

Development of Siblings of Children with Intellectual Disability

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Introduction

Research on the development of siblings of individuals with disabilities has evolved over the past 35 years from simple description into complex methodological designs (Boyce & Barnett, 1993; Hastings, 2007; Shivers, 2013; Stoneman, 1998). This is due to the growth of sibling research and the growth of developmental science in general. In particular, research methodology has become more rigorous and specific. Furthermore, the field has adjusted to a broader set of theoretical frameworks for research with people with disabilities (Boyce & Barnett, 1993; Dykens, 2005; Findler & Vardi, 2009; Rossiter & Sharpe, 2001; Shivers, 2013). The developmental model has changed disability research by emphasizing reciprocal relationships, thus providing more theoretical support for understanding family dynamics as well as etiological factors (Stoneman, 1998). Other research has integrated the environmental perspective into a more traditional psychopathological perspective (Summers, White, & Summers, 1994). Additionally, recent research in studying people with disabilities has followed positive psychology models (Dykens, 2005; Findler & Vardi, 2009; Giallo & Gavidia-Payne, 2006).

Early Research

The study of siblings of people with disabilities began with simple interviews and qualitative studies. These studies were more sociological in nature, overlapped with study of other familial issues, such as poverty, and

investigated large families (Boyce & Barnett, 1993). Even so, early calls were present for a different developmental model specific to the study of families with a disabled member (Blacher, Neece, & Paczkowski, 2005; Stoneman, 1998). It is significant to note that only 20 years prior to such early family studies by Farber in 1968, scientists like Henry H. Goddard were characterizing entire families as not only feeble minded, but also morally deficient (Scheerenberger, 1983). With this in mind, it is reasonable to note the strides taken in our understanding of the acceptability of having a family member with a disability. These developments have contributed to the scope of the research over the past decade (Boyce & Barnett, 1993; Dykens, 2005; Hannah & Midlarsky, 1999; Stoneman, 1998). Researchers previously looked for pathology in the family dynamic, but some have suggested this effort was misguided (Stoneman, 1998). Furthermore, intellectual disability is a category with significant breadth, and the idea of a theory of development for sibling effects within this diverse system has also been seen as a questionable project (Dykens, 2005; Stoneman, 1998).

The first significant and empirical research on the adjustment of siblings of people with disabilities was firmly rooted with an expectation of a negative effect on the sibling (Blacher et al., 2005; Boyce & Barnett, 1993; Dykens, 2005; Stoneman, 1998; Summers et al., 1994). The theory was that a child with an intellectual disability put stress on a family system, thus causing siblings to be at-risk. Boyce and Barnett wrote an early review of the

research on siblings of people with disabilities (1993). Due to the primarily psychopathological model used in most of these studies, five major categories were identified in their research. These were psychological distress, self-concept, activities/time uses, sibling interactional relationships, and stress and coping (Boyce & Barnett, 1993). Based on the studies reviewed, the research showed a puzzling combination of risks and outcomes. In some areas, the research supported that siblings of people with ID had higher risk for depression and anxiety. In other situations, there was no difference, such as activities/time uses. The idea that extra caregiving was burdensome on siblings was not supported by many of these studies. The more methodologically rigorous studies showed siblings of people with mental disability experience some disturbance, but it was deemed unclear if this was causally related to the person with a disability or the family process based variables (Boyce & Barnett, 1993). At the time of the review, the question remained whether the typical sibling development was influenced by their mentally sibling, or by parental factors associated with having an mentally disabled child. Other studies reviewed showed that behavior problems developed among siblings of people with disabilities (Boyce & Barnett, 1993).

Boyce and Barnett's work stands alongside a influential review by Summers, White, and Summers which pushed towards more rigorous research on siblings of children with ID (1994). Summers et al. reviewed many of the same research with the focus on psychological well being and

noted the methodological shortcomings of prior research (1994). The research suggested negative effects of having a sibling with ID, however, oftentimes no comparison groups were used or many disabilities were lumped together as ID (Summers et al., 1994). Many validity issues were subsequently identified in this review and strong call for a better theoretical framework was made. Their results suggested that siblings of children with disabilities have greater risk for poor psychological development. These negative outcomes include increased anxiety, withdrawal, aggression, and dominance. By contrast, the results also suggested that siblings develop more pro-social behaviors as well (Summers et al., 1994).

Recent Research

The majority of the research in regard to the development of siblings of children with disabilities since the two reviews mentioned here has remained equivocal. Some important developments are notable, however. The literature has taken advantage of multi-level modeling to better understand the predictors of negative outcomes. In addition, the use of a positive psychology approach has reframed the expectation of a negative outcome. By contrast, researchers are looking to siblings of children with ID as examples of personal growth.

