What Really Matters?

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Focusing on Quality of Life in Public Policy

Background

- Pressing need to evaluate the efficacy of disability rights interventions and identify best practices
- The construct *quality of life* (QOL) is an appropriate outcome measure for interventions related to the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Karr, 2011; Verdugo, Navas, Gómez, & Schalock, 2012).
- No validated instrument for studying QOL in populations that include persons with visual impairment
- Statistical validation of a QOL instrument requires an established understanding of the meaning of QOL for persons with VI.
- **Problem:** There is no existing theory of QOL as understood and experienced by persons with visual impairment.
- Purpose: to provide researchers, rights organizations, educational advocates, and others with a better understanding of quality of life for young adults who are blind, promoting policy changes which target QOL

Theory of QOL for persons with VI

Instrument validation

Meaningful inclusion of people with VI in QOL studies to evaluate effectiveness of disability rights interventions

Research Questions

Primary question: What is the essence of "quality of life" as experienced by young adult students who are blind and enrolled in postsecondary educational programs? **Secondary questions:**

- 1. How is the essence of quality of life as experienced by young adult students who are blind influenced by the student's primary and secondary school experiences?
- 2. To what extent is the essence of quality of life experienced by young adult students who are blind similar to/different from the theoretical models, constructs, and indicators of quality of life present in existing quality of life instruments and research?

Research from Rebecca Sheffield's Doctoral Dissertation at Texas Tech Univ. with support from OSEP/National Leadership Consortium in Sensory Disabilities Committee: Dr. Rona Pogrund, Dr. Margaret Price,

Dr. Theodore Darid Mauro

Dissertation available for download at www.rebeccasheffield.com

Support from \$ and Mobilit Technology Money Writing Braille State and **Equal access** programs Being accepted and Insensitivity **External** Support college pre System Knowledge Interand Skills dependence Quality of Life Internal Experiences Support System meaningfu Independence Confidence orking har Adaptabilit Making Self-Outlet mistakes determin-**Proactivity** Being in motion Self-reliance advocacy

Building on Theory to Shape Policies that Target QOL

QOL Themes are Important Policy Indicators...

Quality of life for young adults who are blind can be described using six major themes.

- Parents/families as part of the external support system
- Rural vs. urban communities, transportation, efficiency
- Assistive technology
- Balance between independence and interdependence
- Authentic learning experiences; learning from self, parents, and community
- Individuality of internal support system, levels of comfort

... to Shape Education Policy

The essence of quality of life as experienced by young adult students who are blind is influenced in multiple ways by the students' primary and secondary school experiences.

... for Evaluating Disability Rights Interventions

The essence of quality of life experienced by young adult students who are blind is both similar to and different from the models, constructs, and indicators in existing research.

IASSID SIRG-QOL (Schalock & Verdugo, 2002)

- Similarities: "Self determination," "material well-being," "external system of supports," "education," "social inclusion," "interpersonal relations," "emotional well-being"
- Differences: micro-/meso-/macro- structure, "rights," "physical well-being"

WHOQOL (WHO DMHPSA, 1997)

- Similarities: "independence," "environment," "psychological," "social relationships"
- Differences: "knowledge and skills" and "experiences" not present in WHOQOL, "physical health," "spirituality/religion/personal beliefs"

