

*A Research Report Sponsored by a Grant from the
Ohio Developmental Disabilities Council*



The Social Interaction and Behavior Effects of Siblings Who Reside in a Household with a Child with Disability

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EXECUTIVE SUMMARY

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.

To identify the impact on siblings of children with disabilities, a research team from The Ohio State University and Cincinnati Children's Hospital Medical Center received a grant from the Ohio Developmental Disabilities Council. One of the projects supported by this grant resulted in a report on **The Social Interaction and Behavior Effects on Children Living with Siblings Who Have Disability**.

The report examines differences in social

interactions and behaviors in two groups of school-aged siblings. Siblings who reside in a household with a child with disability are compared to siblings in households where no child has a disability. The study used data from the most recent three panels of the Medical Expenditure Panel Survey (MEPS) to produce comparative results between the two groups of siblings.

This report is based on national data but there is no reason to believe that siblings in households with children with disabilities are different in Ohio. We find that compared to siblings in households with no children with disabilities, those that reside in a household with a child with disability are more likely to have social and behavior problems. Interventions to this targeted population will promote healthy family functioning and diminish the risk of compounding problems (e.g., high-risk behaviors, crime) as the child gets older.



INTRODUCTION

Compared to parents who care for typical developing children, parents who care for a child with a disability in Ohio are more likely to experience financial, economic, and emotional stress (Goudie, Havercamp, Jamieson and Sehr, 2010). During a series of recent focus group interviews Ohio parents frequently expressed concern regarding the impact of caring for a child with a disability on the overall well-being of a sibling. These parents agonized that the amount of time required to care for their child with a disability left little time or energy to devote to their other children.

The objective of the study is to provide a more complete picture of the impact on families who care for a child with a disability by understanding the impact of growing up with a sibling who has a disability. The goal is to inform Ohio policy-makers to provide cost-beneficial programs to help families care for their children with disabilities as well as typically developing siblings.

The study of the effect on siblings of living in a household with a brother or sister with a disability is not new (Barlow and Ellard, 2006). Many sibling distress studies focus on internalizing and externalizing behaviors. The psycho-social impact on siblings residing in a household with a child with disability includes increased levels of

aggression, depression, and anxiety manifesting in compromised school performance and poor social functioning (Hartling et al., 2010).

In this study we look at three overlapping domains of behavior. First, we examine sibling social interactions with family and other daily social encounters. Secondly, we focus on settings where poor behavior may be exhibited (e.g. at school or at home). Finally, we explore internalizing aspects of behavior and emotion (eg. level of sadness and lack of fun time) and activity engagement. In all instances, we compare a group of siblings (sib-disability) who live with a brother or sister with disability to siblings who live with typically developing siblings (sib-typical). The definition of disability used in these analyses is consistent with the one used previously to assess caregiving burden on Ohio parents caring for a child with disability (Goudie, Havercamp, Jamieson and Sehr, 2010). To our knowledge, this study is the largest to compare children who have siblings with disability to children whose siblings are typically developing.

Currently in Ohio, there are no wide-spread systematic programs or interventions to help siblings cope with the psychological burden of growing up with a sibling who has a disability

METHODS

This study conducts retrospective secondary data analyses from the Medical Expenditure Panel Survey (MEPS). MEPS is a nationally representative survey of the non-institutionalized, civilian population of the United States conducted by the Agency for Healthcare Research and Quality. Each year a new panel of participants is sampled from the National Health Interview Survey to participate in MEPS. Participants in each panel are interviewed over 5 rounds covering a 2-year time period. In order to increase the number of children with disability in this study to increase the statistical power of comparing siblings in households with a child with disability to siblings in households without a child with disability, we aggregated results from the most recently available data from MEPS panels 10, 11, and 12.

Children from 5 to 17 years of age were included in this study. In rounds 2 and 4 of MEPS, parents responded to a series of questions regarding each child's social interaction and behavior across a number of domains. In this study, responses from round 4 served as the outcome variables of interest. Social interaction questions elicited problems getting along with mom, dad, siblings and other adults and children in general. Behavior questions asked about physical behavior problems (problems at school, home, or getting in trouble in general), engagement level in activities (completion rate of school work and participation in sports or hobbies), and emotions (problems having fun or feeling unhappy or sad). Parents responded to questions about problems 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 subsequently recoded into two categories: no problem and any problem.

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. This question is one of the

validated questions on the children with special health care needs screener (Bethell et al., 2002). If one or more children with disability were identified within a household, the household was flagged and typically developing brothers and sisters of a child with a disability were identified.

We were interested in the impact of having a sibling with a disability in the household, therefore we restricted the control group (children residing in households without a child with disability) to only households with at least two children. This way we could compare the impact of having a sibling with a disability to having a sibling without disability. The clustering effect of siblings sharing similar traits within household was accounted for in all analyses by adjusting for demographic and socio-economic characteristics.

