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## Quality of life in children: A critical examination of concepts, approaches, issues, and future directions

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### HIGHLIGHTS

- Children deserve to experience a good quality of life (QOL).
- We examine three main approaches for understanding children's QOL.
- Issues and opportunities in research on children's QOL are discussed.
- We conclude social indicators and subjective well-being best capture children's QOL.
- QOL should be a universal indicator when we intend to advance well-being of children.

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### ABSTRACT

The quality of children's life is important both as an investment in the future of our society and because children constitute an important group of themselves and deserve to experience well-being presently. Quality of life (QOL) has been conceptualized and studied in children for several decades, but with disparate approaches that have rarely been discussed jointly with application to children in general. Here we describe and critically examine the three main approaches to children's QOL: health-related QOL (HRQOL), social indicators, and subjective well-being (SWB). Although this is not a review of instruments per se, we illustrate these approaches by describing their most prominent measures. Issues and opportunities in research on children's QOL are then discussed related to conceptual clarity, content specification, range of experience, subjective and objective perspectives, development in childhood, reporting source, and malleability of QOL. Finally, directions for advancing children's QOL are considered. We highlight the benefits of focusing on social indicators and SWB, rather than HRQOL, when representing this concept for children in general, the need for applying more sophisticated research strategies, and using QOL as a universal indicator of success whenever we intend to advance the well-being of children through intervention, programs, and policy.

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*Abbreviations:* QOL, quality of life; UNCRC, United Nation's Convention on the Rights of the Child; HRQOL, health-related quality of life; SWB, subjective well-being.

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The notion of quality of life (QOL) appears to have been introduced first in a public arena by President Johnson in 1964, when he stated “the great society is concerned not with how much, but with how good – not with the quantity of goods but with the quality of [its members’] lives” (quoted in [Rapley, 2003](#)). Initially, interest in the quality of children’s lives was mostly focused on survival indicators and objectifiable negative outcomes, including mortality, disease, and social problems affecting children. During the 1990s, it was argued that a concept of QOL could not merely reflect the absence of negative experiences, but had to encompass positive aspects of life as well ([Cummins, 1995](#)). Moreover, concern about QOL had to capture children’s own subjective sense of well-being to be consistent with the United Nation’s Convention on the Rights of the Child (UNCRC) ([United Nations, 1989](#)) Article 12, which states that children have a right to have their view taken into account in matters that affect them ([Ben-Arieh, Casas, Frønes, & Korbin, 2014a](#)).

Subsequently there was an explosion of activities using the concept of QOL, but with a diffusion of meaning such that QOL today can be viewed mainly as a general label to describe an assortment of physical and psychosocial variables covering a variety of more specific concepts. These include, for example, functioning, health status, symptoms, life conditions, material circumstances, perceptions, behavior, well-being, happiness, and lifestyle. Matching this growing interest, many instruments have been developed to measure children’s QOL. Reviews have assembled basic attributes of these instruments and evaluated their use (e.g., [Davis et al., 2006](#); [Huebner & Hills, 2013](#); [Matza, Swensed, Flood, Secnik, & Leidy, 2004](#); [Rajmil et al., 2004](#); [Ravens-Sieberer et al., 2006](#); [Ravens-Sieberer, Karow, Barthel & Klasen, 2014](#); [Zullig, Matthews, Gilman, Valois, & Huebner, 2010](#)). Whereas measurement of children’s QOL has attracted much attention, we believe a critical discussion of broader issues in children’s QOL research and applications will be beneficial. This is needed both to illuminate how the concept of QOL has been used to date and how to proceed for it to be used in the future for the benefit of children.

Whereas broader scholarly discussions have been published regarding adult QOL (e.g., [Eckermann, 2013](#); [Fayers & Machin, 2007](#); [National Research Council, 2013](#)), there have been few discussions of children’s QOL, broadly construed, for over a decade ([Koot & Wallander, 2001a](#)). The publication of a collection of 110 essays on children’s well-being is a welcomed recent exception ([Ben-Arieh, Casas, Frønes, & Korbin,](#)

[2014b](#)). Whereas children’s QOL as an area of inquiry has grown exponentially in the past decade, most of this research has focused on a limited aspect of this concept commonly referred to as health-related QOL (HRQOL). However, discussion of a broader conception of QOL that extends beyond HRQOL and is applied to children in general should be valuable to appreciate the fuller meaning and potential of this concept. Therefore we are concerned here with QOL of children in the population rather than of a specific group, such as patients with a disease. More specifically our aims here are critically to discuss: (1) the importance of addressing children’s QOL; (2) approaches to conceptualizing children’s QOL, focusing on the three main approaches of HRQOL, social indicators, and subjective well-being; (3) conceptual and methodological issues in child QOL research; and (4) directions for advancing understanding of children’s QOL.

## 1. Children’s QOL is important

The quality of children’s lives is important for multiple reasons. About 2.5 billion or about 32% of the world population is under age 20 ([United Nations, 2015](#)). The UNCRC declares that children at a minimum have the rights and freedoms of all human beings, including adequate nutrition, health care, and education, as well as freedom from abuse, violence, and exploitation. It also extends positively children’s right to “the development of [their] personality, talents and mental and physical ability to their fullest potential” (Article 29.1[a]). Consequently, the UNCRC establishes a specific concern about children’s QOL, without using this term.

Indeed, children’s well-being is mentioned in the UNCRC numerous times. Article 3 focuses on the best interests of the child, underscoring that “States’ parties undertake to ensure the child such protection and care as is necessary for his or her well-being...”. Moreover, Article 27 indicates “states parties recognize the right of every child to a standard of living adequate for the child’s *physical, mental, spiritual, moral and social development*” [emphasis added]. The UNCRC has been ratified by 193 of the world’s 196 recognized nations, albeit not by the U.S. (nor Somalia and South Sudan) ([Campaign for U.S. Ratification of the Convention on the Rights of the Child, 2015](#)).

Additionally, children are a vulnerable group. Because they are not empowered, nor commonly able to identify and address their own needs, children are dependent on adults to act on behalf of their rights,

including the right to a life of quality. Moreover, childhood is a specific developmental period that differs from other periods in life. Although it is important to consider children's QOL because they are members of the next generation of our society, this cannot be the sole justification for examining how children experience their lives. They cannot just be viewed as investments in the future because children experience life presently and have a right to a good life in this present (Ben-Arieh & Frønes, 2011). The UNCRC makes it clear that children's current well-being is important in and of itself. Indeed, it is beneficial for a society when all its members experience high well-being (Diener, 2000).

Finally, children's QOL should be important to examine to determine whether it is improving or deteriorating in response to changes that can affect them, planned or otherwise. Usually policies and programs are implemented for children to achieve some specific gains (e.g., educational intervention to achieve better learning; medical intervention to gain better survival), yet such gains must ultimately lead to improvements in the lives that children experience; or at minimum, QOL should not deteriorate over some time when such changes are made (Testa & Simonsson, 1996). Therefore a universal measuring stock should be useful that can be applied across different areas affecting children lives, such as education, social services, health care, and family policies, to evaluate their broader impact on their lives. QOL can be that universal outcome towards which all societal efforts regarding children ultimately should be directed.

