The Quality of Life Supports Model:
Components and Applications

Robert L. Schalock, Ph.D.

Key Note Address: 17th International Conference on Positive Behavior Supports
Miami, Florida-March 12, 2020

Introduction and Overview

Two powerful forces are coming 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 concept’s universal nature, values, focus on the individual, and emphasis on valued 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 individual functioning and personal well-being.

By integrating these two powerful forces into a Quality of Life Supports Model, multiple stakeholders can 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 policies and decision making at the organization and systems level, develop a value-based framework for disability policies, and establish parameters for outcomes evaluation (Thompson, Schalock, Agnosta, Teninty, & Fortune, 2014). As a result of these potential uses, the QOL Supports Model is influencing how support providers approach supports provision (Schalock, Thompson, & Tasse, 2018), is guiding organization and systems level policies and practices internationally (Schalock & Verdugo, 2019), and is creating the impetus for organization transformation and systems change (Schalock & Verdugo, 2013; Schalock, Verdugo, & van Loon, 2018).

The four primary purposes of this presentation are first to describe a QOL Supports Model that integrates the QOL concept and the supports model. This integration includes QOL domains, systems of supports elements, QOL principles and facilitating conditions, and support values and facilitating conditions. The presentation’s second purpose is to describe how the QOL Supports Model can be used for supports provision, organization transformation, and systems change. The third purpose is to discuss the power of evidence in the QOL Supports Model, with the fourth being to discuss the role that an understanding of context and strong advocacy and leadership play in the model’s successful use.
QOL Supports Model

Figure 1 depicts a QOL Supports model developed by the author. The model integrates quality of life domains, systems of supports elements (choice and personal autonomy, inclusive environments, generic supports, and specialized supports), and implementation factors (QOL principles and facilitating conditions and support values and facilitating conditions).

QOL Domains

The attractiveness, power, and utility of the QOL concept involves its values (e.g. equity, inclusion, self-determination, and empowerment), its focus on the person, and its universal nature. Individual quality of life can be defined as a multidimensional phenomenon that is composed of domains that reflect one’s personal well-being. QOL domains are influenced by personal and environmental factors and are enhanced by individualized support strategies. A widely used individual QOL conceptual model is described in Table 1 (Schalock, Verdugo, Gomez, & Reinders, 2016). The 8-domain conceptual model summarized in Table 1 is an
individual-referenced QOL Model that was developed by synthesizing QOL-related literature in the areas of education/special education, mental and behavioral health, mental retardation/intellectual disability, and aging (Schalock & Verdugo, 2002). Subsequent research has confirmed the factor structure of these eight domains (Wang, Schalock et al., 2005); validated the cross-cultural etic (i.e., universal) properties of the eight domains (Jenaro, Verdugo et al., 2005; Schalock, Verdugo et al., 2005); established the hierarchical nature of the eight domains (Wang, Schalock et al., 2005); and described its use in conjunction with logic models in implementing and evaluating intellectual and developmental disabilities policies and practices (Gomez, Schalock, & Verdugo, 2019).

Table 1

<table>
<thead>
<tr>
<th>Quality of Life Domain</th>
<th>Exemplary Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Development</td>
<td>-Education status</td>
</tr>
<tr>
<td></td>
<td>-Personal competency (cognitive, social, practical)</td>
</tr>
<tr>
<td>Self-Determination</td>
<td>-Autonomy/personal control</td>
</tr>
<tr>
<td></td>
<td>-Choices</td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td>-Interactions (e.g., social networks)</td>
</tr>
<tr>
<td></td>
<td>-Relationship (e.g. family, friends, peers)</td>
</tr>
<tr>
<td>Social Inclusion</td>
<td>-Community integration</td>
</tr>
<tr>
<td></td>
<td>-Community roles</td>
</tr>
<tr>
<td>Rights</td>
<td>-Human (respect, dignity, equality)</td>
</tr>
<tr>
<td></td>
<td>-Legal (citizenship, access, due process)</td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td>-Contentment (satisfaction, enjoyment)</td>
</tr>
<tr>
<td></td>
<td>-Lack of stress (predictability and control)</td>
</tr>
<tr>
<td>Physical Well-Being</td>
<td>-Health status</td>
</tr>
<tr>
<td></td>
<td>-Activities of daily living (self-care, mobility)</td>
</tr>
<tr>
<td>Material Well-Being</td>
<td>-Employment status</td>
</tr>
<tr>
<td></td>
<td>-Personal possessions</td>
</tr>
</tbody>
</table>

Systems of Supports Elements

Systems of supports are a broad range of resources and strategies that prevent or mitigate a disability, promote the development, education, and interests of a person, and enhance an individual’s functioning and personal well-being. Since the introduction of the supports model into the IDD field in the mid-1980s, our understanding has increased significantly regarding systems of supports elements (Schalock, Luckasson, & Tasse, 2019). Table 2 provides a listing and description of these elements.
Table 2
Description of Systems of Supports Elements

