THE QUALITY OF LIFE SUPPORTS MODEL: TWENTY FIVE YEARS OF PARALLEL PATHS HAVE COME TOGETHER[1]

El modelo de calidad de vida y apoyos: la unión tras veinticinco años de caminos paralelos

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Abstract: The article presents the operational conjunction of the quality of life and supports paradigms in the new *Quality of Life Supports Model* (QOLSM) that integrates significant characteristics of the current transformation in the field of intellectual and developmental disabilities. These characteristics encompass a holistic and integrated approach, an approach focused on the human and legal rights of people with disabilities, eligibility for services and supports based on significant limitations in major areas of life activity, an emphasis on supports provided within inclusive community settings, and outcome assessment. The objectives of this article are to describe and indicate: (a) the four elements of the MOCA (fundamental values, individual and family quality of life domains, support systems and facilitating conditions); (b) how the MOCA can be used as a framework for the provision of supports, person-centered outcome assessment, organizational transformation and systems change; and (c) how MOCA is essential to the current paradigm shift in the field of Intellectual and Developmental Disabilities.

KEYWORDS: intellectual disability; developmental disabilities; quality of life; supports; model; paradigm; quality of life and supports model.

RESUMEN: El artículo presenta la integración operativa de los paradigmas de calidad de vida y apoyos en un modelo conjunto denominado *Modelo de Calidad de Vida y Apoyos* (MOCA) que integra características significativas de la transformación actual en el campo de las discapacidades intelectuales y del desarrollo. Estas características abarcan un enfoque holístico e integrado, centrado en los derechos humanos y legales, que sirve de base para tomar las decisiones sobre servicios y apoyos en las limitaciones significativas de las principales áreas de actividad de la vida, con un énfasis en los apoyos individualizados proporcionados dentro de ambientes inclusivos de la comunidad y que promueva la evaluación de resultados. Los contenidos de este artículo incluyen: (a) los cuatro elementos del MOCA: valores fundamentales, dimensiones de calidad de vida individual y familiar, sistemas de apoyo y condiciones facilitadoras; (b) cómo se puede utilizar el MOCA como marco para la provisión de apoyos, la evaluación de resultados centrada en la persona, la transformación de la organización y el cambio de sistemas; y (c) cómo el MOCA es esencial para el cambio de paradigma actual en el campo de las discapacidades intelectuales y del desarrollo.

PALABRAS CLAVE: discapacidad intelectual; discapacidades del desarrollo; calidad de vida; apoyos; modelo; paradigma; modelo de calidad de vida y apoyos.

1. Introduction and Overview

OVER THE LAST 25 YEARS two powerful forces have come together to impact how we view and approach people with an intellectual or developmental disability. These two forces are the quality of life concept and the supports model. The concept of quality of life (QOL) provides a framework for policy development, best practices, and outcome evaluation. This is because of the concept's universal nature, values, focus on the individual, and emphasis on valued, person-referenced outcomes. The supports model provides a framework for the planning and delivery of a coordinated set of person-referenced support strategies that prevent or mitigate one's disability; promote the development, education, and interests of the person; and enhance the individual's functioning and personal well-being.
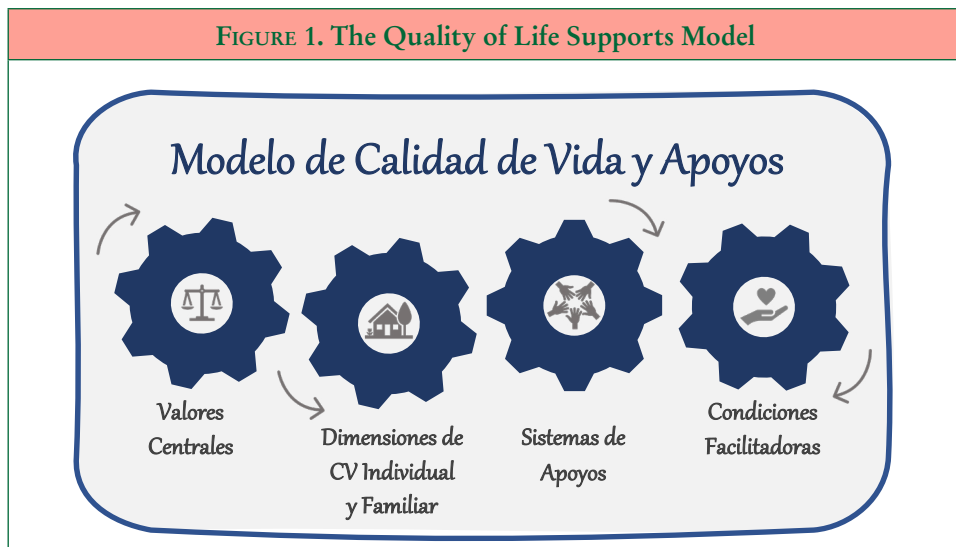
As described in this article, recent work by the authors and others has integrated these two parallel paths into a *Quality of Life Supports Model* (QOLSM) that contributes both theoretically and operationally to the field of intellectual and developmental disabilities (IDD). Theoretically, the model integrates three critical catalysts that bring about positive change in peoples' lives: connections, interactions, and facilitating conditions. The connections a person or a family have with other people, social networks, and technology provide the opportunities to enhance a person or family's well-being and QOL. The interactions that result from these connections provide the systems of supports that facilitate functioning, interests, and well-being. The facilitating conditions that are basic to both the connections and interactions focus on principle-based opportunity development and value-based supports provision.

