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1998

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Recommended Citation

Groh '98, Gretchen K., "Parent-report vs. Child-report of Specific Anxiety in Siblings of Children with Autism: Do Parents Know What Their Children Worry About?" (1998). *Honors Projects*. Paper 83.
http://digitalcommons.iwu.edu/psych_honproj/83

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Parent-report vs. Child-report of Specific Anxiety in Siblings of Children with
Autism: Do Parents Know What Their Children Worry About?
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4-22-98

Abstract

This project explores the anxiety and specific worries of children who have a sibling diagnosed with autism. There is clinical evidence pertinent to this topic but little published empirical research. In addition, this research explores whether parental perception of child fears is correlated with child-reported fears. Participants were recruited through local support groups for parents of children with autism. The siblings studied ranged in age from six and thirteen. Each child was given a standardized measure of general anxiety in addition to a measure of fears specific to siblings of children with autism (to be developed for this study). Parents completed measures assessing their child's general anxiety, autism worries, and internalizing/externalizing problems.

Parent-report vs. Child-report of Specific Anxiety in Siblings of Children with Autism: Do Parents Know What Their Children Worry About?

Siblings of children with disabilities often have special needs of their own that may be overlooked by professionals and parents. These siblings are thought to be at risk for developing emotional and behavior problems (Hannah & Midlarsky, 1985; Gath & Gumley, 1987). For example, sibling's behavior problems have been found to vary in frequency with the severity of the child with the disability's own behavior. That is, if the child with the disability's behavior was much disturbed (as often occurs in the case of autism), then the siblings of that child were more likely to evidence behavior problems (Gath & Gumley, 1987). Hannah and Midlarsky (1985) found that different results can be expected from different families dealing with different handicaps. They suggest that further research needs to be done focusing on the needs of siblings and families of children with disabilities.

Several studies have found elevated levels of anxiety in siblings of children with special needs (Binger, 1978; Carver & Carver, 1972; Meyerwitz & Kaplan, 1967; McHale & Gamble, 1989). These heightened levels of anxiety may result from a lack of information about the manifestations and consequences of the sibling's handicap (Wassermann, 1983). Children often lack information due to their parents' own lack of information, their parents desire not to worry or over burden them, parental confusion about the handicap, or parental denial about the child with the handicap (Seligman, 1991). A deficit of information also leaves a space in the child's mind to be filled with fears, fantasies and misinformation (Seligman & Darling, 1989).

Further, the arrival of a new child can be a very stressful and anxiety provoking event in any family, even more so if the child is discovered along the way to have a handicap (Smith & Neisworth, 1975). Children may naturally reflect their parents' anxiety (Travino, 1979). Perhaps in the case of autism,

which is an even less understood disorder than Down's Syndrome or mental retardation, parents may be more anxious, causing greater anxiety in their children. Because of autism's little understood nature, ignorance about the disability may be a particular problem. Harris (1994) claims that siblings' ignorance about autism can breed fear which damages the child's sense of self and their relationship with their sibling.

The empirical research done with siblings of children with autism suggests that they might be particularly vulnerable to problems and anxieties associated with being the sibling of a child with a disability. Gold (1993) found that siblings of boys with autism were more depressed than a control group of siblings of non-handicapped children. Rodrigue, Geffkin and Morgan (1993) compared siblings of children with autism, mental retardation and children who were not handicapped and found that the siblings of children with autism did not differ in terms of self competence or social competence, but did display more internalizing and externalizing problems.

The current project was designed to explore the nature of anxieties and worries in siblings of children with autism. First, the quantity and nature of these worries were recorded. Then, parent and child agreement about those worries was examined.

Specific Anxieties and Fears in Siblings of Children with Autism

We know little about specific fears of the siblings of children with autism. What we do know is derived chiefly from clinical evidence, not derived exclusively from siblings of children with autism, but a variety of siblings of children with a variety of disorders. In general, clinical and anecdotal information points to a variety of unusual concerns specific to siblings of children with disabilities that can be categorized into four general areas, each of which can be further divided into subcategories. The first general area consists of Self Worries, subcategorized as: 1) the child's own

autism misunderstandings, 2) concerns about their own increased responsibility, and 3) concerns about harm that might be inflicted by the sibling. The second general area involves Sibling Worries, subcategorized as: 1) concerns about the sibling's well being, and 2) concerns about communication with the sibling. This area (of communication) has generally not been well investigated in the clinical literature. The third general area involves Family Worries, subcategorized as: 1) concerns about the lack of parental resources (such as time and money), 2) concerns about the parents' well-being, and 3) concerns about disrupted family interactions. The final general area is comprised of Social Worries, subcategorized as: 1) concerns about the peer group, and 2) concerns about public perception.

Self Worries

Clinicians suggest that siblings of children with autism often misunderstand autism itself. For example, they may worry about catching their sibling's disability the way they might contract a cold or the flu (Featherstone, 1980). They may think that their sibling's autism is a curse or a result of something they have done. For example, they may believe that their jealousy over the new baby or wishing that the sibling would die gave the child the disability. Young children are prone to magical thinking and may believe that if their sibling were to magically get better, they themselves might become disabled (Featherstone, 1980). Clinicians suggest that this type of thinking can lead to tremendous guilt on the part of the sibling.

Siblings of children with autism may experience an increased sense of responsibility, in caretaking of their sibling, in their family, and with regard to their own emotional responses. Children might feel as if it is their responsibility to care for and protect their sibling. In addition, parents may be less tolerant of anger directed at the child with the handicap (Gamble & McHale, 1989), leading children to believe that normal sibling rivalry is bad or

wrong. At the same time, the child may be unable or unwilling to direct his or her anger at the more helpless sibling who often might not even understand this expression. Further children may feel intense parental pressure to excel in both school and other activities to make up for their sibling's inability's and shortcomings (Featherstone, 1980; Grossman, 1972; Klein, 1972). Siblings of children with autism may also worry about their caretaking responsibilities in the future. They may anticipate caring for their sibling after their parents are no longer able to do so.

Children with autism may throw tantrums or exhibit other violent behavior, and it is possible that siblings may worry about danger caused by the sibling's behavior. Very young children may be afraid of their sibling's overt behavior (Harris, 1994), and may worry that the sibling will hurt them or someone else. Bågenholm and Gillberg (1991) found that siblings of children with autism have special problems with their sibling getting into their rooms and breaking their possessions. It is therefore possible that they may have specific worries about such an occurrence.

Sibling Worries

Children may be concerned with their siblings' well-being. Children with autism may display more "bizarre" and unexplained behaviors than do children with other types of handicaps, including throwing tantrums and running away. During temper tantrums and other aggressive behaviors, siblings may worry that the child with autism will hurt themselves (Harris, 1994), or they may worry that their sibling will get lost if running away is a common behavior. They may also worry about their sibling who is away at an institution or away at school. Finally, siblings of children with autism tend to be more concerned with their sibling's future than are siblings of children with other handicaps. This anxiety closely reflects increased parental anxiety about their autistic child's future (Bågenholm & Gillberg, 1991).

Children may also be concerned about their own ability to communicate with their sibling. Because of the frequent inability of children with autism to interact socially, their siblings may not be able to tell what they want, think, or feel. They may worry that their sibling will never be able to communicate appropriately with them.