Descriptive demographic and health status profiles are presented for each group of siblings (sib-disability and sib-typical). Rates of social interaction and behavior problems are also presented across groups. Younger siblings may experience different levels of social interaction and behavior problems compared to older siblings. Therefore, in separate analyses, siblings 5-11 years were compared to those 12-17 years. For children with siblings who have disabilities (sib-disability), being younger versus older than the child with a disability was also compared. Differences across groups were assessed using chi-square tests of association at a 5% significance level. Longitudinal panel weights were included in all analyses.

Multivariable logistic regression was used to model each problem with social interaction and behavior outcome. The main predictor in each model was whether a sibling resided in a household with a child with disability or not (referent category). The main predictor was adjusted for demographic and socio-economic covariates.

RESULTS

Population Demographics and Health Status

In total, 274 siblings of children with a disability (sib-disability) were identified from the data. We also identified 7,270 children with typically developing siblings (sib-typical). There is no age, gender, race/ethnicity or parental structure group statistical difference between siblings groups (Table 1).

Consistent with previous knowledge of households with a child with disability, 38.3% of all siblings with a brother or sister with a disability were residing in a poor or near poor household (<125% of the Federal poverty level) compared to 22.3% of siblings residing in a household without a child with disability.

Table 1. Demographics for Children with Sib-typical and Sib-disability (n, %)

Category	Sib-Typical		Sib-Disability		
	Number	Percent	Number	Percent	
Age	5 - 11	4,078	55.6	144	55.4
	12 - 17	3,192	44.4	130	44.6
Gender	Male	3,698	50.6	128	46.3
	Female	3,572	49.4	146	53.7
Race	White	5,255	77.3	175	74.1
	Black	1,402	14.1	73	16.6
	Hispanic	98	1.0	--	0.3
	Other	515	7.6	22	8.9
Poverty *	Poor/Near Poor	2,670	22.3	130	38.3
	Low Income	1,470	16.8	51	17.4
	Middle/High Income	3,130	60.8	93	44.4
Parental Structure	Mom and Dad	4,939	75.1	174	70.3
	Mom Only	1,952	20.1	82	23.0
	Dad Only	150	2.5	--	4.6
	Other	229	2.3	12	2.1

* Statistical difference across category and sibling group at $\alpha = 0.05$.

While there are few demographic differences between these two groups, there are differences in their health status and outlook. Only 74.3% of the sib-disability group was described by parents as having excellent or very good mental health status, compared to 81.9% of sib-typical

group (Table 2). Compared to parents of typically developing siblings, parents caring for a child with disability were more likely to describe this child's siblings as getting sick more easily than other kids (27.0% to 19.1%) and less likely to have a healthy life (90.8% to 96.1%).

Table 2. Health Status indicators by Sibling Group (n, %)

Category	Sib-Typical		Sib-Disability		
	Number	Percent	Number	Percent	
General Health Status	Excellent/Very Good	5,690	82.5	213	78.9
	Good/Fair/Poor	1,577	17.5	61	21.1
Mental Health Status *	Excellent/Very Good	5,704	81.9	202	74.3
	Good/Fair/Poor	1,564	18.1	74	25.7
Less Healthy Than Other Children	Definitely/Mostly True	368	4.0	15	5.3
	Definitely/Mostly False, DK	6,891	96.0	259	94.7
Child Gets Sick Easily *	Definitely/Mostly True	1,485	19.1	86	27.0
	Definitely/Mostly False, DK	5,775	80.9	188	73.0
Child Will Have a Healthy Life *	Definitely/Mostly True	6,949	96.1	249	90.8
	Definitely/Mostly False, DK	312	3.9	25	9.2

Note: DK=Don't Know

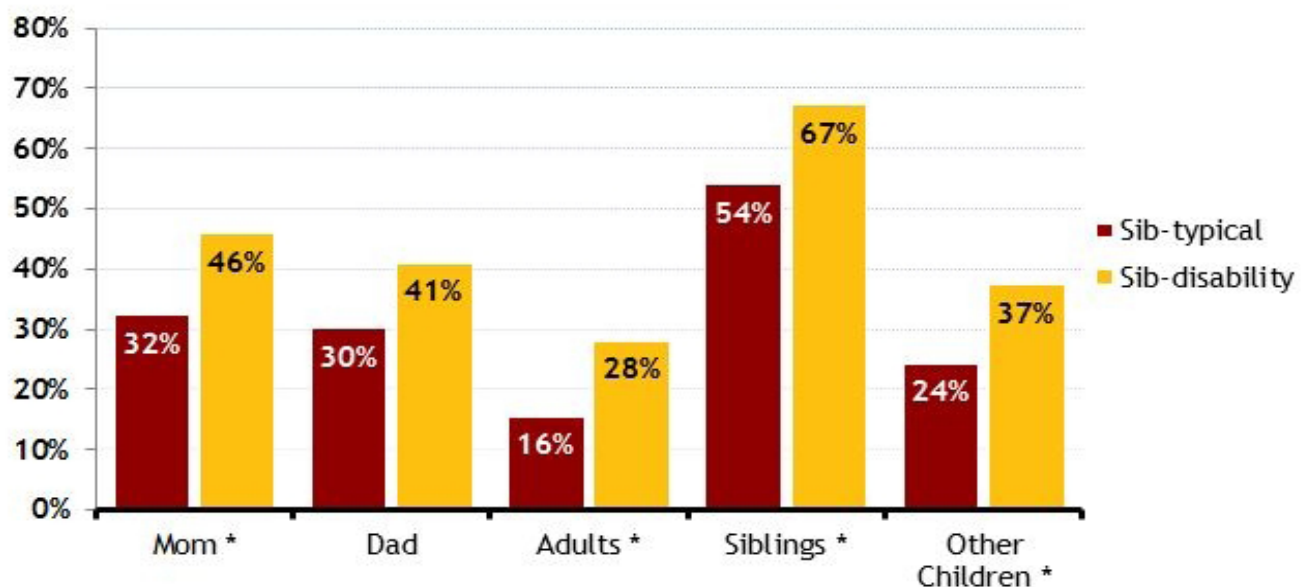
* Statistical difference across category and sibling group at $\alpha = 0.05$.