The added value of the QOL concept for addressing children's rights and well-being as indicated above is that it constitutes a unifying concept that, as we will maintain, should contain the same domains for all children and include representation of their subjective experience. QOL goes beyond negative and performance indicators (e.g., physical impairments, psychopathology, academic achievement). The concept and its measurement can be used for understanding child motivations and needs for change at the individual level, and identify topics that need to be the focus of actions to be taken at higher levels including children's living environment (e.g., family, school) or societal context. The QOL concept may guide the understanding of personal, societal and policy oriented aspects of individuals' lives, as illustrated by decisions on end of life palliative care and decisions on investment in public resources and services. Child QOL as a unifying concept is expected to have its strongest impact if its conceptualization and operationalization are applicable to children at a global scale.

## 2. Current approaches to children's QOL

There are a large number of definitions of QOL, some examples of which are offered in Table 1. In fact, so many different QOL definitions, and corresponding measures, exist that they have been described as almost researcher specific (Borthwick-Duffy, 1996). This plethora led Schalock (1996) to propose that QOL should not be considered "an entity that one has or does not have to some degree, [but] should be viewed as an organizing concept [that] can be used for a number of purposes" (p. 123). Whether applied to children or adults, the various attempts at conceptualizing, and then measuring, QOL can be classified largely into three distinct approaches (e.g., Cummins, Lau, & Stokes, 2004; Diener & Suh, 1997; Michalos, 2004): (1) health-related QOL (HRQOL), (2) social indicators, and (3) subjective well-being (SWB). For each approach, we will provide an overview and highlight illustrative measures (see Table 2) before discussing critical issues associated with each.

### 2.1. Health-related quality of life (HRQOL)

#### 2.1.1. Overview

The health-related quality of life (HRQOL) approach has come to dominate consideration of QOL in children (as well as adults). HRQOL has become the most frequently used approach in epidemiological and clinical health research to assess and monitor children's QOL. Following the World Health Organization's (1948) definition of health as "a complete state of physical, mental, and social well-being, not merely the absence of disease," health consistently has been included as an important aspect of QOL (Moons, Budts, & De Geest, 2006). The concept of HRQOL was therefore developed to capture aspects of an individual's subjective experience related to health, disease, disability, and impairment and the effects of medical treatment (De Civita et al., 2005; Seid, Varni, & Jacobs, 2000). Although HRQOL has been applied in the general population of children (Varni, Burwinkle, & Seid, 2006; Wallander et al., 2012), it has most often been used to measure the status of patient populations, typically as an outcome due to medical activity. In fact, the International Society for Quality of Life Research (2015) stipulates that HRQOL is "the functional effect of a medical condition and/or its consequent therapy upon a patient," further delineating it to encompass "physical and occupational function, psychological

**Table 1**

Examples of definitions of quality of life (QOL)

Calman (1987): The perceived gap between an individual's hopes and expectations and their present experience.
Cummins (1997): QOL 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. Objective domains comprise culturally relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by the importance to the individual.
Felce (1997): QOL is defined as an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, productive, emotional, and civic well-being all weighted by a personal set of values.
Goode and Hogg (1994): QOL is experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in ma or life settings.
International Society for Quality of Life Research (2015): The functional effect of a medical condition and/or its consequent therapy upon a patient...[It is] subjective and multidimensional, encompassing physical and occupational function, psychological state, social interaction and somatic sensation.
Kosher, Jiang, Ben-Arieh, and Huebner (2014): The realization of children's rights and the fulfillment of the opportunities for every child to be all she can in the light of her abilities, skills, and potential.
Leidy, Rich, and Geneste (1999): Individual's subjective perception of the impact of health status, including disease and treatment, on physical, psychological, and social functioning.
Ravens-Sieberer et al. (2006): A multidimensional construct covering physical, emotional, mental, social and behavioral components of well-being and function as perceived by patients and/or other observers.
Schalock and Parmenter (2000): QOL encompasses the basic conditions of life such as adequate food, shelter, and safety plus enrichers such as social, leisure, and community activities. These enrichers are based on the individual's values, beliefs, needs and interests.
Varni (2014): Must be multidimensional, consisting at a minimum of the physical, mental, and social health generic core dimensions delineated by the World Health Organization.
WHOQOL Group (1993): An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations values and concerns, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment.
Wallander (2001): QOL can be defined as the combination of objectively and subjectively indicated well-being in multiple domains of life considered salient in one's culture and time, while adhering to universal standards of human rights.
Woodill, Renwick, Brown, and Raphael (1994): The degree to which a person enjoys the important possibilities of his or her life. This definition can be simplified to "How good is your life for you?"

**Table 2**  
Domains addressed by selected QOL measures.

Selected measures	Domains addressed
<i>Health-related QOL</i>	
PedsQL (Varni et al., 1999)	Physical Emotional Social School
KIDSCREEN-27 (Ravens-Sieberer et al., 2006)	Physical well-being Psychological well-being Parent relations and autonomy Social support and peers School
<i>Social indicators</i>	
Child Well-Being Index (Land et al., 2001)	Family economic well-being Health Safe/risky behavior Educational attainment Community engagement Social relationships Emotional/spiritual well-being
KIDSCOUNT Project (O'Hare, 2012)	Health Education Economic well-being Family and community
<i>Subjective well-being</i>	
Student Life Satisfaction Scale (Huebner, 1991)	Global life satisfaction (specific domains are not addressed)
Brief Multidimensional Students Life Satisfaction Scale (Huebner, 1994)	Family life Friendships School experiences Self Living environment
Personal Well-Being Index-School Children (Cummins & Lau, 2005)	Standard of living Personal health Achievement in life Personal relationships Personal safety Part of community Future security
Subjective well-being measures within the PROMIS framework (Ravens-Sieberer, Devine, et al., 2014)	Positive affect Life satisfaction Meaning and purpose

state, social interaction and somatic sensation." In a similar vein, other scholars have limited HRQOL to deal with life domains within the influence of the healthcare system (Seid et al., 2000; Ware, 1987).

HRQOL thus covers a broader notion than health status, encompassing perceived health, functioning, and impact on life domains (Simon, Chan, & Forrest, 2007), whereas health status is typically restricted to objective measurement of physical functioning. Within this general framework, specific definitions of HRQOL vary widely. Exemplifying this disagreement in defining HRQOL for children, some make reference to the impact of disease and treatment on the patient's perception of functioning in various life domains (Ronen, Rosenbaum, Law, & Streiner, 2001; Seid et al., 2000), whereas others incorporate the notions of personal values, opportunities and constraints related to one's health status (Feeny, Furlong, Mulhern, Barr, & Hudson, 1999). Yet others support a definition that underscores the physical, mental, and social aspects of well-being from the patient's perspective and/or other observers (Goldbeck & Schmitz, 2001; Sawyer et al., 2000). HRQOL has also been defined as the gap between the patient's actual and desired selves as a result of illness (Eiser, Cotter, Oades, Seamark, & Smith, 1999). These varying definitions notwithstanding, there are two central aspects inherent in most definitions of HRQOL in children (Eiser, Mohay, & Morse, 2001; Matza et al., 2004; Wallander, Schmitt, & Koot, 2001).

