



The Essential Guide To Autism

The Essential Guide To Autism Survey 2007

*Helping Us All Gain A Greater
Understanding Of Autism*

Rachel Evans

A survey by Parents for Parents

Discover the books other parents are reading, which products and services they recommend and most importantly...

How they rate the treatments and therapies that they've tried.

Disclaimer: All material in this report is provided for information only and may not be construed as medical advice or instruction. No action or inaction should be taken based solely on the contents of the survey findings. Instead readers should consult their physician or other qualified health professionals on any matter relating to health and well-being. Readers who fail to consult with appropriate health authorities assume the risk of any injuries. The publisher is not responsible for errors or omissions. Reference herein to any specific commercial product, process, or service by trade name, trademark, manufacturer, or otherwise does not necessarily constitute or imply its endorsement, recommendation, or favoring by the publisher.



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Survey Summary

An invitation to complete The Essential Guide to Autism Survey 2007 was sent to a total of 11778 newsletter subscribers in July 2007. However, of these people only around 2000 are thought to be 'active' readers based on email newsletter opening rates.

The survey ran between the 18th July and the 24th July 2007 and a total of 500 people completed the survey, which is 4.2% of the total number of people, but 25% of the estimated 'active' group.

The aim of the survey was to identify the respondents' link to autism, their experiences to date of products, services and treatments and what their overwhelming area of concern was.

The high level summary of all the results are:

The respondents were mainly Mom's with children between the ages of 4 – 8 who have been formally diagnosed with classic autism.

They find the most useful information from books and websites, of which The Essential Guide to Autism Ebook and website were the most mentioned.

Note: these results should be viewed in context as the survey was completed solely by The Essential Guide to Autism newsletter subscribers.

They are interested in receiving practical advice on raising their children, along with having access to educational toys and software. Overwhelmingly, they prefer to receive information via email with 80% of respondents choosing this mode of communication.

When asked to rate treatments that they have tried from a small selection Applied Behavioral Analysis came out with the best rating of 3.7 (where 1 is not useful and 5 is very useful). Out of all the treatments that the respondents were asked to list that they have found helpful, Speech Therapy and Occupational Therapy were mentioned the most.

Respondents are interested in staying up-to-date with the latest research, but want it written in a format that is easy to understand and just picks out the salient points. Also, they are interested to know what others are doing and would like to read about case studies and personal experiences.

The final question dealt with the respondents biggest concern. There were many different questions, but the one that was asked the most was 'Will my child ever lead a normal life?'



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The Survey Results in Detail:

The questions and answers are detailed below with the answers displayed in both text and graph form, along with a brief explanation of the findings.

Where open-ended free form questions were asked, only the most common answers have been included in the survey. The remaining details can be found in the appendices.

Please feel free to pass a copy of this survey onto anyone you feel may be interested in the information.

Alternatively send them to this website address where they can sign up for the free newsletter and get a complimentary copy of the Survey Report:

<http://www.essential-guide-to-autism.com>

Thank you again to all those who took part in The Essential Guide to Autism Survey 2007, your input has been invaluable.

Rachel Evans

Rachel Evans

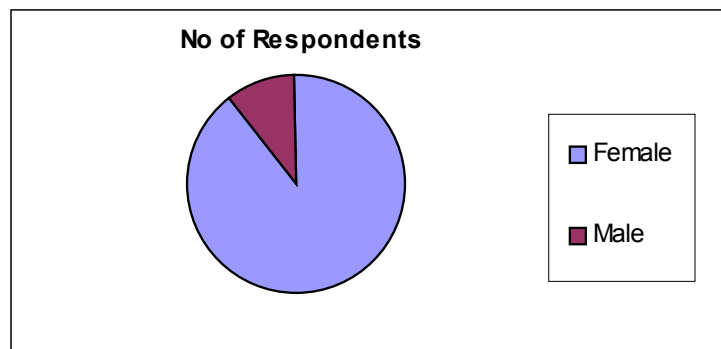
Author: [The Essential Guide to Autism](#) and [The Essential Guide to Asperger's](#)



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1. The first question asked was 'Are you Male or Female'?

	<u>No of Respondents</u>	<u>Percentage</u>
Female	447	89.4%
Male	53	10.6%



What Does This Mean:

The results show overwhelmingly that the females outnumbered males when completing the survey. The reason why the vast majority of survey respondents are female could be down to a number of factors.

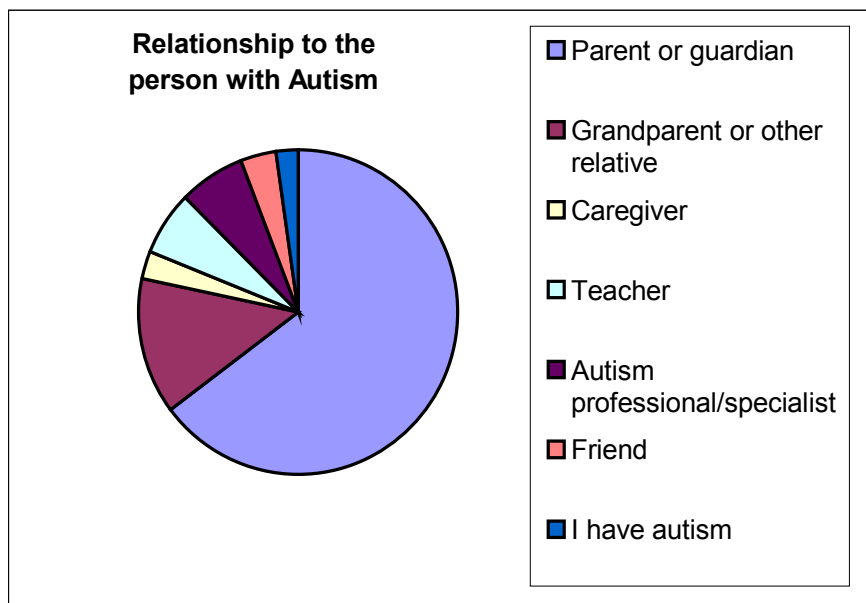
1. That there are more women than men subscribed to The Essential Guide to Autism Newsletter.
2. Women who are subscribed to The Essential Guide to Autism newsletter are more likely to answer surveys.
3. The female newsletter subscribers are more willing to take the time to share information about their circumstances regarding autism and the approaches they adopt.



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2. The second question was to establish the relationship of the person completing the survey was to the individual with autism: 'What Relationship do you have with the person who has autism or suspected autism?'

	<u>No of Respondents</u>	<u>Percentage</u>
Parent or guardian	323	65.6%
Grandparent or other relative	68	13.6%
Caregiver	14	2.8%
Teacher	33	6.6%
Autism professional/specialist	33	6.6%
Friend	18	3.6%
I have autism	11	2.2%



What Does This Mean:

The majority of respondents were Parents or Guardians. And when combining this group with the Grandparent and other Relative group family members made up just over 79% of the total respondents.

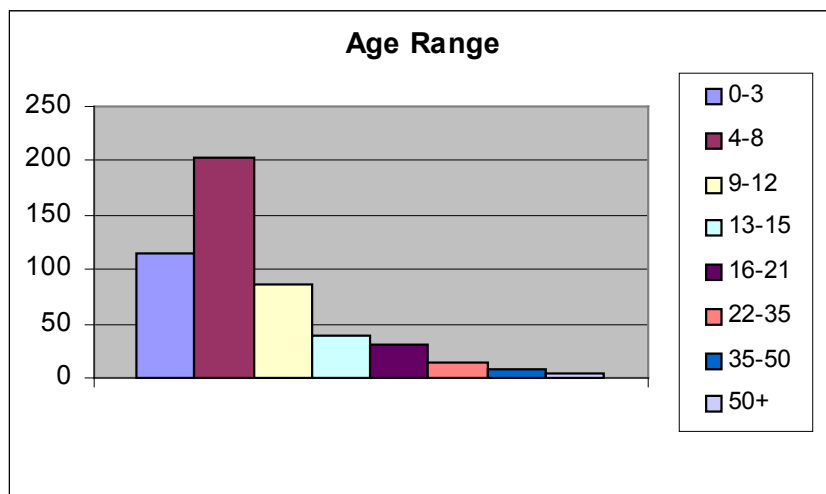
It was also interesting to note that 'teachers' and 'professionals' made up the next highest proportion of respondents, which suggests that they are continuing to keep abreast of the latest knowledge and information about Autism.