<table>
<thead>
<tr>
<th>Systems of Supports Element</th>
<th>Description</th>
</tr>
</thead>
</table>
| Choice and Personal Autonomy | -Opportunities to make choices and exercise self-determination  
-Recognition as a person before the law and to enjoy the legal capacity on an equal basis with individuals who do not have a disability  
-Facilitated through decision making supports |
| Inclusive Environments | -Environments in which:  
>Access is provided to resources, information and relationships  
>Supports are provided to encourage growth and development  
>Opportunities are provided to accommodate psychological needs related to autonomy, competence, and relatedness  
-Examples include supported employment, supported living, inclusive/supported education, aging in place |
| Generic Supports | -Natural supports  
-Technology  
-Prosthetics  
-Education across the lifespan  
-Reasonable accommodation  
-Dignity and respect  
-Personal strengths/assets |
| Specialized Supports | -Professionally-based interventions, therapies, and strategies that are provided by educators, medically trained personnel, psychologists, Psychiatrists, nurses, and therapists such as those involved in OT, PT, and speech |

Implementation Factors

Four contextual factors influence the successful implementation of the QOL Supports Model. These factors operate at the individual, organization, and systems level. Each of these implementation factors is described in Table 3. Descriptive material regarding the QOL factors is based on the work of the Consortium on QOL (2019); descriptive material regarding the support implementation factors is based on the work of Buntinx, Yu Tan, and Aldenkamp (2018), Onken (2018), and Qian, Larson, Tiche, Stancliffe, and Pettingell (2019).
Table 3
Factors Influencing QOL Supports Model Implementation

<table>
<thead>
<tr>
<th>Factor</th>
<th>Description</th>
</tr>
</thead>
</table>
| QOL Principles                  | - QOL is composed of multiple domains that reflect one’s personal well-being  
                                | - QOL domains are the same for all people, but may be valued differently  
                                | - QOL has both subjective and objective aspects  
                                | - QOL is influenced by personal and environmental factors  
                                | - QOL is dynamic and is subject to change.                                                                                         |
| QOL Facilitating Conditions     | - Participation in the community  
                                | - Promoting sense of belonging  
                                | - Maximizing capabilities and opportunities  
                                | - Freedom to engage in major life activities  
                                | - Safe and secure environments  
                                | - Commitment to the goals that are important to the person or family                                                                 |
| Support Values                  | - Conceptualizing supports as a bridge between “what is” and “what can be”  
                                | - Recognizing the person’s capabilities  
                                | - Understanding the person’s support needs  
                                | - Respect and empathy for the person  
                                | - Respect for and enhancement of differences  
                                | - Commitment to addressing the person’s support needs and enhancing their personal goals  
                                | - Fostering opportunities to enhance an individual’s functioning and well-being                                                                 |
| Support Facilitating Conditions | - The availability and accessibility of supports  
                                | - Knowledge about systems of supports elements  
                                | - Competent/knowledgeable support providers  
                                | - Consistency and stability of supports provision  
                                | - Coordination and management of supports                                                                                         |

Use of the QOL Supports Model for Supports Provision

Families, primary care givers, support staff, and teachers are the principle support providers throughout much of the world. For example, in the United States, it is estimated that only 1 in 4 adults with IDD receive formal, or paid disability supports (Braddock, Hemp et al., 2015; Larson, Eschenbacher et al., 2018). Two aspects of the QOL Supports Model are
potentially the most applicable to these individuals: An emphasis on quality of life, including choice and personal autonomy, and the provision of generic supports. These two aspects of the model provide connection points between the supports provider and the supports recipient.

**Emphasis on Quality of Life**

The QOL values of equity, inclusion, self-determination, and empowerment, and the QOL principles listed in Table 3 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 quality of life, regardless of the extent of limitations, is composed of multiple domains that reflect one’s personal well-being; that the core domains listed in Table 1 are the same for all people, even though they may be valued differently; that one’s quality of life has both subjective and objective aspects; and that one’s quality of life is dynamic and subject to change. Additionally, an emphasis on the core domains comprising one’s quality of life incorporates a holistic approach to the person and encourages families and primary care givers to ‘think beyond the person’s disability’ and look at the whole person and their strengths and assets.

**Provision of Supports**

Interactions among support providers and supports recipients involve a number of factors related to support values and facilitating conditions. As summarized in Table 3, the values that underlie supports provision involve recognizing the person’s capabilities, providing or procuring opportunities for growth and development, and conceptualizing supports as a bridge between ‘what is’ and ‘what can be.’ These values are reflected in the relationship between the supports provider and the supports recipient. This relationship should be based on respect and empathy for the person, an understanding of the individual’s support needs, reliable and predictable supports provision, and a commitment to addressing the individual’s support needs and enhancing their personal goals and well-being.

