SAGE researchmethods cases

Researching Quality of Life Among Families of Children With Autism Spectrum Disorder: An Application of Mixed Methods

Abstract

This research methods case describes my dissertation research, which utilized a mixed-methods design to examine quality of life among families of children with autism spectrum disorder. A large group or participants completed surveys over the phone and online, and a smaller subset participated in follow-up interviews. The case presents an overview of the methodological challenges we confronted, including consideration of how best to engage diverse participants and choosing appropriate survey tools, given the unique needs of our population. We describe the strategies we employed to address these challenges and reflect on their effectiveness. In particular, we highlight a unique approach in which we hosted Knowledge Translation events that brought together individuals with autism spectrum disorder and their families with researchers, service providers, clinicians, and government representatives. These events proved critical across the research process, as they informed the original study design, served as a venue for participant recruitment, and inspired the inclusion of key questions within the interview guide. We also discuss methods of engaging hard-to-reach populations. The methodological implications of the study design and methodology are reviewed, and recommendations to future researchers are presented.

Learning Outcomes

By the end of this case, students should be able to

- Understand the challenges associated with engaging families of children with autism spectrum disorder in mixed-methods research
- Understand how research is limited by a lack of participant diversity
- Evaluate different participant engagement strategies, including those aimed at hard-to-reach populations

Overview and Context

The Family Quality of Life (FQOL) project began in 2011. As a researcher in the field of autism spectrum disorder (ASD), I knew that I wanted to focus my dissertation work on examining family outcomes and experiences. Our research lab was involved in the local ASD community, with parent groups and organizations, and family caregivers often shared the profound impact that raising a child with ASD had on all aspects of their lives, including their careers and marriages, and on social relationships. When I turned to the literature to begin my research, however, it was immediately clear that the predominant focus was on families' negative experiences, with most studies considering outcomes such as stress and depression. This one-sided focus was in conflict with what I had observed anecdotally, as families indeed shared their struggles, but many also described positive aspects, and reflected on their children's strengths and family's resilience.

Further examination of existing literature revealed that this breadth of family adaptation was evident within qualitative work, but that quantitative research was largely ensconced within a deficit-based perspective. Moreover, it was apparent that relatively few studies actualized their aim of investigating *family* well-being, adaptation, or functioning, and instead examined only maternal outcomes.

It was when I came across a paper written by my supervisor, Dr. Grace Iarocci, entitled "Family quality of life when there is a child with a developmental disability" that I was exposed to the FQOL construct (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). FQOL emerged as a field of inquiry from work on individual quality of life (QOL). Both reflect a considerable shift from a once limited focus on medical outcomes as sole indicators of health to a broader acknowledgment of the considerable impact surrounding social contexts exert on an individual and family's sense of well-being and ability to meaningfully participate in available opportunities. What I found most appealing about this area of study was that central to its conceptualization was the multifinality of family outcome.

The FQOL field emerged from the work of two main centers, the Beach Center on Disability at the University of Kansas and the International FQOL Project. These groups were instrumental in laying the conceptual and theoretical groundwork that has provided the solid foundation upon which the current science rests. These two centers also worked to develop FQOL instruments that were reflective of the realities of those with lived experience, including individuals with disabilities, their families, and service providers. The most widely cited definition of FQOL is by Park et al. (2003) who suggest it consists of "conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them" (p. 368).

In commencing this project, I hoped to address what I saw as the three primary gaps in the FQOL literature. First, most FQOL research at the time had been conducted with samples that included families of children affected by diverse conditions (e.g., ASD, attention deficit, mental health, hearing and language impairments). Researchers, for the most part, had not yet considered how possible differences in disorder presentation, severity, or functional profile could diversely affect FQOL. As an ASD researcher, I was particularly interested in how the emerging FQOL framework could be applied to this unique circumstance.

Second, very few studies employed mixed-methods designs. Given the complexity inherent to the construct of FQOL, I felt that inclusion of a qualitative component would allow for a deeper understanding of the impact of various child, family, and service characteristics and would provide a rich layer of context. Although quantitative data are best suited to answering some of the big (i.e., generalizable) questions in social science research, qualitative data can enrich our understanding of statistical relationships, giving greater power and meaning to the broader story. Including a qualitative aspect would also help to achieve the goal of identifying service and policy gaps from the family perspective and would support us to make evidence-based suggestions for reform.

