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Internet survey of treatments used by parents of children with autism

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Abstract

We developed an Internet survey to identify treatments used by parents of children with autism. The survey listed 111 treatments and was distributed via colleagues and through chapters of the Autism Society of America and Autism Organizations Worldwide. A total of 552 parents submitted usable returns during the 3-month survey period. On average the parents reported using seven different treatments. The number of treatments used varied as a function of the child's age and type/severity of disability within the autism spectrum. Speech therapy was the most commonly reported intervention, followed by visual schedules, sensory integration, and applied behavior analysis. In addition, 52% of parents were currently using at least one medication to treat their child, 27% were implementing special diets, and 43% were using vitamin supplements. Because parents were using a large number of treatments, many of which lack empirical support, future research should focus on understanding the decision-making processes that underlie treatment selection by parents of children with autism.

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Since Kanner first described autism in 1943, numerous treatments have been proposed to ameliorate the neurological, behavioral, and developmental problems associated with it and related disorders (Matson, 1994). Some treatments (e.g.,

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fenfluramine) initially appeared promising, but have since proven to have too many problematic side effects (Kerbeshian, Burd, & Avery, 2001). Other treatments have proven to be largely ineffective, but surprisingly many of these continue to be promoted by some clinicians. Examples of treatments that lack empirical support include auditory integration training (Gillberg, Johansson, Steffenburg, & Berlin, 1997), facilitated communication (Mostert, 2001), and holding therapy (Tinbergen & Tinbergen, 1983). There are also a number of empirically validated treatments. Examples of empirically supported approaches include a range of procedures based on the principles of applied behavior analysis (Lovaas & Smith, 2003) and the TEACCH program (Mesibov, 1997). Given these numerous options, it would seem important to review the evidence for commonly used treatments.

Along these lines, Heflin and Simpson (1998) reviewed 32 interventions that they believed to be commonly used in the education and treatment of children with autism. Their list of commonly used treatments included procedures representing a range of approaches, including (a) bio-medical (e.g., medications, mineral supplements, diets), (b) physiological (e.g., sensory integration, auditory integration, rhythmic entrainment), (c) relationship based (e.g., holding therapy, floor time, gentle teaching), (d) skills-based interventions (e.g., applied behavior analysis, social stories), and (e) combined programs incorporating a range of procedures (e.g., TEACCH). They found that while several of these treatments were promising or had substantial supporting evidence, many other treatments were ineffective or had no empirical support, despite claims by advocates to the contrary.

While Heflin and Simpson (1998) provided a balanced and objective critique, their selection of treatment options to review was limited to “programs and methods that, in [their] opinion, [were] most commonly applied in practice and most frequently discussed in the literature” (p. 195). However, the extent to which these 32 treatments are in fact commonly used has not been empirically verified. Indeed, there appear to be no empirical studies into the number and types of the treatments being used by parents of children with autism, despite the fact that many parents are implementing home-based treatment programs (Johnson & Hastings, 2002; Sheinkopf & Siegel, 1998). In addition, new, yet unproven treatments such as rapid prompting (Samango-Sprouse, 2004) have emerged since the publication of Heflin and Simpson’s (1998) review, but the extent to which parents are using emerging treatments is unknown.

Given this lack of data, it is important to document the number and types of treatments being used by parents of children with autism. Data of this type may enable professionals to provide parents with the information needed to make more informed choices about treatment selection and promote evidence-based practice. By documenting treatments currently being used by parents, the research community may also be alerted to commonly used treatments that have yet to be examined in controlled scientific studies.

The present study represents a preliminary attempt to document the number and types of interventions, programs, and therapies being used by parents in the treatment of their children with autism. In addition to identifying treatments used by parents, we also sought to determine whether certain parent or child characteristics influenced the number and types of treatments used.

1. Method

The aim of the survey was to document the number and types of procedures, programs, or approaches used by parents in the treatment of their children with autism. To achieve this aim, we developed an Internet survey and distributed this to parents via national and international autism organizations and colleagues.

