

Odette Weiss^{1,2}, Adrienne Perry^{1,2}, & Barry Isaacs^{2,3}

¹York University, ²GO4KIDDS, ³Surrey Place Centre

Background

- Raising a child with a developmental disability (DD) comes with unique challenges for a family because of a number of child factors (e.g., physical challenges, behaviour problems)
- Other life factors (e.g., financial stability, family hardiness, social support) may also play a role in the family's life
- Family quality of life (FQOL) is an umbrella construct that aims to capture different aspects of family life and the level of functioning within those areas (Samuel, Rillotta, & Brown, 2012)
- Family Quality of Life Survey-2006 (FQOLS-2006) is a self-report measure of FQOL (Brown et al., 2006)
- The validity of the FQOLS-2006 is still under examination
- A recent evaluation of the FQOLS-2006 revealed that significant predictors of an overall FQOL rating were mental health and marital satisfaction of the reporting individual (Weiss, Perry, & Isaacs, 2013)
- FQOLS-2006 outcomes may be greatly influenced by factors of the individual respondent, although the aim is to capture a picture of the entire family
- Need to examine other individual respondent characteristics

Purpose and Research Question

- Explore individual respondent factors that may be contributing to an overall FQOL rating
- **Hypothesis:** A number of respondent factors will play a significant role in the overall FQOL rating
 - Mental health
 - Physical health
 - Involvement in day-to-day life of child with DD
 - Whether or not he/she gave up their career or education
 - Perceived level of responsibility for family
 - Perceived level of responsibility for member with DD

Participants

- N = 63
- Parents of children with DD
 - Age 30-63 (M = 44, SD = 6.9)
 - 57 mothers, 6 fathers
 - 41 two-parent families, 20 one-parent families, 2 other constellations
 - Socioeconomically diverse
- Children aged 5-19
 - Many have additional diagnoses (e.g., Autism Spectrum Disorder, Down Syndrome, Cerebral Palsy)