Table 2 described the key characteristics of the elements of systems of supports. Two of these elements are potentially the most relevant to support providers. The two are choice and personal autonomy and generic supports.

**Choice and personal autonomy.** Choice and personal autonomy have the ability to mitigate IDD; promote the development, education, and interests of a person; and enhance the individual’s functioning and personal well-being. Current literature indicates that exercising one’s choice and personal autonomy increases not only one’s motivation and satisfaction of psychological needs for 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 that establishes the rights of people with disabilities to legal capacity. As discussed by Glen (2015), legal capacity means that all people, including those with IDD, have a right to have choices, make their own decisions, and have those choices and decisions recognized legally.
Providing decision making supports is increasingly being used to facilitate choice and personal autonomy (Blank & Martinis, 2015). The provision of decision making supports involves: (a) recognizing the requirements associated with the decision-making process including defining the problem, identifying alternative choice options, evaluating possible consequences of each alternative, and selecting the best alternative based on the individual’s goals; and (b) implementing one or more decision-making activities that can involve instructing, using technology, providing experiences, modeling consequences, and/or advising (Hickson & Khemka, 2013; Shogren & Wehmeyer, 2017).

**Generic supports.** Generic supports involve those general 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 individuals to expand their thinking from professional interventions and paid supports to generic supports that family members, primary care givers, support staff, teachers, or individuals themselves can provide. Examples of generic supports are provided in Table 4. These examples are based on an international Delphi Study (Lombardi, Chui, Schalock, & Clases, submitted for publication).

<table>
<thead>
<tr>
<th>Component</th>
<th>Definition and Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural supports</td>
<td>-Building and maintaining support networks (e.g. family, friends, peers, colleagues), and fostering self-advocacy, friendships, community involvement, and social engagement</td>
</tr>
<tr>
<td>Technology</td>
<td>-Using assistive and information devices such as communication aides, smart phones, electronic tablets, medication dispensing devices, med alert devices, and speech recognition devices</td>
</tr>
<tr>
<td>Prosthetics</td>
<td>-Providing sensory aids and motoric assistance devices such as wheelchairs, robotic arms or legs, visual and hearing aids, and orthotic devices</td>
</tr>
<tr>
<td>Education across the lifespan</td>
<td>-Developing new knowledge and skills</td>
</tr>
<tr>
<td>Reasonable accommodation</td>
<td>-Ensuring physical accessibility to buildings, transport, and work spaces -Creating secure and predictable environments</td>
</tr>
<tr>
<td>Dignity and respect</td>
<td>-Enhancing social role status -Providing equal opportunities -Respecting choice and personal autonomy -Honoring human and legal rights</td>
</tr>
</tbody>
</table>
Use of the QOL Supports Model for Organization Transformation

Disability organizations are currently experiencing challenges related to diminishing resources, increased needs for services and supports, and shifting social-political factors. In addition, one of the greatest challenges facing disability organizations is to continue to evolve and make those changes that facilitate the organization’s ongoing effectiveness, efficiency, and sustainability (Schalock, Verdugo, & Lee, 2016; Schalock, Verdugo, & van Loon, 2018).

Successful organization transformation requires continued organization development and capacity building. As depicted in Figure 2, organizations initially develop rapidly in terms of providing services and supports based on their mission and culture. Despite this initial growth and continued emphasis on quality improvement, organizations often reach a plateau in which the development and improvement slows or ends, stagnation occurs, and organization personnel and stakeholders begin to realize that more of the same is not the answer. During this ‘critical inflection point’ values and current approaches are questioned and challenged, and organization personnel come to realize that instead of doubling down and trying to improve what they currently have and do, it is necessary to transform their organization and create something significantly different. In that regard, organization transformation is all about wrestling with new ideas, believing that something better can be developed, and being willing to help it along (Schalock, Verdugo et al. 2018). The QOL Supports Model can provide those new ideas as well as a framework for capacity building and value-based organization transformation.
Organization transformation also involves integrating into the organization’s policies and practices connection points related to quality of life principles and facilitating conditions, and support values and facilitating conditions. Specifically, organization transformation involves incorporating these connection points by: (a) basing the organization’s policies and practices on QOL principles and support values (i.e., “quality of life-supports thinking”); and (b) implementing a QOL-focused and supports-based delivery system (i.e., “QOL Supports Delivery System”).

Quality of Life-Supports Thinking

How one thinks reflects the deeply ingrained assumptions, generalizations, and images one has to understand the world. Frequently referred to as “mental models”, an organization’s way of thinking forms the vision and culture of that organization. QOL-supports thinking challenges organizations to ‘think differently’ about the rights of people with a disability to experience a life of quality, and the role that systems of supports play in human functioning and personal well-being. The QOL principles and support values listed in Table 3 are basic to QOL-supports thinking.

- **QOL principles** involve believing and acting on the premise that quality of life is composed of multiple domains that are the same for all persons, has both subjective and
objective aspects, is influenced by personal and environmental factors, and is dynamic and subject to change.

