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# A SYSTEMATIC REVIEW OF QUALITY OF LIFE ASSESSMENT TOOLS FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Brianne Leigh Conner

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**A SYSTEMATIC REVIEW OF QUALITY OF LIFE  
ASSESSMENT TOOLS FOR ADULTS WITH  
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

**by**

**BRIANNE L. CONNER**

B.M., Piano Performance, East Texas Baptist University, 2001  
M.M., Piano Pedagogy and Performance, Baylor University, 2003

THESIS

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**ABSTRACT**

**AIM:** The quality of life (QOL) construct is proposed as a method to assess outcomes for people with intellectual and developmental disabilities (I/DD) at multiple levels. The aim of this research is to identify and systematically review QOL assessment tools for adults with all levels of I/DD that could be used within disability service systems to examine the micro (individual), meso (organizational), and macro (system) levels of QOL outcomes. **METHOD:** A systematic search of the disability and QOL literature published between 1990 and 2014 was conducted in order to identify QOL assessment tools that met the inclusion criteria. 35 articles included in the review produced 25 QOL instruments of which 13 QOL instruments were then compared in greater detail. **FINDINGS:** Most of the tools reviewed are based on an accepted QOL theoretical domain theory and assess both objective and subjective QOL. Most of the tools utilize Likert-type scoring and are delivered by a facilitated interview process. Only one tool demonstrated acceptable reliability while four tools demonstrated acceptable validity. Most of the tools demonstrated use at the micro, meso, and macro levels. **CONCLUSION:** QOL assessment tools for adults with I/DD need additional research to demonstrate acceptable reliability and validity.

*Keywords:* quality of life, developmental disability, intellectual disability, assessment, measurement, systematic review

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## **Introduction**

Quality of Life (QOL) is difficult to define; a concept that most people are familiar with, have developed ideas about, but likely would define differently from one person to the next. QOL is a construct that has become integral to the field of intellectual and developmental disabilities (I/DD), utilized at multiple levels to support people with I/DD to live meaningful lives and to guide service delivery. The QOL construct, implemented presently, includes a framework for assessing personal outcomes, a social construct that guides quality improvement at multiple levels, and a criterion for assessing effectiveness (Shalock, Gardner, & Bradley, 2007). This is done using a variety of QOL assessment tools. These tools typically associate ratings with multiple items and/or indicators that are typically organized into a variety of categories called domains. These ratings are then compared to norms or averages of other individuals with I/DD or the general population. Each QOL assessment tool varies in what is included and how it is used.

This systematic review was completed to identify, describe, and compare QOL assessment tools as demonstrated in the current (1990-2014) QOL literature specific to adults with I/DD. This research is intended to provide information for public administrators considering systematic implementation of QOL assessment for adults with I/DD receiving publically funded support services. This research is needed due to the lack of available information examining the use of QOL tools at systems levels as well as limited information available discussing the strengths and weakness of specific QOL tools through the lens of a public administrator.

While most systematic reviews are in and of themselves a detailed literature review, this research is twofold: a historical review of the development of the QOL construct and a systematic review of QOL tools. The QOL literature and research is not limited solely to the development and implementation of assessment tools, but broadly examines QOL concepts, theories, variations or disparities in QOL between the general population and sub populations, as well as other aspects of QOL. Due to this breadth of research on the topic and to gain a framework for understanding a systematic analysis of available QOL assessment tools it is necessary first to gain an understanding of the current QOL construct, how it has been developed, and how it is utilized with adults with I/DD.

This paper first explores the history and development of the QOL construct and how it is applied to adults with I/DD, specifically examining application at a system-wide level. Following this discussion is the presentation of the methodology and results of the systematic review of QOL assessment tools. Finally the discussion and conclusion are presented with the intent to examine the findings related to QOL assessment needs at a systems level to support QOL assessment implementation from a public administration perspective.

There are two systematic reviews of QOL assessment tools for adults with I/DD in the published literature. The first of these two (Townsend-White, Pham, & Vassos, 2012) discusses available QOL assessment tools in English that can be used specifically with persons who exhibit challenging behavior to evaluate individualized services. Townsend-White, Pham, and Vassos (2012) found only six instruments that met

psychometric and measurement criteria established in their review process. Of these six, most assessed QOL from a subjective perspective and measured some (but not all) of the eight QOL domains; none were found to specifically assess QOL for people with I/DD and challenging behavior. This review focused on use of QOL assessment tools at an individual level for a specific sub-population.

The second available systematic review focused on the psychometric and measurement qualities of self-reported QOL assessment instruments (Li et al., 2013). The intent of this systematic review was to provide updated information on current tools, their validity and reliability. Nine QOL assessment tools met the inclusion criteria of the study. The findings from both of these systematic reviews can be applicable for public administrators in identifying appropriate QOL assessment tools. However, neither systematic review provides information on the use of tools at a systems level, nor are tools examined with the intent to include the population of adults with all levels of I/DD receiving services and supports. Therefore, the aim of this research is to identify and systematically review QOL assessment tools for adults with all levels of I/DD that could be used within disability service systems to examine the micro (individual), meso (agency), and macro (system) levels of QOL outcomes.

## **Background and Literature Review**

### **Historical Perspective**

The idea of a life of quality and QOL as a term first made an appearance in the United States in the 1960s (Wolfensberger, 1994). Throughout the 1960s and 1970s QOL was primarily used to refer to objectively measured indicators of national welfare,



such as quality of air, water, employment rates, income, and population health (Cummins, 1997). A series of studies in the mid-1970s called the “Quality of American Life Studies” evidenced a subtle shift from objective population perspectives to more subjective individual perspectives as indicated by the use of self-reported satisfaction (Campbell, Converse, & Rodgers, 1976). In this time period there were examples of QOL as both a population and an individual concept with no clear definition or consistent use. QOL as a concept was general, not specifically defined, and not identified with a particular field or population. By 1974, the published literature that addressed QOL directly amounted to a total of only 40 articles (Nota, Soresi, & Perry, 2006).

It was not until the 1980s did QOL begin to be used in reference to persons with I/DD. The I/DD field embraced the concept as a sensitizing notion and an over-arching principle for developing and planning service delivery (Shalock, 2000). It became a sensitizing notion in that most people could identify with the idea of a life of quality and began to see that all people, regardless of their disability, may have similar desires and needs. During this decade there was a significant shift in the perception of persons with I/DD due to systematic deinstitutionalization throughout the United States, Australia, and parts of Europe (Cummins, 2005). It was in this decade that concepts such as person-centered planning, self-determination, normalization, and individualized supports developed and were used to direct the creation of a community-based service delivery system, as opposed to the institutional model that had been in place for many decades prior (Wolfensberger, 1994). QOL, as a social construct, captured this changing view and embodied these concepts. As a sensitizing notion, QOL provided individuals with I/DD,

support providers, and the general population a common language and common desires. The desire for QOL, inherent to all people, could therefore be applied to newly developing programs and services.

The 1980s generated interest and initiated research into the concept of QOL specifically related to persons with I/DD. By the end of the decade there were more than 100 definitions of the term (Shalock & Verdugo, 2002, p. 13) and thousands of published articles (Nota, Soresi, & Perry, 2006). An overview of these definitions and the research that generated them can be found in Cummins (1996, 1997) and Goode (1994). The I/DD field embraced the QOL concept fully by the end of this decade as evidenced by the use of QOL as a unifying theme to develop service delivery systems, to shift the focus to individualized supports, and to guide program monitoring and evaluation (Shalock, 2000). The agreed upon concept of QOL included the expansion from primarily objective measures captured by assessment tools completed by care providers to the combination of objective and subjective measures as well as a multidimensional approach that included various life domains (Cummins, 1997; Cummins, 2005). With subjective measures included in QOL assessment, it also became important to involve persons with I/DD directly in the assessment process as respondents about their own perceived QOL.