In 2001, Rossiter and Sharpe completed a quantitative meta-analysis of the literature regarding sibling of child with ID development. They note the lack of certainty presented by prior research in firmly establishing either

the existence of negative outcomes or the reasons for them. In particular, they note that some studies could point to subject-related variance as explanatory, while other research was not (Rossiter & Sharpe, 2001). Twenty-five studies were included in their analysis, which were coded as high quality. A majority of these studies matched on gender, had equal numbers for comparison, and employed standardized dependent measures (Rossiter & Sharpe, 2001). The results of this study showed a statistically significant negative effect for having a sibling with ID on the development of a typical sibling. In addition, they found that direct observation studies produced the largest effect sizes. Many other studies used parental report, but this does not take into account the possible bias of parent reports on their children. It is reasonable to assume that parents may under-report negative issues with their other child. Furthermore, a parent is making an observation based on their concept of normal behaviors that may be changed due to having a child with a disability (Rossiter & Sharpe, 2001). Regardless, this review found depression and anxiety as problematic for siblings of children with ID. To further complicate the results, however, Rossiter and Sharpe point out that it is difficult to make a strong inference about the disability itself causing the difficulties. They note that parental interactions and differential treatment may be more associated with the negative outcomes than the ID child themselves (Rossiter & Sharpe, 2001, p. 79). Using meta-analysis, their

results suggested further the need for better research before reliable models of outcomes could be established.

Hannah and Midlarsky conducted research regarding siblings of people with disabilities as well(1999). Using measures of internalizing and externalizing disorders, they studied 52 boys and 48 girls who had siblings with intellectual disabilities. They found no differences from the control group in overall competence. Interestingly, they found that boys with siblings with ID had lower school functioning and girls with siblings with ID demonstrated more internalizing problems (Hannah & Midlarsky, 1999). This study represented a significant finding in that the risk factors that were predicted by previous theory were not found when using controlled, standardized measures and multi-level modeling procedures.

Other research has suggested no significantly negative outcomes in siblings of kids with ID compared with typical siblings. In a study with matched samples, Dyson looked at the outcomes and stability of adjustment over time in siblings of children with disabilities(1999). The results suggested over a 4-year period that family psychological functioning of all participants was the most significant factor in predicting target developmental outcomes. For example, parental stress, social support, and degree of organization were more related to participant development than having a sibling with ID. These results add little to support the idea that a sibling with ID contributes to psychological risk (Dyson, 1999). One finding of this study was that children

who have siblings with disabilities had more stable self-concept, implying some positive outcomes for these siblings.

Petalas, Hastings, Nash, Lloyd, & Dowey studied longitudinal outcomes 25 matched groups of siblings of children with ID only and ID and autism(2009). The findings suggested that emotional and behavioral difficulties were more significant in siblings of children with ID and autism, compared with siblings with ID only and a normative sample. This signifies that siblings of children with ID and autism are more likely to have social behavior problems and emotional problems (Petalas et al., 2009). There was little in these findings to indicate that only the ID was associated with the increased risk. Additionally, it was not clear from this study what element of autistic behavior was a probable explainer for the outcomes found (Petalas et al., 2009). In sum, this research further adds to the specificity with which our understanding of the effect of the presence of ID on a sibling in contrast with other predictors, such as behaviors or poor social skills.

These studies illustrate the significant etiological changes that have affected the study of people with ID, as diagnostic measures have become better at teasing apart children with autism from the ID population (Stoneman, 1998). Perhaps many of the children in the studies of prior decades would be more accurately diagnosed as having autism instead of simply being “mentally retarded”(the term in use at the time). The etiological significance of separating out the reason for the ID is important to recognize.

Furthermore, an organic intellectual disability has circumstances that distinguish it from disability caused by environmental issues (Stoneman, 1998). There is a dearth of research that effectively articulates these etiological issues, as children with mental disabilities are often lumped together for the sake of convenience.