Social Interaction Problems

Compared to children whose sibling is typically developing, children with siblings who have disability are more likely to have problems getting along with mom, siblings or other adults and children in general (Figure 1).

In particular, more than 2 out of 3 of the sib-disability group (67.3%) are reported to have some kind of problem interacting with other siblings (including the sibling with disability).

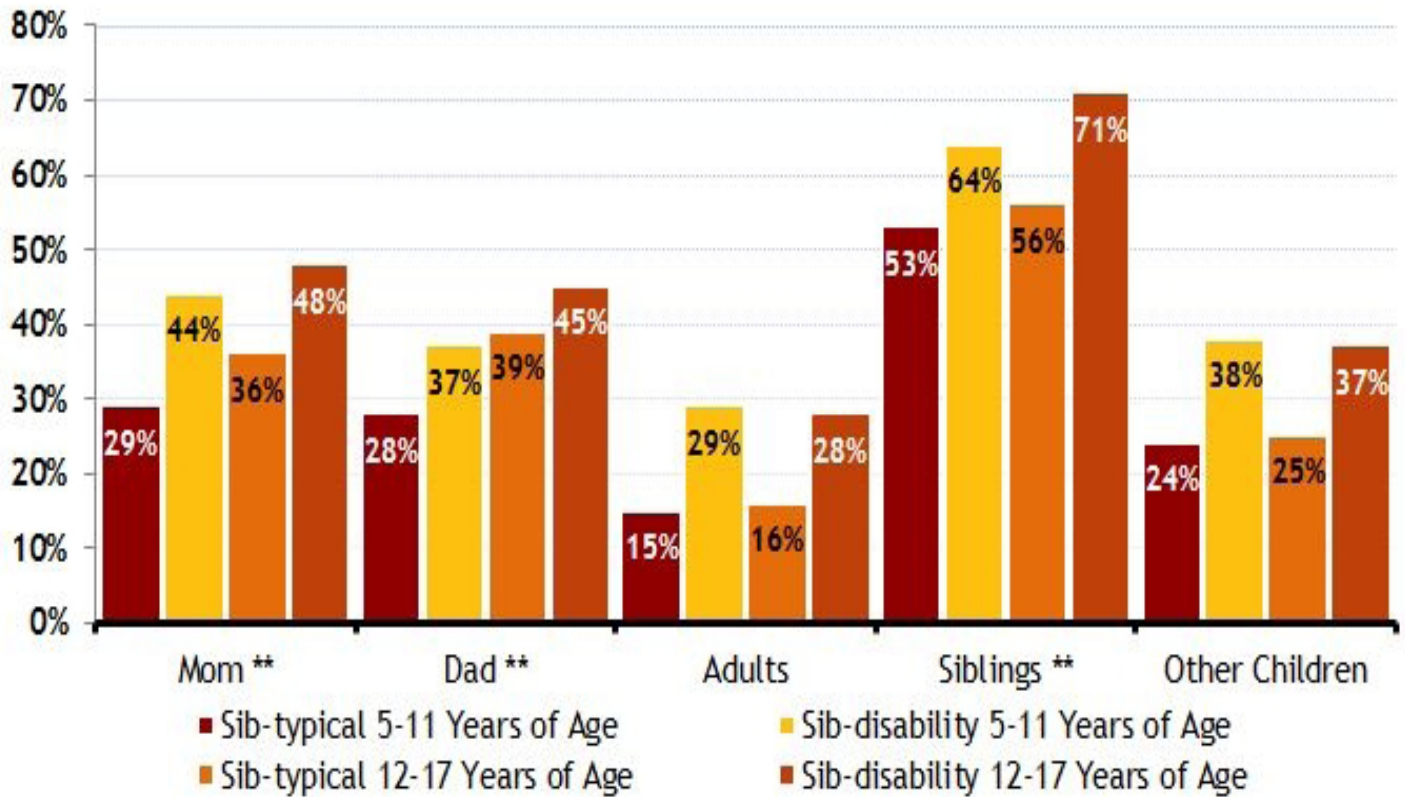
Figure 1. Percentage of Siblings with Social Interaction Problems by Sibling Status and Interaction Groups



* Statistical difference across sibling household groups at $\alpha=0.05$

Figure 2 separates the results of Figure 1 into younger and older age groups. Compared to younger siblings (5 to 11 years of age), older siblings (12 to 17 years of age) contains a higher percentage having problems getting along with mother, father, and other siblings.