- Support values recognize the person’s capacities, understand the person’s support needs, foster opportunities, respect for the individual, conceptualize supports as a bridge between “what is” and “what can be”, and believe that with appropriate individualized supports over a sustained period, a person’s quality of life and functioning generally will improve.

QOL Supports Delivery System

In any organization, there are voluminous policies related to health and safety issues, staff recruitment, training and retention, and reporting/accountability requirements. Although these policies are key to an organization’s functioning, they are not the ones that will facilitate the organization’s transformation (Schalock, Verdugo et al., 2016, 2018). As a prerequisite to implementing a QOL Supports Delivery System, quality of life facilitating conditions and support facilitating conditions need to be incorporated into an organization’s policies and practices.

- QOL facilitating conditions involve participation in the community, promoting a sense of belonging, maximizing the person’s capabilities, allowing freedom to engage in major life activities, being committed to the goals that are important to the person or family, and respecting differences.
- Support facilitating conditions include the availability and accessibility of supports, safe and secure environments, information about systems of supports elements, competent and knowledgeable support providers, consistency and stability of support provision, and coordination and management of supports.

Work in organization transformation (see reference section) has identified five components to a QOL Supports Delivery System. These five components involve: (a) building the delivery system around quality of life domains; (b) basing supports planning and delivery on systems of supports; (c) incorporating a set of Personal Supports Plan principles; (d) using a systematic approach to supports planning and implementation; and (e) placing knowledge in the hands of support teams.

Quality of life domains. QOL domains reflect the multidimensionality of one’s quality of life. As summarized in Table 1, eight core quality of life domains that have been validated cross-culturally involve personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, and material well-being. In a QOL Supports Delivery System, these eight domains are used for multiple purposes including policy development, staff training, supports planning and provision, and outcome evaluation.

Systems of supports. A person’s support needs reflect the current mismatch between one’s personal competence and the environmental demands within which a person lives, works, learns, interacts, and recreates. The essential purpose of systems of supports is to reduce the discrepancy between an individual’s functional limitations and environmental demands and thereby enhance their functioning and personal well-being. The four elements of systems of
supports were described in Table 2. Two the four elements—choice and personal autonomy and
generic supports—were discussed in the previous section on the use of the supports model for
supports provision. The two remaining elements—inclusive environments and specialized
supports—are most relevant to organization transformation.

- **Inclusive environments** provide access to community-based resources, information, and
  relationships; encourage growth and development and support people; and accommodate
  psychological needs related to autonomy, competence, and relatedness. This is done
  frequently by entering into partnerships with other public institutions/organizations,
schools, churches, and volunteer groups. Additionally, inclusive environments need to be
  sensitive to contextual variables that influence opportunities for inclusion (Shogren,
  Luckasson et al., 2018); facilitate coordination among support providers and the
  respective education, employment, or residential environment (Verdugo, Jenaro et al.,
  2017); and make available both formal, paid supports (if necessary) and informal natural
  supports (Sanderson, Burke et al., 2017).

- **Specialized supports** are professionally-based interventions and therapies (see Table 2).
The supports provided by these individuals are frequently related to the theoretical
  perspective they have regarding a disability. Thus, recognizing the different perspectives
  on IDD is an essential part of both a QOL Supports Delivery System and an
  organization’s transformation. As discussed by Schalock, Luckasson, Tasse, and
  Verdugo (2018), these four theoretical perspectives on IDD are: the *biomedical
  perspective* that emphasizes genetic and physiological factors; the *psychoeducational
  perspective* that emphasizes intellectual, psychological/behavioral, and learning
  limitations; *the sociocultural perspective* that emphasizes the interaction between people
  and their environments through which social meaning of IDD develops from society’s
  common beliefs, behaviors, language, and events around people with IDD, and the
  responses of individuals to the interaction; and the *justice perspective* that emphasizes
  that all individuals, including those with a diagnosis of IDD, have the same human and
  legal rights as those without a disability.

**Personal supports plan principles.** A Personal Supports Plan (PSP) is used to coordinate
systems of supports elements. Over the last decade, there have been a number of changes in the
disability field regarding supports plans, including a focus on the person and their rights,
systems thinking and logic models, a strength-based approach to supports planning and delivery,
information technology that puts information into the hands of the user, assistive technology that
enables people with IDD to participate in settings and activities in ways that they otherwise
could not, horizontally structured support teams, evidence-based practices, and outcomes
evaluation (Schalock, Thompson, & Tasse, 2018). These changes have resulted in the following
principles that guide support planning in a transformed organization.

1. The person owns their Personal Supports Plan (PSP), which is a support plan and not a
   compliance plan for a provider agency or for people paid to support the individual.
2. A PSP is based on personal goals and support needs, integrates what is important to the individual with what is important for the individual, and addresses what should stay the same (i.e., maintained) and what needs to change (i.e., acquired or modified).