Throughout the next decade, the 1990s, the concept of QOL was expanded and clarified, with research addressing conceptual and measurement issues. A variety of multidimensional QOL models that demonstrated domains and indicators were solidified and assessment tools based on these models were developed. This decade evidenced not only clarification of the QOL concept but also the identification of QOL as a subject

worthy of scientific research (Brown, 1997). With more than 5,000 articles published by 1999, the literature on QOL continued to grow exponentially both related to individuals with I/DD and other areas of application, such as health-related quality of life (Nota, Soresi, & Perry, 2006). Cummins (1997, p. 118) points out toward the end of this decade that “the literature is now too vast for any individual researcher to fully assimilate.” Related to this fact, and others, Wolf Wolfensberger (1994) recommends abandoning the term ‘quality of life’ and crafting a new term or construct, as it had become increasingly complex to gain an agreed upon understanding of QOL as it applied to research and application in the I/DD field.

Although the QOL concept continued to grow in complexity through research and application, the 1990s also brought forth some clarity with the development of QOL domain theories and validated assessment tools based on these theories. The research into domain theories and validation of assessment tools set the groundwork for the clarification of evidence-based theoretical approaches as well as a movement toward agreement on measurement principles and multivariate research design (Shalock, 2000; Cummins, 2005). The clarification of theoretical and measurement concepts coupled with the attempt to discover the unifying themes in the growing body of literature, led to initiatives in the early 2000s to gain consensus at an international level on QOL for persons with I/DD.

The members of the International Association for the Scientific Study of Intellectual Disability (IASSID)’s Quality of Life Special Interest Research Group (QoL-SIRG) worked over the course of multiple years to identify and clarify a core set of

unifying QOL principles that apply to conceptualization, measurement, and application (Shalock et al. 2002; Brown & Brown, 2005). This group developed three workgroups that included panels of experts, met over the course of multiple years, gathered together at conferences in both Australia and the United States, and finally through meetings and correspondence produced an international QOL consensus document. The report published by this group states its findings are in agreement with other international QOL frameworks such as the World Health Organization's work in this area in 1995 and 1998. The IASSID's 2002 report concludes with the consensus that a full understanding of QOL is still emerging and changing and that future work within the application of QOL and persons with I/DD should proceed into four areas 1) development of public policy, 2) implementation of societal practices, 3) provision of supports, and 4) evaluation and monitoring of these three things (Shalock et al., 2002, p. 467). "The principles and guidelines provided, and continue to provide, a strong roadmap for the philosophy and values, as well as specific measurement methods, for assessing quality of life indicators for people with intellectual disabilities" (Brown, Hatton, & Emerson, 2013, p. 319). It is important to recognize that the development and research of QOL concepts and constructs by the first decade of the new century was pursued at an international level that was not specifically driven by any particular country, institution, or person.

While the 1990s primarily examined the results of QOL assessment at an individual level, the first decade of the 2000s saw the added application of aggregate QOL data at a systems level with both implementation of QOL continuous improvement models in service delivery agencies (Shalock, Gardner, & Bradley, 2007) as well as at the

state systems level with projects like the Maryland Ask Me! Project (Bonham et al., 2004) and provider profiles in Nebraska (Keith & Bonham, 2005). The IASSID continued to refine an international and unified perspective with an emphasis on individual and systemic application. A meeting in 2004, documented by Brown and Brown (2005), produced agreement that application should follow these four strands: 1) QOL should be the basis for intervention and supports, 2) QOL should enhance well-being within cultural contexts, 3) QOL application should be evidence-based, and 4) QOL principles should be part of professional education and training. Trends throughout this decade related to these four recommendations include cross-cultural validation, examination of the cultural properties of domains, indicators, and assessment tools (e.g. Caballo et al., 2005; Jenaro et al., 2005; Verdugo, Gomez, & Shalock, 2009), as well as the continued contribution to the body of evidence on QOL for adults with I/DD.

Additionally since 2000, we see the increased inclusion of adults with I/DD in the process of research development, QOL application, and evaluation, also called participatory action research (Whitney-Thomas, 1997). For example, the Maryland Ask Me! Project (Bonham et al., 2004) included adults with I/DD in the development of the assessment tool as well as utilized them as assessors to administer the tool; therefore we see the progression from gathering primarily objective data about people (1980s), to gathering individual perceptions directly from people (1990s), to involving people at all stages of QOL application (2000s). With the increased body of evidence and application using validated assessment tools, clarification in research methodology continued with the examination of reliability of response, proxy respondents, facilitated-interview

administration, and general agreement on the use of multivariate research design (Shalock, 2004; Cummins, 2005).

The present trends in QOL research and application reflect ongoing work with cross-cultural validation and application sensitive to the etic (universal) and emic (cultural-bound) properties of various domains and indicators (e.g. Wong, Wong, Shalock, & Chou, 2011, Bredemeier et al., 2014), reliability and utility of proxy respondents (e.g. Claes et al., 2012; Verdugo et al., 2014), development of theory-based assessment tools (e.g. Gomez, Arias, Verdugo, & Navas, 2012; Verdugo et al., 2014), and theoretical application aimed at larger systems (e.g. Shalock, Verdugo, & Gomez, 2011; Verdugo, Navas, Gomez, & Shalock, 2012). Brown, Hatton, and Emerson (2013) point out the gap between current application and implementation at the policy and systems level. One window of opportunity, explored by Verdugo et al. (2012), to address this gap is to utilize a rights framework or perspectives such as that posed by the United Nation's Convention on the Rights of Persons with Disabilities. The QOL construct is developmental and continues to build on prior frameworks, concepts, and theories. Its conceptualization and application continue to shift with ongoing research and changing social ideas about disability and QOL.

### **Application to Sub-Populations**

The application of the QOL construct and its agreed upon properties can be seen in populations other than adults with I/DD. The social science research includes other sub-populations such as special education, health related QOL, mental and behavioral health, aging, family-centered QOL, and substance abuse (Shalock & Verdugo, 2002).

Health related QOL has the most extensive history beginning as early as the 1960s. Education, mental and behavioral health, aging, and family-centered QOL saw an increase in application and research in the 1990s. The QOL construct as applied to substance abuse has only been more recently employed. Shalock and Verdugo (2002) detail domains and indicators for each of these sub-populations, demonstrating significant overlap and agreement in domain-theory. More recently Shalock, Verdugo, and Gomez (2011) provide examples of evidence-based applications using the QOL domain theories with these and additional sub-populations.

### **QOL Principles and Theories**

Throughout the current international QOL literature a set of principles has been established that represent the understanding and the application of the QOL construct to date. While there is an extensive list of principles related to the conceptualization and measurement of QOL (e.g. Shalock et al., 2002; Cummins, 2005), the following section describes the principles that overlap and unify the currently utilized QOL domain theories and assessment tools presented in this research. These include three overarching principles: 1) QOL is composed of the same factors and relationships for people with I/DD as those without disabilities, 2) QOL is represented by both objective and subjective components, and 3) QOL is a multidimensional construct represented by core domains and indicators.

#### **Same components for all.**

While this research is primarily concerned with the application of QOL for adults with I/DD, one of the principles of QOL assessment is that any construct or theory of

QOL must be applicable to all people. This is due in large part to the fact that the basic composition of QOL is the same for all persons regardless of disability, where the variation in the composition is found in individual perceptions of QOL and the cultural and societal differences that influence QOL (Cummins, 2005a). Both Wolfensberger (1994) and Cummins (1997) identify the dangers of defining a specific QOL for a minority group, one of which is what Wolfensberger calls “deathmaking.” The basic concern is that because many minority groups have a lower standard of living than the general population, there is a danger in identifying a QOL standard for a sub-population that would be unacceptable for the general population (Cummins, 1997). It is imperative that any view of QOL not be limited by the perceived deficits of the group being assessed, as this can lead to inequitable standards of a life of quality, and in its extreme form promote lack of intervention (“passive deathmaking”) or even active steps toward ending the life of certain sub-groups due to the perceived lack of QOL (Wolfensberger, 1994; Cummins, 1997).