Family Worries

Because, of the extraordinary amount of attention (in relation to both parental time and money) directed toward their sibling, children with siblings with disabilities may worry about a dearth of parental resources. They may interpret this as a sign that their parents don't love them as much as they do the handicapped child (Featherstone, 1980). Not surprisingly, McHale and Harris (1992) found that mothers do spend a disproportionate amount of time with the child with the disability which may lead to further feelings of isolation in the home.

In addition, family interaction may be disrupted in a family with a child with autism. McHale, et al. (1992) report that siblings of children with autism report a less cohesive family and talk about their siblings more negatively than do children in a control group. Children in such a family may perceive their differences from other families and long to do the things that "normal" families are able to do (Harris, 1994). The child may not be willing to confront their parents concerning their confusion about the disorder and their anxieties about their sibling out of concern for the parents' well-being. Siblings of children with autism commonly desire to protect their parents from further stress and worry (Harris, 1994). Children may also feel that the handicap is a taboo subject and should not be discussed in the home (Seligman, 1991). The inability to discuss their concerns can often lead to intense feelings of isolation and loneliness.

Social Worries

As children grow older and become more interested in the social realm outside of the home, they may perceive a sense of being different from other children because of their sibling. This can be upsetting to the child, who may worry about the reaction of their peer group to their sibling. The child may react by refusing to invite friends over to play (Harris, 1994).

Isolation from peer groups, like possible isolation in the home (caused by inability to talk about concerns) may contribute to intense feelings of loneliness (Seligman, 1991). One study of siblings of children with autism found that 35% of the siblings studied described themselves as feeling lonely (Bågenholm & Gillberg, 1991).

In addition, being seen in public with their obviously different sibling may cause embarrassment for the sibling of a child with autism (Harris, 1994). Something like a simple trip to the grocery store can turn into an uncomfortable experience for a child, with a tantruming sibling and curious onlookers.

Other Concerns

Finally, and possibly most disturbingly, there may be additional stressors in a home containing a child with autism. Parents may not understand or be aware of the concerns of their non-disabled children. As was mentioned before, siblings of children with autism report a less cohesive family and talk about their siblings more negatively than do children in a control group, yet mothers of children with autism rate the sibling bond more positively than do control group mothers (McHale, et. al., 1992). This may point to a division between what children are feeling and what parents think they feel. Research has shown that in general, parents underestimate the amount of anxieties their children report (Earls, Smith, Reich, Jung, 1988; Lapouse & Monk, 1959). This may be a particular problem in families with a

child with autism. If parents do not know what their children are feeling, then they are at a disadvantage in helping them to cope.

Current Project

The current project is designed to assess: 1) children's general level of anxiety, internalizing/externalizing problems, and specific autism-related worries, 2) the relation between children's general level of anxiety and their level of specific autism-related worries, and 3) parent-child agreement of specific autism-related worries. During the course of this project, we administered a questionnaire developed for the study and designed to assess anxieties specific to school-age siblings of children with autism. In addition, children were given a general anxiety measure. Parents completed parallel versions of the AWS and anxiety measure as well as a standardized assessment of their child's internalizing/externalizing problems.

Hypothesis Set 1: Elevated Anxiety and Fears. Based on clinical literature and the few existing empirical studies, I expect siblings of children with autism to exhibit: 1) elevated general anxiety, 2) elevated internalizing/externalizing problems, and, 3) some autism related worries. The actual amount of autism worries to be reported cannot be predicted in advance because of the exploratory nature of this study.

Hypothesis Set 2: Autism Worries and General Anxiety. I expect modest correlations between child-report of specific-autism related worries and parent-report of 1) child-report of general anxiety, 2) parent report of general anxiety, and parent report of internalizing/externalizing problems.

Hypothesis Set 3: Parent-Child Agreement. I expect a modest correlation between parent-report and child-report of specific autism-related worries.

Method

Participants

Participants were recruited from several autism support groups located in central Illinois . The sample was composed of 17 white, non-Hispanic children, ranging in age from 6 to 13 years old ($M= 9.79$, $SD = 1.98$) and their parent or primary caretaker. Of these children, 7 were male and 10 were female. Of the 17 typically developing siblings, 2 were identified by their parents as having attention deficit- hyperactivity disorder, and 2 were identified as having reading problems. All 17 of the participating children had a sibling who was diagnosed with one of the following autism spectrum disorders; autism, pervasive developmental disorder-not otherwise specified, autistic-like tendencies or Asperger syndrome. Of the autistic siblings, 12 were male and 5 were female and they ranged in age from 3 to 10 years old ($M= 7.18$, $SD = 2.16$) . Parents ranged in age from 31 to 50 with the majority of parents (65%) in their thirties. Of these parents or primary caretakers, 15 were female and 2 were male. Their years of education ranged from 12 to 18 years ($M = 13.97$, $SD 1.80$).

Procedure

At the beginning of the testing session, the researcher met briefly with both the parent and child to provide a brief rationale for the study. The researcher explained that there are no right or wrong answers on study questionnaires and that both the parent and child's answers would be kept confidential. Informed consent was obtained from parents and assent was obtained from children. The researcher then interviewed child participants while parents completed questionnaires. The child interviews lasted approximately one hour with one short break. Following the testing session, a short debriefing session was held with both the parent and child to discuss

concerns and to provide participants with a blank questionnaire to take home with the and talk about if they so wished.

Measures

Child Measures The children's anxiety and worries were measured using two inventories. The order in which these measures were presented was counter-balanced.

The first of these measures was the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1978) (See Appendix A), also called "What I Think and Feel". This measure is a 37 item self-report questionnaire, using a yes/no response format designed to assess chronic manifestations of children's trait anxiety. It also contains a 9-item lie scale. The RCMAS provides reliable age norms for children and support has been gathered for its construct validity (Reynolds, 1980). Factor analysis of the RCMAS yielded three anxiety subscales: Worry/ Oversensitivity, Physiological, and Social (Cronbach, 1984).

The second measure, the Autism Worries Survey (AWS) (See Appendix A), was developed for this study based on a review of clinical literature. The AWS was originally a 47 item close-ended measure, with open-ended follow up questions, designed to identify worries specific to the siblings of children with autism. However, due to early participant responses during the course of this study, ten items were added, resulting in a 57 item measure for all but four of the participating children (See Table 1). The AWS consists of nine subscale tapping specific worries associated with the four general areas of concern identified in the literature review: (1) Self-Focused Worries, (2) Sibling-Focused Worries (3) Family-Focused Worries, and (4) Social Worries. For each AWS item, the child was shown a statement about an autism worry, for example, "Some kids worry that they might catch their brother's autism." Each statement was accompanied by four simple line drawings of a child's face,

with facial expressions ranging from calm to very worried, and labeled: "This girl really worries", "This girl kind of worries", "This girl worries just a little bit", and "This girl doesn't worry"(See Appendix A for sample pages). The sex of the hypothetical child and sibling was matched to the sex of each participant and sibling. The participants were asked which child they were most like, and directed to place a sticker in the box corresponding to that face. The researcher periodically instructed children to "tell me more" about their responses to certain items.

The following AWS scores were calculated: (1) total number of items endorsed regardless of intensity (internal consistency, $\alpha = .92$ for children and $\alpha = .97$ for parents), (2) Mean overall intensity, (3) Number (and percent) of worries reported for each subscale, and (4) Mean intensity for each subscale. Testing with the current sample indicated that all but one subscale, Autism Misunderstandings had minimally acceptable internal consistencies for both child and parent subscales. Table 1 lists all nine subscales, Cronbach alpha values, and sample items.