First, as evident from these definitions, HRQOL is subjective and therefore should be assessed from the individual's perspective whenever possible. However, the relative emphasis on appraisal of health function compared to meaning of one's health can vary among

conceptualizations of HRQOL (De Civita et al., 2005). Appraisal of functioning is derived from the biomedical perspective, emphasizing maintenance of functional abilities. In contrast, appraisal of the meaning of health informs about subjective satisfaction with health-related aspects of life or how the child feels about his or her relative health states. Meaning-based approaches also tend to shift the perspective from what the child can or chooses to do to what the child perceives as a discrepancy between actual and ideal health states (Eiser et al., 1999). Second, based on the WHO (1948) definition of health, there is consensus that HRQOL is a multidimensional construct. At a minimum, HRQOL addresses physical, mental, and social domains of health, yet there is a range across measures of addressing up to 17 health-related domains (Ravens-Sieberer et al., 2006; Solans et al., 2008). The most common additional domains have been self-esteem, body image, autonomy, family, school, and leisure.

### 2.1.2. Measures

One systematic review identified over 90 instruments for measuring HRQOL in childhood (Solans et al., 2008), divided into generic and disease-specific instruments. Generic, or non-categorical, instruments typically assess multiple domains that can be applied not only across various patient groups, but also in the general population. As a result, these instruments enable comparisons across different groups of children with and without disease (e.g., asthma vs. diabetes, low vs. high SES, across countries).

In contrast, disease-specific instruments obtain information about specific health problems, symptoms, and treatment experience pertaining to a given disease (e.g., brain tumor, end-stage renal disease, otitis media) or symptom (e.g., pain, sleep disturbance). However, because these cannot be used outside a targeted patient population, including in the general population, we will not consider them further here (see reviews by e.g., Matza et al., 2004; Palermo et al., 2008; Solans et al., 2008). Similarly, the utility-based model for measuring HRQOL is also restricted in its use to those experiencing health problems. Here preference value measurements are derived from decision and utility theories (Kaplan, 1989), where the evaluation of different states of health or balance between life quantity and quality is central. The most prominent examples of such systems for youth are the EuroQol (Hennessy & Kind, 2002) and Quality of Well-Being Scale (Kaplan et al., 1995). Because these too are only applicable to those with compromised health, this approach will not be discussed further here.

Just focusing on generic HRQOL instruments, at least 30 are available for use with children, which have been reviewed in detail elsewhere (e.g., Matza et al., 2004; Palermo et al., 2008; Ravens-Sieberer et al., 2006; Solans et al., 2008). Most well-established from among these are the Child Health Questionnaire (Landgraf, Abetz, & Ware, 1996), Child Health and Illness Profile (Starfield et al., 1995), KIDSCREEN (Ravens-Sieberer et al., 2008), Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999), and Youth Quality of Life (Edwards, Huebner, Connell, & Patrick, 2002). To illustrate the measurement of generic HRQOL, we highlight the two instruments currently receiving the most attention.

The PedsQL (Varni et al., 1999) generic module uses 23 items to assess four domains (see Table 2) to inform about both domain-specific and global HRQOL (connected to the PedsQL are also numerous disease-specific modules, applicable only to children with the specific disease in question). Items inquire solely about negative aspects of life, specifically about how much of a problem certain behaviors or experiences have been in the past month. There are parallel self- (5-18 years) and parent- (2-18 years) report forms. The PedsQL has been extensively researched, demonstrating excellent reliability, validity, and sensitivity (Palermo et al., 2008; Solans et al., 2008), in both general and patient populations of youth. Attesting to its wide applicability, over 75 international translations exist.

KIDSCREEN (Ravens-Sieberer et al., 2008) exists in both self- and proxy-report versions of different lengths, which were simultaneously developed in 13 European countries. For example, KIDSCREEN-27 covers five domains (see Table 2) with 27 items. Given the rather broad distribution of these domains, some may question whether KIDSCREEN is a measure of HRQOL or of a broader QOL concept, but its developers primarily refer to as the former. Items inquire about both negative and positive aspects of life in the past week, which is a departure from most other HRQOL measures that only address negative aspects. Research has shown that it is a reliable, valid, and sensitive HRQOL measure in populations aged 8 to 18 years (Ravens-Sieberer et al., 2008). KIDSCREEN has been translated to at least 38 languages.

### 2.1.3. Critique

Among the strengths with the (generic) HRQOL approach is that it broadens the definition of child health, such that it may be possible to capture more fully variability in the population of children (Simon et al., 2007). HRQOL information can be helpful in optimizing therapeutic strategies and in identifying effective treatments or ones to improve, aid in decision making about resource allocation within health care, and may contribute to health care quality assurance (De Civita et al., 2005). In addition to documenting patient reported medical outcomes, having comprehensive subjective measurements of child health may be useful more generally for evaluating policy decisions, identifying health disparities, and tracking population trends (Varni, Burwinkle, Seid, & Skarr, 2003). Several instruments of high psychometric quality are available to measure HRQOL, which have been used in a large body of research.

However, as an approach to understanding QOL in children HRQOL has limitations. Whereas health is an important aspect QOL, it is not synonymous with QOL. Strong self-reported health may occur together with low well-being; weak self-reported health may occur together with high well-being (Holte, 2014). Moreover, HRQOL in its current operationalization does not take changing views of health into account that go beyond the WHO definition. A recent discussion proposes to move from the present static formulation towards a more dynamic one based on the capacity to cope and maintain and restore one's integrity, equilibrium and sense of well-being. This view conceptualizes health as the ability to adapt and to self-manage (Huber et al., 2011). Under these considerations, HRQOL cannot be used to address QOL by itself. Focusing primarily on a limited set of domains disenfranchises other important areas that have arguably as much relevance for the human sense of well-being, such as being productive, having high self-esteem, feeling in control, and having a sense of optimism (Cummins et al., 2004). In essence, HRQOL lacks the conceptual breadth inherent in the concept of QOL.

Another primary problem with HRQOL is that excellent HRQOL is operationalized in the vast majority of applications as the absence of ill-being from the individual's perception. Despite being a positive attribute, HRQOL therefore is paradoxically measured as the inverse of perceived ill-being, such that the absence of perceived ill-being equates to high HRQOL (Cummins et al., 2004). Although not well tested empirically with children, research with adults has demonstrated that high ill-being is not the same as low well-being, and the absence of ill-being is not high well-being (Davis et al., 2006; Holte, 2014). Thus, HRQOL as measured in the vast majority of instruments concerns just one half of the perceptual universe of positive and negative states, and then only regarding health issues. Only recently has a measure exclusively focused on positive health been developed for adolescents, the Positive Health Scale (Warne, Snyder, & Gadin, 2014), consisting of nine items. Among these are items addressing being creative, decisive, and alert. Additional research is needed to evaluate the value of measuring HRQOL from a positive perspective and using this scale specifically.

As consequence of how HRQOL is measured, children with a disease or set of medical symptoms (e.g., pain) will by definition obtain lower

HRQOL than peers in the general population (Varni & Limbers, 2009). This can lead to the interpretation that medically compromised children have lower life quality more generally, which again is not a necessary conclusion. HRQOL as defined prevents such people from registering a level of QOL that is as high, or higher, than the general population mean by ignoring all aspects of life not related to an illness. People with a disease frequently reject being defined solely as diseased.

In conclusion, HRQOL, even in its generic approach, provides a limited perspective on QOL. To regain a fuller consideration of children's QOL, we need to look to alternative approaches. In fact, the development of two alternative approaches to considering children's QOL for the most part preceded the development of HRQOL, but became overwhelmed, in a sense, by the domination of the HRQOL approach.

