

## Learning about Quality of Life for Young People with Severe or Profound Disabilities

*“Embracing the sounding forth of a soul means honouring the nonverbal knowledge and connection that is always already there, while seeking untiringly to give that soul access to the fullest means of expression” ~ Anna Stubblefield*

### Background

Quality of life (QOL) has been **defined and assessed in many ways** depending on the purpose of the inquiry. However, some researchers suggest certain areas of agreement are emerging that include the acknowledgement that assessment involve a **subjective** (i.e., self-perceived) **global appraisal of QOL** by an individual, as well as the identification of **physical, psychological, social, and environmental factors** that are thought to contribute to that appraisal (Logsdon, Gibbons, McCurry, & Teri, 2002).

Increasingly, researchers are **asking children, youth, and young adults** with chronic conditions and disabilities to **directly report** on their QOL. Evidence is emerging about what QOL means to these young people and what is important to it (McDougall et al., 2015).

But what of those young people who have difficulty responding or who are not able to respond to questions about their QOL because they **cannot communicate their thoughts, feelings, and experiences through language?** How can their life quality and the various factors that contribute to it be known?

The QOL of young people with severe or profound disabilities has largely been ignored, especially those living in institutional settings (Gibson, King, Kingsnorth, & McKeever, 2014).

When QOL is studied for these individuals, the focus tends to be on objective and external conditions, such as their physical condition and services offered (Rey, Extremera, Duràn, & Ortiz-Tallo, 2013). Although objective assessments are critical, **innovative research** designed to **understand the subjective QOL** of young people with severe or profound disabilities is also required.

### Purpose of this Summary

The **purpose** of this summary is: a) to review the possible approaches for learning about the subjective QOL of young people with severe or profound disabilities; and b) consider some of the research that has occurred in this area thus far.

### Possible Approaches

#### *Cognitive Evaluations/Modifications*

QOL **self-assessment** should be the **first-line option** when investigating the QOL of children, youth, and young adults with chronic conditions and disabilities. It should not be assumed that they are not able to complete a QOL assessment until it has been indicated otherwise. Careful consideration of young people’s cognitive and language abilities should be given. **Evaluations** of these abilities should take place to identify if they can in fact report on their internal thoughts (White-

Koning et al., 2005). Research has shown that individuals aged 12 to 22 years with a language comprehension and cognitive functioning level of grade three can complete multi-item, Likert scale measures containing psychosocial content, with support from a caregiver/health professional (King et al., 2014).

Moreover, if a young person has the cognitive ability, but **requires another format other than language** to respond to open- or closed-ended research questions about QOL, efforts should be made to facilitate that individual's participation. For example, rather than verbally responding to a Likert scale, use of a pointing device, eye gaze or other **technology may facilitate communication**. Similarly, if a child cannot answer open-ended questions verbally, they may share their thoughts and feelings by identifying or drawing **symbols or pictures** or through **photo elicitation** (King et al., 2014).

If, however, self-assessment is just not possible, there are other options described below that may not be as ideal, but can still **provide valuable insights** into the subjective QOL of these young people and the factors that are related to it.

#### *Proxy Reports using Quantitative Methods*

Proxy reports refers to obtaining ratings of an individual's QOL from another source, such as a **parent or service provider**. Research that compares ratings of individuals with disabilities who are able to report on their QOL with parent and service provider ratings is mixed, with some studies finding significant discrepancy and others finding very close agreement (White-Koning et al., 2005). Proxy ratings are no replacement for self-assessments. However, for individuals with severe or profound disabilities they provide a reasonable alternative.

It is important to involve individuals who have

**in-depth knowledge and a close relationship** with people with severe or profound disabilities when obtaining QOL proxy reports (Petry, Maes, & Viaskamp, 2005). Indeed, it is **critical to involve the family**, as research suggests family members maintain frequent contact and involvement with their children, even if they are living in residential homes (Seltzer, Krauss, Hong, & Orsmond, 2001).