Parental Measures The parent or primary caretaker accompanying the child completed parallel versions of the RCMAS and the AWS. They also completed the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983), a standardized measure used to assess children's internalizing and externalizing problems and social competency. It provides a profile of the child's behavior relative to other children of their age and sex. The CBCL has been extensively researched, finding it to validly screen for behavioral problems in children (Cohen, 1988; Edelbrock & Costello, 1988) Because CBCL scores are sensitive to Attention Deficit- Hyperactivity Disorder, and therefore could have been elevated by scores for children with known diagnosis of their own, two scores were dropped from analysis using CBCL scores.

Results

Because of the exploratory nature and small sample size of this questionnaire development research, the significance level was set at $p < .05$, and $p < .10$ was accepted as indicative of marginal significance.

Description of General Anxiety and Problems

In order to determine whether children in this sample deviated from normative expectations regarding anxieties and problem behavior, a 1-group t-test was used to compare children's scores on both the RCMAS and the CBCL to national norms. The mean scores from this sample did not differ significantly from national norms for total score or subscales for either measure, except for the Total Competency scale of the CBCL (see Table 2). Parents in this sample reported their children as being significantly more socially competent than the norm, $t(13) = 2.33, p < .05$.

In line with prior research, parent report and child report of total anxieties on the RCMAS were moderately positive correlated, $r = .41, p < .06$, although this finding failed to attain significance.

Specific Autism Worries

All of the children interviewed reported at least some autism related worries. The children's number of reported worries ranged from 11 to 43 out of 57 possible items ($M = 25.35, SD = 9.12$). Over one half of the sample endorsed at least 50% of the worries on the questionnaire and 5 of 17 (29%) participants endorsed 75% or more of the worries (See Table 3). Children reported the greatest percentages of worries on the Public scale (77%) and reported low in the areas of Parent Resources (18%) and Autism Misunderstandings (12%). As seen in Figure 1, the profiles for boys and girls were nearly identical, except that boys reported significantly more worries about Increased Responsibility than did girls, $t(15) = 2.54, p < .05$.

Association Between Autism Worries and General Anxiety and Problems

In order to assess the relationship between autism worries and general anxiety and problems, parent and child AWS scores were correlated with parent and child RCMAS scores and CBCL scores using the Pearson correlational coefficient. As illustrated in Table 4, child-reported total number of autism worries was not significantly correlated with either child or parent RCMAS scores for either total worries or for any subscale. In contrast, and yet in line with hypothesis, child report of intensity of autism worries was moderately, positively correlated with child report of general worries on the RCMAS, $r=.49, p<.03$, and approached significance for all three RCMAS subscales, suggesting that as children report more intense autism worries, they also report more generalized anxiety.

The lower left quadrant of Table 4 presents correlations between child report of autism worries and CBCL total problem, internalizing, externalizing, and total competency scores. Child AWS scores for total number of autism worries were moderately negatively correlated with total problems reported on the CBCL, $r = -.60, p < .02$, externalizing scores on the CBCL, $r = -.45, p < .05$, and internalizing scores on the CBCL, $r = -.49, p < .04$. Contrary to hypothesis, this suggested that as total problems, externalizing and internalizing problems increases, report of specific autism worries decrease. Similarly, child AWS scores for intensity of autism worries were also moderately negatively correlated with total problem scores on the CBCL, $r = -.42, p < .07$, although the correlation was only marginally significant.

Correlations between parent AWS scores and CBCL scores reflect some, but not all of the correlations between child AWS scores and CBCL score. First, parent report of number of autism worries was not significantly correlated with either parent or child report of total general anxiety on the RCMAS, nor was it correlated with total problems, internalizing problems, or total

competency on the CBCL. It was, however, moderately, positively correlated with child report on the Physiological subscale of the RCMAS, $r = .45, p < .05$ and parent report on the Worry subscale of the RCMAS, $r = .37, p < .05$. In addition, parent report of child autism worries was moderately negatively correlated with externalizing scores on the CBCL, $r = -.53, p < .03$ (See lower right quadrant of Table 4). Similarly, parent report of intensity of their child's autism worries was significantly negatively correlated with externalizing problem report on the CBCL $r = -.53, p < .03$, while the correlations with total problems on the CBCL, $r = -.43, p < .08$ and the RCMAS Worry scale, $r = .39, p < .10$ approached significance.

Parent-report vs. Child-report

To assess parent's ability to report on their children's autism worries, parent and child AWS scores were correlated using the Pearson correlational coefficient. There was no significant correlation between parent and child report of total number of autism worries, $r = .21, ns$, or parent and child report of intensity of autism worries, $r = .07, ns$. Similarly, parent and child report on AWS scales were uncorrelated (except for Danger from Sibling, $r = .48, p < .05$, a finding that may be due to chance because of the large number of correlations that were run). Despite the lack of correlation between parent and child AWS report, profiles across subcategories appeared to be similar for both groups. This is illustrated clearly in Figure 2.

In order to determine whether parents and children differed significantly in their report of amount and intensity of child worries on AWS subscales, paired samples t-tests were run for AWS scales. There was a marginally significant trend suggesting that parents over-reported total intensity of child worries, $t(16) = -1.39, p < .10$, although no differences were found between parents and child-reported total number of worries. As shown in Table 5, mean number and intensity of worries and did not differ for

subscales with one exception: parents reported significantly more autism worries in the Parental Resources subcategory. Finally, data were examined to determine whether parents were over-reporting or under-reporting on their children's worries. Under-reporting was defined as parents reporting at least 10 questions fewer than their child, while over-reporting was defined as parents reporting at least 10 items more. Three parents (17%) under-reported their children's scores, 8(47%) reported their children's score with relative accuracy, and 6 (35%) over-reported on their child's worries by these criteria.

Discussion

Previous research has suggested that siblings of children with autism may experience elevated levels of anxiety and more internalizing and externalizing problems than other children (Binger, 1978; Carver & Carver, 1972; Gath & Gumley, 1987; Meyerwitz & Kaplan, 1967; McHale & Gamble, 1989). This has important implications for parents and for those working with families with a child with autism. Parents need to be aware if their typically developing children are at risk for problems and professionals need to devote more time to specific sibling issues when helping a family to deal with a child's autism. Further, other literature has suggested that parents are not particularly good at reporting on their child's anxiety. If parents are not even aware of their child's anxiety, how can they be able to help them? This study was designed to address these issues raised by prior research and clinical experience by: 1) identifying children's general anxiety level, internalizing and externalizing problems and autism worries, 2) ascertaining whether those specific autism worries were related to general anxiety and to internalizing and externalizing problems, and 3) determining whether parents can accurately report on their children's autism worries.

Contrary to expectations based on prior research (Binger, 1978; Carver & Carver, 1972; Gath & Gumley, 1987; Meyerwitz & Kaplan, 1967; McHale & Gamble, 1989), we found that this sample did not report significantly more general anxiety or internalizing and externalizing problems than most children. That is, the siblings of children with autism participating in this study did not seem to be more anxious than other children. Their parents furthermore, were not perceiving any more internalizing or externalizing problems in their children than typically occur in a normal population. The children in this sample all came from stable, intact homes, with parents who were concerned and interested enough to participate in this study. Furthermore, all of these families were connected with autism support groups. Perhaps these parents were already taking steps to ensure that their children would not be at risk for problems of this type.

