

## FAQs

Frequently Asked Questions are arranged into major categories as indicated by headings in ALL CAPITAL letters. Each question beneath a heading address one or perhaps more related questions. [Readers are encouraged to suggest additional questions to be discussed in this FAQ section of the website](#)

- AUTISM FEATURES
- The Dreaded "A" Word
- Does Autism Run in Families?
- What is Asperger Disorder?
- Asperger Emotional Challenges
- Obsessive-Compulsive Disorder in Autism
- AUTISM CAUSES
- Does MMR Vaccine Cause Autism?
- Prevalence of Autism Increase
- Quack Cures & False Hope
- Can Medication Prevent Autism?
- Autism Risk Factors: Is Autism Inherited?
- What are Autism Endophenotypes?
- BEHAVIORAL & SOCIAL INTERVENTIONS
- Cost-Benefit Analysis of EIBI
- What is Theory of Mind?
- What are Blended Autism Interventions?
- Components & Family Role in Early Intervention
- What Are Naturalistic Interventions?
- What Are Visual Supports?
- Non-Verbal Autism
- Developmental & Behavioral Approaches
- Ethical Standards in ABA Services
- Individual Differences & Types of Intervention
- Effectiveness of Intensive Early Behavioral Intervention
- Questions for your ABA provider
- School: Should Your Child with ASD Attend School this Fall?
- MEDICAL & BIOLOGICAL INTERVENTIONS
- Epilepsy in Autism
- Diet, Vitamins & Minerals in Autism
- Diets and Parent Beliefs
- DAILY LIVING
- Finding Lost Children with Autism
- Feeding Problems in Autism
- Toothbrushing; How to Deal with Resistance
- Falling and Remaining Asleep
- SPECIAL CHALLENGES
- Aggression, Prevention & Management
- Meltdowns: Preventing & Managing
- ADHD In Autism
- Boredom in High Functioning ASD
- FUTURE PLANNING
- What Does the Future Hold in Autism?
- MISCELLANEOUS

### AUTISM FEATURES

The features of autism are often puzzling to parents and professionals, especially those who were not originally trained in autism. The Q&As in this section address specific issues that often arise about these special features.

---

### The Dreaded "A" Word

A recent email exchange with the mother whose child had been given a tentative autism spectrum diagnosis, reminded me that to some parents, an autism diagnosis is viewed almost as a death sentence. Mother wrote that even hearing the word

## FAQs

autism made her physically ill. It is understandable why some parents will do whatever is necessary to make that dreaded "A" word to go away, which is what makes the notion of recovery so appealing and misleading. Even children who make enormous gains as a result of Early Intensive Behavioral Intervention exhibit some rudimentary autism symptoms on conclusion of treatment. No big deal, but it's an aspect of reality.

There seems to be something unique about being the parent of a child with autism that engenders such violent emotional reactions among parents. One seldom hears such a severe response from parents of a child with cerebral palsy or Down syndrome. There is grief to be sure, but not a sense of utter hopelessness and despair. Part of the challenge has to do with the nature of autism, and part I think arises from the parents themselves. A child with cerebral palsy or Down syndrome has a different appearance that one need not explain to a relative or stranger. It's obvious. Not so with autism.

Relatives and friends often do not understand the behavior of a child with autism and insist that if the parent were just a bit firmer with her or him, he would "shape up." Wouldn't it be nice if that were true? Parents usually feel guilty about their child's condition, not being sure if there was something they did that somehow contributed to their child's autism. It is also deeply troubling that on the outside a child with autism can closely resemble his brothers and sisters, but inside be an entirely different child, lacking the most basic communication and social skills, and having severe behavioral outbursts over events that seems to parents to be almost nothing. It is puzzling and a bit maddening.

Parents of children with autism are often more withdrawn and socially uneasy than parents of typically developing children and as a result may be even further isolated. Many parents of children with autism fit the Broad Autism Phenotype profile, exhibiting some autism-like characteristics in milder forms themselves. They tend to be shy, may be perfectionistic and prefer predictable routines, which is often difficult when parenting a child with autism. Studies have found elevated signs of anxiety and depression among mothers of children with autism in particular, which worsens as the child's behavioral challenges increase. Children with autism typically have limited ability to occupy themselves without nearly constant parental supervision. The child may be unable to play by herself without lapsing into self stimulation, which is very disturbing and stressful to most parents. Teaching a child independent play skills can be helpful to such parents. Using a combination of Visual Schedules for engaging in sequences of appropriate play activities, and TEACCH techniques to promote independent activities, can relieve the need for constant parental supervision.

Similarly, teaching children with autism to participate in community activities that require minimal social and language skills can enable the family to take outings and

enjoy one another's company. In Chapter 6. "Letting the Genie Out of The Bottle" and Chapter 10. "The Importance of Leisure", in my book *Straight Talk on Autism*\* I included lists of potential activities and outings for children of various ages and motor skill levels, including ways of teaching pre-requisite skills.

Autism is a very disabling condition, but it doesn't help to castasrophize, which tends to make matters worse. Most children with autism can become active members of their family, which greatly reduces the parental stress and violent negative emotional reaction. Professionals can often help families develop strategies for finding ways to incorporate their child with autism in typical family leisure and other community activities usually spend less time concerning themselves with whether their child will recover or loose the autism label. Finding enjoyment in the little things that make your child enjoyable can make all the difference in the world. A recent note from a parent with whose child we had previously worked wrote, "it was great to realize once again how far Alice has come.... She is doing well in all her classes she is in. She has made a little friend and they both have similar interests. The little girl (Marilyn) is so cute. One day during snack she asked another little girl to move so she could sit next to her friend Alice. Alice beamed from ear to ear and after class she told me all about her new friend." [names changed for confidentiality]

Try to think less about your child's autism and more about his or her place in the family.

\*Thompson, T. (2008) *Dr. Thompson's Straight Talk on Autism*. Baltimore, MD: Paul H. Brookes Publishing Company.

---

#### Does Autism Run in Families?

Parents often ask whether it is likely a second child will have autism if the first born was diagnosed with that condition. They tend to overestimate the actual risk due to lack of accurate information (Whitelaw et.al. 2007). The short answer is "yes" it is more likely a second child will have autism than if the first-born did not have autism, but the increased risk is not extremely high.

The earliest evidence for autism running in families came from a study by Susan Folstein and Michael Rutter who studied 21 pairs of British twins. For 10 pairs of fraternal (dizygotic) twins none of the fraternal twins were diagnosed with autism, but if they were identical (monozygotic) twins the risk was 36%.

An 1989 study by Ed Ritvo in Utah who found the risk of a second child having autism if the first had autism was 8.6%. If the first child was a boy the risk of a second having autism was 7% but if the first was a girl, the risk was 14%.

A more recent study in Queensland Australia indicates 4-6% of second children will have

## FAQs

autism if the first was so diagnosed, but if two previous children of a couple had been diagnosed with autism the risk greatly increased to 35%. In a recent review, Slatkin (2008) reported family recurrence rates of 4-10% and identical twins of 30-50%.

Risk of having a second child with autism depends on the type of autism. Judith Miles and colleagues at the University of Missouri have studied a large sample of children diagnosed with autism and finds they are of two types. One has unusual physical features and either unusually large or small head size. They have more intellectual, language and social limitations. She called this type Complex Autism. Children who had no different physical features and more closely resembled members of their family had higher IQ and stronger language and social skills (Essential Autism. Among children with Complex Autism 9% of brothers, sisters, parents and cousins have autism, while children with Essential Autism, 20% are diagnosed with autism.

In addition, it is increasingly clear that social and language limitation features of autism are often present in milder forms in siblings, parents and cousins of individuals with autism, though they are not diagnosable as having autism. This is called the *Broad Autism Phenotype* (Constantino et. al; Piven et.al).

## References

Constantino, J. et. al. (2006) Am. J. Psychiatry, 163: 294-6

Folstein S. and Rutter M. (1977). J. Child Psychol. Psychiat. 18, 297-321

Losh, M and Piven, J. (2007) Child Psychol Psychiatr. 48:105-12

Losh, M. et.al. & Piven, J. (2008) Am. J. Med. Genetics B Neuropsychiatr. Genetics. 147B:424-33.

Miles, J.H. et. al. (2005) Am. J. Med Genetics A. 135:171-80.

Queensland Health Australia, <http://www.genetics.com.au/pdf/factSheets/FS43.pdf>

Ritvo, E.R. (1989). American Journal of Psychiatry, 146, 1032-36.

Slatkin, M. (2008) Genetics, 179: 2253–2261.

Whitelaw, C. et. al. (2007) J. Paediatric Child Health, 43:752-4.

---

What is Asperger Disorder?