Finally, there appeared to be a degree of disconnect between how the family unit was conceptualized within FQOL theory and its assessment in practice. A central concept within FQOL theory is that family membership

is broad. Membership does not pertain to only the nuclear unit but is flexible to include "the people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis" (Poston et al., 2003, p. 319). It appeared, however, that a methodological implementation truly reflective of this ecological perspective had not yet been achieved. I hoped to address this gap, and in doing so add a layer of depth to the Family Interaction/Family Relationships domain of FQOL.

Research Practicalities

My PhD research was conducted between September 2011 and September 2014. The work was supported by the Social Sciences and Humanities Research Council of Canada, Autism Research Training Program (Canadian Institutes of Health Research), and the Laurel Foundation. Importantly, the Laurel Foundation provided support for our research lab to host four FQOL-related Knowledge Translation events, which proved to be invaluable opportunities to discuss issues and emerging themes with families and to ensure that this research was reflective of their voices.

In commencing this project, we identified three main methodological issues that we would have to confront in order to successfully meet our aims: engaging the population of interest, finding appropriate tools, and engaging the hard-to-reach.

Engaging the Population of Interest

It is well known that families of children with developmental disabilities experience a myriad of demands. Family advocates are responsible for managing funding, procuring specialized supports, and coordinating services that fall across various public sectors. It has been suggested that families of children with ASD experience the greatest level of demand, as these families are more likely to have unmet healthcare, family support, and referral needs; are less likely to receive coordinated care; and are less satisfied with their child's care than families of children with other health conditions (Kogan et al., 2009). It was therefore imperative that we balance our desire for detailed data with sensitivity to demands on families' valuable time. Similarly, it was essential that we consider ease of participation.

Finding Appropriate Tools

In considering how best to engage families of children with ASD, we also had to ensure that the tools we utilized were reflective of their unique circumstance and that families could see themselves within survey items. In the early stages of the project, we spent time obtaining various instruments assessing behavior problems, adaptive functioning, family resilience, and FQOL and reviewed the items to determine whether they would sufficiently tap into relevant areas of concern for this unique group of participants.

Engaging the Hard-to-Reach

Just as FQOL is intended to capture the diversity of family adaptation, it was important we include a sample that could accurately represent such heterogeneity. This meant working to ensure that our sample was diverse in terms of family income, education level, and family structure, for example. It was also important that fathers participate, as well as caregivers from diverse cultural and ethnic backgrounds. This research was conducted in British Columbia, the most ethnically diverse province in Canada, and we felt that our sample should reflect this broader context. It is possible that families who are new to Canada, or who are not proficient in English, for example, may be particularly at risk, and it was important that we consider their potentially unique perspective on FQOL.

Research Design

This study examined QOL among families of children and adolescents with ASD in British Columbia and addressed three aims. First, the role of risk factors, including child behavior, both problematic and adaptive, was examined. Second, family protective factors were examined using a model of family resilience that considered family belief systems and communication and organizational patterns. Finally, a subset of families participated in a follow-up interview, providing qualitative elaboration on the variables that were examined quantitatively. The project utilized a mixed-methods design, as this approach was felt to be most appropriate to address the great complexity inherent within the FQOL construct. All participants (N = 160) completed surveys either on the phone or online (or both), and a smaller subset (n = 15) participated in follow-up interviews. These took place in person, over the phone, or via Skype. The specific approach was consistent with that of a sequential explanatory design, in which the intent was to first explore the variables of interest quantitatively with a large sample and, subsequently, to utilize a qualitative follow-up component to gain a deeper and more informed understanding of the identified processes. The qualitative results served to provide congruence with those identified in the quantitative component, but importantly, they also illuminated *why* the variables play such a significant role in families' lives. Equal priority was given to both the quantitative and qualitative research, and integration of the data occurred in the final interpretation of the results.

"Method" in Action

Engaging the Population of Interest

A critical element of engaging families of children with ASD for the FQOL project was related to our long-standing involvement with the local ASD community, as lab members organize and attend educational forums, fundraising events, and resource fairs. Because of this network, many of our participants had been involved with the lab prior to their involvement in this particular study (for an average of 2 years prior), as their children had participated in lab-organized summer camps, they had attended various lab-hosted events, and had participated in other research studies. This kind of engagement helped to gain participants' trust, as it not only communicated the credibility of the research but also showed that we valued participants' time and input.

