Assessing Functional Impairment in Siblings Living With Children With Disability

WHAT'S KNOWN ON THIS SUBJECT: Previous research on potential deleterious effects of typically developing children growing up in households with children with disability has produced mixed results. Research methods have been cited as a problem in many studies.

WHAT THIS STUDY ADDS: This is the largest known empirical study comparing functional impairment in siblings living with a child with disability and siblings residing with children who are typically developing. This study also follows the trajectory of functional impairment across 2 measurement periods.

abstract

OBJECTIVE: The purpose of this study was to empirically test if siblings of children with disability had higher levels of parent-reported behavioral and emotional functional impairment compared with a peer group of siblings residing with only typically developing children.

METHODS: This was a retrospective secondary analysis of data from the Medical Expenditure Panel Survey. We included only households with at least 2 children to ensure sibling relationships. Two groups of siblings were formed: 245 siblings resided in households with a child with disability and 6564 siblings resided in households with typically developing children. Parents responded to questions from the Columbia Impairment Scale to identify functional impairment in their children.

RESULTS: On the basis of parent reports and after adjusting for sibling demographic characteristics and household background, siblings of children with disability were more likely than siblings residing with typically developing children to have problems with interpersonal relationships, psychopathological functioning, functioning at school, and use of leisure time ($P < .05$). The percentage of siblings of children with disability classified with significant functional impairment was 16.0% at the first measurement period and 24.2% at the second ($P < .001$). For siblings of typically developing children there was a smaller percentage increase from 9.5% to 10.3% ($P < .001$).

CONCLUSIONS: Functional impairment is a key indicator for the need of mental health services and, as such, early assessment and interventions to limit increasing severity and short- to long-term consequences need to be addressed. Health care professionals need to consider a family-based health care approach for families raising children with disability. *Pediatrics* 2013;132:e476–e483

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KEY WORDS

siblings, disability, functional impairment, mental health

ABBREVIATIONS

CI—confidence interval

CIS—Columbia Impairment Scale

MEPS—Medical Expenditure Panel Survey

Dr Goudie conceptualized and designed the study, obtained the data, conducted the analysis, and drafted the initial manuscript; Dr Haverkamp conceptualized and designed the study and participated in drafting the initial manuscript; Mr Jamieson and Mr Sahr conceptualized and designed the study and critically reviewed the manuscript; and all authors approved the final manuscript as submitted

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Children born with significant health problems and disabilities are living longer and achieving more due to advances in medicine and allied health therapies.^{1,2} The advance of portable technology and the change in social philosophy and legislation to promote caring for children with disability in the home over institutionalization have been instrumental in doubling the number of children with disability being cared for in the home over the past 50 years.^{3,4} These achievements are celebrated but accompanied by increased caregiving burden by all members of a household with a child with disability. This article explores the impact of disability on the family and, in particular, on the typically developing siblings.

Special health care services and therapies for children with special health care needs can be exhaustive, expensive, and not fully covered by health insurance. Because these therapies are effective in improving a child's functioning and long-term outcomes, parents exhaust their financial, physical, and emotional resources to provide for their children with special health care needs.^{5–8} In addition to the significant out-of-pocket expense of these therapies, substantial time is spent learning to navigate the service delivery and eligibility system, coordinating care, advocating for coverage with insurance companies, and augmenting therapy with practice at home.^{9,10}

It is not that parents overlook their other children who are typically developing. Parents worry that they can't provide enough for all their children.¹¹ The typically developing offspring fare relatively well compared with the child with special health care needs, and parents instinctively give more time and energy to the child most in need. Research exploring the impact of disability on typically developing siblings has been mixed. Studies have concluded negative social outcomes^{12–14} and negative be-

havioral or emotional impacts.^{15–17} Suppressing emotions and feelings is a common negative conclusion.^{18,19} There have also been findings of a positive effect (eg, sibling bonding) on siblings residing in a household with a child with disability,^{20,21} whereas other studies have concluded no impact.^{22–24} Vermaes et al²⁵ recently published a meta-analysis studying the psychological functioning of siblings in families with children with chronic conditions and concluded that there is an overall negative effect with no findings to support a hypothesis that some siblings are more resilient and have more positive self-attributes. They concluded that siblings of children with disability are at increased risk of developing negative self-attributes and internalizing problems.

