Chapter 15
Theorizing About Family Quality of Life

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Value of a Theory of Family Quality of Life

In the past two decades, research and scholarship have led to greater advancements in the conceptualization and measurement of quality of life (QOL) for individuals with intellectual disabilities (Cummins, 2005; Schalock et al., 2002; Verdugo, Schalock, Keith, & Stancliffe, 2005). More recently, researchers in the international disability field have begun a similar process of conceptualization and measurement of family quality of life (FQOL) in families of individuals with intellectual disabilities (Isaacs et al., 2007; Turnbull, Brown, & Turnbull, 2004; Turnbull, Summers, Lee, & Kyzar, 2007). Despite these advancements, several critical issues remain unresolved. Several conceptual frameworks proposing domains of FQOL circulate the field (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Verdugo, Cordoba, & Gomez, 2005). This diversity is reflected in a range of measurement indicators and response stems proposed to assess FQOL. The accumulated research also reveals varying stages of psychometric development of the current FQOL assessment tools (Turnbull et al., 2007). Finally, with FQOL researchers primarily directing their attention toward the identification of indicators of FQOL and development of measures to assess FQOL as an outcome, little attention has been devoted to theory development to propose critical elements both within and outside the family that may explain variations in that outcome. To date, no theory of FQOL has been explicated in the literature.

Given research conducted to date, it is an opportune time to engage in the theorizing process to guide future FQOL research. As we will note in this chapter, a theory requires (a) definitions of concepts, (b) a set of propositions hypothesizing the relationships among variables, and (c) an overarching premise that provides an explanation for an outcome of interest. We will demonstrate that current research on

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FQOL in the disability field has provided sufficient evidence to enable us to propose a unified theoretical framework to depict relationships among multiple variables impacting FQOL in families who have a member with a disability. Theory guides research; research informs policy and practice. Therefore, we hope that research derived from a unified theoretical framework of FQOL would (a) inform systemic operations across education, health, and social service agencies to effectively and efficiently serve families who have a child with a disability, (b) result in new and enhanced legislation and agency policy to address families' fundamental needs, and (c) demonstrate the necessity of a sufficient number of appropriately staffed programs to meet families' service and support needs.

Further, it is our aim to present a unified theory of FQOL that would help to inform and organize an interdisciplinary research agenda. As an area of research, FQOL for families who have children with intellectual disabilities does not reside within the disability field alone. Similar to person-first language for referring to an individual with a disability, families who have a member with a disability are a family first– a family that seeks to (a) access and enjoy all the benefits of their community, (b) reside in a safe home and neighborhood, (c) live, grow, and experience all the joys and sorrows a family encounters, and (d) remain emotionally, physically, and financially strong. Families are an integral part of every culture; understanding them and ensuring they remain the core unit of society is paramount. While our immediate aim is to understand families of children who have an intellectual disability, a theory of FQOL with respect to this population must still take into account factors that not only impact all families, but also all families who have children with a variety of disabilities. Meeting these comprehensive goals requires a collective research agenda – one that is guided by a unified theory.

This chapter has three primary purposes. First, we present a brief summary from methodologists and theorists to highlight the components of a theory and to illustrate the process of theory-building. Second, we review current FQOL definitions, conceptualizations, and models to determine if an emergent framework exists that may serve as a beginning step toward theorizing about family quality of life for families who have a member with a disability. Third, based on theory components and the findings from our review, we propose a unified theory illustrated by the theoretical linkage of multiple concepts to explain FQOL. As will be explained later, theories include unified (or grand) theories as well as less ambitious explanations of more narrow phenomena, in the form of middle-range or micro-theories. We will use our proposed unified theory to identify middle-range theories that have been previously tested in the literature to predict FQOL.

Components of a Theory

What Is a Theory?

The most simplistic definition of a theory is that it is an explanation of an observation or experience (Bengtson, Acock, Allen, Dilworth-Anderson, & Klein, 2005). Theories are often used to explain causal relationships. They are valued because they represent a “parsimonious way of summarizing knowledge” (Burr, Hill, Nye, & Reiss, 1979 p. 20). However, beneath this deceptively simple definition lies the fact that a true understanding of a theory encompasses its parts: concepts, variables, and propositions. To understand the proposed theories we will present in this chapter, we first provide brief explanations of each of these terms.

Concepts

Concepts are the most basic components of a theory. Concepts provide individuals with a way to “organize experience” (White & Klein, 2002, p. 10) that precludes the necessity to invent new terms to describe routinely occurring events. Researchers often refer to a concept as the summation of the essential characteristics of a phenomenon (Burr et al., 1979; Fawcett, 1999; Shoemaker, Tankard, & Lasorsa, 2004; White & Klein, 2002).

Variables

Shoemaker et al. (2004) define a variable as a concept which has measurable components assuming two or more values. Shoemaker et al. provide further clarification to distinguish between a concept and a variable, using female and sex as an example. Female is a concept which can be defined by biological characteristics; one typically would not measure femaleness, but instead would measure sex as a dichotomous variable with two outcomes: male or female. Similarly, family is a concept, but size of family is a variable.

Propositions

Fawcett (1999) defines propositions as “a statement about a concept or the relation between concepts” (p. 1). White and Klein (2002) similarly agree that propositions occur when concepts are meaningfully linked by a relation to another concept. These definitions of a proposition appear to have emanated from older research on theory in which propositions were restricted to only “identify relationships between variables” (Burr et al., 1979, p. 19). Concepts and variables represent the building blocks of a theory; propositions represent the link between variables, but a theory usually “comprises several propositions” (White & Klein, 2002, p. 12).

How Is a Theory Organized?

Theoretical and Operational Linkages

Theory organization begins with an explanation of the plausibility of the theory and the relationships therein. Theoretical linkages describe the plausibility – *why* the concepts are included in the theory and why they may be expected to have an impact on the outcome. The purpose of a theoretical linkage is “to give the theory explanatory power” (Shoemaker et al., 2004, p. 52). This can be accomplished in three ways: citing existing theory, using existing literature to illustrate results that are similar to the proposed hypothesis, and using a researcher’s own logic to support hypothesis development (Shoemaker et al., 2004). While theoretical linkages explain the plausibility of a relationship among concepts, *operational linkages* explore the *testability* of the proposed relationships among variables which have been selected to represent those concepts. The relationship among variables may be depicted pictorially or statistically. Simple relationships among two–three variables are easily depicted in graphic format; more complex relationships are often illustrated using path diagrams. Statistical relationships may be stated a priori in the form of strength and direction of a correlation coefficient or other type of effect size.

Unified, Mid-Range, and Micro Theories

A theory may also be organized by its specificity. A grand theory attempts to explain an overall understanding of a phenomenon or provide a general structure of knowledge for a phenomenon (Peterson, 2004). Rather than the term *grand theory,* we prefer to use the term *unified theory* to describe the overarching conceptual theory of FQOL which we will propose in this chapter. Because a unified theory is by its nature intended to provide a broad overview of a phenomenon, it tends to be stated in terms of concepts rather than variables. However, this broadness serves a specific purpose in guiding theory development. The unified theory enables researchers to identify and define concepts as testable variables, to develop a set of propositions illustrating the operational linkages among the variables, and to propose a theory to explain the outcome, in our case, FQOL. Recognizing that no single study could test the broad scope of a unified theory, we will present our overarching conceptual theory as a framework upon which to build FQOL theory one study at a time.

In contrast, middle-range theories are much narrower than unified theories. They consist of “a limited number of concepts and propositions,” are “generated and tested by means of empirical research,” and are typically the type of theories presented within research proposals (Fawcett, 1999, p. 5). Because middle-range theories represent smaller sections of the mosaic of a unified theory, these are the tools for empirical testing through research. Thus, the concepts and propositions of middle-range theories may be translated to variables and testable hypotheses. The unified theory provides both a big picture perspective and an opportunity to place within this big picture a series of middle-range and micro-theories that will allow us to understand results of existing research and to propose next steps in the FQOL research agenda. Micro theories are “less abstract, more specific, and narrower in scope than middle range theory” (Peterson, 2004, p. 34). They are often referred to as practice theories or situation-specific theories. The main goal of a practice theory is to be action-oriented and to “shape reality to create a desired goal” (Peterson, 2004, p. 34). Due to space limitations, we will not address micro theories in this chapter.

Theory Development

Theory-building involves using a combination of sources: (a) existing theory, (b) existing literature, (c) researcher assumptions, and (d) logical reasoning (Shoemaker et al., 2004). Currently, no theory exists to explain FQOL for families of individuals with disabilities; therefore, we must draw upon (a) existing theories in the general family literature, (b) empirically based data from FQOL studies, and (c) our own assumptions to build logical relationships among theoretically important variables. This methodological approach will lead to the development of a logical, testable structure. The value of such a structure is that it presents a *set* of propositions describing relationships among variables which may be tested through individually designed repeated measures, single-subject methodology, and/or correlational research.

A theory of FQOL, like families themselves, should be dynamic, open to change, and based upon a continuous feedback loop which can be re-tested as the field develops a richer understanding of the variables impacting FQOL. It is this inherent flexibility that adds complexity to the development of a theory of FQOL. Borrowing from the more contemporary views of theory, we embrace multiple ways to approach theory development. Bengston and colleagues (2005) present three ways to utilize theories: scientific approach (e.g., explanation and prediction), interpretative approach (e.g., understanding), or critical approach (emancipation or empowerment of oppressed peoples or social groups). Each provides useful explanation "to view and understand the world of families . . ." (p. 13).