Operationally, the QOLSM integrates significant characteristics of the current transformation in the field of IDD. These characteristics encompass a holistic and integrated approach to IDD, a focus on the human and legal rights of people with a disability, the eligibility for services and supports based on significant limitations in major life activity areas, an emphasis on individualized supports provided within inclusive community-based environments, and the evaluation of outcomes. Additionally, the conceptual model represents the operational conjunction of the theoretical sub-paradigm of QOL, which is based on accumulated research, and the sub-paradigm of supports as an alternative professional practice to traditional models of rehabilitation (Schalock *et al.*, in press; Schalock & Verdugo, 2019).

The purposes of this article are to describe and illustrate: (a) the four elements of the QOLSM (i.e., core values, individual and family QOL domains, systems of supports, and facilitating conditions); (b) how the QOLSM can be used as a framework for supports provision, person-centered outcome evaluation, organization transformation, and systems change; and (c) how the QOLSM is central to the current paradigm shift in the field of IDD.

2. The Quality of Life Supports Model

A conceptual model facilitates the description and visualization of a phenomenon and includes the critical elements of the phenomenon and how those elements can be used to apply the phenomenon (Gomez *et al.*, 2020a). As depicted in Figure 1, the four critical elements of the QOLSM involve core values, individual and family QOL domains, systems of supports, and facilitating conditions.

FIGURE 1. The Quality of Life Supports Model

Modelo de Calidad de Vida y Apoyos

Valores Centrales — Dimensiones de CV Individual y Familiar — Sistemas de Apoyos — Condiciones Facilitadoras

2.1. *Core Values*

Core values stem from the beliefs and assumptions that people have about individuals with IDD and their individual worth and potential. These core values guide the policies and practices regarding people with IDD and their role in society. Listed below are the core values incorporated into the QOLSM. These core values are described and discussed more fully in the references associated with each.

– Human and legal rights (Claes *et al.*, 2016; Harpur, 2012; Gomez *et al.*, 2020b; Mittler, 2015; Verdugo *et al.*, 2012).
– The capacity and potential of individuals to grow and develop (Nussbaum, 2011; Wehmeyer, 2013).
– The emphasis on self-determination (Schalock *et al.*, 2019; Shogren *et al.*, 2017).
– The universal nature of the multidimensionality of QOL and its emphasis on inclusion and equity for individuals with a disability and their families (Consortium on Quality of Life, 2019; Isaacs *et al.*, 2007; Morán *et al.*, 2019; Schalock & Keith, 2016).
– Commitment to addressing a person's support needs and fostering opportunities to enhance individual functioning and personal well-being (Buntinx *et al.*, 2018; Onken, 2018; Qian *et al.*, 2019).

2.2. *Individual and Family QOL Domains*

Early work by Brown (1993), Goode (1994), Felce (1997), Keith *et al.* (1996), Parmenter (1992), Raphael *et al.* (1996), and Schalock and Verdugo (2002) lead to the development and publication (Schalock *et al.*, 2002) of 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.

