

Enhancing Family Quality of Life Across the Lifespan

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Why is Family Quality of Life Important?

- Families are the core unit of society and typically the first, most enduring, and most important entity to which individuals with disabilities relate (Turnbull & Stowe, 2001).
- Previous family research has mostly focused on negative family outcomes.
- Family quality of life is universal.



Values Guiding Research

- Participatory action research
 - Researchers and families partner throughout all stages of the research process in order to attain research results and ensure the utilization of results.



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Participatory Action Research as a Model for Conducting Family Research

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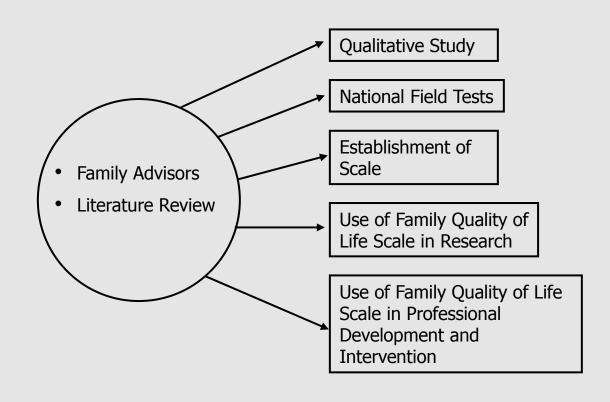
> Carmen Ramirez Austin, TX



Research on the Conceptualization, Measurement, and Intervention of Family Quality of Life



Steps in Conceptualizing and Measuring Family Quality of Life



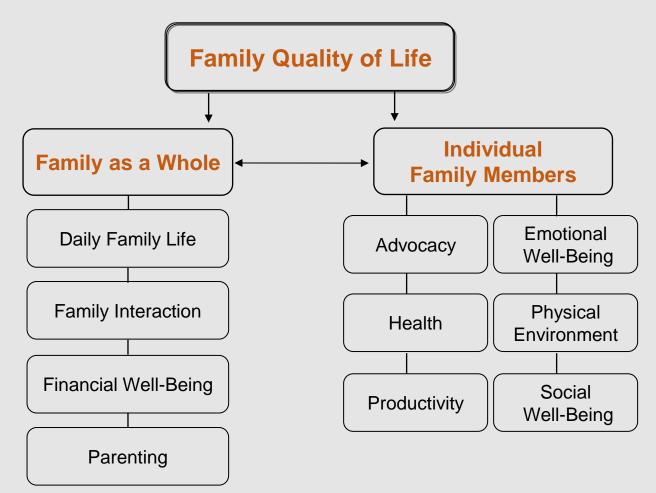


Qualitative Study

- Involved 33 focus groups and 34 interviews
- Used general questions
 - o"Tell us about times when things have gone really well in your family. What helps them go well?"
 - o"Tell us about times when things have been especially difficult. What is it that seems to trigger the difficult times?"
- Resulted in 10 domains of family quality of life.



Qualitative Study: Family Quality of Life Domains





Qualitative Study

MENTAL RETARDATION

VOLUME 41, NUMBER 5: 313-328 | OCTOBER 2003

Family Quality of Life: A Qualitative Inquiry

Denise Poston, Ann Turnbull, Jiyeon Park, Hasheem Mannan, Janet Marquis, and Mian Wang

Abstract

In this qualitative inquiry we investigated the conceptualization of family quality of life. Focus groups and individual interviews were conducted with 187 individuals: family members (e.g., parents, siblings) of children with a disability, individuals with a disability, family of children without a disability, service providers, and administrators. Data were collected in urban and rural settings to elicit the participants' understanding of family quality of life. Ten domains of family quality of life were identified and described in terms of subdomains, indicators, and key points raised by participants. Implications are discussed in terms of future directions for research and family support.