We seek to explain what causes FQOL to vary among families of children with intellectual and other disabilities, with a particular emphasis on understanding the variables that are amenable to change (i.e., policies, programs, services, and supports) and the role of static or unchanging characteristics or demographics (e.g., type of disability or family ethnicity) in predicting FQOL. While static traits should be included in the overall structure of a theory, they should primarily be used to describe interactions with various programs and services (e.g., ethnicity as a moderator variable) in order to create a model predicting optimal FQOL for families with different characteristics. For example, understanding how ethnicity interacts with different program and service variables in predicting FQOL provides useful information to administrators and practitioners to ensure the appropriate cultural adaptation of programs and services. Knowing which variables are responsive to change via supports and services provides an excellent opportunity to inform future research and is an impetus for advocacy at the policy and practice level. Thus, we believe a theory of FQOL should have value for *applications* by policymakers, practitioners, and researchers as well as families.

With these parameters in mind, we present a review of the literature on FQOL. After a brief description of our review methodology, we examine the literature related to the components of a possible theory (i.e., the definitions, concepts, variables, and relationships among variables) to explain FQOL. Based on this analysis, we will conclude by proposing a theory of FQOL, which we hope will be an impetus for intellectual interchange and consensus-building.

Literature Review Methodology

Article Location Methods

We conducted a key word search in 21 databases representing the categories of education, health, and social sciences. In line with our interest of studying FQOL in families of children with disabilities, we chose the following key words and combination of key words: (a) family quality of life, (b) quality of family life, (c) family well-being and disab∗ (∗denotes disabled, disabling, disability, or disabilities), (d) family life and disab∗, (e) famil∗ (denotes family or families) and quality of life, (f) famil∗ and disab∗ and impact, and (g) life satisfaction and famil∗ and disab∗. Because the phrases, family quality of life and quality of family life often resulted in a return of a limited number of articles, in conjunction with the word "disability," the keyword *disability* (or more specifically, disab∗) was not used as a pair word with these two phrases. We also chose to exclude the disability term for key phrases, family quality of life and quality of family life because we were interested in collecting articles on family quality of life and quality of family life outside of the disability field to enrich our understanding of the conceptualization of FQOL for all families.

Article Selection

While a larger key word scope was used to collect articles, the authors used a much narrower scope to select articles for inclusion in this review. Our literature search resulted in 113 articles. We used a two-tiered process to select articles. At the first tier, we selected articles if the title or abstract contained the following key phrases or key phrase and word combinations: "family quality of life," "quality of family life," or "quality of life" and famil∗. This first-tier selection resulted in 37 articles. For the second-tier selection of articles, we selected articles for inclusion in this chapter review based on the criterion that the article provided insight to defining, conceptualizing, measuring, or theorizing about family quality of life (or a related term as long as the article addressed the quality of life of parents or all members of the family). We were primarily interested in quantitative studies that examined predictors of FQOL and selected our articles accordingly. The second-tier selection resulted in 24 articles. For purposes of theory-building, however, we must note that these 24 articles contain some redundancy due to the fact that two research teams are overrepresented. Of the 24 articles included in this review, two were related to the work of the International Quality of Life team (Brown, Anand, Fung, Isaacs, & Baum, 2003; Brown et al., 2006) and six emanated from the FQOL research generated at the Beach Center on Disability at the University of Kansas (Bayat, 2005; Hoffman et al., 2006; Summers et al., 2007; Verdugo et al., 2005; Wang et al., 2006; & Wang et al., 2004).

Table 15.1 presents a brief overview of each of the 24 selected articles, which we have analyzed to identify the essential components of a theory (i.e., the definitions, concepts, variables, and relationships among variables). The first column

Table 15.1 Review of family quality of life studies

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
1. Abbott et al. (2005) Professionals, families, and children/young people with a disability	FQOL Definition: none given FQOL Concepts: Qualitative interviews framed around seven areas: Individual needs: physical environment, financial well-being, social well-being, emotional well-being, skills and learning Family-level needs: daily family life Extra-familial supports: contact with services and professionals	Variables/Methodology: Qualitative Hypotheses proposed: How services are delivered has a positive impact on child health needs but may have a positive or no effect on child/family social and emotional needs. FQOL Relationships: Two thirds of families reported that their FQOL improved due to receiving multi-agency services (e.g., getting more sleep and reduction in number of appointments). Child health needs were met. Social/emotional needs were not addressed well; many families felt they had no one to turn to; young child with disability rarely had emotional support. Families still experienced major difficulties with daily routines (e.g., finding/organizing social activities for themselves and their child). Very little support to help families have short breaks or access to sitters. Very little support for claiming benefits entitlements. Families felt a lack of coordinated and flexible support from the multi-agency services to make home adaptations.

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
2. Anderson (1998) Patient with serious illness and patient designated family member to complete the surveys	FQOL Definition: None FQOL Concepts: Olson & Barnes (1982) – includes 12 subscales assessing satisfaction with: Individual needs: health, home, education, time, religion, employment, financial well-being Family-level needs: marriage and family life Extra-familial supports: friends, extended family, mass media, neighborhood/community	Variables/Methodology: Multiple regression analysis to investigate relationships between FQOL and: Family Characteristics: Family Sense of coherence (FSOC): explains the motivational and cognitive bases for transforming resources into actuality, to cope with stressors and promote health. Includes: (a) spouse agreement about perceptions of the family's ability to manage the demands of life and to see life as meaningful and comprehensible; (b) illness stress, (c) family system balance, (d) income; (e) length of relationship; (f) patient/family member employment status FQOL Relationships: Positive relationship between FSOC and FQOL (r =.55). FSOC as the largest predictor of FQOL (30% of the variance; the greater the FSOC, the greater FQOL). FSOC, illness stress, family system balance, length of family relationship, patient full-time job status, family income accounted for 57.6% of the variance that predicted FQOL. FSOC was a mediator in the impact of illness stress on the family, reducing the direct influence of illness stress on FQOL by half

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
3. Bayat, (2005) Families of children with autism. Primarily mothers (134), some fathers (30), and a few caregivers (11)	FQOL Definition: FQOL refers to the family's overall well-being and ability to meet the family's needs and enjoy life. FQOL Concepts: Use of Beach Center measure, see Hoffman et al. (2006) for a description.	Variables/Methodology: Multiple regression analysis using structural equation modeling (SEM) to investigate relationships among: Child Characteristics: Age of child, severity of autism Family Characteristics: Parental education, income Beck Depression Inventory, and coping strategies, defined through use of Kansas Inventory of Parental Perceptions (KIPP) (Behr, Murphy, & Ann, 1992), which included (a) parents' perceptions of positive contributions of child to family, and (b) parents' attributions of the cause of the autism System/Support Characteristics: Satisfaction with services FQOL Relationships: Structural model using KIPP Positive Contributions as a predictor of FQOL along with demographic variables: Significant predictors were: Income, depression, and child's age. After accounting for all demographic variables parental perceptions of positive effects of autism was a significant predictor of FQOL. Overall percent of variance explained in FQOL was 0.33. Structural Model using KIPP causal attributions as a predictor of FQOL along with demographic variables: Only age of child was a significant predictor of FQOL. After accounting for all demographic variables parental perceptions of the causes of autism was not significant predictor of FQOL. Overall percent of variance explained in FQOL was 0.25

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
4. Ben-Gashir, Seed, and Hay (2002) Families of children with childhood atopic dermatitis (AD). Primarily mothers (105 mothers and 1 father)	FQOL Definition: None FQOL Concepts: 10 items rated by parent; Individual needs: sleep of family members, leisure activities, time spent on shopping, cost of treatment or clothes, tiredness, emotional distress, caregiving impact Family-level needs: housework, food preparation, family relationships	Variables/Methodology: Regression model investigating relationship of FQOL and AD severity at two points in time. Child characteristics: symptom severity, skin color, sex, child's age Family characteristics: Family size and location FQOL Relationships: FQOL significantly correlated to symptom severity at two points in time, after controlling for child and family characteristics
5. Bowman (2001) Young children (0–3) and their families, i.e., mothers ($n = 228$)	FQOL Definition: none, but provides Schalock's, Brown's, and pediatric literature's definition of QOL, not FQOL. FQOL Concepts: Study developed a Quality of Life Interview (QOLI). 28 items in four subscales: Individual: Satisfaction Level, Behavior Problems, Developmental Level, and Psychiatric History	Variables/Methodology: Two analyses: (a) EFA for scale development and (b) MANOVA to examine group differences of QOL among parents whose children have different child characteristics: Child Characteristics: typically developing (TD), developmentally delayed (DD) or experiencing behavior problems (BP). Family Characteristics: race, religion, marital status, maternal education, income, city population FQOL Relationships: 4-factor solution with EFA for FQOL scale: Satisfaction Level, Behavior Problems, Developmental Level, and Psychiatric History MANOVA results: Differences were noted on all three factors of the QOL scale except for Satisfaction scale, which has items more typical of FQOL scales. Total QOL score differed for all three groups (e.g., TD, DD, and BP)