All children were, however, reporting some autism related worries. Concerns about the Sibling tended to be high, while Family worries tended to be low. More specifically, on average, children endorsed more than 50% of the worries in the following subscales: Public Concerns (77%), Danger from Sibling (63%), Communication (62%), Increased Responsibility (58%), and Sibling Well-being (56%). In contrast, children reported fewer than 50% of the worries on these scales: Peers (45%), Family Interaction (37%), Parent Resources (18%), and Autism Misunderstandings (12%). It is possible that heightened sibling worries may even be desirable in children because they indicate compassion and caring directed toward the sibling. Little or no report of worries in this area might be more disturbing if indicative of a lack of regard for the sibling. Children reported uniformly low percentages of worries for the categories of Autism Misunderstanding (12%), and Parental Resources (18%).

Child report of total number of autism worries appeared to be unrelated to child report of general anxiety although, as the intensity of children's autism worries increased, so did their general anxiety levels. This later finding provides some validity for the AWS and suggests that children who are worrying very strongly about their sibling with autism may also be more generally anxious. Child report of total number of autism worries may simply be less sensitive to child anxiety.

An interesting and unexpected correlation occurred between child report of autism worries and CBCL scores. As CBCL scores increased, both children and their parents actually reported that the child had fewer and less intense autism worries. This relationship seemed to be related primarily to report of externalizing problem behaviors, such that higher levels of acting out problems as reported by parents were associated with less specific autism worry in children. Socially appropriate children without a lot of behavior problems may actually be more concerned and connected to their sibling and may report more worries.

As predicted from previous research, we found that parents were not very adept at reporting on their children's general anxiety. Correlations between parent and child RCMAS scores were at best, moderate and marginally significant. However, parents were better at reporting on general anxiety than they were at reporting on autism worries despite the similarity of the overall parent-child profile for AWS subscales. Individual parent and child report of both intensity and number of autism worries were uncorrelated, however, they seemed to agree more on subscales that more directly involve observable events, such as Danger from the Sibling:(eg. I worry that my sibling will hurt someone else). The lack of correlation between parents and children in reporting autism worries may be due to 1) lack of variability in the measure, 2) the low number of participants, 3) an inability of parents or

children to accurately respond to this measure, or 4) parent's lack of knowledge about their children's worries due to the very internal nature of these worries.

In general, parents seemed to over-report their children's worries—especially in the area which directly involves the family. However, this tendency to over-report does not occur in all families or across all subscales of autism worries. Of the subscales, only one is significantly over-reported by parents for both total number of worries and intensity of worries: Parent Resources. Parents may feel guilt over not spending enough time or money on the typically developing sibling, and may therefore perceive the child as worrying a lot about it.

As mentioned before, it appears that some measure that taps specific autism worries could be very useful clinically. Parents may not know what their children are worrying about and therefore might be ill-prepared to help their children to deal with those worries. Having access to a series of questions about specific autism worries (along the lines of the AWS) might aid parents and children in talking about some of those worries and may enhance communication between them. Professionals working with families with a child with autism or those running SibShops or sibling support groups may also benefit from the use of a specific autism related worries measure. They might be able to assess the areas or specific issues about which children are expressing worry and therefore help the child or family to address those issues. Despite the general low report of worry in the subcategory of Autism Misunderstanding, even one item endorsed for a child (e. g., fear of catching autism) might indicate a lack of knowledge and be something that children should have explained to them. Other subcategories, such as Danger from Sibling contain items that children might worry about for good reason. Still,

parents and professionals could help children talk about those worries and come up with creative solutions to address particular problems.

Despite the interesting findings of this study, there were some significant shortcomings in its design, one of the most notable being the small number of participants. Ideally, this study would be replicated using far more siblings and parents of children with autism. Also, because we recruited our participants from autism support groups, we may have tapped a group of parents that have extensively discussed the sibling's autism with their child. Parents who actively seek knowledge for themselves about their son or daughter's autism may be more likely to share that information with their other children. Scores on AWS scales such as Autism Misunderstandings may be artificially low because of the amount of knowledge present in these homes. Given these concerns, there may be problems in generalizing these findings to all siblings and parents of children with autism.

Another potential limitation of this study is the AWS itself. The Autism Worries Survey may not be accurately tapping autism worries. We may be asking questions that parents and children simply do not understand or understand differently. Parents could know exactly how much their children worry, yet problems in our measure render them unable to accurately report them. Based on children's responses when asked if there was anything else concerning their sibling that worried them, the AWS was by no means a complete list of autism worries. Certainly children may worry about other circumstances not included on this questionnaire. For example, the entire Communication subcategory was added based on an early participant's responses. Future surveys need to address these worries.

More studies with many more participants need to be conducted to determine whether the AWS is valid. There are several avenues for future research. One potentially useful study to gather information regarding the

AWS validity would include a control group of sibling of children with another disorder, such as Down Syndrome and a control group of siblings of typically developing children. In future replications of this study, participants would ideally include families involved not only in support groups but also those not connected with any social supports at all in order to be better able to generalize findings to the general population.

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Table 1

Autism Worries Survey Subscales and Sample Items

| Subscale | Sample Items |
|---|---|
| <u>SELF</u> | |
| Autism | <i>Some kids worry that they might catch autism from their brother.</i> |
| Misunderstandings (7 items, child alpha=.34 parent alpha=.78) | <i>Some kids worry that their brother's autism might be a punishment from God.</i> |
| Danger From Sibling (4 items, child alpha=.55 parent alpha=.65) | <i>Some kids worry that their brother will break their things.</i> <i>Some kids worry that their brother will hurt someone else.</i> |
| Increased Responsibility (6 items; child alpha=.57 parent alpha=.61) | <i>Some kids worry that they have to do more chores around the house because their brother has autism.</i> <i>Some kids worry that they will have to take care of their brother when they are older.</i> |
| <u>SIBLING</u> | |
| Sibling's Well-being (8 items; child alpha=.76 parent alpha=.74) | <i>Some kids worry that their brother will get lost.</i> <i>Some kids worry that their brother might get worse.</i> |
| Communication (5 items; child alpha=.76 parent alpha=.79) | <i>Some kids worry that their brother won't ever talk or won't ever talk much.</i> <i>Some kids worry that they don't know what their brother wants.</i> |
| <u>FAMILY</u> | |
| Parental Resources (4 items; child alpha=.93 parent alpha=.66) | <i>Some kids worry that their parents don't love them as much as they love their brother.</i> <i>Some kids worry that their parents spend too much money on their brother and there won't be enough left for them.</i> |
| Family Interaction (8 items; child alpha=.74 parent alpha=.75) | <i>Some kids worry that they can't talk to their parents about their brother.</i> <i>Some kids worry that their brother will mess up their family's plans.</i> |
| <u>PUBLIC</u> | |
| Peers (7 items; child alpha=.70 parent alpha=.83) | <i>Some kids worry that other kids might tease them about their brother.</i> <i>Some kids worry that other kids think they are weird because of their brother.</i> |
| Public (4 items; child alpha=.66 parent alpha=.80) | <i>Some kids worry that people say bad things about their brother.</i> <i>Some kids worry that their brother will embarrass them in public.</i> |