Based on this early work and these conceptualization, measurement, and application principles, a number of QOL conceptual models were developed that focused on either individual-referenced or family-referenced QOL. As discussed by Gomez *et al.* (2011, 2020a), the QOL domains encompassing commonly referenced QOL models are quite similar. In Table 1, we list commonly referenced individual and family QOL domains. These domains reflect the QOL concept's universal property, a clear focus on the individual or family, and application principles related to equity, inclusion, self-determination, empowerment, and valued outcomes. The domains also provide a framework for using the QOLSM for supports provision, person-centered outcome evaluation, organization transformation, and systems change.

TABLE 1. Commonly Referenced Individual and Family QOL Domains	
*Individual Referenced QOL Domains**	*Family Referenced QOL Domains***
Personal Development	Parenting
Self-Determination	Family Interactions
Interpersonal Relations	Emotional Well-Being
Social Inclusion	Physical Well-Being
Rights	Disability Related Supports
Emotional Well-Being	Support From Other People
Physical Well-Being	Career Development
Material Well-Being	Community Interaction

*Based on the work of Felce (1997), Petry *et al.* (2007, and Schalock *et al.*, (2016).
**Based on the work of Brown *et al.* (2006), Isaacs *et al.* (2007), Summers *et al.* (2005), and Zuna *et al.* (2010).

2.3. *Systems of Supports*

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. The QOLSM posits further that: (a) disability is neither fixed nor dichotomized but 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 (Schalock *et al.*, in press; Thompson *et al.*, 2014).

Since the introduction of the concept of supports in the 1992 AAMR/AAIDD manual (Luckasson *et al.*, 1992), the concept of supports and its implementation have impacted the field of IDD in numerous ways. Chief among these are: (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.*, 2018b); 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 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. A commonly used grouping of the elements of systems of supports encompass (Schalock *et al.*, in press):

– *Choice and personal autonomy that involve having opportunities to make choices and exercise self-determination, being recognized as a person before the law, and enjoying legal capacity on an equal basis with those without a disability. Choice and personal autonomy are facilitated through decision making supports.*
– *Inclusive environments are those that provide accesses to resources, information, and relationships, encourage growth and development and support people, and accommodate the psychological needs of autonomy, competence, and relatedness.*
– *Generic supports are those that are widely available to the general population, including natural supports, technology, prosthetics, life-long learning opportunities, reasonable accommodation, dignity and respect, and personal strengths/ assets.*
– *Specialized supports are professionally-based interventions, strategies, and therapies.*

As a key element of the QOLSM, systems of supports provide a framework to 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 described in the following section regarding support provision, person-centered outcome evaluation, organization transformation, and systems change.

2.4. *Facilitating Conditions*

Facilitating conditions are operationalized as contextual factors that influence the successful application of the QOLSM. These contextual factors are influenced by—and interact with—properties of the micro, meso, and macro system

(Shogren *et al.*, 2020 and Shogren *et al.*, in press). Additional information regarding the influence of these facilitating conditions on components of the QOLSM can be found in the work of Buntinx *et al.* (2018), Onken (2018), Qian *et al.* (2019), Shogren *et al.* (2020), and The Consortium on Quality of Life (2019).

– *Quality of life facilitating* conditions involve: participation in the community, promoting a sense of belonging, maximizing capabilities and opportunities, freedom to engage in major life activities, safe and secure environments, and a commitment to the goals that are important to the person or family.

– *Support facilitating conditions* involve: understanding the person's support needs, commitment to addressing the person's support needs and enhancing their personal goals, the availability and accessibility of supports, knowledge about the elements of systems of supports, competent/knowledgeable support providers, consistency and stability of supports provision, and coordination and management of supports.

3. Multiple Uses of the QOLSM

The integration of the QOL concept and the supports model into the QOLSM provides a theory-based and professionally-sound framework for supports provision, person-centered outcome evaluation, organization transformation, and systems change. Each of these uses is described in this section of the article. These four uses reflect how the QOLSM can be used by multiple stakeholders to align an individual's support needs with personalized support strategies and valued outcomes, connect practices at the individual level with priorities and missions of organizations, align polices and decision making at the organization and systems level, develop a value-based framework for disability policies, and establish parameters for person-centered evaluation.