3. A PSP provides wrap-around supports through implementing systems of supports that are aligned with personal goals and support needs.

4. The user-friendly PSP is developed, implemented, reviewed, and evaluated by a horizontally-structured support team that includes the person with IDD.

**Systematic approach to support planning and implementation.** If an organization is serious about transformation based on the QOL Supports Model, it will ensure that the support plans developed and implemented are aligned with the quality of life concept and the supports model. A prototype for accomplishing this is presented in Figure 3 (Schalock, Thompson, & Tasse, 2018). A key aspect of the prototypic PSP shown in Figure 3 is the alignment of QOL domains and support needs. This alignment maximizes the probability of enhancing QOL domains/outcomes, and facilitates the ability to demonstrate the relation between the provision of specific supports and the assessed QOL outcome(s).

**Figure 3**

A Prototypic Personal Supports Plan Based on the QOL Supports Model

<table>
<thead>
<tr>
<th>QOL Domain</th>
<th>Personal Goal</th>
<th>Support Needs</th>
<th>Support Strategies</th>
<th>Implementation Interrogatories (who, what, when, and how)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Development</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Determination</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Inclusion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rights</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Well-Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Material Well-Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Using support teams to develop and implement support plans is an essential feature of a transformed organization. As described more fully in Schalock and Verdugo (2012), support teams are composed of the person whose plan is being developed, members of the individual’s family, direct support staff, relevant professionals, and a support coordinator. The team’s focus and responsibility is to plan, implement, review, and evaluate user-friendly Personal Supports.
Plans. Support teams can use the QOL Supports Model to monitor the plan that is developed and implemented. Critical activities involved in this monitoring involve determining the plan’s coherence to QOL principles and support values.

**Knowledge transfer.** One of the significant challenges to an organization’s transformation is to place research-based information and best practices into the hands of support team members. As discussed by Claes and Schalock (submitted for publication), knowledge transfer is best accomplished via a web-based “knowledge library” that incorporates collaboration, knowledge, and technology. The knowledge library can be used by support teams (and family members) to access information that aligns QOL domains, typical support needs, and best practice support strategies. An example is presented in Figure 4.

**Figure 4**

Knowledge Transfer: The Knowledge Library Based on the QOL Supports Model

<table>
<thead>
<tr>
<th>Quality of Life Domains</th>
<th>Typical Support Needs</th>
<th>Potential Support Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Development</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Determination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Inclusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rights</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Well-Being</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Material Well-Being</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


**Use of the QOL Supports Model for Systems Change**

In a 2015 article entitled, “The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift”, Peter Mittler made a prophetic statement regarding the emergence of a QOL Supports Model and its use in systems change. The statement was 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, the Convention’s Articles incorporate the principles and values embedded in the QOL concept, and the Convention’s goals encourage signatories to make ‘reasonable accommodation’ in their service/support delivery systems to enable people with disabilities to exercise their rights (e.g., UNCRPD Article 2).

Mittler’s prognostication is consistent with two international policy developments influencing systems change (Schalock & Verdugo, 2019). One is to base disability policy development on core concepts and principles such as those embedded in the quality of life
concept and the UNCRPD; the second is to implement disability policies based on the alignment of policy goals with systems of supports elements. Thus, the UNCRPD and recent international disability policy developments incorporate the two primary components of the QOL Supports Model: the concept of quality of life and the supports model.

Developing and implementing a systems change framework is a major challenge to the signatories of the UNCRPD and/or to systems (e.g. nations, regions, jurisdictions) that are challenged to make ‘reasonable accommodations’ to enable people with disabilities to exercise their rights and experience a higher quality of life. Such a framework, which is necessary to guide the translation of UNCRPD goals into specific disability policies and practices, can be based on aligning QOL domains, UNCRPD articles, and systems of supports elements. Significant research has demonstrated the alignment of UNCRPD Convention Articles with the eight QOL domains summarized in Table 1, and with the systems of supports elements described in Table 2. This alignment is shown in Table 5 and described more fully in Claes, Vandeussche, & Lombardi (2016); Lombardi, Chui, Schalock, & Claes (submitted for publication); Lombardi, Vandeussche, Claes, De Maeyer, & Vandevelde (2019); and Verdugo, Navas, Gomez, & Schalock (2012).