1.1. Survey development

The survey presented parents with a comprehensive list of treatment options. This list was derived by supplementing the procedures and programs reviewed by Heflin and Simpson (1998), with additional treatments listed in the MEDLINE and PsycINFO databases. Both databases were searched by inserting the terms *autism* and *treatment* into the Abstract field. A total of 510 and 1154 records were returned from MEDLINE and PsycINFO, respectively. Each abstract was examined and when a treatment for autism was specified, it was added to the draft survey.

The final survey listed 111 treatments, which were grouped under several categories for organizational purposes. The categories included: (a) medications (e.g., anticonvulsants, antidepressants), (b) vitamin supplements, (c) special diets, (d) medical procedures, (e) educational/therapy approaches (e.g., applied behavior analysis, speech therapy, music therapy), (f) alternative therapy/medicine (e.g., acupuncture, aromatherapy), and (g) combined programs (e.g., Baudhuin preschool, giant steps, TEACCH).

For each treatment option, parents were asked to indicate whether: (a) they were currently using the treatment, (b) had used the treatment in the past, but were not currently using it, or (c) had never used the treatment. Additional spaces were provided for parents to add additional treatments and make comments. A copy of the survey is available from the first author.

1.2. Pilot testing of the Internet survey

Five parents of children with autism completed an initial version of the survey. These five parents were sent an e-mail including an attachment of the survey. They were asked to complete the survey and provide feedback on its content and format. These five parents reported that the survey content was comprehensive and the format made it easy to complete. In response to their comments, we made a few minor changes to the wording of items. University staff then tested the online version of the survey. The pilot testing confirmed that the survey could be accessed and completed online using the provided link and that returns would be received and entered into our online database.

1.3. Survey distribution

After pilot testing, the survey was distributed via chapters of the Autism Society of America (ASA), which were located on the ASA website [<http://www.autism-society.org/site/PageServer>], chapters of Autism Organizations Worldwide (AOW), which were located on the AOW website [<http://www.autism-india.org/worldwideorgs.html>], and

colleagues. For the two organizations, the following process was used. First, webpages for individual chapters of the Autism Society of America and Autism Organizations Worldwide were examined to obtain contact e-mail addresses. We were specifically interested in obtaining the contact e-mail addresses for either the president, secretary, or other named contact person for as many individual chapters as possible. Second, once a contact e-mail address was located, we sent the contact person a 134-word e-mail describing the survey, providing the URL link to the survey, and asking the contact person to inform their parent members about the survey. A similar e-mail was sent to seven colleagues in the USA ($n = 3$), UK ($n = 2$), Australia ($n = 1$), and New Zealand ($n = 1$) who we knew had contact with families of children with autism.

In total, 87 initial e-mail messages were distributed over a 3-week period to launch the survey. Once the survey was launched, it remained open for a 3-month period. Following the initial distribution of the survey, we began to receive numerous e-mails from parents who wanted to complete the survey. These parents were sent an e-mail containing the details necessary to complete the survey.

The survey website contained an introductory page which provided information about the study; including details about IRB approval, a consent statement, and the names of the principle researchers. Once a parent completed a survey, the file was automatically entered into a database using FileMaker Pro[®] software. When the 3-month period expired, the complete set of files was exported into a statistical software package (SPSS[®]) for data analysis.

2. Results

2.1. Number of submissions

A total of 764 surveys were submitted to the website during the 3-month data collection period. However, only 552 were considered usable (e.g., the record included at least some demographic information and the respondent had indicated that they had used or were currently using at least one treatment). The analyses reported next were therefore based on the 552 usable submissions.

2.2. Characteristics of the respondents

2.2.1. Gender of the respondents

Of the 552 submissions, 548 (99%) of the respondents included data on their gender. Four respondents did not indicate their gender. Of the 548 respondents who indicated their gender, 499 (91%) were female and 49 (9%) were male.

2.2.2. Educational level of respondents

Educational level was indicated on 546 of the 552 submissions (99%). Of these 546, the majority of respondents ($n = 481$, 88%) indicated that they had attained an education level beyond high school, whereas 57 or 10% of the 546 respondents indicated that they had a

High School Diploma or equivalent. The remaining eight respondents (2%) indicated that their education level was less than high school.