## 2.2. Social indicators

### 2.2.1. Overview

Social indicators are "statistics, statistical series, and all other forms of evidence...that enable us to assess where we stand and are going with respect to our values and goals..." (Bauer, 1966, p.1). They are used to describe characteristics of a good life that are dictated by normative ideals based on religious, philosophical, or other systems (Diener & Suh, 1997). As societal measures, they reflect people's objective circumstances, typically in a defined cultural or geographic unit. Their hallmark is they are based on objective, quantitative statistical representations of people's conditions, rather than individuals' subjective perceptions.

The rapidly growing interest in child social indicators stems, in part, from a movement toward accountable public policy, which demands accurate measures of the conditions children face and the outcomes of programs designed to address those conditions. Common domains addressed by social indicators are wealth and material well-being, housing and living environment, education, health and safety, risk behaviors, and legal status. Social indicators can reflect many different aspects of life. Specific examples relevant to children include indicators of poverty, family structure, residential stability, infant mortality, vaccination and pediatric routine care adherence, classroom size, high school graduation, suicide, mental health diagnosis, tobacco use, and juvenile incarceration among others. Child social indicators are commonly population based, mainly used to reflect the QOL of a demographic group of children rather than measurements of individuals.

Although initially focused on child survival, indicators began to be developed that held societies accountable for more than the safety of children (Ben-Arieh, 2008). A parallel shift occurred in understanding the development of children, their needs and behaviors, and how to support optimal development (Steinberg & Lerner, 2004; Theokas et al., 2005). This new conceptual approach for social indicators was strengths-based, focusing on cultivating children's assets and positive relationships, beliefs, morals, behaviors, and capacities, with the aim to give children the resources they need to grow successfully across the life course. Despite this conceptual broadening, this approach is still challenged by how to incorporate strength-oriented measures alongside the traditional survival focused ones. Most social indicators are formulated in negative terms, a common challenge in measuring children's QOL. Yet, when positive social policies that support children's flourishing are enacted, indicators need to capture these positive changes, else there will be a lack of awareness of the effectiveness of such policies. Indeed, several countries (e.g., Ireland, England, Canada, Australia, New Zealand) have produced child QOL indicators that reflect this balance.

### 2.2.2. Measures

Specific systems of social indicators have been reviewed elsewhere (Fernandes, Mendes, & Teixeira, 2012; Lamb & Land, 2014; O'Hare, 2012). Among the most prominent systems used in the U.S., the *America's Children* report provides statistics on 25–30 key indicators of

child QOL, but only at the national level. The report produces no global index of well-being. As another prominent example, the Foundation for Child Development's *Child Well-Being Index (CWI)* (Land, Lamb, & Mustillo, 2001) is a yearly report using 28 indicators clustered into seven domains (see Table 2). Despite its scope, CWI lacks positive indicators of children's mental health, subjective well-being, or spiritual development. One of the best known indicator systems is the *KIDSCOUNT Project* of the Annie E. Casey Foundation (O'Hare, 2012), which uses multiple indicators mainly to rank the U.S. states in terms of overall child well-being based on four domains (see Table 2). Like most collections of indicators, KIDSCOUNT reflects problems or negative outcomes. In a similar vein, UNICEF (2015) reports annually on the *State of the World's Children*.

### 2.2.3. Critique

Among several strengths of social indicators (cf. Diener & Suh, 1997), objectivity is one. Because these indicators can be relatively easily defined and quantified, it becomes technically convenient to make comparisons across defined groups as well as time. In addition, social indicators typically reflect the normative ideals of a society. As well because these indicators address various life domains, they are able to capture important aspects of life that are not sufficiently reflected in purely economic yardsticks.

A basic issue with social indicators is whether purely objective measures adequately inform about children's QOL. Most definitions of QOL posit that it is primarily a subjective experience. Moreover, the use of social indicators appears inconsistent with the UNCRC, which stipulates that children's views should be taken into consideration in matters that affect them. Therefore, this approach should not be used by itself. One objection to social indicators is that wealth accounts for much variance in most other indicators; consequently, other indicators may add little additional information about children's QOL beyond their wealth. For example, an indicator of national wealth correlates .91 with a composite of a broader range of other social indicators (e.g., physicians per capita, college attendance) (Diener & Suh, 1997) and the most relevant correlates of a multidimensional child well-being index are parental education and professional status (Fernandes, Mendes, & Teixeira, 2013). The counter-argument is that, even with a very high correlation between wealth-related indicators, they are not equivalent, and each provides value-added information not contained in the other.

Despite their apparent objectivity, it is inevitable that value-based decisions enter into selecting and measuring social indicators. Even when there is agreement about what should be measured and these are accurately measured, the question remains whether each indicator unequivocally represents the society's notion of good. For example, infant mortality is a commonly used social indicator of the QOL of children in a state or nation. Yet, whereas infant mortality might be reduced for example from five to one per 1,000 births, this would require enormous medical expense as well as result in more surviving infants with severe disability (Diener & Suh, 1997). Whether this decrease in infant mortality would be desirable and worth the cost to society is a value-based judgment.

Another limitation of objective social indicators is that they may not accurately reflect everyone's experience of well-being. Individuals' sense of well-being is far more complex and multiply determined than assumed by descriptive social indicators based on external circumstances in a defined group. For example, objective social indicators were only modestly correlated with people's reported levels of subjective well-being (Diener & Suh, 1997). Finally, most social indicators, whether considered individually, in a composite, or as systems, are mainly useful to indicate well-being of an identified, typically very large, group of children (e.g., a racial/ethnic group, residing in a state or nation). Whereas this can be useful, social indicators fail to inform about the QOL of individual children. This limits their utility for a variety of purposes that are envisioned for the concept of QOL.

### 2.3. Subjective well-being

#### 2.3.1. Overview

The notion of subjective well-being (SWB) is grounded in the decidedly Western notion that the ultimate purpose of human experience is well-being, expressed for example as happiness, satisfaction, and meaning. Accordingly, the ultimate measure of social good must be the degree to which individuals have achieved such a state. As evidenced by a recent extensive collection of essays, this perspective is also well applied to children (Ben-Arieh et al., 2014b). Subjective measures of QOL were intended to add to but not replace objective social indicators. Yet, subjective appraisal is for many scholars essential for understanding QOL of an individual, a group, or a nation, with some even considering this a moral imperative (Rapley, 2003; Shea, 1976).

Growth in the scientific study of SWB has reflected larger societal trends concerning the value of the individual, importance of subjective views in evaluating life and its conditions, and recognition that well-being necessarily includes positive elements (Diener & Suh, 1997; King, Renó, & Novo, 2014). Indeed, the most important idea about SWB may be that it is typically positive (Cummins, 2010). Whereas most people evaluate their life experience as positive (Cummins, Li, Wooden, & Stokes, 2014), SWB as a construct incorporates the full range of well-being from very low to neutral to very high. In this manner, SWB reports can be sensitive to subtle changes above as well as below the neutral point. As a corollary, high QOL cannot be attributed merely by the absence of problems, but must incorporate degrees of positive experience, such as in terms of happiness, satisfaction, and meaning, to capture the full range of well-being and inform about the quality of people's lives.

