

## **Sources of Information and Support Used by Parents of Children with Autism Spectrum Disorders**

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### **Abstract**

*Parents (n=498) of children with autism spectrum disorders (ASD) reported via web-based questionnaires what sources they use for information (M=6.9; range 0 - 15) and support (M=5.9, range 0 - 16). The most frequent source of both information and support was other parents of children with ASD. Lower-income parents used fewer information sources and reported fewer supports than middle or upper income parents. In particular, lower-income parents were less likely to attend group gatherings around autism issues.*

Parents of children with autism spectrum disorders (ASD) have the complex task of raising children who have communication deficits, difficulties in social interactions, challenging behaviours, and an uncertain future. There is a high level of ambiguity that comes with an ASD diagnosis because of the heterogeneity in abilities and the controversies regarding etiology and treatment (Howlin, 1998). No one can tell parents with complete confidence what the future holds for their children or what treatments they should use. When trying to determine how to best meet their children's needs, parents are faced with an ever-expanding wealth of information regarding ASD. New treatments, dietary programs, medications, and educational interventions are constantly being introduced, and parents may feel personally responsible to stay up with every advance. Just sifting through the onslaught of information can be daunting (Schopler, 1995). Studies in peer-reviewed journals are available in university libraries and sometimes online, but while these provide scientifically sound findings, they are neither available to everyone nor easy to understand. Books, magazine articles, newspaper stories, and television programs provide information that may or may not be reliable. Literally millions of Internet websites deal with autism – some with solid information and some that are useless or even harmful – but because there are so many sites, it is hard to sort through them. Conferences and workshops bring parents the latest information on research, treatments, and educational options, as well as a chance to meet and talk with other parents, but not all parents are able to attend. Parents are hungry

for information but can feel flooded with the process of seeking that which is accurate and most helpful to their families, and they surely cannot absorb all that is available. Physicians can be a source of information, though pediatricians vary widely in their knowledge of ASD (Shah, 2001).

In a small ( $n=20$ ) qualitative study, Pain (1999) found that parents of children with disabilities experience this information seeking as a mixed benefit. Knowledge is power in that it can provide strategies for parents to access services, manage difficult behaviours, and adjust emotionally to their children's disabilities. However, some parents found that the information increased their anxieties if it painted a bleak picture of the future, or outlined services that were not available in their community (Pain, 1999). A question unexplored on a larger scale, and one addressed in the present study, is what sources parents turn to for information about autism. This is examined in relation to children's autism spectrum diagnoses and parents' income level.

A second interest is where parents of children with ASD get their personal support. Mothers of children with autism have been identified as experiencing higher levels of stress than mothers who have children with other disabilities (Abbeduto, et al., 2004; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hodapp, 2002). Studies show that families who cope well have higher levels of social support (Sivberg, 2002; Weiss, 2002). These supports can include ones that were in place prior to the birth of the child (family and friends) as well as ones that develop after the diagnosis (such as professionals and other parents of children with ASD) (Sander & Morgan, 1997). We were interested in where parents of children with varying ASD diagnoses and from different income groups get their support.

As part of a web-based study, parents were asked to self-report their sources of information and support regarding their children's autism spectrum disorder. A web-based methodology was used in order to reach a large number of participants. Recent evidence shows web-based-questionnaire findings to be as reliable as traditional formats (Gosling, Vazire, Srivastava & John, 2004; Kraut, et al., 2004) and that they are especially useful in accessing hard to find populations.

## **Method**

### **Participants**

Participants were parents of 498 children (80% boys) with autistic spectrum disorders and specifically diagnosed with either autism ( $n=298$ , 59.8%), Asperger syndrome ( $n=117$ , 23.5%), or Pervasive Developmental Disorder

- Not Otherwise Specified (PDD-NOS,  $n=83$ , 16.7%). Children averaged 8.6 years and were primarily between 3 and 11 years old (75%). Just 4 children were 2 years or younger and 9 individuals were age 20 or older at the time of the survey. The majority of parents indicated their children's race as white (86.7%), with 6% biracial, 2% African American, 2.2% Hispanic, and 2.8% Asian, Native American, or some other race.