3.1. *Supports Provision*

Families, primary care givers, support staff, and teachers are the principle support providers throughout the world. Across these support delivery platforms, three strategies are the most applicable to these individuals who provide supports: (a) an emphasis on QOL, (b) the provision of supports related to choice and personal autonomy, and (c) the provision of those generic supports that are available to any person and can be provided by multiple support providers. These three strategies provide connections, interactions, and facilitating conditions

Emphasis on quality of life. The QOL principles and values related to dignity, equity, inclusion, self-determination, and empowerment reflect the key role that an emphasis on QOL plays in peoples' lives. Incorporating QOL values and principles into interactions with the person assures that support providers realize that one's

QOL, regardless of the extent of limitations, is composed of multiple domains that reflect one's personal well-being; that QOL domains are the same for all people, even though the domains may be valued differently; that one's QOL has both subjective and objective aspects; and that one's QOL is dynamic and subject to change. Additionally, an emphasis on QOL incorporates a holistic approach to the person that enables support providers to 'think beyond the person's disability' and optimize those conditions associated with principle-based opportunities and value-based supports.

Emphasis on choice and personal autonomy. As a systems of supports element, choice and personal autonomy has the ability to mitigate IDD; promote the development, education, and interests of a person; and enhance the individual's and family's functioning and well-being. Exercising one's choice and personal autonomy increases not only one's motivation and satisfaction of psychological needs related to autonomy, relatedness, and competence, but it also lessens maladaptive behavior (Deci & Ryan, 2012). Choice and personal autonomy is also emphasized in Article 12 of the UNCRPD (United Nations, 2006) that establishes the rights of people with disabilities to legal capacity. As discussed by Glen (2015) and Luckasson *et al.* (2017), all people, including those with IDD, have a right to have choices, make their own decisions, and have those choices and decisions recognized legally.

Use of generic supports. Generic supports involve those support strategies that are available to any person, with or without a disability, and can be provided by multiple support providers. Including generic supports as a systems of supports element allows support providers to expand their thinking from using only professional interventions and paid supports to the provision of generic supports that family members, primary care givers, informal support providers, teachers, or individuals themselves can provide. Generic supports include natural supports, technology, prosthetics, education across the life span, reasonable accommodation, dignity and respect, and personal strengths/assets (Consortium on Quality of Life, 2019; Lombardi *et al.*, 2020; Schalock *et al.*, 2019; Stancliffe *et al.*, 2016; Thompson *et al.*, 2009, 2014).

3.2. *Person-Centered Outcome Evaluation*

Both the QOL concept and the supports model are person-centered. Thus, the QOLSM provides a framework for person-centered outcome evaluation, which is the systematic endeavor that aligns core values with a modern understanding of IDD, individualized supports, valued outcomes, and meaningful impacts. This approach to outcome evaluation involves a collaborative partnership among an individual, a human service organization or system, and a team. The purpose of person-centered evaluation is to employ the knowledge, skills, and resources of the partnership to measure and effectively use outcome information to enhance personal well-being, increase transparency, facilitate accountability, and expand understanding (Schalock & Luckasson, 2020).

A logic model can be used to visualize and implement a person-centered approach to evaluation. As described by Schalock and Luckasson (2020), the four components

of a person-centered outcome evaluation model involve input, throughput, outcome, and output.

- – The input component encompasses core values (such as those listed above) plus a functional approach to IDD and a holistic approach to IDD.
- – The throughput component involves systems of supports that are used to incorporate core values into the evaluation framework, maximize QOL and support facilitating conditions, and enhance personal well-being/QOL outcomes.
- – The outcome component focuses on the selection and measurement outcomes associated with individual and family-referenced QOL domains.
- – The output component emphasizes the meaningful impacts of person-centered evaluation on enhancing personal well-being, increasing transparency, facilitating accountability, and expanding understanding.

A person-centered approach to outcome evaluation that incorporates components of the QOLSM is aligned with the values, priorities, and characteristics of the IDD field. Specifically, these characteristics involve a functional and holistic approach to IDD, the social-ecological model of disability, a supports-based service/support delivery system, evidence-based practices, and a focus on valued outcomes (Schalock *et al.*, 2020).

