

A FAMILY QUALITY OF LIFE STUDY OF FAMILIES WITH
CHILDREN WITH DISABILITIES IN HAWAI'I

A DISSERTATION SUBMITTED TO THE GRADUATE DIVISION OF THE
UNIVERSITY OF HAWAI'I AT MĀNOA IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

IN

EDUCATION
May 2011

By

Phaedra E. Ranges

Dissertation Committee:

Garnett Smith, Chairperson
James Skouge
Pauline Chinn
Hunter McEwan
Bruce Barnes

Keywords: family quality of life, disability, culturally diverse, Hawai'i

Acknowledgments

I would like to dedicate this dissertation to my parents and my brother—I would not have been able to accomplish this without all of their support and encouragement. This is also in appreciation of my fantastic committee chair, Garnett Smith and the rest of my amazing committee—Pauline Chinn, Hunter McEwan, James Skouge, and Bruce Barnes. This dissertation would not have been possible without the assistance of Jean Ann Summers and the Beach Center on Disability, the guys at CCC - Willie, Theo and Chad, Ellen Osborne and WEIS, LDAH and their incredible staff, the family members who participated in the study, Ron Heck, Reginald Worthey, Brynn Leake, the Davis family and all of my wonderful friends and family who cheered me on throughout my program.

TABLE OF CONTENTS

LIST OF TABLES	V
ABSTRACT	VI
INTRODUCTION	1
HISTORY OF NATIVE HAWAIIAN EDUCATION	2
STUDY PURPOSE	6
ISSUE TO BE ADDRESSED	7
RESEARCH QUESTIONS	8
KEY TERMS	9
DELIMITATIONS	10
CONTEXT FOR INQUIRY/LITERATURE REVIEW	12
HISTORY OF EDUCATION IN HAWAI‘I	12
VALUE OF FAMILY IN NATIVE HAWAIIAN CULTURE	14
NATIVE HAWAIIAN FAMILY INVOLVEMENT IN EDUCATION	15
BACKGROUND AND IMPORTANCE OF MEASURING FQOL	18
RESEARCH TO ADDRESS PROBLEM	20
PILOT STUDY	26
SUMMARY OF THE FQOL THEORETICAL FRAMEWORK	33
CONTRIBUTION TO THEORY KNOWLEDGE AND PRACTICE	34
METHODS	36
RESEARCH DESIGN	36
PARTICIPANT DESCRIPTION	36
SAMPLE SIZE	38
MEASURES AND COVARIATES	38
PROCEDURES	40
DATA COLLECTION AND MANAGEMENT	44
RESULTS	48
PARTICIPANT DESCRIPTION	48
DEMOGRAPHICS	49
RESPONDENTS	51
RESEARCH QUESTION 1—	52
PARTNERSHIPS	54
FAMILY QUALITY OF LIFE	56
RESEARCH QUESTION 2—	58
QUALITATIVE ANALYSIS	60
RESEARCH QUESTION 3—	61
AUTHOETHNOLOGY	62
DISCUSSION	67
PARTICIPANTS	67
RATINGS OF SERVICE NEEDS AND ADEQUACY	68
COMPARISON OF RESPONSES TO PREVIOUS SAMPLES	76
TRENDS	77
LIMITATIONS	77
IMPLICATIONS	81
FUTURE RESEARCH	87
CONCLUSION	88
APPENDIX B	93
APPENDIX C	94

APPENDIX E	96
APPENDIX F	97
APPENDIX G	99
FQOL SURVEY-THE BEACH CENTER ON DISABILITY, UNIVERSITY OF KANSAS	99
REFERENCES	100

LIST OF TABLES

Table 1 Participant Demographics.....	50
Table 2 Child's Primary Disability.....	52
Table 3 Service Needs and Adequacy Ratings.....	53
Table 4 Service Provider.....	54
Table 5 Partnership Satisfaction.....	55
Table 6 Importance and Satisfaction Ratings-FQOL.....	57
Table 7 Correlation Coefficients Between FQOL Variables.....	59
Table 8 FQOL Variable Means with Results from ANOVA.....	60
Table 9 Participant Demographics.....	97

Abstract

Research indicates that families of children with disabilities are at risk for a lower quality of life than families of typically developing children, as the impact that a child with a disability has on a family's quality of life (FQOL) is both substantial and complex (Zuna, Selig, Summers, & Turnbull, 2009b; Zuna, Summers, Turnbull, Hu & Xu, 2009c). Attempts to identify approaches that may improve the quality of life of families of children with disabilities has often been neglected, therefore the need remains to examine those supports and services for families with children with disabilities necessary to prevent a lower quality of life (FQOL) for these families and their children (Zuna, Turnbull & Summers, 2009a). Studies conducted in Hawai'i call for the active engagement of culturally diverse populations in the identification of educational problems as well as in the search for solutions in order to be successful (Onikama, Hammond & Koki, 1998; Sileo, Sileo & Prater, 1996). In Hawai'i where family, or 'ohana' is a fundamental aspect of society, to both respect and support this frame of reference, it is imperative we gain more information from indigenous families themselves if our goal is to increase family quality of life (FQOL) for families in Hawai'i with children with disabilities. For more than 20 years the University of Kansas Beach Center on Disability researchers have diligently endeavored to identify and explain reasons why FQOL varies so significantly among families of children with disabilities. Primarily through the administration of their *Family Quality of Life* (FQOL) scale – a measure specifically designed for families with children with disabilities – Beach researchers have tried to gain a greater understanding of the variables that are susceptible to change and the role of fixed characteristics or demographics in predicting FQOL (Zuna et al., 2009c).

Beach Center researchers have been increasingly concerned that in spite of extensive efforts to have a random or representative sample of families in research projects, almost invariably research samples have been drawn from White majority cultures (Markey, et al., 1998; Zuna, et al., 2009c). It is the intent of my dissertation to broaden the research base of the Beach Center on Disability at the University of Kansas in the area of FQOL through the inclusion of samples of culturally diverse families with children with disabilities within and across the state of Hawai'i.

The most important finding from this study was that FQOL and amount of services and supports needed and received by families did vary among groups by ethnicity. Families identifying themselves as Asian/Pacific Islander and Hawaiian indicated a greater level of satisfaction on FQOL than the Caucasian respondents, and also indicated a lower overall need for child and family oriented services.

Keywords: family quality of life, disability, culturally diverse, Hawai'i

CHAPTER I

Introduction

Family quality of life (FQOL) includes family interaction, parenting, emotional well being, health and financial well-being, and disability related supports, and is based on individual and family needs, choices, and degree of control (Beach Center, n.d; Wang & Brown, 2009). A family's capacity to provide support can be extremely challenged by having a family member with a disability (Wang & Brown, 2009; Zuna, Turnbull & Summers, 2009a). The constraints and obligations a family member with a disability places upon FQOL are pervasive and complex are likely to require numerous and comprehensive supports in order to be overcome (Mian et al., 2004; Summers, et al, 2007). Research indicates that families of children with disabilities are frequently at risk for attaining a lesser quality of life than families of typically developing children (Zuna, Selig, Summers, & Turnbull, 2009b; Zuna, Summers, Turnbull, Hu & Xu, 2009c;). Unfortunately, a thorough assessment of what and which supports and services for families with children with disabilities are most likely to prevent or impede the occurrence of a diminished FQOL for these families and their children has rarely been carried out (Mannan, 2005; Zuna, Turnbull & Summers, 2009a). Such assessments are particularly germane for stakeholders providing services to low-income families and families whose cultural and ethnic backgrounds are different than that of the school's.

Hawai'i is a richly diverse state, where cultural and ethnic diversity is more the norm than the exception, and where collectivist values permeate society, such as the importance of family, or *ohana*. As such, as a teacher and researcher I believe that FQOL is an important concept to explore in the field special education in Hawai'i. Hawaiian culture, which is

collectivist in nature “places a high value on the family, with the family being the source of social, economic, and personal support” (Black, Mrasek & Ballinger, 2003, p.24). The education of children in Ancient Hawai’i that once belonged to a symbiotic system of family, community, education, now remains as a separate and disconnected system build upon values from a non-collectivist culture. In stark contrast to the collectivist culture of its’ indigenous population is the culture of the public school system of the Hawaiian Islands. It is therefore germane to offer an historical foundation for this discussion to provide some background on the history of education in Hawai’i, and the status of Native Hawaiian students within this system.

History of Native Hawaiian Education

“Public education in the Islands has never been completely entrusted to the dictates of its citizens” (Solomon, 1980, p.62). From the beginning of formalized public education in Hawai’i, the influence and focus has been dominated by individualist oriented American values, beginning with the missionary schools and continuing with government take over of the schools (Solomon, 1980). The needs of America’s business in Hawai’i have had much influence in public education in Hawai’i, as the goal was to acculturate Native Hawaiians to mainstream American values with little regard for their culture. It is not hard to imagine why Solomon (1980) reported that present day Native Hawaiians are concerned with the role of education in perpetuating the uniqueness of their culture. Sadly, the historical, symbolic, value, and social dimensions of their culture have yet to incorporated into incorporated into our public school system here.

Beginning in the 1970’s researchers began examining the issue of severe academic under-achievement in students of Hawaiian ancestry (Gallimore et al., 1974; Tharp and Gallimore,

1988). In the 80's researchers continued to document the ongoing trend, as according to Tharp and Gallimore (1988), "Hawaiian students in ordinary schools are among the lower achieving minorities in the United States" (p. 351). This data was presented in 1988, yet another decade later, this population of students continues to be correlated with the highest levels of school failure in the state (Tharp & Gallimore, 1988; Yamauchi, 2003). One hypothesis amongst researchers that attempts to explain the low academic achievement of Native Hawaiian students as compared to their peers is the impact of a cultural conflict within the classroom between Western and Hawaiian views of learning (Tharp et al., 1984).

Public school students in Hawaii are expected to behave, learn, and succeed in individualistic style classrooms. Hawaiian culture, which tends to be collectivist in nature, clashes with this individualistic school model (Tharp & Gallimore, 1988). For students of Hawaiian ancestry, as well as students of other CLD backgrounds, educational success relies on their acculturation to the school environment/culture (Solomon, 1980). Families must also acculturate to this educational system, as to many families in Hawai'i the institution of public school represents an unfamiliar cultural and value system that is much separated from that of life in the home and community (Solomon, 1980). An unclear definition of what family involvement entails in an unfamiliar education system represents a fundamental barrier to family involvement from both the school and the community here in Hawai'i (Onikama, Hammond, & Koki, 1998). To overcome existing barriers stakeholders must work together with families and communities to increase the involvement of families in ways that are meaningful for them and aim to increase their FQOL. To assist families in overcoming barriers to involvement within the schools,

stakeholders must be skilled in strategies to increase the involvement of CLD families (Onikama, Hammond & Koki, 1998).

My personal experience with family involvement in education in Hawai'i is derived from over ten years of teaching special education here in a number of public schools on Oahu. From my very first teaching position I immediately came to see that my traditional teacher education program left much to be desired in preparing me to be successful in Hawai'i's schools. Coming here from the continental U.S., or what people in Hawai'i call the 'mainland', and working in the Hawai'i State Department of Education (D.O.E) as a teacher was an extremely challenging situation on a variety of levels. The most challenging aspect for me was that as someone from the mainland, I was seen as an outsider in a social system heavily dominated by an insider-outsider mentality. To overcome some of the barriers I encountered with students, families and school staff by being seen as an outsider I needed to establish my place within this social system in each school I worked at. As such, my experience teaching here over the past ten plus years has been a personal journey as a new teacher, and also a rich, cultural journey where I learned a lot from my students and their families who were from very different cultures and upbringings than myself. Despite having a very different cultural background than that of my students and their families, I was brought up holding the same importance of ohana within my family—and this has been monumental in my personal and professional growth as a teacher and researcher in education in Hawai'i. My interest in improving educational outcomes for Native Hawaiian students and understanding of the importance of ohana drew my attention to FQOL research and its applicability to Hawai'i's families.

The limited FQOL research that does exist indicates that focusing on the evaluation of family satisfaction in regard to the outcomes of service provision and accountability is a key component for determining the subjective quality of those service provisions (Mannan, 2005; Park et al., 2001; Summers et al., 2007; Turnbull, Turnbull, Wehmeyer, & Park, 2003). As a result, there exists a valid claim for documenting family needs related to service provision and supports, (i.e., measuring efficacy and impact of services and supports for families with children with disabilities) (Mannan, 2005; Zuna et al., 2009a). In addition, the positive impact on child and family outcomes makes it essential for stakeholders (i.e., service providers including schools and other agencies that provide contracted services) to both understand FQOL theory and practices as to more effectively apply research findings to create an improved impact on families of children with disabilities (Zuna et al., 2009a).

The variables necessary to support both families and family members with a disability require comprehensive and critical external reviews in order best determine their level and degree of effectiveness (Mian et al., 2004; Summers et al., 2007). What these specific support systems may look like for any family varies immensely, requiring a distinctive array of supports to fit each family's needs (Salisbury & Dunst, 2000). The availability and range of types of supports to families is also dependent upon a number of social factors, such as socio-economic status, and geographic location (Mian et al., 2004). Researchers propose that families with ample financial resources were more likely to provide a home environment that met their child's needs while families lacking these resources were rarely able to provide these same resourceful home environments (Summers et al., 2007). Knokey (2006) found that lower income families are almost twice as likely to report expending effort obtaining services than higher income families (26%

compared to 14%) suggesting possible barriers that pose additional problems in obtaining services such as cultural or language differences which impact the value of services to families. These research findings merit further investigation to its generalization to families living in Hawai'i, as this state has a highly culturally diverse population, and also has many families living in within or below the poverty level (U.S. Census Bureau, 2000). Therefore, it is important that schools provide CLD families adequate information regarding types of services and supports their children and family can access as well as how to access these services (Knokey, 2006).

Study Purpose

Any FQOL research conducted in Hawai'i requires that specific attention be directed toward CLD populations and that family members representative of these populations be genuinely invited and asked to engage in the identification of problems as well as in the search for solutions (Kawakami et al., 2007; Onikama, Hammond & Koki, 1998; Sileo, Sileo & Prater, 1996). Ironically, a fundamental barrier to family quality of life issues within and across the Pacific Basin centers around ambiguous and an often Americanized definition of both what constitutes a family and what family involvement entails (Kawakami et al., 2007; Onikama et al., 1998).

This is particularly vital in Hawai'i where family based on the construct of 'ohana' and community is a fundamental aspect of society (Kawakami et al., 2007; Onikama et al., 1998; Sileo et al., 1996). In order to both respect and support this ohana frame of reference, it is imperative social systems stakeholders gain more information from indigenous family recipients themselves if our goal is to increase FQOL for families in Hawai'i with children with disabilities. Parents from Hawaiian and Pacific Island backgrounds often see themselves as outsiders rather

than stakeholders in Americanized social, educational and financial support systems (Onikama et al., 1998; Sileo et al., 1996). Therefore, it is essential that stakeholders in FQOL supports and service begin to involve CLD families in the construction and assessment of the quality and quantity of services provided to them. The inclusion of CLD families into this process may serve as a bridge in strengthening the partnership between schools, service providers and families in addition to increasing the cultural value of these services (Kawakami et al., 2007). Zuna et al. (2009c) support this contention in their observation that “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” (p. 8). Engaging families from Hawai’i in real time surveys about their FQOL could serve as a major step in understanding how policy makers and service providers might better tailor services and supports that aim to increase FQOL for families in Hawai’i with a child with a disability. Furthermore, Wang and Brown (2009) advocate that FQOL is the ‘ultimate goal and valued outcome’ of policies and practitioners, and the purpose of special education and related services is focusing now on how to improve life for individuals with disabilities.

Issue to be addressed

It is my intent in Chapter 2 to provide a relevant view of the current research on FQOL to this discussion. I supplement this relevant review by adding an in-depth description of a self-directed pilot study done earlier in my doctoral program, the results of which gave the impetus (U.S. Census Bureau, 2000). It is recognized that families who have a member with a disability living at home face incredible challenges related to the family’s capacity to provide support to the individual with the disability (Wang & Brown, 2009). A propositional relationship across

studies from Zuna et al. (2009c), examining family unit characteristics suggests that FQOL is (a) lower among families with low incomes (Hornstein & McWilliam, 2007; Wang et al., 2007), (b) from families whose backgrounds are other than European American (Hornstein & McWilliam, 2007), and (c) among step families (Voydanoff, Fine, & Donnelly, 1994). According to Zuna et al. (2009c) “it is possible that understanding how family unit characteristics (i.e., ethnicity, socioeconomic status, etc.) interact with different program and service variables in predicting FQOL has potential to provide useful information to administrators and practitioners to ensure the appropriate cultural adaptation of programs and services provided to families” (p. 6). This finding lends even greater significance and relevance to the study of family unit characteristics of local families (with children with disabilities) in Hawai’i and the interaction with FQOL, as the state has one of the highest numbers of culturally diverse families, having low socioeconomic status, than typical Caucasian families residing in the continental United States. (U.S. Census Bureau, 2000). This observation alone justifies the claim that FQOL research needs to pay even greater attention to ways and means of incorporating the involvement of culturally diverse families that include a member with a disability. In Chapter 3 I detail the methods I employed in this dissertation study, (e.g., the solicitation and participation of a large sample of culturally diverse families from Oahu and the neighbor islands of Hawai’i. The results from the 43 surveys collected are presented in Chapter 4, ending with an in-depth discussion of implications, recommendations, and limitations of my study in Chapter 5.

Research Questions

The purpose of my dissertation is to expand my investigation of the FQOL survey with families with children with disabilities in Hawai’i. My ultimate goal is to use the results from

this study to expand on my previous findings, and to increase the value of information regarding the need to further investigate the area of FQOL for families in Hawai'i with a child with a disability. This has critical implications for families, as services and support have the potential to positively affect FQOL for families with children with disabilities. Expanding upon the results of my pilot study and review of current literature, I address the following questions in this research study:

1. What are the ratings of importance and satisfaction for families in Hawai'i with children with disabilities of the services and supports their family receives, family-professional partnerships, and FQOL?
2. What is the relationship between FQOL, partnerships and services for families in Hawai'i with children with disabilities?
3. How does the concept of 'ohana' in Hawai'i affect FQOL for families in Hawai'i with children with disabilities?

Key Terms

Family quality of life (FQOL)—according to the Beach Center on Disability is defined as “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” (Zuna et al., 2009c, p. 10).

FQOL theory is defined as follows—“Systems, policies, and programs directly impact individual and family-level supports, services, and practices. Individual member concepts (i.e., demographics, characteristics, and beliefs) and family-unit concepts (i.e., dynamics and characteristics) are direct predictors of FQOL and interact with individual and family-level

supports, services, and practices to predict FQOL. Singly or combined, the model predictors result in a FQOL outcomes that produces new family strengths, needs, and priorities that re-enter the model as new input resulting in a continuous feedback loop throughout the life cycle.” (Zuna et al., 2009a, p. 26).

Family—The definition of family as described by Poston et al. (2003) includes “the people who think of themselves as part of the family, whether related by blood, marriage, or propinquity, and who support and care for each other on a regular basis” (p. 319).

Delimitations

To set the limits of this study, I was only looking at families in Hawai’i from select school districts to participate in this study. Specific schools were selected on the basis of their likelihood to have families and family members that fit the cultural and SES demographics of my study. In addition I gave select preference to the schools in which I had teacher colleagues teaching in those schools, in the hope that this collegial relationship would increase participation. It needs to be mentioned that I did not choose the schools to assess their performance. The purpose of this report is descriptive; as a nonexperimental study my FQOL survey results do not provide data that can be used to address causal questions. The descriptions provided in this dissertation concern only the perceptions of 43 families residing within and across the State of Hawai’i. Because the survey was completed anonymously by family members, I was not able to “validate” respondents’ reports with information on their understanding of the survey items or with the information they supplied as to the validity of their responses concerning their subjective perceptions or experiences. As such, my analyses are descriptive— my personal

experience teaching in Hawai'i, as connected through my autoethnography, supports my discussion of the results.