Cummins (2005a) argues that there is an identifiable set of core building-blocks of QOL that are common to all people. Using these building-blocks and the understanding of the QOL construct it would then be possible to employ assessment tools with any group regardless of culture, socio-economic status, or disability; possibly with the intent to gather information that would be directly comparable between groups and individuals. Brown, Hatton, and Emerson (2013) when discussing indicators of QOL explain that indicators should represent aspects of life that are common to all human beings while also recognizing that QOL is idiosyncratic. Within this principle, that QOL



has the same components for all, the holistic and lifespan aspects of the QOL construct are also emphasized (Brown & Brown, 2005).

### **Objective and subjective.**

The second principle evident in current domain theories and many assessment tools is that QOL is comprised of both objective and subjective components. How to conceptualize and measure these components has been the topic of much debate. For example the dialogue presented in the published series of articles by Cummins (1997, 2001, 2002) and Hatton and Ager (1999, 2002) primarily addresses the utility of including subjective components along with objective components when assessing QOL. The understanding of objective (those able to be observed and independently verified) and subjective (those that are perceptual in nature) components is developmental, evidencing a shift throughout the past three decades of QOL research (Brown, Hatton, & Emerson, 2013). The 1980s and before examined primarily objective components focusing on normalization and the move to community residential support models (i.e. deinstitutionalization). The addition of subjective components began in the 1990s and solidified as a necessary component of the QOL construct. This combination, mirrored in IASSID's statements (Shalock et al., 2002), represents Shalock's (Shalock & Verdugo, 2002, p. 272) principle: "QOL measurement for individuals is based upon both common human experiences and unique, individual life experiences."

Some studies demonstrate a weak link between people's objective social conditions and their subjective satisfaction (McVilly & Rawlinson, 2008). Cummins and Lau (2006) identify early thinking that well-being was directly linked to wealth,

especially when examining populations. However it became evident that wealth and other objective measures do not directly correspond to increased satisfaction and that it would therefore be important to evaluate both objective and subjective measures (Cummins, Lau, Mellor, & Stokes, 2009). Hatton and Ager (2002) raise concerns that using subjective measures alone for people with I/DD can be problematic due to cognitive understanding of what is being measured, communication challenges, resiliency in difficult situations, and lack of exposure to typical environments. Cummins (2002), in response to these concerns, identifies that subjective well-being is homeostatic, meaning the measure is broadly predictable within a range such as blood pressure or body temperature. Cummins (2002) continues to assert that the homeostatic nature demonstrates that subjective well-being is an excellent indicator to predict when there are circumstances or conditions that are directly contributing to decreased satisfaction; however, in agreement with Hatton and Ager (2002), Cummins concedes that humans are resilient creatures and able to adapt to difficult circumstances. Therefore, both subjective and objective indicators are warranted and necessary for a holistic understanding of QOL.

### **Domain theories.**

By the end of the 1990s there was widespread agreement that QOL is a multidimensional concept and cannot be reduced to one item or concept and still be reflective of a whole life (Shalock, 2000; Cummins, 2005). This concept is represented most frequently by the identification of life domains; domains refer to the set of factors that compose personal well-being (Shalock, 2004). The IASSID Quality of Life special interest research group (Shalock et al., 2002) suggests that the number or name of

domains is less important than the recognition of the need for a multi-element framework.

“As QOL research and discussions have evolved, international consensus has moved away from thinking there is one definition or application of quality of life and toward describing and understanding its core domains and the conditions that promote and enhance a good life” (Shalock & Verdugo, 2002 p. 25).

Throughout the 1980s and 1990s QOL researchers posed numerous domain theories as they apply to individuals with I/DD. These can be reviewed in detail in Goode (1994), Brown (1997), Shalock and Verdugo (2002), and Hogg and Langa (2005). The following five domain theories demonstrate the commonality and the variation in thought as to which core domains should be included in the current QOL construct. A comparison of the core domains included in each theory can be seen in Table 1. These five domain theories are included for discussion as they are still referenced today and a number of currently utilized assessment tools, which are discussed and presented for comparison later in this paper, are based upon these domain theories. Over the past 15 years, ongoing research on the QOL construct is developing an understanding of the theoretical and hierarchical nature of domain theories and the multi-dimensionality of the QOL construct (Verdugo et al., 2012).

Table 1

*Quality of Life Domain Comparison*

Shalock, Keith, & Hoffman, 1990	World Health Organization, 1995	Felce & Perry, 1995
Four domains	Six domains	Five domains
<ul style="list-style-type: none"> <li>• Satisfaction</li> <li>• Productivity</li> <li>• Empowerment</li> <li>• Social Belonging</li> </ul>	<ul style="list-style-type: none"> <li>• Physical</li> <li>• Psychological</li> <li>• Environment</li> <li>• Social relationships</li> <li>• Level of independence</li> <li>• Spirituality/religion/ personal beliefs</li> </ul>	<ul style="list-style-type: none"> <li>• Physical well-being</li> <li>• Emotional well-being</li> <li>• Material well-being</li> <li>• Social well-being</li> <li>• Productive well-being</li> </ul>
Cummins, 1997	Shalock & Verdugo, 2002	
Seven domains	Eight domains	
<ul style="list-style-type: none"> <li>• Health</li> <li>• Emotional well-being</li> <li>• Material well-being</li> <li>• Intimacy</li> <li>• Place in Community</li> <li>• Safety</li> <li>• Productivity</li> </ul>	<ul style="list-style-type: none"> <li>• Physical well-being</li> <li>• Emotional well-being</li> <li>• Material well-being</li> <li>• Interpersonal relations</li> <li>• Social inclusion</li> <li>• Personal development</li> <li>• Self-determination</li> <li>• Rights</li> </ul>	

***Shalock, Keith, and Hoffman, 1990.***

Based on an early multidimensional theory, Shalock, Keith, and Hoffman developed the Quality of Life Questionnaire in 1990. This tool was initially comprised of three domains: environmental control, community involvement, and social relations (Shalock & Verdugo, 2002). The three-domain theory and the assessment tool were subsequently revised in 1993 with the revision of the three previous domain categories and the addition of a fourth domain: satisfaction, productivity, empowerment, and social belonging (Brown, Hatton, & Emerson, 2013). The Quality of Life Questionnaire (QOL-Q) has been utilized widely and validated in multiple countries (e.g. Caballo et al., 2005).

Additionally this tool was the basis for the initial version of the Maryland Ask Me! Survey that used the four domains from the 1993 version and an additional domain of Dignity (Bonham et al., 2004). This four-domain theory, while still represented by the use of the QOL-Q, is no longer preferred by its authors in light of the eight-domain theory posed by Shalock and Verdugo beginning in 1996 (described later in this section).

***World Health Organization, 1995.***

The World Health Organization (WHO) initiated the development of an international QOL assessment (WHOQOL) to make it possible to consider QOL from a cross-cultural perspective as well as to contribute to clarifying the QOL construct at an individual, social, and cultural level (The WHOQOL group, 1995). Three agreed upon characteristics of QOL were identified in the literature: 1) QOL is subjective, 2) QOL is multi-dimensional, and 3) QOL includes both positive and negative dimensions (p. 1405). The WHOQOL group (1995) identified six domains of QOL: physical, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. Within each domain there are sub-domains or facets.

Rather than devising these domains exclusively from a review of the existing literature, the WHOQOL group (1995) followed a process of several steps. Initially the principal investigators drafted a provisional list of domains and facets from current research. Using these lists, focus groups from 15 different field centers and countries clarified each domain and detailed definitions of each facet, considering cultural implications. Multiple rounds of focus groups were then facilitated to refine the domains,

facets, and definitions. Sub-populations represented in the focus groups included persons using health services, persons from the general population, and health personnel. This process was not specific to persons with I/DD. The WHOQOL-DIS assessment tool, which is specific for persons with I/DD, was developed based on the WHO domain theory (The WHOQOL group, 1995).