The parents were from almost all states in the U.S. (77%) as well as from Canada, Australia, New Zealand, England, and Ireland (18%); 5% did not report their locale. Most of the reports came from mothers (92.3%). Parents reported their approximate annual income ( $n=470$ , 94.4%) and, for this report, groups were organized into lower, medium, and upper-income brackets. Families with incomes less than \$10,000 ( $n=10$ , 2%) or from \$10,000 to \$25,000 ( $n=56$ , 12%) were grouped as lower-income ( $n=66$ , 14%). Families reporting incomes of \$25,000 to \$40,000 ( $n=83$ , 17.7%) or \$40,000 to \$55,000 ( $n=70$ , 14.9%) were grouped as medium-income ( $n=153$ , 32.6%). Families reporting incomes of \$55,000 to \$70,000 ( $n=79$ , 16.8%), \$70,000 to \$100,000 ( $n=87$ , 18.5%) or more than \$100,000 ( $n=85$ , 18.1%) were grouped as upper-income ( $n=251$ , 53.4%)

### **Procedure**

Data were collected anonymously through a web-based questionnaire. The questionnaire followed Dillman's (2000) recommendations regarding simplicity of web-based questions and question formats. Two mothers of children with autism worked with researchers to ensure that questions and response options were clear and appropriate.

To reach potential participants, study notices appeared in newsletters, web pages, and e-mail list-serves of autism-related organizations. More than 220 such organizations (e.g., local chapters for the Autism Society of America, National Autistic Society) in the U.S. and 7 other English-speaking countries were contacted and asked to disseminate information about the study. Many provided direct electronic links to the study web page, while others informed parent members via paper newsletters. Parents went to the questionnaire website, where they were provided with a description of the investigation and informed consent information. Parent participants described their children and indicated what sources of information and support they used by ticking boxes in relevant checklists. Submitted questionnaires were transferred to a database for later statistical analysis. All data were screened for potential false respondents or repeat reporters; none occurred. The university IRB approved the study protocol. Families received no payment or other benefit for cooperating with the study.

## Results

### Information Sources

*Number of information sources.* On average, parents reported getting information about autism spectrum disorders from nearly 7 different sources ( $M=6.9$ ;  $SD=2.8$ ; Range: 0 - 15, Figure 1 and Table 1). This number differed by child's diagnostic group,  $F(2,495)=6.147$ ,  $p<.002$ , with the autism group ( $M=7.3$ ) using more information sources than either the Asperger ( $M=6.3$ ) or the PDD-NOS ( $M=6.6$ ) groups ( $p<.05$ , LSD). The total number of information sources also differed by parent income group,  $F(2, 467)=5.138$ ,  $p<.006$ , with the lower income group ( $M=5.9$ ) using fewer information sources than either the middle ( $M=7.0$ ) or upper ( $M=7.2$ ) income groups ( $p<.05$ , LSD), and the latter two groups not differing significantly.

Table 1: Information sources used by parents of children with autistic spectrum disorders

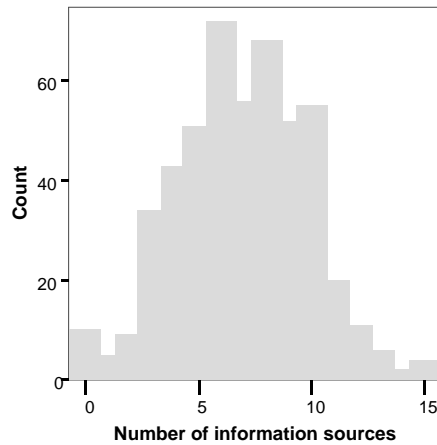
	Diagnostic groups				Income groups			
	Total	Autism	Asperger	PDD-NOS	Total	Low	Medium	High
<i>Number of information sources</i>								
n	498	298	117	83	470	66	153	251
Mean	6.9	7.3	6.3	6.6	6.9	5.9	7	7.2
SD	2.8	2.9	2.7	2.8	2.8	2.7	2.7	2.8
<i>Specific information sources</i>								
	Percentage				Percentage			
<i>Personal relationships</i>								
Other parents of children w/ ASD	72	72	70	72	71	53	69	77
Family members	17	20	9	14	17	18	20	14
Spouse or partner	19	24	9	17	19	12	18	21
Friends, neighbors	17	19	13	13	17	9	20	16
<i>Professional relationships</i>								
Physicians	48	52	41	47	49	45	52	48
Educators	49	55	33	51	50	47	52	55
Other professionals	57	58	58	53	58	53	58	59

continued

Table 1 (cont'd)