Development of the FQOL Scale conceptual framework that guides this dissertation is intended to inform a wide range of stakeholder groups that may be interested in the results of the study, including parents, general and special educators, related service personnel, researchers, and policy-makers at the federal, state, and school district levels (NASET. 2005).

CHAPTER II

Context for Inquiry/Literature Review

History of education in Hawai'i

The objectives of ancient Hawaiian schooling as a planned educational program have been documented as: (a) a knowledge of the principles of government; (b) preparation in the area of war; (c) personal skill; (d) bravery; (e) respect for religious ceremonies and forms of worship; and (f) temperate living (Malo, 1898, as cited in Solomon, 1980). Traditionally, learning took place as the result of “lending a hand toward completion of routine tasks”, and was learned in the natural environment from elder family or community members (Gallimore et al., 1974). The system and focus of education in Hawai'i changed drastically with the first formalized system of education constructed by the missionaries in the early 1800's. Their system of education had an entirely different objective that consisted of teaching Native Hawaiians to read and write in English in order to learn the Christian religion (Solomon, 1980). Once public education came under the control of the government, the focus continued with the acculturation of Native Hawaiian students to American culture with little regard for indigenous ways of learning and knowing (Solomon, 1980).

Historically, the Native Hawaiian education system involved community elders, leaders, churches, and parents as children's first teachers. In stark contrast to this traditional system is the Americanized public education system in Hawai'i, in which the school assumes entire responsibility for educating a child, shifting the educational responsibility away from the home and community. Thus, a prevailing belief now exists among Pacific Islanders that the school is an independent, government-run organization that is separate from the home (Koki & Lee,

1998). Ethnographic studies of Native Hawaiian communities in the late 60's to early 80's concur regarding a definite and ongoing conflict between the culture of the Native Hawaiian community and that of the public school's educational process heightened by the reality of an island-wide centralized school system run and dominated by people of Caucasian and Japanese-American ancestry (Gallimore et al., 1974; Solomon, 1980).

Native Hawaiian experience in education. School achievement data examined by Tharp et al. (1984) over a 20-year period from the 1960s to the 1980s found: "Serious and pervasive social problems exist for this ethnic group. From the first years in school, Hawaiian children begin to experience an educational decline that is steady and pervasive" (p. 97). Documented obstacles to the educational empowerment of Native Hawaiian students in the school system include: socio-cultural factors, low educational achievement, and overrepresentation in special education programs (Kanalaupuni & Ishibshi, 2003; Tharp et al., 1984). Year after year, Native Hawaiian students continue to score below national norms more than any other ethnic group in Hawaii's public school system, have the lowest test scores and graduation rates, are overrepresented in special education programs, are more likely to attend low-quality schools, and have higher rates of poverty, absenteeism, grade retention, juvenile arrests, and are more prone to engage in early sexual activity and drug use than their non-Hawaiian peers (Kanalaupuni & Ishibshi, 2003). The percentage of special education students among Native Hawaiian students has exceeded the percentage among non-Hawaiian students each year since the 1996-97 school year pointing to a significant and persistent over-representation of Native Hawaiians among students identified as needing special educational services (Kamehameha, 2009). A continuing trend in less than optimal educational outcomes for Native Hawaiian students make it imperative

that stakeholders find more effective strategies that will address the educational needs of Native Hawaiian children in the public school system in Hawai'i (Gallimore et al., 1967; Kamehameha, 2009; Solomon, 1980; Tharp et al., 1984).

Value of Family in Native Hawaiian culture

In the Native Hawaiian culture the family system is the principal context for behavior, where every family member is required and depended upon to contribute to the family's daily routines to the degree of their ability in a 'spirit of cooperation and helpfulness' (Gallimore et al., 1974, p. 82). Each individual family member can also expect to depend on others in learning or carrying out tasks (Gallimore et al., 1974; Kanaiaupuni, 2006; Solomon, 1980). Traditionally, households maintained an organized and purposeful socialized system that reinforced increased dependence as it's members became older, and was regarded as 'the only secure source of life's necessities' (Gallimore et al., 1974, p. 101). The shared labor system provided ample opportunities for personal development toward a more important and powerful status' as one matured, became more competent and contributed more considerably to the family unit (Gallimore et al., 1974). The strength of the family system in Native Hawaiian culture is visible in a family's ability to successfully and flexibly deal with a variety of situations (role changes, death, illness, employment or unemployment, marriage, adoption). The family system functions as an interdependent, organized system of role-sharing and collective work, where leadership roles, childcare and household chores are distributed and redistributed depending on the immediate needs of the entire family (Gallimore et al., 1974; Kanaiaupuni, 2006). This system "embraces the virtues of helpfulness, generosity, and cultivates feelings of affection, intimacy and loyalty amongst its' members" (Gallimore et al., 1974, p. 66). What this family system

represents in Hawai‘i’s culture is *ohana*. In order to increase family and community involvement in Pacific education, educators must first understand the diverse value systems of family in the Pacific Island region.

The University of Hawai‘i’s Center on the Family regularly publishes information on their studies about Hawai‘i’s families. The Center on the Family conducts applied and basic research on family issues to generate and disseminate research-based information that aims to improve the quality of life for Hawai‘i’s families. They also aim to increase public awareness of the status and well being of Hawai‘i’s families (Stern & Min, 2010). They describe a portrait of Hawai‘i’s families that is somewhat different than families in the larger United States— slightly larger households, greater percentage of multi-generational households, and a high proportion of multiethnic, multiracial and multigenerational families (Stern & Min, 2010). The families they surveyed placed great value on their *‘ohana* and community; more than half of the families surveyed reported to practice behaviors that strengthen family bonds and promote well-being, such as eating together, doing fun things on a regular basis, and being actively involved in volunteering and participating in community activities (Stern & Min, 2010). Many also consider having a strong and happy family life and giving to the community to be important goals for their children and values that should be perpetuated (Stern & Min, 2010).

Native Hawaiian family involvement in education

Outside of Hawai‘i, little has been published about Pacific Island family participation in education (Koki & Lee, 1998). The traditional system of education in the Pacific Island system involved community elders, leaders, churches, and parents as children’s first teachers. The current system, patterned after the American model of education has little in common the

traditional system. The school assumes entire responsibility for educating a child, which shifts responsibility away from the home and community and results in barriers between home, school, and community (Koki & Lee, 1998). Additionally, a high reliance on the family system to provide supports for many people from the Native Hawaiian culture, many families may prefer to utilize non-formal or agency supported services, as evidenced by the many Native Hawaiian families with young children that opt for unlicensed family-based care (Kamehameha, 2005). A survey from the Center on the Family reports that “eighty-nine percent of Hawai‘i’s families indicated that they can rely on another person in their community, outside of the family, for help in time of need, with Kaua‘i County having the largest percentage of families who feel they can rely on others (92.7%). Turning to neighbors reflects a sense of social connectedness, security, and trust, and contributes to the health of a community” (Stern & Min, 2010, p. 5).

In collaborating to determine and create family supports and interventions with families who are from collectivist cultures such as Native Hawaiians, competing value systems, and a history of negative experiences may bring about several barriers to involvement. Unfortunately there is a limited amount of published research about parental involvement in Pacific education exists to help guide efforts to promote involvement (Koki & Lee, 1998). Many barriers to family involvement may be social and cultural, including lack of cultural awareness among teachers, the importance of community and church events over school activities, low priority given to family involvement by some principals, and parental feelings of being unwelcome or uncomfortable in school surroundings (Koki & Lee, 1998).

Thus, a prevailing belief now exists among Pacific Islanders that the school is separate from the home and is an independent, government-run organization (Koki & Lee, 1998). In order to increase parents’ involvement in Pacific education, educators must understand the

traditional system of education in the Pacific Island region. Historically, the Pacific education system has involved community elders, leaders, churches, and parents as children's first teachers. The current system, however, is patterned after the American model of education, which virtually ignores the traditional system. The school assumes entire responsibility for educating a child, which takes responsibility away from the home and community and results in barriers between home, school, and community.

Family focused interventions aim to work collaboratively with families to provide quality support to families who have a child with a disability, and because supports are tailored to each family, is consumer driven. The family becomes the 'client', and the families the 'unit of intervention.' The services provided to the child with the disability and their family should be such that it empowers, respects, and strengthens the family unit. Integration of the family into the support and intervention maintains family integrity and a sense of control over their lives, enhancing the child's life and that of their family. As part of a team, a family's collaboration with professionals should be viewed as a partnership, where the family's input and decision making is the key to success (Turnbull et al., 2001).

Strengths-based approaches for Native Hawaiian families. Speaking in support of strengths based approach to program development for Native Hawaiians; Kanaiaupuni (2006) suggests that:

Research that documents the "needs" of our people may be careful, it may be conscientious and well intended, and may even be fair. It may exhaustively indicate the limits of the data and cautiously interpret results. How it is used, however, is obviously another story. In addition to potentially being misused,

deficits-based approaches often miss the expertise that exists in our communities and families, viewing instead outside experts as the only ones capable of “fixing” our problems. As in the example of education, deficits-based social policies often disempower individuals, families or communities facing truly difficult situations, and seek solutions by diagnosing, fixing, punishing, or simply ignoring those affected. (p. 35)

He contends that as Hawaiians, as Pacific Islanders, and as scientists, they “must call for a critical, strengths-based approach to research, creating knowledge that addresses the concerns of communities first, and then of policy-makers and science” (p. 35). Strengths based also means a bottom up approach aimed to directly benefit those involved in the process, as opposed to typical top-down, expert-driven deficit models.

Background and Importance of measuring FQOL

Family support enables families to provide support at home, enhance their ability to participate in their communities and allows them flourish as a family unit, which increases FQOL (Wang & Brown, 2009a; Zuna et al., 2009a). Additionally when families are empowered to be able to determine what supports and services they need and how they are delivered the effectiveness of these services significantly increase (Wang & Brown, 2009), and also does their FQOL (Summers et al., 2007). Shalock et al. (2002) believe that the theory of quality of life has potential to create new ways of looking at issues of disability and to be a positive influence on those who work in the field by offering a useful paradigm that can contribute to identification, development, and evaluation of supports, services, and policies for individuals with disabilities. The interest in quality of life comes from ‘the rise of consumer power with its’ civil rights

movement and their emphasis on person-centered planning, personal outcomes, and self-determination' (Schalock et al., 2002, p. 457). Furthermore, "families as consumers will become increasingly involved in identifying and assuring the authenticity" of FQOL, and thus the "indicators identified by them would ideally become the goal and content of the services" (Park et al., 2001). Researchers view the concept of quality of life as a challenge to act in response to in creation of social policy theory and applied research, as well as the design and evaluation of program supports to individuals and groups (Schalock et al., 2002; Zuna et al., 2009a). Stemming from the quality of life movement in disability research is the concept of FQOL, as family quality of life is important for all people, and should be thought of in the same way for all people, with and without disabilities.

Since it's founding in 1988, the University of Kansas' Beach Center on Disabilities has been at the forefront of FQOL research. This research has been gathered in collaboration with families who have members with disabilities; individuals with disabilities; the professionals and policy leaders who serve these families and individuals, and members of the communities in which the families and individuals live. Each of the stakeholders is committed to the common goal to of improving the quality of life of families and individuals impacted by disability (Beach Center on Disability, 2010). Over these last twenty plus years, Beach Center researchers have diligently endeavored to identify and explain reasons why FQOL varies so significantly among families of children with disabilities. The primary means they have use to supply FQOL data has been through the administration of their Family Quality of Life (FQOL) scale a measure specifically designed for families with children with disabilities – Beach researchers have tried to gain a greater understanding of the variables and fixed characteristics or demographics that best

predict FQOL (Zuna et al., 2009c). The FQOL scale is described as a self-report measure that assesses parents' satisfaction with their families' quality of life (Zuna et al., 2009b), and is designed to measure family members' perceptions of the importance of different aspects of family life (Wang et al., 2004a). The Beach Center uses the FQOL scale in their research to examine the relationship of parents' ratings as to the adequacy of services and supports to both family and child outcomes, in addition to carrying out research on performance factors in order to substantiate the impact of a family centered service on FQOL (Summers et al., 2005; Zuna et al., 2009a).

The intent of the Beach Centers research is to provide empirical evidence that establishes relationships among the variables of partnerships, supports and services and overall family quality of life. It is their expectation that identifying these variables will encourage additional assessments of possible barriers to the access of necessary supports for families with children with disabilities (Summers, et al., 2007; Turnbull, 2004; Wang et al., 2004a).

Moreover, Beach Center researchers believe that research drawn from “a unified theoretical framework of FQOL will better: (a) inform systemic operations across agencies as to how to more effectively and efficiently serve families who have a child with a disability, (b) result in new and enhanced legislation and policy to address family needs and, (c) demonstrate necessity of adequate numbers of appropriately staffed programs to meet families' service and support needs” (Zuna et al., 2009a, p. 26).

Research to address problem

Studies show that families with a member with a disability living in the home have increased needs as a result of the family member with the disability, and that the FQOL survey

instrument can be used to assess which needs have low, medium, or high priority (Wang & Brown, 2009). Research related to enhancing the quality of life for children and youth with disabilities has been shown to be useful to a variety of stakeholders (Markey, Santelli, & Turnbull, 1998; Summers et al., 2007). According to Wang and Brown (2009a), FQOL theory represents ‘a new perspective for organizing positive value concerning families and has become a guiding principle for policy development, service delivery, family support and interventions in the field of disability (p. 157). The information gathered from comprehensive surveys, such as the FQOL scale have demonstrated their value to serve as a constructive tool for service providers and educators in determining how to improve the provision of services to families and their children with disabilities (Poston et al., 2003; Summers et al, 2007; Wang, et al., 2004b).

The complex nature of determining appropriate services and supports to families of children with disabilities validates the need for policy makers and leaders to involve families in adding their voice to the collective body of information on program and support development (Salisbury & Dunst, 2000; Summers et al., 2007; Turnbull, Friesen & Ramirez, 1998). Families become empowered through their involvement as an integral part of the informational gathering process, making them feel that their particular needs are important, and that their opinions contribute to shaping supports and services on a local level (Markey et al., 1998; Salisbury & Dunst, 2000; Turnbull et al., 1998). For in the final analysis, in relation to family quality of life, ‘evaluation from the community perspective is about value added to the quality of life that the community (consumer) cares about’ (Kawakami et al., 2007, p. 332).

As noted earlier, FQOL issues relative to families having a member with a disability are highly individualistic and require numerous and comprehensive supports in order to be effective

(Mian et al., 2004; Summers et al., 2007). The amount and type of service or support each family receives varies immensely, requiring a wide range of supports unique to each family's needs (Salisbury & Dunst, 2000). Examples of supports necessary for families with children with disabilities may include: (a) direct services to their child with a disability, (b) access to information and education on disabilities, (c) community supports, and (d) information and assistance with advocacy (Blue-Banning et al., 2004; NASET, 2005; Park et al., 2003; Wang et al., 2004b). The logical corresponding outcome for family support is improved FQOL (Schalock et al., 2002; Turnbull et al., 2004). Zuna et al. (2009a) assert that their "unified FQOL theory proposes a mechanism for why supports for the family affect the well-being of each of its members, including the person with a disability" (p. 22).

In order to more proactively meet the varying needs of families having a member with a disability, multiple check points assessing FQOL are necessary to provide on-going information as to the appropriateness of current services and supports for the families. As a means of applied research and a measure of service and support effectiveness, the FQOL scale has the potential to measure outcomes exploring the effects of family-oriented services and policies on family quality of life (Hoffman et al., 2006). The purpose of this dissertation is to further expand the research base of the Beach Center on Disability in the area of FQOL through the inclusion of a wider sampling of culturally diverse populations, namely families with children with disabilities within and across the state of Hawai'i. As a unique and multidimensional subject, quality of life issues and system supports differ dramatically from individual to individual, and family to family. To address this distinction, the FQOL scale can be a valuable tool for social workers and allied professionals to gain information about a family's overall satisfaction with their family life

across multiple domains to determine individualized family and child oriented supports (Wang & Brown, 2009).

In summary, FQOL research indicates that families of typically developing children have higher FQOL than families of children with disabilities (Zuna et al., 2009c). Summers et al. (2005) believe the ability to identify and assess FQOL outcomes for families of children with disabilities could have policy implications and practical advantages that would allow more positive and effective collaborations across types of supports, services, and settings which would in turn have a positive effect on FQOL. Historically, families of children with disabilities, as well as culturally and linguistically varied and often indigenous families, have been overlooked in terms of research that aims to discover approaches likely to improve their FQOL (Kawakami et al., 2007; Zuna et al., 2009a).

Family quality of life is an emerging field in disability research and practice—the application of FQOL theory is intended to enhance the degree and control families have over services and supports, such as changing options when needed, and increasing opportunities to construct new options for both family and individual services (Poston et al., 2003; Wang & Brown, 2009). The FQOL construct may assist FQOL stakeholders by “providing an overarching framework for conceptualizing social problems, planning intervention strategies, guiding practices, and evaluating outcomes of programs” (Wang & Brown, 2009, p. 159). The FQOL scale has been demonstrated to be an instrument that can be used to measure family outcomes for families who have children with disabilities, and it has been verified to have social and community validity with populations on the continental United States (Wang et al., 2006; Zuna et al., 2009b). Expanding the scale to assist in understanding how ethnicity interacts with

different program and service variables in predicting FQOL offers parents and professionals alike the opportunity to better supply useful information concerning appropriate cultural adaptation of programs and services (Zuna et al., 2009c). Ultimately, application of wider range of culturally and ethnically valid FQOL data could lead to improvements in service and support options for support for the family as well as the individual with a disability (Wang & Brown, 2009).

To date, there remains a limited amount of research on the supports and services that enhance FQOL as a pro-active approach to preventing lower FQOL for families with a child with a disability (Zuna et al., 2009a). Qualitative FQOL research is based upon the assumption that family satisfaction with service providers is a major factor in parental involvement in their child's education (Park & Turnbull, 2001). One may make the case that partnership satisfaction is even more critical in assuring involvement of parents from diverse cultures and ethnic backgrounds (Park & Turnbull, 2001; Sileo et al., 1996). Unfortunately, many families from culturally and linguistically diverse (CLD) backgrounds often feel alienated from the dominant culture that typically inspires and supports the social support systems in their state or community. The expectation for CLD families with a child with a disability to engage and interact with social support systems can serve to lead to further feelings of alienation (Markey et al., 1998; Onikama et al., 1998; Sileo et al., 1996;).

In areas where service provision is determined by a dominant culture, (i.e., one that is different from a particular family's), families often rely more on extended family members and their community to provide supports that may be more helpful to them as the services and support from the dominant culture may not be culturally appropriate (Knokey, 2006; Onikama et

al., 1998). Therefore, a family's cultural background can play a large part in identifying precisely what needs for support and services may need to be (Onikama et al., 1998; Sileo et al., 1996). This finding has great significance for a highly culturally diverse state such as Hawai'i, and highlights the necessity to conduct research in terms of FQOL service and support provided to CLD families. There exists a gap in the research on what the support and service needs are for CLD families in Hawai'i. Family involvement in their children's learning, in the broadest sense, has always been a part of traditional culture in the Pacific region (Onikama et al., 1998; Solomon, 1980). In Ancient Hawai'i families were intricately involved in children's education, as formal schooling took place within the community, and thus, learning took place everywhere (Onikama et al., 1998). The current education system in Hawai'i contains many barriers to the involvement of Pacific Island families that stems from a disconnection to the home and community (Onikama et al., 1998).