2.2.3. *Geographic location of respondents*

When asked to indicate their country of residence, 540 of the 552 respondents (98%) provided data. Most of these 540 respondents lived in the United States of America ($n = 434$, 80%). The next largest groups lived in Canada ($n = 37$, 7%), Australia ($n = 25$, 5%), New Zealand ($n = 13$, 2%), and the Philippines ($n = 8$, 1.5%). The remaining 23 respondents lived in 1 of 11 additional countries: Afghanistan, Albania, Algeria, Denmark, Egypt, Iceland, India, Israel, Malaysia, South Africa, and the United Kingdom.

2.3. *Characteristics of the respondents' children*

2.3.1. *Age*

The age of the children for whom the surveys were completed was indicated on all 552 submissions. Roughly one-third of the children ($n = 190$, 34%) were 5 years of age or less. Another third ($n = 201$, 36%) were 6–10 years of age. Children in the next (11–14 years old) age group comprised 18% of the sample ($n = 97$). The remaining 64 children (12%) were 15 years of age or older.

2.3.2. *Gender*

The gender of the children for whom the surveys were completed was indicated on 548 or 99% of the 552 submissions. The gender was not specified for four children. This sample of 548 included 463 males (84%) and 85 females (16%). Due to the relatively small number of girls in the sample, the data for both boys and girls were combined for analyses.

2.3.3. *Type and severity of disability*

Parents were asked to indicate the type and severity of their child's disability by indicating if the child had a diagnosis of either (a) Asperger's syndrome, (b) mild autism (i.e., high functioning autism), or (c) severe autism (i.e., the child did not speak). Of the 552 submissions, parents provided information on type/severity of disability in 539 cases (98%). Of these 539 cases, 91 children (17%) were recorded as having Asperger's syndrome, 330 (61%) were said to have mild/high functioning autism, and the remaining 118 (22%) were described as having severe autism as indicated by the lack of speech.

2.3.4. *Age by type/severity of disability*

The number of children with Asperger's syndrome, mild, or severe autism was examined for each of the four age groupings as shown in [Table 1](#). The number of children in each age-by-disability cell ranged from 8 to 131. Among the 91 children with Asperger's syndrome, for example, there were relatively fewer children in the youngest age group, but more equal numbers in the three older age groups. A different pattern was obtained among the 330 children with mild or high functioning autism with the largest percentages found within the two youngest age groups. The 118 children with severe autism were evenly distributed across the three youngest groups, however there were very few children in the oldest age group.

Table 1
Demographic characteristics of 539 children with autism

Age group (years)	Type/severity of disability						Total
	Asperger's		Mild		Severe		
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
≤5	8	8.8	131	39.7	44	37.3	183
6–10	36	39.6	124	37.6	37	31.4	197
11–14	25	27.5	46	13.9	24	20.3	95
15–21	22	24.2	29	8.8	13	11.0	64
Total	91		330		118		539

Note: Type/severity of disability was not provided for 13 of the children.

2.4. Most frequently used treatments

Nearly, all ($n = 108$) of the 111 treatments listed in the survey were being used or had been used in the past by at least one parent. A number of “other treatments” were added to the survey by individual parents. Most of these other treatments turned out to be alternative names for medications already listed in the survey. In other cases, parents added specific schools or activities (e.g., gymnastics) that their child attended. A small number of parents (generally five or less) listed a procedure that they were using that had not been included in our original list of 111 treatments (e.g., Reiki therapy, Lekotek therapy). Occupational and/or physical therapy were mistakenly left off the survey and 49 parents said they were currently using one of these two therapies when asked about other treatments.

Table 2 provides a rank ordering for each of the 108 treatments according to the percentage of parents indicating that they were currently using that treatment. Table 2 also shows the percentage of parents who indicated that they had used each treatment in the past and specifies the category that each treatment represented. This categorization is discussed further when considering the data in Table 5. As shown in Table 2, speech therapy was the most commonly used treatment. It was currently being used by 70% of the parents and another 23% of the respondents indicated that they had used speech therapy in the past. After speech therapy, the next most commonly used current treatments included visual schedules, sensory integration, applied behavior analysis, and social stories.