Table 5

Alignment of QOL Domains, UNCRPD Articles, and Systems of Supports Elements

<table>
<thead>
<tr>
<th>Quality of Life Domain</th>
<th>UNCRPD Articles</th>
<th>Systems of Supports Elements*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Development</td>
<td>24</td>
<td>-Life-long learning</td>
</tr>
<tr>
<td>Self-Determination</td>
<td>14, 19, 21</td>
<td>-Personal strengths</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Technology</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Choice and personal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>autonomy</td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td>23</td>
<td>-Dignity and respect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Natural supports</td>
</tr>
<tr>
<td>Social Inclusion</td>
<td>8, 9, 18, 20, 27, 29, 30</td>
<td>-Dignity and respect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Natural supports</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Reasonable accommodation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Inclusive environments</td>
</tr>
<tr>
<td>Rights</td>
<td>5-7, 10-13, 15, 22</td>
<td>-Choice and personal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>autonomy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Specialized supports</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Personal strengths/assets</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Dignity and respect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Natural supports</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Technology</td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td>16, 17</td>
<td>-Choice and personal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>autonomy</td>
</tr>
</tbody>
</table>
The data presented in Table 5 indicates clearly how the QOL Supports Model can be used as: (a) a systems change framework to align the UNCRPD Articles with QOL domains and associated support strategies; and (b) a guide to translate the UNCRPD goals into actionable disability policies and practices. Specifically, the data presented in Table 5 shows the close relation between the 34 UNCRPD Articles and the eight domains of the cross-culturally validated QOL conceptual model summarized in Table 1. This close relation allows systems to use the eight domains for supports planning and provision, outcomes evaluation, and research studies to evaluate contextual factors influencing the obtained outcomes. Additionally, the alignment of specific systems of supports elements with the UNCRPD Articles allows policy makers and other systems-level stakeholders to develop policies that relate specific supports to respective UNCRPD Articles. Finally, the alignment of QOL domains, UNCRPD Articles, and systems of supports elements allows jurisdictions and signatories to make ‘reasonable accommodation’ and develop policies and practices that support both the UNCRPD goals and organization transformation.

The Power of Evidence in the QOL Supports Model

The viability and acceptance of any conceptual model depends on evidence that the model provides adequate explanations, and its use results in desired change. Evidence can be defined as facts or information indicating that adequate explanation is given and that change occurs (Schalock, Gomez, Verdugo, & Claes, 2017; Schalock, Verdugo, & Gomez, 2011). In reference to the QOL Supports Model, establishing the power of evidence requires an understanding of the perspectives on evidence, using a systematic framework for gathering the evidence, and specifying evidence indicators.

Perspectives on Evidence

Although there are multiple perspectives on evidence (see Schalock & Verdugo, 2012 and Schalock, Verdugo, & Gomez, 2011 for a detailed listing and discussion), three are emphasized in this presentation: (a) the post-structural perspective that focuses on the effects of value-based disability-related policies and practices, (b) the phenomenological-existential perspective that focuses on the reported experiences of personal well-being, and (c) the empirical-analytic perspective that focuses on the assessment of outcomes based on a validated
conceptual model (Gomez & Verdugo, 2016; Schalock, Gomez, Verdugo, & Claes. 2017; Schalock, Verdugo, & Gomez, 2010). These three perspectives are consistent with two significant changes that are occurring in evidence-based evaluation. One significant change is the shift that is occurring internationally related to rethinking the criterion used to judge economic growth. In this approach, rather than focusing only on gross domestic product (GNP) as the main measure used to evaluate economic success, there is a shift towards using a “genuine progress indicator” (GPI) to define growth and progress in terms of well-being (Pilling, 2018). The second significant change is the use of “principle-focused evaluation” that focuses on evaluating the meaningfulness, adherence to, and results of principle or value-based policies and practices, and informs choices about which principles are appropriate for what purposes and in which contexts (Patton, 2018).

Evidence Gathering Framework

Based on the three perspectives on evidence, plus the genuine progress indicator concept and the principle-focused approach to evaluation summarized above, the QOL Supports Model can be used as a framework to gather evidence that evaluates the impact of specific support strategies on personal outcomes, to describe the status of organization-level transformation, and to determine systems-level progress towards change. Since the QOL Support Model goes across ecological systems, major data sets and resulting evidence need to be associated with the macro, meso, and microsystems. This association is shown in Table 6, including an indication of the anticipated results of the alignment (column 3).

<table>
<thead>
<tr>
<th>Evidence-Gathering Purpose</th>
<th>Major Data Sets</th>
<th>Anticipated Results</th>
</tr>
</thead>
</table>
| Evaluate the impact of the QOL Supports Model on personal, QOL-related outcomes. (Microsystem) | -Domain-referenced QOL scores  
-Quantification of support strategies employed | -QOL scores that can be used for monitoring, reporting, research, and quality improvement/organization transformation  
-Ability to relate the provision of specific support strategies to QOL domain outcomes |
| Describe the status of organization transformation. (Mesosystem) | -Policies and practices that incorporate OOL pre-conditions, support values and support relations, and  
-Implementing a systematic approach to PSPs  
-Systematic approach to outcomes evaluation | -Fidelity or adherence indicators to evaluate status of organization transformation  
-Information about the implementation of systems of supports elements |
### Evidence Indicators

The “anticipated results” listed in column 3 of Table 6 identifies a number of exemplary indicators aligned with evidence-gathering purposes and major data sets. To evaluate the impact of the QOL Supports Model, relevant evidence indicators are QOL scores from a standardized assessment instrument and a demonstration of the relation between the specific supports provided and the respective QOL domain (purpose # 1, column 1). For describing the status of organization transformation and progress in systems-level change (2nd and 3rd evidence-gathering purposes), evidence indicators are used to evaluate the degree to which policies and practices implemented by the organization or system reflect the components of the QOL Supports Model.