Research indicates family participation remains one of the five national challenges facing education (Johnson, Stodden, Emanuel, Luecking & Mack, 2002). Existing barriers to family involvement within the present system require a concerted effort from stakeholders to overcome. The Americanized system of education in Hawai'i is unfamiliar and possibly intimidating to many families from collectivist cultures. Many Hawaiian families are skeptical of the education system here in Hawai'i, as a history of past evaluation efforts have failed to produce positive changes in the education of Hawaiian students (Kawakami et al., 2007). Lack of positive changes in the education system for Hawaiian students also perpetuates an ongoing barrier for indigenous family involvement in academic or program evaluation in Hawai'i (Kawakami et al., 2007). The

involvement of families in the process of evaluation may help to improve relationships with families and communities.

Pilot Study

In 2005 as part of my doctoral course of studies I proactively attempted to identify a validated scale or instrument with the potential to supply answers to three research questions:

1. What are the satisfaction ratings for families with a child with a disability in Hawai'i relative to their ability to participate in their communities?
2. What are the satisfaction ratings for families with a child with a disability in Hawai'i relative to their level of satisfaction and importance of family professional partnerships?
3. What are the satisfaction ratings families with child with a disability in Hawai'i's relative to aspects of their family quality of life?

I subsequently discovered the Beach Center's FQOL instrument and determined that it would be useful to apply the FQOL survey instrument as the primary tool for a pilot study of FQOL specific to families with children with disabilities in Hawai'i. Because the results of my pilot study served as a significant driving force in the creation of this dissertation I feel that it is important that I provide a fairly comprehensive review of that study.

The FQOL survey used in this pilot study is made-up of three subscales: (a) *family community participation*, (b) *family-professional partnerships*, and (c) the *family quality of life scale*. The *Family Community Participation Scale* aims to evaluate the degree to which families are satisfied with their ability to participate in various activities and places in the community, and the degree to which various factors pose challenges (Park et al., 2001). The FQOL construct was developed to provide "an overarching framework for conceptualizing social problems, planning

intervention strategies, guiding practices, and evaluating outcomes of programs.” (Wang & Brown, 2009a, p. 159). The *Family-Professional Partnership* subscale consists of 18 items and two subscales and is designed to assess parental perceptions of the importance of, and satisfaction with family-professional partnerships (Park et al., 2001). The *Child-Focus* subscale contains items related to parental perceptions of the quality of the professional’s relationships with their child. The *Family-Focus* subscale seeks to measure parental perceptions of the quality of the professional’s relationships with the whole family.

The *Family Quality of Life Scale* aims to measure levels of family perceptions of the importance of different domains of family quality of life and their satisfaction with those domains. (Park et al., 2001). This scale contains twenty-five items and five subscales: *Family Interaction* (six items), *Parenting* (six items), *Emotional Well-Being* (four items), *Physical/Material Well-Being* (five items), and *Disability-Related Support* (four items), (Park et al., 2001). On each of these scales, respondents are asked to rate items according to importance and satisfaction, with possible responses of 1=*a little important* to 5=*critically important*, and/or responses using a range of 1=*very dissatisfied* to 5=*very satisfied*.

In order to secure permission to use the FQOL instrument, I contacted the lead researchers (Jean Ann Summers and George Gotto) and asked for permission to use the scale in my research. After further correspondence with Summers and Gotto I was informed from them that their scale had only been administered to families in several mid-western states as part of piloting and validating their measurement process (Summers, personal correspondence, February 9, 2005). Because their sample was limited by its’ lack of cultural diversity, both researchers welcomed involving Hawai’i as a site for further administration of their scale instrument. As a

result of our communications I was hired by the Beach Center in February of 2005 to serve as a local coordinator of the FQOL scale in Hawai'i. My task was to assist the Beach Center to identify families and collect surveys as a means of expanding their national database of families through the inclusion of families from Hawai'i (Gotto, personal correspondence, February 8, 2005).

Pilot study participation group and procedures. My pilot study targeted families of children with disabilities of school age (four to eighteen years old) attending public schools in the state of Hawai'i. To find family member participants I researched, and subsequently contacted by telephone, two well-respected advocacy agencies for families with children with disabilities in Hawai'i, Hawai'i Families as Allies (HFAA), a statewide network of local support comprised of parents whose children have serious emotional or behavioral challenges, and the Learning Disabilities Association of Hawai'i (LDAH), the Parent Training and Information Center for Hawai'i, serving parents of children with a variety of disabilities. After receiving encouraging feedback, I met with the directors of each agency, both of who readily expressed interest in my study and were highly receptive about the need to provide additional opportunities for families in Hawai'i to have a voice in expanding national perspectives concerning family quality of life.

The director from LDAH, Noe Dela Vega initially expressed some concern that it might prove difficult to recruit a sufficient number of participants for my study within my given time frame due to the fact that the families they served typically attended meetings in small in groups in various locations around the island (Dela Vega, personal correspondence, March 31, 2005). However, because of her expressed interest in using the FQOL scale as a tool to assess their

clients' satisfaction and needs in the services they received Hawai'i's public schools, she did ask for the contact information for the Beach Center so that they could possibly use the tool themselves in the future.

The director from HFAA, Susan Cooper, was also very interested in my study, as she was familiar with work conducted by the Beach Center and was excited to be a part of their research efforts (Cooper, personal correspondence, March 26, 2005). Aside from the prospect of their contribution to the involvement of Hawai'i's families in a National study, she was also curious about the results of the survey from the families they served. Subsequently, Cooper invited me to attend HFAA's annual conference in May of 2005 where as part of the conference program, she publicly acknowledged her support of my study, introduced me to the group, and invited parents to participate.

At the HFAA conference, 40 family members having children diagnosed with emotional or behavioral disorders, volunteered to participate in the study. Families were informed that for volunteering to participate in this study, they would receive ten dollars for their participation from the Beach Center. Since my study replicated the Beach Centers' protocol and procedures as much as possible, only one member per family was allowed to fill out the scale (Summers et al., 2007). Family members interested in participating were given a packet that included information on both studies (mine and the Beach Center's), consent to participate forms, instructions on how to fill out the survey, the FQOL scale, a form to provide their demographic information, and a postage-paid envelope to receive their compensation from the Beach Center for participating. Participants were given 30 minutes to fill out the surveys, and returned them to

me when they were finished. Consent forms were collected separately, and surveys did not include names or identifying information to protect respondent's anonymity.

Pilot Study Results and Discussion. Although general individual and family demographic information was collected on a section of the FQOL survey, I quickly ascertained that in the demographic information section on the Beach Center survey, the Asian/Pacific Islander demographic category was combined into a single entity. This grouping proved to be inadequate since in Hawai'i this dual grouping provided highly misleading results given that these two groups comprise a large and highly distinct population in the state. In order to provide a more valid picture of Asian/Pacific culture specific information for the assessment of service provision in Hawai'i, the two groups should be separated.

The information I derived from my pilot study served to provide a general picture of what the FQOL looked like for families who have a child with a significant emotional and/or behavior problem based on the FQOL items specific to the state of Hawai'i. I was pleased to find out that the data I gathered concerning CLD populations in Hawai'i was helpful to the Beach Center in expanding the validity of their scale by expanding its applicability to multicultural families, thus adding to the literature in this area of research.

Family ratings of satisfaction in community participation—The reality that the families in my pilot study consisted primarily of ones with children with behavior disorders, some areas of satisfaction and dissatisfaction on the scale may be more impacted by this particular disability than others, (e.g., community participation). Reuff and Turnbull (2001) found in their scale of parents with children with behavioral challenges that “individuals exhibiting challenging behavior face a high risk of exclusion from others around them, including their own families” (p.

442). Surprisingly this was not what the results of my pilot scale indicated in Hawai'i, though the respondents indicated they were unsatisfied with how people treated their child within the community, they did report they were able to participate in community activities as much as they wanted to. This could be attributed to the outdoor life-style of many families that live in Hawai'i, or to the strong sense of ohana (family) in Hawai'i, (both large and small community and family activities and events take place on weekends in the parks and beaches of Hawai'i year-round).

Family ratings of professional partnerships —The results from my pilot study concur with the Beach Centers' (Summers et al., 2007) in professional partnerships. The results indicate that the families were satisfied, or mostly satisfied with issues related to the provider's ability to keep their child safe, and treat their child with dignity, but relatively unsatisfied with the provider's ability to meet the individual needs of the child (Summers et al., 2007). Respondents in the pilot study were also satisfied or mostly satisfied with their service provider's friendliness, and least satisfied with the provider's ability to help them gain the skills or information to get what their child needs.

Family ratings of satisfaction with FQOL—Generally, the families surveyed were satisfied with their community participation, family quality of life and, on a surface level, partnership with service providers. Responses on two of the scales—the partnership subscale and FQOL subscale indicate that the FQOL of the families from the study sample did not appear to be affected either positively or negatively by the services the children or the families were receiving from the service providers in Hawai'i.

Pilot study limitations. The main goal in my pilot study was to include as many family members as possible from a wide range of cultural and ethnic backgrounds, and socioeconomic status. However, the parent advocacy agency that was involved in this study served only families of children with behavioral disorders, which may weaken generalization to other populations of children with disabilities, and their families in Hawai'i. The results gained from administration of the FQOL scale to other disabilities may vary within and across other types and levels of disabilities; therefore I believe it would be important to apply the scale with a larger sample across a wider variety of disabilities. Another limitation of my pilot study was the small sample size of 36 completed surveys. Summers relayed to me that they were not able to run a comparison across sites that would produce meaningful results due small numbers of surveys collected across sites (Summers, personal correspondence, May, 2005).

Impetus for expanding. Inviting families into the process of service evaluation and needs assessment can be empowering for all parties involved in the process. I believe the use of the FQOL scale with families with children with disabilities and the stakeholders who serve them may improve collaborative relationships with families, school staff, and service providers in Hawai'i. Some of the local areas of need may not have been addressed in the FQOL survey questions, as they are specific to the culture of mid-western states where they were developed using mostly Caucasian families for validation. To address this, I added two open-ended questions to the survey so that family members would have an opportunity to add their own comments regarding the types of supports they feel would most help their family, and also for them to comment about the impact of ohana on their FQOL. It was my hypothesis that because of the strength of the ohana system here in Hawai'i, that overall FQOL would be higher than

similar samples on the mainland. Consequently, I recommend the development of culturally relevant questions to adequately assess the strengths and needs of culturally diverse areas such as Hawai'i. Zuna et al. (2009c) propose "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" (p. 6). This would be a significant finding for administrators and practitioners in Hawai'i because of its culturally diverse population (U.S. Census Bureau, 2000).

Summary of the FQOL Theoretical Framework

Beach Center researchers advance a theory of FQOL that is intended to explain how various concepts influence variations in FQOL for families of children with disabilities (Zuna et al., 2009). Through their FQOL research they report that individual member concepts and family-unit concepts are direct predictors of FQOL and interact with individual and family-level support, services, and practices to predict FQOL (Zuna et al., 2009). These individual member concepts include demographics, characteristics, and beliefs. The family-unit concepts include dynamics and characteristics. I concur with Zuna et al. (2009) in their contention that "singly or combined, the model predictors result in a FQOL outcomes that produces new family strengths, needs, and priorities that re-enter the model as new input resulting in a continuous feedback loop throughout the life cycle." (Zuna et al., 2009a, p. 26). It is my intent through the creation of this dissertation to provide additional new inputs that will deepen our existing knowledge of this continuous feedback loop.

The Beach Center's FQOL theoretical model aims to aid practitioners to examine which variables (programmatic, ecological, and family) can be changed to positively impact FQOL for

families of children with disabilities. (Zuna et al., 2009a). Additionally, at the heart of the FQOL theory are the performance concepts such as the formal services, support and practices developed and offered to the individuals with disabilities and their families (Zuna et al., 2009a).

Contribution to Theory Knowledge and Practice

In chapters one and two I have proposed a rationale for conducting additional research that increases and emphasizes existing knowledge of effective outcomes of services, support, and practices, validates stakeholders to assess their services and supports to determine whether they are actually working to improve the FQOL of the families and individuals with disabilities they serve (Turnbull et al., 2003; Zuna et al., 2009b). According to their mission statement, the Beach Center strives to through “excellence in research, teaching, and technical assistance, and through collaboration with those dedicated to the same ends to make a significant and sustainable difference in the quality of life of families and individuals affected by disability” (www.beachcenter.org). The Beach Center holds a commitment to collaborate with others to continually advance the FQOL theoretical model in building a unified FQOL theory, as was my personal experience working with the researchers behind the model. For more than five years the researchers from Beach Center on Disability have expressed unwavering enthusiasm in support of my efforts to apply their FQOL scale in Hawai’i due to it’s distinctive mix of culturally diverse populations, thus supplying a much-needed expansion of their FQOL research.

I have previously established that there is a lack of research in the area of FQOL of CLD families with children with a disability (Markey et al., 1998; Zuna et al., 2009b). Beach Center researchers have been increasingly concerned that “in spite of extensive efforts to have a random or representative sample of families in research projects, almost invariably research samples

have been drawn from majority culture” (Zuna et al., 2009c, p.25). In the Beach Center’s review of research literature related to families of students with disabilities, they frequently lament the fact that their research samples are all too often comprised of middle and upper class White parents (Zuna et al., 2009b). This is problematic since the results from research in this area are typically generalized to CLD families (Markey et al., 1998). I hope the use of the FQOL scale with families in Hawai’i having a member with a disability will lead to a reduction in the research gap in regard to the inclusion of CLD families in FQOL research.

I took care to demonstrate cultural sensitivity in choosing my research methods and in the reporting of my findings. Although the FQOL survey has not been utilized with many CLD families, needs assessment surveys as a means for family involvement have been identified by researchers as useful in establishing credibility and trust within CLD populations as well as CLD community organizations (Harry, 2002; Kalyanpur, Harry & Skrtic, 2000; Lamorey, 2002). Involving indigenous families in the assessment of the services provided to them may positively affect partnerships with families through their inclusion in the process, and also may potentially improve FQOL by increasing desired systems of support indicated by the families themselves (Kawakami et al., 2007).

CHAPTER III

Methods

Research design

This study used a mixed methods research design that combined survey methodology and autoethnography. I also added two open-ended questions to the survey. Group participant survey methodologies were used in an attempt to potentially increase the response rate of the scale administration/completion. As a nonindigenous researcher working with a primarily indigenous population I made a conscious effort to respect and incorporate, as far as possible, culturally responsive evaluation methods in my research design. The cultural evaluation methods employed in this study were based on recommendations from indigenous researchers who advocate for the involvement of indigenous families in the assessment of the services that families receive (Kamehameha, 2003).

Participant description

The study participants targeted family members of children with disabilities of school age (four to eighteen years old) attending public schools in the state of Hawai'i. As with my pilot study, my survey procedures replicated the Beach Center's recommendation that only one respondent was used per family (Summers et al., 2007). I made a conscious effort to recruit culturally diverse families in my sample due to their historical under-representation in special education literature on FQOL.

Sampling procedures

Several measures were used to locate study participants from Oahu and neighbor islands: contacting agencies and public schools that serve families with children with disabilities, and attending multi-agency meetings and disability conferences.

I initially contacted the Children's Community Council (CCC) on Oahu, as I had a contact at that agency that I knew was interested in my research topic. With the support of the CCC, I attended three statewide CCC meetings in the communities located in the Central, Leeward, and East Honolulu school districts. At each of these meetings I was provided time on the agenda by the CCC to invite family members in attendance to participate in my research by filling out the surveys at the meeting. Two of the CCC district meetings I attended serve communities more likely to have members underrepresented in FQOL research samples. One of my district meetings, the East Honolulu district CCC meeting, consisted of higher SES respondents I included this district because the parent Co-Chair expressed interest and had announced that I would attend the meeting to distribute and collect surveys. The nine neighbor island CCC's were given letters of invitation for family members to participate in my research, and if interested, were provided a survey packet with my contact information to return the survey to me.

I also participated in two conferences that the Learning Disabilities Association of Hawai'i (LDAH) held on Oahu, and in Maui, where I was supplied with a "vendor's table" to display my study information and provide survey packets to family members who wanted to participate. I was given a few minutes at the beginning of the conference to speak to the group about my research and invite members to join my research project. At the conferences, participants were informed both orally and in writing in the survey packet that their anonymity

would be protected as their names were not required to be on the surveys, and their consent forms would be collected and filed separately.

To solicit the participation of families with children attending public schools, I emailed an informational letter (see Appendix B) describing the purpose of my study to the principals of seven schools I purposefully chose. These schools were chosen for their location on the island as typically neglected populations in FQOL research and were based on their demographics. The schools included: Waimanalo Elementary and Intermediate, Royal Elementary, Kailua High School, Pope Elementary, Nanakuli Elementary, Waianae High School, and Kaiser High School. Waimanalo Elementary and Intermediate School was the only school to grant me permission to send informational letters to family members with children with disabilities to take part in my study. Eighty children at the school identified with a disability from grades kindergarten through eight were given informational packets to take home to their caregivers with the survey and instructions on how to complete and return if someone from their family was interested in participating.

Sample size

My sample population included forty-three family members of children with disabilities from the islands of Oahu, Maui and Hawai'i.

Measures and covariates

The method used to collect data in this study included a survey questionnaire. As mentioned previously, the FQOL Scale is designed for use as a research tool and contains five subscales: Family Interaction, Parenting, Emotional Well-being, Physical / Material Well-being, and Disability-Related Support. The psychometric properties of the survey as reported by

Hoffman et al. (2006), for reliability include: Cronbach's alpha for the FQOL subscales on Importance ratings was .94 and on Satisfaction ratings was .88 (Hoffman et al., 2006). Test-retest reliability was examined in both importance and satisfaction responses for each of the FQOL subscales. All correlations were reported to be significant at the .01 level or beyond (Hoffman et al., 2006). Individually, for *importance*, the correlations between time points were .54 for Family Interaction, .66 for Parenting, .70 for Emotional Well-being, .42 for Physical / Material Well-being, and .77 for Disability-Related Support (Hoffman et al., 2006). Finally, for *satisfaction*, the correlations between time points were .75 for Family Interaction, .71 for Parenting, .76 for Emotional Well-being, .77 for Physical / Material Well-being, and .60 for Disability-Related Support (Hoffman et al., 2006).

The validity of the instrument was analyzed by a *both item-level* overall FQOL structure (a second-order factor of FQOL, measured by five factors, which were in turn measured by their items as observed variables) and a *subscale-level* FQOL structure (a first-order factor of FQOL, measured by the 5 subscale item means as observed variables). The item-level overall FQOL importance model had acceptable fit, $\chi^2(270) = 617.28$, $p < .001$, CFI = .87, RMSEA = .07. The subscale-level FQOL model had excellent fit, $\chi^2(5) = 3.41$, $p = .63$, CFI = 1.00, RMSEA = .00. The convergent validity was tested between the FQOL subscales and relevant existing measures. The Family APGAR, a 5-item measure of family functioning, was significantly correlated with the satisfaction mean for the Family Interaction FQOL subscale, $r(87) = .68$, $p < .001$ (Hoffman et al., 2006). Although the Beach Center does mention attempts to involve a culturally diverse sample population, they report that consistently the samples are drawn from White majority cultures (Markey et al., 1998; Zuna et al., 2009c). The intent of my study was to expand cultural

validation of the instrument through the inclusion of CLD family participants not previously included in the Beach Center's samples.