The wide range of adjustment outcomes within and across studies has been attributed to problems of research methodology (eg, small sample sizes, lack of comparison group), as well as individual differences in response to living with a child with a disability.^{26,27} This study has the advantage of using data from a large representative sample comparing siblings of children with a disability with siblings of typically developing children.

Behavioral and emotional functional impairment in children and adolescents is defined as the inability to engage socially at home, in the community, and at school compared with other children and adolescents of the same age.²⁸ Approximately 1 in 10 children in the United States have been shown to experience significant functional impairment.²⁹ Predictors of functional impairment include experiencing anxiety with stressful situations,³⁰ and previous research has revealed the association between functional impairment and depression and mental health problems.^{31–33} The purpose of this study was to empirically test whether siblings of children with

disability have higher levels of functional impairment compared with a peer group of children with typically developing siblings.

METHODS

Data Source

This study was a retrospective secondary analysis using data from the Medical Expenditure Panel Survey (MEPS). MEPS is a nationally representative survey of the noninstitutionalized, civilian population in the United States and is conducted for the Agency for Healthcare Research and Quality.³⁴ Each year, a new panel of households is randomly selected from the National Health Interview Survey to participate in MEPS. Each eligible member of a household is enrolled to participate and an adult representative of the household is interviewed by telephone and answers mailed self-administered questionnaires (in either English or Spanish) over 5 equally spaced rounds covering a 2-year time period. The participation response rate in 2008 was 64.4%. We combined data from panels 10 (2005–2006), 11 (2006–2007), and 12 (2007–2008) for this study. The household component of MEPS asks about demographic characteristics, health conditions, health status, access to care, satisfaction with care, health insurance coverage, income, and employment. MEPS also solicits parent responses to a series of questions from the Columbia Impairment Scale (CIS). MEPS data are publicly available and do not contain individual identifying variables; as such, this study was deemed exempt by the Cincinnati Children's Hospital Medical Center institutional review board for the protection of human subjects.

CIS Youth Version

The CIS is an interviewer-administered global functional impairment scale that measures 13 areas of problems a child may exhibit in everyday functioning and settings. These areas

are broadly representative of interpersonal relationships, psychopathological functioning, functioning at school, and use of leisure time. The scale demonstrates good internal consistency (Cronbach's $\alpha = 0.78$) and acceptable to good test-retest reliability (intraclass correlation coefficient = 0.63).³⁵ Parents were asked about the level of problems experienced by their children between the ages of 5 and 17 years in the 12 months before the interview. CIS questions were asked during rounds 2 and 4 of the MEPS interviews, time periods that were spaced by ~12 months.

Parents rated the level of problem or impairment a child had on each of the 13 items by using a Likert 5-point scale ranging from 0 (no problem) to 4 (very bad problem). Summing ratings over all items produced a validated global impairment measure in which higher scores indicated greater impairment. A composite score of ≥ 16 was indicative of clinically significant functional impairment.³⁵

Definition of Disability

A child was defined 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 had or was expected to last for a period of at least 12 months. Only children 1 to 17 years of age during the first year of an MEPS panel were assessed for disability in this study. Children not meeting the definition of disability were deemed typically developing.

Our definition of disability is based on a broad question of functional limitations.* We validated this definition

with data from the 2005/2006 National Survey of Children with Special Health Care Needs (data not shown). Children classified as having a disability under this definition included those with difficulty breathing (40.3%), mental retardation (language used in the survey at the time; 33.4%), and difficulty with swallowing, digesting food, or metabolism (27.7%) as well as other non-mutually exclusive disability and chronic conditions.

