# POSITIVE AND NEGATIVE OUTCOMES OF PARENTING A CHILD WITH DEVELOPMENTAL DISABILITIES

go4kidds — Great Outcomes for Kids Impacted by Severe Developmental Disabilities

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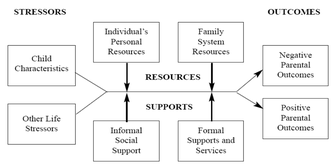
## Background

- Historically there has been a tendency for research to focus on "negative" impacts or outcomes for parents raising a child with a developmental disability (DD) such as stress, depression, divorce, etc.
- More recently, it has been recognized that parents may experience "positive" outcomes as well (such as increased sense of purpose in life, greater compassion)
- Negative and positive not opposite or mutually exclusive, although precise conceptualization of positive outcomes not clear or consistent in literature
- Research tends to show child characteristics, especially maladaptive behaviour, to influence negative outcomes, but unclear how related to positive
- Few studies examine both positive and negative outcomes simultaneously in terms of their relationship with child characteristics and other psychosocial predictors
- Few studies in Canadian samples
- Few studies in samples with severe DD

**Theoretical Model**




- Perry (2004) proposed a "dual outcome" model with domains of factors that may be important as predictors, mediators, or moderators of both parent outcomes in 6 domains (see above)

## Purpose

- The GO4KIDDS initiative included two surveys about the health, well-being, and social inclusion of children with severe DDs in Canada, and the experience of their parents:
  - ***Basic Survey*** – very brief measures of principal constructs
  - ***Extended Survey*** -- longer, more in depth, covering all domains of Perry (2004) model
- In the current study, we explore the correlates and predictors of positive and negative parent impacts using the large, nationwide sample from the Basic Survey

Hypotheses:
1. Positive and negative outcomes are independent
2. Child Characteristics related to negative outcomes; not to positive outcomes
3. Resources & Supports related to both, in opposite directions

## Participants N=444

- parents/caregivers from all across Canada:
  - 90% mothers
  - age 24-65 (M=42)
  - 75% married

- children/adolescents with severe DDs
  - 70% M
  - age 3-21 (M=11)
  - diagnosis (parent report): ID 45%, ASD 55%

## Measures

**Stressors**
- Child age
- Diagnosis(ASD or not)
- Adaptive skills (GO4KIDDS submitted; 8 items; α =.87)
- Maladaptive behaviour & mental health issues (4 items; α=.64)

**Resources**
- SES - Neighborhood income (from postal code)
- Marital status
- Parent's mental health problems (Kesler-6; 6 items; α=.90)

**Supports**
- GO4KIDDS constructed measure of social participation of the family, (6 items; α=.79).

**Negative Outcome**
- Caregiver Burden Scale (Lawton et al. 1989; 9 items $\alpha$=.92)

**Positive Outcome**
- Positive Gain Scale (Pit-ten-Cate, 2004; 7 items, $\alpha$=.85)

**Table 1. Correlations of Predictors and Outcomes**

Strong / Moderate / Weak * $p$<.01

| | Caregiver Burden *r* | Positive Gain *r* |
|---|---|---|
| Stressors | | |
| Adaptive Behaviour | -.28* | .07 |
| Maladaptive Behaviour | .40* | -.19* |
| Age | .07 | -.15* |
| Diagnosis of ASD | .18* | .07 |
| Resources & Supports | | |
| Neighbourhood Income | .04 | .04 |
| Mental health problems | .59* | -.27* |
| Social participation | .47* | -.22* |

**Predictors of Positive Gain (Table 3 below)**
- Child Characteristics account for only 6% of variance (younger → more positive outcomes)
- Resources & Supports account for only an additional 6% (lower mental health problems, greater social participation → more positive outcomes)
- Total variance accounted for = 12% (modest)

**Table 3. Regression to predict Positive Gain**

| Step | | Specific predictors | β | p |
|---|---|---|---|---|
| Stressors | $R^2$ =.06 | Child age | -.16 | .003 |
| Resources & Supports | $\Delta R^2$ =.06 | Mental health problems<br>Social participation | -.19<br>-.16 | .001<br>.04 |
| Total | $R^2$ =.12 | $F$ (8,343)=5.90, $p$<.001 | | |

## Results

**Correlations (Table 1)**
- The two outcomes had a weak inverse relationship ($r$ = -.26)

**Stressors** (child characteristics) :
- Tended to be more strongly related to Burden than to Positive Gain, except for child's age

**Resources and Supports:**
- SES unrelated to both outcomes
- Other two variables related in opposite direction (sensible) but stronger relationship to Burden

**Table 2. Regression to predict Caregiver Burden**

| Step | | Specific predictors | β | p |
|---|---|---|---|---|
| Stressors | $R^2$ =.23 | Child age<br>Adaptive<br>Maladaptive | .12<br>-.26<br>.36 | .015<br><.001<br><.001 |
| Resources & Supports | $\Delta R^2$ =.25 | Mental health problems<br>Social participation | . 43<br>-.25 | <.001<br><.001 |
| Total | $R^2$ =.49 | $F$ (8,343)=40.44, $p$<.001 | | |

**Predictors of Caregiver Burden (Table 2 above)**
- Child Characteristics accounted for 23% of variance (older, lower adaptive skills, higher maladaptive behaviour → more negative outcomes)
- Addition of Resources & Supports accounted for an additional 25% of variance (more mental health problems, lower social participation → more negative outcomes)
- Total variance accounted for = 49% (substantial)

## Discussion

- Hypothesis 1. Positive and negative outcomes independent? We found weak negative correlation ($r$= -.26) but still suggests examining two outcomes separately

- Hypothesis 2. Child Characteristics more related to negative than positive? was generally supported:
  - in Regressions, child factors accounted for one quarter of the total variance vs only 6% for positive outcomes
  - child's age was the only child characteristic that was significantly related to both outcomes in regressions: parents of older children report greater Burden and lower Positive Gain – this has important clinical implications
  - although diagnosis of ASD (vs ID) was associated with greater burden in the zero-order correlations, it dropped out in the regressions, presumably because of common variance subsumed by maladaptive behaviour – so parents of children with ASD do not necessarily have different outcomes based on the diagnosis of ASD per se

- Hypothesis 3. Resources and Supports important for both outcomes? was supported:
  - both variables included (parent mental health problems and family social participation) were significant predictors (in opposite directions) of both outcomes

- In general, we can better account for negative outcomes vs. positive ones → future research challenge to understand positive outcomes better

Strengths: sample large and diverse, Canadian, severe DD

Limitations: sample is mostly mothers, volunteers, representative?, very brief measures, all self-report
- Several important constructs not measured (e.g., other life stress, family functioning, formal support)
- Directionality of these findings is uncertain (e.g., do mental health problems lead to or result from high Caregiver Burden?)

Next steps:
1)Qualitative examination of responses to open ended questions (Luthra et al., RSIG poster)
2)Replication with Extended Survey data – smaller sample but different outcome measures and more measures of other constructs in Perry (2004) model

**Acknowledgments:** Thank you to all the parents who participated. 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