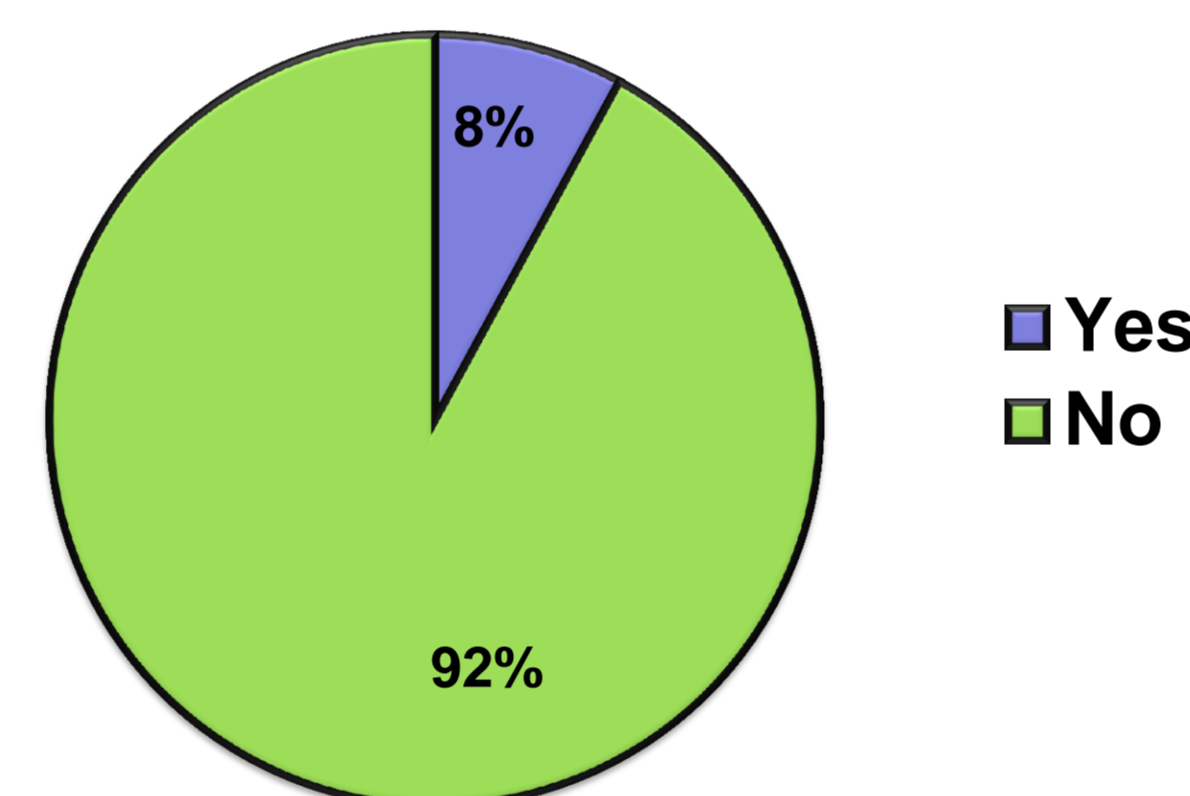
Measures

Family Quality of Life Survey- 2006 (Brown et al., 2006)

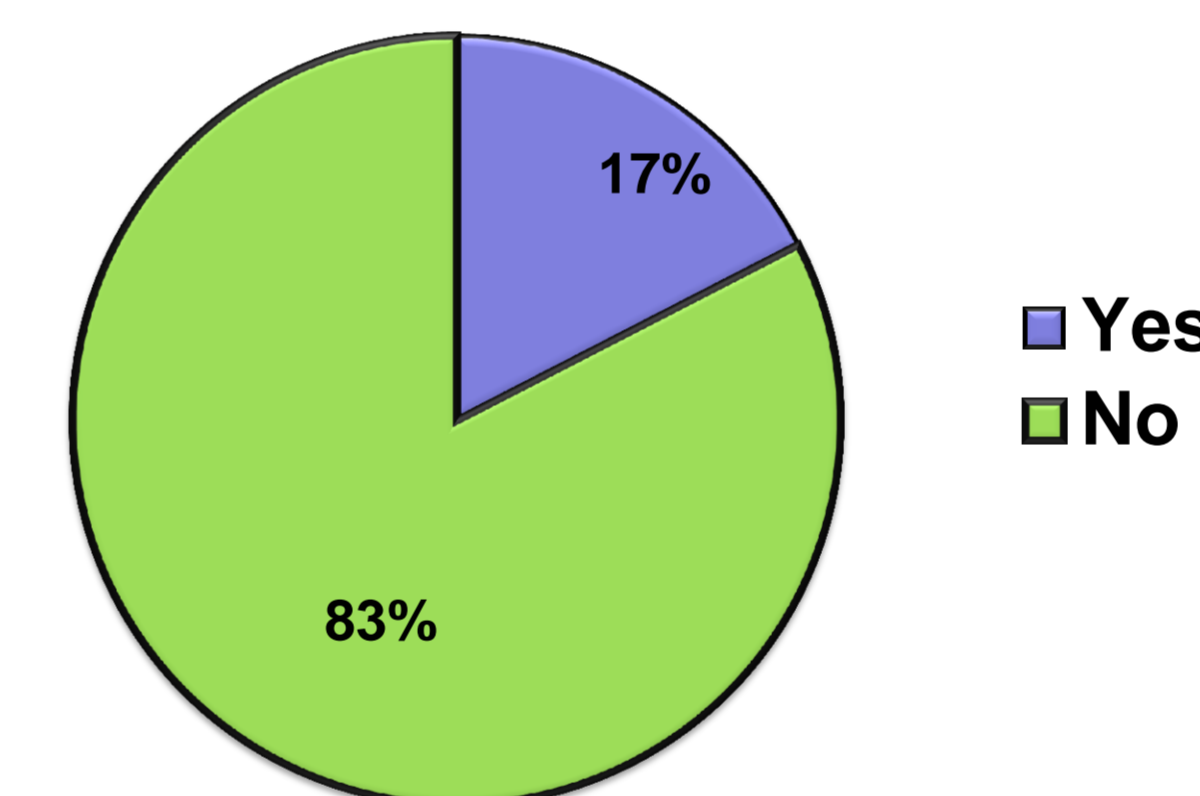
- Coded for "yes"/"no" for individual respondent:
 - Are there major **physical** and/or **mental health** concerns for members of your family?
 - Which family member is **most involved** in the day to day life of your family member with an ID/DD?
 - Have any members in your family **given up their careers or education**?
- Questions in survey directed at individual respondent:
 - How much **responsibility** do you *personally* have in the day to day affairs of your **family**?
 - How much **responsibility** do you *personally* have in the day to day affairs of your **family member with an ID/DD**?
- Two questions about overall FQOL (attainment of, satisfaction with → 5-point scale)