SWB is a multidimensional positively oriented concept that encompasses how well life is going for a person (Ravens-Sieberer, Devine et al., 2014). Other terms essentially synonymous with SWB include perceived QOL (Huebner, Gilman, & Ma, 2012), psychological well-being (González, Casas, & Coenders, 2007), and subjective QOL (Cummins, 2000). A structure to SWB has emerged for adults consisting of three dimensions: (1) hedonic well-being, referring to states of pleasure and happiness; (2) evaluative well-being, referring to satisfaction with life (globally or in specific domains); and (3) eudaimonic well-being, referring to meaning, purpose, and self-actualization (National Research Council, 2013). It is unknown yet whether this structure applies equally well to children. As a complement to global evaluations of well-being, there are also more evaluations of happiness or satisfaction with different domains of life (e.g., work/contribution, residence, relationships). Yet, such dimensional assessments of SWB typically correlate substantially, supporting a higher order, global SWB construct (Cummins, 2005; Diener, Inglehart, & Tay, 2013).

There has been a large amount of research focused on SWB in adults, using a variety of measures (McDowell, 2010), which collectively supports the validity of this concept for adults. This research has found (cf. Cummins et al., 2004; Diener et al., 2013; National Research Council, 2013): (1) Differences in SWB between nations that differ in objective conditions; (2) differences in SWB between groups who live in different circumstances; (3) correlations between self-report and non-self-report measures of SWB; (4) genetic and physiological associations with SWB; (5) systematic patterns of change in SWB before, during, and after significant life events; and (6) prediction by SWB of future behaviors such as suicide. SWB reports also converge with other measures of well-being, such as with the reports of significant others, daily mood ratings, number of positive and negative events recalled, and clinical interviews (Diener et al., 2013). Although affect can influence reports of SWB, the latter is distinguished from transitory affective states (Cummins, 2010). When addressing life as a whole SWB is not strongly related to demographic variables (Huebner, 2004). Although currently growing, a similar expansive nomological net of findings regarding SWB in children is lacking.

Based on the substantial development of this construct, SWB is used to provide national accounts of QOL in over 40 nations now (Diener, Oishi, & Lucas, 2015), which can potentially be used to inform policy deliberations. The Center for Disease Control and Prevention in the U.S. is measuring SWB in some large-scale health surveys. Thus, interest in assessing SWB has become widespread, and the issue of using these measures for policy deliberations is a timely one.

Whereas these broad applications need to address SWB of children from the start, research on children's SWB is less developed currently. A handful of measures have been developed, but programmatic research is rare. Nonetheless, studies of global and domain-based SWB suggest that child and adolescent reports demonstrate moderate stability, reflecting a somewhat enduring trait-like component to SWB in childhood, but also sensitivity to changing life circumstances (Huebner, 2004). SWB appears related to, but separable from, different psychological constructs. A recent review (Cummins, 2014) concluded that adolescents' SWB correlates moderately ( $r_s = .2-.6$ ) positively with internal locus of control, self-esteem, extraversion, social acceptance, attachment, self-efficacy, psychological maturity, low impulsivity, and physical attractiveness, and negatively with stress, anxiety, neuroticism, depressive symptoms, loneliness, shyness, and risk behaviors (e.g., alcohol and drug use, aggressive and violent behavior, sexual activities). Thus assessment of levels of SWB in youth provide important information beyond that based on other psychological constructs, reflecting children's own perceptions of their life experience, as well as project future outcomes (Huebner, Suldo, & Valois, 2005).

This idea is further attested by findings from recent research on the consequences of individual differences in SWB in youth. Although the research base is small, there are now a few short-term (5-12 months) longitudinal studies demonstrating moderate stability of life satisfaction in youth (Lyons, Huebner, & Hills, in press). Moreover, lower levels of life satisfaction in adolescents predict important outcomes such as increases in peer relational victimization and lack of prosocial experiences (Martin, Huebner, & Valois, 2008), school disengagement (Lewis, Huebner, Malone, & Valois, 2011), and behavior problems (Lyons, Otis, Huebner & Hills, 2013). Such information should bolster arguments for the usefulness of collection of SWB data, including for example, in large-scale monitoring efforts as discussed above.

### 2.3.2. Measures

Scales developed to measure SWB and related concepts in youth have been reviewed elsewhere (Casas, 2014; Zullig et al., 2010). Most prominent are: Perceived Life Satisfaction Scale (Adelman, Taylor, & Nelson, 1989), Students' Life Satisfaction Scale (Huebner, 1991), Multidimensional Students' Life Satisfaction Scales (Huebner, 1994), Youth Quality of Life (Edwards, Huebner, Connell, & Patrick, 2002), and Brief Multidimensional Students' Life Satisfaction Scale (Seligson, Huebner, & Valois, 2003). Others have taken scales developed for adults and applied them to adolescents, for example Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) and Personal Well-Being Index (Cummins & Lau, 2005). Three are highlighted here.

Among the scales most examined in the U.S. have been two developed by Huebner and colleagues. The *Student Life Satisfaction Scale* (SLSS; Huebner, 1991) is a seven-item self-report measure for ages 8-19, where youth rate their satisfaction general items (e.g., "My life is better than most kids"). Research supports the SLSS as a brief, psychometrically sound measure of global life satisfaction for youth (Huebner et al., 2005). Among limitations are repetitive wording of items and the lack of a nationally representative normative sample. Because the SLSS measures only satisfaction with life as a whole, the *Brief Multidimensional Students Life Satisfaction Scale* (BMSLSS; Huebner, 1994) was developed as a five-item self-report measure of satisfaction in five specific domains of life (see Table 2). BMSLSS has satisfactory psychometric properties for ages 8-18. A growing research program further supports the utility of both SLSS and BMSLSS for measuring SWB in youth (e.g., Chappel, Suldo, & Ogg, 2014; Valois, Zullig,

Huebner, & Drane, 2009), including several translations and international applications (e.g., Barros, Petribú, Sougey, & Huebner, 2014; Zappulla, Pace, Cascio, Guzzo, & Huebner, 2013).

The *Personal Well-Being Index-School Children* (PWI-SC, Cummins & Lau, 2005) is an extension to school-age of a scale developed for adults (Cummins, Eckersley, Pallant, Van Vugt, & Misajon, 2002). Among eight items are included a global SWB item ("Happy with life as a whole") and seven domain specific items (see Table 2). These seven specific domains are designed to represent the first level deconstruction of global SWB, and contribute unique variance when regressed jointly against it (Tomyn & Cummins, 2011). An 11-item elaboration has recently been proposed with good model fit in two different cultures (Casas, Tiliouine, & Figuer, 2014). Thus far few studies have used PWI-SC with youth and apparently none in the U.S., but its psychometric performance in Australian and other samples shows promise. A drawback with this instrument is it is not recommended for children under 12 (Cummins, 2014).

In addition to these established measures, an item-bank for the assessment of children's SWB is currently being developed under the PROMIS framework (Ravens-Sieberer, Devine, et al., 2014). Thus far qualitative methods have been completed leading to a definition of SWB in children and identification of potential items that are now undergoing psychometric and cognitive testing. An iterative process including literature searches and interviews with experts, parents, and children, led to the identification of three subdomains of SWB in children (see Table 2). It remains to be seen how well measures based on this conceptualization and item generation will fare in empirical use.