## Asperger Disorder: Background & Characteristics\*

**As of DSM-5 in 2013 it is possible the Diagnostic category Asperger Disorder may no longer exist. However, the individuals WITH this condition will exist and need to be understood and cared for appropriately.**

Ashley, who was three-years old at the time, had bright blue eyes and tawny hair. She was evaluated at our clinic for possible autism services. She was alert, but

## FAQs

exhibited very little eye contact, was preoccupied with playing with a toy merry-go-round and associated animals, and she talked incessantly, using vocabulary far beyond her age. Though she talked she didn't seem to listen to adult responses to her comments. Any attempt to redirect her led to a severe tantrum with screaming and hitting. She was overwhelmed with intolerance for change and perfectionism. She had little self-regulation and exhibited little empathy. Today, after 18 months of naturalistic early behavioral intervention, she is enrolled in a regular education science magnet school and is largely indistinguishable from her peers.

Yasar was also three years old at intake assessment. His sparkling dark brown eyes gave his facial expression a mischievous quality. His family was bilingual, but intervention was in English. He exhibited no eye contact at program onset. He was a whirling dervish of non-stop physical activity, climbing on and under furniture. He paid little attention to adult direction. If his parents forced him to stop one activity and begin another, he descended into a tantrum. He had little empathy, except for his older brother Jamal. Despite these limitations he had a surprisingly large vocabulary and learned very rapidly. It was obvious that he was very bright. He was intensively preoccupied with vehicles and Legos as well as several other construction activities. He and his brother were constantly fighting over access to toys. Therapy was largely discrete trial at the beginning and gradually transitioned, so for the last year it was entirely naturalistic. After three years of intervention, he is now enrolled in a regular education classroom without special education support.

Ashley and Yasar are typical of the children diagnosed with Asperger Disorder by their referring mental health professionals who have been referred to our clinic. The challenge was to develop early behavioral intervention strategies that matched their developmental profiles. This article provides background about Asperger Disorder, how it differs from Autism (or doesn't), and implications for intervention.

**HANS ASPERGER:** An Austrian pediatrician, Hans Asperger, published an article in February 1944 that described the behavior of four boys, who were between the ages of 6 and 11 years of age whom he identified as exhibiting a pattern of behavior and abilities that he called "autistic psychopathy." The pattern included a lack of empathy, little ability to form friendships, one-sided conversation, intense absorption in a special interest, and clumsy movements. Hans Asperger called children with AS, "little professors" because of their ability to talk about their favorite subject in great detail. The children Asperger identified did not engage in ma

ny of the unusual body movements like those of the children that Leo Kanner dealt with. The children did not seem different until about 3 years of age. The embedded image shows Asperger as a young pediatrician in Vienna.

Asperger employed an empathetic nurse named Sister Viktorine, or Viktorine Zak, as she was called. They opened a school for children with AS in October 1944 that provided music, speech therapy, play and exercise. However, the school only lasted

## FAQs

for four months. It was destroyed during an allied air raid in February 1945. Sister Viktorine was killed, and as a result, much of Hans Asperger's work was lost. Asperger's original 1944 article was finally translated into English by Utta Frith in 1991 in her book *Autism and Asperger*. Hans Asperger, who some people believe demonstrated Asperger behavioral traits himself, died in Vienna on Tuesday 21st October 1980, at the age of 74. [From Kevin Phillips Asperger's Syndrome site]

**DIAGNOSIS:** According to modern diagnostic criteria (DSM-IV TR) to qualify for an AS diagnosis the child must exhibit at least two of the following:

- A) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
- (B) failure to develop peer relationships appropriate to developmental level
- (C) a lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g.. by a lack of showing, bringing, or pointing out objects of interest to other people)
- (D) lack of social or emotional reciprocity.

In addition, the child must also exhibit at least one of the following:

Restricted repetitive & stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

- (A) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (B) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (C) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
- (D) persistent preoccupation with parts of objects

In addition, the child must have no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by age 3 years) and have no clinically significant delay in cognitive development or in the development of age-appropriate self help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood. To meet the diagnostic criteria for AS, the foregoing symptoms must interfere with daily family social interactions and ability to function in the school and community. Although it not required for diagnosis, physical clumsiness and atypical use of language (often called hyperlexia) are frequently reported.

**CONTROVERSIES;** Controversies about AS persists in two respects. Increasingly, many experts doubt that Asperger Disorder is really qualitatively distinct from high functioning autism. It has been proposed that the diagnosis of Asperger's be eliminated, to be replaced by a diagnosis of autism spectrum disorder on a severity scale in DSM-V. This view is strongly opposed by professionals as well as parents

and individuals with AS.

A second controversy concerns whether Asperger Disorder is different from Non-Verbal Learning Disability (NLVD), which shares many (most?) features. Some researchers (often neuropsychologists) have reported differences, such as the NLD group showing particular difficulty on visual-spatial, visual-motor, and abstract reasoning measures compared to the AS group. Other research indicates the NLD and AS groups both experience difficulty understanding emotional and nonverbal cues, and show more signs of sadness and social withdrawal compared to the other groups of children (e.g. ADHD). As a practical matter, intervention strategies for HFA, NLVD and Asperger Disorder are not distinctively different. Many Occupational Therapists emphasize the hypothesized executive function and visual perceptual motor function difficulties in NLVD (contrasted with HFA and Asperger Disorder), but it is noteworthy that both of the latter share similar features.

In practice, early behavioral intervention for children with AS will be similar to that for children with NLVD, with emphasis on effective communication, social skills and organization.

#### Bibliography

Asperger, H. (1944). Die 'aunstisehen Psychopathen' im Kindesalter. Archiv fur psychiatrie und Nervenkrankheiten 117,76-136.

Frith, U. (1991) Autism and Asperger. Cambridge University Press.

Kamp-Becker, I. et. al. (2010) Categorical and dimensional structure of autism spectrum disorders: the nosologic validity of Asperger Syndrome. J. Autism Dev. Disord. 40: 921-9.

Semrud-Clikeman, M. et. al. (2010) Neuropsychological differences among children with Asperger syndrome, nonverbal learning disabilities, attention deficit disorder, and controls. Dev Neuropsychol. 35: 582-600.

Semrud-Clikeman, M. et.al. (2010) Direct and indirect measures of social perception, behavior, and emotional functioning in children with Asperger's disorder, nonverbal learning disability, or ADHD. J. Abnorm. Child Psychol. 38: 509-19.

Williams, DL, et. al. (2008) Do individuals with high functioning autism have the IQ profile associated with nonverbal learning disability? Res. Autism Spect. Disord. 2: 353-61.

Wing, L. (1981) Asperger Syndrome: A Clinical Account. Psychological Medicine. 11: 115-129

[\* *The children's names are fictitious to protect confidentiality, but they refer to actual children with AS*]

---

#### **Asperger Emotional Challenges**

As children with AS and High Functioning Autism grow older, other emotional and behavioral symptoms often emerge. A study in Finland examined co-morbid psychiatric disorders associated with Asperger syndrome (AS)/high-functioning autism (HFA) in a combined community- and clinic-based sample of fifty 9- to 16-year-old children and youth. The prevalence was 74% with some type of mental health challenge, and often multiple co-morbid psychiatric disorders in AS/HFA. Behavioral disorders were shown in 44%, anxiety disorders in 42% and tic disorders in 6%. Oppositional defiant disorder, major depressive disorder and anxiety disorders as comorbid conditions indicated significantly lower levels of functioning. To target interventions, routine evaluation of psychiatric co-morbidity in subjects with AS/HFA is emphasized. Parents of late adolescent and young adults with AS should take these susceptibilities and needs for support in planning for adult transitions.

**INTERVENTIONS:** Don't be fooled. Just because your son or daughter with AS talks up a storm and is smarter than all get out, doesn't mean you can simply plunk him or her down in the midst of a group of 25-30 regular education students and expect your child to make a smooth adjustment. Most children with AS require preparation before entering school and additional supports during transition to school for the experience to be successful.

The most important interventions for children with AS are designed to improve a child's ability to interact with other people and function effectively in society and be self-sufficient. Many children with AS profit from an Early Intensive Behavioral Intervention approach that incorporates some naturalistic (Incidental) teaching strategies along with limited use of Discrete Trial Interventions. Many children with AS may not require 30+ hours per week of EIBI therapy, but most profit from 10-20 hours of combined naturalistic and some discrete trial teaching, depending on severity of symptoms when beginning intervention (Thompson, in press).

#### *School programs*

While some children with AS adjust well to regular education settings, others are overwhelmed by the social demands and lack of structure. The non-compliant behavior of children with AS is often misinterpreted by school personnel as willful disobedience. Parents and teachers of youngsters with AS are often misled by their large vocabularies and apparent understanding of most adult conversation. In practice, their practical understanding may be limited and their ability to act on the information may be even more limited. Parents should be less concerned about academics than communication and social skills. Parents seeking an appropriate school setting for their child should look for:

Small work groups with individual attention.

A communication specialist with an interest in social skills training.

Opportunities for social interaction in a structured setting and in supervised activities.

A concern for teaching real-life skills and encouraging a child's special interests and talents.

A willingness to individualize the curriculum. Even though the child may have an IQ within the average or above range, his/her other characteristics usually requires some acomodation.

A sensitive and knowledgeable school "point person," who is the liaison between the child, home and school

An emphasis on respect for diversity and empathy for students with the faculty and student body. Children with AS are especially prone to bullying because of their compulsive rituals and anxiety problems.