Table 2

Overall Anxiety and Problems: Revised Children's Manifest Anxiety Scale (n=17)
and Child Behavior Checklist (n=15)† vs. National Norms

| Measure | Sample M (SD) | Norm | t(16) |
|------------------|---------------|---------|-------|
| RCMAS (child) | | | |
| Total Anxiety | 52.25 (11.73) | 50 (10) | .77 |
| Physiological | 10.44 (3.46) | 10 (3) | .51 |
| Worry | 9.94 (3.00) | 10 (3) | -.08 |
| Social | 9.94 (3.15) | 10 (3) | -.08 |
| CBCL | | | |
| Total Problems | 49.4 (8.77) | 50 (10) | -.31 |
| Externalizing | 49.3 (8.32) | 50 (10) | -.34 |
| Internalizing | 51.53 (8.87) | 50 (10) | .64 |
| Total Competency | 54.14 (6.64) | 50 (10) | 2.33* |

†2 children were dropped to prevent confounding due to diagnosis of ADHD

* $p < .05$

Table 3

Total Number and Percent of Autism Related Worries

| <u>AWS Scales</u> | <u>Number of Autism Worries Reported</u> | | | <u>Mean Intensity Score</u> |
|--------------------------|--|-------------------------|------------------------|-----------------------------|
| | <u>Mean # reported</u> | <u>Total # possible</u> | <u>Mean % endorsed</u> | |
| Total Worries | 25.35/57* | | 44% | .82 |
| SELF | | | | |
| Autism Misunderstanding | .82/7 | | 12% | .18 |
| Increased Responsibility | 3.47/6 | | 58% | 1.10 |
| Danger from Sibling | 2.53/4 | | 63% | 1.16 |
| SIBLING | | | | |
| Sibling Well-being | 4.47/8 | | 56% | 1.20 |
| Communication | 3.08/5 | | 62% | 1.03 |
| FAMILY | | | | |
| Parent Resources | .71/4 | | 18% | .37 |
| Family Interaction | 2.94/8 | | 37% | .56 |
| SOCIAL | | | | |
| Peers | 3.18/7 | | 45% | .78 |
| Public | 3.06/4 | | 77% | 1.64 |

*4 children only were presented with 47 items

Table 4

Autism Worries vs. General Anxiety: Child and Parent Report on the Autism Worries Survey correlated with Child and Parent Report on the Revised Children Manifest Anxiety Scale and Parent Report on the Child Behavior Checklist

| | | Child | | AWS | Parent | |
|------------------------------|---------------------|--------------|------------------|-------|--------------|------------------|
| General Anxiety and Problems | | <u>Total</u> | <u>Intensity</u> | | <u>Total</u> | <u>Intensity</u> |
| CHILD | RCMAS TOTAL | .22 | .52* | .03 | .32 | |
| | RCMAS PHYSIOLOGICAL | .16 | .44† | .45* | .26 | |
| | RCMAS WORRY | .27 | .39† | .14 | .39† | |
| | RCMAS SOCIAL | -.04 | .42† | -.12 | .26 | |
| PARENT | RCMAS TOTAL | -.11 | .18 | .21 | .11 | |
| | RCMAS PHYSIOLOGICAL | -.26 | -.02 | -.02 | -.10 | |
| | RCMAS WORRY | -.15 | .05 | .37* | .28 | |
| | RCMAS SOCIAL | .09 | .39* | .16 | .07 | |
| | CBCL TOTAL | -.60* | -.42† | -.28 | -.43† | |
| | CBCL EXTERNALIZING | -.45* | -.31 | -.53* | -.58* | |
| | CBCL INTERNALIZING | -.49* | -.30 | .11 | -.15 | |
| | CBCL COMPETENCY | -.16 | -.56* | .16 | .17 | |

* $p < .05$ † $p < .10$

Note: Correlations computed using the Pearson Correlation Coefficient with one-tailed significance, $n = 15-17$ (variability due to missing data).

Table 5

Means and Paired Samples T-Tests for Autism Worries Survey Subscales

| Subscale | <u>Number of Worries</u> | | | <u>Intensity</u> | | |
|---------------------|--------------------------|-------------|--------|------------------|-------------|--------|
| | Child Mean | Parent Mean | t(16) | Child Mean | Parent Mean | t (16) |
| Total Worries | 25.35 | 30.06 | -1.66 | .83 | 1.04 | -1.39† |
| SELF | | | | | | |
| Misunderstanding | .82 | .65 | .48 | .18 | .12 | .72 |
| Responsibility | 3.47 | 3.47 | .00 | 1.10 | 1.01 | .43 |
| Danger from Sibling | 2.52 | 2.47 | .22 | 1.16 | 1.46 | -1.81 |
| SIBLING | | | | | | |
| Sibling Well-being | 4.47 | 4.41 | -.13 | 1.20 | 1.14 | -.35 |
| Communication | 3.08 | 3.38 | -.49 | 1.03 | 1.22 | -.69 |
| FAMILY | | | | | | |
| Parent Resources | .71 | 2.76 | -4.85* | .38 | 1.22 | -3.42* |
| Family Interaction | 2.94 | 3.59 | -1.03 | .56 | .81 | -1.53 |
| SOCIAL | | | | | | |
| Peers | 3.18 | 3.82 | -.94 | .78 | .90 | -.59 |
| Public | 3.06 | 3.41 | 1.19 | 1.37 | 1.64 | 1.18 |

*p<.005 †p<.10

Note= n varies slightly due to missing data

Figure Caption

Figure 1 . Mean percent of autism worries reported by boys and girls.