Procedures

To gain access to possible participants to complete the FQOL survey for my study, I first contacted agencies on Oahu who work with families of children with disabilities in the areas of advocacy, empowerment and provision of information, training, and support. I also contacted school Principals and teacher colleagues to seek involvement of local area schools. Invitations to participate were distributed to a variety of agencies and service providers in regional locations on Oahu. My goal was to obtain a diverse sample of cultural and socioeconomic backgrounds, with a variety of disabilities in my survey sample. After the initial contact with the agencies and school administrators, I emailed information containing cover letters (Appendix A), introductions to the study (Appendix B), and copies of the survey (Appendix C). From my contacts with agencies soliciting participation and assistance with my research, only the Community Children's Council (CCC) of Hawai'i, LDAH, and Waimanalo Elementary and Intermediate School were active in assisting me to gain access to family members with children with disabilities. I will first describe the process I went through with the agencies (CCC and LDAH), and then I will describe the data collection process used with the school, as they were slightly different.

Children's Community Council. There are seventeen CCC's throughout the Hawaiian Islands each of which act as advisory committee. These CCC's were created as a result of the Felix Implementation Plan mandating that local community based planning and evaluating bodies be organized around school complex communities. The staff members at the CCC placed

me on their monthly meeting agendas so that I could come and describe my study, ask for family member participants, and distribute and collect surveys at the meetings. The outer island CCC meetings also provided information on my study to family members in attendance. If family members were interested they were given a survey that the CCC member collected and sent to me on Oahu. On Oahu at each of the CCC meetings I met with interested family members to distribute participation packets that included the scales to be used in the study—The Partnership and Family Quality of Life Scale, open-ended questions, demographic information, and consents to participate in the study (see Appendix). Surveys from family members that completed the survey there were collected at the site, and if additional time was needed from participants, I arranged individually how they would return their completed survey to me. To protect anonymity consent forms were separated from completed surveys.

LDAH Conferences. The LDAH is the Parent Training and Information Center (PTI) for Hawai'i, serving families of children with a variety of disabilities. I attended two disability conferences held by the LDAH on Oahu, and on Maui. At each conference I was given a vendor's table where I displayed my materials for family members to look at during break times. I was allowed a brief time at the beginning of the conference, along with the other vendors where I introduced my study and myself and asked family members to participate.

Waimanalo Elementary and Intermediate School. One public school agreed to participate in this study—Waimanalo Elementary and Intermediate School. The student services coordinator (SSC) assisted me in distributing informational letters and survey packets to parents of students identified as having a disability and receiving services at the school. Eighty students from grades Kindergarten to eighth grade were identified to receive survey packets. Survey

packets and informational letters were sent home, inviting parents to participate in the study and instructing parents to return surveys to the school completed and they would receive a five-dollar gift card from McDonalds. The length of participant involvement was estimated to be a half hour, participants were given a packet which included information on my study, consent to participate forms, instructions on how to fill out the survey, the Partnership and FQOL Scale, two open-ended questions, and a section within the scale to provide participant demographic information (see Appendix).

Culturally Responsible Evaluation and Research. Currently there are no specific protocols or procedures for conducting indigenous, or Native Hawaiian research, merely guidelines for improving methodological practices with indigenous communities (Kamehameha, 2003; Kawakami et al., 2007). However, leading researchers in indigenous evaluation methods in Hawai'i such as The Policy Analysis and System Evaluation (PASE) committee at Kamehameha Schools have tried to establish culturally relevant evaluation (CRE) procedures for Pacific Island researchers and educators (Kamehameha, 2003; Kawakami et al., 2007).

According to Ah Sam, Lee, Martin, and Malina-Wright (2009), CRE within a Native Hawaiian context involves the inclusion of the “Five R’s”— *relationship, relevance, rigor, resilience, and responsibility* in each evaluation step. I was careful to attend to each of the “Five R’s” throughout my research. I was able to address the *relationship* aspect as a result of working as a teacher in the areas of the island from which the families live. I have both an understanding of, and a shared experience (*relationship*) with, the topic that I am surveying the participants in my survey about. For *relevance*, I believe that the survey I have used in my research attempts to assess areas of FQOL which are central to the Hawaiian family concept of ohana, wellness, and

Hawaiian `ike, (self-sufficiency and stewardship). To address *rigor* within my evaluation design I employed a mixed methods approach with the use of a standardized survey instrument, as well as an unconventional approach with the open-ended questions of allowing participants to ‘talk story’ with me about their answers as opposed to writing them out. For *resilience*, in analyzing my data I made an active effort to discover strengths identified by the families, not merely deficits. Finally, to attend to *responsibility* based on a CRE model, I will be disseminating my results in various formats to those persons involved in my research project first as it is my hope this information will somehow benefit them and their children.

To develop rapport and trust with the family members I shared my own experiences of being a special education teacher in Hawai’i. I clearly expressed to the families the purpose of my study and how I believe it could benefit them directly before formally inviting them to enter into discussion about my research and their willingness to participate. In collecting data within Hawaiian communities, The *Evaluation Hui* from the Kamehameha School suggests the use a cultural ‘bridge’ in the process of data collection from the Hawaiian community. They recommend that if the researcher is considered an ‘outsider’ the use of a cultural bridge—a person or group who has an established relationship with or similar background as the Hawaiian community, may be empowering to the families (Kamehameha, 2003). I prefer the concept of a cultural liaison as opposed to a bridge, which suggests a wide gap between opposing sides. The cultural liaisons I used for my study were the CCC members, the people who work for LDAH, and the student services coordinator at Waimanalo Elementary and Intermediate School. Based upon the high response rate I received from the small number of parent participants at the

meetings I attended, I feel the use of a cultural liaison was an effective means of establishing the worth of this study for the participants, and increased my survey response rate.

Data Collection and Management

Data collection procedures will be described in terms of the instrument and coding procedures.

Instrumentation. As I have all ready detailed, the survey questionnaire to be used in this study was developed at the University of Kansas Beach Center on Disability. The survey instruments used in this study included the Beach Center Family Quality of Life Scale, and Family-Professional Partnership Scale. The Community Integration section of the survey used in my pilot study was taken out of the updated version of the FQOL scale used in the present study. Jean Ann Summers suggested to me that it did not work well psychometrically with the other subscales (Summers, personal correspondence, January 25, 2010). Research on Culturally Responsive Evaluation (CRE) within a Native Hawaiian context recommends that evaluation designs employ the use of mixed methodology to obtain information, with an emphasis on qualitative methods (Ah Sam et al., 2009; Kamehameha, 2003). Because the FQOL scale is quantitative, I added two open-ended questions to the FQOL questionnaire as a cultural adaptation to the survey to allow family members to provide their own comments. The open-ended questions asked family members to comment on what kind of services and/or supports they thought would most improve their family quality of life here in Hawai'i, and how the system of ohana here in Hawai'i has affected their family's quality of life, of having a child with a disability.

Data Analysis, Interpretation, and Presentation. Data was gathered from returned, fully completed surveys. Items on the scale were pre-coded for entry into a computer database (excel) for later analysis using excel. The responses from the surveys were analyzed and compared using mixed methods including descriptive statistics, ANOVA, and qualitative methods.

Descriptive Statistics. I used descriptive statistics to provide summaries about the sample and FQOL measure by calculating and observing the response frequencies and distributions as percentages. Percentages of the sample's responses to each category for items on the scale are presented in tables for each subscale of the questionnaire, and also compared across each of the subscales. Mean domain scores were also computed for independent and dependent variables. The independent variables included family and child characteristics as reported on the demographic questions on the survey. The dependent variables included the sample's ratings on the survey's three subscales.

ANOVA. I used a one-way analysis of variance to test whether there were any significant differences between the three different ethnic groups in my sample and the three FQOL sub-scales.

Qualitative Methods. In qualitative research, grounded theory methodology is the most commonly used methodology for developing theory. In this type of methodology theory development begins with the data. Data was recorded into a word processing document from the responses on the open-ended questions. Theory is developed throughout the research process as data interpretation takes place with new data that is collected. An important principle is that grounded theory tries to develop and elaborate theory by constant comparison with the data

gathered during the research process. This method requires the researcher to be steadily reflexive, and continually draw connections between realities and interpretations (Charmaz, 2005).

One major drawback of any type of survey information gathering is its tendency to introduce and maintain an impersonal, overly objective process to gain information from large sample populations. These procedures are often contrary to the preferred formats for different data collection methods reported to work with Hawaiian communities include collecting data in informal settings, using focus groups, and “talk story” sessions, where confidentiality is explicitly maintained (Kamehameha, 2003). In an attempt to overcome this preference mismatch I offered to conduct “talk story” sessions for two family members per CCC meeting site after the meetings who would prefer to talk to me about their answers to the open ended questions.

Two open-ended questions were included on the scale for the purpose of giving families an opportunity to provide their own responses regarding services and/or supports for their family or child with a disability. Family member open-ended responses were analyzed using qualitative inquiry methods to derive themes in personal experiences. Since there were a small number of respondents who filled out the open-ended questions attached to the survey, a full qualitative inquiry with prolonged engagement, triangulation, and transferability was not conducted in this study.

Due to the constraint of time of access I had to the family members at the meetings, I let the family members know if they would prefer to speak to me over the phone or meet somewhere in their community to talk about their answers after they have had some more time to think about their answers they can do so within two days of completing the survey.

Autoethnography. The second type of qualitative method used in this study is autoethnography—which I used to balance the use of quantitative research methods and to add my personal experience to this study. My ten years of teaching experience in the public schools in Hawai'i provided me with ample information to reflect on and bring to the discussion and implications of this study. As part of my study I wanted to document the importance of and relationship between ohana and FQOL for families in Hawai'i with children with disabilities, as I feel it has a positive and significant impact.

Autoethnography is defined as reflecting on the subjective self in context with others (Spry, 2001, p. 713). It is an emerging qualitative research method that allows the author to write in a highly personalized style, drawing on his or her experience to extend understanding about a societal phenomenon (Wall, 2006). It requires the author to be “vulnerable and courageous in rendering scholarship, enabling one to step out from behind the curtain and reveal the individual at the controls of academic-Oz” (Spry, 2001, p. 714). I am stepping out from behind the curtain to provide my personal insights as autoethnographic data to balance this dissertation with qualitative data based on my experiences as a special education teacher and doctoral student in Hawai'i. My teaching experience was a marriage of practice and culture, so it makes logical sense that I should use autoethnography in my dissertation.

CHAPTER IV

Results

The three research questions guided the analysis of the data gathered from the FQOL survey. The intention of this study was to examine ratings of FQOL with families from Hawai'i with children with disabilities. The design for this study included mixed methods, which combines quantitative analysis of survey items and qualitative analysis of open-ended survey items to address the following questions:

1. What are the ratings of importance and satisfaction of families in Hawai'i with children with disabilities of the services and support their family receives, their family-professional partnerships, and their overall FQOL?
2. What is the relationship between FQOL, partnerships and services for families in Hawai'i with children with disabilities?
3. How does the concept of 'ohana' in Hawai'i affect FQOL for families in Hawai'i with children with disabilities?

I will begin my results discussion first by reviewing the family populations included in my survey and then will that review with the results of the surveys addressing my research questions.

Participant Description

The study sample was taken from several sources, including one local public school, multi-agency meetings, and from professional/family conferences. Study participants resided on the islands of Oahu, Maui and Hawai'i. Eighty surveys were sent home to families residing on Oahu, of that eighty twenty-five were returned giving a response rate of 32 percent, making up

more than half of the total study participants (n=25). This may have been due to the monetary incentive I provided for filling out and returning the survey back to the school, or because they were distributed *en mass*.

Unfortunately the multi-agency CCC meetings I attended in my attempt to actively solicit parent involvement had very low parent turnout, with only one to three family members in attendance for each meeting. This only expanded my database by five surveys. The disability conferences through LDAH provided an additional ten surveys on Oahu, and three from Maui.

Demographics

Table 1 provides demographic information on the participants. Family members that filled out the surveys were from Oahu, Maui, and the big island of Hawai'i. More than half of the respondents reside in a rural area or town of between 2,500 and 50,000 people.

Table 1
Participant Demographics

	N	%
Relationship to child with disability		
Parent	37	86
Other relative	4	9.3
Other non-relative	2	4.7
Educational background		
No schooling completed	0	0
Formal schooling but no high school diploma or GED	1	2.3
High school graduate (diploma or GED)	18	41.9
Some college but no degree	13	30.2
Associate degree	4	9.3
Bachelor's degree	4	9.3
Graduate degree	3	7.0
Ethnicity		
Asian/Pacific Islander	27	62.8
Caucasian	6	14.0
Hawaiian	10	23.3
Income		
Less than \$14,999	8	18.6
\$15,000 and \$19,999	4	9.3
\$20,000 and \$24,999	1	2.3
\$25,000 and \$29,999	7	16.3
\$30,000 and \$34,000	1	2.3
\$35,000 and \$39,999	2	4.7
\$40,000 and \$49,999	2	4.7
\$50,000 and \$59,999	4	9.3
\$60,000 and \$74,999	5	11.6
Over \$75,000	8	18.6
Level of child's disability		
Mild	16	37.2
Moderate	20	46.5
Severe	3	7.0
Unknown	4	9.3
Community type		
Large city or metropolitan area (>200,000)	6	14.0
Urbanized area (50,000-200,000)	1	2.3
Town or small city (2,500-50,000)	23	53.5
Rural area or town (<2,500)	12	27.9
Missing	1	2.3

Respondents

The majority of the respondents who filled out the survey identified themselves as the parent (86%), 9.3% as relative other than the parent (i.e. grandparent, aunt, sibling, etc.), and 4.7% as other non-relative (family friend, foster parent etc.). More than half of the respondents reported that they were married, at 53.5%, and 46.5% reported they were not married. The mean number of highest level of education completed was the category 'some college or post-high school, but no degree'. One person responded they had formal schooling but no high school diploma or GED, 41.9% responded they had a high school diploma, 30.2% responded they had some college or post-high school, but no degree, and 9.3% reported to have an Associate degree, and equally reported to have a Bachelor's degree, and 7% reported to have a Graduate degree. For reported total household income, more than half of the respondents indicated an annual family income of \$39,999 or less a year, and the rest was distributed as: 4.7% between \$40,000 and \$49,999, 9.3% between \$50,000 and \$59,999, 11.6% between \$60,000 and \$74,999, and 18.6% responded total family income was over \$75,000.

Ethnicity. The majority of the survey sample (62.8%) identified themselves as Asian/Pacific Islanders, 23.3% respondents wrote in identifying themselves as Hawaiian, and 14% identified themselves as Caucasian. It is relevant to point out here that the Asian/Pacific Islander category comprises the largest population of Oahu, with two distinctly different cultural groups.

Child's Primary Disability. Table 2 provides the information provided by the family members on the child's disability. The identified gender of the majority of the children was male

(72.1%). The primary disability of the child is shown in Table 3, where 9.3% responded their child's primary disability was Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD), 30.2% responded their child had Autism Spectrum Disorder, 23.3% responded their child had a Developmental delay or early childhood disability, 7% indicated their child had an Emotional or Behavioral disorder, 2.3% as Hearing Impairment (including deafness), 11.6% identified their child with a Learning disability, 7% identified their child with Mental Retardation, 4.7% of the children were identified with a Speech or Language impairment, and 2.3% were identified as having a Health impairment, 2.3% were not identified with a specific diagnosis. The level of the child's disability was reported by 9.3% as unknown, 37.2% as mild, 46.5% as moderate, and 7% as severe.

Table 2

Child's Primary Disability		
<i>Variable</i>	<i>Frequency</i>	<i>Percent</i>
ADD or ADHD	4	9.3
Autism Spectrum Disorder	13	30.2
Developmental delay	10	23.3
Emotional or behavioral disorder	3	7.0
Hearing impairment or deafness	1	2.3
Mental retardation	5	11.6
Speech or language impairment	3	7.0
Health impairment	2	4.7
Other disability	1	2.3
No specific diagnosis	1	2.3
Total	43	100.0

Research Question 1—

What are the ratings of importance and satisfaction for families' in Hawai'i with children with disabilities of their services and support, family-professional partnerships, and family quality of life?

Services and Supports. Table 3 presents the number and percentage of respondents who indicated a need for a particular service or support on a scale from 1-23. Of those who indicated a need, percentages were reported on whether they felt they were receiving ‘none’, ‘some’, or ‘enough’ of any specific service. The overall mean and standard deviation for supports and services needed was 9.63 (6.28), and for supports and services received was 10.40 (8.40), indicating a wide range. The correlation coefficient for supports needed and received was .68 ($p<.05$).

Table 3

Service Needs and Adequacy Ratings

Survey Items	# Need	% Need	None	Some	Enough
<i>Child Oriented Supports & Services</i>					
1. Special equipment to help your child live, learn, and grow (assistive and communications technology)	15	33	34	7	2
2. Health services (medical evaluations, nutrition, nursing)	15	35	31	8	4
3. Hearing and/or vision services	9	21	35	5	3
4. Physical and/or occupational therapy	12	28	34	7	2
5. Speech and/or language services	30	72	14	15	14
6. Special education services	37*	86	6	19	18
7. Counseling and psychological services	16	37	27	11	5
8. Behavior support	27	63	20	18	5
9. Transportation and/or mobility services	13	30	31	2	10
10. Self-care skills training(help with dressing or bathroom use)	15	35	28	6	9
11. Service coordination	20	47	25	7	11
12. Transition services	20	47	27	12	4
13. Employment or vocational services	8	19	36	5	2
14. Other (please describe)	2	5	41	2	0
<i>Family Oriented Services</i>					
15. Respite care	8	19	38	2	3
16. Child care	13	30	36	4	3
17. Money to help pay bills	20	47	35	8	0
18. Homemaker and/or housekeeping services	8	19	42	0	1
19. Transportation	13	30	35	4	4
20. Support groups	17	40	29	10	4

21. Counseling	17	40	33	6	4
22. Sibling support	9	21	36	5	2
23. Parent or family training	15	35	30	10	3
24. Information about specific disabilities	12	28	32	9	2
25. Information about where to get services for your child	15	35	30	12	1
26. Information about where to get services for your family	14	33	33	9	1
27. Information about legal rights	1	0	0	0	0
28. Other	5	21	-	-	-

* It is important to note here that 37 respondents identified a need for special education services, but all of the respondents have a child identified with a disability, so this number should have been the entire sample (43).

Partnerships

Service Provider. On the partnership section of the survey, parents were asked to identify the service provider who has worked the most with their child over the past six months. Seven types of providers were identified in Table 4: behavior therapist (n=2), special education teacher (n=32), occupational therapist (n=2), speech therapist (n=2), case manager or service coordinator (n=1), Doctor (n=1), and other (n=2).

Table 4

Service Provider		
<i>Variable</i>	<i>Frequency</i>	<i>Percent</i>
Behavior therapist	2	4.7
Special Education Teacher	32	74.4
Occupational Therapist	2	4.7
Speech Therapist	2	4.7
Case Manager	1	2.3
Doctor	1	2.3
Other	2	4.7
Missing	1	
Total	43	

Table 5 shows the mean responses across all respondents for all items across the Partnership domain on a scale of five. The data suggests overall high satisfaction, with means above the midpoint (3) on the scales. Almost all of the means are above 4.0 on the scale. Overall, the combined mean and standard deviation for partnership satisfaction was 4.16 with a standard deviation of 1.03 (not tabled).

A closer inspection of the individual items in the table revealed several interesting findings. The items with the highest means of satisfaction were: keeps your child safe when in his/her care (4.38), pays attention to what you have to say (4.43), is a person you can depend on and trust (4.35). The items with the lowest means of satisfaction (<4) were: helps you gain skills or information to get what your child needs (3.67), has the skills to help your child succeed (3.79), and provides services that meet the individual needs of your child (3.83). These results indicate a higher satisfaction with the relational aspects of a partnership than their satisfaction with the service provider's ability to provide the services.