Figure 2. Percentage of Siblings with Social Interaction Problems by Sibling Status, Age, and Interaction Groups



** Statistical difference across age groups at $\alpha=0.05$

While differences in social interaction are consistent across age groups it does not make a difference if the sibling is older or younger than the brother or sister with a disability (data not shown).

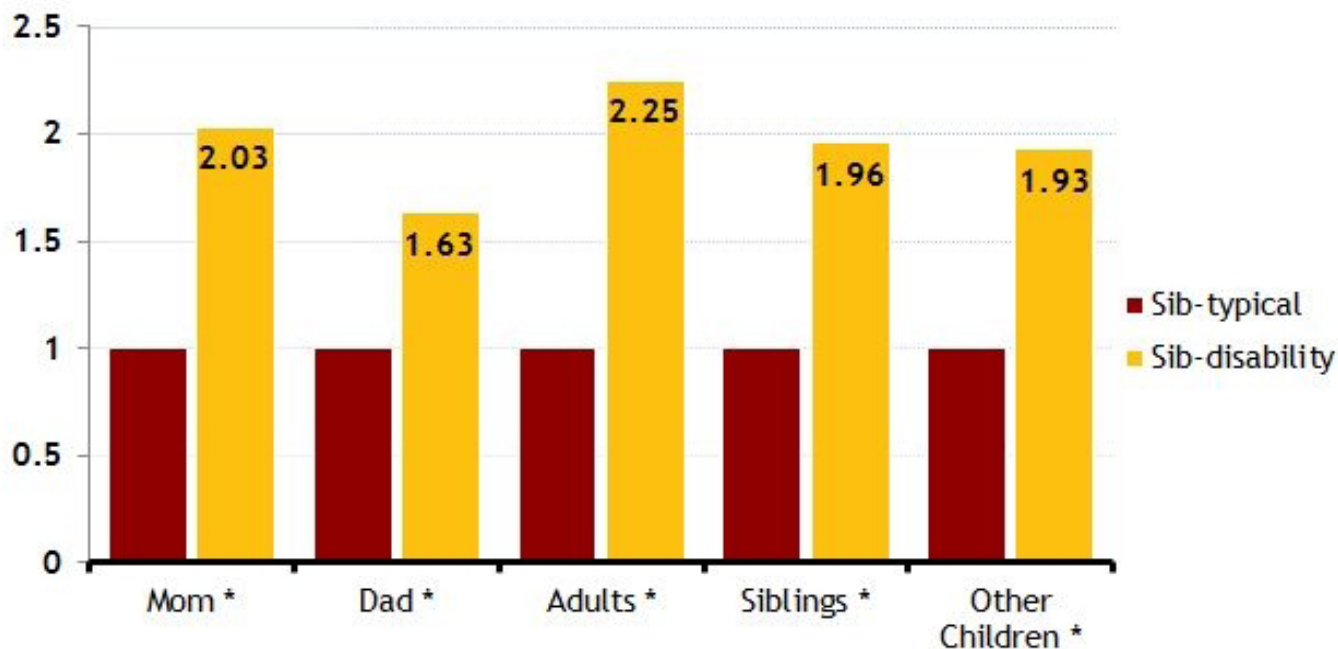
The population percentages presented in Figure 1 do not account for subpopulation demographic or socio-economic differences. Figure 3 presents adjusted odds ratios for the likelihood a sib-disability has a problem getting along with mother, father, other adults, siblings, or other children as compared to siblings of typically developing children. The likelihood is adjusted to take into account the sibling's age, gender, race/ethnicity, household poverty status, and parental family structure.

On average, children who have siblings with disabilities are approximately twice as likely as

children with typically developing siblings to have social interaction problems with all interaction groups. Unlike in Figure 1, and after adjusting, the likelihood of having problems getting along with the father is higher for sib-disability than for siblings of children who are typically developing.



Figure 3. Adjusted Odds Ratio Differences in Social Interaction Problems in Children with Siblings Who Have Disability Compared to Children with Typically Developing Siblings