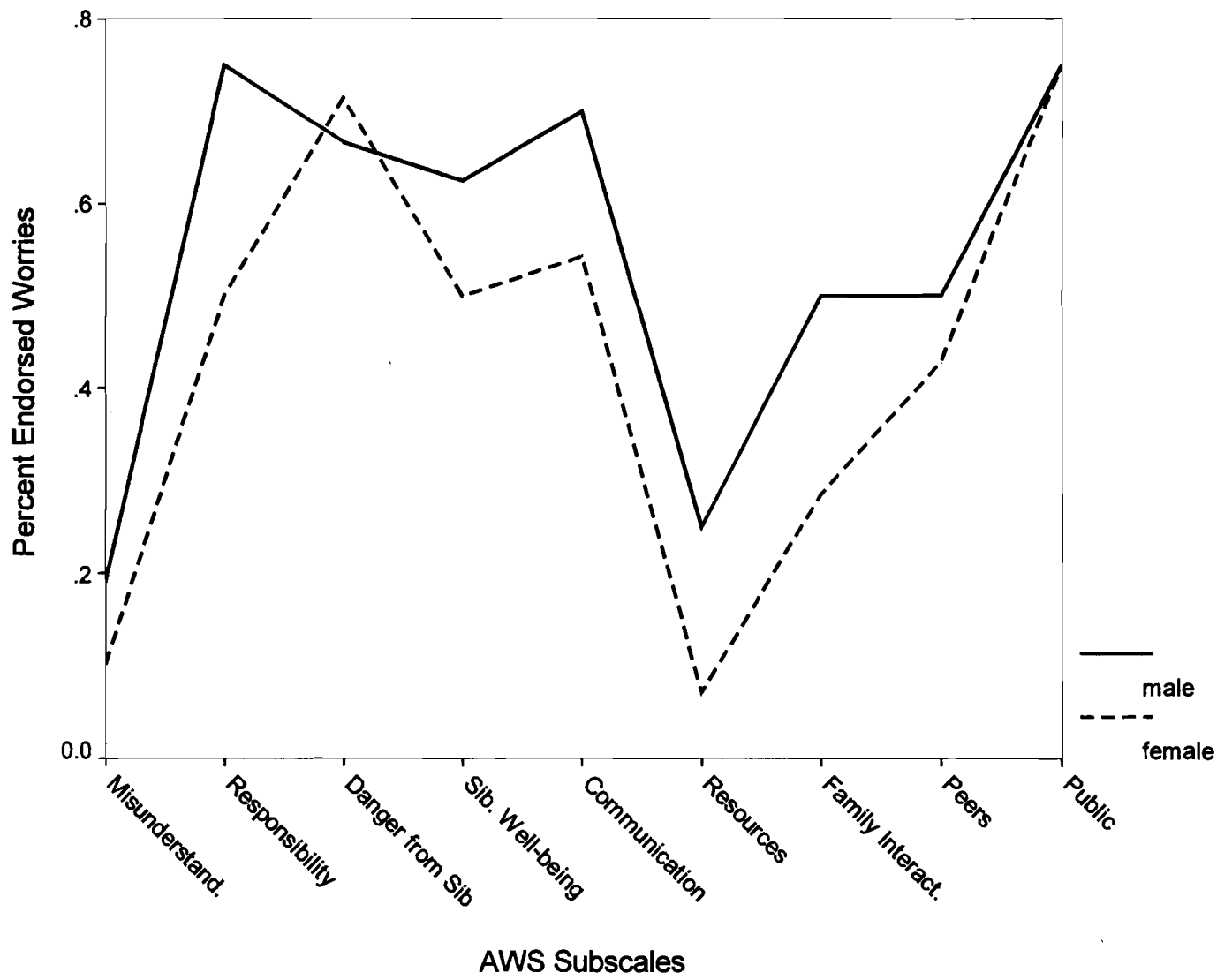
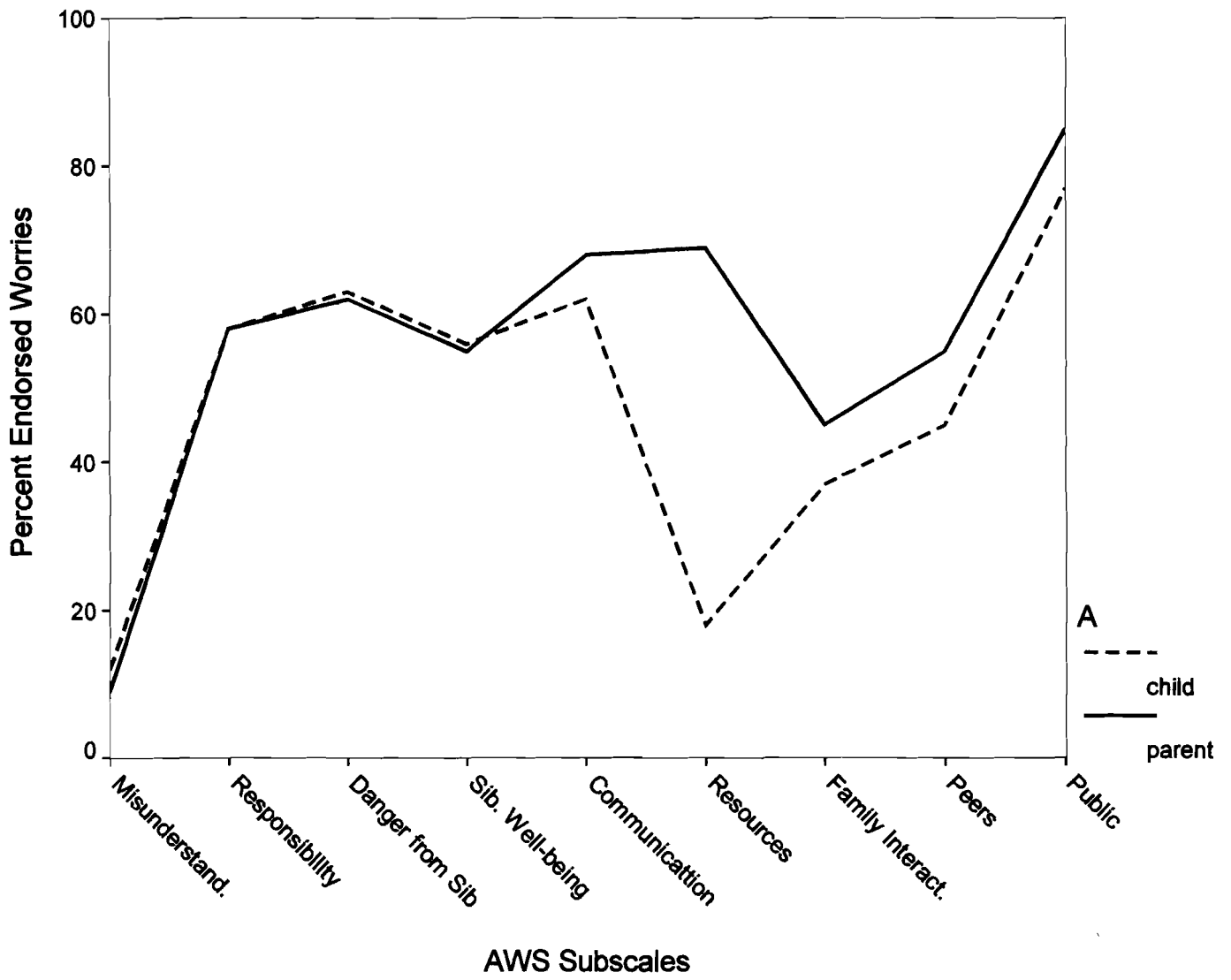


Figure Caption

Figure 2 . Mean percent of autism worries reported by parents and children.



Appendix A

- RCMAS
- AWS (directions and sample pages)
- Parent AWS

“WHAT I THINK AND FEEL” (RCMAS)

Cecil R. Reynolds, Ph.D. and Bert O. Richmond, Ed.D.

Name: _____ Today's Date: _____

Age: _____ Sex (circle one): Girl Boy Grade: _____

School: _____ Teacher's Name (Optional): _____

DIRECTIONS

Here are some sentences that tell how some people think and feel about themselves. Read each sentence carefully. Circle the word “Yes” if you think it is true about you. Circle the word “No” if you think it is *not* true about you. Answer every question even if some are hard to decide. Do not circle both “Yes” and “No” for the same sentence.