A unique approach we employed to encourage participation was hosting four Knowledge Translation events, all of which focused on FQOL, both broadly and in relation to specific topics (school, mental health, transitions). These events brought together individuals with ASD and their families with researchers, service providers, clinicians, and government representatives. At the first event, we disseminated findings from a review we had recently published that synthesized previous FQOL conceptualizations, measurement approaches, and research findings and identified existing literature gaps and methodological limitations (Gardiner & Iarocci, 2012). This event served as an important opportunity to obtain feedback on the proposed dissertation, in order to ensure that resulting practice and policy recommendations were both evidence-based and meaningful to individuals with ASD and their families. At subsequent events that took place when the study was underway, attendees were informed about the research and given the opportunity to participate if they were interested. Importantly, these events served as gestures of reciprocity, as it allowed us to access participants but gave families a venue to exchange stories, network, speak with experts in the field, and learn about available community resources.

The discussion content of the events also directly informed the dissertation methodology, as the most salient issues that emerged became important points of discussion during participant interviews. For example, although the events focused on different themes in relation to FQOL (school, mental health, transitions), the topics of service delivery and families' experiences with the school system were predominant within each. Similarly, interview discussions quickly turned to the profound impact that interactions with the child's service system had on the broader family unit. Having participated in the events made me aware that this was a pervasive concern for families and prepared me to ask relevant questions when related topics arose.

Finding Appropriate Tools

The two main centers of FQOL research have both developed instruments that are widely used and specifically intended for our context. It was therefore important that we spend time determining which would be a better fit for our study aims. Specifically, we considered aspects such as administration time, ease of self-completion, and psychometric properties. Given the time demands facing this group of caregivers, we opted for the Beach Center tool, which is considerably shorter (approximately 20 min to complete) as compared to the International FQOL Project's measure, which takes about 40 min to fill out. Moreover, research comparing the two finds that although there is overlap in measure content, the Beach Center tool is easier for families to understand (Rillotta, Kirby, & Shearer, 2010). Its strong psychometric properties also make it appropriate for quantitative research. This was an important consideration for us, as including a qualitative aspect was an essential component of the research design, and the International FQOL Project's measure includes extensive open-ended qualitative questions. We decided, however, that we should develop the interview guide based on our review of relevant literature, discussions with families, and from FQOL event content. We also adapted the FQOL measure so that families could provide qualitative elaboration if they wished. This turned out to be a very useful strategy, as 97% of participants took advantage.

Obtaining measures assessing behavior problems and adaptive functioning, our other variables of interest,

was relatively straightforward. Psychometrically sound tools were readily available, and they had been extensively validated with our population of interest. Finding an appropriate measure to assess the construct of family resilience, however, proved to be more challenging. Although tools abound, we felt that they did not effectively lend themselves to the complex context of raising a child with ASD. While conducting an extensive search, we came across a tool that was developed as a doctoral project, the Family Resilience Assessment Scale (Tucker Sixbey, 2005). The measure was based on a conceptual model that aligned with FQOL theory and had been used by other researchers to assess family resilience across a range of populations, including families of individuals with ASD. Inclusion of this measure was somewhat of a risk, as it was unpublished. However, the dissertation described its validation, and we were satisfied that the items could accurately portray the breadth of family processes in this unique circumstance. Although some may identify the inclusion of an unpublished measure as a limitation, we felt that it was more important to utilize an instrument that was meaningful to the population of interest than to choose a tool simply based on its widespread use.

Engaging the Hard-to-Reach

In order to reach out to a wide range of participants, we recruited through a number of avenues. In particular, our research lab had a large database of over 500 families of children with ASD who indicated they would be interested in participating in future research. These were families who had participated in previous research, signed up at community events, and who had become aware of and contacted the lab through word-of-mouth. These families were contacted by email and invited to participate. Recruitment advertisements were also placed on the lab website and social media pages, as well as on the websites, social media pages, and in the waiting rooms of community ASD organizations, upon being granted permission to do so. Families were also invited to participate at lab-hosted summer camps, which were free day camps for children aged 7-12 years, in which they and their caregivers participated in research. Families were also told about the study and participated through the lab-hosted knowledge translation events, as described.