***Felce and Perry, 1995.***

Felce and Perry (1995) undertook a literature review to identify overlap between authors and synthesize domains relevant to QOL. The literature review considered areas from the general population, I/DD population, those with physical disabilities, and those with mental health diagnoses. They identified five major categories of QOL domains through this process: physical well-being, material well-being, social well-being, emotional well-being, and productive well-being. Felce (1997) expanded his theory by adding an additional domain in 1997, civic well-being. This domain was added following review of Shalock's 1996 book chapter discussed below in the Shalock and Verdugo, 2002 theory. Felce pointed out that there is significant overlap with other domain theories and states he is not specifically set on the domain categories "as long as the content is covered" (Felce, 1997, p. 130). Felce and Perry (1997, p. 63) define QOL in the following manner: "Quality of life constitutes a general well-being influenced by objective circumstances and subjective perceptions across a variety of life domain issues." Their review does not specifically identify indicators, however does include topics sub-grouped within each domain.

*Cummins, 1997.*

Robert Cummins (1997) introduces his chapter on assessing QOL in *Quality of Life for People with Disabilities* with the emphasis that QOL concepts are not unique to people with I/DD and should relate to people both with and without disabilities.

Additionally he describes three propositions that have general acceptance in the literature in relation to the definition of QOL at this time: 1) the term QOL refers to both objective and subjective axes, 2) the objective axis incorporates norm-referenced measures of well-being, and 3) the subjective axis incorporates measures of perceived well-being (also called ‘subjective well-being’) (p. 118). Cummins points out that there is little agreement as to the number or the scope of QOL domains and utilizes 27 definitions in the relevant literature across all populations to determine the domains supported by the research at that time.

Five domains were initially identified: Material, Health, Productivity, Intimacy, and Emotional. Cummins (1997) argues that, based on the evidence, these five domains should be included in any QOL definition or model. Cummins (1997) proposed two additional domains, Safety and Community; both of which were also represented to a lesser extent in the review of definitions. Cummins developed the Comprehensive Quality of Life Scale (1993) based on the following definition of QOL: “Quality of life is both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being” (p. 132). Along with the previously mentioned Quality of Life Questionnaire (Shalock

& Keith, 1993), the Comprehensive Quality of Life Scale has been widely utilized and validated in multiple countries (e.g. Verri et al., 1999).

In more recent years Cummins has focused his research specifically on subjective well-being (Cummins, 2005; Cummins et al., 2009). He argues that subjective well-being may be the single most important subjective measure in a hierarchical QOL construct (Cummins et al., 2009, p. 30). Cummins has taken this specific subjective measure and reworked the satisfaction scale of the Comprehensive Quality of Life Scale into the Personal Wellbeing Index (Cummins, 2005, p. 132). The Personal Wellbeing Index is theoretically embedded in the seven-domain theory and continues to be used with general adult samples as well as persons with I/DD on a large scale in Australia (Cummins et al., 2012). Cummins advocates the measurement of subjective well-being at a population level to inform policy, to shape society, and to distribute resources in ways that enhance population wellbeing (Cummins et al., 2012).

*Shalock and Verdugo, 2002.*

This theory was initially introduced by Shalock in 1996 in a book chapter titled “Reconsidering the conceptualization and measurement of quality of life” (Shalock & Verdugo, 2002). In this chapter Shalock reexamined his previous four-domain theory posed with Keith and Hoffman (1990) and moved to a more robust eight-domain theory. This theory clarified objective and subjective indicators and expanded the domains based on a synthesis of international research in the area of quality of life for persons with I/DD (Shalock & Verdugo, 2002). The eight domains included in this theory are emotional



well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. An analysis of the international QOL literature identified the three most common indicators for each of the eight core domains, resulting in the 24 indicators that are included in this theory (Shalock, 2004, p. 206).

Shalock and Verdugo (2002) suggest that researchers should move to consensus on core QOL domains and indicators; this suggestion is consistent with the desire expressed by Felce (1997) to synthesize information in domain areas and concerns with the lack of a single definition or theory presented by Wolfensberger (1994). Beginning with the introduction of this theory, international literature reflects a growing consensus on the eight domains posed by Shalock and Verdugo (Shalock et al., 2002; Shalock & Verdugo, 2002; Bonham et al., 2004; Shalock, Bonham, & Verdugo, 2008). Additionally, work by the IASSID also represents this desire for consensus. However, while Cummins (2005a, p. 701) acknowledges the commonality between domain listings, he points out that few are based on a theoretical justification and recommends the development of a testable and hierarchical domain theory for the future of the QOL construct.

Shalock and Verdugo continue with application of this eight-domain theory to the present day, as do many other QOL researchers. Additional empirical support through published research has evidenced its validity, verified its factor structure and cross-cultural validity, and identified the role of mediating and moderating variables (Verdugo et al., 2012). This domain theory is increasingly applied to fields beyond I/DD including

ageing, physical disability, mental health, special education, chemical dependency, and other vulnerable populations (Verdugo et al., 2012). It appears that with ongoing longitudinal and cross-cultural research this eight-domain theory may satisfy Cummin's (2005a) concerns for a more theoretical justification of the QOL construct. Numerous QOL assessment tools have been developed based on this theory (e.g. Claes et al., 2012; Verdugo et al., 2012).

### **Application of QOL Assessment**

QOL as a concept began as a sensitizing notion during a time when there was widespread deinstitutionalization of people with I/DD. It has over the past few decades become a change agent, providing information through assessment on outcomes at an individual level (micro), an organizational level (meso), and at a systems and policy level (macro). The information gained from QOL assessment is utilized for development of person-centered supports at the individual level, quality improvement efforts at the organization level, and to inform policy at the systems level. However, as Brown, Hatton, and Emerson (2013, p. 322) point out, "...policy principles and organizational goals ostensibly designed to improve quality of life do not always match well with one another, and further, they do not match well with quality of life indicator measures at the individual level." So while much research has gone into the development of valid theoretical approaches to assess and evaluate QOL domains and indicators at an individual level, this information is not yet effectively or consistently reflected in organizational implementation of services, in systemic oversight of services, nor in development of policy that impacts people with I/DD.

QOL assessment has contributed to a change in the previous thinking that technological and medical advances could singularly improve an individual's QOL; there is now awareness that preferences, values, and environment may play a more significant role in QOL (Brown, Shalock, & Brown, 2009). Shalock and Verdugo (2002, p. 4) discuss a number of reasons why they believe it is important to assess and apply the QOL concept at all levels: 1) QOL is impacting program development and service delivery in many social service fields (i.e. education, ageing, health, I/DD), 2) the QOL concept is utilized as a means to evaluate the effectiveness of programs and services, and 3) QOL impacts individuals, organizations, and systems.

#### **Individuals/microsystem.**

At the microsystem QOL assessment informs the development of person-centered outcomes and can provide information to improve individual QOL. At the individual level what impacts QOL can vary widely, however it has been demonstrated through cross-cultural validation of QOL domains and indicators that people value the same broad aspects of QOL across and within cultures (Brown, Shalock, & Brown, 2009; Jenaro et al., 2005). There are multiple approaches to QOL at the microsystem level. First, personal life outcomes are identified and supported by QOL assessment. These outcomes frequently reflect the philosophy of engagement in a normative life, examples of which include concepts of inclusion, equity, choice, and self-determination. A second approach is seen in the inclusion of individual's with I/DD in the process of QOL assessment in several ways: providing self-report during assessment, assessing other individuals (e.g. Bonham et al., 2004), and working with researchers to determine and define QOL

domains and indicators. Finally, person-centered planning being the thrust of most systems of service delivery, personal outcomes and measurable indicators that are identified through QOL assessment are tied directly to service implementation and planning. Consequently, at the microsystem we see the emphasis on the evaluation and implementation of personal outcomes.