Results

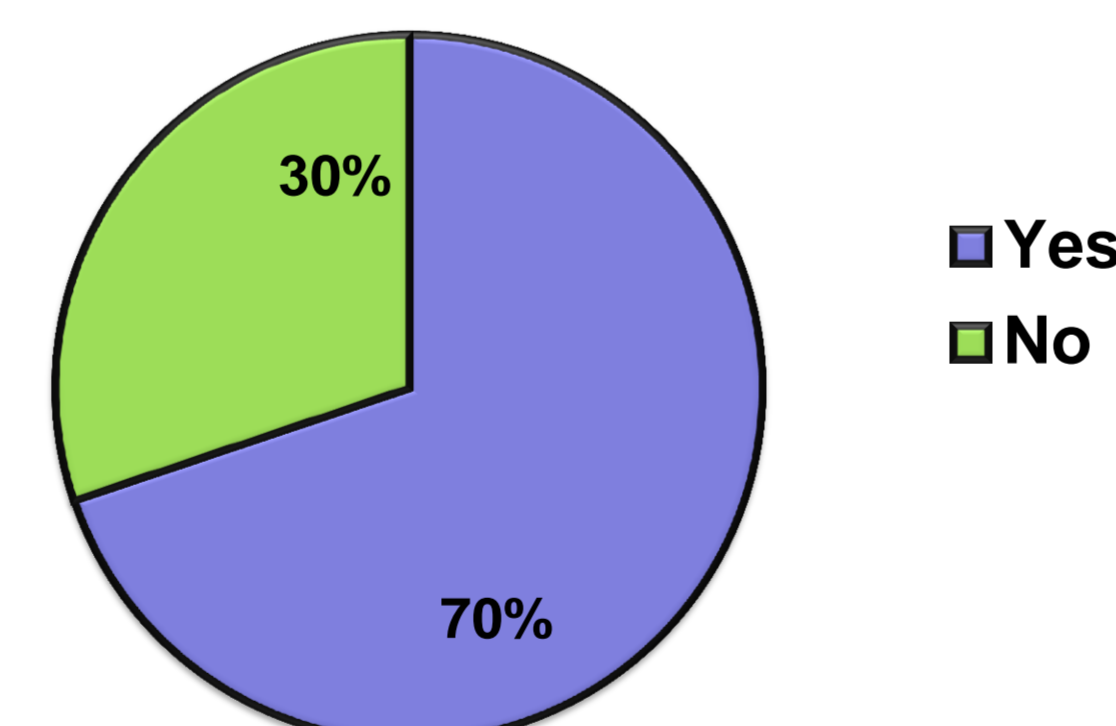
Does the Respondent Report any Mental Health Issues?