### *Social Skills Training & Cognitive Behavior Therapy*

Social Stories® and other social skills training programs are extremely popular among parents, school personnel and many therapists, but few have been rigorously evaluated. Social skills training methods generally assume a level of language complexity that exceeds that of many younger children with AS. There have been numerous problems in studies of social skills training, beginning with disagreements about exactly what one means by social skills.

Many of the reports have involved ratings by practitioners providing the services, and have been seldom blind to treatment conditions. In most instances, the gains associated with their implementation have been modest. Incorporating social skills activities within more structured intervention at home and curriculum at school is a good idea, but ought not be a free-standing activity that is an end in itself. The purpose should be to enable the child to function in family or school typical social context. A recent review article of this literature concluded, "Overall, it is clear that, despite their widespread clinical use, empirical support for SST programs for children with AS/HFA is minimal at this time" (Raio, Biedel and Murray, 2010).

Cognitive Behavior Therapy techniques are also popular, particularly with children in middle school and older. Perhaps the most widely adopted approach is Tony Attwood's. Despite their popularity, evidence to support their effectiveness is limited. Sottronoff, Attwood and Hinton (2005) reported, that, "The intervention was endorsed by parents as a useful programme for children diagnosed with Asperger

syndrome and exhibiting anxiety symptoms, and active parent involvement enhanced the usefulness of the programme.” In another study, Sottronoff, Attwood et.al (2007) reported, “Parent reports indicated a significant decrease in episodes of anger following intervention and a significant increase in their own confidence in managing anger in th

eir child.” It is difficult to know what to make of such evaluations based entirely on subjective parent impressions. The lack of independent evaluation by professionals blind to the children’s treatment status weakens support for these methods.

Most clinical reports of CBT claim significant gains, often from complex treatment involving several components. For example, (Wood et. al., 2009) used a “...CBT model (that) emphasized behavioral experimentation, parent-training, and school consultation,” within a randomized clinical trial and claimed positive outcomes. Lang et. al (2010) concluded “CBT has been modified for individuals with ASD by adding intervention components typically associated with applied behaviour analysis (e.g. systematic prompting and differential reinforcement),” pointing out that it is impossible to know what aspects of treatment have contributed to outcomes.

Cognitive behavior therapy study data suggests that these methods may be helpful for some children and young adults, but it is unclear whether intervention based on verbal cognitive mediation alone is effective for very many people with AS or HFA. It is a very popular idea which affords the possibility of being less time intensive and costly than typical applied behavior analytic interventions, but the combination may be more likely to be effective.

#### *Blended Behavioral Intervention:*

In our experience, children like Ashley and Yasar described in the first part of this report, do very well in a Blended behavioral intervention approach incorporating some Discrete Trial Intervention when introducing new skills and employing largely Incidental Teaching methods thereafter working whenever possible in natural environments, and focusing on the child’s strengths and interests. In our experience, children with AS in Blended Intervention make significant gains with 10-20 hours per week of intervention and seldom require 30+ hours per week. Children with AS prosper when expectations are clear, rules are followed (that's the way they view it), and consequences are reliable. Combining some CBT techniques with Blended Intervention makes a lot of sense, but hasn't been evaluated empirically.

#### **Bibliography**

Attwood, T (2004) Exploring Feelings: Anxiety: Cognitive Behavior Therapy to Manage Anxiety. Fugure Horizons.

Lang, R. et. al. (2010) Treatment of anxiety in autism spectrum disorders using

cognitive behaviour therapy: A systematic review. *Dev. Neurorehabil.* 13: 53-63

Rao, PA et. al. (2008) Social skills interventions for children with Asperger's syndrome or high-functioning autism: a review and recommendations. *J. Autism Dev Disord.* 38: 353-61

Sofronoff, K, Attwood T. et.al. (2007) A randomized controlled trial of a cognitive behavioural intervention for anger management in children diagnosed with Asperger syndrome. *J. Autism Dev. Disord.* 37:1203-14.

Sofronoff, K, Attwood, T. Hinton, S. (2005) A randomised controlled trial of a CBT intervention for anxiety in children with Asperger syndrome. *J. Child Psychol Psychiatry* 46:1152-60.

Thompson, T. (2011 in press) *Individualized Autism Intervention*. Baltimore; Paul H. Brookes Publishing Co,

Wood JJ et. al. (2009) Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: a randomized, controlled trial. *J. Child Psychol Psychiatry.* 50: 224-34.

---

#### **Obsessive-Compulsive Disorder in Autism**

Obsession has been a recurring theme in literature and motion pictures. Shakespeare's *Hamlet* was obsessed with death. In Melville's *Moby Dick*, Captain Ahab displayed the epitome of an obsession. He was fixated on revenge against Moby Dick, the ferocious sperm whale that had destroyed Ahab's previous ship and cost him the lower part of his leg. Ahab ranted, "...I'll chase him round Good Hope, and round the horn, and round the Norway maelstrom, and round perdition's flames before I give him up." In *Basic Instinct*, Sharon Stone's character Catherine Tramell was erotically obsessed with the detective, Nick Curran played by Michael Douglas.

Charles Dickens had a habit of rearranging furniture whenever he stayed in a hotel room and inspecting his children's bedrooms every morning, leaving behind notes when he was not satisfied with their tidiness. Michael Slater, emeritus professor of Victorian literature at Birkbeck college, London, suggests that *Little Dorrit*, the main character in Dickens's novel of the same name, reflected his own character. "There she is, the epitome of neatness, in the squalid atmosphere of the Marshalsea prison.... sweeping and cleaning and tidying all the time."

Adrian Monk, the television detective portrayed by Tony Salhoub is

uncomfortable with many aspects of the world around him, which he perceives as being tainted and disorderly, creating humorous vignettes within the main story lines. While we find amusement at some of his phobias, true Obsessive Compulsive Disorder causes great distress, which distinguishes the condition from Obsessive Compulsive Personality Disorder, in which the individual experiences no special discomfort as a consequence of the obsession about an idea, or compulsion to engage in a specific ritual. Moreover, people with OCD often exert great effort to suppress or control their obsession or compulsion, while those with OCPD do not.

Most individuals with autism spectrum disorders display aspects of OCD to some degree, while some clearly meet the diagnostic criteria for the disorder and often profit from the same medications as others with OCD. When a preferred routine or ritual is disrupted, often meltdowns occur, in some cases including severe tantrums, aggression and self injury. A little girl with Asperger disorder with whom we worked, screamed and scratched her face if her preferred bedtime routine was altered.

Among typical populations OCD begins as early as the age of two, but most often begins in the late teens for males and the early twenties for females. Studies have placed the prevalence between one and three percent. Family studies have demonstrated that OCD is familial, and results from twin studies demonstrate that the familiarity is due in part to genetic factors. Most experts believe multiple genes are involved in aspects of OCD, so it unlikely a single "smoking gun" gene will be identified.

It has been argued that OC traits may have historically conferred advantages in an evolutionary sense to human kind. The majority of compulsions such as checking, washing, counting, needing to confess, hoarding and requiring precision, all carry the potential to benefit society. A series of studies by John Constantino (shown here), Richard Todd and

colleagues strongly suggest some components of autistic traits are broadly expressed within the general population, including lack of some social skills, shyness and rigidity or compulsiveness.

Simon Baron-Cohen proposed individuals with autism exhibit what he described as the *extreme male brain*, characterized by a drive to systematize, while being deficit in empathy. He points out that typical males have on average superior skills in spatial relation tasks, while females are generally better at perspective taking than males. He has further suggested that men

## FAQs

and women both of whom carry genes increasing susceptibility to autism, are more likely to marry and have children, than they are to marry and procreate with someone who does not carry autism susceptibility genes. "My new theory is that it's not just a genetic condition," he says, "but it might be the result of two particular types of parents, who are both contributing genes. This might be controversially received....But the genetic theory has a lot of evidence, and what we are now testing is that if two "systemizers" have a child, this will increase the risk of the child having autism."

This controversial idea (assortative mating) may, in part, explain the higher than expected prevalence of high functioning autism and Asperger syndrome over the past two decades. Many more high paying jobs for individuals with strong systematizing skills in computer science, information technology and financial services, began becoming available around 1990 with the high tech "boom." This increased the chances that like-minded couples would meet one another, marry and have children than in the past. Women who are also systematizers may be more likely to be attracted to and tolerate less socially competent men who are also systematizers. Not surprisingly, they create children who are little systematizers, much like themselves.

I reviewed the occupations of 23 pairs of parents of children with autism spectrum disorders served by the Minnesota Early Autism Project over the first 3 years of operation, and found that in 71% of families at least one parent was employed in computer and/or IT, financial or statistical fields or medical sciences. In 1/4th of the families both parents had computer or technical occupations. The remaining couples were employed in education, social work, construction or service jobs (some of which had technical components). This occupation pattern seems unlikely to be attributable to chance.