### **Organizations/mesosystem.**

The mesosystem of organizations, agencies, and communities lies between the individual perspective of the microsystem and the level of societal systems and policy at the macrosystem. Personal outcomes discovered through QOL assessment not only impact the lives of individuals but also the activities of organizations. As Shalock, Gardner, and Bradley (2007, p. 53) discuss, personal outcomes guide the values, methodology and metrics for designing, implementing, and evaluating success at the organizational level. One example at this level is the development and utilization of the 21 personal outcome measures that the Council on Quality and Leadership (CQL) has been using for over twenty years (Smith & Melda, 2014). These quality indicators are applied at the organizational level to assess, accredit, and transform service agencies (Brown, Hatton, & Emerson, 2013, p. 322).

A benefit of multiple organizations having the same conceptual and measurement framework is the ability to share information, learn from one another, develop partnerships with other organizations, revise organizational approaches to service delivery and quality improvement, and provide information to compare organizations throughout a community (van Loon et al., 2013). An example of this is seen with

Catholic Social Services in Alberta, Canada and their use of the assessment tool *My Life: Personal Outcomes Index*. This organization no longer measures inputs and outputs, but now uses personal outcome data and is able to make evidence-based decisions as well as compare their effectiveness with other organizations in Alberta, Canada. Within the mesosystem there is a growing recognition, through using personal outcome data, that the real standard of comparison is not the individual or even the organization, but rather the community (Shallock, Gardner, & Bradley, 2007; Cummins, Lau, Mellor, & Stokes, 2009; van Loon et al., 2013). Therefore, the emphasis at the mesosystem is on implementation of personal outcomes at the organizational level to design systems to improve QOL as well as QOL comparison within a local community.

#### **Systems/macrosystem.**

The use of personal outcomes at the systems level, or the macrosystem, must be examined first within the context of personal and human rights. Both legislative and legal trends at a national and international level have demonstrated the intent to ensure the rights of persons with I/DD. For example, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) represents the same underlying values as those reflected in the various QOL domain theories and has now been signed by 158 countries. Verdugo et al. (2012, p. 1037) argue that the concept of QOL is a relevant concept both to public policy determination and as an outcome for social policies. This connection between rights of persons with I/DD and the concept of QOL along with the emphasis at the systems level on accountability and efficiency is directing service

systems to develop performance indicators based on personal outcomes (Shalock, Gardner, & Bradley, 2007, p. 93).

An example of implementation at the macrosystem is the Ask Me! Survey used in the Maryland I/DD service system. This tool was developed by self-advocates in Maryland based on indicators of the eight QOL domains (Bonham et al., 2004). The survey is conducted annually and provides comparisons of an organization's average QOL with a statewide average as well as with the organization's previous averages. Additionally an annual report of the survey results presents system-level aggregate data, analysis of this data, and recommendations based on this analysis. Agencies use this information at an organizational level and the Maryland DDA uses the survey results at the systems level to establish system goals and measure achievement against established goals (van Loon et al., 2013). Finally, the survey results provide data to inform and guide policy development in Maryland.

Another example of implementation at the macrosystem is the use of Provider Profiles in Nebraska and in Catalonia, Spain (Verdugo et al., 2012). In Nebraska the aggregated results of the eight core QOL domains are published by organization and compared with an index of scores for persons both with and without I/DD in the organization's city. In this way comparisons can occur between organizations, with surrounding communities, and statewide. In Spain aggregated results are compared between people with I/DD, people without I/DD, as well as other sub-populations including people with mental health conditions, older people, people with drug dependencies, and people with HIV/AIDS (Gomez, Verdugo, Arias, Navas, & Shalock,

2013). Finally, at the macrosystem the QOL concept provides a framework for policy development and for systems level indicators.

### **Utilization by Systems**

As demonstrated by the macrosystem examples, the QOL concept and aggregate assessment data can be a useful tool for systems that develop and monitor the implementation of I/DD services at a county, region, state, province, or country level. Shalock (2004, p. 214) succinctly states that what we continue to learn about QOL and its application should make a difference in both peoples' lives as well as the policies and practices that impact those lives. However, due to the vast amount of research on QOL as well as numerous QOL assessment tools available it is a substantial challenge for public administrators to identify an evidenced-based process and an appropriate tool for this purpose. Gomez et al. (2013, p. 23-24) emphasize the usefulness of gaining information from a reliable and valid QOL measure to guide quality improvement, organizational change, evidence-based practice, and to improve QOL outcomes at both system and individual levels.

Additionally there are other considerations when planning to implement the use of QOL assessment at a systems level. First, policy makers, public administrators, and stakeholders must recognize the need for both financial and physical resources to develop the infrastructure needed to successfully implement QOL assessment. At the very least this would include the resources to administer the assessment and the development of an information management system for electronic data collection, analysis, and reporting. Second, there must be a shift in thinking from inputs and outputs to indicators that are

focused on outcomes. Planning at all levels of the system to realign process with outcomes in mind must occur for successful implementation (van Loon et al., 2013).

Third, implementing the QOL construct at a systems level will require overcoming administrative, regulatory, physical, and social barriers. One result of not addressing these barriers is failing to utilize data that was gathered through QOL assessment in strategic planning or management. Another result could be the exclusion of part of the population due to severity of disability, lack of access, lack of understanding and implementation at the organizational level, and/or ineffective use of the assessment tool which would result in inaccurate data. All of these items are of concern, as any one of them can render the process of implementation ineffective. A final consideration for use of QOL assessment at a systems level, van Loon et al. (2013, p. 86) emphasize that the provision of training at all levels is essential to develop the knowledge needed to implement QOL assessment and work with the resulting data.

#### **Proxy respondents.**

Of particular concern is the challenge of ensuring all individuals served within a system are represented in data collection. Considering the population of individuals with I/DD this can be difficult for those who have severe cognitive disabilities and/or significant challenges with communication. One way in which this concern is addressed is through the utilization of proxy respondents. This issue is discussed frequently throughout the body of the QOL research with specific emphasis on the reliability and validity of proxy respondents. Findings in the research are mixed and appear to be impacted by the degree of observability, complexity of the assessment tool, the



educational level of the proxy, as well as the relationship and familiarity with the person being assessed (McVilly & Rawlinson, 1998).

There is evidence of higher concurrence between individuals and proxies with objective information than subjective information (Shalock, Gardner, & Bradley, 2007). Cummins (2001) expressed concern with the use of proxies for reporting subjective QOL and recommends the use of proxy report only with objective QOL. McVilly, Burton-Smith, and Davidson (2000) demonstrate a high level of agreement using proxies as long as the proxy had close and regular contact with the person; they found little variability from gender, co-habitation, or role in the person's life (i.e. parent, sibling, or support staff). Conversely, Schwartz and Rabinovitz (2003) and Claes et al. (2012) found significant differences in agreement between support staff as proxies versus family members as proxies, with family members demonstrating a higher level of agreement particularly with subjective QOL. These are only a few of the available examples of conflicting findings related to the use of proxy respondents.

Some recommendations for consideration related to the issues of proxy response include utilization of a tool that has data on proxy response (e.g. Li, Tsoi, Zhang, Chen, & Wang, 2013), averaging the ratings of two proxies (e.g. Bonham et al., 2004; Shalock, Gardner, & Bradley, 2007), ensuring proxies know the person well (e.g. Schwartz & Rabinovitz, 2003), and inclusion of family members as proxy when possible (e.g. Claes et al., 2012). There is a general call for more research into the reliability and validity of proxies as well as the development of tools that can potentially gather self-report from individuals with severe cognitive disabilities and/or significant challenges with

communication. The San Martin Scale, developed and utilized recently in Spain, is a QOL assessment tool designed specifically for this sub-population that uses proxy respondents (Verdugo et al., 2014).