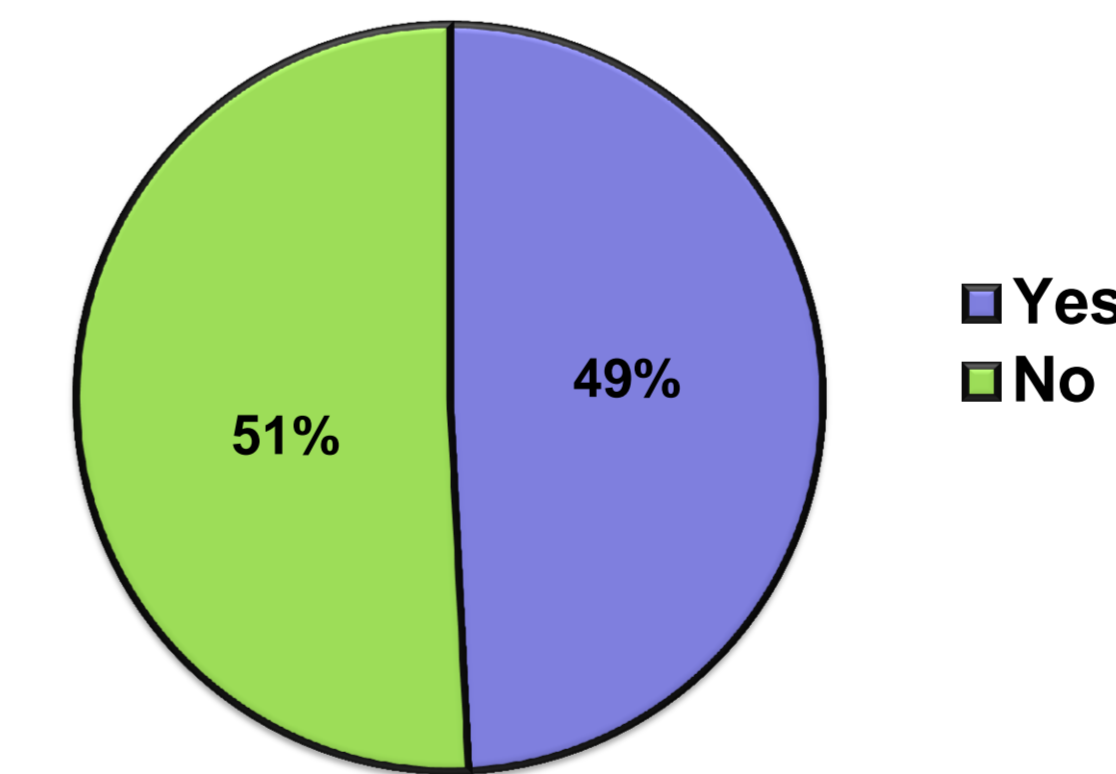
Does the Respondent Report any Physical Health Issues?



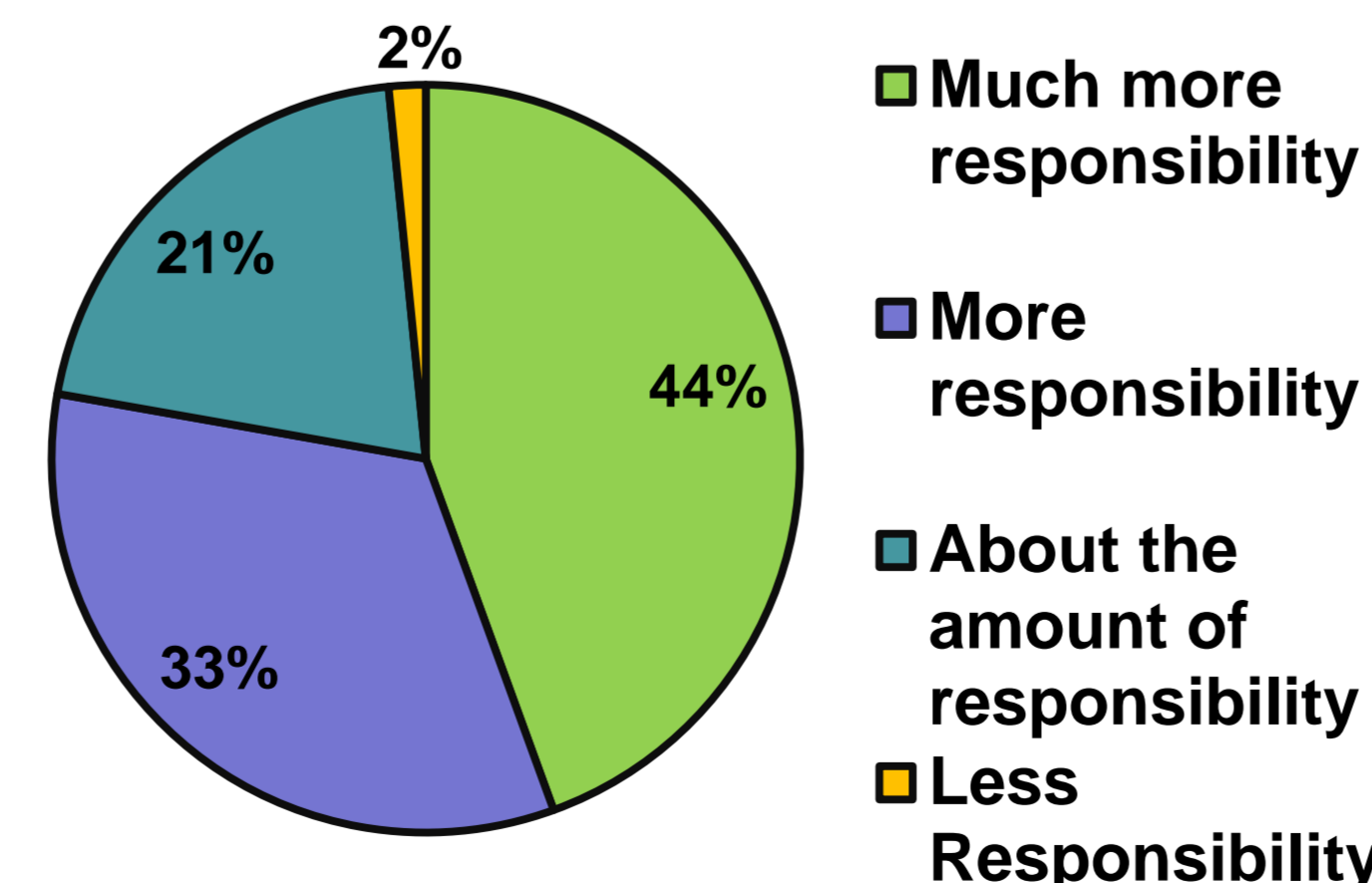
Is the Respondent the Most Involved In Day-to-Day Life?