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
6. Brown et al. (2003) Mothers and fathers of children with intellectual disabilities; however, it was unclear if scores were averaged or scores were jointly agreed upon	FQOL Definition: None given FQOL Concepts: four concepts or dimensions: Opportunities–options available to families taking advantage of available opportunities Initiative-taking advantage of available opportunities Attainment-getting, having, or accomplishing those things that the family wants and needs. Satisfaction-overall perception of family members These four concepts were assessed for each of nine areas of FQOL as listed below; response stems included a mix of frequency and satisfaction Individual Needs: Health, financial well-being, careers and preparing for careers, spiritual and cultural life, leisure, community and civic involvement Family-level Needs: family relationships Extra-familial supports: support from others, support from services	Variables/Methodology: Bivariate correlations among families' assessment of opportunities, initiative, attainment, and satisfaction as related to the nine areas from the FQOL scale FQOL Relationships: Only selected correlations are displayed to conserve space. Positive correlation between attainment of health and satisfaction of health Positive correlation between attainment of financial well-being and satisfaction of financial well-being Opportunities: Lowest mean score was support from others, highest was spiritual/cultural beliefs Initiative: Lowest mean was support from others, highest was careers. Attainment: Lowest mean was support from others, highest was spiritual/cultural beliefs Satisfaction: Lowest mean was support from services, highest was spiritual/cultural beliefs
7. Brown et al. (2006) Primarily mothers of children ages 3–13 with Down syndrome, autism, and control group	FQOL Definition: None FQOL Concepts: Same as Brown et al. (2003)	Variables/Methodology: Correlation, analysis of variance, and descriptive data focusing on satisfaction with each of the nine domains; comparisons of families in three groups Child characteristics: Comparisons of families of typically developing children, Down syndrome, and autism Family characteristics: highest correlation of the combined groups between domains and FQOL include family relations, leisure/enjoyment of life, careers/preparing for careers, and health. FQOL Relationships: Families in the comparison group had the highest FQOL, followed by children with Down syndrome and then children with autism

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
8. Dunst et al. (2006) 801 parents of children with disabilities in early intervention	FQOL Definition: None FQOL Concepts: Global concept with a single-item assessment of respondent's FQOL, on a 10-point scale on the extent to which the "family had the worst or best life possible" (p. 241).	Variables/Methodology: A linear regression analysis focusing on the difference between two approaches to natural learning environments. Child Characteristics: Extent of delay/disability Family Characteristics: Parent age, ethnicity, education, marital, and employment status. Researchers also assessed parents' positive and negative well-being System/Support Characteristics: Implementation of early intervention in family and community activity settings, implemented by the practitioner versus by the parent FQOL Relationships: Using everyday family activities as learning opportunities was associated with enhanced parent well-being and family quality of life and decreased negative parent well-being; professionals implementing EI in activity settings was associated with reduced positive parent well-being and family quality of life and increased negative parent well-being
9. Feldman and Werner (2002) Families of children with DD and behavior disorders: 34 mothers, 1 father, 1 grandmother	FQOL Definition: None FQOL Concepts: Eight questions asking parents to rate the degree to which the child's behavior creates problems in the areas of: Individual Needs: daily activities/routines, learning Family-level needs: community integration, family social functions in home Extra-familial supports: participant's peer relationships, others' positive response toward participants	Variables/Methodology: MANOVA to identify differences among groups on variables. Child Characteristics: Degree of problem behaviors measured by Child Behavior Management Survey. Family Characteristics: Parental stress, depressive affect, self-efficacy, therapist rating of parental behavior management skills, and parent satisfaction with training System/Support Characteristics: Behavioral parent training, comparison of training with wait-listed group FQOL Relationships: Families receiving behavioral training had higher FQOL and self-efficacy

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
10. Gupta and Sharma (1998) 455 Indian working women	FQOL Definition: Enrichment of life, a socio-economical and socio-psychological process running through (a) social production of values concerning QOL, (b) social distribution of values concerning QOL, and (c) social perception of values concerning QOL. Scale adapted from Moos & Moos (1986) FQOL Concepts: Initial measure used 16 items including: Individual needs: intellectual enrichment, sharing problems, sharing day's happenings Family-level needs: Helpfulness, cooperation, caring, eating together, encouragement, team spirit, appreciate new ideas, emotional bond, communication, responsible, adjusting, relationship with other members. Other: criticizing habit	Variables/Methodology: Factor analysis of field test resulted in a 3-factor solution: Family Characteristics: (a) close-knit family environment, (b) cohesive–supportive family life, and (c) team spirit in family life FQOL Relationships: Three factor solution identified: Family cohesion (e.g., eating together, bonding), Helpfulness, and Team Spirit. Relationships not identified as this is an instrument development article
11. Hoffman et al. (2006) 208 families (Study 1) and 280 families (Study 2), of children with disabilities. Primary respondents were mothers	FQOL Definition: None given FQOL Concepts: Beach Center FQOL Scale: measured family perceptions of the importance and satisfaction of 25 questions in five domains: Individual needs: physical/material well-being, emotional well-being Family-level needs: family interaction, parenting Extra-familial supports: Disability-related supports	Variables/Methodology: Structural equation model depicting covariation of five lower order latent constructs (i.e., five FQOL domains) assessed by observable item indicators FQOL Relationships: SEM model supports five lower order latent constructs and FQOL as a higher-order construct; relationships not identified as this is an instrument development article

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
12. Hornstein and McWilliam (2007) 454 Parents, primarily mothers, of children with autism spectrum disorders, aged 0–6	FQOL Definition: none given FQOL Concepts: modification of an instrument previously used to measure FQOL in families of children who are deaf or hard of hearing (McWilliam, 2005, as cited in Hornstein and McWilliam, 2007). Parents rate satisfaction on 40 items, in five factors: Individual needs: Competence, knowledge, well-being Family-level needs: cohesion Extra-familial supports: alliances	Variables/Methodology: Exploratory-factor analysis to identify factors, correlations with family demographics: Family Characteristics: Family SES, ethnicity Service/Support Characteristics: Hours of services received FQOL Relationships: Variance explained in indicators by factors: Competence (15.57%); Knowledge (11.81%); Alliances (7.81%); Cohesion (7.69%); and Well-being (6.26%) Knowledge is lower in families with lower SES, and with fewer hours of service Cohesion is lower in nonwhite families Well-being is lower in families with lower SES
13. Mellon and Northouse (2001) 123 dyads: Cancer patient and family member; approximately half included spouse and another one third included adult children as a second respondent	FQOL Definition: None FQOL Concepts: Uses Olson & Barnes (1991) measure – see Anderson (1998) in this table.	Variables/Methodology: Model testing involving correlational analysis, hierarchical multiple regression, and regression equation testing for mediation Individual characteristics: Illness survival stressors – concurrent stressors from family, fear of recurrence, and somatic concerns, patient employment Family characteristics: Family hardiness, family meaning of cancer illness System/support characteristics: Family social support FQOL Relationships: 63% of variance in FQOL was explained by the model; FQOL was impacted by patient employment status, concurrent family stressors, family member fear of recurrence, family social supports, and family meaning.

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
14. Poston et al. (2003) Qualitative study to identify indicators and meaning of FQOL; 78 family members, 50 professionals	FQOL Definition: None FQOL Concepts: Framework presented as a result of qualitative, grounded theory research study. Domains include: Individual needs: Advocacy, Emotional Well-Being, Health, Environmental Well-Being Family-level needs: Daily Family Life, Family Interaction, Financial Well-Being, Parenting	Variables/Methodology: Qualitative study using a combination of focus groups and individual interviews of non-English-speaking family members; sampling plan includes a diversity of SES and ethnicity, as well as both family members and professionals FQOL Relationships: FQOL framework is the outcome of the study. No relationships were reported as this is an exploratory study intended to identify dimensions of FQOL
15. Rettig & Bubolz (1983) A study of 250 couples to validate perceptual indicators of family well-being	FQOL Definition: Integration of human needs, economic and psychological resources, and interpersonal satisfaction as a basis for development of perceptual indicators of family well-being FQOL Concepts: Structure of resources are based on two coordinates: concrete-symbolic, and universalistic–particularistic (higher value when resource is provided by a specific other individual) for six resources: Individual needs: Love, status, services, information, money, goods FQOL is measured with a global item – "how do you feel about your own family life" on the 7-point "delighted to terrible" scale	Variables/Methodology: Cluster analysis to identify hierarchical clustering of the six resources, and predictive contributions to global rating of FQOL. Satisfaction with resources received on a 7-point "delighted-terrible scale," and frequency with which resources are received on an 8-point scale, from "never" to "2–3 times a day" FQOL Relationships: Social–psychological and economic resources are important to FQOL. More particularistic resources (love, status) make stronger contributions to FQOL