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3. Question 3 was designed to identify the age groups of the individuals with autism. Respondents were asked to select the most appropriate age group:
‘What is the age of the person with either suspected or diagnosed autism?’

	<u>No of Respondents</u>	<u>Percentage</u>
0-3	115	23.0%
4-8	202	40.4%
9-12	87	17.4%
13-15	39	7.8%
16-21	30	6.0%
22-35	15	3.0%
35-50	8	1.6%
50+	4	0.8%



What Does This Mean:

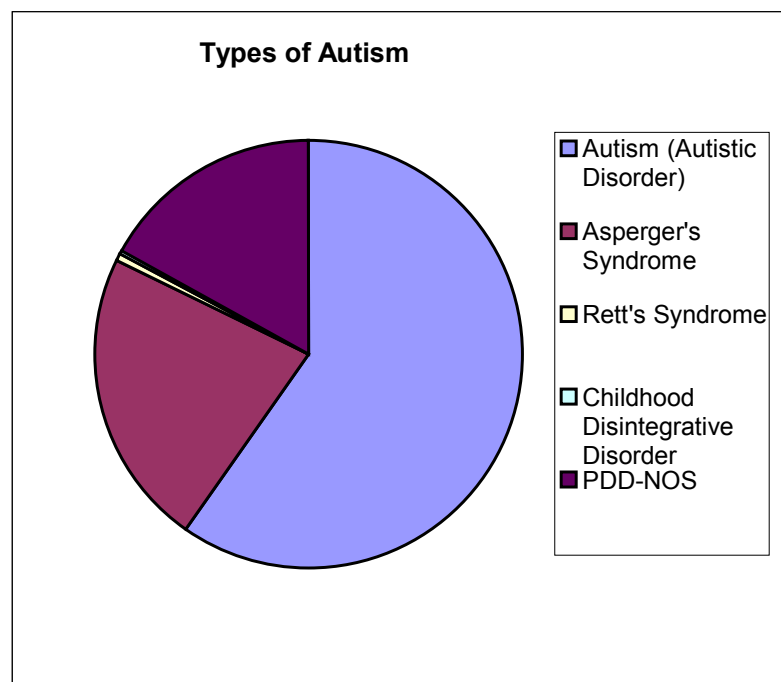
The largest group by far was the age range between 4 – 8, with children under 12 making up just over 80% of all the individuals with autism or suspected autism.



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4. The purpose of this question was to establish which types of ASD were most prevalent. Respondents were asked to select the appropriate type of Autism:
'What type of autism does the person have or is suspected of having? '

	<u>No of Respondents</u>	<u>Percentage</u>
Autism (Autistic Disorder)	299	59.8%
Asperger's Syndrome	112	22.4%
Rett's Syndrome	3	0.6%
Childhood Disintegrative Disorder	1	0.2%
PDD-NOS	85	17.0%



What Does This Mean:

Classic Autism (Autistic Disorder) is the classification of Autism that is most prevalent for this survey group, followed by Asperger's Syndrome. However, these two types of ASD combined made up over 82% of the survey group.



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Rett's Syndrome and Child Disintegrative Disorder were the least represented ASD.

Rett's Syndrome is seen almost always in females, although rarely it can be seen in males. The prevalence of Rett's Syndrome is 1:10,000 to 1:23,000 live female births.

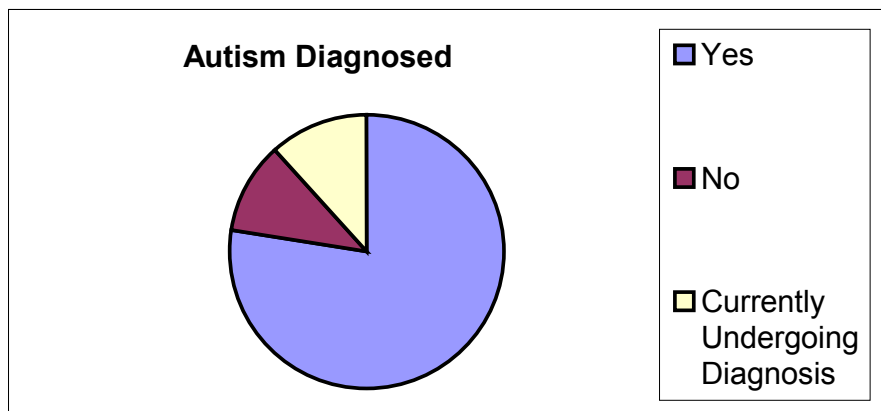
Childhood Disintegrative Disorder occurs rarely and is thought to appear in 1:100,000, but effecting boys four times more often than girls.



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5. This question was asked to find out specifically if the person with autism had been formally diagnosed. This knowledge is important as it puts the information gathered on future questions into greater perspective. Respondents were asked to chose one answer:
'Has an autism diagnosis been received from medical practitioner?'

	<u>No of Respondents</u>	<u>Percentage</u>
Yes	388	77.6%
No	54	10.8%
Currently Undergoing Diagnosis	58	11.6%



What Does This Mean:

With over 77% of respondents indicating that a formal diagnosis of Autism has been received it can be surmised that those answering the survey are more likely to have an intimate knowledge of the products, services and treatments that are discussed later in the survey.



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- 6 This question was an open question where the respondents were asked:
‘Which products or services have you used in the past that have been helpful to you?’**

	<u>No of Respondents</u>	<u>Percentage</u>
Books/Ebooks	212	42.4%
Doctor's Advice	12	2.4%
Forums/Online Support Groups	28	5.6%
Dedicated Autism Professionals	42	8.4%
Magazines	68	13.6%
Websites	194	38.8%
Seminars/Conferences/Workshops	21	4.2%
Newsletters	85	17.0%
Essential Guide to Autism Newsletter & eBook	98	19.6%
Therapies (including alternative & dietary interventions)	58	11.6%
Other Parents	27	5.4%
DVD's/Videos	7	1.4%
Schools/Teachers	26	5.2%
Local Services/Associations (Offline)	59	11.8%
TV	8	1.6%
Membership Sites	31	6.2%
Friends and Family	7	1.4%

What Does This Mean:

Of the types of products and services mentioned two stand out as being the most popular for respondents:

Books/ebooks at 42.4%, and
Websites with 38.8%

A number of people mentioned specific books and Websites, along with other products and services and the most popular are listed below for those categories where items were mentioned more than once. The figures in the popularity column indicate how many times each item was mentioned by individual people.

The full list can be found in the Appendices at the end of the report.



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<u>Books</u>	<u>Popularity</u>
The Essential Guide to Autism by Rachel Evans (Ebook)	13
The Out-of-Sync Child by Carol Stock Kranowitz	7
Dr. Temple Grandin's books	5
The Curious Incident of the Dog in the Night Time by Mark Haddon	4
Son-Rise - by Barry Neil Kauffman	3
The Autism Sourcebook by Karen Siff Exkorn	3
The Complete Guide to Asperger's Syndrome by Tony Attwood	3
A Parents Guide to Asperger Syndrome & High Functioning Autism by Sally Ozonoff, Geraldine Dawson, James McPartland	2
Autism Spectrum Disorders, The Complete Guide by Chantal Sicile-Kira and Temple Grandin	2
Carol Gray's publications	2
Teaching Young Children With Autism Spectrum Disorder by Clarissa Willis, Deborah Johnson, and Marie Ferrante Doyle	2
Raising a Sensory-Smart Child by Lindsey Biel and Nancy Peske	2
Stanley Greenspan's books	2
Strange Son by Portia Iverson	2
Educating Children With Autism by The National Research Council	2