Even so, more research has investigated the effects on siblings of people with ID using fewer assumptions of psychopathology. This has led to a theoretical framework that highlights opportunities for growth and investigations of other family factors as predictors (Findler & Vardi, 2009; Giallo & Gavidia-Payne, 2006). In a study from 2006, Giallo and Gavidia-Payne investigated whether family factors contribute above the presence of a sibling with a disability. They also looked and if any issues of adjustment were mediated by socio-demographic status, presence of a sibling with disability, or parental traits (Giallo & Gavidia-Payne, 2006). The results indicated that siblings of people with disabilities had more negative adjustment problems, emotional problems, peer issues, and were lower on pro-social measures. In addition, families that had fewer resources were more at risk for adjustment issues. This study did not find a connection between sibling daily stress, but did find parent stress to be a strong predictor of negative outcomes. This adds to the evidence that the whole family dynamic (and less so the existence of a disability) is a significant factor in understanding adjustment of siblings (Giallo & Gavidia-Payne, 2006). In

addition, family routines and communication were found to predict more positive outcomes. This finding may support the presence of an ID sibling being either a risk or a resilience factor depending on the circumstance. Many children with ID have strong family routines in place, however, their care needs may be unpredictable at times. This study is limited in its utility due to the fact that it did not determine the disability category of the participants. Therefore, there is little to be inferred about the influence of intellectual disability on sibling development, since it is unclear the levels and types of disability that were present (Giallo & Gavidia-Payne, 2006).

By contrast a study looking at 2 years of longitudinal data found no evidence that siblings of children with ID are at risk for adjustment problems. Hastings studied 75 siblings of children with ID and autism. Standardized measures were used and demographic measures were controlled for (Hastings, 2007). This research found not only that there were no differences from the control group, but also that siblings of children with Downs syndrome were better adjusted than the normative group. Furthermore, the results supported a relationship between the existence of behavior problems and negative adjustment in the typically developing sibling. This suggests that when there are behavior issues at home, both siblings are struggling and that the typical sibling is affected. This relationship appears to be bi-directional and linked by time, instead of disability status (Hastings, 2007). It is possible, however, that due to the

nature of the self-report measures used in this research, that the mothers reporting on their children over-estimated their adjustment in order to appear as better parents (Hastings, 2007).

It is reasonable to also review research about the adolescent years for siblings of children with intellectual disability. Findler and Vardi discovered patterns that suggest the positive effects on a sibling when their brother or sister is ID (2009). By characterizing their study as a study of growth, this research shifted away from models based on psychopathology. The authors looked at level of parent treatment/preference, stress, and coping resources in regard to self-differentiation. Their results are striking, as they suggest higher responsibility, more sensitivity, and more personal strength in adolescents who have siblings with a ID (Findler & Vardi, 2009).

One trend in the research is apparent with regard to the association between behaviors and sibling issues. A few studies support the assertion that negative behavior in the child with disability is the most likely explainer of sibling developmental difficulties (Blacher et al., 2005; Hastings, 2007) Shivers investigated this line of explanation further and found a more complicated picture by utilizing a multi-level modeling approach to investigate mediated moderation of the family outcome variables (2013). This study targeted which specific factors related to outcomes for siblings of people with ID and also examined the mediating relationships in these target factors utilizing a control group. The results indicated that sibling behavior and

adjustment issues were related to the presence of these issues in the child with ID (Shivers, 2013, p. 23). Moderated mediation analysis also contributed to significant findings. The data indicated that sibling anxiety was mediated by parental perceptions of cost of a child with ID. In addition, the relationship between functioning of the ID child and sibling negative outcomes was significantly mediated by parents' feelings about the disabled child (Shivers, 2013, p. 27). Overall, Shivers found few differences in the typical sibling development and development of siblings in families with a child with ID. The siblings were not more empathetic, as some have theorized. By contrast, this data showed that siblings were more likely to feel anxiety regarding their brother or sister if the sibling had ID. Other results shed light on the family dynamics at play as well. These data indicated that typical children in families with a child with ID are much more susceptible to parental attitudes for their development. Taking this into account, practitioners may better target interventions to the family system a whole instead of focusing on the sibling relationship (Shivers, 2013).

Conclusion

The research regarding the development of siblings of persons with an intellectual disability is still relatively unclear. Some trends have emerged and better methodological approaches to the family ecosystem have been applied to these questions. One important change is the shift from expectation of negative outcomes, as much research has shown that children

with disabilities may contribute to positive development in siblings. In addition, some research indicates that familial dynamics or the specific behavioral outcomes of the child with a disability are the true explainers of sibling outcomes. With regard to the practical applications of the sibling research, the research has done much to dispel the idea that a child with ID in family is a de facto risk factor for everyone in the family. Certainly, more dynamic approaches to the research are warranted and continuing development of more sophisticated empirical techniques will bolster this area of inquiry. According to the current research, siblings of individuals with disabilities appear to have developmental trajectories that are unique in some ways, but typical in others.

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