<i>Specific information sources</i>	<i>Percentage</i>				<i>Percentage</i>			
<i>Written sources</i>								
Books	88	89	88	86	88	86	86	90
Scientific journals	44	46	43	40	44	30	44	49
Web pages	86	87	84	88	87	89	87	87
Autism newsletters	69	71	63	67	69	62	70	71
<i>Group gatherings</i>								
Conferences	48	51	43	46	47	29	44	54
Workshops	43	47	37	37	42	26	45	45
Autism group meetings	44	48	37	41	43	23	46	47

Figure 1. Total number of information sources used by parents of children with ASD



*Use of specific information sources.* Table 1 shows the percentage of parents who reported using specific sources of information, both for the total sample and for subgroups based on child's diagnosis and parental income. Among personal and professional relationships, the largest source of information was other parents of children with ASD (72%). "Other parents"

were relied upon for information more often than any other personal relationship, including family members (17%), spouses (19%), or friends/neighbors (17%), as well as more often than any professionals, including physicians (48%), educators (teachers) (49%), and other autism professionals (e.g., early interventionists, speech, occupational therapists, psychologists, etc.) (57%). Parents obtained much of their information from written sources. Books were cited by the highest percentage of parents (88.0%), followed closely by web pages/e-mail list-serves (86%), as well as autism newsletters (69%) and scientific journals (44%). Group gatherings were sources of information for a little less than half of the parents, with 48% citing conferences, 43% workshops, and 44% autism-group or organizational meetings.

*Group differences in use of information sources.* The specific sources that parents used for information differed somewhat in relation to their children's diagnosis. Parents of children with autism more often got information from family members,  $F(2,495)=3.914$ ,  $p<.02$ , and from spouses,  $F(2, 495)=6.914$ ,  $p<.001$ , than did those from either the Asperger or PDD-NOS groups, and parents of children with Asperger syndrome less often got information from educators,  $F(2, 495)=8.417$ ,  $p<.0001$ , relative to parents from the other two diagnostic groups (contrasts each  $p<.05$ , LSD).

Other differences existed in relation to income. The lower-income parents were less likely to use specific resources in three areas – personal relationships, written materials, and group meetings – than the medium- and upper-income parents. Specifically, lower-income parents were less likely to get information from other parents of children with autism,  $F(2,467)=7.67$ ,  $p<.001$ ; scientific journals,  $F(2,467)=3.60$ ,  $p<.028$ ; conferences,  $F(4, 267)=7.07$ ,  $p<.001$ ; workshops,  $F(2,467)=4.27$ ,  $p<.01$ ; and autism-group meetings,  $F(2,467)=6.73$ ,  $p<.001$  than did the middle- and upper-income groups, which did not differ significantly.

### **Sources of Support**

On average, parents reported relying on between 5 and 6 different sources of support ( $M=5.9$ ,  $SD=3.4$ , Table 2 and Figure 2). This number did not differ significantly by child's diagnosis. Number of supports differed by parent income group,  $F(2,467)=4.25$ ,  $p<.01$ , with parents in the lower-income group ( $M=4.8$ ) utilizing fewer supports than either the middle- ( $M=6.2$ ) or upper- ( $M=6.1$ ) income groups ( $p<.05$ , LSD), with the latter two groups not differing significantly (contrasts each  $p<.05$ , LSD).