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<u>Website</u>	<u>Popularity</u>	<u>Description</u>
www.essential-guide-to-autism.com/blog	43	The Essential Guide to Autism blog - informative articles covering a wide variety of autism topics
www.autismspeaks.org	19	Autism Speaks
www.nas.org.uk	18	The National Autistic Society - NAS
www.autism-society.org	15	Autism Society of America - ASA
www.autismtoday.com	6	Autism Today
www.cureautismnow.org	5	Cure Autism Now - CAN
www.teacch.com/	5	TEACCH is an evidence-based service, training, and research program for individuals of all ages and skill levels with autism spectrum disorders
www.autism.com	4	Autism Research Institute - ARI
http://autism.fsu.edu/	3	The Center for Autism & Related Disabilities (CARD) provides support and assistance
www.nationalautismassociation.org	3	National Autism Association - NAA
http://www.autismsociety.org/	2	Autism resources site
http://www.ldonline.org	2	LD Online - web site on learning disabilities and ADHD
http://www.rdiconnect.com/	2	Relationship Development Intervention Program for Autism Spectrum Disorders--the RDI® Program by Steven E. Gutstein
www.Schwablearning.org	2	Schwablearning.org - A Parents Guide to Helping Kids With Learning Difficulties
www.asperger.net	2	Aspergers and Autism Publishing Company - autism bookstore
www.autism.com/dan/index.htm	2	Defeat Autism Now! DAN!
www.autismresearchcentre.com	2	Autism Research Centre - ARC
www.autismvoice.com	2	Autismvoice is an autism podcast and weblog for parents of children with autism, Aspergers, PDD, PDD-NOS, and related autism spectrum disorders
www.autismwebsite.com/ARI/dan/dan.htm	2	Defeat Autism Now! (DAN!) A Project of the Autism Research Institute
www.bellaonline.com	2	BellaOnline -- The Voice of Women



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<u>Website</u>	<u>Popularity</u>	<u>Description</u>
www.cafemom.com	2	CafeMom - A place for moms, to stay in touch with friends, find new friends, and express themselves
www.do2learn.com	2	Do2Learn: Educational Resources for Special Needs
www.feat.org	2	Families for Early Autism Treatment - FEAT is a non-profit organization of parents, educators, and other professionals dedicated to providing Education, Advocacy and Support for the Northern California Autism Community
www.generationrescue.org	2	Generation Rescue - Biomedical treatments
www.wrongplanet.net	2	Wrong Planet is a web community designed for individuals (and parents of those) with Asperger's Syndrome, Autism, ADHD, and other PDDs

<u>Magazines</u>	<u>Popularity</u>	<u>Website</u>
The Spectrum Magazine	6	www.spectrumpublications.com/
Autism Digest Magazine	4	www.autismdigest.com/
Autism Advocate Magazine	3	www.autism-society.org
EP magazine	2	www.EParent.com
S.I. Focus	2	www.sifocus.com
The Autism Perspective (TAP) magazine	2	www.theautismperspective.org/



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Newsletters

Popularity

Website

The Essential Guide to Autism Newsletter	42	http://www.essential-guide-to-autism.com
Schafer Autism Report	4	http://www.sarnet.org - Subscription-based email newsletter
Newsletters from COSAC	3	http://www.njcosac.org/cosacjoin - New Jersey Center for Outreach and Services for the Autism Community
Autism Society Of America	2	http://www.autism-society.org/site/PageServer?pagename=asanet
E-Spectrum (in Australia) newsletter	2	http://www.autismvictoria.org.au/newsletter/archives.php
Sandra Sinclair's newsletters	2	http://www.autismvoice.com/

Membership Sites

Popularity

Website

SPD-TIPS	2	http://www.spdbayarea.org/SPD-TIPS.htm - SPD-TIPS is WORLDWIDE internet based resource group for parents of children diagnosed with Sensory Processing Disorder- SPD
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The full results can be found in the Appendices at the end of the report.

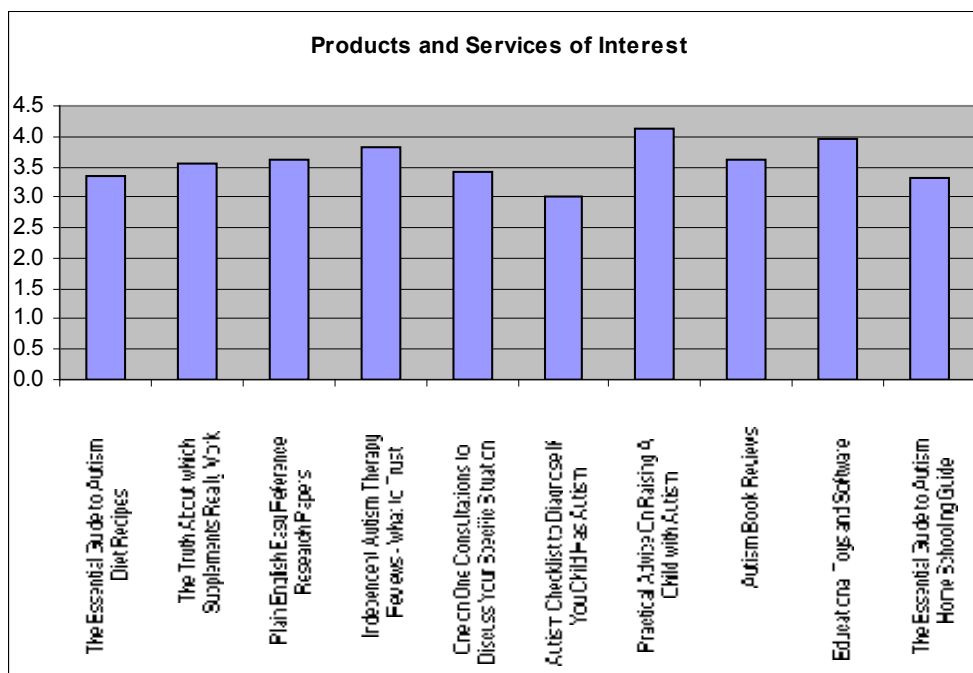


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7. The purpose of this question was to discover what information the respondents of the survey would be interested in receiving. A rating of 1 to 5 was used with 1 being not interested and 5 being very interested:

‘Which of these products or services would be of interest to you?’

<u>Potential Information</u>	<u>Rating</u>
The Essential Guide to Autism Diet Recipes	3.4
The Truth About Which Supplements Really Work	3.6
Plain English Easy Reference Research Papers	3.6
Independent Autism Therapy Reviews - What to Trust	3.8
One on One Consultations to Discuss Your Specific Situation	3.4
Autism Checklist to Diagnose If You Child Has Autism	3.0
Practical Advice On Raising A Child With Autism	4.1
Autism Book Reviews	3.6
Educational Toys and Software	4.0
The Essential Guide to Autism Home Schooling Guide	3.3



What Does This Mean:

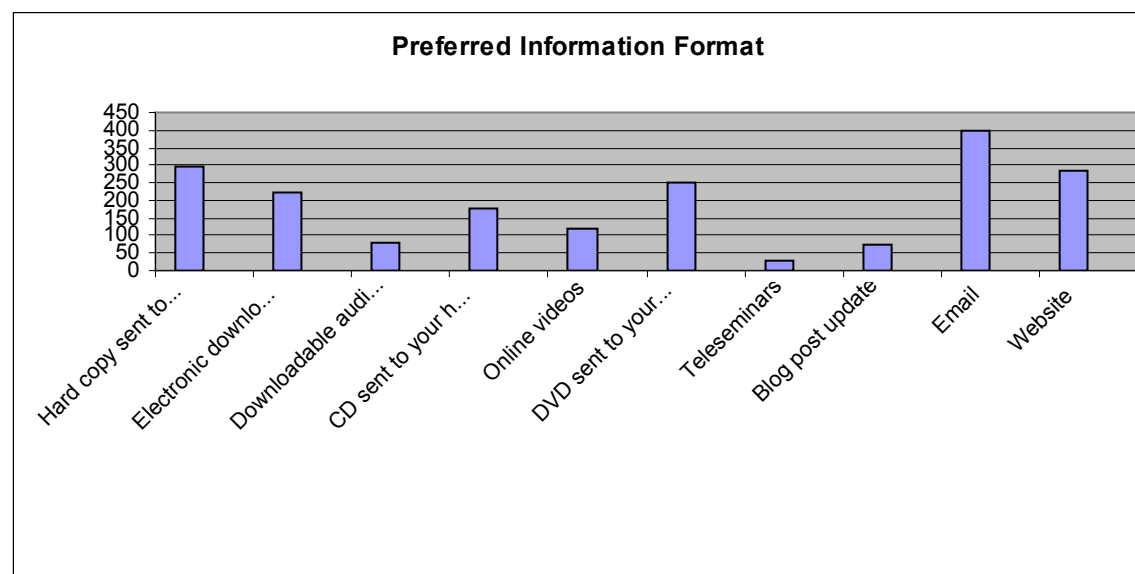
The answers show that the respondents are looking for help with parenting tips and are also keen to know which Educational Toys and Software would be helpful.



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8. Respondents were asked in which formats do you prefer to receive autism information? Respondents were asked to select all the answers that applied.