3.3. *Organization Transformation*

Organizations that have implemented one or more components of the QOLSM have changed their policies and practices, and thereby transformed in significant ways. Examples include implementing systems of supports, aligning an individual's support needs with specific support strategies and valued outcomes, connecting practices at the individual or family level with priorities and missions of the organization, aligning QOL and supports-related policies and decision making at the organization and systems level, developing a QOL-supports based framework for policies and practices, and conducting QOL-focused outcome evaluation (Amor, 2019; Amor *et al.*, 2020; Baker *et al.*, 2016; Schalock & Keith, 2016; Schalock & Verdugo, 2013; Thompson *et al.*, 2014).

Organizations transform when they develop new ways of thinking and implement new policies and practices related to their service delivery system. The QOLSM can guide the application of a QOL Supports Delivery System (Reinders & Schalock, 2014). Such a system can be visualized and facilitated through the use of a logic model whose input, throughput, and outcome/output components are shown in Figure 2.

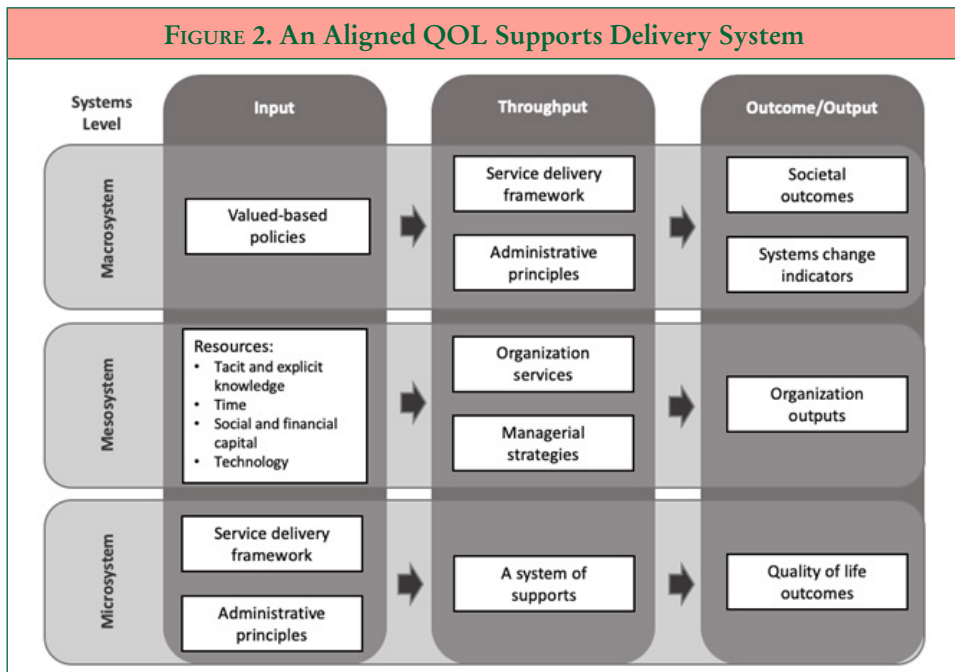FIGURE 2. An Aligned QOL Supports Delivery System

Figure 2 also shows how the input, throughput, and outcome/output components of the system can be analyzed and aligned both vertically and horizontally. Horizontal alignment positions the supports delivery components into a logical sequence for planning, implementation, monitoring, and evaluation. Vertical alignment ensures that at the "input" level, macro-system value-based policies are aligned with organization-level resources, the service delivery framework, and administrative principles. At the "throughput" level, vertical alignment ensures that the service delivery framework and administrative principles are aligned with organization-level services and managerial strategies, and that individualized supports are provided. At the "outcome/output" level, vertical alignment ensures that outcomes/outputs associated with support provision, organization transformation, and systems change are conceptually and operationally related to components of the model.