These efforts, however, proved to be ineffective in engaging a sufficiently diverse range of participants. Within the larger quantitative component, 86% of respondents were mothers, and most (78%) were married or in common-law relationships with above-average family incomes. This suggests that the sample was a very "resource-rich" group, who may face fewer challenges than single or low-income parents of children with ASD, for example. Although there was some diversity in terms of ethnicity, with less than 35% identifying themselves as "Canadian," over 90% indicated that English was their family's primary language. Finally, the majority (70%) of participants resided within the province's largest regional district, indicating that we did not do an adequate job of reaching families living in rural and remote centers.

Within the qualitative interview, it was our hope that "caregiving partners" would participate, so we could ascertain a more well-rounded perspective on FQOL and its determinants than previously described. However, of the 12 families who participated in this component, only 3 involved mother–father dyads, and all indicated that they were "Very Satisfied" (the highest rating) with their overall FQOL.

The conclusions of the study, though valuable, are limited by the lack of diversity represented within the sample. It is clear that families who may be particularly isolated were not represented, and the findings may not generalize to their unique circumstance. It is critical that methods of engaging families who live in rural or remote locations and who represent diverse ethnic and cultural backgrounds are developed, so their voices are included within this research. Such an approach would acknowledge the rich diversity represented within the FQOL construct and ensure that evidence-based recommendations have value for all families of children with ASD. Suggestions for ameliorating the identified methodological challenges will be discussed within "Practical Lessons Learned."

Practical Lessons Learned

Conducting the FQOL project was a powerful experience. Families shared their very personal experiences of trial and triumph, and we gained insight into how FQOL was affected, for better or worse, by having a member affected by ASD. With the benefit of hindsight and time for reflection, the following outlines tips that I would pass on to researchers beginning a mixed-methods study in a related field:

1. *Qualitative analysis will evolve.* An important lesson in conducting the qualitative analysis is to be open to evolutions and changes in your approach to coding. When analysis initially began, two interviews were randomly selected and inductive open coding took place. Each interview was coded line-by-line and initial codes were developed from identifying salient words, phrases, and paragraphs. Although this fit with what I had read about conducting content analysis, as well as with how I had analyzed qualitative data in previous projects, it did not appear to be a good fit for the breadth of our data, as such a wide range of topics were discussed during interviews. This was confirmed after meeting and reviewing the initial codes with a co-coder, who agreed that the coding scheme should be substantially revised. At the time, it was somewhat devastating to discard hours of work; however, the result was worth it. This experience emphasizes the importance of remaining open and flexible to having your overall coding scheme evolve as new themes emerge, and confirming and disconfirming evidence is uncovered.

2. *Keep memos.* A very useful strategy was writing memos throughout the project. One memo pertained to coding, included reflections on the appropriateness of different approaches (i.e., inductive vs. deductive), and documented observations about how emerging themes fit with prior research. Another memo related to project development and documented attendance at qualitative workshops, useful resources, meetings with the co-coder and primary supervisor, and researcher-participant correspondence regarding member checks of interview transcripts. The final memo included iterations of evolving theme definitions. As mixed-methods research may occur over a longer time period than is the case when using one approach, these documents were helpful aids when it came time to writing up the methods and results.

3. *Interviews are demanding—be prepared!* Fully immersing yourself in an in-depth interview is

labor-intensive. As the interviewer, it is your role to ask questions, actively listen to participant's comments, prompt appropriately, interpret nonverbal cues, let silences hang, and be attuned to participants' reactions to discussing sensitive material. Many interviewers also opt to take notes, including general observations and reminders of what to follow up on, which must be done inconspicuously while maintaining appropriate eye contact and the flow of conversation. If I could pass on advice to myself during this process, it would be to not underestimate the concentration demands this places upon you. Although scheduling multiple interviews per day is time efficient, it is very difficult to give the later interviewees the necessary attention.