There are no right or wrong answers. Only you can tell us how you think and feel about yourself. Remember, after you read each sentence, ask yourself “Is it true about me?” If it is, circle “Yes.” If it is not, circle “No.”

| | Raw Score | Percentile | T-Score or Scaled Score |
|---------------|-----------|------------|-------------------------|
| Total: | _____ | _____ | _____ |
| I: | _____ | _____ | _____ |
| II: | _____ | _____ | _____ |
| III: | _____ | _____ | _____ |
| L: | _____ | _____ | _____ |

Published by

wps **WESTERN PSYCHOLOGICAL SERVICES**
12031 Wilshire Blvd., Los Angeles, CA 90025-1251
Publishers and Distributors

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| | | |
|--|-----|----|
| 1. I have trouble making up my mind | Yes | No |
| 2. I get nervous when things do not go the right way for me..... | Yes | No |
| 3. Others seem to do things easier than I can..... | Yes | No |
| 4. I like everyone I know | Yes | No |
| 5. Often I have trouble getting my breath | Yes | No |
| 6. I worry a lot of the time | Yes | No |
| 7. I am afraid of a lot of things | Yes | No |
| 8. I am always kind..... | Yes | No |
| 9. I get mad easily | Yes | No |
| 10. I worry about what my parents will say to me | Yes | No |
| 11. I feel that others do not like the way I do things | Yes | No |
| 12. I always have good manners | Yes | No |
| 13. It is hard for me to get to sleep at night | Yes | No |
| 14. I worry about what other people think about me..... | Yes | No |
| 15. I feel alone even when there are people with me | Yes | No |
| 16. I am always good..... | Yes | No |
| 17. Often I feel sick in my stomach | Yes | No |
| 18. My feelings get hurt easily | Yes | No |
| 19. My hands feel sweaty | Yes | No |
| 20. I am always nice to everyone | Yes | No |
| 21. I am tired a lot..... | Yes | No |
| 22. I worry about what is going to happen | Yes | No |
| 23. Other people are happier than I..... | Yes | No |
| 24. I tell the truth every single time | Yes | No |
| 25. I have bad dreams | Yes | No |
| 26. My feelings get hurt easily when I am fussed at | Yes | No |
| 27. I feel someone will tell me I do things the wrong way | Yes | No |
| 28. I never get angry | Yes | No |
| 29. I wake up scared some of the time | Yes | No |
| 30. I worry when I go to bed at night | Yes | No |
| 31. It is hard for me to keep my mind on my schoolwork..... | Yes | No |
| 32. I never say things I shouldn't | Yes | No |
| 33. I wiggle in my seat a lot..... | Yes | No |
| 34. I am nervous | Yes | No |
| 35. A lot of people are against me | Yes | No |
| 36. I never lie..... | Yes | No |
| 37. I often worry about something bad happening to me..... | Yes | No |

The Autism Worries Survey

Draft 1 (January, 1998)

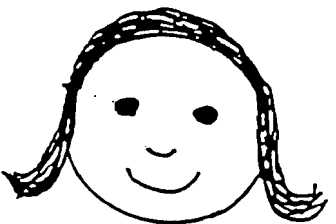
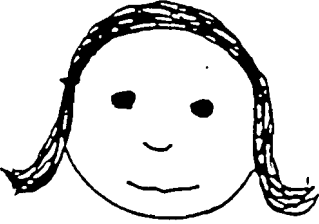
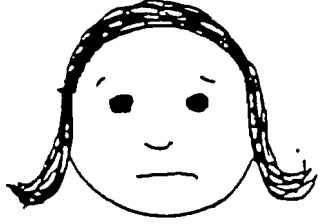
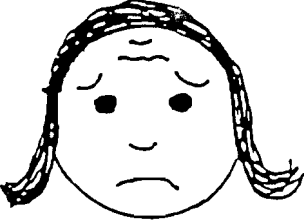
Participant Number _____ Sibling Disability _____
Date of Birth _____ Age of Sibling _____
Date of Administration _____ Gender of Sibling _____
Researcher _____ Number of Siblings _____

General Directions:

Each item will be presented in the format shown below. The child will be asked to indicate which child they are most like by placing a sticker in the corresponding box. The sex of the hypothetical child and their sibling will be matched to each individual participant and their sibling. The experimenter will instruct the child with the following:

"Sometimes children worry about a lot of different things. I am going to ask you about some of the things you might worry about. Some of these are things you probably don't worry about, and you might even think they are sort of silly. But some of these are things that you probably do worry about. There are no right or wrong answers about these worries. If there is an item you don't want to answer, you don't have to and if you don't understand something or have a question, please ask me. Are you ready to begin?"

Some kids worry that they might catch autism from their sister .



This girl really worries.

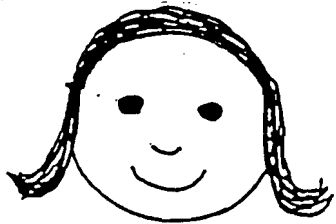
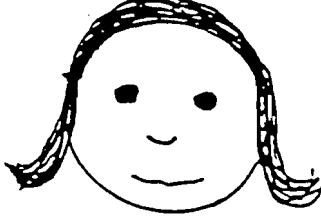
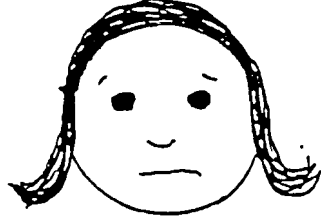
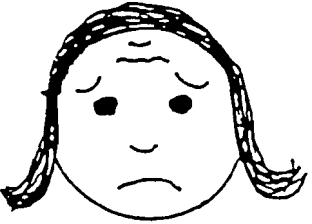
This girl kind of worries.

This girl worries just a little bit.

This girl doesn't worry.

Which one are you most like?

Some kids worry that they will get punished because of something their sister did .



This boy really worries.

This boy kind of worries.

This boy worries just a little bit.

This boy doesn't worry.

Which one are you most like?

2 [For a girl with a sister who has autism]

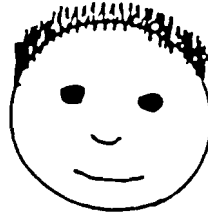
Some kids worry that they have to do extra well in school to make up for what their brother can't do .



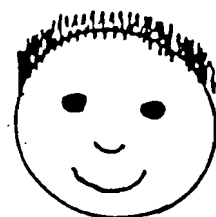
This boy really worries.



This boy kind of worries.



This boy worries just a little bit.



This boy doesn't worry.

Which one are you most like?

39

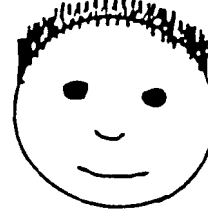
Some kids worry that their extended family members don't really understand their brother .



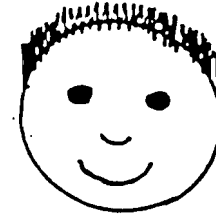
This boy really worries.



This boy kind of worries.



This boy worries just a little bit.



This boy doesn't worry.

Which one are you most like?

40

[for a boy with a brother who has autism]

Some kids worry that they aren't nice enough to their brother .



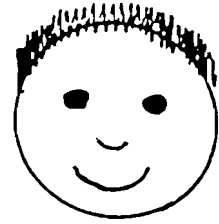
This boy really worries.



This boy kind of worries.



This boy worries just a little bit.



This boy doesn't worry.

Which one are you most like?

41

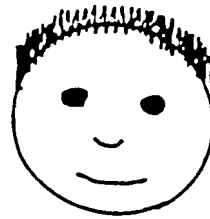
Some kids worry that other kids think they are weird because of their brother .



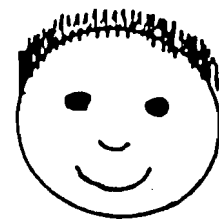
This boy really worries.



This boy kind of worries.