Under some circumstances it may be advantageous for an individual to possess some compulsive traits. Consider the skills necessary to be a good computer programmer. In addition to being intelligent, it requires: (1) attention to detail (2) focusing on parts rather than "the big picture," (3) perfectionism, intolerance for errors (4) willingness to repeat similar or the same routines over and over (5) willingness to stick to rules (6) excessive devotion to work and production (7) reluctance to delegate tasks. In the past, most of our ancestors had occupations that required more flexibility, adjusting to changes in weather patterns, infestations of insects damaging crops and changes in entrepreneurial opportunities. Aside from repetitive factory work, most jobs required flexibility in response to changing circumstances. But characteristics

## FAQs

that make one a good computer programmer may not be optimal for being a spouse or parent, which heaven knows, requires a great deal of flexibility. But then again, if one's spouse is like-minded, maybe everything is copacetic. It isn't really a new idea after all. In 1599, in *The Dictionarie in Spanish and English*, which was compiled by the English lexicographer John Minsheu, the phrase "Birdes of a feather will flocke together."

## References

BehaveNet Clinical Capsule Obsessive Compulsive Personality Disorder DSM IV-TR = 300.3; <http://www.behavenet.com/capsules/disorders/o-cd.htm>

BehaveNet Clinical Capsule Obsessive Compulsive Personality Disorder DSM IV-TR = 301.4; <http://www.behavenet.com/capsules/disorders/o-cpd.htm>

Baron-Cohen, S. (1999) The extreme-male-brain theory of autism. Tager-Flusberg, H, (ed) Neurodevelopmental Disorders. MIT Press (1999)

Baron-Cohen, S. Edge the Third Culture, [http://www.edge.org/3rd\\_culture/baron-cohen05/baron-cohen05\\_index.html](http://www.edge.org/3rd_culture/baron-cohen05/baron-cohen05_index.html) ).

Constantino, JN and Todd, RD (2005) Intergenerational Transmission of Subthreshold Autistic Traits in the General Population. *Biol. Psychiatry* 57:655–660

Constantino, JN and Todd, RD (2010). Autistic Traits in the General Population. Downloaded from [www.archgenpsychiatry.com](http://www.archgenpsychiatry.com) July 8, 2010

Melville, H. (1851) *Moby Dick: The Whale*. Chapter 36, page, 161 <http://www.princeton.edu/~batke/moby/moby-1.html>

Monk TV Series. USA network. Andy Breckman et al. Executive Producers. Universal Cable Productions in association with Mandeville Films and ABC Studios

Polimeni, J. et. al. (2005) Could obsessive–compulsive disorder have originated as a group-selected adaptive trait in traditional societies? *Medical Hypotheses*. 65: 655-64.

Slater, M. (2009) *Charles Dickens*. New Haven: Yale University Press.

Willyson.com. HAMLET: a translation into modern English. 7 May 2007. 8 Oct 2010. .

---

## AUTISM CAUSES

---

### Does MMR Vaccine Cause Autism?

There have been numerous controlled studies since 1998 when the first false claim was published (and later withdrawn), that the MMR vaccine causes autism. Still, many parents believe the vaccine causes autism. In late 2011 and again in 2012 studies were published showing once again that MMR vaccine does not cause autism. Here is the latest.

Parents and advocates can stop worrying, and attorneys looking for a quick buck from pharmaceutical companies' deep pockets, can stop focusing on MMR vaccine as the cause of a child's autism. The latest review of over 1000 published reports indicates there is no association between MMR vaccine and autism, summarized in a report published in today's *New York Times*.

"The M.M.R. vaccine doesn't cause autism, and the evidence is overwhelming that it doesn't," Dr. Ellen Wright Clayton, the chairwoman of the panel, assembled by the Institute of Medicine, said in an interview. She was referring to a combination against measles, mumps and rubella that has long been a focus of concern from some parents' groups.

The panel did conclude, however, that there are risks to getting the chickenpox vaccine that can arise years after vaccination. People who have had the vaccine can develop pneumonia, meningitis or hepatitis years later if the virus used in the vaccine reawakens because an unrelated health problem, like cancer, has compromised their immune systems. Dr. Clayton commented: "We looked at more than a thousand peer-reviewed articles, and we didn't see many adverse effects caused by vaccines. That's pretty remarkable." August 26, 2011, on page A19 of the New York edition of the *New York Times* with the headline: *Vaccine Cleared Again as Autism Culprit*.

So why should you care about getting mumps? About five percent of people with Mumps develop pancreatitis, infection of the body's organ that regulates blood sugar and protects you against Diabetes. From 1-10% develop meningitis, which causes high temperature (fever) of 38°C (100°F) or above, headache, nausea and vomiting. Encephalitis with hearing loss is relatively rare, but does occur with Mumps. The risk of Measles is more significant with 1 out of every 20 children with measles getting pneumonia, and about 1 child in every 1,000 who get measles will develop encephalitis with convulsions, and can leave the child deaf or permanent intellectual disability. For every 1,000 children who get measles, 1 or 2 will die from it. Measles also can make a pregnant woman have a miscarriage, give birth prematurely, or have a low-birth-weight baby. In several countries, most notably the UK there have been measles epidemics due to parents refusing to have their children vaccinated. In the US there has been a Pertussis epidemic due to parents refusing to have their children vaccinated.

---

#### Prevalence of Autism Increase

**Many people are asking what is responsible for the increase in identified autism cases?** Not many years ago the prevalence was estimated to be 1 in 1000, today the CDC reports it is 1 in 150 children. It has been demonstrated repeatedly and convincingly that MMR and Thimerisol® are not responsible for the reported increased ASD cases. What then what *is* responsible? The problem with this question is that it begins with the assumption that there has been a sudden and unexpected increase in the number of new autism cases. But increasing evidence suggests that *the actual number of cases* may not have increased. What increased was *the number of identified cases*. It appears there were *always* more children with ASDs than was apparent from earlier prevalence studies that relied on older diagnostic criteria. Many cases simply weren't recognized using older diagnostic methods. What has contributed to the appearance that there has been an "autism epidemic"?

Lovaas's (1987) landmark study: Prior to the late 1980s' it was generally believed there were no effective interventions for young children with autism. In 1987, psychologist Ivar Lovaas, reported follow up results for a group of children who had received intensive early intervention, that indicated that half of children with autism diagnoses greatly profited from intensive early behavior therapy, so much so that they tested in the typical range intellectually and could participate in regular education classrooms.

Following Lovaas's (1987) publication, understandably, parents began clamoring for better methods for identifying autism among young children and greater access to such early intervention services. To that point, there had been no generally agreed upon test for autism, which made diagnosis difficult.

A new test for autism and more professionals trained to classify and diagnose Autism Spectrum Disorders: The first widely recognized and accepted test for autism, the Autism Observation Diagnostic Schedule (ADOS), was published in 1989 (Lord et.al, 1989), the year before the abrupt increase in reported autism cases. A very large number of university-based and community professionals and public school personnel began being trained to administer the new test. Many medical and educational professionals began recognizing signs of autism among children that had been labeled something else in the past. Autism diagnoses began emerging like crocus in spring time. As the number of people trained to diagnose autism increased, the number of identified cases increased.

Introduction of autism as a special education service category: Prior to 1991 children with autism were often included in the category of "emotionally disturbed" or "other health impairments" in special education school programs. Many were also categorized as having intellectual disability or learning disability. There was no separate educational category of "autism." In the 1991-2 school year the U.S. Department of Education issued a directive indicating that among the special education service categories, a new one was added, Autism. In testimony before Congress in 2002, the Autism Society of America announced that over the 8-year period 1991-2000 the number of students with autism [ages 6 to 21] in America's schools increased 1,354%. What the report didn't say was that there was no autism category prior to 2001 so there were no meaningful statistics regarding the number of children with autism in schools. From one year to the next, the number of children receiving autism services in public school programs doubled and tripled according to Child Count statistics, a clear misrepresentation of reality on the ground (Gernsbacher, Dawson and Goldsmith, 2005). Those children had been in our schools all along, but had received a different label.

Change in Diagnostic Criteria: In 1994 the American Psychiatric Association released new diagnostic criteria (DSM-IV) that broadened the definition of autism spectrum disorders. Many children who may have been labeled

emotionally disturbed, intellectually or language disabled in the past were now being diagnosed as having mild ASDs using more inclusive, modern criteria. When I began working in the autism field in the late 1960s and early 70s, only children with more severe autistic disorder were diagnosed with “autism.” They typically were minimally verbal or non-verbal, engaged in repetitive stereotype flapping and twirling, and exhibited either aggression or self-injury. Children who today are diagnosed Asperger’s Disorder or PDD-NOS would not have been so diagnosed at that time.

Increased parental demand for autism services: These events made it clear to parents that early diagnosis was very important, and that effective intervention was possible for many of their children with ASDs. As more parents became aware of ASD signs, they began seeking diagnoses from pediatricians and autism services in public schools. Public schools responded by creating more autism services. Once more services were available, schools began identifying more children as qualifying for specialized autism services, and the number of children receiving autism services greatly increased. Presumably those children had been in school all along, but they were identified for educational purposes as having another condition.