Inclusion Criteria

We included only households with at least 2 children and where at least 1 of the children did not meet the definition of having a disability. Two groups were formed: 1 group included all typically developing siblings who resided in a household with a child with disability and the other group contained all siblings who resided in households with other children who were also typically developing. Children with disability were not included in the analysis. Also, we retained only children whose parents responded to all 13 CIS items at round 4 (90.1%).

Statistical Analysis

Due to the low frequency of responses in CIS question categories representing bad or very bad problems (ie, 3 or 4), we dichotomized the CIS item categories to 0 (no problem) and 1 (at least some problem). As a test of sensitivity of the chosen dichotomous cutoff, we replicated all multivariable analyses by using a cutoff between 1 and 2 (ie, 0 or 1 response and 2, 3, or 4 responses). No statistical changes for the main predictor variable (sibling group) were observed (data not shown). We also summed the 13 CIS original scaled (0–4) items to construct a composite measure of functional impairment (range: 0–52).

A demographic, household, and child health status categorical profile of each

group of siblings is presented containing the actual number of MEPS respondents along with population-weighted percentages. A Rao-Scott χ^2 test of significance ($\alpha = 0.05$) determined if demographics, household characteristics, and child health status were significantly different across sibling groups. To assess unadjusted differences in parent-reported CIS item problems across sibling groups, a series of logistic regression models were fit with each dichotomous CIS item and overall functional impairment status as the dependent variable in each model. Odds ratios and 95% confidence intervals (CIs) were used to determine if siblings of a child with disability had higher odds of experiencing individual CIS item problems compared with siblings of typically developing children. We also present similar differences adjusted for child's age, gender, race/ethnicity, and parents' educational level, family composition (eg, 2 parents, single mom, etc), poverty status, and the number of children residing in the household. The difference in CIS composite scores between data collection rounds was calculated and used as a dependent variable in a regression analysis to test if, on average, siblings of children with disability increased their CIS composite score between rounds 2 and 4 compared with siblings of typically developing children. For those categorized with and without significant functional impairment at round 2, the adjusted average CIS score (using least-squared means) was calculated for siblings of children with disability and for siblings of typically developing children at rounds 2 and 4. All analyses were performed by using SAS Enterprise Guide 4.3 (SAS Institute, Cary, NC).

RESULTS

In total, for parents responding to all CIS items, there were 6564 siblings identified residing in households with only typically developing children and

*We consistently used the term "functional impairment" to include behavioral and emotional conditions and distinct from functional limitation that includes chronic physical conditions.

245 siblings identified residing in households in which at least 1 other child had a disability. There were no differences in age, gender, race/ethnicity, parents' educational level, and family composition across the sibling groups under study (Table 1). However, siblings of children with disability were more likely to be the oldest child compared with siblings of typically developing children ($P < .001$) and less likely to reside in middle- to high-income households ($P < .001$).

Compared with siblings of typically developing children, parents indicated that siblings of children with disability were less likely to have a very good or excellent mental health status ($P < .05$), generally agreed that the sibling gets sick more easily ($P < .05$) than other children of the same age, and the sibling was less likely to live a healthy life ($P < .001$).

As shown in Table 2, siblings of children with disability were more likely than other children to have parent-reported interpersonal relationship problems with their mother ($P < .05$), with their siblings ($P < .05$), and with other adults and children in general ($P < .001$). Parents also reported that they were also more likely to experience feeling unhappy or sad ($P < .05$), were nervous or afraid ($P < .05$), and had problems with behavior at home ($P < .001$). In addition, parents reported they had more problems with behavior at school ($P < .05$), completing school work ($P < .05$), and participating in leisure or sports activities ($P < .05$).