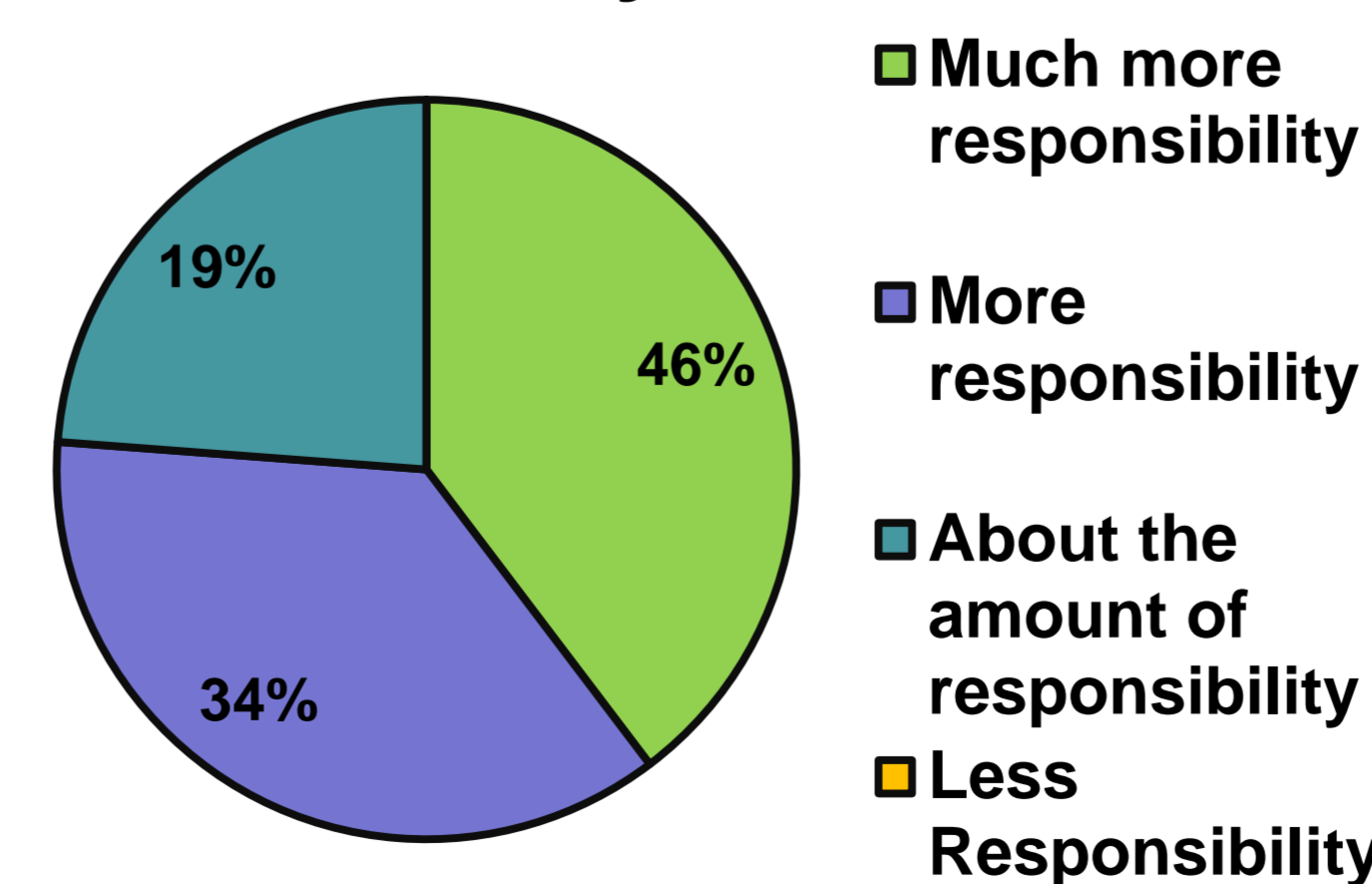
Has the Respondent Given Up Career/Education?