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
16. Rettig and Leichtentritt (1999)	FQOL Definition: An individual's experience of family life will depend upon the extent to which personal needs are met, as judged by the personal values, standards, and aspirations one has for an ideal family life Framework/Theoretical orientation: Three "nested" theories: Human ecological systems theory, resource theory, and facet theory FQOL Measure: See Rettig and Bubolz (1983), this table	Variables/Methodology: Results analyzed using Multidimensional Scaling analysis to determine underlying structure, using scatter diagrams to learn proximities Using this mapping strategy, the purpose was to determine whether the six resources would cluster in the hypothesized circular pattern FQOL Relationships: The results confirmed the model. Items representing love and money are on the vertical axis (e.g., OK to get money from many sources, need love from specific people), and on the concrete-symbolic horizontal axis (money is concrete, expressions of love may be symbolic)
17. Ricci, Bendandi, Bellini, Patrizi, and Masi (2007) A study of 45 Italian parents of children with atopic dermatitis (AD)	FQOL Definition: None FQOL Concepts: 10 questions, same as Ben-Gashir et al. (2002), this table	Methodology/Variables: Descriptive correlation between three levels of severity and FQOL questions Child Characteristics: Mild, moderate, and severe AD FQOL Relationships: FQOL appeared to be moderately altered in families of children with more severe AD with greatest problem being disrupted sleep
18. Summers et al. (2007) A study of 180 parents (Primarily mothers) of young children 0–5 with disabilities	FQOL Definition: none given FQOL Concepts: Beach Center FQOL Scale. See Hoffman et al. (2006), this table	Methodology/Variables: Structural equation model examining the mediating effect of family–professional partnerships on the relationship between service adequacy and FQOL. Variables: System/Support Characteristics: (a) parents' ratings of adequacy of services received for child and family; (b) parents' ratings of satisfaction with the quality of partnership with the early childhood professional FQOL Relationships: Service adequacy significantly predicted FQOL. Family–professional partnerships was a partial mediator of the effects of service adequacy on FQOL

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
19. Verdugo, Cordoba, & Gomez (2005) 385 parents (primarily mothers) of children with disabilities in Cali, Columbia	FQOL Definition: none given FQOL Concepts: Spanish version of Beach Center FQOL Scale, see Hoffman et al. (2006), this table	Methodology/Variables: Structural equation modeling to assess the fit of the 5-factor measurement model of the Spanish version of the Beach Center FQOL Scale. Participants rated both importance and satisfaction with all items FQOL Relationships: All item factor loadings were greater than 0.50. Model fit was excellent: Importance: GFI = 0.99; NFI = 0.99; RFI = 0.99 Satisfaction: GFI = 0.98; NFI = 0.97; RFI = 0.97
20. Voydanoff et al. (1994) Study of stepfamilies and first marriage families. *N* = 3,120 in sample where both spouses participated	FQOL Definition: Not defined FQOL Concepts: Global construct questions rating: Individual Needs: none Family-level needs: (a) happiness with marriage, (b) satisfaction with quality of relationship of parent with each child Extra-familial supports: None	Methodology/Variables: Data were drawn from a large National Survey of Families and Households. Analysis involved multiple regression models to determine contributions of: Family-level characteristics: Family demographics (education, income, race), family structure (first marriage versus stepfamilies), role organization (task/role divisions in work and household tasks), disagreements over household tasks, sense of equity about role divisions FQOL Relationships: Parents in stepfamilies report lower quality of parent–child relationships; no clear relationship to marital quality. Role organization satisfaction was related to marital happiness

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
21. Wang et al. (2004) 130 fathers and 234 mothers of young children (0–5) with disabilities	FQOL Definition: none given FQOL Concepts: Beach Center FQOL Scale, see Hoffman et al. (2006), this table	Variables/Methodology: Structural equation modeling to predict relationships of variables to FQOL: Child Characteristics: level of severity of child's disability based on parent report Family characteristics: Family income defined as total household income FQOL Relationships: Mothers: income was a weak but significant positive predictor of FQOL. Severity of disability was a strong negative predictor of FQOL Fathers: income, while a positive predictor of FQOL was not significant. Severity of disability was a strong negative predictor of FQOL For both mothers and fathers, the interaction effect was not significant. The final SEM model explained 17% of the variance in FQOL for mothers and 16% for fathers
22. Wang et al. (2006) Mothers and Fathers from 107 families of young children (0–5) with disabilities	FQOL Definition: none given FQOL Concepts: Beach Center FQOL Scale, see Hoffman et al. (2006), this table	Variables/Methodology: Structural equation model testing measurement invariance across mothers and fathers on FQOL, in addition to examining differences in means, variances, and correlations for the two latent FQOL constructs: importance and satisfaction FQOL Relationships: Measurement invariance held for mothers and fathers in terms of importance and satisfaction; there were no significant differences between mothers and fathers for importance and satisfaction in terms of FQOL means, variances, or correlation between importance and satisfaction

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
23. Weigel et al. (1995) 328 mothers and 187 fathers who were State-classified employees at land grant universities who had children under the age of 18	FQOL Definition: Authors proposed three variables to represent FQOL: family satisfaction, family cohesion, and family decision-making. Predictor variables were used for each of these three outcomes FQOL Concepts: Adapted from Bloom's (1985) revised Self-Report of Family Functioning. The measure includes five statements rated on a 4-point scale (very untrue to very true for my family) in three areas: Individual needs: None Family-level needs: Cohesion (emotional bonding and contact among family members), decision-making style process of evaluation in choosing or resolving alternatives, family satisfaction (positive or negative assessment of family life)	Variables/Methodology: Path analysis by gender (mothers/fathers but not in same family) examining mediating role between seven work family characteristics (e.g., job quality, job value, housework, age of youngest child) and Work-Family Conflicts and Stress in predicting Quality of Family Life Parent characteristics: job type, hours worked, stress, work–family conflict Family characteristics: composition and structure of family (age of youngest child, division of household labor) FQOL Relationships Mothers: Stress was a significant direct negative predictor of FQOL for family satisfaction (F.S.); family cohesion (F.C); and family decision-making (F.DM). Age of youngest child was also a significant negative predictor for all three FQOL variables. Variance accounted for in overall model for the three FQOL indicators: $R^2 = 0.45$ (F.S.), $R^2 = 0.37$ (F.C.), and $R^2 = 0.23$ (F.DM) Fathers: Stress was a significant negative predictor for two of the FQOL variables for fathers: family satisfaction (F.S.) and family cohesion (F.C.); there was not direct path between stress and family decision-making (F DM). There was no direct path between age of youngest child and F.S.; a negative relationship was reported between stress and F.C.; and a positive relationship was reported between stress and F.DM. Variance accounted for in the overall model for the three FQOL indicators: $R^2 = 0.32$ (F.S), $R^2 = 0.28$ (F.C.) $R^2 = 0.21$ (F.DM).

Table 15.1 (continued)

Reference/sample	FQOL definition and concepts	Variables/methodology to assess FQOL relationships
24. Zabriskie and McCormick (2003) Relationships between family leisure involvement and FQOL in 179 families including 1 parent and 1 youth aged 12–15 from each family	FQOL Definition: None FQOL Concepts: Modified version of Satisfaction with Family Life Scale (SWFL) (Diener et al., 1985), including five statements about family life rated on a 7-point scale from strongly disagree to strongly agree (specific items are not described in this chapter), therefore we are treating the construct for our purposes as a global indicator of FQOL	Variables/Methodology: Regression model to predict FQOL: Family Characteristics: Satisfaction and involvement with leisure activities using Family Leisure Activity Profile (FLAP); family demographics including age, gender, ethnicity, marital status, family size, and income FQOL Relationships: Data analyzed three ways: youth only, parents only, and combined parent/youth means Youth: Demographic block ($R^2 = 0.103$, $p<0.05$) Family Leisure block did not result in a statistically significant change in variance. (R^2 change $= 0.016$, $p>0.05$) Parents: Demographic block did not account for a significant proportion of variance in SWFL. ($R^2 = 0.08$, $p>0.05$) Family Leisure block did result in a statistically significant change in variance. (R^2 change $= 0.083$, $p<0.05$) Combined: Demographic block did not account for a significant proportion of variance in SWFL ($R^2 = 0.099$, $p>0.05$) Family Leisure block did account for a significant additional amount of variance in explaining SWFL (R^2 change $= 0.052$, $p = 0.01$)

includes the reference and a brief description of the sample. The second column includes a description of the FQOL definitions and concepts described in the chapter. The third column includes a description of the specific variables, methodology, and results as depicted through the relationships among the variables to predict FQOL. To construct a unified theoretical framework of FQOL, we focused primarily on the concepts, variables, and relationships among the variables shown in Table 15.1.

A Proposed Unified Theory of Family Quality of Life

Defining FQOL – The Outcome

A first step in building a theory is to clearly identify and define the concepts used. Logically, the first concept to define is the outcome, in this case FQOL. We begin by reviewing the definitions of FQOL identified in the literature, which we listed in the second column of Table 15.1. Consistent with a similar review of family outcomes in the disability literature (Turnbull et al., 2007), we also observed that only 6 of these 24 articles provided an explicit definition of FQOL. We hasten to say that this does not mean these research teams do not have a definition; rather, the definitions were not articulated in the articles. In attempting to determine how these researchers were defining FQOL, we made some inferences from the measures they used as well as any explicit definitions provided.

We identified several common themes among the FQOL definitions. First, satisfaction as a concept was mentioned explicitly in three definitions. Family sense of well-being, perceptual indicators, and judgment by personal values were also mentioned as definitional components. Collectively, these components suggest a principle: The nature or quality of family life is not to be judged by outsiders but rather is dependent on the *subjective* impressions of family members' satisfaction with their quality of life. Family satisfaction, in short, is "one's positive or negative assessment of family life" (Weigel, Weigel, Berger, Cook, & DelCampo, 1995, p. 10). In terms of measurement, satisfaction as an explicit concept was operationalized as all or part of the dependent variable (i.e., satisfaction used as the response stem in measurement of the respondent's ratings across a variety of items) in 15 of the 24 articles in this review.