### 2.3.3. Critique

A primary strength of using SWB to understand QOL is that it enables children to appraise their own personal QOL, using the full range from negative to positive well-being. SWB measures can take individual's values and preferences into account. Multidimensional SWB measures can reveal which life circumstances are more and less important in how young people experience the quality of their lives. These measures can provide information to the public and policy makers both about individuals and groups of people. There is a large body of research on adult SWB that may guide research on children.

On the negative side, there remains a conflict how to conceptualize SWB, whether it should be entirely about the global perspective or whether satisfaction with or happiness in specific domains matters. For now, measuring SWB both globally and in specific domains should be advantageous to build the knowledge base about SWB in childhood. More generally, research on SWB in children is severely underdeveloped in comparison with that on adult SWB. For example, it remains unclear whether the hypothesized structure of SWB for adults comprising hedonic (states of pleasure and happiness), evaluative (life satisfaction), and eudaimonic (meaning and purpose, personal growth, and goal attainment) dimensions (National Research Council, 2013) is relevant to children, although recent work under the PROMISE framework supports this (Ravens-Sieberer, Devine, et al., 2014). A range of studies are needed both to inform about the structure of SWB and begin to understand what contributes to variation in SWB in children (Huebner, Hills, Siddall, & Gilman, 2014; Proctor, Linley, & Maltby, 2009).

Although the psychometric quality of instruments using subjective appraisals by children of their own life experience has been evaluated, more research is needed into the moderation of the psychometric quality. Age and/or cognitive development are expected to influence the reliability and validity of such appraisals, but research has not yet addressed this systematically. Other potential confounders need to be examined as well, such as differences in life experiences. Because many children do not experience large changes in their life circumstances, the question remains how can they appraise their lives on a broad dimension of well-being not realizing the possible high and low points? Likewise, we know little about how culture affects SWB appraisals. Similarly, we need to know more about how psychological

factors (e.g., personality, coping behaviors) affects these appraisals (Lyons, Huebner, & Hills, *in press*). There is not yet a substantial body of research contributed by different investigators, using different approaches and instruments, with different samples of youth, to know much about the variation of SWB under different circumstances.

A conceptual limitation is that, as defined and measured, SWB may be missing a critical dimension of human well-being that is the more intangible, cultural, moral, and existential aspects of life that reflect and reveal the depths of the human psyche and the complexities of human affairs (Eckersley, 2013). It has been argued that SWB, like other conventional indicators, is measuring Westernization or modernization, rather than improved QOL or human progress and development (Eckersley, 2013). Whereas the qualities being included in SWB may be desirable, even necessary, they may not be sufficient for a life of quality. How this concern applies to SWB in childhood needs to be addressed.

### 3. Conceptual issues

#### 3.1. Conceptual clarity

There is a poor distinction when discussing QOL between its indicators and determinants. Indicator variables (the perception of life quality) constitute a measured end state, whereas determinants are elements that influence that end state. To disentangle indicators and determinants Cummins (2005) proposed first that all measures relevant to QOL may be characterized as addressing either indicator variables or determinants. Second, the indicator variables need to be hierarchically organized from general to specific, where the former may be characterized as “life as a whole” and the latter would constitute core domains of life, such as personal relationships, health, and achievements. This set of core domains could be determined by the criterion that each must contribute unique variance to the measure of life as a whole. The core domains could then be further deconstructed into sub-domains, if this is determined to be valuable. Both theoretical models and instruments to measure QOL should then reflect this hierarchical structure. When adopting this distinction, it then makes no conceptual (or psychometric) sense to combine indicator variables from different levels of this hierarchy (e.g. adding items addressing satisfaction with relationships and satisfaction with life as a whole) to achieve a composite of QOL. Rather QOL domains should be classified into levels.

Related to this issue is the distinction between indicators of child QOL and indicators of the child's context (Lee, 2014; Lippman, Moore, & McIntosh, 2011). Some measures of QOL combine items that directly address children's personal well-being with items assessing the quality of children's contexts (e.g., KIDSCREEN, BMSLSS). Children are embedded within multiple contexts including the family, peer group, school, and community, which likely to contribute to QOL. Because the process of interaction between the individual and context is central to child development (Bronfenbrenner, 1986), contexts are important for understanding children's QOL. However, they should be carefully distinguished from the indicators of QOL.

The use of HRQOL has also added to conceptual confusion. Researchers and clinicians have behaved, explicitly sometimes, implicitly often, as if high HRQOL equates to a high life quality generally. However, HRQOL does not have a simple linear relationship to ratings of overall well-being (Cummins, 2000), but represents limited aspects of well-being. Moreover, HRQOL is often used interchangeably with health or health status (Drotar, 2004). Yet a meta-analysis (Smith, Avis, & Assmann, 1999) substantiate that QOL and health are two distinct concepts. It has been proposed that QOL should address only well-being, such that domains that address ill-being not be included in the concept of QOL because the optimal functioning in health-related domains can have at most a neutral effect on QOL, not a positive effect (Hagerty et al., 2001). For example, if a child has no pain or symptoms, this could have no more than a neutral and not a positive effect on QOL.

Rather than behaving as if HRQOL informs about QOL, in part or wholly, conceptual clarity could be achieved if HRQOL is reformulated as a patient's perceived or subjective health and removed of apparent or perceived connections to QOL. That is, we should desist in referring to this as HRQOL. This reformulation appears consistent with the emphasis placed on patient reported outcomes in evaluations of medical interventions (Basch, Torda, & Adams, 2013; Doward & McKenna, 2004). Notwithstanding this, there is no doubt that health is an important domain to be considered in the broader concept of QOL.

#### 3.2. Content specification

It is intuitive that QOL may be described by its components, commonly referred to as life domains, but these can vary considerably across different approaches to QOL, as illustrated in the selected measures in Table 2. For example, social indicator systems uniformly capture economic status or wealth together with a few other domains. Most SWB and HRQOL approaches encompass well-being and/or functioning in the physical, mental, and social domains, but then vary considerably in the nature and number of domains that are added to these core domains. Added domains may include, for example, family, school, autonomy, future expectations, leisure, and environment. However, as discussed, it becomes confusing when indicators and determinants of QOL are mixed (Cummins, 2000; Lee, 2014).

Whereas the composition of QOL should be the same for all children, it is unclear how such domains should be characterized. Their identification must operate according to some theoretical principle(s). When theory is absent, confusion typically results (Wallander, 1992), and because the number of potential domains is so large, idiosyncratic opinions of researchers have ruled. A testable theoretical justification is rarely provided for each specific domain selection, including empirical support for the respective domains to represent the QOL construct.

Moreover, these domains have typically been generated and prioritized by parents and/or professionals. This approach however may overlook domains that are important from the children's own perspective, their feelings and personal experiences of well-being. It simply is unclear how well the generators have represented, or even can represent, the experience of children. Rather, identification of life domains that are important for children should be based to a large extent on information provided by children. Therefore the specification of QOL domains for children may benefit from a great deal of formative research to obtain the views of children's own well-being and its indicators (Crivello, Camfield, & Woodhead, 2009; Ravens-Sieberer, Devine, et al., 2014).