National Field Tests

- Confirmatory Factor Analysis
 - Involved two studies with a total of approximately 500 families in seven states
 - Confirmed the factor structure with a five-factor solution and 25 items
 - Established validity in terms of the correlation with other quality of life/well-being measures
 - Established test-retest reliability



National Field Tests

LESA HOFFMAN The Pennsylvania State University

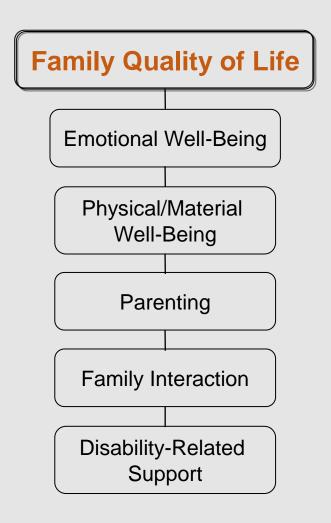
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Assessing Family Outcomes: Psychometric
Evaluation of the Beach Center Family Quality
of Life Scale



Family Quality of Life Framework









Emotional Well-Being

Definition: Refers to the feeling or affective parts of family members and family life

Sample Indicators:

- My family members have the support we need to relieve stress.
- My family members have some time to pursue their own interests.
- My family members have friends or others who provide support.



Friends or Others who Provide Support





Physical/Material Well-Being

Definition: Refers to the resources available to the family to meet its members' needs

Sample Indicators:

- My family gets medical care when needed.
- My family members have transportation to get to the places they need to be.
- My family members feel safe at home, work, school, and in the neighborhood.

Feeling Safe at Home, Work, School, and in the Neighborhood







Family Interaction

Definition: Focuses on the relationships among family members

Sample Indicators:

- My family members show that they love and care for each other.
- My family members support each other to accomplish goals.
- My family enjoys spending time together.







Disability-Related Support

Definition: Focuses on support from family professionals, friends, and provided in order to benefit the family member with a disability

Sample Indicators:

- My family member with a disability has support to accomplish goals at school or at work place.
- My family member with special needs has support to accomplish goals at home.
- My family has good relationships with the service providers who provide services and supports to our family member with a disability.

Having a Good Relationship with Service Providers









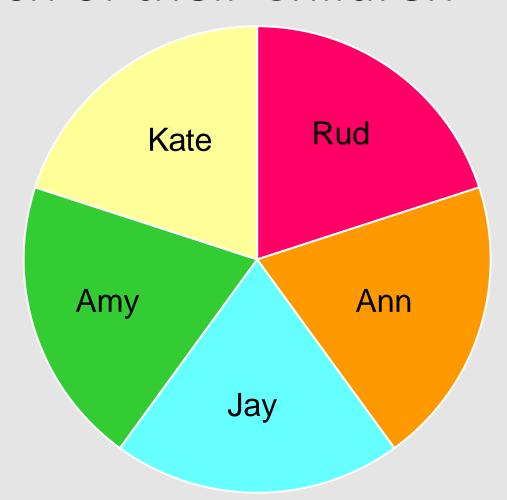
Parenting

Definition: Refers to activities that parents do to help their sons and daughters develop.

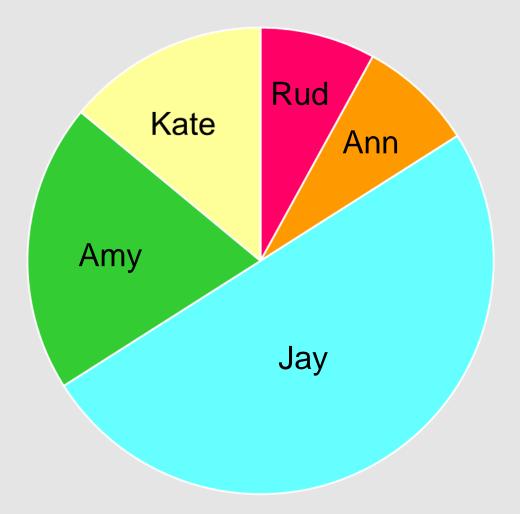
Sample Indicators:

- Adults in our family teach their sons and daughters to make good decisions.
- Parents help their sons and daughters learn to be independent.
- Adults in my family have time to take care of the individual needs of each of their children.