### **Aim**

The aim of this research is to identify and systematically review QOL assessment tools for adults with all levels of I/DD that could be used within disability service systems to examine the micro (individual), meso (agency), and macro (system) levels of QOL outcomes.

### **Methodology**

QOL assessment tools were identified from a search of published peer-reviewed literature. These parameters were chosen to be consistent with the two previously published systematic reviews on this topic. Searches were limited to the publication dates 1990 to 2014. This time frame was determined due to the fact that there was a substantial increase in the amount and quality of research on QOL for individuals with I/DD beginning in 1990 (Wong, Wong, Shalock, & Chou, 2011). Wong et al. (2011) describes a 13% increase in the amount of research in the last decade alone as compared with the previous twenty years. While there is some consensus within the literature that QOL research for this population began in the 1980s, the theoretical frameworks more widely recognized and utilized for this population began to materialize in the early 1990s (Brown & Brown, 2005; Shalock, Bonham, & Verdugo, 2008; Verdugo, Gomez, & Shalock, 2009). Therefore any assessment tools that have been utilized and validated from 1990 forward will more likely encompass accepted theoretical frameworks.

Articles were identified from a systematic search of all databases available within the University of New Mexico's EBSCOhost reference system. EBSCOhost is an online repository of more than 375 research databases including CINAHL, Medline, PsychINFO, and ERIC. Combinations of the following three groups of keywords were used for the initial search which occurred in December 2013: (1) Quality of Life; AND (2) assessment, OR evaluation, OR measurement; AND (3) intellectual disability, OR developmental disability, OR cognitive disability, OR mental retardation. The initial search was also limited to the previously stated date range (1990-2014) and articles in the English language. This initial search resulted in 755 articles. Two additional limits were then applied: (1) peer-reviewed, AND (2) NOT child. The search with these additional limitations resulted in 330 articles.

In the following initial screening phase the titles and abstracts of all 330 articles were reviewed to determine if the article included QOL measurement and a sample of adults with I/DD. Articles that did not include these two criteria were discarded. Articles focused exclusively on Health-Related Quality of Life (HRQL) or family QOL were also excluded. Duplicate articles (4) were also removed. The initial screening phase resulted in a sample of 97 articles.

The remaining 97 articles were read in their entirety. Using the same inclusion/exclusion criteria as in the initial screening phase, an additional 64 articles were excluded. These articles were primarily theoretical, addressed HRQL or family QOL, or examined a sample other than adults with I/DD. This resulted in a final sample of 33 articles that demonstrated the utilization of a QOL assessment tool with a sample of

adults with I/DD. Reference lists in each of the articles were reviewed to discover additional articles meeting the inclusion criteria. No additional articles were found. A search following the same procedure was replicated in May 2014 to ensure no additional articles had become available. This search produced two additional articles that met the previously established criteria. The final number of articles utilized for this systematic review was 35 articles (see the Appendix for references to included articles). See Figure 1 for a flow diagram of the article selection process.

Data were extracted from 35 articles to produce a body of information to allow for comparison of assessment tools. The following data were included in this comparison: name of assessment tool, sample size, sampling strategy, target population of the study, self/proxy administered, how administered, response format, number of items in the tool, study design, reported findings of reliability or validity, other analyses reported in the study, and recommendations of the study. This information was documented in an excel spreadsheet.

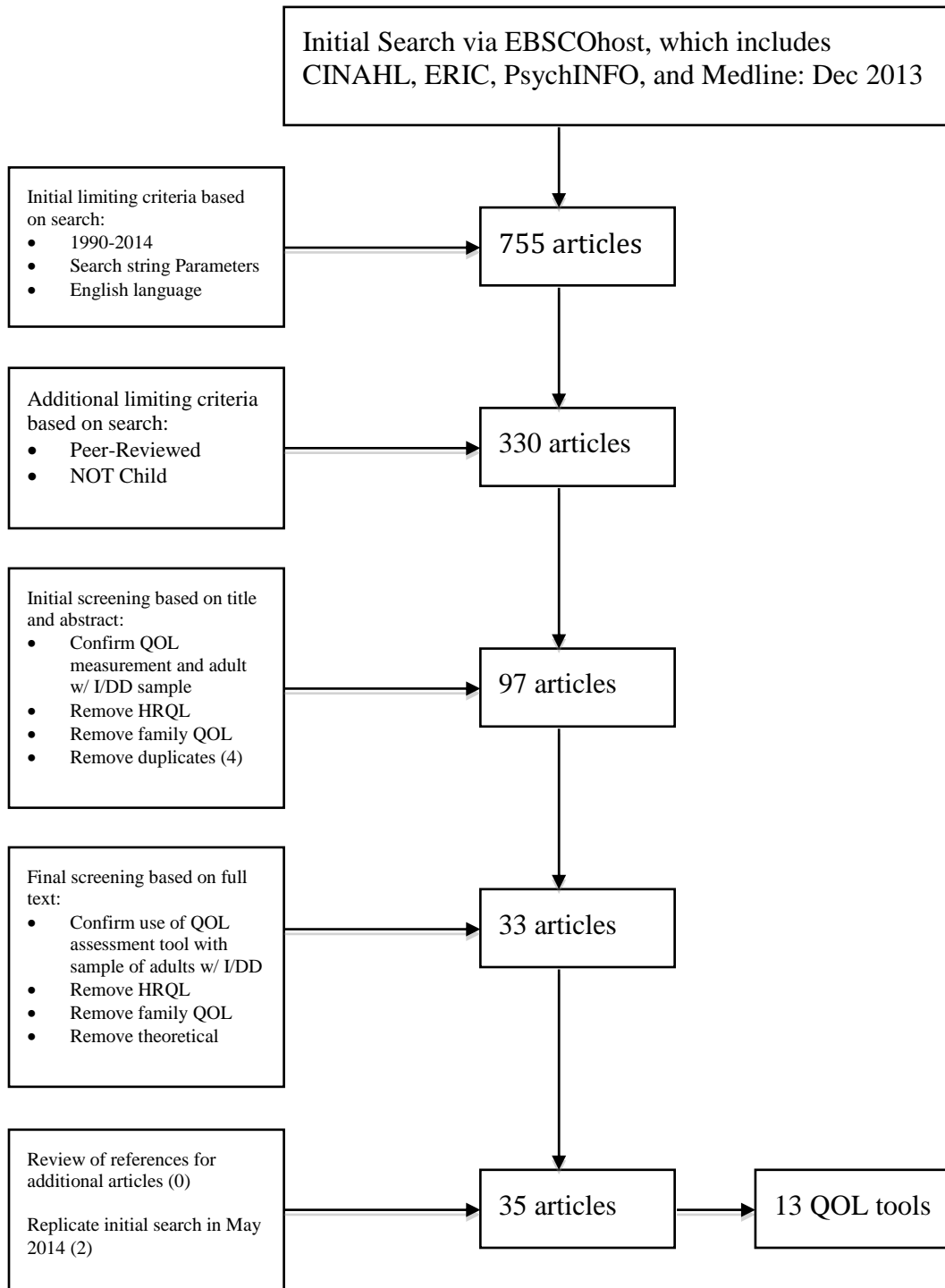


Figure 1. Flow chart of the systematic literature search. QOL = Quality of Life, HRQL = Health Related Quality of Life, I/DD = Intellectual and Developmental Disabilities

Tools were included in the final comparison if they had an English language version available (even if the study was examining the tool in another language), demonstrated theoretically based QOL factors, and were not limited to a specific residential setting. A total of 25 QOL assessment tools were utilized in the 35 articles, 13 were retained for the final comparison based on these criteria. Four tools were excluded because they had no English-language equivalent, three tools were excluded because they were in a language other than English but were based on an existing English language tool, one tool was excluded because it was not based on theoretical factors, two tools were excluded because of language and factors, one tool was excluded for a limitation in residential setting, and one tool was excluded because not enough information was provided in the article to determine if the tool used was different from the originating tool on which it was based. See Table 2 for a list of the 13 QOL assessment tools retained for comparison.