3.4. *Systems Change*

In a 2015 article entitled "The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift", Peter Mittler stated that: "The UNCRPD provides a unique opportunity to improve the quality of life of a billion people. In parallel with the development of the UN post-2015 Sustainable Development Goals,

it calls for a fundamental reappraisal of policy and practice by governments, members of professional and voluntary organizations, service planners and providers, the research community, and in the last analysis society as a whole" (Mittler, 2015, p. 79). As described by Mittler, Convention Articles incorporate the principles and values embedded in the QOL concept, and Convention Goals encourage signatories to make 'reasonable accommodation' in their support delivery systems to enable people with disabilities to exercise their rights.

Implementing systems change is a major challenge to the signatories of the UNCRPD and to systems, nations, regions, and jurisdictions that are challenged to make 'reasonable accommodations' to enable people with disabilities and their families to exercise their rights and experience a higher QOL. In reference to the UNCRPD, systems change can be based on the alignment of QOL domains, UNCRPD articles, and systems of supports elements. Significant research has demonstrated that the UNCRPD Convention Articles, QOL domains, and systems of supports elements can be clearly aligned. This alignment is described more fully in Claes *et al.* (2016), Gomez *et al.* (2020b), Lombardi *et al.* (2019, 2020), and Verdugo *et al.* (2012).

The alignment of the UNCRPD Articles with QOL domains and associated support strategies provides an evidence-based framework for implementing the UNCRPD. Specifically, the framework can be used to guide systems-level efforts to translate UNCRPD goals into actionable disability policies and practices, use QOL domains for the provision of supports and the evaluation of desired outcomes, and develop organization-based practices aligned with specific UNCRPD Articles.

Progress regarding the use of a QOL-referenced evidence-based framework for implementing the UNCRPD has recently been summarized by Gomez *et al.* (2020b). The publication includes a summary of the QOL conceptual models used to monitor the UNCRPD, the QOL instruments used to assess the rights set out in the UNCRPD, and personal outcomes associated with specific rights contained in the Convention.

4. The QOLSM and the Emerging QOL Supports Paradigm

A paradigm is the set of beliefs, assumptions, policies, and practices shared by individuals that guide the collective efforts of multiple stakeholders to solve problems and develop new knowledge (Thompson *et al.*, 2014). The field of IDD is currently experiencing a 'paradigm shift' in this set of beliefs, assumptions, policies, and practices. This emerging paradigm, which we refer to as the QOL Supports Paradigm (QOLSP) replaces the historical paradigm that emphasized defectology, segregation, devaluation, and facility-based services with a community-based approach based on the concept of quality of life and individualized supports (Gomez *et al.*, in press; Schalock *et al.*, 2020).

The QOLSM and is central to the emerging QOLSP. As discussed by Gomez *et al.*, (in press), the QOLSP is characterized by its being:

– *Theory driven* and based on a validated conceptual model such as the QOLSM. As depicted in Figure 1, the critical elements of this model involve core values, individual and family-referenced QOL domains, systems of supports, and facilitating conditions.

– *Ethic* and encompasses core values. As discussed previously in this article, these core values involve individual worth and autonomy, the capacity of individuals to grow and develop, the universal nature of the multidimensionality of QOL and its emphasis on inclusion and equity, and a commitment to addressing a person's support needs and fostering opportunities to enhance an individual's functioning and personal well-being.

– *Flexible* and used for multiple purposes. These purposes, which were described earlier in the article, involve supports provision, person-centered outcome evaluation, organization transformation, and systems change.

– *Adaptable* and provides a framework to accommodate context-based facilitating conditions.

– *Measurable* and can be evaluated. Although beyond the scope of this article, the influence and impact of the emerging QOLSP can be evaluated through the use of one or more evaluation strategies: principle-focused, utilization-focused, outcome-focused, and/or process-focused (Gomez *et al.*, in press; Schalock *et al.*, 2020).

5. Conclusion

Individually, the QOL concept and the supports model have had a significant impact on the field of IDD over the last 25 years. By integrating these two into the QOLSM described in this article, multiple stakeholders now have an even more powerful catalyst to bring about positive changes in policies and practices in the field that enhance the QOL of people with IDD and their families. This powerful catalyst is the result of the vision of those pioneers in the areas of QOL and supports; those organizes, researchers, and practitioners who did the hard and dedicated work involved in conceptualization and measurement, organization transformation, and systems change; and the commitment and efforts of people with IDD and their families to advocate for those core values, opportunities, policies, and practices that are supports based and quality of life focused.

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