* Statistical difference across sibling household groups at $\alpha=0.05$

Behavior Problem Setting

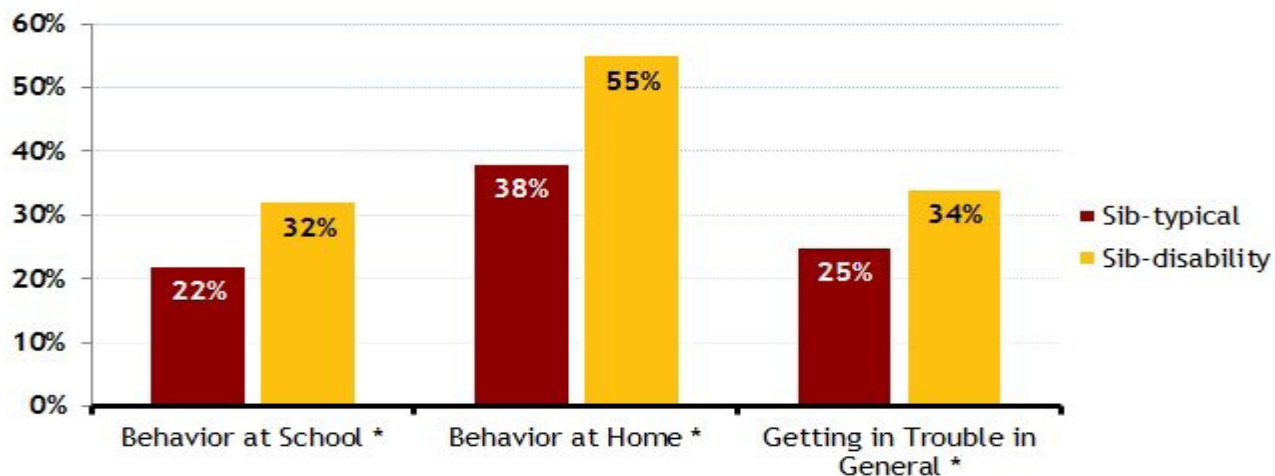
Problems getting along with others are common manifestations of externalizing behavior problems. The setting of behavior problems for children is likely to be at school, home, or just a general problem getting in trouble.

The results presented in Figure 4 illustrate that, as a group, children with siblings who have disability are more likely to experience behavior problems

at school and at home, and are generally more likely to get into trouble than siblings of typically developing children.

Aligned with results from Figure 1 where 2 out of 3 in the sib-disability group had interaction problems with siblings, more than one-half of parents (54.5%) report that children with siblings who have disability have problems with behavior at home.

Figure 4. Percentage of Siblings with Behavior Problems by Sibling Group and Problem Setting

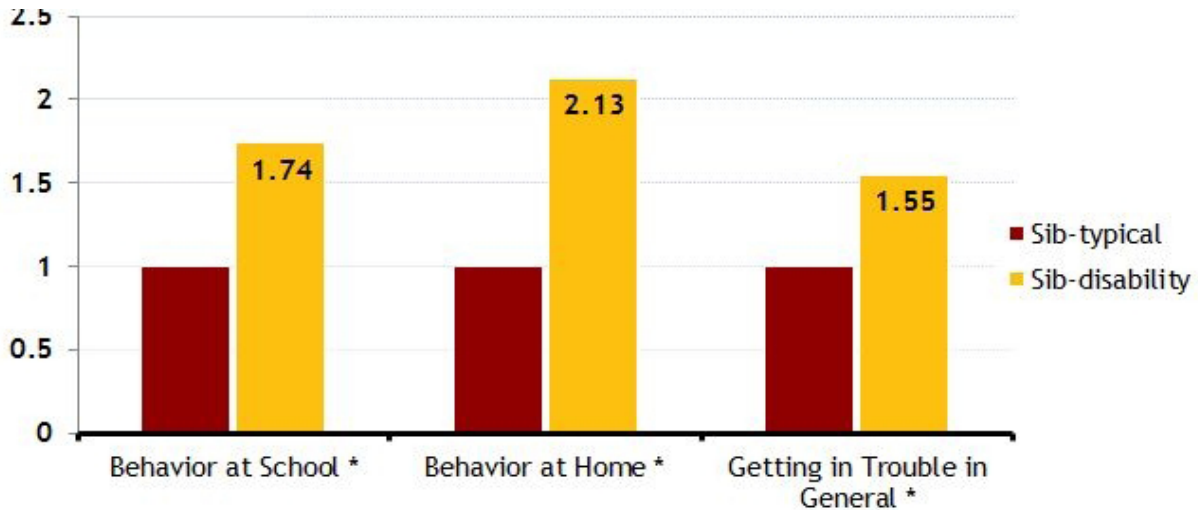


* Statistical difference across sibling household groups at $\alpha=0.05$

Compared to children with typically developing siblings, sib-disability are 1.7 times as likely to have behavior problems at school, 2.1 times as likely to exhibit behavior problems at home, and

1.6 times as likely to have problems getting in trouble in general, adjusted for other demographic and socio-economic group characteristics (Figure 5).

Figure 5. Adjusted Odds Ratio Differences in Behavior Setting Problems Across Sibling Groups