Table 2

*QOL Assessment Tools Identified for Comparison*

QOL Tool	Author(s)
Comprehensive Quality of Life Scale-ID (ComQol-ID)	Cummins, 1997
Evaluation of Quality of Life Instrument (EQLI)	Nota & Soresi, 2002
INTEGRAL Quality of Life Scale	Verdugo, Gomez, & Arias, 2007
Life Situation Survey	Chubon, 1987
Lifestyle Satisfaction Scale	Heal & Chadsey-Rusch, 1986
Maryland Ask Me! Project	Bonham, et al., 2004
Personal Outcome Measures	Gardner, Nudler, & Chapman, 1997
Personal Outcomes Scale	Claes, et al., 2009
Personal Wellbeing Index-ID (PWI-ID)	International Wellbeing Group, 2006
Quality of Life Questionnaire (QOL-Q)	Shalock & Keith, 1993
Questionnaire on Quality of Life (short form)	Craig & Harrison, 1986
San Martin Scale	Verdugo, et al., 2013
WHOQOL-DIS	WHOQOL-Dis Group, 2010

### Findings

The thirteen tools identified were compared in the following categories: theoretical basis and purpose, tool properties, psychometric characteristics, and intended or demonstrated use of results. Each category was chosen to provide information to guide public administrators when considering systemic implementation of a QOL assessment tool.

#### Theoretical Basis and Purpose

Within this category each tool was examined to determine its agreement with an accepted QOL domain theory as well as reflective of both objective and subjective QOL factors. All thirteen tools represent multiple QOL domains, as this was an element of the initial inclusion criteria. Five of the tools are not based on a current QOL domain theory in the literature, but do include multiple domains reflected in the literature. These tools are the Evaluation of Quality of Life Instrument (EQLI), Lifestyle Satisfaction Scale, Life Situation Survey, Personal Outcome Measures, and Questionnaire on Quality of Life.

The WHOQOL-DIS is based on the World Health Organization's domain theory. The Quality of Life Questionnaire (QOL-Q) is based on the 1993 Shalock and Keith four domain theory. Two of the tools, the Comprehensive Quality of Life Scale-ID (ComQol-ID) and the Personal Wellbeing Index-ID (PWI-ID), are based on the seven domain theory of Cummins (1997). Finally, there are four tools based on the Shalock and Verdugo (2002) eight-domain theory. These include the INTEGRAL Quality of Life Scale, Maryland Ask Me! Survey, Personal Outcomes Scale, and San Martin Scale.

One tool examined only objective measures, the Questionnaire on Quality of Life. Four tools examined only subjective measures: EQLI, WHOQOL-DIS, PWI-ID, and Lifestyle Satisfaction Scale. The EQLI, WHOQOL-DIS, and PWI-ID are designed to accompany another tool that includes objective measures and are recommended as a supplementary tool to look specifically at subjective QOL. The remaining eight tools included both objective and subjective measures: ComQol-ID, INTEGRAL, Life Situation Survey, Maryland Ask Me! Survey, Personal Outcome Measures, Personal Outcomes Scale, QOL-Q, and San Martin Scale.

### **Tool Properties**

Some of the considerations in choosing a tool include the length of the tool and how it is administered, as these two things impact resource utilization. Seven of the assessment tools are administered through a facilitated interview with a trained assessor and range from 7 to 56 items: Personal Outcomes Scale (48 items), Life Situation Survey (20 items), Maryland Ask Me! Survey (56 items), INTEGRAL (47 items), Personal Outcome Measures (25 items), Lifestyle Satisfaction Scale (29 items), ComQol-ID (35



items) and PWI-ID (7 items). One tool, Questionnaire on Quality of Life, is administered through a group discussion in either its full form of 70 items or its short form of 30 items. Two assessments, EQLI (18 items) and San Martin Scale (95 items), are in a questionnaire format. The QOL-Q (40 items) and the WHOQOL-DIS (13 items) are available in either facilitated interview or questionnaire formats.

All but one of the assessment tools utilize a Likert-type scale ranging from 2 points to 11 points. The Personal Outcome Measures creates an individual definition of each outcome measure accompanied by a yes/no designation. The following assessment tools provide an optional simplified version with fewer Likert-type options as well as face cards representing response choices: ComQol-ID (2-, 3-, and 5-point), PWI-ID (2-, 3-, 5-, and 11-point), Questionnaire on Quality of Life (3- and 4-point), and WHOQOL-DIS (3- and 5-point). The 3-point administration option occurred most frequently, represented as an option in seven of the thirteen assessment tools.

Additionally, it is important to consider if the tool is appropriate for all individuals with I/DD within a service system: Is it designed for all levels of I/DD and is there a proxy response option for people who are unable to self-report? The following three tools were only demonstrated with self-report and would therefore exclude those who are unable to self-report: INTEGRAL, PWI-ID, and WHOQOL-DIS. Three tools were designed or administered only to proxy respondents: EQLI, San Martin Scale, and Questionnaire on Quality of Life. This leaves seven assessment tools that provided the preferred option for self-report and/or proxy: Personal Outcomes Scale, Lifestyle Satisfaction Scale, Life Situation Survey, Personal Outcome Measures, QOL-Q,

ComQol-ID, and Maryland Ask Me! Survey. Finally, an additional consideration, the San Martin Scale was designed specifically for individuals who cannot participate in self-report due to profound I/DD and/or barriers to communication.

### **Psychometric Characteristics**

A detailed analysis of the psychometric properties of each of the reviewed assessment tools is beyond the scope of this project and is also limited due to minimal psychometric investigation in to most scales (Cummins, 2005). The systematic review of Li et al. (2014) provides detailed psychometric and measurement properties for six of the thirteen assessment tools included in this review: ComQol-ID, QOL-Q, Lifestyle Satisfaction Scale, PWI-ID, Maryland Ask Me! Survey, and Personal Outcome Measures. Li et al. (2014) discuss that the information available on reliability and validity of instruments varies widely and is frequently unavailable for comparison.

Comparison of reported psychometric properties was limited to information provided in articles reviewed and based on the recommended ranges published by Shalock, Gardner, and Bradley (2007, p. 36-38). Each tool was examined for evidence of reliability coefficients of equal to or greater than .80 in three categories: internal consistency, test-retest, and interrater. Personal Outcome Measures had no data reported for internal consistency reliability. The ComQol-ID, Maryland Ask Me! Survey, and PWI-ID had internal consistency reliability coefficients reported at under the .80 threshold. The remaining nine tools all reported an overall internal consistency reliability at or above the .80 threshold. There was limited data available on test-retest or interrater reliability, however three tools, ComQol-ID, QOL-Q, and Life Situation Survey, reported

test-retest reliability at or above the .80 threshold. The QOL-Q and the Lifestyle Satisfaction Scale reported interrater reliability at or above the .80 threshold. While one tool, QOL-Q, met the criteria in all three areas of reliability, findings have been inconsistent between multiple studies for this tool.

Validity was examined for each tool in the articles reviewed in three ways in accordance with the definitions and parameters published by Shallock, Gardner, and Bradley (2007, p. 36-38). Content validity was determined met if the article described the process by which the items in the tool were developed and that this process matched current domain theory as well as included input from experts. All thirteen tools included a description that demonstrated content validity. Construct validity was determined met if the article included information on completion of factor analysis for the current form of the tool. Eight of the thirteen tools described a satisfactory factor analysis. Finally, concurrent validity was determined met if the article described a statistical comparison with another QOL-related instrument. Five of the thirteen tools included information on satisfactory concurrent validity with another QOL-related instrument. Four tools demonstrated validity in all three categories: INTEGRAL, San Martin Scale, EQLI, and QOL-Q.

