A Health Care Policy Brief Sponsored by the Ohio Developmental Disabilities Council

The Social Interaction and Behavior Effects on Siblings who Reside in a Household with a Child with Disability

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Introduction

Previous research in Ohio demonstrated that parents caring for children with disabilities experienced higher levels of stress, curtailed employment opportunities, and diminished rates of general well-being compared to parents caring for children without disabilities. There is also evidence that caring for children with disabilities impacts all members of a family. This study, using data from the Medical Expenditure Panel Survey (MEPS) compares siblings in households where no child has disability (sib-typical) with siblings of children who reside in a household with a child with disability (sib-disability) to determine if sib-disability have more problems than sib-typical with:

1) Social interaction with mom, dad, siblings, and other adults and children in general;
2) Behavior in school, home and getting in trouble in general; and
3) Feeling unhappy or sad, completing school work, and participating in sports or hobbies.

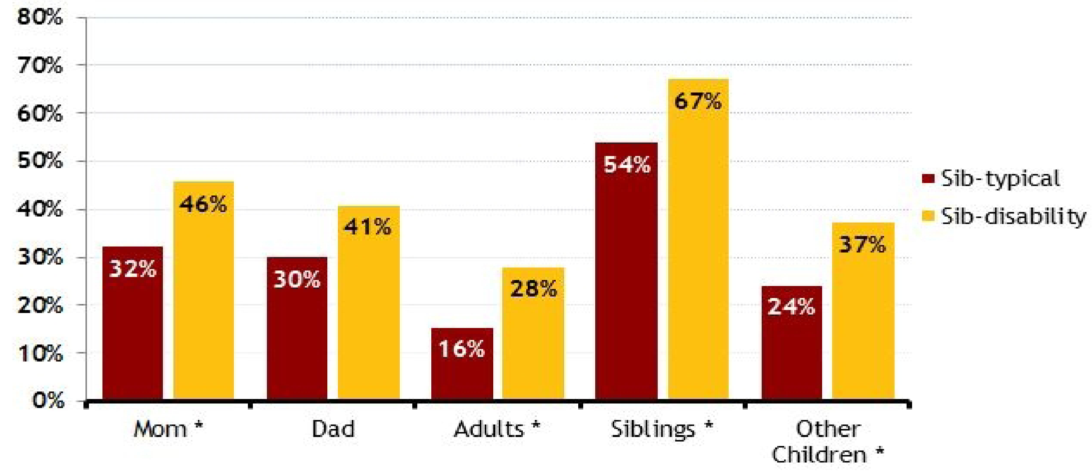
Study Design

Children were identified as having a disability if a parent responded "yes" to the question "Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?" and this limitation was due to a medical condition that has or will last for a period of at least 12 months. Children without disability from households with at least two children ranging from 5 to 17 years of age surveyed in MEPS panels 10, 11, and 12 were included in this sibling group study. Parents responded to questions about child problems with social interaction, physical behavior, emotional problems, and problems engaging in activities on a 5-point Likert scale ranging from 0 (no problem) to 4 (a very big problem). In order to ensure adequate category sizes for statistical comparison, responses were recoded into two categories: no problem and any problem.

Problems with Social Interactions

Parents indicate that roughly two out of three siblings residing in a household with a child with a disability have problems getting along with other siblings, two out of five have problems getting along with mom or data, and one out of three have problems interacting with other children. Graph 1 indicates that the sib-disability group is approximately twice as likely to have greater problems interacting with mom, dad, other adults, siblings, or other children, compared to the sib-typical group of siblings. These numbers are adjusted to take into account a sibling's age, gender, race/ethnicity, household poverty status and marital status of parents.