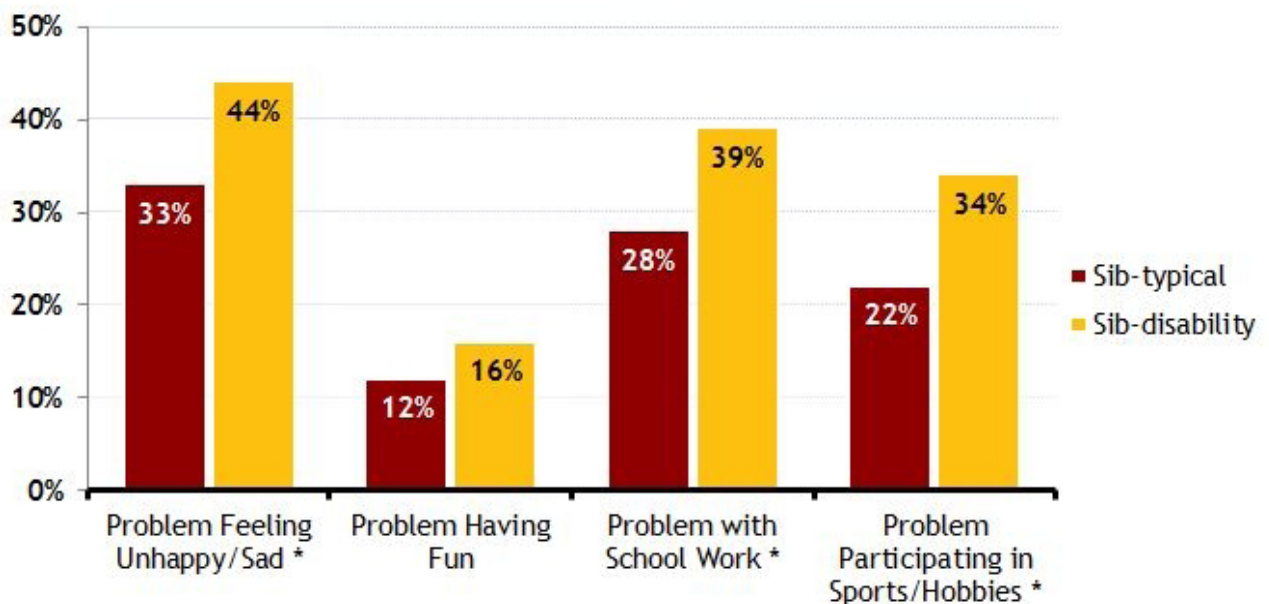
* Statistical difference across sibling household groups at $\alpha=0.05$

Emotional Behavior and Activity Engagement

The results presented in Figure 6 illustrate that parents are more likely to report that sib-disability have some problem with feeling unhappy or sad compared to children with typically developing siblings (44.1% compared to 33.2%). A higher

percentage of siblings of children with disability also have problems completing school work (39.1% compared to 27.8%) and engaging in sports or hobbies (22.0% compared to 33.9%) than siblings of typically developing children.

Figure 6. Percentage of Siblings with Emotional or Activity Engaging Problems by Sibling Group

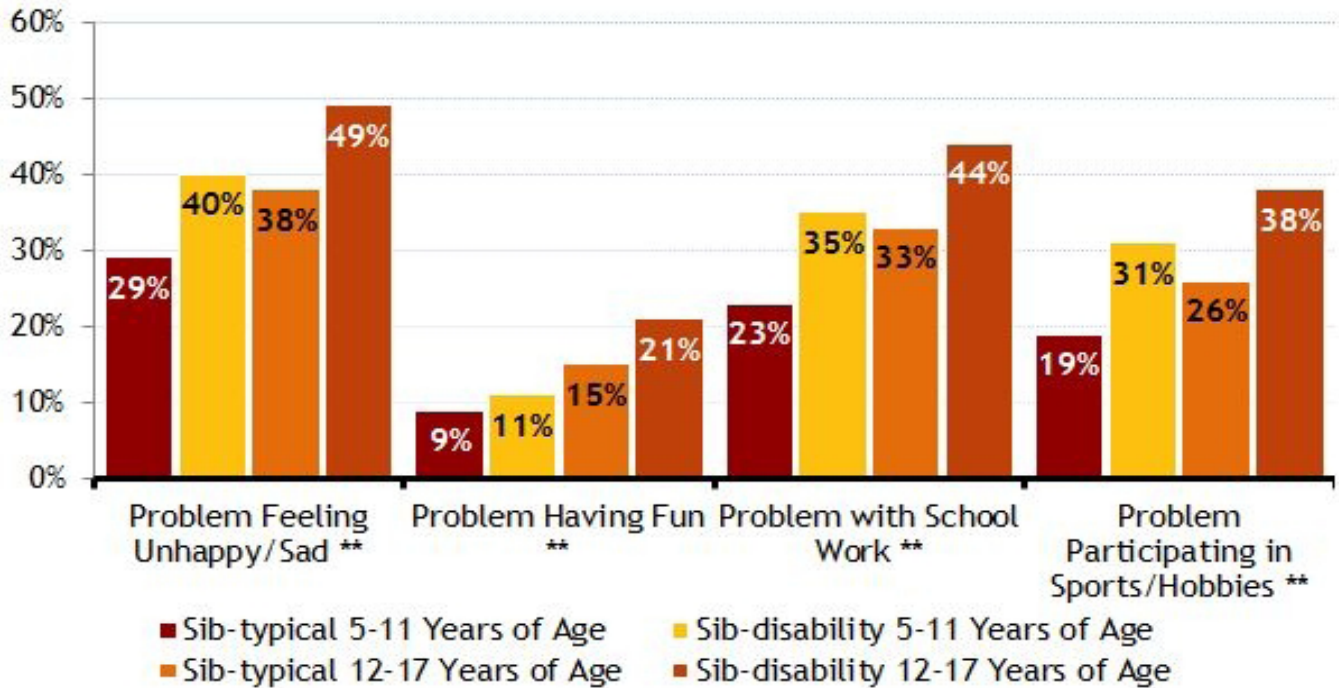


* Statistical difference across sibling household groups at $\alpha=0.05$

In addition to differences in problems with emotions and activity engagement across sibling groups there are also differences across age groups (Figure 7). Parents report that nearly one-

half (48.8%) of all sib-disability 12 to 17 years of age have some problem with feeling unhappy or sad, have problems with school work (43.5%) and problems engaging in sports and hobbies (37.7%).