<u>Delivery Format</u>	<u>No of Respondents</u>	<u>Percentage</u>
Hard copy sent to your home address	298	59.6%
Electronic downloadable documentation I.e. ebook	224	44.8%
Downloadable audio files	81	16.2%
CD sent to your home address	179	35.8%
Online videos	117	23.4%
DVD sent to your home address	248	49.6%
Teleseminars	31	6.2%
Blog post update	72	14.4%
Email	400	80.0%
Website	286	57.2%



What Does This Mean:

The top three preferred methods of information delivery are:

- Email with 80%
- Hard Copy sent to home address with 59.6%
- Website access with 57.2%

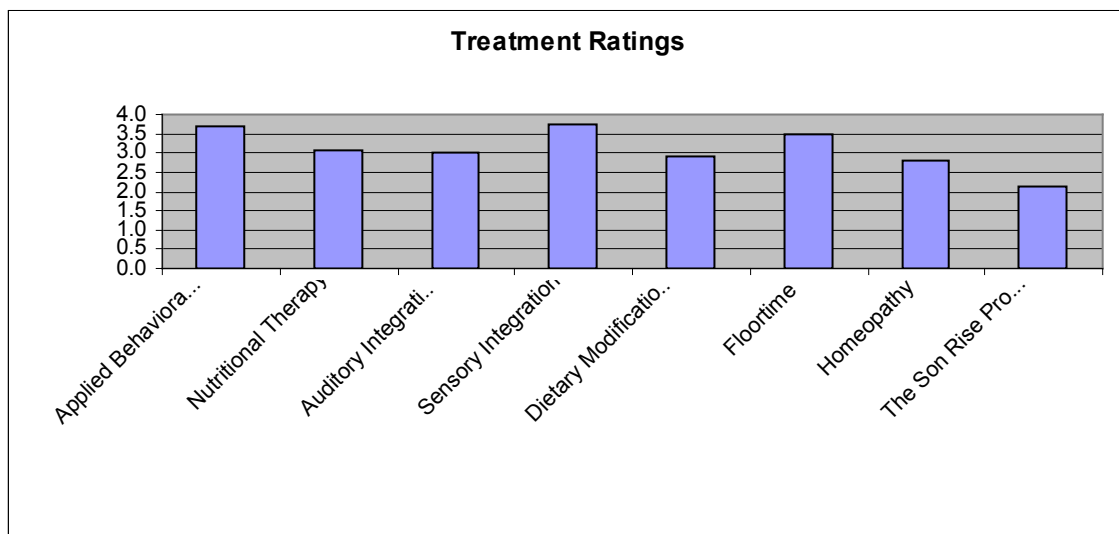
This information is useful as it allows the tailoring of information delivery to best meet respondents needs.



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- 9 The purpose of this question was to discover which treatments, from a prepared list, the respondents had tried and how useful they had found them using a rating of 1 to 5. With 1 being not useful and 5 being very useful. Respondents were asked not to rate treatments they had not used.

<u>Treatments</u>	<u>Rating</u>
Applied Behavioral Analysis (ABA)	3.7
Nutritional Therapy	3.1
Auditory Integration Therapy	3.0
Sensory Integration	3.7
Dietary Modifications incl. GFCF & Feingold Diets etc	2.9
Floortime	3.5
Homeopathy	2.8
The Son Rise Program	2.1



What Does This Mean:

Interestingly, none of the treatments scored over 4. Most of the treatments were rated as being moderately useful.

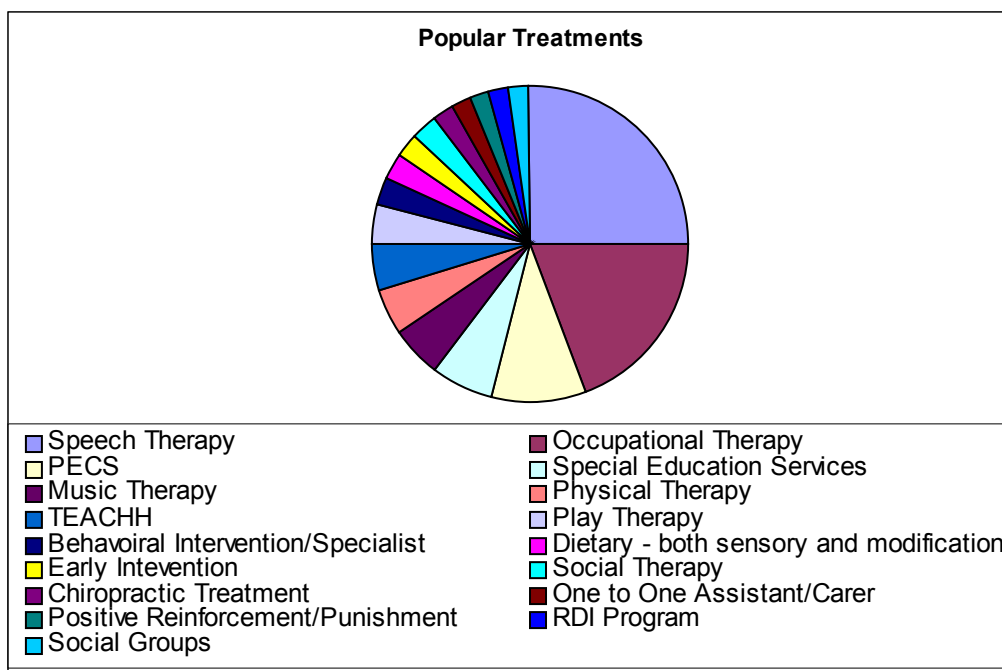
The highest scoring treatments were:
Sensory Integration and Applied Behavioral Analysis (ABA), both with scores of 3.7 each.



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10. Following on from the previous question the respondents were asked to enter any other treatments they had used that did not appear in Question 9 and rate it. Listed below are the treatments entered as having a positive effect by 3 or more people.

	<u>No of Respondents</u>	<u>Percentage</u>
Speech Therapy	37	7.4%
Occupational Therapy	28	5.6%
PECS	14	2.8%
Special Education Services	9	1.8%
Music Therapy	8	1.6%
Physical Therapy	7	1.4%
TEACHH	7	1.4%
Play Therapy	6	1.2%
Behavioral Intervention/Specialist	4	0.8%
Dietary - both sensory & modification	4	0.8%
Early Intervention	4	0.8%
Social Therapy	4	0.8%
Chiropractic Treatment	3	0.6%
One to One Assistant/Carer	3	0.6%
Positive Reinforcement/Punishment	3	0.6%
RDI Program	3	0.6%
Social Groups	3	0.6%





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There were some treatments that were not reported unfavorably and these are shown below with the number of people who found them unhelpful listed.

<u>Negative Treatment</u>	<u>No of Respondents</u>	<u>Comment</u>
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<u>Negative Treatment</u>	<u>No of Respondents</u>	<u>Comment</u>
Medications	4	too many side effects and not that effective
BUILDING BLOCKS® (early intervention)	1	no result
Chelation	1	no result
Early Intervention	1	no result
PECS	1	not that helpful
Professionals	1	dismissive attitudes towards parents

What Does This Mean:

While there is some consensus among the survey respondents on effective treatments with Speech and Occupational Therapy being nominated as the most popular, there were 80 separate treatments entered by respondents. Due to the large number of differing treatments available, finding the 'best fit' treatment can be challenging.

This is highlighted by some of the positive treatments also appearing on the negative treatment list.

The remaining treatments can be found in the Appendices at the end of the report.