The percentage of siblings of children with disability classified with significant functional impairment was 16.0% at the round 2 data collection period and 24.2% at round 4 ($P < .001$). For siblings of typically developing children there was a smaller percentage increase, from 9.5% to 10.3% ($P < .001$). At round 4, siblings of children with disability were 2.79 times as

TABLE 1 Demographic and Health Status Characteristics by Sibling Group

	Sibling of Typically Developing Children		Sibling of a Child With Disability		<i>P</i>
	<i>n</i>	Weighted Percentage	<i>n</i>	Weighted Percentage	
Demographics and household status					
Category					
Child's age					
5–11 years	3618	54.3	123	52.3	.66
12–17 years	2946	45.6	122	47.7	
Child's gender					
Male	3338	50.5	117	47.8	.40
Female	3226	49.5	128	52.2	
Child's race/ethnicity					
White	4746	77.7	156	73.9	.58
Black	1259	13.8	65	16.3	
Hispanic	85	1.0	—	0.3	
Other	474	7.5	20	9.5	
Birth order					
Oldest child	2795	43.8	132	56.4	<.001
Not the oldest child	3769	54.2	113	43.6	
Household poverty status					
Poor/near poor	2278	21.0	113	37.0	<.001
Low income	1342	16.6	48	18.5	
Middle/high income	2944	62.4	84	44.5	
Parents' education					
High school or less	3350	38.6	118	36.0	.62
More than high school	3214	61.4	127	64.0	
Family composition (parents in household)					
Mother and father	4684	77.7	162	72.7	.66
Mother only	1573	18.0	67	20.9	
Father only	135	2.5	—	4.2	
Other	172	1.8	11	2.1	
Health status					
Response					
General health status					
Excellent/very good	5137	82.5	192	78.4	.20
Good/fair/poor	1424	17.5	53	21.6	
Mental health status					
Excellent/very good	5165	82.1	182	74.1	.02
Good/fair/poor	1397	17.9	63	25.9	
Less healthy than other children					
Definitely/mostly true	336	4.0	14	5.7	.17
Definitely/mostly false, DK	6226	96.0	231	94.3	
Child gets sick more easily					
Definitely/mostly true	1329	18.8	75	26.4	.02
Definitely/mostly false, DK	5234	81.2	170	73.6	
Child will have a healthy life					
Definitely/mostly true	6294	96.1	22	90.4	<.001
Definitely/mostly false, DK	270	3.9	245	9.6	

Categorical cells containing <10 unweighted responses were not identified (—). Source: Medical Expenditure Panel Survey panels 10, 11, and 12.³⁴ DK, don't know.

likely (95% CI: 1.82–4.28) to be reported to have significant functional impairment than siblings in households with typically developing children.

After adjusting for sibling demographic characteristics (age, gender, race/ethnicity, birth order) and household

background (parents' educational level, family composition, poverty level, and number of children in household), siblings of children with disability experienced higher odds of experiencing problems on all CIS items (95% CI >1.0), with the exception of getting in trouble in general and having fun,

TABLE 2 Social Interaction and Behavior Problems by Area of Functioning and Sibling Group

Area of Functioning and Specific Problem	Weighted Percentage ^a		Odds Ratio (95% CI)
	Sibling of Typically Developing Children (n = 6564)	Sibling of a Child With Disability (n = 245)	
Interpersonal relationship (problem with ...)			
Mother	32.2	46.3	1.82 (1.25–2.63)*
Father	32.8	41.3	1.44 (0.99–2.08)
Other adults	15.3	27.9	2.14 (1.46–3.15)**
Siblings	54.1	66.3	1.67 (1.10–2.53)*
Other children	24.0	37.0	1.86 (1.27–2.72)*
Psychopathology functioning			
Getting into trouble	25.2	32.1	1.41 (0.97–2.06)
Feeling unhappy or sad	32.9	43.8	1.59 (1.09–2.31)*
Feeling nervous or afraid	35.7	49.0	1.73 (1.15–2.60)*
Problem with behavior at home	38.0	53.4	1.87 (1.30–2.70)**
Functioning at school (problem with ...)			
Behavior at school	20.1	23.9	1.69 (1.18–2.44)*
Completing schoolwork	27.5	38.1	1.62 (1.15–2.29)*
Leisure time			
Problem having fun	11.8	14.8	1.30 (0.85–1.98)
Getting involved with sports/hobbies	21.9	34.6	1.89 (1.27–2.82)*
Functional impairment round 2 (CIS score ≥ 16)	9.5	16.0	1.84 (1.22–2.77)*
Functional impairment round 4 (CIS score ≥ 16)	10.3 ^b	24.2 ^b	2.79 (1.82–4.28)**

Source: Medical Expenditure Panel Survey Panels 10, 11, and 12.³⁴ * $P < .05$; ** $P < .001$.