Graph 1, Adjusted Differences in Social Interaction Problems between Siblings Groups (Odds Ratios)

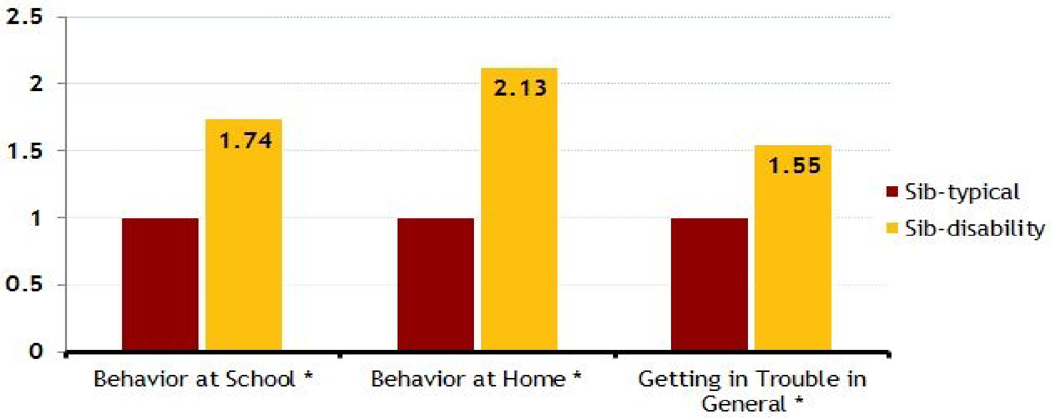


* Statistical difference across sibling household groups at α=0.05

Behavior Problems

Behavior problems were examined across the following settings: at school, home, or just a general problem getting in trouble. More than one-half of the sib-disability group has problems with behavior at home and approximately one-third has problems with behavior at school, or getting in trouble in general. After adjusting for other variables, Graph 2 indicates that the sib-disability group are at least one and a half times as likely to have behavior problems in all settings, compared to the sib-typical group.

Graph 2, Adjusted Differences in Behavior Setting Problems across Sibling Groups (Odds Ratios)

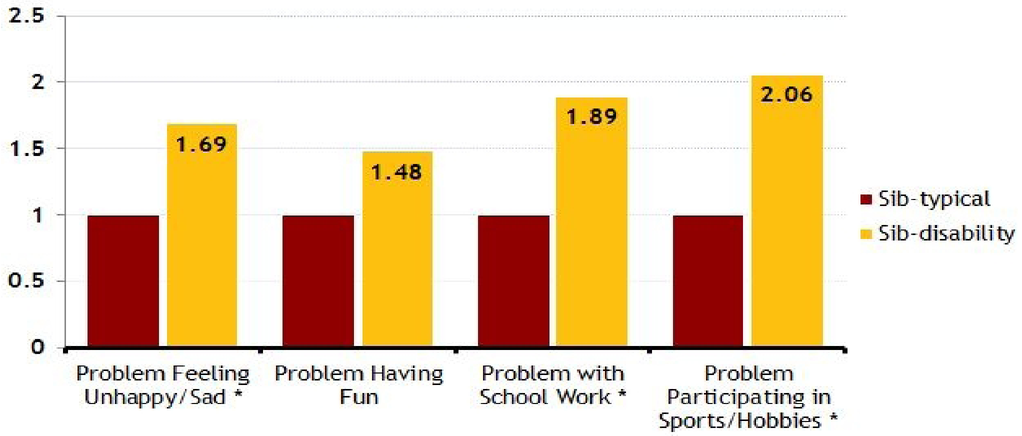


* Statistical difference across sibling household groups at α=0.05

Emotional Behavior and Activity Engagement

Parents report that 44% of children who have siblings with a disability have problems feeling unhappy or sad, 15% have problems having fun, 39% have problems completing school work, and 34% have problems participating in sports or hobbies. After adjusting for other variables, Graph 3 shows that the sib-disability group is one and a half to twice as likely to have emotional behavior and activity engagement problems, compared to the sib-typical group.

Graph 3, Adjusted Differences in Emotional Behavior and Activity Engaging Problems between Sibling Groups (Odds Ratios)



* Statistical difference across sibling household groups at α=0.05

Conclusions

The results of this study are consistent with previous findings indicating that children growing up with a sibling who has disability are 1.6 to 2.0 times as likely to develop emotional and behavioral problems compared with children with typically developing siblings. It is important to note that we have accounted for demographic and socioeconomic status in our multivariable models. This is the largest known comparative study exploring the internalizing and externalizing behavior of siblings of children with and without disability. However, potential study limitations should be mentioned. The results are based on parent reports, which have been shown to be more negative than child self-reports. Notwithstanding, and without further research, there is no reason to think that reports would differ between the two sibling groups compared in this report.