Implementation fidelity is increasingly being used as an evidence indicator of organization transformation and systems change (Proctor, Silmere et al., 2011; Schalock & Verdugo, 2012). Logic models are frequently used in this process. Specifically, a logic model is used in conjunction with fidelity indicators to guide the evaluation of the status of organization transformation or systems change. The utility of logic models, with their input, throughput, and output/outcomes components, relates to their ability to articulate relationships between processes or activities and their effects. Thus, the use of logic models to generate evidence indicators provides a basis for not just scientific explanation, but also to operationalize indicators such as those listed in column 3 of Table 6. Examples of such use are found in Claes, Ferket et al. (2017), Gomez, Schalock, and Verdugo (2019), Schalock et al. (2010, 2017), and Schalock and Verdugo (2012).

### The Need for Understanding Context and Strong Advocacy and Leadership

**Understanding Contextual Factors**

An understanding of context captures the complexity of change and the multiple system-level factors and their interactions that influence outcomes. Context can be viewed as an independent variable, an intervening variable, or an integrative construct. As an independent
variable, context includes personal and environmental characteristics that are not usually manipulated such as age, language, culture and ethnicity, gender, and family. As an intervening variable, context includes organizations, systems, and societal policies and practices that can be manipulated to enhance human functioning and personal outcomes. As in integrative construct, context provides a framework for describing and analyzing aspects of human functioning such as personal and environmental factors, planning systems of supports, developing disability policy, and delineating the factors that affect, both positively and negatively, human functioning and personal outcomes (Shogren, Luckasson, & Schalock, 2017).

Based on recent work (Schalock, Luckasson, & Schalock, in preparation; Shogren, Luckasson, & Schalock, in press), a multidimensional model of context can be used to understand context as being multilevel (i.e., micro, meso, and macrosystem), multifactorial (see Table 7), and interactive.

### Table 7

**Contextual Factors That Influence Human Functioning and Personal Outcomes**

<table>
<thead>
<tr>
<th>Microsystem Level</th>
<th>Mesosystem Level</th>
<th>Macrosystem Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal strengths/assets</td>
<td>Alignment of services and supports to personal goals and assessed support needs</td>
<td>Community access and participation</td>
</tr>
<tr>
<td>Social networks</td>
<td>Person-centered planning</td>
<td>Community-based alternatives</td>
</tr>
<tr>
<td>Family involvement</td>
<td>User-friendly Personal Supports Plans</td>
<td>Living and employment supports</td>
</tr>
<tr>
<td>Choices/opportunities</td>
<td>Environmental accommodation</td>
<td>Justice and fairness in the legal system</td>
</tr>
<tr>
<td>Decision making supports</td>
<td>Organization policies that emphasize quality of life, systems of supports, human rights</td>
<td>Legal rights and protections</td>
</tr>
<tr>
<td>Self-advocacy</td>
<td></td>
<td>Transportation availability</td>
</tr>
<tr>
<td>Augmentative communication systems</td>
<td></td>
<td>Societal attitudes, public policies, and system practices</td>
</tr>
<tr>
<td>Information and assistive technology devices</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Natural supports</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Based on work reported in Shogren, Luckasson, & Schalock (2017, 2018, in press).

The interactive component of a multidimensional model of context identifies and describes the variety of ways in which levels and factors interact to influence personal outcomes. An interaction is a reciprocal action or influence that occurs between multilevel and multifactor contextual variables. Examples include increasing one’s social inclusion in school through implementing a program that promotes social inclusion of students with disabilities at multilevels using a school-wide approach; increasing a person’s opportunities to live independently and be included in the community by modifying housing codes; and improving one’s nutritional status through providing information and monitoring proper nutrition.

An interaction varies in intensity due to its relevance and importance to an individual. The interaction also represents a connection point between the elements of the multi-dimensional model of context and the respective elements of a Quality of Life Supports Model or a Human Rights Model based on the UNCRPD (see Schalock, Luckasson, & Shogren, in preparation).
In reference to the QOL Supports Model:
- **Multi-level factors** influence QOL domains/outcomes at the microsystem level through factors such as personal and family attitudes and expectations about the person’s disability, their strengths and limitations, and the availability of resources, services, and supports. At the mesosystem level, QOL domains and outcomes are affected by legislative and statutory opportunities and systems of supports provided in the community. At the macro-system level, QOL domains and outcomes are influenced by societal and cultural concepts of disability with associated stereotypes and attitudes, and the resources a society devotes to quality of life enhancement.
- **Multi-factors** influence QOL domains and outcomes through the influencing factors listed in Table 7.
- **Interactions** that occur between multi-levels and multi-factors effect QOL domains and outcomes through the presence of QOL facilitating conditions and support facilitating conditions (see Table 3). These interactions are typically operationalized and measured in terms of QOL domains or UNCRPD Articles.