Table 5
Partnership Satisfaction

Survey Items	N	Mean	SD
1. Helps you gain skills or information to get what your child needs.	42	3.67	1.35
2. Has the skills to help your child succeed.	42	3.79	1.42
3. Provides services that meet the individual needs of your child.	42	3.83	1.34
4. Speaks up for your child's best interests when working with other service providers	42	4.02	1.25
5. Lets you know about the good things your child does	42	4.17	1.24
6. Keeps your child safe when your child is in his/her care	42	4.26	1.19
7. Treats your child with dignity.	42	4.38	1.14
8. Builds on your child's strengths	42	4.21	1.09
9. Values your opinion about your child's needs.	42	4.17	1.26
10. Is honest, even when there is bad news to give.	40	4.18	1.15
11. Is available when you need them.	40	4.22	1.12

12. Uses words that you understand.	40	4.20	1.15
13. Protects your family's privacy.	40	4.22	1.18
14. Shows respect for your family's values and beliefs.	40	4.25	1.14
15. Listens without judging your child or family.	40	4.27	1.10
16. Is a person you can depend on and trust.	40	4.22	1.16
17. Pays attention to what you have to say.	40	4.35	1.12
18. Is friendly	40	4.43	1.05

The results from this study concur with both my pilot study (Ranges, 2005), and the Beach Centers' results in the ratings of satisfaction with professional partnerships. The results indicate that the families were satisfied, or mostly satisfied with issues related to the provider's ability to keep their child safe, treat their child with dignity, and be friendly, but relatively unsatisfied with the provider's ability to meet the individual needs of the child (Ranges, 2005; Summers, et al., 2007).

Family Quality of Life

The mean responses for importance and satisfaction on the FQOL items are listed in Table 6. The overall mean for FQOL satisfaction was 4.09 on a scale of 5.0, signifying a rather high level of satisfaction as to their FQOL. The items marked with the *highest importance* were: my family members teach the children how to get along with others, my family members show that they love and care for each other, and my family gets medical/dental care when needed. The items of *lowest importance* were: my family members have friends or others who provide support, my family has outside help available to us to take care of special needs of all family members, and my family member with a disability has support to make friends. The items on life *satisfaction* that were ranked the highest were: my family enjoys spending time together, my family members show that they love and care for each other, and my family gets dental care when needed. The items of *lowest satisfaction* were: my family has the support we need to

relieve stress, my family members have friends or others who provide support, my family has outside help available to us to take care of special needs of all family members, and my family member with a disability has support to accomplish goals at school or workplace.

Table 6
Importance and Satisfaction Ratings—FQOL Scale

Survey Items	Importance		Satisfaction	
	Mean	SD	Mean	SD
1. My family enjoys spending time together.	4.33	0.93	4.43	0.94
2. My family members help the children learn to be independent.	4.33	0.90	4.31	1.07
3. My family has the support we need to relieve stress.	4.17	1.01	3.64	1.34
4. My family members have friends or others who provide support.	3.88	1.21	3.60	1.31
5. My family members help the children with schoolwork and activities.	4.00	1.08	4.05	1.25
6. My family members have transportation to get to the places they need to be.	4.12	1.29	4.12	1.37
7. My family members talk openly with each other.	4.14	1.14	3.98	1.28
8. My family members teach the children how to get along with others.	4.45	0.88	4.25	1.10
9. My family members have some time to pursue their own interests.	3.98	1.07	3.95	1.11
10. My family solves problems together.	4.05	1.06	3.85	1.29
11. My family members support each other to accomplish goals.	4.28	1.01	4.00	1.30
12. My family members show that they love and care for each other.	4.53	0.91	4.43	1.06
13. My family has outside help available to us to take care of special needs of all family members.	3.48	1.41	3.33	1.54
14. Adults in my family teach the children to make good decisions.	4.35	0.89	4.33	1.05
15. My family gets medical care when needed.	4.43	0.89	4.48	0.89
16. My family has a way to take care of our expenses.	4.29	0.94	3.93	1.33
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	4.17	0.99	4.38	0.73
18. My family is able to handle life's ups and downs.	4.21	0.95	4.24	0.91
19. Adults in my family have time to take care of	4.21	0.92	4.12	1.02

the individual needs of every child.				
20. My family gets dental care when needed.	4.43	0.89	4.50	1.04
21. My family feels safe at home, work, school, and in our neighborhood.	4.38	0.88	4.50	0.86
22. My family member with a disability has support to accomplish goals at school or workplace	4.24	1.16	3.64	1.48
23. My family member with a disability has support to accomplish goals at home.	4.02	1.20	4.12	1.06
24. My family member with a disability has support to make friends.	3.95	1.32	3.90	1.21
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	4.07	1.24	4.07	1.09

Research Question 2—

What is the relationship between FQOL, partnerships and services for families in Hawai'i with children with disabilities?

My aim in asking this question was to discover the nature of the relationship between FQOL, partnerships, and services delivered to families with children with disabilities in Hawai'i within and across my sample of 43 people. Table 7 shows the correlations that examine the relationship among the FQOL variables; I discovered that in my sample there is a negative correlation between FQOL and support needs ($r=-.48$) and also between FQOL and support received ($r=-.38$), which can be interpreted as FQOL being higher when supports needed and received are lower. Table 8 also shows that support needs and support received are highly related ($r=.68$). The partnership satisfaction variable was not significantly related to FQOL, or to support needs or received. I also examined correlations between the FQOL variables and family size, education and income. Only the relationship between level of education and support needs ($r=.32$) was significant at a level of significance of .05.

Table 7

Correlation Coefficients Between FQOL Variables

	<i>S.Needs</i>	<i>S.Received</i>	<i>Life Satisfaction</i>
Partner Satisfaction	.05	.20	-.00
Support Needs		.68**	-.48**
Supports Received			-.38

Note: ** $p < .01$.

I also assessed whether overall there was a significant difference between the FQOL variables and the categorical demographic variables provided by the survey participants in the demographic section of the survey. My analysis of the interaction among the demographic variables and the FQOL survey subscales indicated that the only demographic variable that had significantly different means was ethnicity. These analyses were conducted using analysis of variance (ANOVA) procedures. ANOVA examines whether there are significant differences between group means. I examined the relationship between these variables using a one-way ANOVA, which allowed me to examine ethnicity, gender, etc. on the perceptual scales or variables that were created. Three ethnic groups were categorized from the demographics—participants identifying themselves as Asian/Pacific Islander, participants identifying themselves as Caucasian, and participants identifying themselves as Hawaiian. From the data, only ethnicity was shown to have significantly different means on FQOL and support received. The means and ANOVA results are reported in Table 8. The means for the participants identifying themselves as Caucasian and the participants identifying themselves as Hawaiian are significantly different at the .01 level (FQOL-.001; Supports received-.06). This shows a significant difference between the three groups in two areas of the survey: needed supports, and received supports.

Table 8

FQOL Variable Means with Results from ANOVA

Ethnic Group	FQOL	S Needs	S Received	Partnership
Asian/PI (n=27)	4.3 (0.7)	9.9 (6.8)	10.0 (7.1)	3.9 (1.2)
Caucasian (n=6)	3.0 (0.8)	13.6 (3.4)	20.8 (10.7)	4.4 (.5)
Hawaiian (n=10)	4.2 (0.7)	6.4 (4.0)	5.0 (3.5)	4.1 (.6)
ANOVA F (2.42)	7.66**	2.81	9.42**	1.10

Note: ** $p < .01$.

Qualitative Analysis

Only seven respondents out of forty-three answered the two open-ended questions that were attached to the survey. The written responses to the two questions are listed below.

What kind of services and/or supports do you think would most improve your family quality of life here in Hawai'i?

- We are happy with the services we have here.
- Anything that teaches/helps rather than hides/hinders getting services and supports for my family.
- Money and personal advocate, advocacy support groups, parent support groups.
- Qualified teachers- especially special education teachers. They seem to only know the basics, do not have proper resources, nor desire to acquire more knowledge about the children they are servicing. They all seem to do 'blanket' teaching where they teach all the children the same way instead of individualizing the plan to the child. Especially for a diagnosis that is so widespread like autism. They do not have the proper training at all.

- A single resource to go to for help. Right now we're provided a multitude of organization acronyms and websites, and brochures to try to process, all while trying to deal with our child's disability. A resource to learn how to deal with the primarily adversarial relationship with the DOE. We naively assumed they really want to help but have found it is always a struggle.
- New to Hawai'i— a resident only six weeks. Still networking to find resources.
- Social skills groups with other children with similar ages and interests. Respite care, big brother/big sister program for kids with special needs.

Research Question 3—

Do you think that the strong sense of 'ohana' here in Hawai'i has a positive effect on your family's quality of life? How?

- Yes it has, we have services here that we may not get anywhere else.
- Not as much as it should. I have many friends but only a few have ever volunteered to help, assist, etc. with my son and his/our needs.
- Yes- people to grumble to, yell at, cry at, laugh with, people who cheer you up.
- Somewhat-but when it comes to the education of my special needs child, no. The education here in Hawai'i is severely lacking. Public schools on the mainland have so much more resources.
- I don't think that 'ohana' is uniquely Hawaiian, and I don't think that every family has this sense. Those that do obviously helped by the extra support and understanding.
- Yes! Why I selected Hawaii to move to with my disabled child. The strong sense of family and the importance of family and the smaller, community based towns.

- Yes, child can learn in a safe environment.

Authoethnology

Family is the most important thing to me, without it I would not have had the support I needed to be able to finish my doctorate. Spending time with my family, extended family, and close family friends was a huge part of my upbringing. Though I grew up in Vermont, I learned about ohana through my own family very far away from Hawai'i. I would not have moved to Hawai'i from California in 1998 if it weren't for my family—my dad had been diagnosed with terminal cancer and was given six months to live. Because of my dad's grave diagnosis I applied for a full time teaching position with the D.O.E. Although I possessed a general education teaching credential I pursued a special education teaching position, as those positions were more readily available. I had a couple of years of experience substituting in both inner-city schools in Los Angeles, and rural schools in Lake Tahoe which provided me with some background teaching students from CLD backgrounds. I naively assumed that these experiences would prepare me somehow for Hawai'i's culturally diverse schools.

In Hawai'i I taught special education for ten years, grades Kindergarten through twelve, in six different schools, in two different school districts on Oahu. I taught fully self-contained classes and resource classes where my students were labeled as having an emotional or behavioral disorder, a learning disability, mental retardation or autism. Three of the six schools I taught at had high populations of Hawaiian and Pacific Island students, and consequently also had high percentages of students identified as requiring special education services and supports. During my teaching experience in Hawai'i I became aware of the high number of students of Native Hawaiian ancestry identified as having a disability. Throughout my master's and doctoral

program at the University of Hawai`i, I became interested in researching the area of Native Hawaiian education and their over-representation in special education. My research interests tied directly into my teaching practice as I was working full time teaching special education and pursuing advanced degrees. To say the least I was immersed. Once I began to learn of the history of and experience first-hand the detrimental effects of education on the Native Hawaiian youth in Hawai`i, I became disconcerted with the ongoing trend of less than optimal educational outcomes for these students, decade after decade.

Living in Hawai`i was a much different experience than coming here on vacation. When I first started teaching in the public schools here I immediately felt like an outsider, disconnected from the inside network in the schools because I was not from Hawai`i. The insider-outsider theme was prevalent in all of the schools that I worked in, and at each school I needed to make a concerted effort to not be perceived as the typical new teacher who moves here from the mainland and goes home discouraged and defeated after a year or two of teaching here. In order to become connected with the inside school network I saw that I needed to make a conscious effort to establish genuine relationships at my school—which meant spending more time interacting informally with my students, fellow teachers and also families. I had to let them know who I was, where I was from, why I was in Hawai`i—as I came to realize that if they didn't know who I was, they weren't really going to bother with me, or with getting to know me. Until I made real connections with my students my job was going to be tougher too—as I noticed how much more engaged my students were with teachers that they respected, trusted and seemed to care about. This was much different than the formalness of the mainland school atmosphere I came from where professional-personal boundaries and student-teacher relationship were very

traditional and formal. Here in Hawai`i I came to learn quickly that relationships are very important in the school environment.

Because of my own idea of professional-teacher relationships in the school environment, I was concerned at first with the amount of time that I felt was wasted on casual, informal conversations with my colleagues, school staff, students and parents, but I soon came to realize the more time I put into my daily interactions with others in the school environment the easier my job became and the happier I was at school. When I let myself put relationships first, and my teacher duties second I felt that my daily experiences with others at school were for the most part adding richly to my experience as a teacher in Hawai`i. As a reflective teacher striving for ways to become more effective, I came to realize this began with getting to know my colleagues, students and student's family members in a more personal way that was not 'all business as usual'—which was typical for my interactions previously. Once I had established genuine relationships with my students and colleagues I started to feel like I was part of the ohana at school and had gained credibility and their trust.

The role of culture in special education is something that took me a while to comprehend. I believe that it took me a while to understand because I first needed to see how cultural views of disability may impact a family's idea of what they believe their child's education should encompass, and also what kinds of support or service they will ask for or utilize. From the many interactions I had with the families of Hawaiian ancestry I got the sense that they were generally accepting of their child having a disability, they did not necessarily view it as a negative thing, because they accepted their child for who they were. For their child's education they wanted whatever the teachers could do at school that was going to help their child advance from grade to

grade, and generally trusted that the teachers would be able to provide this to their children. What was effective for me in connecting with these families was taking the time to talk with them informally and establish relationships with them—to share with them about myself, and to tell them positive things about their child before I ‘got down to business’ with whatever school affairs needed to be taken care of. It also helped me establish good relations with them by using my knowledge of ‘the system’ as an insider to take the time and effort to help connect them with agencies that could provide services or support that was not available at the school level.

The interaction I had with the families of Hawaiian ancestry was much different than what I had experienced with the Caucasian families at the other schools I worked at. I felt that the Caucasian families tended to be less accepting of their child having a disability, and believed the focus of their child’s education was basically to fix them, or catch them up to par with their peers. The Caucasian parents I worked with expressed great interest in a teachers’ ability to provide the services that their child required. For these parents, my ability to provide required services to their child and be easily accessible via phone or email outside of school for any concerns they had about their child were of top priority, and also determined the nature of my relationship with them.

There remains a distinct insider-outsider dynamic in the social culture of schools in Hawai’i which can be a barrier if you are seen as an outsider within this system. From my experience, if you are seen as an outsider to the families you are working with and you plan to do research involving them or their children, it will not be met with much interest. Therefore, when working with families it is important to let them know who you are, and why you are interested in doing the research, and also provide them information on how you feel this research stands to

benefit them or their children. I believe it is of vital importance when collecting information from families to do so in culturally responsive ways. Because I aimed to have a large sample population for my study I felt that the distribution of a survey through the school or agency that the families are familiar with and have good relationships with would be an appropriate means to gain information from families in a culturally responsive manner.

As mentioned earlier in my methods section, I took care to make personal contact with the family members at the meetings where I was able to interact with family members, including talking about my experience in teaching special education in Hawai'i, and how I felt the information gained from the survey could be used to improve services and support to their child with a disability and to their families. As part of this personal contact I let family members know that if they would prefer to talk to me about their answers I was available for them to share that information with me.

Teaching in Hawai'i was an incredibly challenging experience for me, and I attribute my success with my students and their families to my willingness to acculturate to the local culture, to slow down, and take the time to form genuine relationships.

CHAPTER V

Discussion

The purpose of this study was to investigate the ratings of importance and satisfaction for families in Hawai'i with children with disabilities of the services and supports their family receives, family-professional partnerships, and FQOL. One of my primary goals was to extend and expand upon the findings from the pilot study I conducted in 2005 to determine the prospective use of the FQOL survey instrument with a culturally diverse sample of Hawai'i's families in measuring FQOL. It is my hope that the results of this study will also assist service providers in creating and delivering support and services that are most appropriate to families residing in Hawai'i (i.e. culturally relevant and empowering). This study also aimed to investigate how families felt the role of 'ohana' affected their FQOL; as it was my hypothesis that the significance of ohana in Hawai'i's culture would positively impact FQOL. Responses from 43 surveys were analyzed to determine the findings. In this chapter I will summarize the results, and then discuss my findings, limitations and areas for future research. I will also suggest some possible implications for stakeholders based on my research findings. My interpretation of this data also is drawn from my personal and professional experience teaching in schools with high populations of Hawaiian and Pacific Island students.

Participants

While this study has a small sample size, the sample itself is culturally diverse, and is also a reflection of the demographics in the state of Hawai'i, making it a valid extension of the research in the area of FQOL and with the FQOL survey. Although my small sample is a

limitation of this study, my findings are significant enough to warrant my belief that similar findings would also be evidenced if larger, similar samples in Hawai'i were surveyed.

Ratings of Service Needs and Adequacy

Table 7 shows the number and percentage of respondents who indicated a need for a service or support, and the percentages they indicated receiving of the particular service they indicated a need for— 'none', 'some', or 'enough'. There was an overall mean of 9.63 for services or supports needed out of a possible 23, with a broad range of responses, from 3.35-15.91. The mean represents a fairly low average of indicated need from the sample, though the range shows there were families that had fairly high needs and others with few needs. Largely, family members indicated a lower need for family-oriented services than child-oriented ones. My results concur with those of Summers et al. (2007), where respondents indicated a higher need for child-oriented services than family-oriented services. Additionally the number of families that specified a need for a particular service or support, which was always larger than the number who indicated they received enough of the services, was also similar (Summers et al., 2007). The items rated of highest need for child-oriented services and supports were: special education services, behavior support, and service coordination. The items rated of highest need for family-oriented services were: money to help pay bills, support groups, and counseling. The lowest need for child-oriented services were: hearing and/or vision services, and employment or vocational services. The lowest need for family-oriented services were: respite care, homemaker and/or housekeeping services, and sibling support.

The overall mean for services or supports received was 10.07, which suggests relatively low perceptions of supports received. As a result, it appears that individuals had relatively low

perceptions of needs, and thus appeared to be ‘fairly’ satisfied with services. This is confirmed with the correlation between the two variables of (.68, $p < .05$), which suggests a substantial relationship between perception that needs are being received. Although the data suggests a substantial relationship exists between the perception that needs indicated are being received, levels of indicated adequacy were spread out among the three categories of none, some, and enough for individual items of support or service. The range for services received was wide (2-18.8), showing a significant variation in responses. Ratings of both need and satisfaction with the amount of services provided to the families in this study’s sample are significantly varied—of particular concern is a large number of the sample that responded that they were not receiving enough of a needed service for their children and to their family. My personal concern as a special education teacher about an indicated lack of service provision is legally justified. A child’s individualized education plan (IEP) is a legally binding educational plan that specifies individualized services and supports a child with a disability requires, including precisely documented quantities of those services and supports to be provided. This finding alone provides stakeholders with an excellent opportunity to use the FQOL survey results as a basis for assessing strengths and needs of the child and family before doing an annual IEP review.

Child-oriented supports. Though the responses for child-oriented supports indicated questionably sufficient adequacy, the items marked as receiving the highest amount of (i.e., in the ‘enough’ category) were speech and/or language services, special education, and service coordination. Other services reported as a high need but were reported receiving none or some of the services were: special equipment, health services transition services, behavior support, money to help pay bills, and family support groups and counseling.

Family-oriented services. The items rated for highest need in family-oriented supports were: money to help pay bills, parent or family training, and information about where to get services for your child/family. Unfortunately, these items were also ranked high in ‘not receiving such services’. These findings are consistent with similar studies that suggest a low percentage of families who report they are not receiving enough information about services (Mannan, 2005). The reasons for the low ratings of need for family services cannot be determined from the data, but researchers speculate this could either be due to a low need for those services, or because families do not know about them (Mannan, 2005).

Financial Resources—Though income did not have a significant interaction with any of the FQOL variables, the family members did signify a need for financial assistance on the survey and in the open-ended questions.

Access to support from local agencies—This includes parent and family training, and information about services to support the family through the school and community. Family members also responded a need for this type of support on the open-ended question.