The National Research Council report: A committee of experts on early intervention convened to review evidence from studies of early interventions for children with autism spectrum disorders, and was commissioned to prepare a report on their findings. Lord and McGee (2001) summarized the committee’s findings that indicated that autism spectrum disorders could be reliably diagnosed as early as two years of age, and proposed that all preschool age children with ASDs should receive a minimum of 25 hours per week of structured intensive early intervention. That increased the pressure even more for early identification and enhanced services.

Misidentification by schools: There is growing evidence school identification has led to inaccurate prevalence estimates. It appears that children previously identified as having learning disabilities, dyslexia or mild intellectual disabilities were now being identified as having autism in public schools. As the number of students receiving ASD classification increased (from 0.6 to 3.1 per 1000 from 1994 to 2004) the percent of students qualifying for learning disabilities and mental retardation services decreased proportionately (Shattuck, 2006). Laidler (2005) studied US Dept of Education statistics for children receiving autism services and found that within a group of children born in a given year, the number identified as having an ASD increased with

time. This increase is puzzling, since within a group of children of the same age, there is no obvious reason why more should develop ASDs as they grow older. Typically autism is apparent by 3 or 4 years of age if it is going to occur. In addition, this progressive increase was substantially reduced when children reached 12 years of age, i.e. entering junior high school. This suggests administrative factors may have partially determined which children were identified as qualifying for autism services. Since fewer specialized autism services may be available for older children with ASD, perhaps they were assigned a different classification for educational purposes (e.g. learning or intellectual disability, or emotional/behavior problems) rather than autism spectrum disorder services. Consistent with this idea was a study by Palmer et. al. (2005) that examined the relation between school district funding and autism prevalence within school districts. Districts with more financial resources identified a larger proportion of children with autistic disorder. This may mean children with ASDs in less affluent districts went unidentified, while students receiving an ASDs classification in affluent districts are more likely to be incorrectly identified as having autism because specialized services are available, or both.

Misdiagnosis by community providers: Pediatricians, child psychiatrists, psychologists and other community practitioners providing services to children with autism are often not trained to accurately diagnose ASDs. They may be expert in ADHD, mood disorder or other neurodevelopmental disorders, but have had little experience with ASDs. Moreover, they are often unable to provide interdisciplinary team evaluations, which are often important in identifying alternative reasons a child may exhibit some autism spectrum signs, but not have an ASD. A study conducted in Queensland, Australia sheds light on this issue. Queensland is the second largest and third most populous state of Australia. Skellern, Schluter and McDowell (2005) conducted an anonymous survey of pediatricians and psychiatrists in Queensland who had diagnosed or treated children with autism spectrum and related developmental disorders. They found that 58% of surveyed psychiatrists and pediatricians reported that, when they were unsure of a child's diagnosis, they had erred on the side of providing an ASD diagnosis for educational purposes and 36% of clinicians had provided an autism diagnosis in order to make it possible for the child and family to receive funding for specialized services, *even when they knew the child did not meet the criteria for an autism diagnosis*. Comparable studies have not been

conducted in the US or Canada, though it seems unlikely these diagnostic problems are limited to Australia.

**Summary:** Though spectacles were used prior to the 1860s, they were primarily employed by people who did a lot of close up work, like doctors, lawyers, writers and surveyors. If other people complained of blurred vision when trying to make out objects at a distance, eyestrain or frequent headaches, their doctor or pharmacist often recommended they try wearing spectacles. They purchased eyeglasses at a nearby pharmacy or general store, determining the appropriate strength by trial and error. But when the Dutch eye doctor, Hermann Snellen published his famous letter chart for visual acuity in 1862 it became possible for any doctor's office to screen for near sightedness in a matter of minutes. Snellen Eye Charts were hung on pharmacy walls and in doctors' offices, and optometry practices began springing up in the 1870s and 80s. Over the next decade, a great many people discovered they suffered from *near sightedness* that hadn't had a formal diagnosis in the past. Had *Time* and *Newsweek* magazines existed at the time, no doubt they would have announced the nation was experiencing a *myopia* (near sightedness) epidemic. As Henny Penny discovered, there is a downside to shouting the sky is falling when it isn't. People stop listening to you.

---

#### Quack Cures & False Hope

#### Purveyors of False Hope

An advertisement on [Science Daily](#) Internet Site offers "Life Changing Brain Based Therapy: Receive 2 Free Visits! **DISCOVER AN EXCITING NEW DRUG FREE TREATMENT FOR AUTISM AND AUTISM SPECTRUM DISORDERS (ASPERGER'S/PDD-NOS)!**" Wow, that sounds pretty terrific, so I decided to look into it. *Science Daily* is a commercial web site run by Dan and Michelle Hogan. Dan is a free lance science writer who has worked for NIH, the Jackson Labs and other well known as well as lesser known organizations doing science writing to popularize genetics and other medical research, and Michelle was a fifth grade science teacher. There appears to be little screening of the veracity of ads on their website, and it is not at all obvious how the reader is to distinguish between science news originating in legitimate professional publications, other news reports from newspapers and television or the internet, and commercial advertisements on the *Science Daily* website. The website is a hodge-podge of blocks of text, graphic images, video clips, some of which are reports from scientific journals, others are ads for questionable products or services. So which is this ad for AN EXCITING NEW...TREATMENT?

## FAQs

The ad goes on to say the person offering the service in the Minneapolis-St. Paul area is "... a *board eligible chiropractic neurologist*." He says, "*I have advanced training in blood chemistry analysis and functional endocrinology. I am the clinic director.... I consult with hundreds of doctors around the country [The ad doesn't say what kind of doctors, perhaps osteopaths and chiropractors?] and am the author of (an) alternative medicine bestseller.... It's time to stop believing the myths you've been told about autism, that it is a genetic disorder and nothing can be done for your child.*" [As an aside, I'm not aware of anyone who says "nothing can be done for your child."] Note that he does not say he is a board certified Chiropractic Neurologist of which there are six in the Minneapolis-St. Paul Area. *Board eligible* describes a person who is eligible to take the specialty board examination by virtue of having graduated from an approved school, completed a specific type and length of training, and practiced for a specified amount of time, but who has not passed the specialty examination.

The person advertising "Life changing brain based therapy" that is "an exciting new drug free treatment for autism and autism spectrum disorders," has completed a Bachelor's of Science degree at Northwestern Health Sciences University in Bloomington, MN and Doctor of Chiropractic from The Carrick Institute of Neurology in Florida. Northwestern Health Sciences University offers degrees in acupuncture, chiropractic and massage therapy, and does not appear to be an accredited university in Minnesota. To qualify as a board eligible chiropractic neurologist, the candidate must have completed a bachelor's degree in chiropractic plus 200 hours of courses on-line, podcast and some face-to-face courses to which the student usually needs travels to attend. Carrick Institute offers brief courses all over the US, Australia and other countries, which seems like a nice way to have a vacation.

The Carrick Institute is a business operated by Frederick Carrick that specializes in distance training of chiropractors specializing in neurological and neurodevelopmental conditions, from migraine to vertigo, ADHD, autism, dyslexia, Tourette syndrome, Obsessive Compulsive Disorder, chronic pain, spinal cord injuries, neuromuscular disorders, "Functional Disconnection Syndrome," immune gastrointestinal disorders, anxiety, and mood disorders, as well as many other conditions. The program offers supplementary certification in developmental disabilities, neurochemistry and nutrition. Frederick Robert Carrick, is a graduate of Parker College of Chiropractic in Irving, Texas and he claims to have earned a PhD from Walden University, Minneapolis, MN 1996 in *Education: Brain-Based Learning*. Walden University now offers a PhD in psychology but not education. I'm not aware of any other university that offers such a doctorate from a college of education.

I wouldn't want to single out the chiropractic neurologist who advertised in *Science Daily*, because there are now other very similar outfits called *Brain Balance* also operated by graduates of the Carrick Institute, one in Minnetonka and the other in Woodbury Minnesota. They say, "Functional Disconnection—an imbalance in the connections and function between and within the hemispheres (sides) of your

## FAQs

child's brain—this condition is responsible for a host of behavioral, academic, and social difficulties.” They claim their chiropractic neurology treatments correct such “disconnections,” though there is no evidence from any controlled studies that such any such treatment is effective.

There seems to be no end of hocus-pocus in the field of autism services. Desperate parents will spend their hard-earned cash on nearly anything that offers hope, even though there is no evidence the offered service has any lasting effect on their child's functioning whatsoever. It is very disappointing that numerous internet sites, not just *Science Daily*, will post nearly any advertisement, no matter how disreputable, as long as it brings in revenue. The reader who would like to catch up on various questionable remedies might find it useful to take a look at [Quack Watch](#).