A second theme emerging from these definitions is the notion of *meeting individual family member needs*. For example, Rettig and Leichtentritt (1999) note: An individual's experience of family life will . . . "depend upon the extent to which personal needs are met, as judged by the personal values, standards, and aspirations one has for an ideal family life" (p. 310). Thus, the idea of FQOL reflects the belief that the family as a unit has a responsibility to meet the individual needs of each of its family members. This idea may or may not be true across all cultures, as in some cultures there is a much stronger collectivist as contrasted to individualistic orientation (Lynch & Hanson, 2004; McGoldrick, Giordano, & Pearce, 1996). However, five of the six available definitions mention the notion of meeting individual family member needs. In terms of measurement, the theme of meeting individual family needs resulted in the creation of a series of domains or factors which the researchers used to categorize aspects of individual need. These included, for example, daily family life (Abbott, Watson, & Townsley, 2005); emotional, physical, and social well-being (Brown et al., 2003; Hoffman et al., 2006); and satisfaction with resources (Rettig & Bubolz, 1983).

Finally, a third theme is that the family as a *unit* has characteristics of its own that cannot be described simply by understanding its individual members. The Weigel et al.'s (1995) definition refers to family cohesion, family decision-making, and family satisfaction as components of FQOL, suggesting that different knowledge may be gained by considering the family as a unit as opposed to assessing and aggregating the satisfaction of individual needs of each family member. In terms of measurement, only a few researchers measured FQOL as a collective or summative construct using multiple family members' perspectives (Anderson, 1998; Rettig & Bubolz, 1983; Rettig & Leichtentritt, 1999; Zabriskie & McCormick, 2003) or at a minimum assessed FQOL by considering multiple family sub-systems (e.g., marital, parental) (Voydanoff, Fine, & Donnelly, 1994). Anderson (1998), using the Olson and Barnes QOL measure (1982), calculated a family mean score to "represent the behavior of the family as a unit" (p. 177). Both Rettig and Bubolz (1983) and Rettig and Leichtentritt (1999) assessed FQOL as a collective average of husband and wife scores across six areas of family life (e.g., love, goods, money) using a scale ranging from 1 (terrible) to 7 (delighted). Zabriskie and McCormick (2003) collected FQOL scores from parents, as well as youth, using a revised version of the Satisfaction with Family Life Scale (SWFL) (Diener, Emmons, Larsen, & Griffin, 1985). The revised SWFL scale measures individual family members' satisfaction of their collective family life on a scale from 1 (strongly disagree) to 7 (strongly agree). Finally, Voydanoff et al. (1994) conceptualized FQOL as overall satisfaction within two family sub-systems: marital relationships and child–parent relationships.

Based on the three themes, we have identified as common across the articles we reviewed, we offer the following definition of FQOL as an *outcome* for purposes of theorizing about FQOL:

Family quality of life is a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.

FQOL Concepts – Explanatory or Influencing Concepts

Consistent with theory-building principles, we now turn to identifying and defining the specific concepts within the overall FQOL model. In a later section, we provide examples of how the variables are used within the selected research studies to predict FQOL. In reviewing the studies, we chose concepts that were directly or indirectly related to FQOL as an outcome. To build our unified theory, we identified the concepts represented by the variables used as predictor, independent, or mediator variables in the studies we reviewed (see the third column of Table 15.1). While we primarily included quantitative studies ($n = 22$) to develop our theoretical model, we also included two qualitative studies that provided additional theoretical insight (Abbott et al., 2005; Poston et al., 2003). Across all of the studies, four clusters of concepts emerged: (a) family-unit concepts, (b) individual family-member concepts, (c) performance concepts (e.g., services, practices, and supports), and (d) systemic concepts (e.g., systems, policies, and programs). To clarify, the individual and family-unit explanatory concepts described in this section are different concepts than individual and family-level *needs* previously discussed and defined as part of FQOL as an outcome. The concepts described herein represent the broad categories from which variables are selected as predictors of FQOL, not defining components of an FQOL measure. These four concepts, together with their theoretical linkages to each other and to the FQOL outcome, form our proposed unified theory.

Before attempting a parsimonious statement of our unified theory, we first present an in-depth explanation of the four concepts, each of which encompasses a large number of potential variables. Because FQOL as a field of study is still in its infancy (as compared to individual quality of life), sufficient empirical data are not available across all four concepts. In fact, much of the available research assesses the impact of individual and family-unit performance concepts (e.g., services or practices) on FQOL. However, the lack of empirical data across the four concepts should not preclude theory development. On the contrary, it provides an opportunity for *theorizing*. In this manner, we incorporate both tested and untested hypotheses within one theoretical model and use evidenced-based data from empirical studies and novel ideas and assumptions from researchers to build a theoretical model. Interjection of researcher assumptions within theory-building is in line with contemporary views of theory-building (Bengtson et al., 2005; Fawcett, 1999; Shoemaker et al., 2004) which encourage creativity and curiosity as an input to inform science.

Family-Unit Concepts

The family-unit is defined as the collective number of individuals who consider themselves to be part of a family and who engage in some form of family activities together on a regular basis (e.g., eating, social gatherings, school/sporting events). A family-unit describes a family as a whole. Two family-unit concepts consistently reported in the FQOL literature were family characteristics and family dynamics (Fig. 15.1). We define family-level *characteristics* as traits or descriptors of the family as a whole, including, for example, family income, size of family, family geographic location, religious preference, ethnicity, or family form (e.g., stepfamily versus first marriage family). We define family *dynamics* as aspects of interactions and ongoing relationships among two or more family members. Examples of family dynamic concepts typically assessed include family sense of coherence, adaptability, hardiness, and decision-making. Of the 24 articles we reviewed, nine studies included one or more family characteristic or family dynamic concept which were operationalized as variables and then used either as a predictor or as a mediator related to the FQOL outcome.

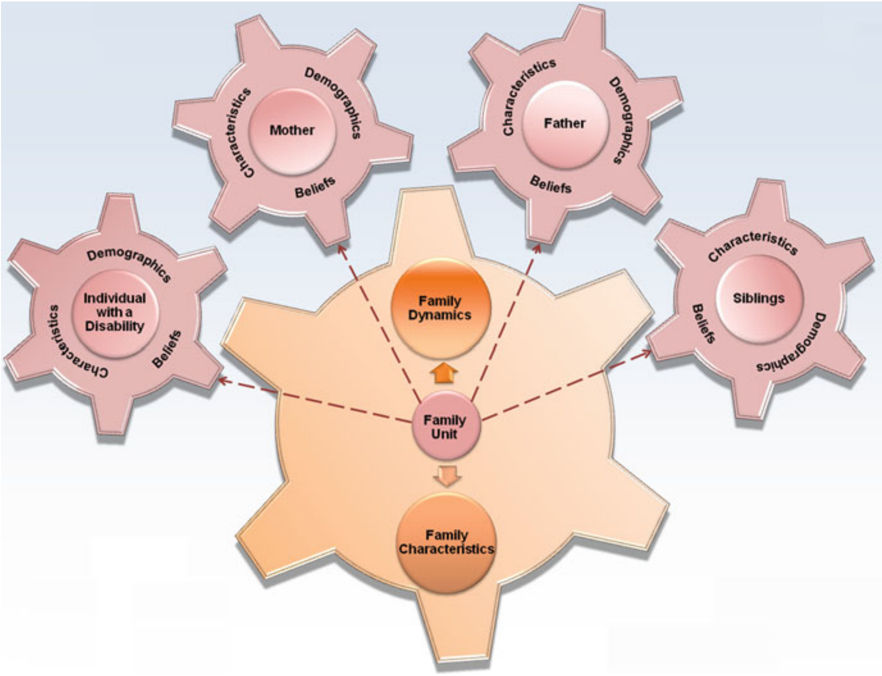

Fig. 15.1 Family-unit and individual family member interaction

Individual Family Member Concepts

In contrast to family-unit concepts, individual family member concepts refer to aspects of the person with a disability, parent, siblings, or other individual family member. Individual family member concepts, especially those related to the child with the disability, were frequently operationalized as variables and used as predictors in many of the FQOL studies included in this review. We identified three types of individual family member concepts: individual family-member characteristics, demographics, and beliefs (Fig. 15.1). We define *individual demographics* as basic traits such as the child's age, type of disability, or gender; or parent's education level, ethnicity, or employment status; or sibling's age or gender. We define *individual characteristics* as more complex and multidimensional traits which might vary over time, such as child behavior, parent depression, or sibling health status. We define *beliefs* as an individual family member's attributions of meaning, expectations, or understanding about a phenomenon, such as the meaning of the child's disability for the family, expectations about the child's future, or understanding/expectations about parental roles in partnership with professionals. We found that 11 of the 24 articles included one or more individual characteristics and/or demographic concepts articulated as variables and used in the research. However, only two studies (Bayat, 2005; Mellon & Northouse, 2001) utilized beliefs as a variable.