Demographics (ethnicity)— When examining the mean responses across the three ethnic groups respondents identified themselves as, there was significant variance in their ratings as to service needs and adequacy. The lowest mean (and SD) for services needed was 6.4 (4.) by the participants identifying themselves as Hawaiian, 9.9 (6.8) by the participants identifying themselves as Asian/Pacific Islander, and 13.6 (3.4) for the respondents identifying themselves as Caucasian. Conversely, the highest mean for services received was 20.8 (10.7), the sample population identifying themselves as Caucasian, the sample population identifying themselves as Asian/Pacific Islander was 10 (7.1), and the sample population identifying themselves as

Hawaiian was 5.0 (3.5). Based on my study's sample, it appears that the respondents identifying themselves as Hawaiian report the lowest needs and also have the lowest mean score for services received. The sample population identifying themselves as Caucasian received the highest amount of services and supports, in addition to receiving more than they indicated a need for. The sample population identifying themselves as Asian/Pacific Islander reported needs and receives was almost equal. The results across groups signify distinct differences in levels of perceived and received supports based on ethnicity, which is well worth a further investigation to explore possible explanations.

As hypothesized throughout this dissertation, a family's cultural background can and does play a large part in identifying precisely what their needs for support and services may be (Onikama et al., 1998; Sileo, et al., 1996). This is particularly pertinent in areas such as Hawai'i, where service provision is frequently determined by a dominant culture, and where families frequently indicate that supports provided by extended family are more helpful to them than are the services and supports generated from the dominant culture (Onikama et al., 1998). Informal supports provided by extended family or ohana, are considered natural supports as opposed to formal supports such as those services or support provided to families by school or service providers. Often, when families fail to receive assistance from service providers, they forsake the service or the providers and continue to rely on extended family or neighbors for support. Also, these types of natural supports most likely will continue throughout the child's life, so we want to encourage sustainable and meaningful support systems families already have in place. It would be considered culturally relevant practice for stakeholders to access this network, as

sometimes these natural supports are only way for professionals to effectively work with people who otherwise avoid dealing with professional service systems.

Additionally challenging for child and family-oriented service provision in special education with families from collectivist cultures is that the needs of the family often override the needs of individual family members, which is contrary to the system of special education that emphasizes individual needs. This may create a barrier for the stakeholders charged with providing special education services, as collectivist family values focus on the needs of the group over the individual and also of self-sufficiency, and allowing outsiders to provide supports might seem like the family is not fulfilling their responsibilities. Understanding a family's view of disability within this family system would be beneficial for stakeholders when suggesting or implementing services and support to families and their children.

Ratings of Satisfaction of Family-Professional Partnerships. The means across items were calculated for the entire sample, and are reported in Table 6. The overall mean for the sample was 4.16 (out of 5) with a standard deviation of 1.03 indicating that the respondents were generally satisfied with their service provider partnerships, and were within the typical variation shown in other FQOL studies. Though family members rated their satisfaction with partnerships fairly high, a closer look at the ratings of individual items produced several revelations. The highest rated items for partnerships were more related to relationship qualities (e.g., is friendly, is someone who is dependable and trustworthy, and pays attention to what you have to say). The lowest items are of the most concern however (e.g., helps you gain skills or information to get what your child needs, has the skills to help your child succeed, and provides services that meet the individual needs of your child). These findings are remarkably consistent with my pilot study

(Ranges, 2005), as well as with the Beach Centers research findings. Their findings also indicated low parent satisfaction with the providers' ability to help parents gain skills or information to get what their child needs, and implies that families do not feel that their needs are being met in acquiring what they need to support their child with a disability (Summers et al., 2007). This has implications for stakeholders to address through professional development, or for providing additional resources to families regarding services and supports both in and outside of school.

The fact that family members indicate that the professional who works most with their child is concurrently rated as lacking in introducing family members to training procedures that helps them gain skills or information to get what their child needs is a red flag indicator that demands immediate attention. The value of a school having information pointing to a specific service which is greatly needed and possibly legally mandated, requires immediate attention from the administrator and special education staff to assure these needs were being met, and also that the school was in compliance with the child's IEP. Finally, low parent satisfaction with the professional's ability to provide services that meet the individual needs of their child calls for an immediate appraisal of the current services and supports being delivered to the family and the child with a disability, as families are suggesting that their needs are not being met in this critical area. These services could be ones that are on their child's IEP, or ones that they hadn't needed up until that point; in either case it would be appropriate to investigate which services or supports were insufficient or nonexistent to help support the family as soon as possible.

Ratings of Importance and Satisfaction of Family Quality of Life. Table 7 lists the mean responses for importance and satisfaction on the surveys' FQOL items. The overall mean

of 4.09 on a scale of 5 indicates that the families are fairly satisfied with their quality of life, which is consistent with other studies such as Mannan (2005), and Summers et al. (2007). The lowest rated items were related to support for the family and the child with the disability: having friends or others who provide support, having outside help to take care of special needs of all family members, and support for family member with a disability to make friends. Researchers have hypothesized that families with children with disabilities are at risk for a lower FQOL. The families that participated in this study did not indicate a low FQOL, supplying evidence to the contrary. Both groups of participants identifying themselves as Asian/Pacific Islander and as Hawaiian scored themselves higher on FQOL than the participants identifying themselves as Caucasian providing results contrary to what the literature says across studies examining family unit characteristics, which suggest that FQOL may be lower from families whose backgrounds are other than European American (Hornstein & McWilliam, 2007). It may be that families residing in Hawai'i report a higher FQOL because of the collectivist nature of the island culture here and the importance of 'ohana'.

Relationship between FQOL, Partnerships and Services. In my analysis exploring the relationship between family background variables, I found that marital status, income, and family size to be unrelated to perceptions of needs or services received (or satisfaction with them). The data did reveal that higher education was associated with greater perception of support needs, but not on services received or partnership satisfaction. Also, higher standing in life satisfaction was associated with lower standing on supports needed, received, and also satisfaction with what was needed and received.

Supports needed and received were highly related to each other and to FQOL. This relationship may imply that families with higher needs have lower FQOL, as having a child with a more severe disability typically requires more services, and conversely a child with low needs requires less services and less is involved in supporting that family member's needs. Satisfaction with partnerships was not found to be highly related to FQOL with my survey sample. However, other studies have found a high correlation between partnership satisfaction and FQOL (Mannan, 2005; Summers et al., 2007). What is also uncertain from the results of this survey is the relationship between high partnership satisfaction and the actual quality of the services provided to the family and the child with the disability.

Family Member Comments. The responses to the open ended questions provide some insights into what services and support family members thought would improve their quality of life here in Hawai'i. One family member wrote that they were "happy with the services we have here." Access to and information about supports and resources for the family were mentioned by four of the respondents, including: "money and personal advocate, advocacy support groups, parent support groups", "anything that teaches/helps rather than hides/hinders getting services and supports for my family", "a resource to learn how to deal with the primarily adversarial relationship with the DOE—we naively assumed they really want to help but have found it is always a struggle", and "a single resource to do for help". Specific services or support mentioned were: "Qualified teachers— especially special education teachers, they seem to only know the basics, do not have proper resources, nor desire to acquire more knowledge about the children they are servicing, they all seem to do 'blanket' teaching where they teach all the children the same way instead of individualizing the plan to the child. Especially for a diagnosis

that is so widespread like autism. They do not have the proper training at all”, and “Social skills groups with other children with similar ages and interests. Respite care, big brother/big sister program for kids with special needs.” To provide more information into desired supports and services, I would recommend a follow-up inquiry with family members who took the time to answer the open ended questions.

Ohana. Four out of the seven responses to the open ended questions indicated a positive effect of ohana on their quality of life here in Hawai’i, including: “Yes it has, we have services here that we may not get anywhere else”, “Yes! Why I selected Hawai’i to move to with my disabled child, the strong sense of family and the importance of family, and the smaller, community based towns”. Two respondents were neutral in their replies: “not as much as it should—I have many friends but only a few have ever volunteered to help, assist, etc. with my son and his/our needs”, “Somewhat—but when it comes to the education of my special needs child, no. The education here in Hawai’i is severely lacking. Public schools on the mainland have so much more resources”, and “I don’t think that ‘ohana’ is uniquely Hawaiian and I don’t think that every family has this sense. Those that do obviously helped by the extra support and understanding.”

While there were few responses to the open-ended questions, I believe that the concept of ohana here in Hawai’i is worth further qualitative investigation, as more than half of the respondents indicated that they feel ohana has a positive effect on their quality of life here, as something that is unique to Hawai’i.

Comparison of Responses to Previous Samples

Several of my findings are very similar to my pilot study, and also to studies using the FQOL survey on the continental U.S. (Mannan, 2005; Ranges, 2005; Summers et al., 2007). One of these areas was the high rating of FQOL and with partnerships. On individual survey items there were also similarities to the results of other studies (e.g., how specific partnership items were rated, and the specific family-oriented needs that were considered necessary).

The fact that over half the participants in this survey reported a total household income of \$39,999 or less a year and indicated high satisfaction with FQOL provides some evidence that for this sample, lower FQOL may not be associated with lower income as the existing literature suggests.

Trends

Variations between family members ratings of services needed and what level of adequacy they believed they were receiving of these services is an area that warrants immediate investigation from the agencies providing the services. Although the measurement of adequacy of 'none', 'some', and 'enough' is an ambiguous rating that may require clarification for respondents filling out the survey, it still serves as a gauge for service providers for areas of service provision that may need immediate attention. Also, the responses of satisfaction may also depend on other family factors not measured by the FQOL scale, which unless a qualitative component accompanies the survey, stakeholders and family members may not be aware of.

Limitations

Sample. A small sample size of 43 is a limitation of this study in being able to generalize the findings to other families in Hawai'i who have children with disabilities. The small sample size also limited the type of statistical analyses that could have been performed

with the data collected, which is why I used correlation data and one-way ANOVA. The significance of some of the correlations make an argument for a replication of this study with a much larger sample to further investigate these relationships.

It is important to note that on the demographic section of the FQOL survey, the Asian/Pacific Islander demographic category was combined into a single entity. In Hawai'i this dual grouping proves inadequate as well as misleading given that these two groups comprise a large and highly distinct percentage of the population with different cultural values. In the reporting of survey responses for the respondents identifying themselves as Asian/Pacific Islander, I merely reported their responses, but did not attempt to analyze them. For this reason and in order to better attain culture specific information for the assessment of service provision in Hawai'i, the two groups should be separated when the survey is used in the Pacific Islands.

Methods. As mentioned earlier, as a means of gathering data, surveys have the disadvantage of inflexibility, restricting responses to predetermined options for questions and responses, which may not fully reflect participants' opinions about what the survey itself is trying to measure. As a means of collecting a large sample for a study, surveys also tend to have a low response/return rate, even when sent out in mass distribution. The lengthiness of the survey may have discouraged potential participants, coupled with the addition of two open-ended questions to an already lengthy survey, or the amount of paperwork required to accompany the survey may have discouraged the majority of parents from answering and returning the open-ended questions with their completed surveys. Surveys are also a fairly impersonal means of collecting data, which could help or hurt a sample—(a) either the anonymity would make respondents feel safe to share or express needs without having to do this face to face, or without

fear of repercussions, which may be difficult for some cultures; or (b) the informal/impersonal nature of surveys are seen as too impersonal of a means of asking for information from families, thus possibly discouraging some families to offer information because of prior experiences of volunteering information without it benefiting them (East Honolulu CCC meeting, personal communication, October 2010).

As the FQOL survey is not available electronically/online, the director of LDAH and I speculated if it had been possible to put this survey online the size of the sample might have been larger. Or, if my study was not occurring the same time that LDAH was asking their family members to complete an online survey for IDEA regulation purposes, I might also have had more family members participate at the conferences or meetings.

Due to the very low number of respondents who took the extra time to fill out the open-ended questions, I did not have enough data to do a full analysis. So although I was not able to do a full analysis the bias in interpreting data was reduced. I am simply reporting what the family members wrote in response to the questions. Furthermore, since I was not able to solicit a participant to review my findings, this potential bias emphasizes the importance of having other researchers, particularly Native Hawaiian (or Asian/Pacific Islander) researchers, replicate my findings.

I had limited amount of time at the meetings and conferences where I had access to the family members. In those settings I did not have ample time to sit and talk with family members, as I would have preferred to do. A qualitative study on FQOL with families in Hawai'i with children with disabilities would be a compliment to this study, and would also be more a more culturally compatible research method to use with the population of families I surveyed. I

believe that a more culturally compatible means of gaining similar or more information from families as would have been to do small focus groups in an informal and neutral setting (away from a school or conference) with a parent leader/liaison from the community to help facilitate where the responses may have been more detailed and genuine. However, to sit and talk with family members, hoping for them to share to a stranger about their FQOL, partnerships, and needed and received services and supports may present a challenge to someone seen as an outsider by families here in Hawai'i, as a certain amount of trust typically needs to be established before personal, private information like that would be shared with someone unknown to them. The three local agencies (Waimanalo Elementary and Intermediate School, the CCC, and LDAH) that participated in this study are dedicated to providing information to families as well as in aiding families in becoming involved in decision-making regarding supports and services delivered to their children or the family.

From my experience teaching here in Hawai'i, I believe that in general, the local culture here in Hawai'i is typically more reserved than that of the continental U.S., so when family members interact with school employees or service providers (especially ones who are not from here), they may not be forthcoming about service or support needs, particularly if they have to ask for them. This is why it is exceptionally important to assess the FQOL of families from Hawai'i, as this information may not be volunteered freely. The assessment and establishment of a relationship between FQOL and services, supports, and partnerships for CDL families would also strengthen and justify the need for a multi-systemic effort targeting both family-oriented and child-oriented supports on a local level. Differences in cultural background may also effect individual perceptions of satisfaction, as some cultures may set the bar high in their expectations

of services, and others may be satisfied with less, particularly if it is culturally appropriate for the family to take responsibility for certain areas of care giving or support and not expect others (i.e. stakeholders) to provide this.

Cautions in interpreting findings/comparisons with the general population. Any interpretation of the data generated by this study is intended to be viewed at the exploratory analysis level and readers are cautioned to bear this in mind when interpreting the results of this study. The survey sample was intentionally targeted to include schools and local areas comprised of high populations of Hawaiian and Pacific Island families. This was done in order to more fully survey typically excluded populations residing within and across the state of Hawai'i. Therefore, care should be taken not to extend the findings from this small sample to other typically excluded populations.

Implications

According to the FQOL literature, a large percentage of Hawai'i's population stands to be at risk for a lower FQOL, and particularly so if they have a child with a disability. A key finding from this study that is contrary to the literature is the high FQOL ratings from the culturally diverse population from this study's sample, regardless of the low amount of services they received. Additionally, the culturally diverse population from the survey also indicated a higher FQOL than the population identifying themselves as Caucasian—who as a group received more than twice as many supports or services than the other two populations from the study. My interpretation of this data is that many families in Hawai'i rely on natural supports for family needs, so the relationship between services, supports and FQOL is not as significant for families

here in Hawai'i as they are on the continental U.S. This is an area that is not tapped into by the FQOL survey.

FQOL Survey. The majority of the study's sample are from collectivist cultures where a common belief is that the family should take care of their own, and a willingness to accept assistance from outside agencies may not be viewed as acceptable as it would be looked at as avoiding family responsibilities. Additionally, a family's view of disability may also make them unwilling to accept help, as taking care of a family member with a disability is seen as the family's duty, and help from the outside is seen as an intrusion. As I proposed earlier, it is possible there are cultural explanations for the low indication of family oriented needs. Because the data nor the survey instrument cannot determine this, it is important to further explore the impact of these variables on services, support, and FQOL through qualitative measures or a culturally relevant constructed version of the FQOL survey. This study provides an extension of the use of the FQOL survey with a culturally diverse sample of families with children with disabilities. Questions arose throughout the study particular to the appropriateness of its' application to CLD families in Hawai'i, as the FQOL survey has not been widely used with a culturally diverse population. It is my firm belief that the results derived from this study establish a clear rationale for future studies investigating the use of culturally compatible measures of FQOL for families with children with disabilities in Hawai'i.

It is of utmost importance in assessing FQOL with families with disabilities in Hawai'i to consider the family's view of disability, which brings about certain implications regarding a willingness to accept assistance for their child with disability from outside agencies (Black et al., 2003). The measurement of non-formal, or natural supports, is not contained within the FQOL

survey, nor are questions regarding the family's view of disability, both of which are valuable information to gain from families in collectivist cultures as they may have a significant impact on FQOL that is not currently being measured by the FQOL instrument.

Teacher preparation. From as early as the 1960's, researchers have recommended for teachers (and stakeholders) to understand the social values that are infused within Hawaiian communities and how this may play into cultural conflicts between the education system and that of the family and community (Gallimore et al. 1974; Solomon, 1980). Teachers must also have an understanding of the past history of education here in Hawai'i to be aware that many families may have had negative experiences within the school system and as a result limit their interactions with the school staff. According to Solomon (1980), "the Hawaiians have become skeptical of the American education system, insisting that it is doing little in uniting the American school and Hawaiian homes" (p.121). For that reason, the curriculum for teacher training programs in Hawai'i should include learning opportunities directed towards increasing family involvement. Learning the skills needed to engage family participation in education would be of benefit to everyone, including the teacher. Relationships are very important in Hawaiian culture. Taking the time to establish and cultivate relationships with students, families, community members will pay off ten-fold, when they see a genuine effort being made to get to know them as well as sharing things about yourself to them, and not all business as usual.

To assist in overcoming cultural barriers between schools and Hawaiian families, it is important to solicit the unique perspectives of the families and community members that reflect the values and norms of the students' home environment. It would also be advantageous for teachers to "be aware of social values that are operable within Hawaiian communities—values

such as self-help, mutual assistance, cooperative living and attitudes of friendliness and generosity are considered to be among the values that yield positives, both personal and social in a Hawaiian community” (Solomon, 1980, p. 122).

One recommendation for meaningful engagement with families, communities and schools from Kanaiaupuni (2006) is— “when individuals and social groups engage critically with historical discourses, social meanings, and power relations, they not only challenge sociocultural and political processes of domination by a system but also redefine their experiences and expectations.” (p. 36). He goes on to advocate for a strengths-based approach to engage families and communities that employs strategies based on a family’s competencies, capabilities, and expertise, and is based on a worldview of the Hawaiians that stresses relationships first, treating others with compassion, and goals for the collective good (Kanaiaupuni, 2006).

A teachers’ ability to identify a family’s individual, collective, and environmental strengths to establish the direction and means of supports and services involves building upon a family’s existing *natural supports*—the people and resources in the community who are outside the professional service system but have the capacity to effectively provide supports. Furthermore, culturally sensitive individualization coupled with professionals’ focus on developing and sustaining a families’ *natural supports* may increase positive outcomes when working with CLD youth and their families (Leake, Black, & Roberts, 2004). Teachers are the ones families come to, or expect to receive information regarding services or support available to their child or family, and particularly so if the school culture or system is foreign to them. It would profit teachers to be knowledgeable about the types of services and supports so that they

can connect families to them—including taking the extra effort and initiative to contact the service providers or agencies for the families.

Using Culture-Based Education to increase Parent Involvement. Hawaiian culture, which tends to be collectivist in nature, often clashes with the traditional school model. Increasing the involvement of the students will increase the involvement of the families. Brynn, a teacher friend of mine who teaches in a school with a predominant population of Native Hawaiian and Pacific Island families spoke of how she integrates traditional Hawaiian values into the classroom—treating students with aloha, and as part of your ohana, bringing Kupuna into the classroom and school, using peer teaching, and ho’opono’pono (Brynn Leake, personal communication, March 14, 2011). One strategy that Brynn referred to on several occasions when speaking about her classroom was that of ‘creating a community’ within her classroom (Brynn Leake, personal communication, March 14, 2011). She transitions her classroom environment from an authoritarian classroom to one of shared, cooperative activity where all students feel safe to learn and explore new subjects as a group. She added that teachers could ask students to collaborate with ohana on projects of benefit to their family and community, such as their community garden. She commented that if there were things going on at school that the kids were really into—such as the community garden, even the ones with very challenging behaviors would come to tend to even after school with family members.