---

### Can Medication Prevent Autism?

At this time the answer is "no," there is no medicine, diet or other biological method to prevent autism. However, future holds great promise for preventing and reversing autism symptoms for many children affected with the disability. A promising line of work combines medication to promote brain connectivity with intensive early intervention, possibly as early as 1 year to 18 months of age. Dr. Diane Chugani and her colleagues at Wayne State University have conducted very promising work suggesting that treating children diagnosed with autism at 2 years of age with low doses of a medicine (buspirone) normalizes serotonin in their brain cells, which would otherwise be deficient. Proper levels of serotonin are necessary for normal brain connectivity. Dr. Chugani and her colleagues are currently combining EIBI with medication to determine whether these interventions produce a synergistic effect, possibly preventing emergence of autism in some susceptible children (D.C. Chugani, 2010). Related work suggests it may be possible to treat youngsters with fragile X syndrome with a medication that corrects the balance of proteins that make components of brain synapses (Dolen, Carpenter, Ocain, & Bear, 2010; Penagarikano, Mulle, & Warren, 2007). About one quarter of children with fragile X syndrome meet the diagnostic criteria autism. Together with EIBI, this may make it possible to reduce or eliminate many of the symptoms of autism among children with fragile X and autism.

## REFERENCES

Chugani, D. (2010) Wayne State University, personal communication, June 24, 2010

Committee on Educational Interventions for Children with Autism, N. R. C. (2001). *Educating children with autism*, C. E. Lord and J. McGee, Editors) Washington, DC: National Academies Press.

Dölen G, Carpenter RL, Ocain TD, Bear MF. Mechanism-based approaches to treating fragile X. *Pharmacol Ther*. 2010 Jul;127(1):78-93. Epub 2010 Mar 18.

Penagarikano O, Mulle JG, Warren ST. The pathophysiology of fragile x syndrome. *Annu Rev Genomics Hum Genet.* 2007;8:109-29.

Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders*, 39(1), 23-41.

Sherer, M. R., & Schreibman, L. (2005). Individual behavioral profiles and predictors of treatment effectiveness for children with autism. *Journal of Consulting and Clinical Psychology*, 73(3), 525-538.

Thompson, T and Contributors (2011) *Individualized Autism Intervention for Young Children; Blending Discrete Trial and Incidental Approaches*, Baltimore: Paul H. Brookes, Inc

---

#### Autism Risk Factors: Is Autism Inherited?

**Genetic Risk:** Current evidence suggests that as many as 12 or more genes on different chromosomes may be involved in autism, to different degrees. These genetic differences likely account for the wide variability in autism. Some genes may place a person at greater risk for autism, called *susceptibility genes*, and may run in families. Other genes may cause *specific symptoms* or determine how severe those symptoms are. Or, genes with physical errors called *mutations* can happen spontaneously and add to the symptoms of autism because the genes or gene products aren't working properly. It is generally thought these mutations account for a minority of autism cases.

**Runs in Families:** Among some brothers or sisters of a child with autism there is only a moderate risk of also having autism, for example 2%. While this is much higher than the likelihood of a child having autism if there are no siblings with ASD, it is still fairly low. On the other hand, in some types of autism the likelihood of recurrence in the same family is much higher, e.g. 10-15% depending on the type of autism. Consult your pediatrician's clinical geneticist for accurate information in your family's case.

**Disabilities Associated with Autism:** Other risk factors for autism. Children with Tuberous Sclerosis or Fragile X syndrome are also more likely to have autism. Families with other biological relatives with autism spectrum disorders, such as parents, grandparents, aunts or uncles and first cousins are at higher risk for having a child with autism. Cornelia de Lange Syndrome and Prader Willi Syndrome are also associated with autism risk.

**Infection and Drug Risks:** A variety of physical risk factors are associated with autism. Maternal pregnancy during which measles, mumps, rubella, influenza,

chicken pox, herpes or pneumonia were contracted increases autism risk. Infections an infant experiences after birth can increase the risk, such as meningitis, have been implicated in ASD. Of specific infections known to affect the developing brain, rubella has been most commonly reported to be associated with ASD. There is an association of fetal alcohol syndrome with autism risk and a larger association of maternal use of some anti-epileptic drugs and autism risk.

**Epilepsy and Autism:** Other problems commonly associated with autism: About 1/3 of individuals with autism develop some form of epilepsy by adulthood. These seizures can nearly always be controlled with anti-epileptic medication.

**Summary:** The bulk of evidence suggests most forms of autism result from genetic susceptibility genes combined with other genes which control specific autism symptoms. Some genetic risk runs in families which has to be determined on a case by case basis. Just because you have one child with autism does not automatically mean there is very high risk other children will have autism, though it is clearly higher than chance. There is very strong evidence a variety of maternal infections and early post-natal children's infections (e.g. Rubella) can increase the risk of autism. There is some evidence very low birthweight babies born prematurely also have increased autism risk.

---

#### What are Autism Endophenotypes?

Most experts believe it is very unlikely a single gene on a single chromosome is causally responsible for most cases autism, as is true of Sickle Cell Anemia and Huntington's Disease.

Instead, autism is most likely produced by several genes working together, residing on different chromosomes, possibly with some genes influenced by other external factors. This latter idea is called the "two hit" theory among autism experts, i.e. there is one gene causing susceptibility to autism and a second gene that determines the specific features such as language deficits or excessive responsiveness to some sensory stimulation. One gene may make a child generally susceptible to developing autism and two or three other genes may determine the particular ratio of the the main three symptoms, communication deficit, lack of social understanding, insistence on sameness and non-functional compulsive routines. Most or all of the genes may function by the same underlying process, but exert their influence in different parts of the developing brain.

**"Endophenotype"** is one of those \$25 words that flummox most of us. A *phenotype* is a characteristic regulated by one or more genes, such a blue eyes or red hair. **Endophenotypes** (i.e. features within a given phenotype) are measurable components along the pathway between a disorder and the genes that underlie the condition. As a result many autism genetics researchers are searching for components of autism and the genes responsible for each feature. One way of thinking of it is that the cute quirky and puzzling child Mom and Dad see every day

## FAQs

at home, exhibits features composed of several component endophenotypes most linked to different genes.

Endophenotypes are especially useful in studying variable and genetically complex disorders like autism and schizophrenia. An endophenotype may be neurophysiological (e.g. an functional MRI features), biochemical (a brain chemical receptor difference), cognitive, or behavioral (e.g. lack of social perceptiveness). The criteria that a endophenotype must fulfill include: The endophenotype feature is associated with a disorder in the population. The endophenotype is heritable. The endophenotype is present in an individual whether or not illness is active (e.g. in schizophrenia or children who have recovered from many symptoms). Within families, the endophenotype and disability occur together. The endophenotype found in a family member with diagnosed symptoms is also found in other family members who are not diagnosed with ASD at a higher rate than in the general population (e.g. brothers and sisters without autism have more problems with social perceptiveness than unrelated people in the population).

By piecing together discoveries of most of the endophenotypes of which autism is composed, it should be possible to construct a better understanding of autism genetics and potentially target symptoms more specifically for treatments.

See Gottesman and Gould (2003) The endophenotype concept in psychiatry: etymology and strategic intentions. *Am J Psychiatry*. Apr;160(4):636-45.

---

## BEHAVIORAL & SOCIAL INTERVENTIONS

Following a child's diagnosis, one of the early questions parents ask are about the optimal services for their child to promote communication, social, cognitive and behavioral development. Recommendations of various may be confusing and conflicting at times. In these articles, I have attempted to provide information for parents and practitioners about various intervention approaches. Assumptions behind developmental and behavioral interventions are discussed in a later article, as well as naturalistic or sometimes called "incidental" teaching approaches. Many times teachers or parents confuse a specific technique, like Visual Schedules or PECs, with a theoretical approach, like ABA versus Developmental. Visual Schedules and PECs can be used in either theoretical framework and are not a choice

among them.

---

#### Cost-Benefit Analysis of EIBI

Applied Behavior Analysis Early Behavioral Intervention is typically provided to children with autism for 2-3 years beginning at 2-4 years of age, costing an average of \$50,000 per year for a total of \$100-150,000. A lifetime cost analysis incurred by individuals with autism conducted by Michael Ganz of th

e Harvard School of Public health indicated “the total annual societal per capita cost of caring for and treating a person with autism in the United States was estimated to be \$3.2 million....,” of which direct medical costs totaled \$305,956. (Ganz, ML (2007) The Lifetime Distribution of the Incremental Societal Costs of Autism. *Arch Pediatr. Adolesc Med.* 161).

Numerous studies indicate that approximately half of children with autism who receive Early Intensive Behavioral Intervention for 2+ years function in the typical range by 6-7 years of age and are able to participate in regular education, community and family life. Those individuals do not require on-going intensive medical treatment or the additional costs associated with home health care or group home/residential care typically covered by Medicare, private insurance supplemented by family out-of-pocket expenditures,

are obviated.

This suggests medical and indirect care costs incurred by individuals with autism who have received EIBI should be reduced by half (i.e. \$1.6 million over lifetime per individual), assuming their health care costs should approximate those of a typically developing child (i.e. \$11,000 from birth to 18 years of age). This substantial savings can be realized by providing the best scientifically validated, evidence-based treatment available, i.e. Early Intensive Behavioral Intervention. These estimates do not include reduced costs of caring for half of individuals with autism who experience significant, but less dramatic improvements as a result of EIBI.