This boy worries just a little bit.



This boy doesn't worry.

Which one are you most like?

42

Autism Worries Survey
(Parent Version)

Directions: Read the following items and respond to show how much your child worries. Answer as best you can. If you don't know, circle D/K.

- 1=doesn't worry
- 2=worries just a little bit
- 3=kind of worries
- 4=really worries
- d/k= don't know

How much does your child worry that _____

| | Doesn't Worry | | Really Worries | | | |
|--|------------------|---|-------------------|---|--|-----|
| | 1 | 2 | 3 | 4 | | |
| 1. He/she might catch autism from his/her sibling. | 1 | 2 | 3 | 4 | | D/K |
| 2. He/she might get punished because of something his/her sibling did. | 1 | 2 | 3 | 4 | | D/K |
| 3. Something he/she did, said, or thought caused his/her sibling's autism. | 1 | 2 | 3 | 4 | | D/K |
| 4. His/her sibling will hurt him/herself. | 1 | 2 | 3 | 4 | | D/K |
| 5. His/her mom or dad worries too much about his/her sibling. | 1 | 2 | 3 | 4 | | D/K |
| 6. His/her parents don't love him/her as much as they love his/her sibling. | 1 | 2 | 3 | 4 | | D/K |
| 7. His/her family can't do things that other families do because of his/her sibling. | 1 | 2 | 3 | 4 | | D/K |
| 8. Other kids might tease him/her about his/her sibling. | 1 | 2 | 3 | 4 | | D/K |
| 9. His/her sibling will act weird in front of other people. | 1 | 2 | 3 | 4 | | D/K |
| 10. He/she will have to take care of his/her sibling when they are older. | 1 | 2 | 3 | 4 | | D/K |
| 11. He/she might also have autism. | 1 | 2 | 3 | 4 | | D/K |
| 12. His/her sibling will break his/her things. | 1 | 2 | 3 | 4 | | D/K |
| 13. He/she gets angry at his/her sibling too much. | 1 | 2 | 3 | 4 | | D/K |
| 14. His/her sibling will get lost. | 1 | 2 | 3 | 4 | | D/K |
| 15. His/her mom/dad can't handle his/her sibling's problems. | 1 | 2 | 3 | 4 | | D/K |

| | Doesn't Worry | | | Really Worries | |
|--|------------------|---|---|-------------------|------|
| 16. He/she doesn't get enough attention from his/her parents because his/her sibling needs so much of their attention. | 1 | 2 | 3 | 4 | D/K |
| 17. He/she can't talk to his/her parents about his/her sibling's autism. | 1 | 2 | 3 | 4 | D/K |
| 18. He/she doesn't have very many friends because his/her sibling has autism. | 1 | 2 | 3 | 4 | D/K |
| 19. People say bad things about his/her sibling. | 1 | 2 | 3 | 4 | D/K |
| 20. His/her sibling will never be able to have a job when he/she is older. | 1 | 2 | 3 | 4 | D/K |
| 21. He/she is going to eventually get autism | 1 | 2 | 3 | 4 | D/K |
| 22. His/her sibling will hurt him/her. | 1 | 2 | 3 | 4 | D/K |
| 23. Something bad will happen to his/her sibling while he/she is taking care of them. | 1 | 2 | 3 | 4 | D/K |
| 24. His/her sibling's teachers don't take care of them as well as they should. | 1 | 2 | 3 | 4 | D/K |
| 25. If his/her parents knew how he/she really feels about his/her sibling, they would be upset. | 1 | 2 | 3 | 4 | D/K |
| 26. His/her parents spend too much money on his/her sibling and there won't be enough left for him/her. | 1 | 2 | 3 | 4 | D/K |
| 27. His/her family fights too much about his/her sibling | 1 | 2 | 3 | 4 | D/K. |
| 28. He/she can't talk to his/her friends about his/her sibling. | 1 | 2 | 3 | 4 | D/K |
| 29. His/her sibling will misbehave in a public place. | 1 | 2 | 3 | 4 | D/K |
| 30. If he/she has children when he/she grows up, the children might have autism. | 1 | 2 | 3 | 4 | D/K |
| 31. If his/her sibling somehow got well, he/she might get sick. | 1 | 2 | 3 | 4 | D/K |
| 32. His/her sibling will hurt someone else. | 1 | 2 | 3 | 4 | D/K |
| 33. He/she has to do more chores around the house because his/her sibling has autism. | 1 | 2 | 3 | 4 | D/K |

| | Doesn't Worry | | Really Worries | | |
|--|---------------|---|----------------|---|-------|
| | 1 | 2 | 3 | 4 | D/K |
| 34. Something bad might happen to his/her sibling. | 1 | 2 | 3 | 4 | D/K |
| 35. He/she has to take care of his/her mom or dad a lot. | 1 | 2 | 3 | 4 | D/K |
| 36. His/her parents don't spend enough time with him/her because they are busy with his/her sibling | 1 | 2 | 3 | 4 | D/K |
| 37. His/her sibling will mess up their family's plans. | 1 | 2 | 3 | 4 | D/K |
| 38. If he/she have friends come over, his/her sibling will do something embarrassing. | 1 | 2 | 3 | 4 | D/K |
| 39. He/she has to do extra well in school to make up for what his/her sibling cannot do. | 1 | 2 | 3 | 4 | D/K |
| 40. His/her extended family members don't really understand his/her sibling. | 1 | 2 | 3 | 4 | D/K |
| 41. He/she isn't nice enough to his/her sibling. | 1 | 2 | 3 | 4 | D/K |
| 42. Other kids think he/she is weird because of his/her sibling. | 1 | 2 | 3 | 4 | D/K |
| 43. People stare at his/her sibling. | 1 | 2 | 3 | 4 | D/K |
| 44. His/her sibling will not be able to live on his/her own when he/she is older. | 1 | 2 | 3 | 4 | D/K |
| 45. Other kids think his/her sibling is weird. | 1 | 2 | 3 | 4 | D/K |
| 46. His/her sibling will embarrass him/her in public. | 1 | 2 | 3 | 4 | D/K |
| 47. His/her sibling's autism might be a punishment from God. | 1 | 2 | 3 | 4 | D/K |
| 48. If kids at his/her school knew about his/her brother/sister, the kids would think or say bad things. | 1 | 2 | 3 | 4 | D/ K |
| 49. His/her brother/sister won't ever talk or won't talk much. | 1 | 2 | 3 | 4 | D/K |
| 50. His/her brother/sister has too many bad habits. | | 1 | 2 | 3 | 4 D/K |
| 51. He/she doesn't understand what his/her brother/sister feels. | 1 | 2 | 3 | 4 | D/K |
| 52. His/her brother/sister might get worse. | 1 | 2 | 3 | 4 | D/K |

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| 53. That they might do something to set their brother/sister off. | 1 | 2 | 3 | 4 | D/K |
| 54. He/she can't figure out what is wrong when his/her brother/sister is upset. | 1 | 2 | 3 | 4 | D/K |
| 55. He/she doesn't know what his/her brother/sister wants. | 1 | 2 | 3 | 4 | D/K |
| 56. His/her brother/sister can't explain what is wrong with him/her. | 1 | 2 | 3 | 4 | D/K |
| 57. He/she has to be extra careful around his/her brother/sister. | 1 | 2 | 3 | 4 | D/K |