**Symposium Title:** Siblings Of People with Intellectual Disability (ID): Behavioral, Well-Being and Family Interrelationship Outcomes across Life Stages

**Chair:** Lauren V. Usher

**Co-Chair:** Nikita Hayden

**Discussant:** Kristin Long

**Overview:** Informed by family systems perspective, members of families are often assumed to influence and affect one another in multiple ways (Kovshoff et al., 2017). The sibling relationship is the longest lasting relationship throughout the lifespan (Myers & Bryant, 2008). Siblings of youth with intellectual disability (ID) can serve a caregiver role and provide support to both parents and their brother or sister with ID (McHale et al., 2012). In this symposium, we present three papers examining effects that individuals with ID have on their siblings, as well as effects that siblings of people with ID have on their mothers. The first paper uses a population-based sample to examine behavioral and emotional well-being outcomes for siblings who have a brother or sister with ID. The second paper uses longitudinal data to investigate the trajectory of impact that siblings with and without ID have on their brothers and sisters from childhood through adolescence. The third paper examines the role that siblings without a disability have on maternal mental and physical health in the context of families of an adolescent or adult with fragile X syndrome, the most common inherited cause of ID. Cumulatively, the presentations in this symposium highlight the complexities of how factors relating to the individual with ID, such as behavior problems, and familial factors, such as socioeconomic status, impact sibling and family functioning in the context of ID.

**References/Citations:**


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**Paper 1 of 3**

**Paper Title:** The Psychological Well-Being of Children Who Have a Brother or Sister with Intellectual Disability: A Secondary Analysis of the Millennium Cohort Study

**Authors:** Nikita Hayden, Richard Hastings, Vasiliki Totsika and Emma Langley

**Introduction:** Although existing literature in this area is somewhat inconsistent, cognisant of family systems theory, having a brother or sister with intellectual disability (ID) is often considered a risk factor for poor sibling outcomes. The inconsistent nature of existing results is likely due to methodological and sampling issues. There are very few representative samples in the existing literature, and none are UK-based population studies. The benefit of studies such as these is they are less affected by referral biases and may allow conclusions about the whole population of siblings or the whole population of siblings of children with ID. Existing studies using population data to explore sibling outcomes have defined disability in rather broader ways (Emerson & Giallo 2014; Goudie et al., 2013; Neely-Barnes & Graff 2011), whereas the present study focused on the outcomes of children more specifically who have a brother or sister with ID.

**Methods:** The present research is a secondary analysis of data from the third wave of the Millennium Cohort Study (MCS), an ongoing UK-based longitudinal birth cohort study. Weights were applied in the analysis so the data is representative of the general population. We explored group differences between the nearest-in-age older siblings (aged five to 15) of those MCS cohort member children identified as having (n of siblings = 257) or not having (n of siblings = 7,246) ID. Behavioral and emotional well-being was measured using the Strengths and Difficulties Questionnaire (SDQ).

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Results: Chi-square tests indicated that the ID sibling group were more likely to have elevated scores than the non-ID sibling group for SDQ total behavior problems ($\chi^2 = 6.045, p = .031$), peer problems ($\chi^2 = 16.569, p < .001$) and conduct problems ($\chi^2 = 9.855, p = .004$). No statistically significant group differences were found for hyperactivity ($\chi^2 = 1.738, p = .171$), prosocial behavior ($\chi^2 = 1.365, p = .269$) and emotional problems ($\chi^2 = .769, p = .500$). Logistic regression models were then used to examine elevated SDQ problems once additional potential risk factors, such as socio-economic position, were controlled. No sibling group differences remained except that ID siblings were slightly less likely to be identified as hyperactive ($\beta = -1.208, p = .027$). Overall, older sibling well-being was predicted mainly by socio-economic factors, sex of the older sibling and whether their brother or sister with ID had an elevated SDQ total behavior problems score themselves. These three variables were statistically significant in all six logistic regression tests. Both primary caregiver mental health and being from a single parent household were also found to be statistically significant in most models.

Discussion: Data suggest group differences in ID and non-ID siblings are not simply a direct result of having a brother or sister with ID. However, the data still indicate ID siblings remain a risk group due to indirect effects. Descriptive statistics indicated older siblings of a child with ID were also more likely to be from a low socio-economic position household ($\chi^2 = 192.970, p < .001$), a single parent household ($\chi^2 = 83.325, p = .001$), and for their primary parent/carer to have potential emotional disorder ($\chi^2 = 66.545, p < .001$). These variables are often considered risk factors for poorer well-being for children in general. In the present study, we found that these factors were statistically significantly contributing to older siblings’ scores on the SDQ. Therefore, the data suggest that any (small) group differences between ID and non-ID siblings are likely related to an array of complex, interacting factors and experiences affecting families, rather than simply as a direct result of having a brother or sister with ID. The explaining power of the logistic regression models remained rather low, indicating other factors, not controlled in this study, were also affecting group differences. In the logistic regression models, though not in the chi-square analysis, children with a brother and sister with ID were less likely to be identified as hyperactive compared to those children whose brother or sister did not have ID. This result may be due to the perceptions of the parent/carer respondents rather than a robust sibling group difference.