^a Percentage with any problem.

^b Functional impairment significantly different between rounds 2 and 4, $P < .001$.

compared with siblings of children who were typically developing (Fig 1). In fact, even after adjustment, siblings

of children with disability were still almost 3 times as likely (adjusted odds ratio: 2.77; 95% CI: 1.77–4.34) to be

classified with significant functional impairment in round 4 than siblings residing only with other typically developing children.

As shown in Table 3, siblings of children with disability were more likely to increase CIS scores from round 2 to round 4 compared with siblings of typically developing children. The adjusted least-squared means indicate that the average adjusted increase in CIS score over 12 months was 2.88 for siblings of children with disability and 1.13 for siblings of typically developing children, which reflects an adjusted average CIS composite score increase of 1.75 ($P < .001$) compared with siblings of typically developing children. In general, children with higher round 2 CIS scores had lower CIS scores at round 4 ($P < .001$).

Siblings without significant functional impairment at round 2 had a slightly higher CIS composite score at round 4 (Fig 2). Siblings with significant functional impairment at round 2 had lower CIS scores at round 4, especially

FIGURE 1

Likelihood of siblings of children with disability having functional impairment problems compared with siblings of typically developing children. Interpersonal and behavior functioning problems were obtained from round 4. Odds ratios were adjusted for child age, gender, race/ethnicity, parents' education, parent marital status, poverty status, birth order of siblings, and number of children in household. AOR, adjusted odds ratio. Source: Medical Expenditure Panel Survey panels 10, 11, and 12.³⁴

TABLE 3 Predictors of 12-Month Change in CIS Composite Scores

Predictor	Category	Estimate	SE	P
Sibling group	Resides with child with disability	1.750	0.033	<.001
	Resides with typically developing children	Reference		
CIS round 2	Continuous (0–52 composite score)	–0.354	0.058	<.001

Estimates were adjusted for child age group, gender, race/ethnicity, and parents' education, family composition, household poverty level, birth order of siblings, number of children in household, and MEPS panel. Siblings of children with disability had an adjusted increase in CIS composite score of 2.88 compared with 1.13 for siblings of typically developing children.

Source: Medical Expenditure Panel Survey panels 10, 11, and 12.³⁴

siblings of typically developing children ($P < .001$).

DISCUSSION

After adjusting for child and household characteristics, parents reported that siblings of children with disability experienced greater problems with interpersonal relationships, psychopathology, functioning at school, and leisure time compared with siblings of typically developing children. More dramatic is the difference in significant functional impairment between the sibling groups. We found that the rates of functional impairment for siblings of typically developing children were comparable to normative rates reported in the literature³⁶ and were stable over 2 measurement periods at ~10%. However, siblings of children with disability had higher initial rates (16%), and these rates increased over 12 months to where 1 in 4 of these siblings had sig-

nificant functional impairment at the time of the second measurement. For children classified with functional impairment in round 2 of the MEPS interviews, the CIS composite scores at round 4 were lower on average but more so for siblings of typically developing children. The average CIS composite score for siblings of children with disability remained high. For children classified without functional impairment in round 2, average CIS composite scores increased equally between rounds 2 and 4 for both sibling groups. Although not tested in this study, we speculate that the decline in CIS composite score measurements between rounds 2 and 4 for siblings of typically developing children with significant functional impairment may have been due to intervention. Parents of typically developing children have, in general, more time and resources to seek help for children with significant

functional impairment than do parents raising a child with disability.