For many of the treatments listed in Table 2, there was an increase in the percentage of parents using that treatment currently as compared to the past. For example, essential fatty acids were used by 15% of participants in the past, but were now being used by 28% of the parents. On the other hand, there was also a noted decrease in the percentage of parents currently using some treatments in comparison to the past. For example, the use of a weighted vest or blanket decreased from 25% of respondents (past) to 12% (current) and use of the vitamin supplement DMG (dimethylglycine) dropped from 27.4% (past) to 14% (current). Auditory integration was also used by a greater percentage of parents in the past (20%) than currently (9%).

Many of the treatments listed in Table 2 were only used by a small percentage of the respondents, including many specific medications. However, the percentage of parents using some type of medication made it one of the more commonly used categories of treatments (see Table 5).

Table 2

Rank order of treatments in terms of percentage of parents reporting use

No.	Treatment name	Category	Percentage of parents	
			Currently using	Used in past
1	Speech therapy	Standard therapy	70.0	23.2
2	Visual schedules	Skills based	43.2	18.6
3	Sensory integration	Physiological	38.2	33.2
4	Applied behavior analysis	Skills—ABA	36.4	22.7
5	Social stories	Skills based	36.1	18.0
6	Vitamin C	Vitamin supplement	30.8	13.4
7	Vitamin B6	Vitamin supplement	30.1	25.7
8	Essential fatty acids	Vitamin supplement	28.7	15.2
9	Picture exchange communication systems	Skills—ABA	27.6	31.1
10	Casein-free diet	Alternative diet	26.8	18.5
11	Magnesium	Vitamin supplement	26.5	17.6
12	Gluten-free diet	Alternative diet	23.1	21.7
13	Vitamin A	Vitamin supplement	22.0	13.0
14	Cognitive/behavioral therapy	Skills—ABA	21.3	16.4
15	Probiotics	Medication (digestive aid)	20.5	10.6
16	Discrete trial training (Lovaas)	Skills—ABA	18.7	20.5
17	Music therapy	Standard therapy	16.0	18.5
18	Mega-vitamin therapy	Vitamin supplement	15.8	20.5
19	TEACCH	Combined program	15.7	14.9
20	DMG (dimethylglycine)	Vitamin supplement	14.0	27.4
21	Floor time	Relationship based	13.0	16.3
22	Weighted vest/blanket	Alternative therapies/medicines	12.8	25.7
23	Augmentative and alternative communication	Skills based	12.6	9.0
24	Melatonin	Medication (sleep aid)	10.8	14.6
25	Risperdal	Medication (antipsychotic)	10.2	12.2
26	Homeopathy	Alternative therapies/medicines	10.2	12.1
27	L-Glutamine	Vitamin supplement	10.1	9.1
28	Conductive education	Physiological	10.0	2.2
29	Gentle teaching	Relationship based	10.0	6.1
30	Facilitated communication	Skills based	9.8	10.2
31	Auditory integration training	Physiological	9.1	21.0
32	Yeast-free diet	Alternative diet	7.6	12.1
33	Chelation	Detoxification	7.4	7.8
34	Rapid prompting	Skills based	7.0	6.0
35	Antihistamine	Medication (sleep aid)	6.7	20.5
36	Visual integration training	Physiological	6.5	6.5
37	Clonidine	Medication (antihypertensive)	6.0	11.8
38	Pyridoxine	Vitamin supplement	5.0	3.9
39	Prozac	Medication (antidepressant)	4.9	10.8
40	Craniosacral manipulations	Alternative therapies/medicines	4.7	8.4
41	Ritalin	Medication (stimulant)	4.6	17.4
42	Nystatin	Medication (antifungal)	4.6	20.6
43	Reduced L-glutathione	Detoxification	4.4	3.2
44	Holding therapy	Relationship based	4.3	8.1

Table 2 (Continued)