There will likely be substantial differences in the extent to which any life domain will be individually valued because of cultural and developmental differences. Nonetheless, there should exist an identifiable set of essential and fundamental building-blocks of life quality that are common to all children (Cummins, 2005). This implies it is possible to create a measurement of QOL that can be validly employed with any group irrespective of culture, socioeconomic status, disease, or disability, but much research is needed to achieve this end.

#### 3.3. The range of human experiences

There has been a strong preference for addressing negative experiences when evaluating QOL among both the social indicators and HRQOL approaches. Items included in many instruments refer to problems or difficulties, intensity or frequency of ill feelings, and/or comparisons between experienced self and ideal self and between self and other children. Consequently, the absence of negative evaluations is assumed to indicate good QOL, but this is false as previously argued. Good QOL can exist in face of adversity and the absence of adversity cannot be assumed to equal good QOL. This problem is generally not present for SWB approaches, which typically evaluate the full range of negative to positive states and experiences.

A construction of QOL must therefore include both negative and positive states and experiences to capture the full range of human experience. Whereas this seems self-evident, several challenges to the development of positive indicators of children's well-being have been identified (Lippman et al., 2011): (a) positive elements may reflect middle class expectations and need to be tested in diverse populations; (b) abstract and complex concepts need to be presented concretely and simply to children of varying developmental levels; (c) response bias due to social desirability needs to be minimized; (d) item wording and response categories with young and low-education respondents require testing; and (e) what parents can validly report about their children and what must be asked of children themselves needs to be evaluated, with attention to how the choice of reporter affects data quality. These challenges need to be addressed to capture the full range of children's experience.

#### 4. Methodological issues

##### 4.1. Objective and subjective perspectives

Objective perspectives on QOL focus on external, quantifiable conditions of life, such as family income levels, access to medical resources, and student-teacher ratio. In contrast, subjective approaches focus on individual internal evaluations of life conditions (e.g., degree of problem, satisfaction, happiness). Because the relationships between the two approaches have been quite modest, each presumably contains unique, complementary information that is relevant to understanding QOL (Huebner, 2004), with different strengths and weaknesses (Diener and Suh (1997). This argues that QOL should encompass both objective and subjective elements (De Civita et al., 2005; Wallander, 2001).

However, there is also a sentiment that QOL is purely a subjective experience determined by subjective appraisal of one's life condition, subjective well-being, and life satisfaction (Moons et al., 2006). Arguing for this perspective is also that QOL is not strongly determined by one's objective life condition (Cummins, 2000). Adopting a completely subjective perspective, however, is not without problems. It opens the door to individually determined criteria for QOL, rendering it difficult to compare groups of children or establishing a standard for good or minimally acceptable QOL. Moreover, the demonstrated lack of variability over time in individual's subjective well-being, even as objective conditions change (Cummins, 2014), possibly due to response-shift (e.g., Sprangers & Schwartz, 1999; Schwartz & Sprangers, 2000), may limit the utility of such an approach. This vexing dilemma of objective vs. subjective emphasis warrants considerable empirical attention to clarify, if not resolve.

##### 4.2. Development in childhood

More than adults, children are rapidly developing beings; they continually change in complex ways over time. The question of developmental sensitivity has challenged the construction of most measures for children, including QOL. Children have their own perception of what constitutes a good life, which may change over time as they mature (Koot & Wallander, 2001b). For example, an adolescent's QOL may include a greater focus on social roles and independence, whereas for a younger child it may be more focused on physical activity (Drotar, 2004). Developmental research is needed on what is a life of quality at different developmental periods. However, developmental comparisons of QOL have been rare, in particular using prospective longitudinal methods. Cross-sectional studies, for example, have shown that youth report decreasing SWB from age 12 to 16 (Casas, 2011; Casas et al., 2012).

In addition, QOL measures need to consider cognitive development, reading ability, and emotional maturity in the construction of an instrument (Eiser et al., 2001; Matza et al., 2004). Children at

different developmental stages may well understand and interpret questions differently (De Civita et al., 2005). The majority of the measures fail to take into account the need for different types of items and response formats for different developmental levels (Palermo et al., 2008). One exception is the PedsQL, which has versions tailored to children at different ages. It has been estimated that children can begin reporting on highly concrete domains of their own QOL between ages 4 and 6 (Matza et al., 2004; Varni, Limbers, & Burwinkle, 2007), whereas questions about life satisfaction provide valid assessment only as early as 8 years of age (Huebner, 1991).

##### 4.3. Reporting source

It is common when measuring children's QOL that adults, typically parents, report on the functioning and perceptions of children, either in addition to or in place of child self-report. However, this may be an improper application of the QOL concept, betraying its spirit of capturing the perceptions, evaluation, and aspirations of the individual being studied. As a result, we frequently speak of children's QOL, when in fact we often have available only adult perceptions of children's QOL. Understandably, there may be circumstances in which children are too young, too ill, or lacking the capabilities to report on their QOL. Parent reports have been used in such cases, often referred to as proxy-report (Quittner, Davis, & Modi, 2003).

However, the poor to moderate correlations and substantial discrepancy that characterize parent and child responses to parallel QOL items (Jozefiak, Larsson, Wichstrom, Matzejat, & Ravens-Sieberer, 2008; Upton, Lawford, & Eiser, 2008) have challenged the value of a parent as a straightforward substitute for a child's own report. Parent-child agreement is normally greater for ill compared with healthy children, and parents' reports appear to be in better agreement with the child's for observable behaviors, such as physical symptoms and function, but less so for cognitive and emotional attributes (Eiser & Jenney, 2007). A common assumption (although usually unstated) is that information from a parent is to be treated as proxy-report. The implication of labeling this as proxy report is that the parent is seen as an agent or substitute authorized to act for the child, and therefore should match that provided by the child if he or she could report. The basis for this assumption is debatable. Research comparing child and parent proxy reports in the general population has shown that parents evaluated their child's well-being and QOL on most life domains as better than the child him/herself (Jozefiak et al., 2008; Upton et al., 2008).

However, despite these disadvantages of parents' reports, they also have advantages, at least in the assessment of QOL in younger children. Parents have more developed evaluation capacities, while children perceive and evaluate the quality of their lives more in the present moment (Jozefiak, 2014). To resolve the role of parents' report of children's QOL, a reasonable argument is that parents can provide important *complementary* information about children (Eiser & Jenney, 2007), but this information should be treated and referred to for what it is, parent report rather than proxy report. By the definition of QOL, child report should be considered as the prime authentic report whenever it can be obtained, and parent report could represent important supplemental information about children's QOL (Jozefiak, 2014).

##### 4.4. Malleability of QOL

Brickman and Campbell (1971) first proposed that people have a set point for subjective QOL. For example, in a longitudinal study of adults, Headey and Wearing (1989) showed that, whereas negative life events tended to depress SWB, this was usually short-lived and people tended to recover their base-line levels some time later. This implies subjective QOL is not simply free to vary over its potential full range, but rather is held under some form of homeostatic control, in a manner analogous to blood pressure (Cummins, 2000). Accordingly, subjective QOL was proposed to be maintained by various cognitive devices that may include a

sense of control and positive cognitive biases. The purpose of this cognitive homeostasis could be to keep people feeling positive about themselves and their lives and avoid dominance by the negative states recognized as depression, anxiety, and stress. For example, lottery winners have been reported not to be significantly happier than non-lottery winners (Brickman, Coates, & Janoff-Bulman, 1978). The mean value from population surveys of subjective QOL conducted in Western nations lie within the narrow range of 70–80% of the upper end of QOL (Cummins, 2000). Even when objective changes are induced, for example when survival changes due to organ transplant, subjective (HR)QOL may not change accordingly (Sprangers & Schwartz, 1999). The set point or homeostatic theory of SWB would imply individual and societal efforts to increase well-being are doomed to failure.