4. *Let interviewees drive the process*. Given that this participant group is an extremely strained one in terms of family demands and the often-heightened levels of stress present within their family environments, it was immediately apparent that the traditional model of face-to-face interviews was not going to be appropriate. As such, it was essential that I read about conducting interviews through alternate mediums, such as over the phone or via videoconference. This proved very useful, as in the end, only one interview was conducted in person, with all other participants requesting that our discussion take place over the phone or on Skype. Helpful strategies when conducting phone or Skype interviews included having multiple contacts with participants before conducting the interview, paying close attention to voice changes and pauses, and using silent probes to elicit further information and to ensure participants had time to share their thoughts (Rubin & Rubin, 2005).

5. *Engaging hard-to-reach populations requires specialized efforts*. Implementing targeted strategies likely would have resulted in a more diversified and representative sample. In turning to the literature, there are research-based strategies for engaging hard-to-reach and vulnerable populations (Benoit, Jansson, Millar, & Phillips, 2005). The most frequently cited is the development of community-academic partnerships. Members of the community of interest can be included as partners in the early research planning phase, which will help to ensure that the research questions and study aims are meaningful to them. They can also advise regarding the adaptation of study materials, so they are culturally appropriate and sensitive. It is also suggested that community members be formally involved in the research process. For example, trusted members or organizations can be partnered with to disseminate information about the study and community members can be hired as research assistants. Although we did utilize a number of these strategies to reach families of children with ASD, including obtaining early input and feedback and having trusted organizations share study information, it is likely that had we applied them to more specific groups (e.g., rural families of children with ASD), we would have obtained a more diverse sample with more widely applicable implications.

Methodological Implications

Within the FQOL project, I set out to address three methodological gaps, including the lacking ASD

perspective, predominance of quantitative designs, and family conceptualization–practice disconnect. In doing so, we gained detailed insight into FQOL processes operating within a particular group of families. Specifically, we identified how various child characteristics, including child behavior, could place FQOL at risk (Gardiner & Iarocci, 2015) but also identified that family communication and connectedness could serve important protective roles, thereby contributing to an improved understanding of how many families thrive despite their exposure to continued and significant challenge. The utilized approach, however, of focusing only on families of children with ASD precluded us from making comparisons across populations. Although the presence of a disability likely comes with a number of common family implications, we cannot postulate as to how the identified risk and protective factors comparatively operate within families of children with other conditions.

The use of the described mixed-methods approach represented somewhat of a departure from the emphasis that dominates the discipline of Psychology, which can be very focused on quantitative measurement and statistical significance. Incorporating interviews and options for qualitative comments into the research design, however, was critical in allowing us to gain an additional layer of insight that would not have been possible with surveys alone. Interviews remove the boundaries imposed by standardized tools and provided rich context to the wealth of data we obtained online and over the phone. Participants were encouraged to share their experiences, and this revealed significant gaps in the existing service system.

Finally, we aimed to address the "family perspective" through encouraging both mothers and fathers to complete surveys and by having caregiving dyads participate in follow-up interviews. As described, this approach was not overwhelmingly successful; mothers constituted the majority of survey participants, and few caregiving dyads agreed to be interviewed. Broadly speaking, this is consistent with most research assessing parental and family outcomes among children with disabilities and is also likely reflective of the distribution of parental responsibility in many families. The fact that much of the data are representative of only one family member's perspective, however, is an important limitation, and future research should continue to make efforts to include a range of individuals from the family system, including caregivers, siblings, affected children, and individuals from extended social support networks. As a whole, the field has a ways to go before Poston et al.'s astute definition is successfully actualized. It will be important to consider whether this aim can be achieved beyond qualitative research and whether and how quantitative methodologies can begin to address this issue.

Conclusion

Robert Schalock (2005), a pioneer of the QOL field, suggests that "methodological pluralism" constitutes a defining characteristic of current QOL research. Following from this, we examined both subjective and objective indicators of FQOL with a methodology that reflected a balance between the quantitative and qualitative. Such between-methods triangulation leant a "balanced approach" from which circumstances of risk and resilience could be understood (Schalock, 2005, p. 696), and this study revealed a number of new

and important insights into FQOL processes using an innovative research design.

Exercises and Discussion Questions

1. A critical element of engaging families described in this case was the research lab's existing involvement in the ASD community. How could an investigator who is new to this area of research or community forge such links and recruit participants?

2. The case describes how the Knowledge Translation events served as important opportunities to gain feedback on the research and to recruit participants. Are there potential downsides to such an approach?