No.	Treatment name	Category	Percentage of parents	
			Currently using	Used in past
45	Integrated movement therapy	Physiological	4.3	5.5
46	Infant massage	Alternative therapy/medicine	4.1	19.3
47	Aromatherapy	Alternative therapy/medicine	4.1	4.7
48	Zoloft	Medication (antidepressant)	3.9	6.1
49	Depakote	Medication (anticonvulsant)	3.6	9.3
50	Multisensory environments (Snoezelen)	Physiological	3.5	4.4
51	Adderall	Medication (stimulant)	3.2	13.3
52	Paxil	Medication (antidepressant)	2.8	7.9
53	Feingold diet	Alternative diet	2.7	7.1
54	Transfer factor	Medication (antiviral)	2.4	3.6
55	Dance therapy	Alternative therapy/medicine	2.4	2.5
56	Joint action routines	Skills based	2.2	5.9
57	Tegretal	Medication (anticonvulsant)	2.0	6.1
58	Bolles sensory learning method	Physiological	1.9	2.1
59	Neurofeedback (biofeedback)	Physiological	1.8	2.5
60	Fast forward	Skills based	1.7	4.6
61	Secretin	Medication (digestive aid)	1.6	11.3
62	Irlen lenses	Physiological	1.6	1.6
63	Dexedrine	Medication (stimulant)	1.4	5.9
64	Lindamood bell	Skills based	1.4	1.8
65	Interactive metronome	Physiological	1.4	1.6
66	Pepcid	Medication (digestive aid)	1.2	6.8
67	Bethanechol	Medication (digestive aid)	1.2	3.3
68	Azrin 24-h toilet training	Skills—ABA	1.1	3.8
69	Clonopin	Medication (anticonvulsant)	1.0	3.9
70	Xanax	Medication (anti-anxiety)	1.0	.2
71	Clozapine	Medication (antipsychotic)	1.0	3.4
72	Tenex	Medication (antihypertensive)	1.0	3.0
73	LEAP (Strain & Hoyson, 2000)	Combined program	1.0	1.6
74	Buspar	Medication (anti-anxiety)	1.0	3.8
75	Osteopathy	Standard therapy	1.0	2.0
76	Self-injurious behavior inhibiting system (SIBIS)	Skills—ABA	1.0	2.6
77	Diffucan	Medication (antifungal)	.8	8.1
78	Options	Combined program	.8	1.4
79	Clathration	Detoxification	.8	.0
80	Extended breast-feeding	Relationship based	.8	11.3
81	Sporanox	Medication (antifungal)	.6	2.5
82	Institute for human potential (doman-delacto patterning)	Combined program	.6	1.6
83	Vancomycin	Medication (antibiotic)	.6	7.7
84	Lithium	Medication (mood stabilizer)	.6	.6
85	Rhythmic entrainment interventions	Physiological	.6	1.0
86	Acupuncture	Alternative therapy/medicine	.6	1.8
87	Atavin	Medication (anti-anxiety)	.4	2.8
88	Naltrexone	Medication (opiate antagonist)	.4	1.8
89	Neural therapy	Physiological	.4	.6

Table 2 (Continued)

No.	Treatment name	Category	Percentage of parents	
			Currently using	Used in past
90	Watsu	Alternative therapy/medicine	.4	.2
91	Intravenous immunoglobulin	Medication (antiviral)	.4	1.4
92	Electro-aversive therapy (Faradic skin shock)	Skills—ABA	.4	.2
93	Dilantin	Medication (anticonvulsant)	.2	2.3
94	Tofranil	Medication (antidepressant)	.2	2.3
95	Thorazine	Medication (antipsychotic)	.2	1.4
96	Haldol	Medication (antipsychotic)	.2	3.2
97	Baudhuin preschool	Combined program	.2	.6
98	Valium	Medication (anti-anxiety)	.2	1.8
99	Eden program	Combined program	.2	.8
100	Inderal	Medication (beta-blocker)	.2	1.4
101	Vagal nerve stimulation	Medical procedure	.2	.2
102	Van Dijk approach	Skills based	.0	.0
103	Dolphin therapy	Alternative therapy/medicine	.0	1.2
104	Rolfing	Alternative therapy/medicine	.0	.8
105	Giant steps	Combined program	.0	1.0
106	Hagashi school	Combined program	.0	.2
107	Cylert	Medication (stimulant)	.0	2.0
108	Pentoxifylline	Medication (antiviral)	.0	.2

Note: In some cases a parent did not indicate (a) current, (b) past, or (c) never for a particular treatment. Such omissions were classified as missing data. As a result of missing data, the sample sizes varied across treatment, with a minimum sample size of 494 for magnesium and a maximum sample size of 530 for speech therapy.