Environmental factors including stress, parenting styles, poverty status, and living arrangement during childhood, together with biological factors, can have a direct and indirect impact on functional impairment in a child.^{29,37} We contend that one such environmental factor of note is growing up with a sibling who has a disability. Professionals working with families need to consider the impact of disability on siblings as well as the identified child and their parents. Given that family context plays a critical role in determining sibling adjustment difficulties, interventions that focus on supporting the whole family, in addition to directly supporting siblings, may be most effective. In particular, interventions aimed at helping parents to manage stress, improve parenting skills, strengthen family communication and problem-solving skills, as well as maintain family routines may be useful.³⁸ Strengthening sibling, parent, and overall family functioning may also improve family members ability to cope with and meet the needs of the person with a disability.

Functional impairment is a key indicator for the need for mental health services³³ and, as such, early assessment and interventions to limit increasing severity and short- to long-term consequences need to be addressed. When time and attention are disproportionately spent on the child with disability, early signs of functional impairment problems in typically developing siblings may be overlooked or dismissed. Untreated mental illness can be more severe, difficult to treat, and more likely to involve comorbid mental conditions.^{39,40} Mental illness is prevalent in preschool-aged children, and >1 in 2 cases of mental illness have begun by age 14 years, but only 1 in 5 children are identified and receive

FIGURE 2

Adjusted change in average CIS composite score by functional impairment status at MEPS round 2. Source: Medical Expenditure Panel Survey panels 10, 11, and 12.³⁴

treatment.^{41,42} Untreated mental illness is associated with serious risk of suicide, poor educational attainment, future high health care use, and criminal activity.⁴³

This study was limited by the fact that child CIS data were gathered by parent report only without child self-report or clinical assessment. We also used a general definition of disability based on parent response to screener items and not clinical diagnoses. The possible response bias associated with increased caregiver stress was considered. Studies have found mixed effects looking at the association between parenting stress and the reporting of child psychopathology.⁴⁴ However, even among studies that have found a small to moderate higher reporting of psychopathology, none have targeted CIS item response bias associated with differential caregiver burden of chil-

dren with disability. Other limitations included lack of background knowledge as to the extent or level of any intervention children with functional impairment may have received between rounds 2 and 4 of the MEPS interviews, which may, in part, explain the decline in average CIS composite score for children classified with functional impairment at round 2. The strength of this study stems from its ability to compare siblings growing up in 2 household environments and contexts. We have shown that siblings of children with disability are at higher risk of having significant functional impairment. If brothers and sisters are provided with the support and information they need, they can help their siblings maintain a high quality of life from childhood to their senior years. Truly family-friendly care and services will be achieved only when

siblings are actively included in agencies' definition of family.

CONCLUSIONS

This study revealed that compared with siblings residing only with other typically developing siblings, those in households with a child with disability were more likely to experience significant functional impairment. Whereas much of the health care focus is on the well-being of the child with disability, health care professionals (and payers) need to consider a family-based health care approach for all family members at higher risk of health problems. Functional impairment is a key indicator for the need of mental health services, and as such, early assessment and interventions to limit increasing severity and short- to long-term consequences need to be addressed.