Figure 7. Percentage of Siblings with Emotional or Activity Problems by Sibling Group and Age Group



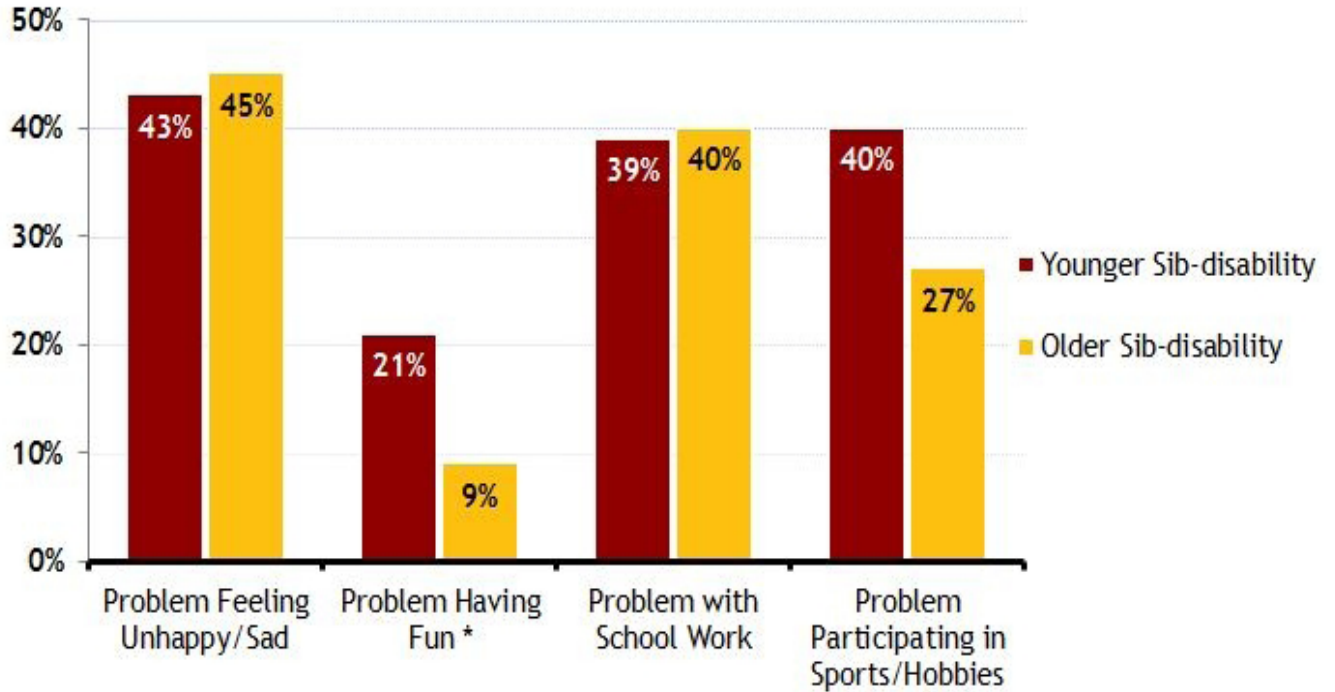
** Statistical difference across age groups at $\alpha=0.05$

As depicted in Figure 8 (see next page), children whose older sibling has a disability are more likely to have problems having fun compared to children

whose younger sibling has a disability (20.6% compared to 9.3%).