2.5. Number of treatments being used by parents

The mean number of current treatments being used by parents was seven, which was similar to the mean number of treatments used in the past ($n = 8$). The highest number of different treatments used by any 1 parent was 47 (currently) and 39 (in the past).

A two-way analysis of variance was conducted on the total number of treatments currently used with type/severity of disability and age serving as the factors. As shown in Table 3, the main effects of type/severity of disability and age group were statistically significant, whereas the interaction between these variables was not. Because the total number of treatments used was positively skewed, we used a square root transformation, which greatly reduced this skew, and conducted a two-way ANOVA with the transformed scores. Since none of the statistical test results differed when using the transformed scores, the results reported in text are based on the original score values.

Table 4 shows that more treatments were used when the child was described as having severe autism, whereas the fewest number of treatments were used when the child was described with Asperger's syndrome. These trends held for each of the age groups. Table 4 also shows that parents with children in the younger age groups were using more treatments than were parents of children in the older age groups, a pattern which generally held across type/severity of disability.

Table 3
Analysis of variance for total number of treatments currently used ($n = 539$)

Source	d.f.	<i>F</i>
Severity (<i>S</i>)	2	12.36*
Age (<i>A</i>)	3	5.61*
<i>A</i> × <i>S</i>	60	.95
Error	527	(28.96)

Note: Value enclosed in parenthesis represents the mean square error.

* $p < .001$.

Table 4
Total number of treatments currently used by age group and type/severity of disability

Age group (years)	Type/severity of disability			Combined
	Asperger's	Mild	Severe	
≤5	4.6	8.9	9.3	7.6
6–10	6.2	7.9	10.3	8.1
11–14	3.6	7.0	9.4	6.7
15–21	3.5	5.1	5.8	4.8
Combined	4.5	7.2	8.7	

2.6. Types of treatments

To analyze the types of treatments being used by parents of children with autism, we grouped the treatments that were used currently into 12 different categories, based on the classification system used by Heflin and Simpson (1998). One category (medical procedures) was subsequently dropped for this analysis because it contained just one treatment (vagal nerve stimulation) that was currently used by only one parent. Table 5 shows the percentage of respondents who indicated current use of a treatment within each category. As shown in Table 5, the most frequently used category of treatment was standard therapies, with 69.9% of the survey respondents indicating they were currently using one of the treatments within this category (e.g., speech therapy, music therapy). In contrast, less

Table 5
Percentage of respondents indicating current use for each treatment category

Treatment category	%
Standard therapies (e.g., speech, music)	69.9
Other skills based (e.g., fast-forward, lindamood bell, social stories)	61.4
Skills training based on principles of applied behavior analysis (e.g., ABA, discrete-trial training)	56.3
Medications (e.g., Haldol, Risperdal, Zoloft)	52.5
Physiological (e.g., auditory integration training, sensory integration)	46.7
Vitamin supplements (e.g., Vitamin B6, Vitamin C)	42.6
Alternative diets (e.g., casein-free, gluten-free)	26.8
Alternative therapies/medicine (e.g., aromatherapy, dance therapy)	25.9
Relationship-based treatments (e.g., holding therapy, gentle teaching)	19.7
Combined programs (e.g., Eden, giant steps, TEACCH)	16.3
Detoxification (e.g., chelation, clathration)	8.9

Table 6
Percentage of use for each treatment by type/severity of disability

Treatment category	Type/severity of disability		
	Asperger's	Mild	Severe
Standard therapies**	41.8	74.2	79.7
Other skills based**	37.4	64.8	70.3
Skills training based on principles of ABA**	24.2	56.4	80.5
Medications*	56.0	48.2	63.6
Physiological**	29.7	47.3	58.5
Vitamin supplements	33.0	45.2	42.4
Alternative diets**	9.9	29.4	32.2
Alternative therapies/medicine	23.1	24.5	31.4
Relationship-based treatments**	6.6	20.3	28.0
Combined programs**	3.3	15.2	30.5
Detoxification	3.3	10.3	10.2

Note: Sample size varied per treatment, with a minimum sample size of 490 for detoxification programs and a maximum of 537 for skills training based on principles of ABA.