Level of Responsibility for Member with DD



Level of Responsibility for Family



Results (continued)

Correlations of Respondent Factors vs. Overall FQOL

Respondent Factor	Overall FQOL (r)
Mental Health	-.28*
Physical Health	-.17
Involvement in day-to-day life	-.23
Perceived level of responsibility (family)	.10
Perceived level of responsibility (DD)	.14
Giving up career or education	-.38**

*p < .05, ** p < .01

Respondent Factors as Predictors of Overall FQOL Score

Step and Predictors	B	SE B	β
1. Constant	8.32	.59	
Career and Education	-1.22	.38	-.38**

*p < .01 Note: ΔR² = .13 (p < .01), F (1, 61) = 10.54 (p < .01)

- A stepwise regression resulted in only one of the six entered variables being a predictor of overall FQOL.

Discussion

- Large portion of sample reports:
 - To be the most involved in day-to-day life
 - Have more or much more Responsibility than they would like for both family and taking care of member with DD
 - Have given up their career or education.
- Whether or not **career/education** were given up predicts a large portion of the variance of overall FQOL
 - Individuals who gave up their career or education report lower overall FQOL
- Career/education → influence because of financial implications or other factors (e.g., social life at work/school, "escape" from home, fulfillment of personal goals)
- Still not clear whether or not FQOLS-2006 is capturing a picture of the individual rather than the entire family but current results provide some support for the latter

Limitations & Future Research

- Small sample size
- Limited selection of respondent-focused responses in FQOLS-2006
- Question format could lead to omission of information (e.g., mental and physical health)
- Some crude coding of qualitative variables.
- Future studies should construct questionnaires specific to exploring respondent factors to examine with a larger sample
- Assess other individual characteristics of both parents vs. overall FQOL

Acknowledgments

•The authors would like to thank all the families who as agreed to be interviewed. The authors would also like to thank the interviewers: Carly McMorris, Vicki Lopes, Kimberly Hurd, Chloe Matheson, and Nidhi Luthra. Finally, thank you to those who helped enter and clean up the data: Jordan Cleland, Azin Taheri, Rebecca Shine, Victoria Ting, Tiffany Guanlao, and Naveen Hassan.

•Data for this study were collected as part of the CIHR Team: GO4KIDDS: Great Outcomes for Kids Impacted by Severe Developmental Disabilities, Nominated Principal Investigator: Adrienne Perry, York University. (www.go4kidds.ca)