3. When selecting appropriate tools, administration time, ease of self-completion, and psychometric properties were considered. What else might be relevant to think about when choosing study instruments?

4. Although efforts were made to engage diverse participants, they were largely unsuccessful. What else could the researchers have done to recruit participants who were diverse in terms of family income, education level, family structure, and ethnicity?

5. Although the researchers hoped to interview "caregiving dyads" in the follow-up interview, only three couples agreed, and all indicated that they were "Very Satisfied" with their FQOL. What kinds of conclusions can we make based on this observation, and how could we explore this in future research?

Further Reading

Bazeley, P. (2009). Analysing mixed methods data. In **S. Andrew**, & **E. J. Halcomb** (Eds.), *Mixed methods research for nursing and the health sciences* (pp. 85–118). Oxford, UK: Wiley-Blackwell.

Brown, I., **Brown, R. I.**, **Baum, N. T.**, **Isaacs, B. J.**, **Myerscough, T.**, **Neikrug, S**, … Wang, M. (2006). *Family quality of life survey: Main caregivers of people with intellectual disabilities*. Toronto, Ontario, Canada: Surrey Place Centre.

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, 1069–1083. doi:http://dx.doi.org/10.1111/j.1741-3737.2006.00314.x

Tashakkori, A., & **Teddlie, C.** (Eds.). (2003). *Handbook of mixed methods in social & behavioral research*. Thousand Oaks, CA: SAGE.

Walsh, F. (2012). Family resilience: Strengths forged through adversity. In **F. Walsh** (Ed.), *Normal family processes* (4th ed., pp. 399–427). New York, NY: Guilford.

Web Resources

http://autismlab.psyc.sfu.ca/

https://www.youtube.com/channel/UCPfwmDLhTvnhIRr5JH_blGw

References

Benoit, C., **Jansson, M.**, **Millar, A.**, & **Phillips, R.** (2005). Community-academic research on hard-to-reach populations: Benefits and challenges. *Qualitative Health Research*, 15, 263–282. doi:http://dx.doi.org/10.1177/1049732304267752

Brown, R. I., **MacAdam-Crisp, J.**, **Wang, M.**, & **Iarocci, G.** (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 238–245. doi:10.1111/j.1741-1130.2006.00085.x

Gardiner, E., & **Iarocci, G.** (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, 33, 2177–2192. doi:10.1016/j.ridd.2012.06.014

Gardiner, E., & **Iarocci, G.** (2015). Family quality of life and ASD: The role of child adaptive functioning and behavior problems. *Autism Research*, 8, 199–213. doi:http://dx.doi.org/10.1002/aur.1442

Kogan, M. D., **Strickland, B. B.**, **Blumberg, S. J.**, **Singh, G. K.**, **Perrin, J. M.**, & **van Dyck, P. C.** (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics*, 122, 1149–1158. doi:http://dx.doi.org/10.1542/peds.2008-1057

Park, J., **Hoffman, L.**, **Marquis, J.**, **Turnbull, A. P.**, **Poston, D.**, **Mannan, H.**, & **Nelson, L. L.** (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research*, 47, 367–384. doi:http://dx.doi.org/10.1046/j.1365-2788.2003.00497.x

Poston, D., **Turnbull, A.**, **Park, J.**, **Mannan, H.**, **Marquis, J.**, & **Wang, M.** (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, 41, 313-328. doi:http://dx.doi.org/10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2

Rillotta, F., **Kirby, N.**, & **Shearer, J.** (2010). A comparison of two family quality of life measures: An Australian study. In **R. Kober** (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 305–348). Dordrecht, The Netherlands: Springer.

Rubin, H. J., & **Rubin, I. S.** (2005). *Qualitative interviewing: The art of hearing data* (2nd ed.). Thousand Oaks, CA: SAGE.

Schalock, R. L. (2005). Introduction and overview. *Journal of Intellectual Disability Research*, 49, 695–698. doi:http://dx.doi.org/10.1111/j.1365-2788.2005.00737.x

Tucker Sixbey, M. (2005). *Development of the Family Resilience Assessment Scale to identify family resilience constructs*. Available from ProQuest Dissertations and Theses database. (UMI No. 3204501)