* $p < .05$.

** $p \leq .001$.

than 10% of respondents reported that they were currently using a treatment within the detoxification category (e.g., chelation, clathration). Skills-based treatments (ABA and other skills-based procedure) appeared to be very popular among these parents with over 50% of the sample indicating that they were currently using at least one of the treatments within these two categories. Furthermore, 52% of the parents reported that they were currently using some type of medication.

As stated above the average number of individual treatments in current use was seven. These seven individual treatments were likely to come from an average of four different categories. Some respondents indicated that they were using treatments from up to 10 of the 11 different categories and at least 10% of the sample, were using treatments within 7 of the 11 different categories.

Table 6 lists the types of treatments currently being used by respondents as a function of the child's type/severity of disability. Table 6 is organized by frequency of use, with the most frequently used category of treatments appearing first. The relations between type/severity of disability and treatment use observed in the two-way ANOVA on overall use tended to be consistent for each of the 11 treatment categories. That is, chi-square tests indicated that type/severity of disability was related to treatment use for 8 of the 11 categories. Inspection of Table 6 shows that individuals with severe or mild autism generally had similar treatment use rates, whereas those with Asperger's syndrome often had much lower use rates. The exceptions were vitamin supplements, alternative therapies and detoxification, where treatment use was similar across three groups.

3. Discussion

The results of this Internet survey enable us to provide preliminary comment on commonly used treatments and some demographic variables that seem to influence the

number and types of treatments used by parents. From a list of 111 treatments, 108 of these were used by at least 1 parent. This finding would seem to confirm our introductory note that the field is characterized by a rather large number of treatment options. It is interesting to note that parents reported using an average of seven different treatments currently and had used an average of eight treatments in the past. In addition, 10% of the sample reported using 15 or more treatments at the current time. It is difficult to judge whether these numbers of treatments used should be considered too much, too little, or the right amount. However, in light of the results, which showed that parents are using treatments from four different categories, this would seem to make it difficult to evaluate the effects of any one treatment due to possibilities of multiple treatment interference.

The most commonly used treatments (Table 2) included those with and without empirical support. It is perhaps not surprising that speech therapy was the most commonly used treatment given that communication impairment is a defining feature of autism (Ogletree, Pierce, Harn, & Fischer, 2002). In contrast, the third most frequently used treatment (i.e., sensory integration) currently lacks scientific validation (Baranek, 2002; Dawson & Watling, 2000). The less commonly used treatments in Table 2 (e.g., those used by 25% or less of the respondents) also included some treatments with and some without empirical support. Overall, these trends suggest that the presence or absence of empirical evidence did not differentiate between commonly used and rarely used treatments.

However, the data on most commonly used treatment must be interpreted with caution. Common use may not necessarily indicate preference for the treatment. In addition, the various treatments listed in Table 2 cover different levels of specificity and should not be viewed as parallel. Speech therapy, for example, is a general intervention, whereas the Picture Exchange Communication System (PECS, Bondy & Frost, 2002) is a more specific procedure. Although both are geared towards amelioration of communication deficits, they can nonetheless be viewed as separate and distinct treatments.

When we grouped treatments into 11 categories (Table 5), we found that standard therapies and treatments focusing on skills training, especially those based on the principles of ABA, remained among the most commonly used. Given that autism is associated with substantial deficits in adaptive behavior (American Psychiatric Association, 2000), it is perhaps not surprising that many parents were implementing treatments that are primarily aimed at teaching new behaviors. However, it was not possible in this survey to determine what particular skills were being targeted in these skills-based treatments. It could be that the treatments were often directed at teaching non-functional behaviors. Thus, even if well-established skills-based treatments are commonly used, the value of these treatments would seem to depend on the specific skills that are targeted for intervention.