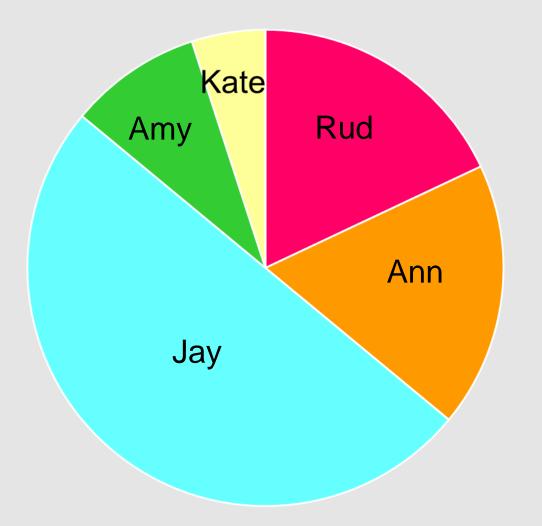
Having Time to Take Care of the Individual Needs of Each of their Children













Sample Excerpt from Beach Center Family Quality of Life Scale

Но	w <u>satisfied</u> am I that	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1.	My family enjoys spending time together.					
2.	My family members help the children learn to be independent.					
3.	My family has the support we need to relieve stress.					
4.	My family members have friends or others who provide support.					
5.	My family members help the children with schoolwork and activities.					
6.	My family members have transportation to get to the places they need to be.					



http://beachcenter.org/sites/beach.drupal.ku.edu/files/images/general/Families/1.%20Beach%20Center%20Quality%20of%20Life%20Scale.pdf

Beach Center Family Quality of Life Scoring Guide

BEACH CENTER FAMILY QUALITY OF LIFE SCALE Psychometric Characteristics and Scoring Key



The Beach Center Family Quality of Life Scale (hereafter referred to as FQOL Scale) assesses families' perceptions of their satisfaction with different aspects of family quality of life. The focus of our original development of the FQOL Scale was on families of children with disabilities ages birth through 21. We are currently studying its application to families of children without disabilities and families of adults with disabilities.

General Description

The FQOL Scale contains five subscales: Family Interaction, Parenting, Emotional Wellbeing, Physical / Material Well-being, and Disability-Related Support. This scale is designed to be used as a research tool. Some examples of potential uses of the scale include:

- As a pre- and post-test to measure the effectiveness of an intervention
- As an outcome measure for programs or services
- As a measure of a dependent or independent variable

The FQOL Scale is not to be used to determine or deny eligibility for services nor is it a clinical measure for diagnostic purposes.



http://beachcenter.org/sites/beach.drupal.ku.edu/files/images/general/Families/Family%20Q uality%20of%20Life%20Psychometric%20Characteristics%20and%20Scoring%20Key.pdf

Beach Center Family Quality of Life Conversation Guide

Family Quality of Life Conversation Guide

Developed by the Beach Center on Disability,
University of Kansas,
in partnership with
families, service providers, and researchers



Use of Family Quality of Life Scale in Research

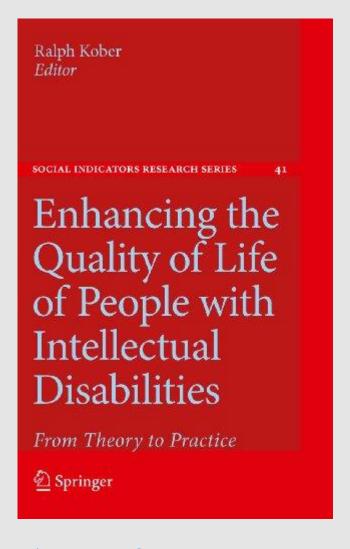
- Domains of least satisfaction
 - Emotional well-being
 - Disability-related support
- Domains of greatest satisfaction
 - Parenting
 - Family Interaction



Summary of Family Quality of Life Research

- Four characteristics associated with higher family quality of life
 - Higher family income/income supplements
 - More support from family, friends, and community
 - More effective disability-related services
 - More trusting partnerships with professionals