Performance Concepts

The three performance concepts include services, supports, and practices. The performance concepts represent the crux of the FQOL theory and are represented at the individual (Fig. 15.2) and the family (Fig. 15.3) level. As the name suggests, performance concepts imply an action – something that is delivered or acted upon on behalf of individuals with intellectual disabilities and their families. In our unified theory, these are the formal services, supports, and practices developed and offered to individuals with intellectual disabilities and their families. *Services* are a range of educational, social, and health-related activities expected to improve outcomes for the individual or of the family as a whole. Examples include respite care, counseling, medical/dental care, or therapies such as speech-language therapy. *Supports* are more difficult to define, and we recognize that the distinction between services and supports is not always clear. For purposes of our theory, we suggest that supports are less tangible resources provided to the individual or to the whole family which are expected to improve outcomes for the individual or family. Examples of supports include the emotional supports provided through a parent's interaction with an early intervention service provider, knowledge and information

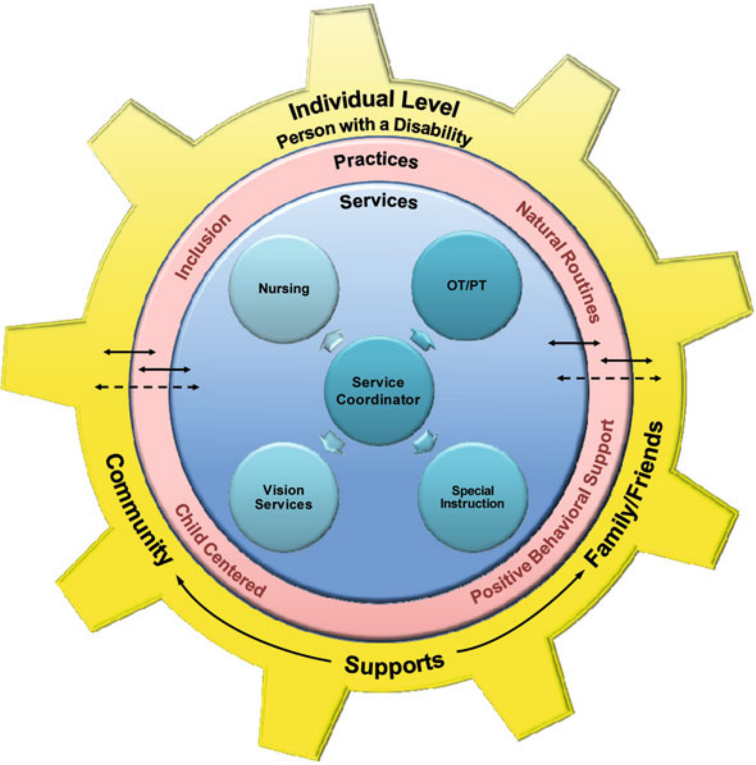

Fig. 15.2 Individual level performance concepts

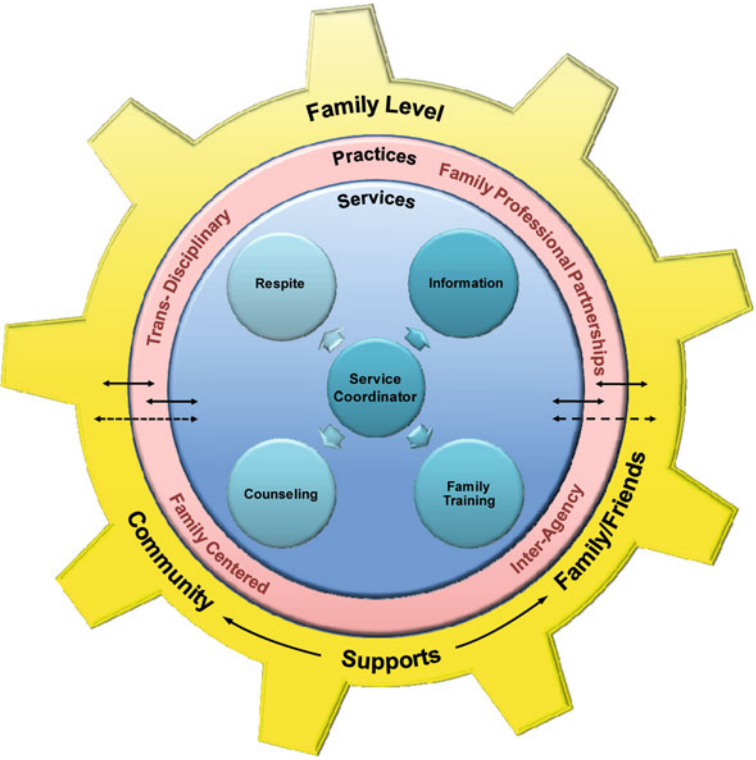

Fig. 15.3 Family-level performance concepts

received through participation in a parenting class on positive behavior support, or self-advocacy skills achieved by an individual with a disability through participation in a self-determination training. Finally, we define *practices* as specific procedures or processes through which services and supports may be delivered. Examples of practices include routines-based early intervention (i.e., incorporating interventions such as range of motion or language activities in the family's daily routine) and positive behavior support (i.e., describing a set of procedures to assess behavior and rearranging the environment to reduce the individual's challenging behavior). Among the 24 articles we reviewed, only eight utilized some aspect of services, supports, or practices, with services and supports being the most frequently researched.

Systemic Concepts

We identified three systemic concepts which we propose as influencing FQOL: systems, policies, and programs. We define *systems* as a collection of interrelated networks organized to meet the various needs of society, such as health care, education, and legal systems. These systems are present in all industrialized nations and have often been linked to quality-of-life issues (Phillips, 2006). *Policies* are guidelines establishing, organizing, and regulating the procedures for implementing programs and systems. Policies differ by country. With respect to the United States, a few policies relevant to FQOL theory include: Individuals with Disabilities Education Act (IDEA), Americans with Disabilities Act (ADA), and Family Opportunities Act (FOA). Policies might also be established to encourage cross-systems cooperation. An example of this policy would be a government regulation requiring the creation of inter-agency (across systems) agreements to ensure services provided to families are coordinated across programs and systems. We define *programs* as formally or informally organized entities that provide services and supports to an identified population. Examples include early intervention agencies serving young children with disabilities and their families, developmental disabilities agencies that provide supports and services to children and adults with disabilities, or family support programs such as Parent to Parent (Santelli, Turnbull, Marquis, & Lerner, 2000), providing supports to families by matching a veteran parent with a parent needing supports. Programs, in other words, are located within systems or networks, and are regulated by policies. None of the 24 articles examined the impact of programs, systems, or policies on FQOL using a quantitative predictive model; however, one article qualitatively examined the impact of multi-agency systems on families' quality of life (Abbott et al., 2005).

Variables and Propositions – A Unified Theory of Family Quality of Life

Figure 15.4 is a graphic representation of our unified theory of family quality of life. It depicts the complex interactions (i.e., their theoretical linkages) among the concepts which we propose as explaining variations in FQOL outcomes. Figures 15.1, 15.2, and 15.3 are subsumed within the larger theoretical framework represented in Fig. 15.4. Following is a description of a few relational linkages drawn from our proposed unified theory that researchers could use to develop middle-range theories:

- Family characteristics and dynamics interact with individual characteristics to influence FQOL outcomes.
- Family and individual performance factors (i.e., supports, services, and practices) act as mediating or moderating variables on the effects of family-unit or individual family member factors to predict FQOL.
- Program quality predicts implementation of best practices; implementation of best practices impacts an individual child factor (e.g., reduction in tantrums), which in turn impacts FQOL.

In Fig. 15.1, the family-unit and individual family member cogs illustrate the interaction among family dynamics and family characteristics with each individual member's characteristics, demographics, and beliefs. Figures 15.2 and 15.3 illustrate the performance factors for the individual and family-unit, respectively. The inner

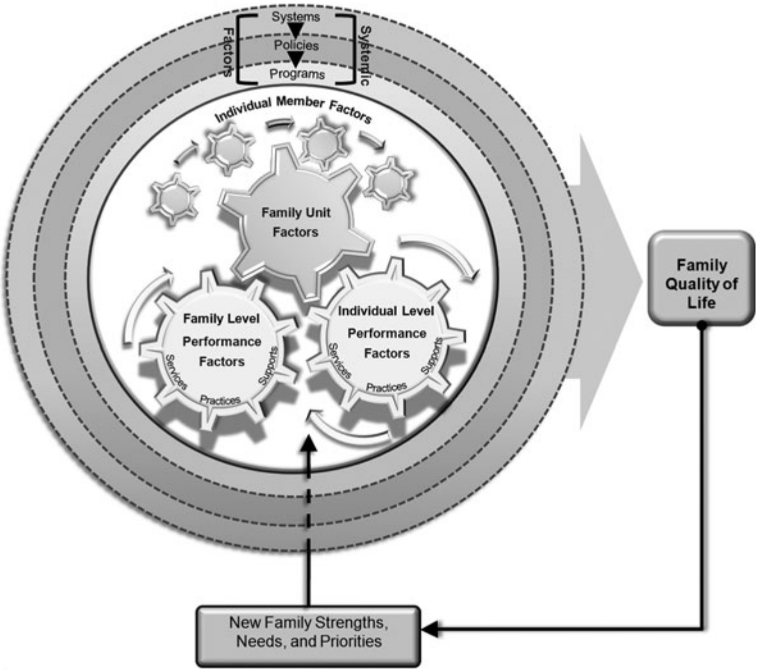

Fig. 15.4 Unified theory of FQOL

circle of Fig. 15.4 illustrates the multiple interactive operational linkages between the family-level and individual-level performance factors, between family-unit and individual member factors, and among all seven inner cogs. Figure 15.4 also illustrates the distal impacts of systems, polices, and programs; these are represented by the outer circles. We placed the systemic factors as circles with dashed lines around the edge of the interactive cogs to emphasize their role as indirect influences on the directly interactive elements within the inner circle of the theoretical model.