#### **The health and economic consequences of lack of appropriate early treatment are serious and can be severe and life-altering**

According to the National institute of Neurological Disorders and Stroke, “Autism varies a great deal in severity. The most severe cases are marked by extremely repet

itive, unusual, self-injurious, and aggressive behavior. This behavior may persist over time and prove very difficult to change, posing a tremendous challenge to those who must live with, treat, and teach these individuals.... Adolescence may worsen behavior problems in some children with autism, who may become depressed or increasingly unmanageable.” **NINDS Autism Fact Sheet, 2010; May**

#### 4, 2010

[http://www.ninds.nih.gov/disorders/autism/detail\\_autism.htm](http://www.ninds.nih.gov/disorders/autism/detail_autism.htm)

Prior to the late 1980s when autism early behavioral intervention was first introduced, many individuals with autism exhibited downwardly worsening severe behavior problems (aggression, self-injury, property destruction), combined with lack of communication and social skills, that led to institutional or specialized residential placement in settings for people with developmental disabilities, often for the rest of their lives. These

services are funded by Medicaid with cost in state public institutional costs ranging from \$100-\$200,000 (mean= \$134, 619) per year per resident. The average annual cost of care in private community residential facilities is \$52,585. (Braddock, D., Hemp, R and Rizzolo, MC (2004) State of the States in Developmental Disabilities. *Mental Retardation*. 42: 356-70). [David Braddock shown in embedded photo.]

Not only do we value the lives of the children with autism with whom we work, it makes economic sense as well. This does not imply that every child with an ASD medically requires 40 hours per week of EIBI for four years, but it makes a strong case for individualization of EIBI services for children with autism matching their profiles of characteristics.

---

What is Theory of Mind?

#### **Theory of Mind: A Tale of Mental Mischief**

A lot of smart psychologists, with way too much time on their hands, have spent time speculating about *Theory of Mind* in general, and the autism, in particular. A 1978 study by David Premack and Woodruff titled "Does the chimpanzee have a Theory of Mind?" started it all. In the study, a chimp named Sarah observed a video of an actor trying to solve a problem... reaching for bananas with a stick. After the video was turned off, the Chimp was shown two pictures of the actor trying two ways of solving the problem. Sarah reliably chose the picture corresponding to the better solution. P&W assumed this meant Sarah assumed the actor's motives. What followed was a great deal of mischief and speculation, eventually focusing upon children with autism. You can't believe how many people have spent years messing with this, to absolutely no practical consequence whatsoever.

In an insightful article, C.M. Heyes (1998) showed that all of the studies claiming to show non-human primates have mental understanding of other's thoughts or motives are seriously flawed. Professor Heyes concluded, "The idea that primates have a theory of mind is important and intriguing, and a great deal of careful labor has been devoted to its investigation. Therefore, it can be disappointing and irritating to be reminded that there are other, less exciting explanations for the reported data, especially when the recognition of these other possibilities requires close examination of methodology. It can seem as if elegantly bold ideas are

## FAQs

meeting carpingly narrow objections, and in such a contest our instincts, or at least my instincts, are not to shout for the methodologists. But it is precisely because Premack and Woodruff's question is important and intriguing that it warrants a reliable answer; and without some sober reflection, acknowledging the limitations of current research, we may never know whether nonhuman primates have a theory of mind." In other words Chimps and other primates don't think about what others are thinking, even though it's fun to assume they do.

In 1985 Baron-Cohen, Leslie and Frith conducted the *Sally and Ann False Belief Test* using dolls as the characters in a skit. They tested children with autism, others with Down Syndrome and a third group of typical comparison children. In the skit, two little girl dolls, Sally and Ann are in a room as well as a basket covered by a blanket and a box with a cover. Sally puts her ball in the basket and covers it with the blanket while Ann watches. Sally leaves the room while Ann remains behind. While Sally is gone, Ann takes the ball out of the basket, replacing the blanket, and places the ball in the box and closes the cover. Sally returns. *Question:* Where will Sally look for the ball. Most typically developing kids over 4 years of age say she will look in the basket where Sally had originally placed, while most children with autism will say Sally will look in the box where Ann moved the ball. In other words they are not able to separate their own belief about the reality of the situation (Ann placed the ball in the box) from Sally's point of view, i.e. she had placed it in the basket.

The tendency to assume another person's perspective has been mistakenly called "Theory of Mind." I say mistakenly because it isn't a theory at all. A theory is an idea based on objective premises and conclusions following rules of logic. No one believes young children with autism or typically developing children have such a theory, nor do Chimps as far as anyone can tell. The only way in which the word "theory" is involved, is in the common sense every day idea that a theory is some explanation for an event that you can't see happening, like what might be going on in another person's mind. That isn't what a theory, though some people get a kick out talking about it as though a theory is involved.

There are problems with this test. Simon Baron Cohen has consistently argued that this inability of children with autism to accurately predict Ann's behavior is due specifically to a social deficit related to understanding of others' motives and beliefs. Grant, Riggs and Bocher tested this idea in a study titled, *Counterfactual and mental state reasoning in children with autism* published in 2004. They found that impaired performance on standard false-belief tasks in autism is associated with limited competence with *physical tasks which do not require either an understanding of social beliefs* (or some of its component skills), plus defective competence in inferential reasoning, but that impaired performance is not caused by an inadequate understanding of belief. In other words, the deficit is largely difficulty with inferential reasoning.

Years ago my wife Anneke Thompson was tutoring a pre-teenage boy with high

functioning autism. It had just begun sprinkling outdoors but the rain was not yet visible from inside the window. A man walked by outdoors along the sidewalk and she asked the student why the man was holding an umbrella. Despite being otherwise very bright, the student had no idea. Perhaps the deficit was lack of understanding of human behavior when it rains, but he had no ability to inferentially reason why the man was holding an umbrella. Now try showing the same youngster two pictures, one of a house with a chimney with smoke coming out, and the second a similar house with a chimney but no smoke emanating from the house. In both cases we make certain trees or other seasonal cues are removed. It is very likely the young man with autism would also have trouble answering the question, *Why is Smoking Coming Out of The Chimney of This House but Not That House?*, such as one is in the winter or that the weather is cold and the other is in warm weather. Inferential reasoning requires a great deal of practice. I presented an analysis of the conditions required to give rise to the kind of skills that permit a child with autism to “pass” the Sally-Ann false belief test, as well as display other self-awareness skills [Thompson (2008)] .

Schlinger (2009) in reviewing theory of mind stated “Spradlin and Brady (2008) listed three requirements for a child to succeed on the false belief task. First, she must observe where Maxi initially placed the object. Second, she must remember where the object was placed. And third, she must have observed that people usually look for objects where they placed them or were seen last. Concerning the last requirement, Spradlin and Brady explained:

*The child from a well organized home will have had numerous opportunities to observe that other people look for objects where they placed them. If the child observes the mother place the jelly jar in the pantry, the mother will generally look for the jam jar in the pantry. Moreover, the child will have had numerous opportunities to place objects and look for them. Most often, looking where one placed the object will be reinforced. Less frequently, a child may have seen someone place an object in one place and have someone else move the object and then observe the first person look for the object where he/she initially placed it. Probably more frequently, the child will have had personal experience in placing an object in one place and having a sibling or parent place the object somewhere else. (p. 345)”*

The long and short of it is that failure to exhibit *Theory is Mind* in autism is a misnomer that refers to difficulty with more complex inferential reasoning among children who lack relevant experience. Inferential reasoning in the Sally-Anne test involves responding to cues to which children with autism seldom attend, such as facial expressions including stimuli arising from eyes, and understanding and imitation of motor movements, it would make sense such children would have difficulties. Until children with autism are explicitly taught that those cues are important, they fail to attend to them. No theory is involved whatsoever. As English psychologist Alan Costall and a colleague wrote, “Theory of Mind is now...not so

much a theory, more a way of life”

Baron-Cohen, S., Leslie, A.M., & Frith, U. (1985) Does the autistic child have a ‘theory of mind’? *Cognition*, 21, 37-46

Costall, A. and Leudar, I. (2007) Getting Over “the problem of other minds”: Communication in Context. *Infant Behavior & Development*. 30:289-95.

Premack, D. and Woodruff, G.(1978) Does the chimpanzee have a Theory of Mind? *Behavioral Brain Sciences*, 1, 515-526

Grant, CM, Riggs, KJ, and Boucher, J. (2004) Counterfactual and mental state reasoning in children with autism. *J. Autism and Developmental Disorders*. 34: 177-88.

Heyes, CM (1998) Theory of mind in nonhuman primates. *Behavior and Brain Sciences*, 21: 101-48.

Schlinger, H.D. (2009) Theory of Mind: An overview and Behavioral Perspective. *The Psychological Record*, 2009, 59, 435–448.

Spradlin, J. E., & Brady, N. (2008). A behavior analytic interpretation of theory of mind. *International Journal of Psychology and Psychotherapy*, 8, 335–350.

Thompson, T. (2008) Self-Awareness: Behavior analysis and neuroscience. *The Behavior Analyst*. 31: 137-144.