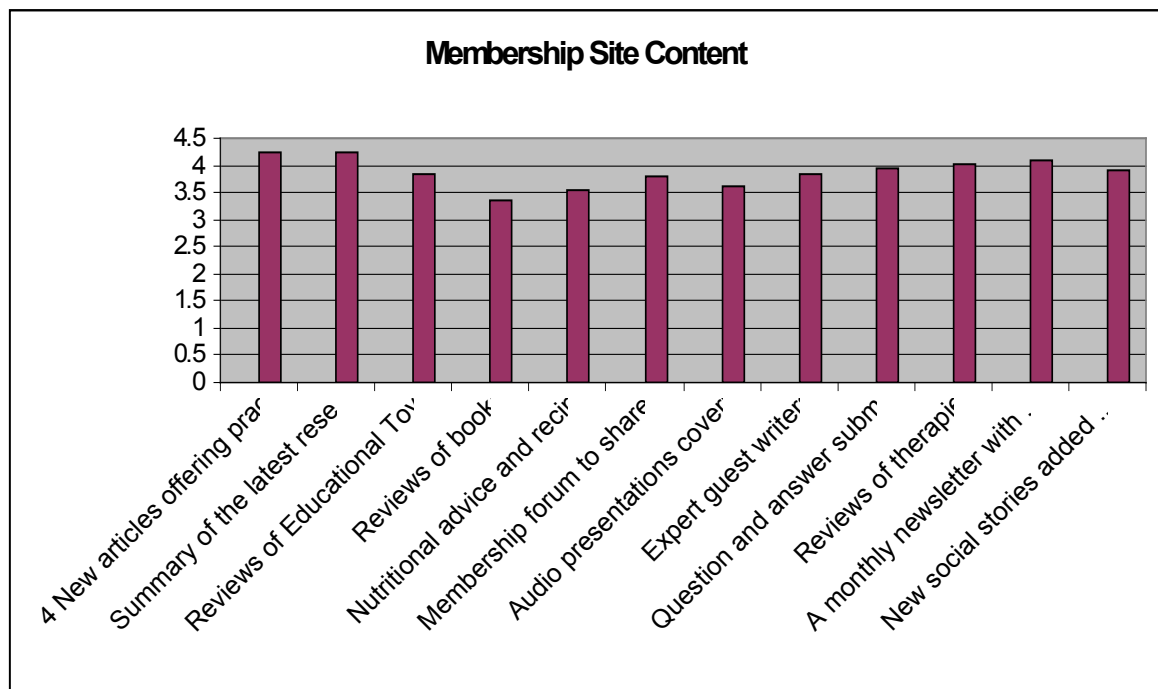


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11. The purpose of this question was to discover the information the survey respondents would be interested in receiving through a membership site.

‘I was thinking of introducing a membership/forum site. What information and content would be useful to you? A rating of 1 to 5 was used with 1 being not useful and 5 being very useful.’

	<u>Rating</u>
4 New articles offering practical help and advice	4.2
Summary of the latest research on Autism in plain English	4.3
Reviews of Educational Toys and Software	3.8
Reviews of books	3.4
Nutritional advice and recipes	3.5
Membership forum to share information and advice	3.8
Audio presentations covering key topics relating to autism	3.6
Expert guest writers	3.8
Question and answer submission service	3.9
Reviews of therapies	4.0
A monthly newsletter with case studies and personal stories	4.1
New social stories added monthly	3.9





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What Does This Mean:

The answers to this question show the respondents want to keep up to date with the latest Autism Research, but that they want the information in an easy to read accessible format.

Also scoring highly were articles offering practical help and advice. From this we can see that the survey respondents are looking for proven methods they can use when facing the day to day challenges of Autism.

This is backed up by a keen interest in case studies and personal stories, whereby the reader could learn from others successes.



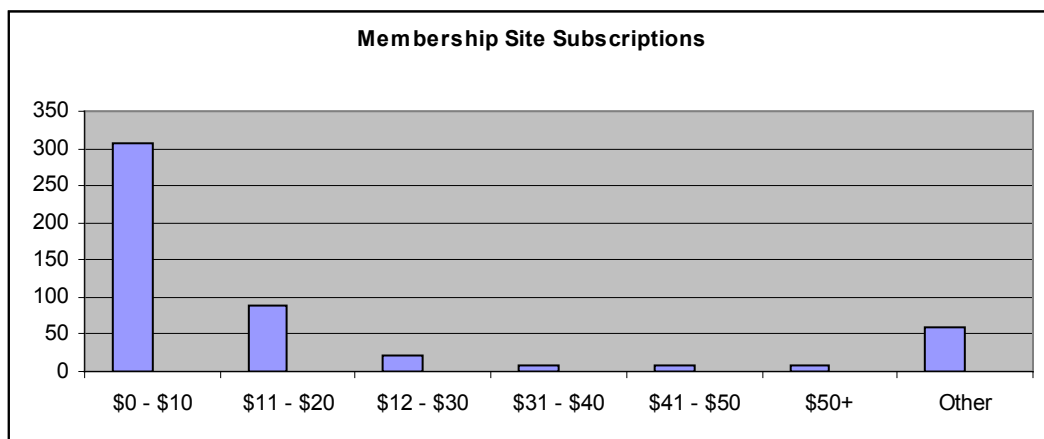
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12. Question 12 was designed as a follow up to question 11, asking the respondents how much they would pay for the items they indicated as being useful in question 11.

‘For the items you have chosen in Question 11 as being useful (4 or 5), how much would you pay on a monthly basis’

Respondents were asked to select the appropriate price range

	<u>No of Respondents</u>	<u>Percentage</u>
\$0 - \$10	307	61.4%
\$11 - \$20	88	17.6%
\$12 - \$30	22	4.4%
\$31 - \$40	9	1.8%
\$41 - \$50	8	1.6%
\$50+	7	1.4%
Other	59	11.8%



What Does This Mean:

The vast majority of respondents indicated that they would be willing to spend up to \$10 a month on a membership site that included the information they rated as the most useful.

From the comments collated in the ‘other’ field it can be concluded that many parents already have a number of financial commitments and that a trial period of any membership would be welcome. This would allow them to assess the usefulness of the information prior to paying a subscription.



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13. The final question was an open form question designed to find out what the main area of concern is for those involved with Autism:

‘If you could ask one question about autism which if answered would make life better for you and your loved ones, what would it be?’

The answers were grouped, where applicable and the following is a summary of the common questions that 10 or more people asked.

<u>Question (Percentage)</u>	<u>No of Respondents</u>
1. Can someone with autism live a 'normal' life? (8.8%)	44
2. What causes autism? (8.4%)	42
3. Is there a cure/how do you prevent autism? (6.4%)	32
4. How do I deal with the anger/mood swings/aggressiveness? (5.0%)	25
5. Where do you go for advice on testing and diagnosis if you're a parent or a teacher? (3.8%)	19
6. How do I get financial help and support for schooling/therapies? (3.4%)	17
7. What help is there for adult autism including finding jobs, therapies and adults seeking diagnosis? (3.0%)	15
8. How do I maximize the potential of someone with autism? (3.0%)	15
9. How do I know I'm getting through to my autistic child? (2.8%)	14
10. How do I understand how my child sees the world - are they happy? (2.6%)	13
11. How to explain autism to others so they understand what it means and don't judge behaviors? (Including high - functioning) (2.2%)	11
12. How to potty train an autistic child (all ages) (2.2%)	11

What Does This Mean:

The top three questions center on the cause, prevention and/or cure with the concern over people with autism leading a normal life being the most pressing.

These three questions made up 23.6% of the responses received to this open-ended question. The remaining questions can be found in the Appendices.



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Appendices

Question 6 Full Results

<u>Books</u>	<u>Popularity</u>
The Essential Guide to Autism by Rachel Evans (Ebook)	13
The Out-of-Sync Child by Carol Stock Kranowitz	7
Dr. Temple Grandin's books	5
The Curious Incident of the Dog in the Night Time by Mark Haddon	4
Son-Rise - by Barry Neil Kauffman	3
The Autism Sourcebook by Karen Siff Exkorn	3
The Complete Guide to Asperger's Syndrome by Tony Attwood	3
A Parents Guide to Asperger Syndrome & High Functioning Autism by Sally Ozonoff, Geraldine Dawson, James McPartland	2
Autism Spectrum Disorders, The Complete Guide by Chantal Sicile-Kira and Temple Grandin	2
Carol Gray's publications	2
Teaching Young Children With Autism Spectrum Disorder by Clarissa Willis, Deborah Johnson, and Marie Ferrante Doyle	2
Raising a Sensory-Smart Child by Lindsey Biel and Nancy Peske	2
Stanley Greenspan's books	2
Strange Son by Portia Iverson	2
Educating Children With Autism by The National Research Council	2
1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders by Veronica Zysk and Ellen Notbohm	
The Autistic Spectrum: A Parent's Guide to Understanding and Helping your Child by Lorna Wing.	
A Real Boy: A True Story of Autism, Early Intervention, and Recovery by Christina Adams	
A Slant of Sun: One Child's Courage by Beth Kephart	



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A Treasure Chest of Behavioral Strategies for Individuals with Autism by Beth Fouse and Maria Wheeler

A User Guide to the GF/CF Diet for Autism, Asperger Syndrome and ADHD - Luke Jackson