The cultural pride that students, families and the community shows for annual May Day programs is something wonderful to experience. I did notice low parent involvement in my student’s education, as evidenced by the difficulty I had in trying to get in touch with them, and with lack of follow through with school paperwork or school homework/projects. This was not

the case with cultural events connected to Native Hawaiian culture such as May Day. In both the middle and high schools that I worked at I saw a committed effort from many family and community members in all of the jobs necessary to pull together such an elaborate event—from music, staging, costumes, and teaching hula.

Kamehameha School researchers also recommend teachers learning to use culture-based education (CBE) with the Hawaiian themes of family and community integration to increase both family and community involvement in schools (Ledward, Takayama, & Kahumoku, 2008). With CBE Teachers do not have to be experts themselves to provide students with a culturally relevant educational experience, because these educational practices bring the knowledge and skills of family and community into the classroom. Best practices for infusing family and community themes into the classroom include: active participation of family members in educational activities, and using the community as a setting for student learning (Ledward et al., 2008).

Brynn’s answer in response to what types of activities or programs would families in rural areas such as Waimanalo be receptive to considering or utilizing was—“Programs such as Alu Like, or anything that is attached to Kamehameha, because they are culturally based, and whose goal is to benefit Hawaiian students specifically” (Brynn Leake, personal communication, March 14, 2011). She also mentioned that the use of a kapuna as a cultural mediator may also help to facilitate conversations with families in a group talk story meeting to come up with collective ideas and goals (Brynn Leake, personal communication, March 14, 2011). “The community is not involved in the schools and kapunas are coming out even more now to help

support the schools in reaching out to the communities” (Brynn Leake, personal communication, 2011).

Another recommendation Brynn had was to establish and maintain partnerships with community agencies who can provide contextualization for programs, as they are the means to providing valuable feedback as to how education can be framed in a way that will be of worth for students outside of school. Increasing the value of school programs by aligning them to home and community goals will impact the students and their families.

Future Research

Warranting further investigation from the results of this survey is the discrepancy between a family members’ indicated need and adequacy of received supports, particularly among CLD families. A relevant extension of this study could be an exploration of why some CLD families may not ask for family support or services, as the reasons cannot be determined from the data. In the findings there were significant differences between the three identified cultural backgrounds of the families from the survey sample in the respondent’s indication of services needed and what was actually received. These differences warrant a further examination to determine if: (a) family member expectations are different based on cultural background, and (b) with a larger sample, if it could be determined if certain services are more likely to be needed in schools that service particular cultural groups. Furthermore, involving CLD families on the assessment of the quality and quantity of services provided to them may serve as the connection to strengthening partnerships & increasing the cultural value of these services (Kawakami et al., 2007).

Another finding of concern is that a large number of the sample responded that they were not receiving enough of a service they specified as a need for their child or family. Levels of adequacy in service provision varied tremendously overall, which may possibly indicate there are inconsistencies in service provision that could depend on the school, district of the school, the family receiving them, or a combination of the three. There are several issues related to this, including legal ramifications if these needed services or supports were on a child's individualized education plan (IEP) and the child was not receiving what was mandated. I further maintain that information gleaned from the FQOL survey offers stakeholders numerous policy and practice advantages, such as increasing the appropriateness and amount of services to families and their children, and for allowing more positive and effective collaboration across types of supports, services, and settings. Additionally, in expanding the research it is important to use the FQOL survey with a much larger sample population in order to expand the present investigation of FQOL in Hawai'i.

Conclusion

Family quality of life is a highly subjective and multidimensional concept where the interaction of a variety of family and child variables has potential to increase or decrease quality of life for families with children with disabilities. Current research promotes and supports family involvement as a key component to quality outcomes for children with disabilities (Mannan, 2005; Markey et al., 2004; Turnbull et al., 2003). FQOL theory places an increased importance on family involvement in the selection and evaluation of services and support provided to them with accountability measures directed at stakeholders for positive outcomes. To address accountability issues, I recommend the use of the FQOL scale for stakeholders who provide

these services, programs and supports to families and their children with disabilities in Hawai'i to assure what they are providing is benefiting the families and their children with special needs using culturally responsive means. For in a culturally diverse state like Hawai'i, unless programs for individuals with disabilities and their families are designed in a culturally appropriate manner the opportunity to make real and effective changes is lost (Ankeny, Wilkins & Spain, 2009; Valenzuela & Martin, 2005).

In addressing issues of FQOL, something that is very personal and individual, we must take care to not impose our own values and ideals of this concept on others, as FQOL is a subjective concept, and should not to be judged by outsiders. It is not hard to understand why Native Hawaiian researchers reject "prevailing views of Native Hawaiians failing to succeed in Western society" (Kanaiaupuni, 2006, p.37). FQOL is indeed a subjective concept, as Gallimore et al. (1974) concluded with a powerful comment about the Westside community they resided in for three years while doing their research: "though of little means, quality of life in no uncertain terms was fairly high for the rural community" (p. 60). The interaction between an Americanized public school system and an indigenous culture in Hawai'i leaves much to be explored in terms of providing family and child-oriented that is culturally appropriate and empowering for a population that has been marginalized by past and existing systems.

Based upon the results of this dissertation, I am in agreement with Beach Center researchers who believe it is possible that understanding how family unit characteristics (i.e., demographics such as ethnicity) interact within and across a wide range of program and service variables is essential in measuring FQOL. Local administration and possible cultural adaptation of the FQOL scale has the potential to provide useful information to administrators and

practitioners, information that better assures appropriate cultural adaptation of programs and services provided to families (Zuna et al., 2009c). Future research with larger samples in Hawai'i should address not only areas of need, but also areas of satisfaction, so that schools and families can develop strengths based programs of support for CLD families.

As hypothesized earlier, engaging families from Hawai'i in the process of surveying FQOL could be a major step in understanding how policy makers and service providers can tailor services and supports that aim to increase FQOL for families in Hawai'i with a child with a disability. It is my hope that involving families in the process of assessing FQOL could assist in overcoming one barrier to indigenous family involvement in academic or program evaluation in Hawai'i, which stems from a history of past evaluation efforts that failed to produce positive changes to the community (Kawakami et al., 2007). As culturally competent professionals we must assume the responsibility of assuring culture sharing with families as an established practice so that we are not perpetuating the marginalization of culturally diverse populations. Some CLD families may not pursue support from service providers due to a lack of trust in the agencies from a devaluing and disrespect of the family's culture. It is therefore imperative for stakeholders to establish and maintain trust with CLD families in the services provided to them is of paramount importance. Furthermore, when CLD families request for and receive services, as stakeholders we want to assure that this experience is positive and the families experience high levels of satisfaction which will hopefully contribute to a higher FQOL.

When used as a tool to gain a picture of overall FQOL (as related to services and supports provided to) of families and their children with disabilities, I believe the scale holds great promise as a needs and strengths appraisal. Family members, service providers and parent

advocates may benefit to use the FQOL survey for as a valuable tool to use before an annual IEP meeting to assess strengths and needs of the child and family before doing an annual review. Given an increased emphasis on family involvement for program and service accountability, I recommend stakeholders to assess their services and supports using the FQOL or similar scale to determine whether they are actually working to improve quality of life of the families and children they serve, as well as to identify areas of priority and compliance with IDEA.

In conclusion, I believe it is culturally compatible, and also best practice, for stakeholders to assist in empowering families in Hawai'i to have the means to direct the types and amount of services their family receives, as this will increase their relevance and meaningfulness to families. Beach Center researchers Summers et al. (2007) propose that the short-range outcomes of supports and services (i.e., empowerment) lead to the ultimate outcome of FQOL. To increase FQOL for families in Hawai'i we need to begin with the goal of empowerment, use existing systems families already have in place, and provide them with the tools and support to better enable their lives and that of their children's.

APPENDIX A

Informational Letter of Solicitation to Agencies

(Agency Director)

(Date)

Dear (Agency Director),

My name is Phaedra Ranges. I am a doctoral student in the college of Special Education at the University of Hawaii, and a former special education teacher in the D.O.E. with ten years of experience teaching special education in Hawai'i. My experience in working with students with disabilities and their families inspired me to direct my area of research toward increasing family involvement and participation in the services and supports provided to their family and child with a disability.

I am very interested in giving families from Hawai'i a voice in the process of increasing involvement, collaboration and empowerment in the services provided to their children and themselves. Because of this, I am contacting agencies in Hawaii who work with families of children with disabilities in the areas of advocacy, empowerment and provision of information, training, and support for possible participants in my study.

I believe that involving families in the research process as partners in the problem solving process will increase the relevance, acceptability, appropriateness, and success of the interventions and the collaborations with schools and agencies of support.

I am collaborating with the Beach Center on Disability from the University of Kansas who constructed the measures I will be using in this study which are designed to collect valuable information from families in the areas of service adequacy, parent-professional partnerships, and family quality of life. It is our goal that that the information from these surveys will to help improve policies and services for children with disabilities and their families.

If you are interested in this research, please contact me and I would be happy to come in and talk with you!

Thank you for your time, I look forward to hearing from you! Please feel free to contact me if you have any questions as well at 808-551-3252, or phaedra.ranges@gmail.com

Sincerely,

Phaedra E. Ranges, M.Ed
Doctoral Student in Exceptionalities, University of Hawai'i, Mānoa

APPENDIX B

Informational Letter of Request to Participate for D.O.E Schools

(Principal)

(Date)

Dear (Principal X),

My name is Phaedra Ranges. I am a doctoral student in the college of Special Education at the University of Hawai'i , and a former special education teacher with ten years of experience in the D.O.E. teaching special education here in Hawai'i. The topic of my dissertation is directly related to my experience working with students with disabilities and their families in Hawai'i . My experiences inspired me to direct my area of research toward increasing family involvement and participation in the services and supports provided to their family and their child with a disability.

I would like to provide an opportunity for families from all over Hawai'i to participate in a research project that relates to their family quality of life as associated to the services provided to their children and themselves. To gain family member involvement, I am contacting agencies in Hawai'i who work with families of children with disabilities. As a former teacher I understand the numerous time-consuming demands of the profession, will take up as little of your time as possible, and assure you that the families who do want to participate are aware that this survey is not coming from the school but is for a doctoral student's PhD research.

This study will involve adult family members of children with disabilities of school age (four to eighteen years old) receiving special education services within the state of Hawai'i. The survey should take participants approximately a half hour, as they will receive information about the study purpose, consent to participate forms, instructions on how to fill out the survey, the Partnership and Family Quality of Life Scale to fill out, and a section within the survey for participants to provide their demographic information.

I will be attending the Community Children's Council meetings on the Big Island to meet with parents, and to distribute and collect surveys as part of the CCC agenda for the meetings. I will be on the Big Island for the CCC meetings in North Hawai'i on 8/23 from 5:30-7:30pm, and 9/2 in Hilo from 5:30-7:30pm. This information will be included on the letter of invitation for family members so that it will be clear that this is not a D.O.E survey, and if they have any questions they need to contact me, not the school their child goes to about this research or their participation. To be compliant with confidentiality, all of the information provided by families will be kept confidential. The names of participants will not be attached to any of the information included on the surveys

The measure I will be using for my research is the Partnership and Family Quality of Life survey from the Beach Center on Disability at the University of Kansas. The scale is designed to collect information in the areas of parent-professional partnerships, service appropriateness, and family quality of life. The scale is designed as a research tool to measure the variables that might affect family quality of life, and participation in education

If you are able to assist me in this step in my research, please contact me at 808-551-3252, or phaedra.ranges@gmail.com Please feel free to contact me if you have any questions as well. If you would be willing to help me in this step of my research process, could you please provide me the name of your SSC so that I can contact them regarding how many letters about my study and the CCC meeting they can attend to participate I should send to your school for distribution?

Thank you for your time and all that you do for the children in Hawai'i 's public schools!

Sincerely,

Phaedra E. Ranges, M.Ed

Doctoral Student in Exceptionalities, University of Hawai'i, Mānoa

APPENDIX C

Invitation to Family Members

(This copy is for you to keep)

HOW CAN YOUR FAMILY HAVE THEIR VOICES HEARD ABOUT SPECIAL EDUCATION IN HAWAII?

If you are interested in having your voice count in the provision of services and supports for your child with a disability and your family, I invite you to participate in this study by completing a survey about parent-professional partnerships, family quality of life, and the services and supports provided to your family and child with a disability.

To participate in this study you may attend a parent meeting where you will receive the surveys and complete them. The survey will take you approximately thirty minutes to complete. Your names will not be attached to the survey in any way to protect your identity, as they will be kept separate from completed surveys.

Your answers may be used in the following ways:

- Agencies in Hawai'i may use this information to evaluate their services to fully benefit families and their children with disabilities.
- Your responses will be used for general reporting to researchers, administrators, and policymakers in order to improve services and supports for families with children with disabilities and their child with a disability.

Information about your identity will be collected separately to keep your answers to the survey completely confidential. Because of this precaution, your name will never be associated with any reports or other materials that might come from this study.

You may choose to withdraw from the study at any time and may choose to refuse to answer any individual questions on the survey, without penalty of any kind.

If you have any questions please contact me, Phaedra Ranges at 808-551-3252, email: phaedra@hawaii.edu

Finally, please know that I understand the many demands on your time and truly appreciate your help!

Phaedra Elisabeth Ranges, M.Ed
Doctoral Student
University of Hawaii, Mānoa

If you have any questions regarding your participation in this study you may contact University of Hawaii, Committee on Human Studies (CHS) Biomedical Bldg, Room B-104, 1960 East-West Road, Honolulu, Hawaii 96822, Telephone: (808) 956-5007

APPENDIX D

Consent Form to Participate in Study

What do I need to do?

Read the instructions and fill out the questionnaire. It should take less than half an hour to complete. When you are finished, please return survey to the envelope marked “Questionnaires”, and return your signed consent form to the envelope marked “Consent Forms.”

If you would prefer to talk to me about your answers to the two open-ended questions at the end of the survey, please feel free to call me at 808-551-3252 and I will write up your answers to include it in the results! If you would like to be involved in the data analysis of the open-ended questions please let me know!

Information about your identity will be kept apart from your completed surveys to keep your answers completely confidential (i.e. your names will not be connected to your responses). Because of this precaution, your name will never be associated with any reports or other materials that might come from this study.

You should not feel psychologically harmed in any way by filling out this questionnaire. If you do feel uncomfortable you may choose to withdraw from the study at any time and also may choose to refuse to answer any individual questions on the survey.

Finally, please know that I understand the many demands on your time and that I truly appreciate your help!

If you want more information about this study you can call Phaedra Ranges at 808-551-3252 or email phaedra@hawaii.edu.

Please sign below to indicate your consent to participate in this study.

Participant signature

If you have any questions regarding your participation in this study you may contact University of Hawaii, Committee on Human Studies (CHS) Biomedical Bldg, Room B-104, 1960 East-West Road, Honolulu, Hawaii 96822, Telephone: (808) 956-5007.

APPENDIX F

Table 9
Participant Demographics

	N	%
Relationship to child with disability		
Parent	37	86
Other relative	4	9.3
Other non-relative	2	4.7
Marital status		
Single	20	46.5
Married	23	53.5
Educational background		
No schooling completed	0	0
Formal schooling but no high school diploma or GED	1	2.3
High school graduate (diploma or GED)	18	41.9
Some college but no degree	13	30.2
Associate degree	4	9.3
Bachelor's degree	4	9.3
Graduate degree	3	7.0
Ethnicity		
Asian/Pacific Islander	27	62.8
Caucasian	6	14.0
Hawaiian	10	23.3
Income		
Less than \$14,999	8	18.6
\$15,000 and \$19,999	4	9.3
\$20,000 and \$24,999	1	2.3
\$25,000 and \$29,999	7	16.3
\$30,000 and \$34,000	1	2.3
\$35,000 and \$39,999	2	4.7
\$40,000 and \$49,999	2	4.7
\$50,000 and \$59,999	4	9.3
\$60,000 and \$74,999	5	11.6
over \$75,000	8	18.6
Level of child's disability		
Mild	16	37.2
Moderate	20	46.5
Severe	3	7.0
Unknown	4	9.3
Sex of child with disability		
Male	31	72.1
Female	12	27.9
Community type		

Large city or metropolitan area (>200,000)	6	14.0
Urbanized area (50,000-200,000)	1	2.3
Town or small city (2,500-50,000)	23	53.5
Rural area or town (<2,500)	12	27.9
Missing	1	2.3

APPENDIX G

FQOL SURVEY-The Beach Center on Disability, University of Kansas

--	--	--	--	--	--	--	--	--	--

***Beach Center
on Disability***

at the heart of research on disability, families and policy

**Partnership and
Family Quality of Life
Survey**



*Developed by the Beach Center on Disability,
The University of Kansas,
in partnership with families, service providers, and researchers
© Beach Center 2003*

Survey Information and Instructions

Thank you for agreeing to complete this survey. This survey has questions about:

- the services you and your child need and/or receive,
- how you feel about the main person who works with you and your child,
- the things that make your life together as a family good,
- you and your family in general.

We will use your answers to help us improve policies and services for children with disabilities and their families.

All the information you give us is confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that make you feel uncomfortable.

When answering these questions, please think about your experiences **over the last 6 months**. Please use a pencil to shade completely the circles for your answers. If you change any answers, please erase completely any previous answers or any extra pencil marks on the page. Please do not make any stray marks, including comments, on the form, except where you are asked (for example, in the general information section).

Thank you so much for sharing your opinion with us!

By completing this survey, you indicate that you have been informed of the important aspects of this study and you are willing to participate.

General Individual and Family Information (cont.)

The following questions pertain to your family. Remember, your answers will be kept confidential.

14. Which of the following best describes the size of the community in which you live?

- Large city or metropolitan area (population greater than 200,000)
- Urbanized area (between 50,000 and 200,000)
- Town or small city (between 2,500 and 50,000)
- Rural area or town with population less than 2,500

15. What was your total household income from all sources for the past year? Be sure to include income from all sources (such as family subsidy or child support).

- Less than \$14,999
- Between \$15,000 and \$19,999
- Between \$20,000 and \$24,999
- Between \$25,000 and \$29,999
- Between \$30,000 and \$34,999
- Between \$35,000 and \$39,999
- Between \$40,000 and \$49,999
- Between \$50,000 and \$59,000
- Between \$60,000 and \$74,999
- Over \$75,000

16. How many people are supported on this income?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8 or more

Thank you! You have finished completing this survey.
Please make sure you erase any extra marks and have answered all the questions.

General Individual and Family Information (cont.)

12. What is the nature of your child’s **PRIMARY** disability? (Please shade **ONLY** one.)

- ADD or ADHD
- Autism spectrum disorder
- Developmental delay or early childhood disability
- Emotional or behavioral disorder
- Hearing impairment including deafness
- Learning disability
- Mental retardation
- Physical disability
- Speech or language impairment
- Traumatic brain injury
- Vision impairment including blindness
- Health impairment (Please specify) _____
- Other disability (Please specify) _____
- No specific diagnostics

13. Does your child have any **SECONDARY** disabilities in addition to the primary disability?

- Yes
- No

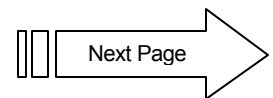
Where does your child usually receive services? (Shade only one)

- At home
- At a community preschool or childcare center (*for children with and without disabilities; such as KinderCare or church preschool*)
- Public school
- Private school
- Special or alternative school
- Other community setting
- Work setting
- Other _____

Support and Services

A. Please tell us about the type of services your CHILD **needs** and **receives**.

Which of the following services...	Does your child currently need ?		If YES , how much service does he or she get ?		
	Yes	No	None	Some, but not enough	Enough
Services for your CHILD with special needs:					
1. Special equipment to help your child live, learn, and grow (assistive and communications technology)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Health services (medical evaluations, nutrition, nursing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Hearing and/or vision services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Physical and/or occupational therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Speech and/or language services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Special education services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Counseling and psychological services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Support and Services (cont.)