If one of the system factors changes (i.e., elimination of a program or policy), this will disrupt the smoothly running "cogs," leading to changes in FQOL until adaptation or homeostasis occurs within the individual or family. For example, if a service is denied or a support falls through, this impacts FQOL. If a parent suddenly loses his or her job or becomes chronically or terminally ill, this again impacts FQOL. If a child "ages out" of the educational system and needs to be served by an adult service system, FQOL will be impacted while a whole new set of performance factors, with new services, practices, and supports, is activated. Each factor addresses the complexity of families' lives at the unit and individual level. The model is complex because families are complex. Using our theoretical model (Fig. 15.4), we now present our unified theory. A unified (or grand theory) is the most abstract of the three levels of theory (i.e., grand, middle-range, and micro theory) (Peterson, 2004).

A grand theory is often viewed as a way to organize knowledge using a conceptual framework and serves as the "starting point for middle-range theory development" (Fawcett, 1999, p. 5). We state our unified FQOL theory as:

> Systems, policies, and programs indirectly impact individual and family-level supports, services, and practices; individual demographics, characteristics, and beliefs and family-unit dynamics and characteristics are direct predictors of FQOL and also interact with individual and family-level supports, services, and practices to predict FQOL. Singly or combined, the model predictors result in a FQOL outcome that produces new family strengths, needs, and priorities which re-enter the model as new input resulting in a continuous feedback loop throughout the life course.

If nothing has changed, then FQOL will be relatively stable; if, as indicated earlier, services are dropped, policies are changed, or new practices are implemented, this may result in new levels of FQOL. Our theoretical model represents FQOL as an outcome of a dynamic process consisting of multiple interactive factors – an outcome to be individually experienced and defined by the family and its members. It is the innermost framework of the model (Figs. 15.1, 15.2, and 15.3) that is unique to each family resulting in unique FQOL outcomes. Each individual and family will have different characteristics and beliefs that interact with the provision of services, supports, and practices leading them to make unique decisions about their life and their family's life.

Current FQOL assessment tools have typically measured FQOL at one point in time, not throughout the lifespan. Further, researchers have represented FQOL as a relatively stable trait; however, this is yet to be determined. Because the goal of FQOL researchers is to lead to improvements in FQOL, we can not avoid that which is difficult to measure or complex to articulate. Disability is one aspect of families; a theory of FQOL of families who have a member with a disability must address multiple aspects of families' lives. Our model aims to meet this goal.

Our general theoretical framework enables us to proceed in two steps. First, our unified theory enables us to present a "thoughtful and insightful appraisal of existing ideas or creative intellectual leaps beyond existing knowledge rather than by means of empirical research" (Fawcett, 1999, p. 4). Second, it provides us with a useful unified theoretical model to present and generate middle-range theories with the explicit purpose of validating empirical research. Recognizing that no single study could test the broad scope of the unified theory, we present it as a framework and a procedure to build FQOL theory one study at a time. Next, we present examples of propositional statements that are supported by the current literature on FQOL. We will situate these research findings within the unified theory to illustrate how they contribute to explaining FQOL.

Middle-Range Theories of Family Quality of Life

The unified theory we propose in Fig. 15.4 not only summarizes the many components involved in predicting or explaining variations in FQOL, but it also presents a useable model for researchers to generate multiple testable theoretical statements.

Shoemaker et al. (2004) note that using models is an excellent method to "suggest new theoretical statements," to recognize subsets of variables that "represent chains of causes or effects," and to eliminate nonsensical relationships through the use of "time ordering of variables" (p. 135). Our unified theoretical model clearly illustrates that the systemic concepts are distal inputs, while the family-unit, individual family member factors, and performance factors are the key or direct predictors of FQOL, both singly and interactively, as mediators and moderators.

Much of the available research on FQOL is characterized by simpler propositional statements using a limited number of variables – statements which are logically and statistically capable of being tested. As we noted earlier in the chapter in defining elements of theories, middle-range theories provide testable propositions through the use of a more manageable subset of a larger, unified theory. This unified theory serves as an organizing theoretical framework from which researchers can draw down specific testable middle-range theories based upon their own research interests. Additionally, researchers can work collaboratively from a unified theoretical framework to understand FQOL. In this section, we present middle-range theories identified from our literature review that fit within our unified theoretical model. At this juncture, we also transition our use of terminology from concepts to variables to illustrate the variables arising from individual member concepts, family-unit concepts, and systemic concepts, and how they are used in a predictive model. For example, an individual child characteristic is a concept, but the severity of the child's disability is a variable that might be used to predict FQOL.

Individual Family Member Variables

Eight of the 24 articles used some type of child characteristic or demographic as a predictor variable in the research design. In general, severity of the disability and presence of behavior problems were negatively related to FQOL. Similarly, families of typically developing children tended to have higher FQOL than families of children with disabilities. For example, Brown et al. (2006) found significant differences in overall FQOL scores among families who have children with Down syndrome, families who have children with autism, and families of typically developing children. Wang et al. (2004) also demonstrated that for both mothers and fathers, the severity of the child's disability was a strong negative predictor of FQOL.

Other family member demographics, characteristics, and beliefs were also investigated as predictors of FQOL. For example, Wang et al. (2006) examined

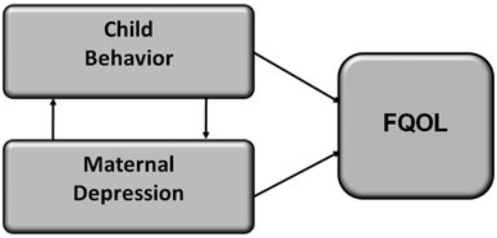

Fig. 15.5 Individual member relationship with FQOL

differences in FQOL conceptualization by parent gender and found no differences. Similarly Zabriskie and McCormick (2003) found no relationship between parent gender and family satisfaction. Individual family member characteristics may also impact FQOL. Mellon and Northouse (2001), in their examination of family member illness, found that family member's fear of recurrence (designated a "belief" in our FQOL theory) contributed to the variance of FQOL. Four studies included a measure of stress, depression, or negative well-being in parents (Bayat, 2005; Dunst, Trivette, Hamby, & Bruder, 2006; Feldman & Werner, 2002; Weigel et al., 1995). In general, higher levels of depression and/or stress had a negative relationship with FQOL. Collectively, these results are consistent with family research utilizing other outcomes variables such as stress or depression (i.e., disability tends to create challenges in families) (Turnbull et al., 2007). Figure 15.5 depicts how these individual family factors may be expected to predict FQOL.

Family-Unit Variables

The propositional relationships identified across the studies examining family-unit characteristics suggested that FQOL was lower in families with low incomes (Hornstein & McWilliam, 2007; Wang et al., 2004), from backgrounds other than European American (Hornstein & McWilliam, 2007), and in stepfamilies (Voydanoff et al., 1994).

Family dynamics identified within our article review included such variables as family sense of coherence (Anderson, 1998), family hardiness (Mellon & Northouse, 2001), satisfaction with division of family labor (Voydanoff et al., 1994), and work–family conflict (Weigel et al., 1995). Higher scores on all of these variables had a significant relationship with higher levels of FQOL, with the exception of work–family conflict, which had an inverse relationship. Figure 15.6 depicts these relationships.

The individual concepts (e.g., demographics, characteristics, and beliefs) and family-unit concepts (e.g., characteristics and family dynamics) are abstract enough to allow for multiple theories to be generated from these broad concepts; yet, they also are narrow enough to identify variables for a testable theory. At a more abstract level, one example of a middle-range theory of FQOL could state that the interaction of individual and family-unit factors together predict FQOL. A finer distinction of a middle-range theory may simply propose that individual factors

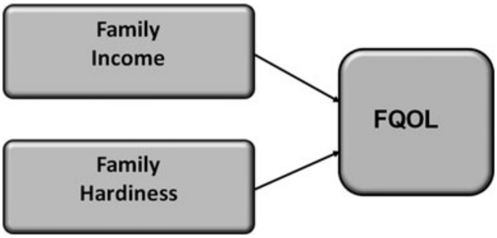

Fig. 15.6 Family-unit relationship with FQOL

predict FQOL, while another middle-range theory might state that family-unit factors predict FQOL. Both Figs. 15.5 and 15.6 provided examples of what might be considered smaller testable components within the larger middle-range theories of individual and family-unit factors predicting FQOL.

Performance Variables

One example was found in the FQOL literature illustrating the relationship between how a service was delivered (i.e., practice) and FQOL. Dunst et al. (2006) reported that parents who used everyday family activities as learning opportunities to enhance their child's development experienced higher FQOL; however, when professionals implemented early intervention within everyday activities, FQOL was reduced. This finding was consistent with the work of Rettig and Bubolz (1983) and Rettig and Leichtentritt (1999) whose work suggests that satisfaction of some types of individual and family needs (e.g., emotional needs) varies depending on *who* addresses the needs.