ABA therapy More Than Word Children with starving brain by Jaquelyn Mccandles

Adolescents on the Autism Spectrum (C.Sicile-Kira)

all the Wrightlaw books

Asperger Parent by Jeffrey Cohen

Asperger Syndrome in the Family by Liane Holliday Willey

Asperger Syndrome: What Teachers Need to Know by Matt Winter

Autism spectrum disorders (a research review for practitioners) Sally Ozonoff

Biological Treatment by William Shaw

Book by Lynn Hamilton

Books by Ellen Notbohm

Books by Paula Kluth

Books by Reuven Feuerstein

Born on a Blue Day - Daniel Tammet

Children, Youth And Adults With Asperger Syndrome: Integrating Multiple Perspectives by Kevin P. Stoddart

Daniel isn't Talking - Marti Leimbach

Diet Intervention and Autism, A Practical Guide for Parents - Marilyn Le Breton

Difficult Moments - Brenda Smith Nyles and Jack Southwick

Does my child have autism? by Dr. Wendy Stone

Dr.Edward Ritvo's survey and books

DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition),

Emergence - Labeled Autistic - by Temple Grandin and Margaret M. Scariano



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Engaging Autism by Dr. Stanley Greenspan et al
Essential Life Skills by Jan Katz
Evidence of Harm by David Kirby
Gut & Psychology Syndrome by Dr Natasha Campbell-Mc Bride
Helping Children with Autism Learn - by Bryna Siegel
Hyperbaric oxygen for CP and the brain injured child by Richard A. Neubauer
I'm not Naughty, I'm Autistic - Jean Shaw
Infant/Toddler Sensory Profile by Winnie, Ph.D. Dunn
Is this your child's world? By Dr. Doris Rapp
It's So Much Work to Be Your Friend by Richard Lavoie (Author), Mel Levine (Foreword), Michele Reiner (Preface), Rob Reiner (Preface)
Kids in the Syndrome Mix by Martin L., M.D. Kutscher, Robert R. Wolff, and Tony Attwood
Life Behind Glass, A Personal Account of Autism Spectrum Disorder - Wendy Lawson
Making It a Success: Practical Strategies and Worksheets for Teaching Students With Autism Spectrum Disorder by Sue Larkey and Tony Attwood
Making Peace with Autism, by Susan Senator
Nobody Nowhere, The Remarkable Autobiography of an Autistic Girl - Donna Williams
Not Even Wrong, by Paul Collins
Overcoming Autism by Lynn Kern Koegel and Claire LaZebnik
Raising a child with autism by Shira Richman
Recognizing and Treating ADHD (ebook) by Sue Perkins
Rhode Island Resource Guide for Families of Children with ASD Autism Spectrum Disorders by Chantal Sicile-Kira and Temple Grandin
Sleep Better!: A Guide to Improving Sleep for Children With Special Needs by Vincent Mark Durand
Special Diets for Special Kids by Lisa Lewis



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Taca literature

Teaching Children With Autism to Mind-Read : A Practical Guide for Teachers and Parents by Patricia Howlin, Simon Baron-Cohen, and Julie Hadwin

Ten Things Every Child with Autism Wishes You Knew by Ellen Notbohm

The Bipolar Child: The Definitive and Reassuring Guide to Childhood's Most Misunderstood Disorder -- Third Edition by Demitri Md Papolos and Janice Papolos

The Failsafe Cookbook by Sue Dengate

The New Strong-willed Child: Birth Through Adolescence by James C. Dobson

The OASIS Guide to Asperger Syndrome: Completely Revised and Updated: Advice, Support, Insight, and Inspiration by Patricia Romanowski Bashe, Barbara L. Kirby, Simon Baron-Cohen & Tony Attwood

Thinking in Pictures by Temple Grandin

Tony Atwood's books

Unraveling the Mystery of Autism Asperger Syndrome by Karen Seroussi

Unwritten Rules of Social Relationships - by Temple Grandin and Sean Barron

Wendy Lawson's publications.

When Snow Turns to Rain: One Family's Struggle to Solve the Riddle of Autism by Craig B. Schulze

You're Going to Love This Kid!: Teaching Students With Autism in the Inclusive Classroom by Paula Kluth

Websites

Popularity

Description

www.essential-guide-to-autism.com/blog	43	The Essential Guide to Autism blog - informative articles covering a wide variety of autism topics
www.autismspeaks.org	19	Autism Speaks
www.nas.org.uk	18	The National Autistic Society - NAS
www.autism-society.org	15	Autism Society of America - ASA
www.autismtoday.com	6	Autism Today
www.cureautismnow.org	5	Cure Autism Now - CAN



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<u>Website</u>	<u>Popularity</u>	<u>Description</u>
www.teacch.com/	5	TEACCH is an evidence-based service, training, and research program for individuals of all ages and skill levels with autism spectrum disorders
www.autism.com	4	Autism Research Institute - ARI
http://autism.fsu.edu/	3	The Center for Autism & Related Disabilities (CARD) provides support and assistance
www.nationalautismassociation.org	3	National Autism Association - NAA
http://www.autismsociety.org/	2	Autism resources site
http://www.ldonline.org	2	LD Online - web site on learning disabilities and ADHD
http://www.rdiconnect.com/	2	Relationship Development Intervention Program for Autism Spectrum Disorders--the RDI® Program by Steven E. Gutstein
www.Schwablearning.org	2	Schwablearning.org - A Parents Guide to Helping Kids With Learning Difficulties
www.asperger.net	2	Aspergers and Autism Publishing Company - autism bookstore
www.autism.com/dan/index.htm	2	Defeat Autism Now! DAN!
www.autismresearchcentre.com	2	Autism Research Centre - ARC
www.autismvoice.com	2	Autismvoice is an autism podcast and weblog for parents of children with autism, Aspergers, PDD, PDD-NOS, and related autism spectrum disorders
www.autismwebsite.com/ARI/dan/dan.htm	2	Defeat Autism Now! (DAN!) A Project of the Autism Research Institute
www.bellaonline.com	2	BellaOnline -- The Voice of Women
www.cafemom.com	2	CafeMom - A place for moms, to stay in touch with friends, find new friends, and express themselves
www.do2learn.com	2	Do2Learn: Educational Resources for Special Needs



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<u>Website</u>	<u>Popularity</u>	<u>Description</u>
www.feat.org	2	Families for Early Autism Treatment - FEAT is a non-profit organization of parents, educators, and other professionals dedicated to providing Education, Advocacy and Support for the Northern California Autism Community
www.generationrescue.org	2	Generation Rescue - Biomedical treatments
www.wrongplanet.net	2	Wrong Planet is a web community designed for individuals (and parents of those) with Asperger's Syndrome, Autism, ADHD, and other PDDs
depts.washington.edu/uwautism	1	University of Washington Autism Center - Intervention Strategies and Programs for Children with Autism Spectrum Disorders
http://amenclinics.com/ac/bitn/bitn_detail.php?articleID=106	1	Amen Clinics, Inc. is dedicated to optimizing the brain-life connection in our patients and people worldwide, and to utilizing the latest medical advances in the treatment of psychiatric disease
http://forums.delphiforums.com/n/main.asp?webtag=aspies&nav=start&prettyurl=%2Faspies	1	Aspie Hangout - This is a forum for those of us on the autism spectrum to get together and talk about our issues and lives
http://momnos.blogspot.com/	1	Blog on raising a son on the autism spectrum, progressive politics, pop culture, and coffee addiction.
http://nonprofits.aclink.org/faces/index.asp	1	"Families for Autistic Children Education and Support Groups of South Jersey (FACES) "
http://saintsinternational.org	1	Saints International Organization - non-profit foundation established for the care, cure and prevention of autism, cancer and cerebral palsy
http://susansenator.com/	1	Susan Senator - author of Making Peace with Autism: One Family's Story of Struggle, Discovery, and Unexpected Gifts
http://tiwid.blogspot.com/	1	This is What I Do - Laura's blog - mom of autistic son