Policy Implications

Internalizing and externalizing problems manifested at an early age are correlated with continued high-risk activities and poor health outcomes. Children growing up with a sibling who has a disability need social programs and interventions to maximize their current and future well-being. The return on investment will be immediate, ranging from less disruptive classrooms and increased high school productivity to lower risk of crime and incarceration, and long lasting.

Supporting these children to develop into fully functioning well-adjusted adults may favorably dispose them to contribute to the planning for, and care of, their sibling with a disability. Most children with chronic disabilities are living well into adulthood with a higher probability of living longer than their parents, who are the primary caregivers. Having siblings who are willing and able to keep a family structure of caregiving would benefit the brother or sister with a disability and society in general.

The findings in this report support the development of policies that encompass all family members, including the child with disability, their parents or primary caregivers, and other siblings and children in the household.

Given that a disproportionate number of siblings of children with disabilities are in poor or near poor households and eligible for, public Medicaid coverage, Medicaid-eligible services should be directed to siblings and not just a child with disability. Also, flexible support coverage such as concierge and respite care would allow parents to devote more time and energy to typically-developing children who reside in a household with a child with disability.

Policies will benefit from further research that assesses the problem in the Ohio population more closely and studies the cost-benefit or cost-utility of potential interventions. Interventions to aid siblings in households with a child with disability may be cost-beneficial to Medicaid from potential mental health cost savings alone.

Formally, and based on the findings and discussion presented in this brief and the Evaluating Services that Support Families with Children with Disabilities report, we make the following policy recommendations:

1) Families, health care providers, and agencies who provide services to children with disabilities must be made aware of the significant impact on the mental health status of developing siblings residing in households with a child with disability. Caregivers and providers be sensitive to emotional or behavioral difficulties in typically-developing siblings and offer support and arrange mental health services, as appropriate;

2) Departments or agencies that provide support services to families caring for children with disability (e.g., Ohio county boards of developmental disabilities) universally establish age-appropriate support groups for siblings in households with a child with disability;

3) School counselors need to receive specialized training in how to detect problems associated with residing in a household with a child with disability and how to effectively counsel siblings of these children;

4) Family-based programs be developed and implemented to help all members of households caring for a child with disability adapt and cope; and

5) Ohio-based research needs to be funded to assess the cost-benefit of proposed intervention programs and implemented programs need to be evaluated for effectiveness.

About the Authors

Anthony Goudie, Ph.D. is an Assistant Professor in the Center for Applied Research and Evaluation at the University of Arkansas for Medical Sciences and Arkansas Children's Hospital. Formerly of the Child Policy Research Center in the Cincinnati Children's Hospital Medical Center, he has an interest in studying health outcomes and evaluating the policy and economic implications of children from vulnerable populations as they intersect the health care system and how contextual factors affect the health care they are able to obtain. His most recent research stream has focused on how caring for a child with a disability impacts the health of all members in a family. Contact Dr. Goudie at agoudie@uams.edu.

Timothy Sahr, MA, MPH, MDiv, ThM is the Director of Research and Analysis for the Ohio Colleges of Medicine Government Resource Center. His prior employment included Director of Research at the Health Policy Institute of Ohio, Head of Policy at the Franklin County, Ohio, Board of Health, and survey researcher with Gallup International/ Gallup Poll. He is also a Dr. George Gallup Foundation Fellow for Health and Humanities.

Susan Havercamp, Ph.D. received her doctorate at the Ohio State University Nisonger Center in the area of in clinical and MRDD psychology. She conducted research and provided direct clinical services to children and adults with developmental disabilities through previous positions. At the University of South Florida she focused on improving the health of persons with disabilities through educating healthcare providers and health promotion activities for children and adults with disabilities. She is currently an Associate Professor of Psychiatry and Psychology at the Ohio State University Nisonger Center where she continues her work on health and healthcare for children and adults with disabilities.

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