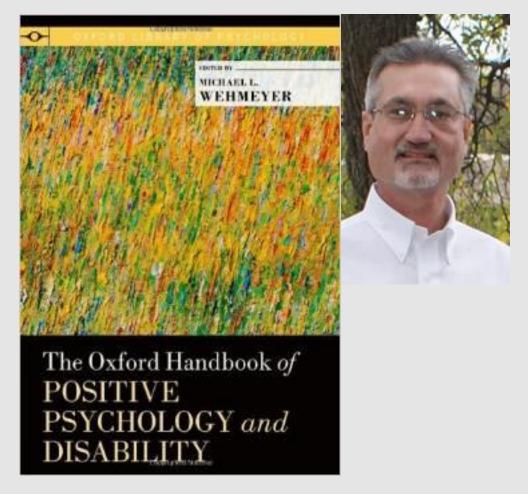


https://www.amazon.com/Enhancing-Quality-People-Intellectual-Disabilities-ebook/dp/B00F8JZTH2/ref=sr_1_1?ie=UTF8&qid=1506700479&sr=8-1&keywords= Enhancing +the +Quality+of+Life+of+People+with+Intellectual+Disabilities

Abstract

In this chapter we present a unified theory of family quality of life (FQOL) for families of children with intellectual and other disabilities. We begin with a review of the definitional and explanatory components of FQOL and the variables forwarded in the family quality of life (FQOL) literature. We depict FQOL as an interactive process in which individual family member demographics, characteristics, and beliefs interact with family-unit dynamics and characteristics within the context of individual and family-level supports, services, and practices. This interactive inner framework of the model is further impacted by federal, state, and local systems, policies, and programs. Using the basic building blocks of theory and empirical data from the family quality of literature, we illustrate how these unique components combine to produce an explanation of FQOL. We end with a working theoretical model of FQOL which serves as a guide for researchers to generate multiple testable theoretical statements.







https://www.amazon.com/Handbook-Positive-Psychology-Disability-Library/dp/ 0190227508/ ref=sr_1_1?ie=UTF8&qid=1506701597&sr=8-1&keywords=The+oxford+ handbook+ of+positive+psychology+and+disability CHAPTER

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Family Quality of Life

Caya Chiu, Kathleen Kyzar, Nina Zuna, Ann Turnbull, Jean Ann Summers, and Vivi Aya Gomez

Abstract

Family quality of life (FQOL) shares a mutual goal with positive psychology in its emphasis on strengths and the enhancement of well-being. This chapter reviews trends in family research related to family quality of life in the disability field and draws parallels with the positive psychology field in terms of a gradual evolution from a negative to a positive orientation. This evolutionary progress is highlighted in terms of reviewing current research (published after 2000) within a FQOL theoretical framework, with a focus on systemic factors, family-unit factors, individual-level factors, family and individual support, and outcomes. Recommendations are provided for future research that will contribute to enhancing FQOL in families who have children with disabilities.

Key Words: family quality of life, family, systemic factors, family-unit factors, individual-member factors, support factors, supports



Use of Family Quality of Life Scale in Professional Development

- Doctoral level special education family seminar
 - Use domains and indicators of as a way to organize seminar for readings, discussion, and literature reviews
- Masters and undergraduate courses
 - Use Beach Center Family Quality of Life Conversation Guide to interview families and to learn ways to provide relevant support to them



Beach Center Family-Professional Partnership Scale

How <u>satisfied</u> are you that your child's service provider	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
 Helps you gain skills or information to get what your child needs. 					
2. Has the skills to help your child succeed.					
3. Provides services that meet the individual needs of your child.					
4. Speaks up for your child's best interests when working with other service providers.					
 Lets you know about the good things your child does. 					
6. Is available when you need them.					
7. Treats your child with dignity.					
8. Builds on your child's strengths.					



https://beachcenter.lsi.ku.edu/sites/default/files/inline-files/1.%20Beach%20Center%20Quality%20of%20Life%20Scale.pdf

Beach Center Family-Professional Partnership Scoring Guide

BEACH CENTER FAMILY-PROFESSIONAL PARTNERSHIP SCALE Psychometric Characteristics and Scoring Key



General Description

The Partnership Scale contains two subscales: Child-Focused Relationships, and Family-Focused Relationships. This scale is designed to be used as a research tool. Some examples of potential uses of the scale include:

As an evaluation tool to measure satisfaction with programs.