Which of the following services...	Does your child currently need ?		If YES , how much service does he or she get ?		
	Yes	No	None	Some, but not enough	Enough
Services for your CHILD with special needs:					
8. Behavior support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Transportation and/or mobility services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Self-care skills training (example: help with dressing or bathroom use)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Service coordination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Transition services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Employment or vocational services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Other (please describe) _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

General Individual and Family Information (cont.)

8. What is your relationship to the child with a disability in your family?

- Parent (Biological, Step, Foster or Adoptive)
- Other relative (grandparent, aunt, uncle, sibling, etc.) Please specify:

- Other non-relative (family friend, etc.) Please specify: _____

Now we want to ask you a few questions about your **child with a disability**. If you have more than one child with a disability, please consider the one who has the most impact on your family life. Remember, your answers will be kept confidential and only reported as a group, not as individuals or families.

9. What is the gender of your child with a disability?

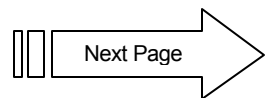
- Male
- Female

10. What year was your child with a disability born?

--	--	--	--

11. What is the level of your child's disability?

- Mild
- Moderate
- Severe
- Unknown



General Individual and Family Information (cont.)

5. What is your marital status?

- Married/Living with someone
- Not married (widowed, divorced, separated, never married)

6. What is your employment status?

- Working **full-time** for pay or profit for a company or family business
- Working **part-time** for pay or profit for a company or family business
- Unemployed but looking
- Not employed (for example, stay-at-home parent or care-giver, retired, public assistance pay, disability)

7. What is the highest level of education that you have completed?
(Please shade **ONLY** one.)

- No schooling completed
- Formal schooling but no high school diploma or GED
- High school graduate (diploma or GED)
- Some college or post-high school, but no degree
- Associate degree (AA, AS, etc.)
- Bachelor's degree (BA, BS, etc.)
- Graduate Degree

Support and Services (cont.)

B. Please tell us about the type of services your FAMILY **needs** and **receives**.

Which of the following services...	Does your family currently need?		If YES , how much service does your family get ?		
	Yes	No	None	Some, but not enough	Enough
Services for your FAMILY:					
15. Respite care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Child care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Money to help pay bills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Homemaker and/or housekeeping services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Support and Services (cont.)

Which of the following services...	Does your family currently need?		If YES , how much service does your family get ?		
	Yes	No	None	Some, but not enough	Enough
Services for your FAMILY :					
22. Sibling support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Parent or family training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Information about specific disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Information about where to get services for your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Information about where to get services for your family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Information about legal rights	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Other (please describe) _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

General Individual and Family Information

The last thing we need to do is to ask a few questions about you and your family. We will use this information to generally describe the people who responded to our survey. We will describe people in groups, never as individuals, so your answers will be kept confidential.

Please answer these questions about **yourself**.

1. What is your gender?

- Male
- Female

2. What year were you born?

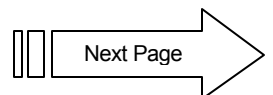
--	--	--	--

3. Are you of Hispanic or Latino origin?

- Yes
- No

4. What is your race? (Shade all that apply.)

- American Indian or Alaskan Native
- Asian or Pacific Islander
- Black or African American
- White
- Other (Please specify) _____



Family Quality of Life (cont.)

Please answer the following questions about your child with a disability. If you have more than one child with a disability, please keep in mind **the one who has the most impact on your family quality of life.**

	How important is it that...					How satisfied am I that...				
	A little important	Important	Critically important	Very dissatisfied	Neither	Very satisfied				
22. My family member with a disability has support to accomplish goals at school or workplace.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. My family member with a disability has support to accomplish goals at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. My family member with a disability has support to make friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Partnership

There may be many different service providers who work with your child with special needs, such as teachers, social workers, or speech, occupational, physical, or behavior therapists. Think about the service provider who has worked **THE MOST** with your child over the **last six months**. Please tell us what type of service provider you are thinking about:

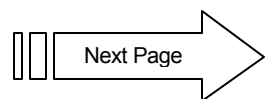
(shade only one circle)

- Behavior therapist
- Special education teacher
- Occupational therapist
- Physical therapist
- Social worker
- Counselor or therapist
- Speech therapist
- Case manager or service coordinator
- Doctor
- Job Coach
- Nurse
- Vocational counselor
- Other (please specify) _____

Now, with that person in mind, please answer the following questions:

Please shade in the circle in the next set of columns to show how satisfied you are with that statement.

- Shading the **first circle** means you are **very dissatisfied**.
- Shading the **last circle** means you are **very satisfied**.



Partnership (cont.)

How satisfied are you that your child's service provider...

	Very Dissatisfied		Neither		Very Satisfied
1. Helps you gain skills or information to get what your child needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Has the skills to help your child succeed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Provides services that meet the individual needs of your child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Speaks up for your child's best interests when working with other service providers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Lets you know about the good things your child does.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Keeps your child safe when your child is in his/her care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Treats your child with dignity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Builds on your child's strengths.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Values your opinion about your child's needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

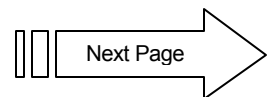
Family Quality of Life (cont.)

How **important** is it that...

How **satisfied** am I that...

For my family to have a good life together...

	A little important	Important	Critically important	Very dissatisfied	Neither	Very satisfied
15. My family gets medical care when needed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. My family has a way to take care of our expenses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. My family is able to handle life's ups and downs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Adults in my family have time to take care of the individual needs of every child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. My family gets dental care when needed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. My family feels safe at home, work, school, and in our neighborhood.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

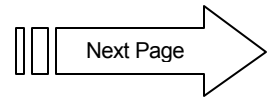


Family Quality of Life (cont.)

For my family to have a good life together...	How important is it that...					How satisfied am I that...				
	A little important	Important	Critically important	Very dissatisfied	Neither	Very satisfied				
8. My family members teach the children how to get along with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. My family members have some time to pursue their own interests.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. My family solves problems together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. My family members support each other to accomplish goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. My family members show that they love and care for each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. My family has outside help available to us to take care of special needs of all family members.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Adults in my family teach the children to make good decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Partnership (cont.)

How satisfied are you that your child's service provider...	Very Dissatisfied		Neither		Very Satisfied
10. Is honest, even when there is bad news to give.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Is available when you need them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Uses words that you understand.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Protects your family's privacy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Shows respect for your family's values and beliefs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Listens without judging your child or family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Is a person you can depend on and trust.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Pays attention to what you have to say.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Is friendly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Family Quality of Life

In this section of the survey, we want you to tell us how you feel about your life together as a family. We will use what we learn from families to improve policies and services for children with disabilities and their families.

Your “family” may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people

- Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and
- Who support and care for each other **on a regular basis**.

For this survey, please **DO NOT** think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past six months.

Step 1: Importance – First, please shade in the circle in the first set of columns to show how important you think that statement is.

- Shading the **first** circle means you think the statement is only a **little important**.
- Shading the **fifth** circle means you think that statement is **critically important**.

Step 2: Satisfaction – Please shade in the circle in the next set of columns to show how satisfied you are with that statement.

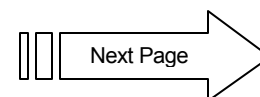
- Shading the **first** circle means you are **very dissatisfied**.
- Shading the **last** circle means you are **very satisfied**.

Please remember to answer both IMPORTANCE and SATISFACTION for each question.

Thank you so much for sharing your opinion with us!

Family Quality of Life

	How important is it that...					How satisfied am I that...				
	A little important	Important	Critically important	Very dissatisfied	Neither	Very satisfied				
For my family to have a good life together...										
1. My family enjoys spending time together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. My family members help the children learn to be independent.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. My family has the support we need to relieve stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. My family members have friends or others who provide support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. My family members help the children with schoolwork and activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. My family members have transportation to get to the places they need to be.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. My family members talk openly with each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



References

- Ah Sam, A., Lee, H., Martin, D., Malina-Wright, V., (2009) Culturally responsible evaluation. Powerpoint presented at H-PEA Conference, Hawai'i .
- Ankeny, E.M., Wilkins, J., & Spain, J. (2009). Mothers' Experiences of Transition Planning for their Children with Disabilities. *Teaching Exceptional Children*, 41(6), 28-36.
- Black, R.S., Dimino-Mrasek, K., & Ballinger, R. (2003). Individualist and Collectivist Values in Transition Planning for Culturally Diverse Students with Special Needs. *Journal for Vocational Education Special Needs Personnel*, 25(2) 20-29.
- Blue-Banning, M., Summers, J.A, Frankland, H.C, Nelson, L.L, & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, 70(2), 167-184.
- Charmaz, K. (2005). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. SAGE Publications ISBN-13: 9780761973539
- Gallimore, R. Boggs, J .W. & Jordan, C (1974). *Culture, behavior, and education: A study of Hawaiian-Americans*. Beverly Hills: Sage Publications, 1974.
- Harry, B. (2002). Trends and issues in serving culturally diverse families of children with disabilities. *Journal of Special Education*, 36(3), 131-138.
- Hoffman, L., Marquis, J., Poston, D., Summers, J.A. & Turnbull, A., (2006) Assessing Family Outcomes: Psychometric Evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family*, 68(4), 1069-1083.

- Hornstein, S., & McWilliam, R.A. (2007). Measuring family quality of life in families of children with autism spectrum disorders. Paper presented at the 2007 Annual Conference of the Division for Early Childhood. Abstract retrieved April 20, 2010 from <http://www.decsped.org/pdf/annualconference/FAM117%20Poster%20S27%20Measuring%20Family%20Quality%20of%20Life.pdf>
- Johnson, D. R., Stodden, R., Emanuel, E., Luecking, R., & Mack, M. (2002). Current challenges facing secondary education and transition services: What research tells us. *Exceptional Children*, 68(4), 519-531.
- Ka Huaka‘i 2005 Native Hawaiian Educational Assessment Executive Summary. Policy Analysis & Systems Evaluation (PASE): Honolulu, HI, 2005.
- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families’ participation in special education. *International Journal of Disability, Development and Education*, 47(2), 119-136.
- Kamehameha Schools. (2009). Native Hawaiian educational assessment update 2009: A supplement to Ka Huaka‘i 2005. Honolulu: Kamehameha Schools, Research & Evaluation Division.
- Kanaiaupuni, S. M., & Melahn, C. (2001). *Census 2000 highlights: Hawaiians in the United States* (Kamehameha Schools Policy Analysis and Data System Evaluation Report No. 2001–2002: 06). Retrieved February 4, 2003, from http://www.ksbe.edu/services/pase/pdf_lib/hawaiian_popula- tion/01_02_06.pdf
- Kana‘iaupuni, S.M., & Ishibashi, K. (2003). Left behind? The status of Hawaiian students in Hawai‘i public schools. *PASE Report*, 02-03:13.

- Kana'iaupuni, S. M. (2006). Ka'aka-lai Ku-Kanaka: A Call for Strengths-Based Approaches from a Native Hawaiian Perspective. *Educational Researcher*, June/July 2005, 32-38.
- Kawakami, A.J., Kanani, A., Cram, F., Lai, M.K., & Porima, L. (2007). Improving the practice of evaluation through indigenous values and methods; Decolonizing evaluation practice- Returning the gaze from Hawai'i and Aotearoa. *Hulili: Multidisciplinary Research on Hawaiian Well-Being*, 4(1), 319-348.
- Knokey, A. M. (2006, May). *National Longitudinal Transition Study-2: A Synthesis of Three NLTS2 Reports on Going to School, Youth Achievements and Services and Supports*. Retrieved February 19, 2011 from <http://www.projectforum.org/docs/NLTS2forweb.pdf>
- Koki, S., & Lee, H. (1998). Parental involvement in education: What works in the Pacific? PREL (Pacific Resources for Education and Learning). December 1-4.
- Lamorey, S. (2002). The effects of culture on special education service: Evil eyes, prayer meetings, and IEPs. *Teaching Exceptional Children*, 34(5), 67-71.
- Ledward, B., Takayama, B. & Kahumoku, W., III. (2008). Kikī Nā Wai: Swiftly Flowing Streams. Examples of Ohana and Community Integration in Culture-Based Education. Honolulu: Kamehameha Schools, Research & Evaluation Division
- Mannan, H. (2005). Examining family outcomes in early childhood services for families of children with disabilities (Doctoral dissertation). Retrieved from ProQuest. Publication Number: AAT 3185192.

- Markey, U., Santelli, B., & Turnbull, A.P. (1998). Participatory action research involving families from underserved communities and researchers: Respecting cultural and linguistic diversity. In B.A. Ford (Ed.), *Compendium: Writings on effective practice for culturally and linguistically diverse exceptional learners*. Reston, VA: Council for Exceptional Children, Division for Culturally and Linguistically and Diverse Exceptional Learners.
- Mian, W., Turnbull, A.P., Summers, J.A., Little, T.D., Poston, D.J., Mannan, H., & Turnbull, R. (2004). Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. *Research and Practice for Persons with Severe Disabilities*, 29(2), 82-94.
- National Alliance for Secondary Education and Transition (2005). National Standards & Quality Indicators: Transition toolkit for systems improvement, 2005 National
- Ogata, V., Sheehey, P.H., & Noonan, M.J. (2006). Parent Involvement in Educational Decision-Making: A Hawaiian Perspective. *Rural Special Education Quarterly*, 25 (1) 7-15.
- Onikama, D.L., Hammond, O.W., Koki, S. (1998). Family involvement in education: A synthesis of research for Pacific educators. Honolulu, HI: *Pacific Resources for Education and Learning*. Leadership Summit Edition.
- Park, J., Hoffman, L., Marquis, J., Turnbull, A.P., Poston, D., Mannan, H., & Wang, M. (2001). Cross-cultural competency and special education: Perceptions and experiences of Korean parents of children with special needs. *Education and Training in Mental Retardation and Developmental Disabilities*, 36(2), 133-147.

- Policy Analysis & System Evaluation Report. (2002). Losing ground: Longitudinal trends in Hawai'i DOE test scores for major ethnic groups. *Kamehameha Schools InfoBrief*. Policy Analysis & System Evaluation, Honolulu, Hawai'i
- Policy Analysis & System Evaluation (PASE). (2003). Evaluation Hui: Toward guidelines for culturally responsible evaluation and research. *Kamehameha Schools InfoBrief*. Policy Analysis & System Evaluation, Honolulu, Hawai'i.
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, 41(3), 313-328.
- Ranges, P. (2005). [A family quality of life survey with families with children with disabilities in Hawai'i]. Unpublished raw data.
- Reuf, M.B., & Turnbull, A.P. (2001). Stakeholder opinions on accessible informational products helpful in building positive, practical solutions to behavioral challenges of individuals with mental retardation and/or autism. *Education and Training in Mental Retardation and Developmental Disabilities*, 36(4), 441-456.
- Salisbury, C. L., & Dunst, C. L. (2000). Home, school, and community partnerships: Building inclusive teams. In B. Rainforth & J. York-Barr (Eds.), *Collaborative teams for students with severe disabilities: Integrating therapy and educational services* (2nd ed.). Baltimore: Brookes.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R.A., Felce, D., Matikka, L., Keith, K.K., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40(6), 457-470.

- Sileo, T.W., Sileo, A.P., & Prater, M.A. (1996). Parent and professional partnerships in special education: Multicultural considerations. *Intervention in School and Clinic*, 31(3), 145-153.
- Solomon, A.L. (1980). Cross-cultural conflicts between public education and traditional Hawaiian values (Doctoral dissertation). Oregon State University, Corvallis, Oregon.
- Spry, T. (2001). Performing Autoethnography: An embodied methodological praxis. *Qualitative Inquiry*, 7(6), 706-732.
- Stern, I.R. & Min, H. (2010). *Hawai'i Family Touchstones*. Honolulu: University of Hawai'i, Center on the Family.
- Summers, J.A., Marquis, J., Mannan, H., Turnbull, A.P., Flemming, K., Poston, D.J., Wang, M., & Kupzck, K. (2007). Relationships of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programs. *International Journal of Disability, Development and Education*, 54(3), 319-338.
- Tharp, R.G. & Gallimore, R. (1988). *Rousing minds to life: Teaching, learning and schooling in social context*. New York: Cambridge University Press.
- Tharp, R. G., Jordan, C., Speidel, G. E., Au, K. H., Klein, T. W., Calkins, R. P., Sloat, K. C. M., & Gallimore, R. (1984). Product and process in applied developmental research: Education and the children of a minority. In M. E. Lamb, A. L., Brown, & B. Rogoff (Eds.), *Advances in developmental psychology*, Vol. III (pp. 91-141). Hillsdale, NJ: Lawrence Erlbaum & Associates, Inc.

- Turnbull, A., Brown, I., & Turnbull, R.H. (2004). *Families and people with mental retardation: and quality of life: International perspectives*. Retrieved from <http://books.google.com/books>
- Turnbull, A.P., Friesen, B.J., Ramirez, C. (1998). Participatory action research as a model of conducting family research. *Journal of The Association for Persons with Severe Handicaps*, 23(3), 178-188.
- Turnbull, A.P., & Turnbull, H.R., (2001). *Families, professionals, and exceptionality: collaborating for empowerment*, 4th edn. Upper Saddle River, NJ: Merrill.
- Turnbull, R.H., Turnbull, A.P., Wehmeyer, M.L., & Park, J. (2003), A quality of life framework for special education outcomes. *Remedial and Special Education*, 24(2), 67-74.
- United States Census Bureau (2000). <http://www.census.gov/>
- Valenzuela, R. L., & Martin, J.E. (2005). Bridging Values of Diverse Cultures and Secondary Education. *Career Development for Exceptional Individuals*, 28 (1) 4- 14.
- Voydandoff, P., Fine, M.A., & Donnelly, B.W. (1994). Family structure, family organization, and quality of family life. *Journal of Family and Economic Issues*, 15(3), 175-200.
- Wang, M., & Brown, R. (2009). Family quality of life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work*, 12, 144-167.
- Wang, M, Mannan, H, Poston, D, Turnbull, A., Summers, J.A. (2004a) Parents' Perceptions of Advocacy Activities and Their Impact on Family Quality of Life. *Research and Practice for Persons with Severe Disabilities*, 29(2), 144-155.

- Wang, M., Summers, J.A., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. *Journal of Intellectual Disability*, 50(12), 977-988.
- Wang, M., Turnbull, A., Summers, J., Little, T., Poston, D., Mannan, H., & Turnbull, R. (2004b). Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. *Research and Practice for Persons with Severe Disabilities*, 29(2), 82-94.
- Wall, S. (2006). An autoethnography on learning about autoethnography. *International Journal of Qualitative Methods*, 5(2), 1-12.
- Yamauchi, L. A. (2003). Making school relevant for at-risk students: The Wai'anae High School Hawaiian studies program. *Journal of education for students placed at risk*, 8(4), 379–390.
- Zuna, N., Selig, J.P., Summers, J.A., & Turnbull, A.P. (2009b). Confirmatory factor analysis of a family quality of life scale for families of kindergarten children without disabilities. *Journal of Early Intervention*, 31(2), 111-125.
- Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., Xu, S. (2009c). Theorizing about family quality of life. In R. Kober (Ed.), *Quality of life for people with Intellectual disability*. New York: Springer.
- Zuna, N., Turnbull, A.P., & Summers, J.A. (2009a). Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities*, 6(1), 25-31.