References/Citations:

Paper Title: Mother Reports of Typically Developing Siblings across 10 Years: Impact of ID and Child Behavior Problems

Authors: Yasamine Bolourian 4, Jan Blacher and Bruce Baker 5

Introduction: Siblings of youth with intellectual disability (ID) often bear the responsibility of caregiver and provide support to both parents and the sibling with ID (Krauss et al., 1996). Despite this important role within families, relatively few longitudinal studies have examined how having a child with a diagnosis of ID can affect typically developing (TD) siblings as they age. Previously, in a sample of children (ages 5-8) with ID, we reported challenging behaviors as a significant predictor of sibling impact (Neece et al., 2010), suggesting that behaviors affect TD siblings more so than disability status during childhood. The present study aims to extend these results to examine youth from childhood to mid-adolescence. Our research questions were: (1) What is the trajectory of sibling impact, as reported longitudinally by mothers over a 10-year period? and (2) Do behavior problems mediate the relationship between ID status and sibling impact through mid-adolescence?

Methods: Participants were parents of youth with ID ($n = 78$) or TD ($n = 120$) who were drawn from a larger study assessing children ages 5 to 15 years. At seven time points, parents completed the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993), which provides a Sibling Negative Impact subscale, and the Child Behavior Checklist (CBCL; Achenbach, 2000; Achenbach & Resorla, 2001), to measure behavioral functioning. Maternal health, which was collected through an interview, significantly

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negatively correlated with both ID status and negative sibling impact, and thus was entered into analyses as a covariate. Longitudinal growth curves were modeled to determine initial levels and changes in sibling impact by ID status. We then utilized hierarchical regression to examine how behavior problems related to ID status and sibling impact.

**Results:** A linear growth model fit the data, which revealed that the ID group had a higher initial level of sibling impact \(B_0 = 5.99, p < .001\) compared to the TD group \(B_0 = 4.26, p < .001\). While negative sibling impact appeared to significantly decrease across time for the TD group \(B_1 = -.09, p = .01\), the change rate for the ID group remained stable \(B_1 = -.01, ns\). In the regression analysis, sibling impact at age 5 and maternal health were controlled for. These did not enter significantly. Results revealed that ID status no longer accounted for significant variance in sibling impact once behavior problems were accounted for, \(b = .31, t(85) = 2.51, p < .05\). The final model with behavior problems as a significant predictor explained 42% of the variance, \(F(1, 85) = 6.27, p < .05\).

**Discussion:** Main findings were that maternal perceptions of negative sibling impact decreased over time for the TD group. For the ID group, they were initially significantly higher, and did not decrease over time. While the change in impact for TD groups may be developmentally appropriate, the difference in families of youth with ID speaks to non-normative changes across critical developmental periods (early childhood, middle childhood, adolescence). Further, results revealed that behavior problems fully mediated the relationship between ID status and sibling impact through mid-adolescence. This raises a red flag when young children have early behavioral issues, as their impact can often persist across a decade and, as the present results show, can continue to have an adverse impact on siblings.

**References/Citations:**
questions about developmental, mental, and medical diagnoses of all living biological siblings of the individuals with FXS. Adolescents and adults with FXS were mostly males (85.8%) and were in their twenties on average ($M = 24.60$, $SD = 6.96$, ranged in age from 15 to 45 years of age). Most adolescents and adults with FXS lived with their mothers (86.2%), and had between zero and four siblings who were unaffected by any developmental, mental health, medical problems or diagnoses. Unaffected siblings were mostly males (69.5%) and were in their twenties on average ($M = 26.96$, $SD = 9.41$, ranged in age from 9 to 50 years of age).

**Results:** Multiple regression analyses were conducted to examine the proportion of unaffected siblings in the family as a moderator of the association between behavior problems and functional limitations of the adolescent or adult with FXS and maternal physical and mental health. A larger proportion of unaffected siblings was associated with fewer maternal depressive symptoms, $\beta = -0.23$, $p = .022$. The proportion of unaffected siblings significantly moderated both the association between behavior problems and maternal overall health, $\beta = 0.22$, $p = .034$, and the association between functional limitations and maternal overall health, $\beta = -0.22$, $p = .040$. When mothers had a low proportion of unaffected siblings, higher levels of behavior problems and functional limitations of the adolescent or adult with FXS were significantly associated with lower maternal overall health. However, when mothers had a high proportion of unaffected siblings, behavior problems and functional limitations were unrelated to maternal overall health. Maternal CGG repeat length had a significant curvilinear association with overall health rating, $\beta = 0.27$, $p = .047$, indicating that mothers with mid-range repeat lengths reported the lowest levels of overall health, while mothers with low and high repeat lengths reported higher levels of overall health.

**Discussion:** Findings indicate that social support may operate in different ways for different constructs: There were main effects of the proportion of unaffected siblings in the family on maternal depressive symptoms, providing evidence for a direct effects model of social support. However, there was also evidence for a buffering model of social support, with the proportion of unaffected siblings interacting with family stressors of behavior problems and functional limitations and their association with maternal self-rated overall health. Consistent with previous research, mothers with varying levels of genetic liability may have variable risk for health problems.

**References/Citations:**