As an outcome measure to assess pre- and post- effects of training on the family-professional partnerships.

As a measure of a variable (relationship satisfaction) that might affect other family outcomes, such as family quality of life, participation in education, etc.



https://beachcenter.lsi.ku.edu/sites/default/files/inline-files/Family%20Quality%20of%20Life%20Psychometric%20Characteristics%20and%20Scoring%20Key.pdf

Beach Center Family-Professional Partnership Self-Assessment Guide

1. I help parents gain the skills or information to be able to get what their child needs (provide training to parents, help parents access information on resources).

Score	What Helps	What Hinders	

2. As a professional, I have the skills to help children succeed (have basic competencies, engage in continuous learning to gain new information and skills, hold high expectations for the child's achievement and provide meaningful opportunities for him or her to succeed).

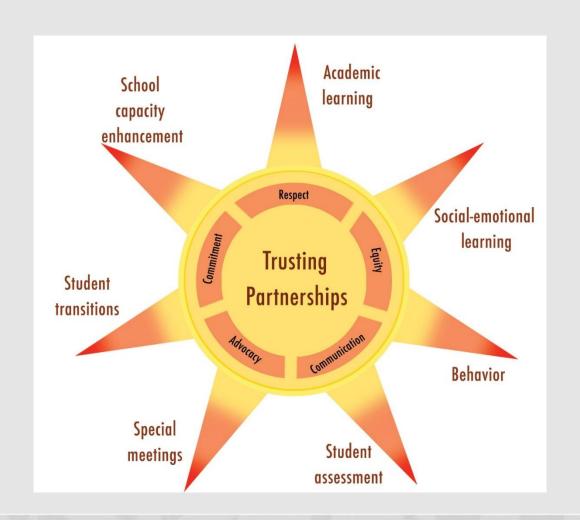
Score	What Helps	What Hinders



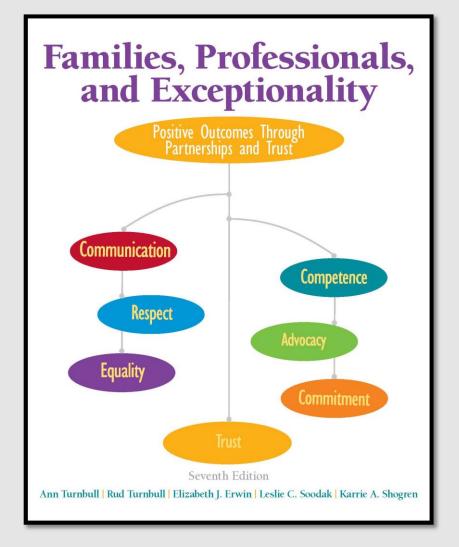
Research: Using the Partnership Scale

- Families who experience stronger partnerships with educators experience less family stress (Burke & Hodapp, 2014).
- Satisfaction with partnerships leads to increases in family quality of life (Eskow, Summers, Chasson, & Mitchell, 2018; Kyzar, Brady, Summers, Haines, & Turnbull, 2016).
- Families' satisfaction with services depends on the level of satisfaction they have with their partnerships with professionals (Kyzar, Brady, Summers, Haines, & Turnbull, 2016; Summers et al., 2007).
- Professionals' partnership skills are needed for higher family quality of life; and these
 partnership skills may buffer the effects of low outcomes of student progress in
 knowledge and skills (Kyzar, Brady, Summers, & Turnbull, 2018).

Sunshine Model of Trusting Partnerships









https://www.amazon.com/Families-Professionals-Exceptionality-Partnerships-Loose-Leaf/dp/0133833682



Alone we can do so little; together we can do so much.

— Helen Keller —

AZ QUOTES