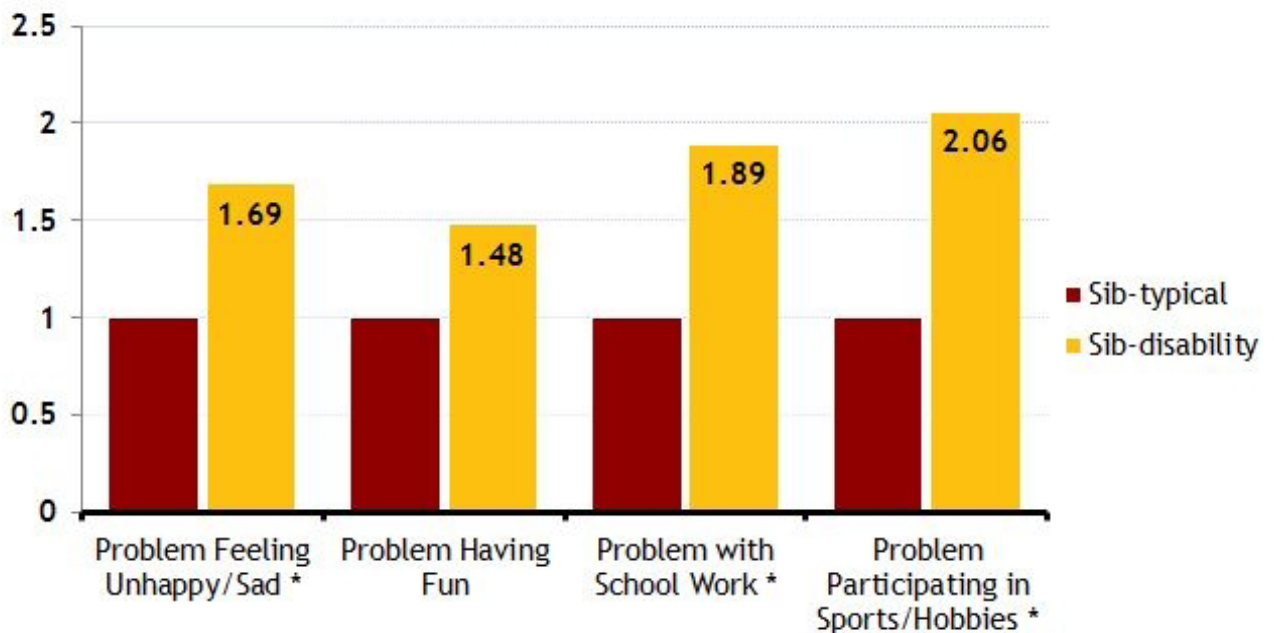
Figure 8. Percentage of Sib-Disability Group with Emotional or Activity Engaging Problems by Younger/Older than Child with Disability



* Statistical difference across older and younger than child with disability groups at $\alpha=0.05$

Compared to children with typically developing siblings, siblings of children with disability are 1.7 times as likely to have problems with being unhappy or sad, 1.9 times as likely to have problems completing school work and 2.1 times as likely to have problems engaging in sports or hobbies, adjusted for other demographic and socio-economic group characteristics (Figure 9).

Figure 9. Adjusted Odds Ratio Differences in Emotional or Activity Engaging Problems in Children with Siblings Who Have Disability Compared to Children with Typically Developing Siblings



* Statistical difference across sibling household groups at $\alpha=0.05$

DISCUSSION

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 (Cadman, 1988). It is important to note that we have accounted for socioeconomic status in our multivariable models. The advantage of our study is that it is based on a large representative population of US school-aged children.

Hartling and colleagues (Hartling, 2010) have compiled a systematic review of interventions that have been implemented to help children cope and adapt to having a sibling with disability. In structured clinical trials, sessions ranging from one hour visits to multiple-day camps with illness education and psychosocial counseling have been shown to be effective in lowering anxiety levels and improving problems with behavior (Williams, 2003; Gursky, 2007). In uncontrolled studies, support group interventions were found to be beneficial for psychosocial adjustment, self-concept, reduction in anxiety, improvement in self-esteem, and overall chronic condition knowledge and understanding needs of children with disabilities (Evans, 2001; Houtzager, 2001; Barrera, 2004; Metzgar, 2004).

Families, and siblings, are very different in how they react and adapt to caring for, and living with, a child with disability. For some families, this is a unifying and gratifying family and personal experience. It may be that these households face fewer financial, economic, or psychological challenges that often accompany disability. More research is needed to better understand how successful families cope, adapt, and care for a



child with disability. This will help develop and target cost-beneficial interventions to the families that need the help most.

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 (Sharpe, 2002). 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 outcomes (Katz, 1999; Cohen, 2002). 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.

Developing skills to better cope and adapt to living and caring for persons with disability is needed in early childhood. 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 holistically 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 are in poor or near poor households and receiving, or seemingly 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. Benefits will include lowering what are hypothesized to be differential levels of health care utilization between the comparable sibling groups in this study. 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 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. Screening siblings for mental health conditions must be an available option.
- 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 will 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.
- 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.

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Susan Haverkamp, 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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ACKNOWLEDGMENTS

This project was funded by a Grant from the Ohio Developmental Disabilities Council. The authors gratefully acknowledge the assistance provided by the following people:

Allison Lorenz	Government Resource Center
Sara Samson	Government Resource Center
Kay Treanor	Ohio Developmental Disability Council
Linda Garrick	Ohio Department of Mental Health
Peggy Martin	Ohio Department of Developmental Disabilities
Jody Fisher	Ohio Department of Developmental Disabilities
Sam Chapman	Ohio Department of Health
Wendy Grove	Ohio Department of Health/Help Me Grow
Shawn A. Henry	Ohio Center for Autism and Low Incidence (OCALI)
Laura Leach	Ohio Department Of Jobs and Family Services
Tammy Savage	Ohio Sibs
Mary Hall	Ohio Provider Resource Association
Tom Fish	Nisonger Center- Ohio State University
Mark Smith	Ohio Department of Education