#### *Proxy Reports using Qualitative Methods*

Most studies of QOL using proxy ratings for individuals with severe or profound disabilities have been **quantitative in nature**. Moreover, the measures used in those studies have rarely been created with this specific group in mind. One study revealed that mothers of transition-aged young adults with severe intellectual disabilities were dissatisfied with the standardized measure of QOL they completed for their children (McIntyre, Kraemer, Blacher, & Simmerman, 2004). They felt that it **did not capture the idiosyncratic nature** of their children's lives. The researchers then interviewed the mothers using a **qualitative interview** approach. Findings revealed unique information about the young adults. For most young people of this age, transition to work or vocational opportunities is an indication of life quality. In this group, only 2 of 30 mothers identified work as essential to the QOL of their children. This may speak to the need to **reconsider what makes life good** for young adults with severe or profound disabilities at this point in their life (McIntyre et al., 2004; Gibson et al., 2014).

Other qualitative research in this area has included **multiple proxy reporters**. One study examined the domains of QOL for children, youth, and adults with profound multiple disabilities living at home or in community settings as operationalized by 40 parents and 36 direct support staff who were familiar with the individuals (Petry et al., 2005). What contributes to QOL for people with profound

multiple disabilities was found to be similar overall but different in important and distinct ways from other groups of people. Families and staff were found to have **high agreement** when rating QOL domains for individuals.

### *Observation*

An alternative approach to the subjective appraisal of QOL for young people with severe or profound disabilities is **direct or video observation**. Satisfaction or dissatisfaction of individuals can be identified through their expressions, mood, and behaviours when observed in their natural environments (Petry et al., 2005). The subjective experiences of people who have severe or profound disabilities can be identified by observing and learning what makes their day-to-day life good, such as the enjoyment of sensory experience, the company of another, or doing an activity. To date, little QOL research has employed this approach with young people. In one study involving 27 young and older adults with severe and profound intellectual disabilities, behavioural observations provided specific information about the affective life of these individuals, and indicated that mood and emotions can be distinguished from each other (Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2013a).

### *Physiological Measures*

The use of physiological measures to assess subjective QOL of persons with severe or profound disabilities is just starting to be explored. This approach involves investigating how the **respiratory, cardiovascular, thermal and/or electrodermal response systems** are associated with emotions. A study including three adults with profound disabilities showed physiological differences exist between positive and negative emotions, and that individuals tried to avoid negative stimuli (Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2010). Use of observation and physiological measures may be helpful for understanding

more about individuals' communicative abilities, their interests, their response to the environment, and, ultimately, their subjective QOL (Petry & Maes, 2006).

### *Triangulation of Methods*

Obtaining information about the QOL of young people with severe or profound disabilities using a variety of methods and comparing across those methods could be the best way to obtain a **comprehensive and valid assessment**. Initial research shows the merit of this type of approach (Petry & Maes, 2006; Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2013b). If it is not at all possible for people to communicate their thoughts, feelings, and experiences through language or a modified approach, then obtaining quantitative and qualitative data from multiple proxy reporters close to the individuals, in addition to the use of physiological measures and/or direct observation in natural settings, may be the next best way to learn about their subjective QOL. Moreover, objective assessments of people's health, their support, and their environment are essential as they depend on others to ensure they are safe and treated with respect and dignity.

### **Conclusion**

#### **All lives are precious and deserving of quality.**

Despite the difficulties in studying the subjective QOL of children, youth, and young adults with severe or profound disabilities, more efforts should be made in this regard. The development and testing of measures and measurement approaches for assessing QOL specifically for this group based on their direct feedback when possible, and family and staff who work closely with them, would help QOL research to move forward and ultimately inform service delivery. The **primary goal** of obtaining this type of information is to ensure that individuals **enjoy their life to the fullest** and that they are receiving the benefits of living in safe and supportive environments.

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