Table 2: Sources of support used by parents of children with autistic spectrum disorders

	<i>Diagnostic groups</i>				<i>Income groups</i>			
	<i>Total</i>	<i>Autism</i>	<i>Asperger</i>	<i>PDD-NOS</i>	<i>Total</i>	<i>Low</i>	<i>Medium</i>	<i>High</i>
<i>Number of supports</i>								
n	498	298	117	83	470	66	153	251
Mean	5.9	6.1	5.5	5.4	5.9	4.8	6.2	6.1
SD	3.4	3.4	3.3	3.4	3.4	3.2	3.1	3.5
<i>Sources of support</i>								
	<i>Percentage</i>				<i>Percentage</i>			
<i>Personal relationships</i>								
Other parents of children w/ ASD	68	71	65	65	69	48	68	74
Family members	53	58	41	51	54	53	54	54
Spouse or partner	56	60	46	54	56	36	53	63
Friends, neighbors	43	45	38	40	43	29	48	44
Religious community	17	19	12	14	17	18	18	16
<i>Professional relationships</i>								
Physicians	36	37	36	34	37	39	38	36
Educators	48	51	42	47	49	44	44	53
Other professionals	46	47	50	40	47	35	52	47
<i>Written sources</i>								
Books	28	30	29	23	29	32	30	28
Scientific journals	7	7	8	6	7	6	8	7
Web pages	43	41	49	45	44	41	48	43
Autism newsletters	30	30	30	28	30	29	33	29
<i>Group gatherings</i>								
Conferences	23	22	24	24	23	9	25	26
Workshops	21	22	21	17	21	9	22	24
Autism group meetings	37	39	33	36	36	21	42	37

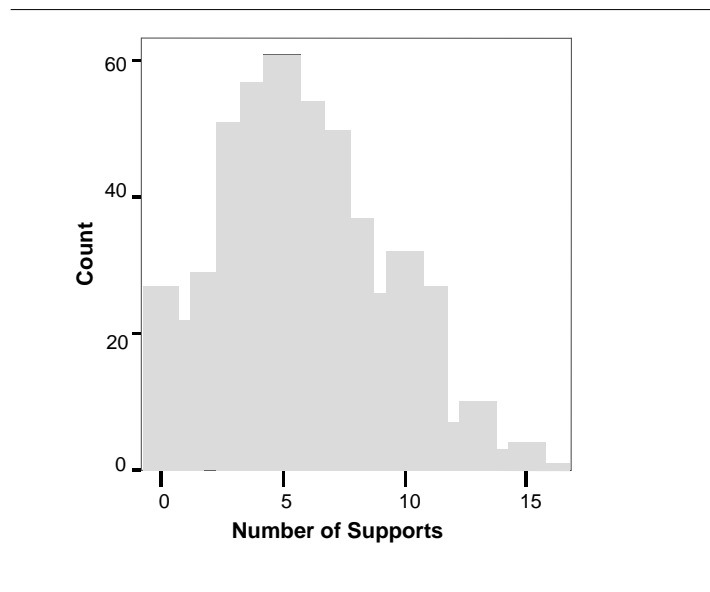
*Use of specific support sources.* Table 2 lists the percentage of parents who reported using each support, overall and by child's diagnosis and parents' income group. Personal relationships were a large source of support. The most common source of support was other parents of children with ASD

(68%). Just over half of the participants viewed a spouse or partner (56%) as providing support; however, this differed by marital status, with 63% of married parents reporting support from their spouses and 24% of not-married parents reporting support from a partner. Family members were seen as supports for about half of the sample (53%). Fewer saw their friends or neighbors (43%) as supports, and fewer still regarded their religious community as a support (17%).

Professional relationships provided support to some parents. About half saw educators (48%) and other professionals (46%) as sources of support. About a third (36%) viewed their children's physicians as a source of support.

Written sources were considered as support sources by some parents. Web pages, in particular, were considered a support to 43%, followed by newsletters (30%) and books (28%).

Figure 2. Total number of sources of support used by parents of children with ASD



*Group differences in specific supports used.* Fewer parents of children with Asperger syndrome reported support from either family members,  $F(2, 496)=5.279$ ,  $p<.005$ , or spouses,  $F(2,496)=3.557$ ,  $p<.03$ , than did parents of children with either autism or PDD-NOS (contrasts each  $p<.05$ , LSD).