REFERENCES

- Campbell FA, Ramey CT. Effects of early intervention on intellectual and academic achievement: a follow-up study of children from low-income families. *Child Dev*. 1994; 65(2 spec no):684–698
- Eapen V, Crnčec R, Walter A. Clinical outcomes of an early intervention program for preschool children with autism spectrum disorder in a community group setting. *BMC Pediatr*. 2013;13(1):3
- Reichman NE, Corman H, Noonan K. Impact of child disability on the family. *Matern Child Health J*. 2008;12(6):679–683
- Weisz V, Tomkins AJ. The right to a family environment for children with disabilities. *Am Psychol*. 1996;51(12):1239–1245
- Leiter V, Wynngaarden Krauss M, Anderson B, Wells N. The consequences of caring: effects of mothering a child with special needs. *J Fam Issues*. 2004;25(3):379–403
- Williams PD, Williams AR, Graff JC, et al. A community-based intervention for siblings and parents of children with chronic illness or disability: the ISEE study. *J Pediatr*. 2003;143(3):386–393
- Batshaw ML. *Children With Disabilities*. 5th ed. Baltimore, MD: Brookes; 2002
- Dauz Williams P, Piamjariyakul U, Graff JC, et al. Developmental disabilities: effects on well siblings. *Issues Compr Pediatr Nurs*. 2010;33(1):39–55
- McCann D, Bull R, Winzenberg T. The daily patterns of time use for parents of children with complex needs: a systematic review. *J Child Health Care*. 2012;16(1):26–52
- Gallimore R, Bernheimer LP, Weisner TS. Family life is more than managing crisis: broadening the agenda of research on families adapting to childhood disability. In: R Gallimore, LP Bernheimer, D MacMillan, S Spence, & S Vaughn, eds. *Developmental Perspectives on Children With High-Incidence Disabilities*. Mahwah, NJ: Lawrence Erlbaum Associates; 1999:55–80
- Centre for Community Child Health. *Parenting Information Project*. Canberra, Australia: Royal Children's Hospital Melbourne, Commonwealth of Australia; 2004. Available at: www.parentingrc.org.au/~prcorgau/images/stories/PIP/pip_vol_2_litreview.pdf. Accessed June 10, 2013
- Andersson E. Siblings of mentally handicapped children and their social relations. *Br J Spec Educ*. 1988;15(1):24–26
- Bågenholm A, Gillberg C. Psychosocial effects on siblings of children with autism and mental retardation: a population-based study. *J Ment Defic Res*. 1991;35(pt 4):291–307
- O' Brien I, Duffy A, Nicholl H. Impact of childhood chronic illnesses on siblings: a literature review. *Br J Nurs*. 2009;18(22):1358–1365
- Rossiter L, Sharpe D. The siblings of individuals with mental retardation: a quantitative integration of the literature. *J Child Fam Stud*. 2001;10(1):65–84
- Sharpe D, Rossiter L. Siblings of children with a chronic illness: A meta-analysis. *J Pediatr Psychol*. 2002;27(8): 699–710
- Lamorey S. Parentification of siblings of children with disability or chronic disease. In: Chase ND, ed. *Burdened Children: Theory, Research and Treatment of Parentification*. Thousand Oaks, CA: Sage; 1999: 77–91
- Houtzager BA, Grootenhuys MA, Hoekstra-Weebers JE, Last BF. One month after diagnosis: quality of life, coping and previous functioning in siblings of children with cancer. *Child Care Health Dev*. 2005;31(1):75–87
- Wood LJ, Sherman E, Hamiwka LD, Blackman M, Wirrell E. Depression, anxiety, and quality

