

Schalock R. L., & Verdugo M. A. (2019). International developments influencing the field of intellectual and developmental disabilities. In K. A. Keith (Ed.), *Cross-cultural psychology: Contemporary themes and perspectives (2^{nd} Ed.)* (pp. 309-323). Wiley-Blackwell.

Schalock R. L., Verdugo M. A., & Gómez L. E. (2011). Evidence-based practices in the field of intellectual and developmental disabilities: An international consensus approach. *Evaluation and Program Planning, 34*, 273–282. Doi: 10.1016/j.evalprogplan.2010.10.004.

Schalock R. L., Verdugo M. A., & Lee T. (2016). A systematic approach to an organization's sustainability. *Evaluation and Program Planning, 56*: 56-63. Doi: 10.1016/j.evalprogplan.2016.03.005.

Schalock R. L., Verdugo M. A., & van Loon J. (2018a). Understanding organization transformation in evaluation and program planning. *Evaluation and Program Planning, 67*: 53-60. Doi: 10.1016/j.evalprogplan.2017.11.003.

Shogren K. A., Luckasson R., & Schalock R. L. (2021). Leveraging the power of context in disability policy development, implementation, and evaluation: Multiple applications to enhance personal outcomes. *Journal of Disability Policy Studies, 31*(4): 230-243. Doi: 10.1177/1044207320923656.

Stancliffe R. J., Arnold S. R.C., & Riches V. C. (2016). The supports paradigm. In R. L. Schalock and K. D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of people with intellectual disabilities* (pp. 133-142). American Association on Intellectual and Developmental Disabilities.

Tamarit J. (2015). La transformación de los servicios hacia la calidad de vida. Una iniciativa de innovación social de FEAPS [The transformation of services towards the quality of life. An initiative of social innovation from FEAPS]. *Siglo Cero, 46*(3): 47-71. Doi: 10.14201/scero20154634771.

Thompson J. R., Bradley V. J., Buntinx W., Schalock R. L., Shogren K. A., Snell M. E., Wehmeyer M. L., Borthwick-Duffy S., Coulter D. L., Craig E. P. M., Gomez S. C., Lachapelle Y., Luckasson R. A., Reeve A., Spreat S., Tassé M. J., Verdugo M. A., & Yeager M. H. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities, 47*: 135-146. Doi: 10.1352/1934-9556-47.2.135.

Thompson J. R., Bryant B. R., Schalock R. L., Shogren K. A., Tasse M. J., Wehmeyer M. L., Campbell E. M., Craig E. M., Hughes C., & Rotholz D. A. (2015). *Supports Intensity Scale – Adult Version User's Manual*. American Association on Intellectual and Developmental Disabilities.

Thompson J. R., Schalock R. L., Agosta J., Teninty L., & Fortune J. (2014). How the supports paradigm is transforming the developmental disabilities service system. *Inclusion, 2*: 86-99. Doi: 10.1352/2326-6988-2.2.86.

Thompson J. R., Wehmeyer M. L., Hughes C., Shogren K. A., Seo H., Little T. D., Schalock R. L., Realon R. E., Copeland S. R., Patton J. R., & Tasse M. J. (2016). *Supports Intensity Scale-Children's Version (SIS-C)*. American Association on Intellectual and Developmental Disabilities.

Turnbull R., & Stowe M. (2017). A model for analyzing disability policy. *Intellectual and Developmental Disabilities, 55:* 223-233. Doi: 10.1352/1934-9556-55.4.223.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. -- https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.

van Loon J. H., Bonham G. S., Peterson D. D., Schalock R. L., Claes C., & Decramer (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. Doi: 10.1016/j.evalprogplan.2012.08.002.

Verdugo M. A. (2011). Dignidad, igualdad, esarrol, esarroll, autodeterminación y calidad de vida [Dignity, equality, freedom, inclusion, self-determination and quality of life]. *Siglo Cero*, *42*(240): 18-23.

Verdugo, M. A. (2018). Conceptos clave que explican los cambios en la esarroll de apoyos a las discapacidades intelectuales y del esarrollo en España [Key concepts and principles that explain changes in the provision of supports for intellectual and developmental disabilities in Spain]. *Siglo Cero, 49*(1): 35-52. Doi: 10.14201/scero20184913552.

Verdugo M. A., Aguayo V., Arias V. B., & García-Domínguez L. (2020). A systematic review of the assessment of support needs in people with intellectual and developmental disabilities. *International Journal of Environmental Research and Public Health*, *17*(24): 9494. Doi: 10.3390/ijerph17249494.

Verdugo M. A., Jenaro C., Calvo I., & Navas P. (2017). Disability policy implementation from a cross-cultural perspective. *Intellectual and Developmental Disabilities*, *55*(4): 234-246. Doi: 10.1352/1934-9556-55.4.234.

Verdugo M.A., Navas P., Gómez L.E., & Schalock R.L. (2012). The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research, 56*(2): 1036-1045. Doi: 10.1111/j.1365-2788.2012.01585.x.

Verdugo M.A., Schalock R.L. y Gómez L.E. (2021). The quality of life supports model: twenty-five years of parallel paths have come together. *Siglo Cero, 52*(3): 9-28. Doi: 10.14201/scero2021523928.

Vicente E., Guillén E. V., Gómez L. E., Ibáñez A., & Sánchez S. (2019). What do stakeholders understand by self-determination? Consensus for its evaluation. *Journal of Applied Research in Intellectual Disabilities, 32*: 206-218. Doi: 10.1111/jar.12523.

Wehmeyer M. L. (2020). The importance of self-determination to the quality of life of people with intellectual disability: A perspective. *International Journal of Environmental Research on Public Health, 17*(19): e7121. Doi: 10.3390/ijerph17197121.

Wehmeyer M. L. (Ed.) (2013). *The Oxford handbook of positive psychology and disability*. Oxford University Press.

World Health Organization (2001). *International Classification of Functioning, Disability and Health*. Ginevra.