Much more commonly observed and measured in the FQOL literature and consistent with our review was the impact of services and supports on FQOL within programs. Seven of the 24 articles in our review included a variable related to services or supports from formal and/or informal sources. In all cases there were some positive associations between services and supports and FQOL, but in some cases the results were equivocal. For example, Abbott et al. (2005) investigated the relationship of multi-agency coordinated services and found that families experienced improved sleep but other factors (e.g., daily routines) were not affected. Other relationships were more clear-cut, such as the relationship between type of service and FQOL. For example, Feldman and Werner (2002) found higher FQOL in families receiving behavioral training than those who did not receive training or received a reduced number of hours of training. Similarly, Mellon and Northouse (2001) found higher FQOL in families who had positive family social supports. Both amount of and satisfaction with services was also related to FQOL. Hornstein and McWilliam (2007) found FQOL to be lower with fewer hours of service, while Summers et al. (2007) observed higher scores on parents' ratings of service adequacy for themselves and their child related to higher levels of FQOL. Figure 15.7 illustrates the testable theory of the impact of services and supports on FQOL.

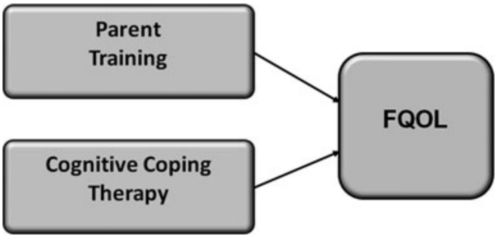

Fig. 15.7 Performance factor relationship with FQOL

Systemic Variables

None of the 24 studies in our literature review attempted to assess quantitatively the impact of these large and distal entities (e.g., systems, policies, and programs), and a comprehensive research effort to do so would be necessarily multifaceted and cumbersome. However, historical trends exist that provide insight into the impact of systems, policies, and programs on FQOL. For example, the passage of IDEA, affording rights to a free and appropriate education to children with disabilities (Turnbull, Stowe, & Huerta, 2007) likely freed many parents who previously had been required to stay at home with their children to enter the job market when their children were allowed to go to school and, thus, did not require daily care during school hours. Parent first-person accounts of raising children without the current array of policies provides compelling testimony to the impact of policies on FQOL (Turnbull & Turnbull, 1978, 1985). Without policies in place, very few programs, services, and supports for families of children with disabilities would exist. It is this reason that we include systems, policies, and programs as the backdrop for our FQOL theory. While the proximal variables are more easily measurable, the distal variables still have a rightful place in a FQOL theory. Currently, the only way to assess the distal variables is through state and national data. In the United States this includes federal agency reporting requirements assessing programs (e.g., early intervention programs) within agencies (Department of Education). Figure 15.8 illustrates the hypothesized relationship of US early intervention policy and FQOL. In Fig. 15.8, Variable 1, parents know their rights, is a federal reporting requirement for all states as well as variable 2, the child's use of appropriate behavior to meet their needs (Hebbeler, Kahn, Barton, & Greenwood, 2007). The mediator model in Fig. 15.8 illustrates the direct effect of parents' knowing their rights (e.g., parents' knowledge about the right to request a functional behavioral assessment for their child) on the child's use of appropriate behavior and the direct effect of the child's behavior on FQOL. This model also illustrates the indirect effect of parents' knowing their rights on FQOL.

Research Limitations

Before considering the implications of these findings for theory-building, we should insert a caveat about the quality of the research we reviewed. There were a number of limitations that warrant caution in the interpretation of these findings across all the

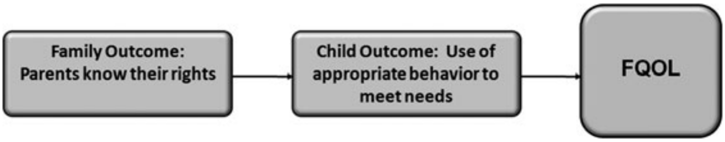

Fig. 15.8 Systemic factor relationship with FQOL

studies. First, limitations from a design point of view include the fact that the majority of studies utilized convenience samples; in fact, many did not include a control or comparison group, and still others were qualitative studies and as such should be considered primarily exploratory. Second, limitations to generalizability are raised due to the lack of diversity of study respondents across the pool of available literature. For example, the majority of these studies purporting to report family data focused on responses from one family member (i.e., the mother). Also, while many of these articles did not report the ethnicity or income level of study participants, those that did so reported a predominance of European American and middle-income families. Finally, the research is limited by the fairly small community of researchers represented by this literature. Much of the FQOL research from which the empirical data were drawn to develop this theory (eight of the 24 studies) comes from two of the most active FQOL research agendas: the International Quality of Life Research Project (Brown et al., 2003; Brown et al., 2006) and the Beach Center on Disability (Bayat, 2005; Hoffman et al., 2006; Summers et al., 2007; Verdugo et al., 2005; Wang et al., 2006; & Wang et al., 2004).

Beyond these research limitations, we should note an important conceptual and operational limitation in our theory-building, and that is the unfinished business of the development of consensus about the nature and measurement of FQOL as an outcome. While we do not advocate that all FQOL researchers in the disability field should embrace one measure of FQOL over another, we do hope for continued dialogue and consensus-building about the purpose of measures and the multiple factors currently used to represent FQOL. We also need to closely examine the distinction between predictors and outcomes used within the domain structure of FQOL measures. For example, if FQOL is an outcome and the purpose of the research is to explore the impact of services and supports (as we present in our theory), then measures of the FQOL outcome cannot include assessments of the quality of services and supports as a domain factor. A further issue is the lack of variability in response when satisfaction is the primary construct for measuring FQOL. The tendency of families to report fairly high levels of satisfaction (see, e.g., Hoffman et al., 2006) means that the data are negatively skewed, creating a number of problems both statistically and conceptually. These and other conceptual and measurement issues should be addressed to enable more meaningful exploration of an FQOL theory.

Conclusion: Recommendations for a Research Agenda

In our proposed unified theory of family quality of life for families of individuals with intellectual and other disabilities, we presented a larger theory than what is currently supported by research data. Thus, many parts of the theory require additional research to validate the theory we propose. Similar to a research agenda, our unified theoretical framework lays the foundation to build upon FQOL theory one proposition at a time. We hope our contribution provides researchers with a road map to guide their research – a place to fit their particular research agenda into the model, whether it is research on an individual family-member factor (i.e., impact of parents' physical or emotional well-being on FQOL), a performance factor (e.g., investigating the impact of a family-centered services on FQOL), or investigating a systemic factor (e.g., the impact of specific policies of FQOL). Particularly at the systemic level, a coherent theory forces us to think about different aspects of families' quality of life prior to implementing policies and also to consider how we would develop questions to investigate the impacts of policy implementation in terms of overall FQOL.

As we review those elements of our proposed theory that have empirical support, we note that the majority of research in the family literature focuses on the impacts of individual and family factors on outcomes such as FQOL. More recent research has begun to investigate the impacts of performance factors (e.g., practices, supports, and services) on family outcomes. Turnbull and colleagues (2007) make this observation as well, and call upon the field to move away from repeatedly investigating what is well-established (e.g., children's behavior problems negatively impact family well-being or FQOL) to investigating relationships that are less well-established and also amenable to change. For example, the work by Dunst et al. (2006, see Table 15.1) suggests that informal supports in everyday family activity settings are more effective in terms of family well-being, than supports or services implemented by early intervention professionals. More research is needed along these lines to determine the nature of specific performance factors (the *who*, *what*, *how*, and *where* of supports and services) that are most predictive of positive FQOL.

However, we cannot be so naive to assume the current FQOL assessment tools are sensitive enough to measure changes by the various predictors we present in our theoretical model. This is why continued work to refine the current FQOL measures is critically necessary. We also need to continue our work in middle-range and micro theory development to validate further our proposed FQOL theory. For example, research on the impact of parent training programs (e.g., performance factor) should investigate the impact of that intervention on family and individual characteristics such as parents' sense of empowerment and competence as a pathway to the FQOL outcome. Different aspects of FQOL may be impacted by different systemic and performance factors. We need to carefully construct follow-up assessments that are sensitive enough to detect these changes. However, this unified theory provides the opportunity for us (and others) to make recommendations for and implement future research in the inchoate field of FQOL.

Finally, as if our proposed FQOL theory were not complex enough, we must risk further complexity by pointing out the need to connect FQOL with outcomes for the individual. In our theory (see Fig. 15.4), we explicitly note that the performance factors (e.g., practices, services, and supports) impact both the family-unit and individual members. We try to show how the quality of life of individuals within the family (including the person with a disability) is intimately intertwined with the FQOL as a whole. But from the point of view of policymakers, this is not enough. Policymakers do not always accept families of people with disabilities as appropriate beneficiaries of programs enabled by their policies (Turnbull et al., 2005).

Advocates for families must, therefore, not only continue to justify the need for family supports on the rationale that all family members are affected by the disability of a family member, but also to justify family supports in terms of their critical link to effective outcomes for the child or adult with a disability. Our unified FQOL theory proposes a mechanism for why that is true (i.e., supports for the family affect the well-being of each of its members, including the person with a disability). Additionally, we need an explicit research agenda to continue strengthening the linkage between family and individual quality of life.

In conclusion, as we have engaged in theorizing about FQOL, we have embraced the idea of building theories as a "thoughtful and insightful appraisal of existing ideas or creative intellectual leaps beyond existing knowledge" (Fawcett, 1999, p. 4). Families and the world in which they live are extremely complex, and we have tried to articulate that complexity. Unified theories, such as the one we propose, are like a large-scale mural or other work of art. One must stand back to see how the parts fit together. But to truly understand it, one must look closely, piece-by-piece, to analyze the contributions of each part to the whole. It is a challenge. But it is one we hope you will agree is critical to the continued improvement of the quality of the lives of individuals with intellectual disabilities and their families.

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