- of life in siblings of children with intractable epilepsy. *Epilepsy Behav.* 2008;13(1):144–148
20. Roeyers H, Mycke K. Siblings of a child with autism, with mental retardation and with a normal development. *Child Care Health Dev.* 1995;21(5):305–319
 21. Grossman FK. *Brothers and Sisters of Retarded Children: An Exploratory Study.* Syracuse, NY: Syracuse University Press; 1972
 22. Tomeny TS, Barry TD, Bader SH. Birth order rank as a moderator of the relation between behavior problems among children with an autism spectrum disorder and their siblings. [published online ahead of print October 8, 2012] *Autism*
 23. Bischoff LG, Tingstrom DH. Siblings of children with disabilities: psychological and behavioral characteristics. *Couns Psychol Q.* 1991;4:311–321
 24. Auletta R, DeRosa AP. Self-concepts of adolescent siblings of children with mental retardation. *Percept Mot Skills.* 1991;73(1):211–214
 25. Vermaes IP, van Susante AM, van Bakel HJ. Psychological functioning of siblings in families of children with chronic health conditions: a meta-analysis. *J Pediatr Psychol.* 2012;37(2):166–184
 26. Lobato D, Faust D, Spirito A. Examining the effects of chronic disease and disability on children's sibling relationships. *J Pediatr Psychol.* 1988;13(3):389–407
 27. Cuskelly M. Adjustment of siblings of children with a disability: methodological issues. *Int J Adv Couns.* 1999;21(2):111–124
 28. Storch EA, Lack CW, Simons LE, Goodman WK, Murphy TK, Geffken GR. A measure of functional impairment in youth with Tourette's syndrome. *J Pediatr Psychol.* 2007;32(8):950–959
 29. Parens E, Johnson J. Mental health in children and adolescents. In: Crowley M, ed. *From Birth to Death and Bench to Clinic: The Hastings Bioethics Briefing Book for Journalists, Policymakers, and Campaigns.* Garrison, NY: The Hastings Center; 2008:101–106
 30. Ezpeleta L, Granero R, de la Osa N, Guillamón N. Predictors of functional impairment in children and adolescents. *J Child Psychol Psychiatry.* 2000;41(6):793–801
 31. Nagar S, Sherer JT, Chen H, Aparasu RR. Extent of functional impairment in children and adolescents with depression. *Curr Med Res Opin.* 2010;26(9):2057–2064
 32. Kovacs M, Goldston D, Gatsonis C. Suicidal behaviors and childhood-onset depressive disorders: a longitudinal investigation. *J Am Acad Child Adolesc Psychiatry.* 1993;32(1):8–20
 33. Rapee RM, Bögels SM, van der Sluis CM, Craske MG, Ollendick T. Annual research review: conceptualising functional impairment in children and adolescents. *J Child Psychol Psychiatry.* 2012;53(5):454–468
 34. Ezzati-Rice TM, Rohde F, Greenblatt J. *Sample Design of the Medical Expenditure Panel Survey Household Component, 1998–2007.* March 2008 ed. Rockville, MD: Agency for Healthcare Research and Quality; 2008
 35. Bird HR, Shaffer D, Fisher P, Gould MS. The Columbia Impairment Scale (CIS): pilot findings on a measure of global impairment in children and adolescents. *Int J Methods Psychiatr Res.* 1993;3(3):167–176
 36. Shaffer D, Fisher P, Dulcan MK, et al. The NIMH Diagnostic Interview Schedule for Children Version 2.3 (DISC-2.3): description, acceptability, prevalence rates, and performance in the MECA Study. Methods for the Epidemiology of Child and Adolescent Mental Disorders Study. *J Am Acad Child Adolesc Psychiatry.* 1996;35(7):865–877
 37. Bird HR, Yager TJ, Staghezza B, Gould MS, Canino G, Rubio-Stipec M. Impairment in the epidemiological measurement of childhood psychopathology in the community. *J Am Acad Child Adolesc Psychiatry.* 1990;29(5):796–803
 38. Giallo R, Gavidia-Payne S. Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *J Intellect Disabil Res.* 2006;50(pt 12):937–948
 39. Kessler RC, Olfson M, Berglund PA. Patterns and predictors of treatment contact after first onset of psychiatric disorders. *Am J Psychiatry.* 1998;155(1):62–69
 40. Wang PS, Demler O, Kessler RC. Adequacy of treatment for serious mental illness in the United States. *Am J Public Health.* 2002;92(1):92–98
 41. US Department of Health and Human Services. *Mental Health: A Report of the Surgeon General.* Rockville, MD: US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institutes of Mental Health; 1999
 42. National Alliance on Mental Health. Facts on children's mental health in America. 2010. Available at: www.nami.org/Template.cfm?Section=federal_and_state_policy_legislation&template=/ContentManagement/ContentDisplay.cfm&ContentID=43804. Accessed February 25, 2013
 43. Currie J, Stabile M. *Mental Health in Childhood and Human Capital.* Cambridge, MA: National Bureau of Economic Research; July 2007. NBER Working Paper Series 13217
 44. Stokes J, Pogge D, Wecksell B, Zaccario M. Parent-child discrepancies in report of psychopathology: the contributions of response bias and parenting stress. *J Pers Assess.* 2011;93(5):527–536