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Background

- Both children with developmental disabilities (DD) and their parents face challenges that may result in reduced quality of life
 - E.g., parents of children with DD have difficulty identifying friends for their children (Guralnick et al., 2006) although they believe friendships positively contribute to quality of life (Overton and Rausch, 2002)
 - Parents also report difficulty maintaining their own social relationships due to the increased time associated with caring for a child with DD (Heltzer, Cunningham, Sabo, VanLeit, and Crowe, 2002)
- Outcomes are not homogeneous and it is possible that factors such as the child's specific diagnosis (Sigman & Ruskin, 1999) and social skills may be predictive of the subjective well-being and quality of life of the child their parent

Purpose

The goal of the present study was to determine what factors are predictive of quality of life in children with severe DD and their parents

Potential predictors of quality of life included:

- Specific diagnosis (DD, ASD, or both)
- Social Skills:
 - Language ability
 - Parent ratings on the extent to which the child understands spoken language and uses it to communicate
 - Social Interaction
 - Parent ratings on extent to which child engages in social interactions with other people

Method

This study is part of a larger project looking at the experiences of children with severe DD in Canada
Parents of 454 children with severe DD (age M=11.18, 70% male) completed surveys on the general health, well-being and social inclusion of both themselves and their children

Parent quality of life was inferred through self-report ratings on the following item:

- "Overall, how satisfied are you with your life?"

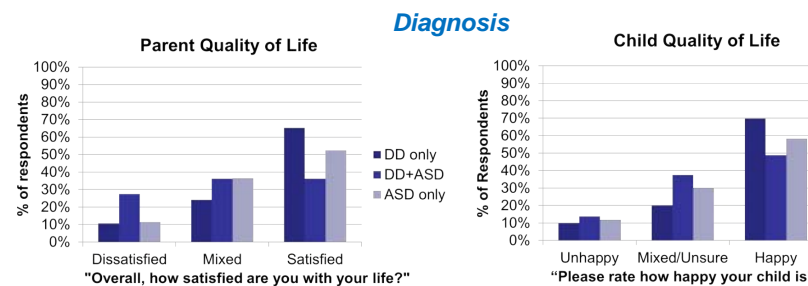
Quality of life in children was inferred through parent ratings on:

- "Compared to other children you know, please rate how happy your child is"
- "Do you think your child is achieving as much as he/she has the potential to?"

Results

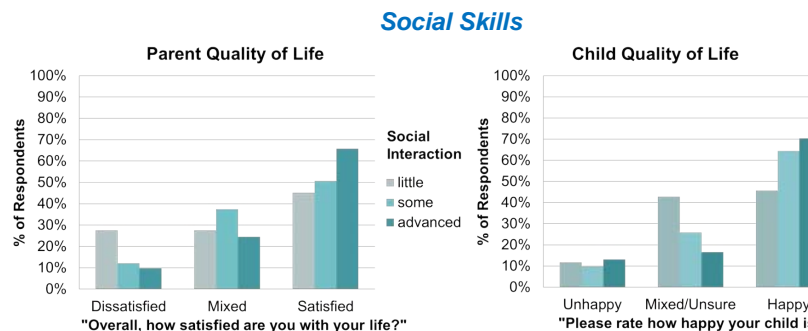
Overall:

- 54% of parents in our sample indicated that they were satisfied with their lives, 31% had mixed feelings and 15% were dissatisfied
- 62% of children in our sample were rated as happy, 27% received a rating of "mixed/unsure", and 11% were rated as unhappy
- 29% of children were rated as achieving their potential, 29% received a rating of "mixed/unsure", and 42% were rated as not achieving their potential



Parent ratings of satisfaction with life were significantly related to their child's diagnosis ($\chi^2=25.98, p<.001$). Parents of children with both ASD and DD were more likely to endorse ratings of dissatisfaction.

Parent ratings of their child's happiness were significantly related to their child's diagnosis ($\chi^2=16.12, p=.041$). Parent ratings of the extent to which their child was achieving his/her potential were not significantly related to diagnosis.



Parent ratings of satisfaction with life were significantly related to the extent to which their child interacted with others ($\chi^2=24.24, p<.001$). Parent satisfaction ratings were also related to their child's language abilities ($\chi^2=18.60, p=.017$).

Parent ratings of their child's happiness were significantly related to the extent to which their child interacted with others ($\chi^2=22.52, p<.001$) but not to the child's language abilities. Parent ratings of the extent to which their child was achieving his/her potential were significantly related to both the child's level of social interaction ($\chi^2=23.23, p=.003$) and their language abilities ($\chi^2=15.53, p=.05$).

Discussion

- Although children with severe DD and their families face increased challenges to social well-being and quality of life, results are variable
- Variable outcomes highlight need to look at resilience factors and individual differences that may promote positive outcomes (Gardiner & Larocci, 2012)
- Also highlight need for services and interventions to support subgroups with poorer outcomes
- Our findings suggest families of children with a combined DD and ASD diagnosis may require additional support to reach the same outcomes as peers
- Our results also point to importance of social interaction interventions for children with severe DD
 - The importance of social interaction has been echoed in previous findings from the GO4KIDDs project
- Overall, information presented here can be used to guide family interventions and inform provision of services for families of children with severe DD

Limitations

- Measures used were brief items included in larger survey, no psychometrics are available for these items
- No standardized measure for quality of life
 - Not clear extent to which ratings of satisfaction with life, happiness and achieving potential approximate true "quality of life"
- Use of self-report for parent ratings and "other" ratings for children
 - Parent ratings of child's happiness may not be accurate reflection of child's feelings

Acknowledgments

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