Medications of one type or another were a commonly used category of treatment. Just over half (52%) of the respondents indicated that they were giving their child at least one type of medication. In the case of anticonvulsants, these were probably given for seizure disorders, but the reason for use of other medications is unclear. For example, we do not know if antidepressants were given because the child had clinical depression. While some of the medications being used could be viewed as having few side effects (e.g., antihistamines), others, such as antidepressants and anti-anxiety drugs, can have significant negative side effects (Kereshian et al., 2001). Given the common use of medications in

this survey, it would seem important for the field to strive for some type of consensus statement on the use of medication in the treatment of autism.

Relatively few respondents indicated that they were currently using one of the treatments that focus on relationship building (e.g., gentle teaching, floor time). To clarify this issue, future research should examine the decision-making process related to the use and non-use of various treatment options. Another category of treatments that were less commonly used were the more comprehensive and combined educational programs such as TEACCH. This could reflect the fact that programs such as TEACCH are generally implemented in school settings and may thus be viewed as somewhat less practical in a home-based program. Still, 15% of the sample indicated that they were currently using TEACCH and it is probably the case that many more parents were also using components of the TEACCH program (e.g., visual cues, structured teaching).

The average number of treatments currently being used varied as a function of the child's age and the type/severity of the child's disability. Specifically, parents of children with severe autism and parents of younger children tended to use more treatments. This could indicate that parents seek out a multitude of treatments when the behavioral deficits of their child are greater. The decrease in the number of current treatments being used as a function of the child's increasing age (regardless of the type or severity of the disability) could indicate that as children move into late adolescence parents have already exhausted many of the available treatments and eliminated those that were perceived to be ineffective.

The type/severity of the child's disability also appeared to influence the categories of treatments used. For example, 80% of parents who had a child with severe autism – but only 24% of parents who had a child with Asperger's syndrome – were using treatments that fell within the category of skills training based on principles of applied behavior analysis. Such differences could reflect the fact that children with more disability typically have greater deficits in adaptive behavior functioning and may also present with more serious problem behaviors. Thus, these children might be thought to be in need of a greater range of treatments. Interestingly, this general trend did not hold for the use of medications or alternative therapies/medicine. That is a substantial number of parents of children with Asperger's syndrome were also using medications and the percentage of parents using alternative therapies/medicines was similar across the three disability groups.

Comparison of past and current use (Table 2) suggests that many treatments were implemented for a period of time, but then abandoned. We do not know how long such treatments were used nor why they were discontinued. Future research should seek to identify factors that influence the decision to discontinue a particular treatment. While the lack of empirical support may not be influential in such decisions, it is probable that the parents experience and perceptions of the treatment's effectiveness are critical. It would therefore seem important to study parental experiences with respect to their use of various treatment options in the home.

The main limitation of this study is that the sample may not have been representative as evidenced by the lack of variability in the gender and education level of the respondents. Ensuring representative samples in an Internet survey is difficult because once an Internet survey is launched, the researcher loses control over its distribution (Bourque & Fielder, 2003). Another limitation associated with Internet surveys is that they require the

respondent to have Internet access (Hewson, Yule, Laurent, & Vogel, 2003), which in this case may have restricted participation to Internet literate parents. Despite its limitations, our approach also has some advantages. In particular, the study was inexpensive and yet we were able to target a specific group and obtain a large number of respondents from around the world.

In summary, our findings showed that parents were using a wide range of treatment options. The most commonly used treatments have varying degrees of empirical support. In addition, the number and types of treatments currently being used by parents varied with the age and type/severity of the child's disability. One implication of these findings is that parents should have ready access to objective and data-based – yet consumer-friendly – information on a range of specific treatments; depending on the age and type/severity of the child's disability.

Given the preliminary nature of this study, there is a need for additional research to understand the decision-making processes that parents use in selecting treatments for their children with autism. Identifying variables that influence the decision-making process should help to inform future efforts focused on promoting greater use of evidence-based practice by parents in the treatment of their children with autism.

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