However, this long-dominant theory of SWB has been challenged more recently by contradictory evidence (Diener, Lucas, & Scollon, 2006; Headey, 2010). For example, long-term longitudinal evidence indicate that about one-fifth of the population record substantial and apparently more or less permanent changes in their SWB (Wagner, Frick, & Schupp, 2007). Whereas the unexpected death of a child has been shown not surprisingly to change SWB set point (Wortman & Silver, 1987), so too has cosmetic surgery (Frederick & Loewenstein, 1999) and other experiences (Headey, 2010). Diener et al. (2006) focus on major life events in explaining set-point change. In contrast, Headey (2010) propose that personality traits and life goals make some significantly more likely than others to change their long-term SWB.

Because these observations are based on research on adults, the question remains to what extent children's subjective QOL also exhibits characteristics of homeostasis, but research is scant. On the one hand, Cummins (2014) report emerging evidence that support this case. On the other hand, the moderate test-retest reliability when measuring SWB over one and two years (Antaramian & Huebner, 2009) and changes in responses to planned and unplanned life experiences (Gilman & Handwerk, 2001; Lyons, et al., in press) suggest subjective QOL may be more malleable in youth. Intriguingly, a 10-week group wellness-promotion intervention was found, when evaluated in a randomized controlled trial, to improve previously depressed SWB in middle school students, which was maintained at six months follow-up (Suldo, Savage, & Mercer, 2014). Further research is into the malleability of QOL in childhood is needed.

## 5. Advancing children's QOL

### 5.1. Advancing the QOL concept

We have reviewed three common approaches to QOL in childhood – HRQOL, social indicators, and SWB – and concluded that to advance understanding of children's QOL, research and applications need to emphasize social indicators and SWB, providing information about objective and subjective QOL, respectively (Wallander et al., 2001). Our view is that HRQOL provides an inadequate perspective on QOL because it restricts consideration of children's QOL chiefly to limited specific domains and to ill-being rather than well-being.

### 5.2. Advancing research on QOL

We have argued that child QOL is an important concept for understanding children's experience. However, we pointed to a number of conceptual issues regarding the distinction between QOL indicators and possible determinants, and the need for QOL domains to apply to all children, reflect the child perspective, and the range of experiences. Several methodological issues were also noted, including the distinction between objective and subjective perspectives, the need for a developmental approach to conceptualization and measurement, the use of child and parent reports, and the problem of homeostasis.

Research on children's QOL has been rather limited to date, leaving many questions to be informed empirically, of which only a few can

be highlighted here. Most studies on child QOL have focused on specific, typically small populations, such as children with particular health problems. Only a few studies have examined QOL in large community samples (e.g., Jozefiak et al., 2008; Varni et al., 2006; Wallander et al., 2012) and cross-national comparisons are scarce (Ravens-Sieberer et al., 2008). As well, the vast majority of studies have compared the QOL of some defined population to another, identified correlates of QOL, or examined QOL changes in response to an intervention. The restricted range of research on QOL in children has retarded its development as a useful construct for advocating for children. To advance the field, a few important topics for future research can be identified:

#### 5.2.1. Theoretical development

We need to clarify the meaning of QOL for children and its relationship to related concepts to develop theoretical models of QOL. In addition, research on children's QOL needs to address its etiological influences, developmental trajectories, and factors that may moderate and mediate these trajectories to inform theoretical developments. Theories must be refined to make specific predictions about how input variables differentially influence the components of QOL. In the past, many researchers have treated QOL as a monolithic entity, but there are separable components to QOL that may exhibit unique patterns of relations with different variables (Diener, Suh, Lucas, & Smith, 1999).

#### 5.2.2. Methods

Sophisticated research designs beyond cross-sectional surveys need to be implemented to advance understanding of QOL in children, such as cross-cultural, longitudinal, causal modeling, experience sampling, and experimental approaches. In fact, researchers have only rarely explored the causal status of variables that might influence QOL. We need to move beyond examining the main effects of traits and processes that may on average promote QOL and rather study the factors that determine when, for whom, and to what extent those factors are associated with QOL (McNulty & Finchman, 2012). Different measurement methods should also be explored (e.g., based on experience sampling) to move beyond the predominance of self- and parent-report questionnaires.

#### 5.2.3. Objective and subjective perspectives

It is as yet unclear what objective indicators may add to subjective assessment of well-being in childhood QOL. Despite this, it may be simply impossible to obtain reliable subjective information from some youth themselves, when for example they are too young or cognitively limited. However, it is unclear how the typical global indicators in use today can inform about individual children's QOL. Therefore we might need to turn to objectifiable indicators (e.g., decrease in school achievements or peer contacts) that may signal deterioration in a specific child's QOL. Research is needed identifying such objective indicators.

#### 5.2.4. Addressing development

We need to find ways to identify domains and subdomains of QOL that are applicable to children across the globe and are sensitive to developmental change in experience and importance. In line with that we need to develop objective and subjective indicators that can be reliably assessed at different ages and are sensitive to developmental changes, but at the same time facilitate comparisons across age periods. Formative research may be useful to meet these needs.

#### 5.2.5. Child and informant reports

Given the lack of congruence between self- and parent-reports of child QOL with the simultaneous need for informant reports for some groups of children, it is imperative to find ways to test the validity of self-reports and increase the validity of informant reports. We also need to develop useful strategies for how to combine these sources of information, a challenge in much child development research. Not only should we examine from what age and under what capabilities

child reports are valid or invalid, but also when we should use child self-reports, parent reports, or both.

### 5.2.6. Malleability

Research is needed on children's adaptation to life circumstances and whether homeostasis seeking is powerful, such as when it does and does not occur, its limits, and the processes associated with some likely maintaining and others demonstrating malleability in their QOL over time and experiences. People in ill health, physically unattractive people, and victims of crime often show average levels of QOL, reflecting ability to adapt (Diener, Wolsic, & Fujita, 1995; Michalos & Zumbo, 2000). Yet the processes responsible for adaptation are poorly understood, especially in children. Research that examines how habituation, coping strategies, changing goals, and supports influence adaptation will shed light on the processes responsible for QOL (Diener et al., 1999).

### 5.3. Advancing QOL as the ultimate goal

Given that a major motivation in contemporary society is for individuals to experience a life of quality, QOL should be adopted as the universal outcome towards which all our efforts regarding children ultimately should be directed. It would be the most general, overarching goal to which more specific goals would be added that would reflect specific applications. QOL thus should be measured to evaluate impact of all applications that affect children, to be able to evaluate impact on children's life experience. For example, QOL should be evaluated in large-scale evaluation of effects of social policy or different models of human service provisions or interventions; to specify issues and groups in need of research, training, and service development; for development of models for the provision of individually-centered services and interventions; and to screen for problems at the population level and identify vulnerable subgroups (Rapley, 2003; Wallander et al., 2001). To advance this agenda, the considerations offered in this review might offer a fruitful starting point.

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