In reference to a Human Rights Model based on the UNCRPD:
- **Multi-levels** are reflected in the obligations that signatories are committed to. These obligations involve modifying or repealing laws, customs, and practices that discriminate directly or indirectly against people with disabilities; reframing any practice inconsistent with the UNCRPD; consulting with people with disabilities and their organizations in implementing the UNCRPD; and making ‘reasonable accommodation’ in all relevant aspects of the environment so as to enable people with disabilities to exercise their rights.
- **Multi-factors** are reflected in the Convention’s General Principles that encompass respect for inherent dignity and individual autonomy; equality and non-discrimination; full and active participation and inclusion in society; respect for differences and acceptance of persons with disabilities as part of humanity; accountability; equality between men and women; and respect for the evolving capacities of children with disabilities and the right to preserve their identities.
- **Interactions** between these multi-levels and multi-factors have been selected and mandated by the international community to promote the Articles identified in the UNCRPD. The relation between these 34 Articles and the 8 core QOL domains listed in Table 1 are presented and discussed in Claes, Vandenbussche et al. (2016), Lombardi, Vandenbussche et al. (2019) and Verdugo, Navas et al. (2012).

Understanding how these context-based factors influence individuals, organizations, and systems facilitates the successful implementation and use of the QOL Supports Model for support provision, organization transformation, and systems change. These uses were described in the preceding sections of this presentation, and are described with additional examples in Schalock, Luckasson, et al. (in preparation).
Strong Advocacy and Leadership

Significant change requires strong advocacy and leadership that shares and communicates a clear vision, describes and implements specific change strategies based on a validated cross-cultural model and evidence-based practices, and forcefully promotes change through multiple platforms. Advocacy and leadership are both a shared process. Strong and effective advocacy requires multiple stakeholders including self-advocates and their families, peers and colleagues, professionals, community and national leaders, and policy makers. Shared and strong leadership involves mentoring and directing, coaching and instructing, inspiring and empowering, and collaborating and partnering (Schalock & Verdugo, 2012). Across these functions and roles, the effectiveness of efforts to implement the QOL Supports Model require a clear vision, organized strategies, and forceful promotion.

Clear vision. The vision that persons with disabilities have about their lives is that, despite their disability, their human and legal rights are acknowledged and respected; they are included in their communities; and they are empowered to make decisions and experience self-determination; and that the supports they receive will lead to increased independence, productivity, and community integration. That vision is embodied in both the QOL Supports Model and the UNCRPD Articles. It is also reflected in the mission statement of countless disability organizations. The challenged faced by these organizations, however, is to “both talk the talk and walk the walk.” The question, then, is how to make a clear vision become a reality?

Organized strategies. Earlier sections of this presentation described the change strategies involved in using the QOL Supports Model by multiple support providers, and by organizations and systems. At the core of these strategies at the micro and meso systems levels is to align personal goals and support needs with specific systems of supports elements; and at the macro-system level is to align disability policy with the quality of life concept and the supports model.

Forceful promotion. The promotion of the QOL Supports Model needs to occur at multiple levels. Within the network of support providers, the model can be promoted by self-advocates, family members, primary care givers, support staff, and teachers who see its promise and ‘do-ability’. Within an organization, it can be promoted through strategic execution that involves communication, shared and mult-level leadership, networked partnerships, and data engagement (Schalock, Verdugo, et al., 2018). Within a community or larger society, it can be promoted through information provision, knowledge sharing, advocacy, and changes in policies and practices. The key to forceful promotion is for advocates and other spokespersons to have a clear vision of the potential of the QOL Supports Model and a specific and organized approach to value-based change.

Summary

In summary, the QOL Supports Model discussed in this presentation encompasses QOL domains, systems of supports elements, and factors (i.e., QOL principles, support values, and respective facilitating conditions) that influence its implementation. The advantages of QOL Supports Model includes its relevance to people with a disability, its alignment with current best
education and habilitation practices, its utilization by multiple stakeholders including consumers and their families, support providers, policy makers, and researchers, and its focus on value-based policies, practices, and outcomes.

The major challenge to successfully implementing the QOL Supports Model relates to the need to incorporate quality of life principles and facilitating conditions and support values and facilitating conditions into disability-related policies and practices that go across support providers, education and rehabilitation agencies and programs, and the general public. How we address this challenge represent our future agenda.
References


Lombardi, M., Chu, C., Claes, C., & Schalock, R. L. (submitted for publication). Towards an international definition of supports, systems of supports, and elements of systems of supports.


24