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<u>Website</u>	<u>Popularity</u>	<u>Description</u>
http://www.bexleysnap.34sp.com/	1	Bexley SNAP - parent-led support agency for families of disabled children and young people in Bexley
http://www.eiclearinghouse.org/autism.php	1	Illinois Early Childhood Intervention Clearinghouse library on Autism, Asperger Syndrome and sensory integration disorders
http://www.ganoderma.com.au	1	Australian and New Zealand resource
http://www.hbot.com/	1	Information for the benefits and applications of Hyperbaric Oxygen Therapy
http://www.kimstagliano.blogspot.com/	1	Kim Stagliano - Mom to three on the autism spectrum
http://www.liquidsalt.com.au/yourshout/index.php	1	Your Shout - Australian youth site for those with a sibling with a disability or chronic illness
http://www.makaton.org/	1	Makaton sign language
http://www.mayoclinic.com/	1	Mayo Clinic is a not-for-profit medical practice dedicated to the diagnosis and treatment of virtually every type of complex illness.
http://www.olea.com.au	1	Olive Leaf Extract - Australian site
http://www.option.org/about_us/atca.php	1	The Son Rise Program
http://www.suelarkey.com/	1	Australian and New Zealand resource
http://www.usevisualstrategies.com/	1	Linda Hodgdon, M.Ed., CCC-SLP, is a Speech Pathologist who has pioneered the development of using visual strategies for supporting communication
members.ozemail.com.au/~rbmitch/Asperger.htm	1	The Australian Aspergers Information Centre
momscoffeebreak.wordpress.com	1	Mom's Coffee Break is a way for all working moms, to take a break, socialize, and engage in great discussions about a variety of important topics.
Wrightslaw.com	1	Wrights Law - information about special education law, education law, and advocacy for children with disabilities
www.aboutautism.com/	1	Funny Wiring: Living With and Piecing Together the Puzzle of Autism Ebook



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<u>Website</u>	<u>Popularity</u>	<u>Description</u>
www.aboutourkids.org	1	New York University Child Study Center
www.aspect.org.au	1	Autism Spectrum Australia (Aspect)
www.ausm.org	1	Minnesota Autism site
www.autism-ascc.org	1	Autism Society of Collin County (ASCC)
www.autismcoach.com	1	Autism Coach - Autism and Asperger's Syndrome product catalog
www.autisminspiration.com	1	Autism Inspiration - on-line resource for parents and teachers of children with autism spectrum behaviors
www.autismlink.com	1	AutismLink - Support and Information for Autism Spectrum Disorder
www.autismndi.com	1	Autism Network for Dietary Invention - ANDI
www.autismnz.org.nz	1	Autistic Association of New Zealand
www.autismsa.org.au	1	Autism Association of South Australia
www.autismsocietycanada.ca	1	Autism Society Canada
www.bild.org.uk/o3journals_gap.htm	1	Good Autism Practice Journal - GAP is a journal for those working and living with children and adults with an autistic spectrum disorder
www.disabilityinfo.gov	1	Disability related information and resources for America
www.dore.co.uk	1	UK based program for children with learning difficulties
www.dougflutiejrfoundation.org	1	The Doug Flutie Jr. Foundation for Autism, Inc. Provides funding for services for financially disadvantaged families who need assistance in caring for their autistic children
www.dr carbone.net	1	The Carbone Clinic - applied behavior analysis (ABA) services
www.dukehealth.org	1	Duke Medicine
www.floortime.org	1	The Floortime Foundation
www.gfcfdiet.com	1	The Official GFCF Diet Support Group FREE Informative Website
www.hriptc.org/	1	The Pfeiffer Treatment Center is a not-for-profit medical research and treatment facility in Warrenville, Illinois specializing in research and treatment of biochemical imbalances
www.hyperlexia.org	1	American Hyperlexia Association



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<u>Website</u>	<u>Popularity</u>	<u>Description</u>
www.kellydorfman.com	1	Kelly Dorfman is a health program planner and nutritionist with twenty-five years of clinical experience.
www.ldaamerica.org	1	Learning Disabilities Association of America - National organization of parents, professionals and individuals with learning disabilities
www.med.yale.edu/chldstdy/autism/	1	Yale Child Study Center - Developmental Disabilities Clinic Comprehensive, multidisciplinary evaluations for children and adults with social disabilities, usually focusing on the issues of diagnosis and intervention.
www.mnautism.org	1	Minnesota Autism site
www.ncb.org.uk	1	National Children's Bureau - british charity
www.nclد.org	1	The National Center for Learning Disabilities
www.nimh.nih.gov	1	The National Institute of Mental Health (NIMH) website provides information from the Federal agency that conducts and supports research on mental illnesses
www.ninds.nih.gov	1	National Institute of Neurological Disorders - Information on neurological and neurodevelopmental disorders from a leading supporter of biomedical research on the brain and nervous system
www.nomercury.org	1	Information site on Mercury in vaccines
www.nysparentnetwork.org	1	The NYS Parent Network is a coordinated group of organizations that provide support and information for parents of children with disabilities
www.poac.net	1	Parents of Autistic Children - POAC providing services to children with autism, their families, and the professionals who serve them
www.positivelyautism.com	1	Positively Autism ~ A free eMagazine celebrating the sunny side of Autism
www.safeminds.org	1	Safe Action For Ending Mercury-Induced Neurological Disorders



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Website Popularity Description

www.tasksgalore.com	1	Tasks Galore - structured teaching methods and parent/professional collaboration
www.ucdmc.ucdavis.edu/mi ndinstitute/	1	The M.I.N.D. Institute is an international, multidisciplinary research organization, committed to excellence, collaboration and hope, striving to understand the causes and develop better treatments and ultimately cures for neurodevelopmental disorders
www.unlockingautism.org	1	Unlocking Autism - Christian awareness and education organization.
www.widgit.com/index.htm	1	Widget Software - software for learning disorders

Magazines Popularity Website

The Spectrum Magazine	6	www.spectrumpublications.com/
Autism Digest Magazine	4	www.autismdigest.com/
Autism Advocate Magazine	3	www.autism-society.org
EP magazine	2	www.EParent.com
S.I. Focus	2	www.sifocus.com
The Autism Perspective (TAP) magazine	2	www.theautismperspective.org/
Mothering magazine	1	www.mothering.com
ION magazine	1	
Autism Society of America Council for Exceptional Children Sensations Magazine	1	
Unlocking the secrets of Autism, Newsweek Magazine, November 27 2006	1	



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<u>Conferences</u>	<u>Popularity</u>	<u>Website</u>
Carol Gray's conferences - The Gray Center for Social Learning and Understanding	1	http://www.thegraycenter.org/cg_speakingschedule.cfm - The Gray Center for Social Learning and Understanding
Michelle Winner Garcia - Workshops, Training, Consultation, Assessment & Therapy For Persons with Social Thinking Challenges	1	http://www.socialthinking.com/
NAS workshops - UK based workshops	1	http://www.nas.org.uk
Tony Atwood lecture material - Workshops and Conferences		http://www.tonyattwood.com.au/

<u>DVD</u>	<u>Popularity</u>	<u>Website</u>
Autism Essentials DVD Training Program	1	www.autism-essentials.com
Baby Babble DVD - speech-enhancing video prepared by speech-language pathologists for you and your child	1	http://www.talkingchild.com/shop_BabyBabbleDVD.aspx
Baby Bumble Bee DVD - educationally appropriate materials for infants and toddlers	1	http://www.babybumblebee.com/store/main_store.cfm
In my world DVD's - Each My World Learning DVD is designed to build competency and inspire independence in children with learning disorders	1	http://myworldlearning.com/DVDs-Resources.htm
Spectrum Connection DVD's - Spectrum Connections is developmentally appropriate entertainment uniquely designed for children with Autism Spectrum Disorders.	1	http://www.spectrumconnections.com/index.php



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Newsletters

Popularity

Website

The Essential Guide to Autism Newsletter	42	http://www.essential-guide-to-autism.com
Schafer Autism Report	4	http://www.sarnet.org - Subscription-based email newsletter
Newsletters from COSAC	3	http://www.njcosac.org/cosacjoin - New Jersey Center for Outreach and Services for the Autism Community
Autism Society Of America	2	http://www.autism-society.org/site/PageServer?pagename=asanet
E-Spectrum (in Australia) newsletter	2	http://www.autismvictoria.org.au/newsletter/archives.php
Sandra Sinclair's newsletters	2	http://www.autismvoice.com/
Autism Spectrum Newsletter	1	http://www.autismspectrum.net/DesktopDefault.aspx
Autism NZ society newsletters.	1	http://www.autismnz.org.nz/
Dave Angel's newsletter	1	http://www.parentingaspergers.com/newsletter.htm
News/courses sponsored by NZ Government	1	http://www.asdin.org.nz/main/behaviour/gov.html
Newsletter from the CNY Autism Association - Central New York Chapter of the Autism Society of America	1	http://www.cnyasa.org/
The AUTISM Mailing List	1	http://www.autism-resources.com/maillinglist.html
UC Davis Mind Institute newsletters	1	http://www.ucdmc.ucdavis.edu/mindinstitute/newsroom/newsletter/