Lower-income parents were less likely to report receiving support from 2 personal resources – other parents of children with autism,  $F(2,467)=8.191$ ,  $p<.0001$ , and friends and neighbors,  $F(2,467)=3.679$ ,  $p<.03$ , – than either the middle- or upper-income groups (contrasts each  $p<.05$ , LSD). (Although it initially appears that lower-income parents received less support from a spouse or partner,  $F(2,467)=7.829$ ,  $p<.0001$ , this difference disappears when only married parents are examined. Fewer lower-income parents were married [48%] than the middle- [72.5%] or upper-income [93.6%] parents.) There were no group differences for support from professionals. The lower-income group was less likely to feel support from all three of the group meeting sites – conferences ( $F(2,467)=4.501$ ,  $p<.02$ ), workshops, ( $F(2,467)=3.515$ ,  $p<.03$ ) and autism group meetings ( $F(2,467)=4.338$ ,  $p<.02$ ; contrasts each  $p<.05$ , LSD), – than middle- or upper-income families.

## Discussion

This large, web-based sample provided a look at where parents of children with ASD turn for information and support. Clearly these parents felt the necessity to stay up with advances in what is known about autism and what might help their children. This pursuit of information no doubt adds a time demand on parents who already have their hands full. Yet this seeking out of information may also provide a coping mechanism, allowing the parents to feel more knowledgeable and in control in the face of their children's disabilities (Goldbeck, 2001; Pain, 1999).

Our findings provide evidence that lower-income parents are at a disadvantage in terms of both information and support. They are less likely than middle- and upper-income families to gain either information or support by attending workshops, conferences, and autism support groups. Attending workshops and conferences costs money for registration and sometimes for travel and hotels. Indeed, one stereotype about autism is that it affects only upper-income children; this misperception may come about in part because these wealthier families are more visible at conferences and other public events focused on autism. Local autism support groups are free of charge, but financial restraints can create barriers for low-income families to attend support groups and other events that incur a fee (Biegel, Shafran, & Johnson, 2004). With less access to organized events and the chance to meet other parents attending these meetings, the lower-income participants were also less likely to report that they turned to other parents of children with ASD for information or support. Fewer lower-income parents were married than in the middle- or upper-income groups. Their single-parent

status no doubt contributes as well to their not being able to attend organized events and meetings, for there is no spouse to watch the children and reliable childcare for their special-needs child could be both hard to find and too expensive. In addition, the lower-income parents were less likely to find their friends and neighbors to be a support.

One notable finding is the degree to which parents counted on other parents for both information and support. Other parents of children with ASD were reported as sources of information more often than any group of professionals – physicians, educators, or autism specialists. Other parents were also cited as the most common source of support, surpassing spouses, family members, friends and neighbors, and religious communities. The "walking in our shoes" factor is no doubt important here. Families' religious communities trailed in with only about one in six parents reporting them as supportive. Interestingly, written sources-books, web pages, and newsletters-were noted as sources of support and not just as information.

A question that remains unanswered is the degree to which the information parents receive is accurate and helpful. Parents are clearly hungry for information and support, and yet they likely receive both information and misinformation. With other parents, books, and websites outranking professionals as information sources, the validity of that information might be in question. Also unanswered is the perceived adequacy of parents' support. The top 5% said they used 12 or more sources of support, while the bottom 5% reported having no supports whatsoever. The number of supports cannot speak, however, to whether that support feels like "enough."

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The number of children diagnosed with an Autism Spectrum Disorder has increased dramatically in the last 20 years. Parents of children with autism experience a variety of chronic and acute stressors that can erode marital satisfaction and family functioning. Family therapists are well-suited to help parents stay connected to each other as they create a "new normal." However, family therapists need updated information about autism, and they need to understand how family therapy can help parents of children with autism. Because having a child with autism affects multiple domains of family functioning, family therapists need to be aware of the emotional difficulties that children with autism spectrum disorders may have difficulty regulating their emotions or expressing them appropriately. For instance, your child may start to yell, cry, or laugh hysterically for no apparent reason. When stressed, he or she may exhibit disruptive or even aggressive behavior (breaking things, hitting others, or harming him or herself). (Center for Parent Information and Resources). Screening and Diagnosis "A guide to the evaluation used to diagnosis autism spectrum disorder. (Centers for Disease Control and Prevention). Asperger's Syndrome "Diagnosis, educational issues, and what the disorder looks like in adults.