### **Use of Results**

Review in this category examined the use of each tool in the articles reviewed and categorized each assessment tool by its level of demonstrated usage: micro, meso, and/or macro. The Lifestyle Satisfaction Scale had demonstrated use at only a micro level. The Questionnaire on Quality of Life and the Personal Outcomes Scale were demonstrated at

both a micro and meso levels, but had no application in the available research at the macro level. The remaining ten assessment tools had demonstrated use at all three levels in the articles reviewed: ComQol-ID, EQLI, INTEGRAL, Life Situation Survey, Maryland Ask Me! Survey, Personal Outcome Measures, PWI-ID, QOL-Q, San Martin Scale, and WHOQOL-DIS.

### **Discussion**

When considering findings related to the theoretical basis and purpose for each assessment tool, it is preferable if the tool is based on a current QOL domain theory (Cummins, 2005). This provides an element of validity with the intended use of the tool as well as the process. Additionally, with a basis in current QOL domain theory there is increased opportunity for comparison between systems utilizing tools based on the same QOL domain theory. In conjunction with domain theory, unless the QOL tool chosen is a supplement to another QOL assessment tool or process, it is recommended by IASSID (Shalock et al., 2002) that both objective and subjective QOL be assessed. From a systems perspective, information on both objective and subjective QOL will provide a better data set with which to evaluate service implementation.

Implementation at a systems level requires public administrators to consider the characteristics of the QOL assessment tool and the resources required for successful system-wide implementation. These would include the ability to assess all individuals receiving services as well as the process by which the tool is administered. From this perspective it has been demonstrated as preferable to provide assessment through facilitated interview with the availability of a simplified scoring protocol to ensure that

the highest number of people with I/DD can provide self-report (Cummins, 2005; Shalock, Gardner, & Bradley, 2007). Additionally, there must be a proxy respondent option to include those who are unable to provide self-report. While the research previously discussed recognizes some limitations to the reliability of proxy respondents, it would be discriminatory to omit assessment data for people unable to provide self-report and would result in an incomplete data sample.

The psychometric characteristics of the assessment tool should demonstrate acceptable reliability and validity. Unfortunately, this aspect of QOL assessment is not consistently addressed with the development of each new assessment tool and lacks rigorous demonstration throughout the QOL literature. While efforts have continued to improve existing tools and develop new tools that demonstrate better psychometric properties, this review echoes the findings that Li et al. (2014) demonstrate in their research that there are few existing tools that meet recommended guidelines. This poses a challenge for future research in this area as well as for public administrators considering their options for implementation at systems levels. Cummins (2005) and Li et al. (2014) recommend to researchers to improve, develop, and refine existing instruments.

The review of psychometric properties provided in this research is not without limitations. First, not all tools included data for each type of reliability and validity examined. Next, even for those tools that do have data available the included measures (sample size, different domains, rating scales, etc.) are not heterogeneous and therefore not specifically comparable. Finally, each tool has a varying amount of research available to demonstrate its psychometric properties. While it is important for public

administrators to examine the psychometric properties of each tool under consideration, practitioners would be better served by an understanding of the limitations in the QOL research in general into reliability and validity of QOL assessment tools. This review, and others, should provide insight toward selection of a tool rather than direct a single choice. Reliability can also be examined using a specific tool during the implementation process with a pilot study.

Finally, previous demonstrated use at a systems level will provide public administrators with an example of how the tool was used, what information was gathered, and how that information was utilized. While this is not a pre-requisite to implement a QOL assessment tool at a systems level, it does allow public administrators to learn from past implementation processes as well as prepare to address the many considerations of QOL assessment at a systems level. Tools that have only been demonstrated at the micro level may not be appropriate for aggregation of data. It is recommended that public administrators consider tools that have already been demonstrated at the macro level.

Table 3 demonstrates a summary of the findings based on this discussion of preferred characteristics for implementation of a QOL assessment tool at a systems level. There is only one tool that meets all of the recommendations of this review, the QOL-Q. At this point, that is primarily due to lack of research into psychometric properties of each assessment tool. Tools that had no data available on a particular type of reliability or validity were marked as not meeting recommended criteria for reliability or validity. Additionally, while there are recommendations related to choosing an assessment tool for systems implementation, there are also decisions that must be considered that may impact

the choice of the assessment tool. For example, the use of proxy respondents and the use of resources to administer a facilitated interview type of assessment are considerations that will have a significant impact on which tool would best serve the needs of a particular system. Finally, this review is limited to a point in time. There may be new tools available or revisions to an existing tool that are better options than those reviewed here at a later date.

Table 3

*Summary of Findings*

QOL assessment tool	Based on current domain theory	Includes both objective and subjective	Administered by facilitated interview	Simplified Likert-type scale (2- or 3-point)	Proxy and self-report options	Acceptable reliability in three categories	Acceptable validity in three categories	Demonstrated use at micro, meso, and macro levels
ComQol-ID	Y	Y	Y	Y	Y	N	N	Y
EQLI	N	N	N	N	N	N	Y	Y
INTEGRAL	Y	Y	Y	N	N	N	Y	Y
Life Situation Survey	N	Y	Y	N	Y	N	N	Y
Lifestyle Satisfaction Scale	N	N	Y	N	Y	N	N	N
Maryland Ask Me! Survey	Y	Y	Y	Y	Y	N	N	Y
Personal Outcome Measures	N	Y	Y	N	Y	N	N	Y
Personal Outcomes Scale	Y	Y	Y	Y	Y	N	N	N
PWI-ID	Y	N	Y	Y	N	N	N	Y
QOL-Q	Y	Y	Y	Y	Y	Y	Y	Y
Questionnaire on Quality of Life	N	N	Y	Y	N	N	N	N
San Martin Scale	Y	Y	N	N	N	N	Y	Y
WHOQOL-DIS	Y	N	Y	Y	N	N	N	Y

Reliability and Validity are reported N if findings did not meet acceptable thresholds and/or if there was no data reported.



### **Conclusion**

The aim of this research was to identify and systematically review QOL assessment tools for adults with all levels of I/DD that could be used within disability service systems to examine the micro (individual), meso (agency), and macro (system) levels of QOL outcomes. Following specific inclusion and exclusion criteria, 35 articles from 1990-2014 were included in the review (references for included articles are listed in the Appendix). 25 QOL assessment tools for adults with I/DD were identified through the systematic review. Of these 25 QOL assessment tools, 13 were retained for comparison based on the following criteria: 1) an English language version is available, 2) the tool demonstrates theoretically based QOL factors, and 3) the tool was not limited to a specific residential setting. The thirteen tools identified were compared in the following categories: theoretical basis and purpose, tool properties, psychometric characteristics, and intended or demonstrated use of results. The intent of this comparison was not to identify a recommended tool, but rather to provide information on a variety of tools and how they may be utilized at a systems level. So while only one tool, the QOL-Q, met all of the recommendations of this review this is primarily due to a lack of available psychometric data for many of the other QOL assessment tools.

Final recommendations from this research include the need for additional research to improve available information on reliability and validity of existing tools, as well as to develop and validate new QOL assessment tools based on accepted theoretical factors. For public administrators planning or considering implementation of a QOL assessment tool at a systems level there are many considerations for success. Choosing an adequate

tool, planning appropriate resource allocation for implementation, providing training and developing understanding throughout a service system as part of implementation, gathering accurate data, and planning for utilization of data are only some of the considerations for success. This research was intended to provide a broad overview of the concept and construct of QOL as it is currently applied with people with I/DD, as well as a systematic analysis of QOL assessment tools appropriate for utilization at multiple levels (micro, meso, and macro). The QOL concept, integral to the field of I/DD, when utilized successfully can support people with I/DD to live meaningful lives.

## Appendix

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