Membership Sites

Popularity

Website

SPD-TIPS	2	http://www.spdbayarea.org/SPD-TIPS.htm - SPD-TIPS is WORLDWIDE internet based resource group for parents of children diagnosed with Sensory Processing Disorder- SPD
Autism Northern Ireland (PAPA)	1	http://www.autismni.org/



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Question 10 Full Results

Positive Treatment Experiences

Treatment **No of Respondents** **Comments**

Speech Therapy	37	
Occupational Therapy	28	
PECS	14	
Special Education Services	9	
Music Therapy	8	
Physical Therapy	7	
TEACHH	7	
Play Therapy	6	
Behavioral Intervention/Specialist	4	
Dietary - both sensory and modification	4	
Early Intervention	4	
Social Therapy	4	
Chiropractic Treatment	3	
One to One Assistant/Carer	3	
Positive Reinforcement/Punishment	3	
RDI Program	3	
Social Groups	3	
Vitamins and Supplements	6	
Auditory Integration Training	2	very effective for listening, writing and reading
Chelation	2	
Counseling	2	
Cranial Treatment	2	
Hippotherapy	2	
Hyperbaric Therapy/HBOT	2	
Lovan (antidepressant)	2	
Psychologist	2	
Risperdal (anti-psychotic)	2	
RT (Remedial Therapy)	2	
Socialization camp	2	
Sports Classes and Activities	2	
Tomatis	2	
Adapted Sensory Based Program	1	
AFX - Maxxam Labs	1	Great but expensive



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Treatment **No of Respondents** **Comments**

Treatment	No of Respondents	Comments
Alopathic Treatments	1	
Alternative Energy Healing	1	Especially good for ADHD
Animal Assisted Therapy (AAT)	1	
Aromatherapy	1	
Art Therapy	1	
Ayurvedic	1	
Biofeedback	1	
Biomedical	1	
Brushing	1	
Clay Baths	1	
Cognitive Behavioral Therapy	1	
Connect Therapy	1	
DMG (Dimethylglycine) supplementation	1	
Dr Pauc's Method - Tinsley House Clinic	1	
DT Trainer in School	1	
Ear plugs	1	
Enzymes	1	
Floor Time	1	
Focalin	1	
Ganoderma capsules	1	
Herbal Treatments	1	
Homeopathy	1	
ICELP Training (Feuerstein)	1	
IEP at School	1	
IV Therapy	1	
Makaton Sign Language	1	
Massage	1	
NAET Treatment	1	
Natural Cellular Defense Zeolite	1	
Oral DMSA	1	
Osteopathic Treatment	1	
Pace School	1	
Pivitol Response	1	
PMP at School	1	
Probiotics	1	
Reliv For Kids - vitamin nutritional therapy	1	
Service Dogs	1	



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Treatment No of Respondents Comments

Social Stories	1	
STAR Autism Program	1	
Stem Enhancement Therapy	1	
The HANDLE Institute	1	
The SCERTS Model	1	
Trazadone	1	
Tree Planting	1	
Vision Therapy	1	
Vitamin B12 Shots	1	
Yeast Therapy	1	

Negative Experiences

Treatment No of Respondents Comments

Medications	4	- too many side effects and not that effective
BUILDING BLOCKS® (early intervention)	1	- no result
Chelation	1	
Early Intervention	1	- no result
PECS	1	- not that helpful
Professionals	1	- dismissive attitudes towards parents
Speech Therapy	1	



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Question 13 Full List of Summarized Respondent Questions

<u>Question</u>	<u>No of Respondents</u>
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Can someone with autism live a 'normal' life?	44
What causes autism?	42
Is there a cure/how do you prevent autism?	32
How do I deal with the anger/mood swings/aggressiveness?	25
Where do you go for advice on testing and diagnosis if you're a parent or a teacher?	19
How do I get financial help and support for schooling/therapies?	17
Help for adult autism including finding jobs, therapies and adults seeking diagnosis	15
How do I maximize the potential of someone with autism?	15
How do I know I'm getting through to my autistic child?	14
How do I understand how my child sees the world - are they happy?	13
How to explain autism to others so they understand what it means and don't judge behaviors? (including high - functioning)	11
How to potty train an autistic child (all ages)	11
What is the best treatment for MY child?	9
How to deal with the obsessive, self-stimulating and repetitive behavior?	8
Where do I find opportunities and recreational activities in my area?	7
How do you improve communication skills to have a conversation? Will they ever talk?	7
How do you get them to communicate better - including eye contact?	7
How to include/integrate autistic children into mainstream school/high school?	7
How do you get autistic kids to interact with regular kids?	6
How do you get siblings to understand a diagnosis of autism?	6
Do vaccinations cause autism?	5
What do you do when the parents are in denial over their children's diagnosis?	5
How do you improve family life that's been impacted by autism?	5
Will my child need to be cared for forever - what can I do now to prepare and what help is available?	5
How to you encourage them to socialize with others better?	5
What can parents do at home that doesn't cost anything?	5
Why is the diagnosis of autism increasing?	5
How do you get other kids at school to accept autistic kids and not make fun of them?	4
Can children with autism have other difficulties I.e. ADHD, Dyslexia, attachment issues and schizophrenia and how do you differentiate between them?	4



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Question	No of Respondents
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How do you teach autistic children to understand and show emotions?	4
How to you get your child individualized attention at school?	4
Do autistic children regress once they've started making progress with treatments?	4
What are the chances that a second baby will have autism too?	3
As a parent what do you do about the guilt, anger and sadness?	3
How to help autistic children sleep at night?	3
What medication can they take? What are the pros and cons? I.e. Ritalin	3
How to you improve a diagnosed child's self esteem?	3
What to you do next after a diagnosis?	3
How do you improve anxiety and fear and show them how to not be scared of the world?	3
What treatment has the highest success rate for recovery?	3
How effective is a GFCF diet for ASD's	3
What are the different types of autism?	2
Do autistic children have to have special education or can they be taught in mainstream school?	2
Do younger siblings mimic an older autistic child and if so what to do?	2
How to get over eating problems - both in terms of textures and taste?	2
How to you get an autistic child to understand the difference between right and wrong?	2
How do you get the school to look at autism as a different way of learning rather than being mentally challenged?	2
How to calm kids down after a meltdown?	2
Disciplining autistic child (when they are non-verbal and time out didn't work?)	2
Why do a lot of autistic kids have problems with their digestive tract?	2
How do I find an expert in my area?	2
How do I keep my child focused/improve concentration for a long time?	2
Coping and planning skills for parents so they can deal with the unexpected?	2
What is the right age for a diagnosis - how young is too young?	2
How do you remove heavy metals from the body?	2
How to get autistic children to pay attention?	1
What natural methods can help control anger, depression and attention deficit?	1



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Question	No of Respondents
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What are the best schooling methods?	1
Where to go for job training advice?	1
Do you treat autistic and regular kids the same?	1
Do things improve over time?	1
How to control hyperactivity?	1
How can family members help - when they live close or far away?	1
How to teach parents to enable their child to be self-sufficient?	1
What help is there for people in other countries?	1
How do autistics handle personal relationships?	1
Does ASD's impact males and females differently?	1
How do you explain death and big life events to autistic children in a way that they understand?	1
How do you show others how to interact with an autistic child?	1
How do you link home and school therapies to ensure a consistent approach?	1
Are natural approaches better than medications?	1
How do you deal with sexual awareness and appropriateness of behavior?	1
Is there an approved medicine to deal with attention span?	1
How do you deal with autism behaviors in public when people are disapproving?	1
What medication is available for epilepsy instead of Epilan?	1
What are the key interventions for a child starting school?	1
What biomedical treatments work for older children and adults?	1
What research into autism is currently being conducted?	1
What are good preschool activities and what is the best group size?	1
Where do you get funding for home education?	1
Does Dolphin therapy work?	1
Where to go for information about autism in general?	1
What are the statistics on autism and how it's grown?	1
Why do autistic children tiptoe?	1
Can I pass autism onto my children?	1
Can Stem Cell Therapy cure autism?	1
Are autism and memory loss connected?	1
How to find others to connect with either by phone or in groups?	1
Will hormone testing on mice with fragile X syndrome eventually help kids with Asperger's?	1