---

#### **What are Blended Autism Interventions?**

The *Oxford English Dictionary* defines the verb “blend” as, “Mix (components) intimately or harmoniously so that they are inseparable and their individuality is obscured.” (Brown, L. 1933/1993). When providing Intensive Early Behavioral Intervention to children with autism, we combine elements of Pivotal Response Treatment (Koegel and Koegel, 2006), Milieu Language Teaching (Kaiser and Hester, 1994), Incidental Teaching (Hart and Risely, 1975), Activity-Based Early Intervention (Pretti-Frontczak and Bricker, 2004) with Discrete Trial Intervention (Lovaas, 1987) in various proportions, depending on the child’s needs. Of the children receiving services from the Minnesota Early Autism Project, about 25% each receive Discrete Trial or entirely Incidental Teaching therapy, and half receive a Blended Combination.

A somewhat skeptical colleague asked me if Blended Intervention means the same thing as eclectic. Eclectic usually means a practitioner incorporates a little bit of this and a little bit of that depending on their personal preference, usually whether there is any evidence of efficacy or not. Choice of eclectic interventions is usually highly subjective. I refer to that as the “Little Dab’l Do Ya” approach, drawing on the old

## FAQs

Brylcreem hair grooming commercial, for those of you old enough to remember those ads. The notion is that some people believe a little dab of lots of things is better than two or three interventions implemented in a much more systematic fashion.

An eclectic approach leads many parents to conclude that the more and varied interventions to which they expose their child the better her or his chances of developing typical skills and overcoming autism symptoms. I know of no evidence whatsoever that this is a good idea. It will guarantee the child will be confused trying to learn to adjust to the way numerous adults speak with her or him and socially interact while implementing their interventions. Everything we know about young children with autism suggests this is a bad idea. It also assures parents will be exhausted as a result of transporting their child from lesson to therapy to school and back home again, often frenetically rushing from one to the next.

In addition to 20-35 hours per week of one to one behavioral intervention with each child (including time working with parents) during the first year of our intensive behavioral therapy, all of the children we have treated receive speech therapy and nearly all of them are enrolled in Early Childhood Special Education for anywhere from 3-15 hours per week depending on their stage of intervention.

We are currently statistically analyzing and summarizing outcomes for children who have received one or more year of MEAP autism services and plan to submit the findings to publication within the next few months. I can report that thus far, they are very encouraging, indeed.

## References

- Brown, L. (1933/1993) *The New Shorter Oxford English Dictionary (2 Vol)*. NY: Oxford University Press
- Hart, B. and Risley, TR (1975) Incidental teaching of language in the preschool. *Journal of Applied Behavior Analysis*. 8: 411-20.
- Kaiser, AP. and Hester, PP (1994) Generalized effects of milieu teaching. *Journal of Speech Hearing Research*. 37:1320-40.
- Koegel, RL and Koegel, LK. (2006) *Pivotal response treatments for autism: Communication, social and academic development*. Baltimore: Paul H. Brookes Publishing Co.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- Pretti-Frontczak, K. and Bricker, D.(2004) *An Activity-Based Approach to Early Intervention*. Baltimore: Paul H. Brookes Publishing, Inc.

---

## Components & Family Role in Early Intervention

Educational and health care cost containment mandates employing the most effective aspects of interventions for specific students or clients. The National Research Council Report, *Educating Young Children with Autism* (2000) and Reichow and Wolery's (2008) quantitative summary of autism early intervention studies, contained two important conclusions: (1) Early Intensive Behavioral Intervention is highly effective for many children with autism, and (2) Which aspects of early behavioral intervention are responsible for these outcomes in subgroups of children is not well understood. We must do a better job of identifying which children benefit most from specific aspects and intensities of intervention. The goal is to identify which components of comprehensive early intervention treatments account for the bulk of treatment outcome, so children optimally benefit from more focused interventions. Growing evidence indicates that for children who are most responsive to Early Intensive Behavioral Intervention, the bulk of improvements occur in the first 12-18 months. It may prove possible to tailor make Blended Interventions that focus on child-specific skill needs and intervention methods to optimize gains during this period of rapid development (Thompson, 2010, In Press).

### **Family Factors in Intervention Effectiveness and Adjustment**

After therapists and special teachers have finished their work with a child with autism and their family, it is up to parents to sustain the gains achieved and incorporate effective interventions into their lives. While nearly all children with autism spectrum disorders benefit from Early Intensive Behavioral Interventions, and the relation between parents and the child with autism greatly improve over the course of intervention, some families integrate these therapies into their families' lives with greater ease than others. Strategies for determining which families will find EIBI approaches most compatible with their lives, and devising ways of reducing the stressfulness of intensive intervention for some parents, will be the focus of greater efforts drawing on the work of Grindle, Koshoff, Hastings and Remington, (2009) and Remington, Hastings, Koshoff, et. al. (2007).

### **References**

Chugani, D. C. (2010). Conversation with Diane Chugani regarding research on buspirone and intensive early behavioral intervention, 3-15-2010

Dolen, G., Carpenter, R. L., Ocain, T. D., & Bear, M. F. (2010). Mechanism-based approaches to treating fragile X. *Pharmacology and Therapeutics* 2010

March 18, Epub ahead of print.

Gillberg, C., & Coleman, M. (2000). *The Biology of the autistic syndromes, 3rd Edition*. Cambridge, UK: Cambridge University Press.

Grindle CF, Kovshoff H, Hastings RP, Remington B. (2009) Parents' experiences of home-based applied behavior analysis programs for young children with autism. *Journal of Autism and Developmental Disorders*. 39(1):42-56.

Lederberg, J. (2001). The meaning of epigenetics. *The Scientist*, 15(8), 6.

Meehl, P. E. (1962). Schizotaxia, schizotypy, schizophrenia. *American Psychologist*, 17, 827-838.

Morrow, E. M., Yoo, S. Y., Flavell, S. W., Kim, T. K., Lin, Y., Hill, R. S. et al. (2008). Identifying autism loci and genes by tracing recent shared ancestry. *Science*, 321(5886), 218-223.

Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders*, 39(1), 23-41.

Remington B, Hastings RP, Kovshoff H, degli Espinosa F, Jahr E, Brown T, Alford P, Lemaic M, Ward N. (2007) Early intensive behavioral intervention: Outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation*. 112(6):418-38.

Rutter, M, Anderson-Wood, L, Beckett, C, Bredenkamp, D, Castle, J, Groothues, C., Kreppner, J et. al. (1999). Quasi-autistic patterns following severe early global privation. *Journal of Child Psychology and Psychiatry*, 40(4), 537-549.

Rutter, M., Kreppner, JM, O'Connor, TG and the English and Romanian Adoptees (ERA) study team (2001). Specificity and heterogeneity in children's responses to profound institutional deprivation. *British Journal of Psychiatry*, 179, 97-103.

---

#### What Are Naturalistic Interventions?

Parents often feel at a loss when they attempt to carry out behavioral intervention or

## FAQs

teaching methods on their own that were suggested by therapists or school personnel. Some Applied Behavior Analysis approaches may seem contrived to them and even contradictory to their natural tendencies, such as conducting repeated learning trials in a discrete trial format, or ignoring crying and paying attention when the child is following directions and behaving cooperatively. Parents say, "It just doesn't feel right." Many parents already have a full time job working outside the home or managing the household and caring for other children. Trying to find time for conducting additional therapy or teaching can seem daunting.

Parents often find it possible to fit therapy activities within normal daily routines, which they are going to be doing anyway in the future. Naturalistic intervention or incidental teaching can be very effective for children who already have some basic skills of following directions, play skills, and who have participated in some of the following activities in a Discrete Trial Format either at school or home. Higher functioning children tend to do best with naturalistic interventions that occur in the context of normal daily routines and activities.

Children with extremely short attention span, or who do not follow one-step instructions consistently or who bolt or elope from the area, are usually not good candidates for an incidental teaching approach. Typically, if a child begins to acquire skills in these contextually nested daily activities, they generalize with minimal additional specific teaching. This approach also encourages learning related vocabulary that fits within each context, and specific responses that are appropriate to those settings.

### *Community Outings*

You are going to go to the library and pick up some books and return old ones, and then you promised your child you would take him to the park. Make a list of 3-6 objects or things your child is likely to see on his outing, at the library and then in the park. For example, the words, book, clock, CDs, and librarian are obvious. Think about action words that your child is likely to encounter in the park, such as running, jumping, swinging, laughing, throwing and so on. At the library you might say "Where is the clock?" "Give the librarian the book," "Put the book in the bag," and so on. At the park, you might say, "What is that boy doing?" (Running), "Which girl is throwing?" and "Which child is swinging." These questions and requests can be interpolated between climbing on the monkey bars, teeter tottering or riding the merry-go-round. They should definitely not be showered upon the child as a non-stop string of questions, which defeats the purpose. The child should see your queries as making sense in the context of what she or he is doing.

You can also use emotions expressed by others in outdoor settings, like the park, as a way of naturalistically teaching emotions. Point to a child who is laughing and ask, "How does that boy feel?" "Point to the sad girl," referring to a child who is crying. Making this work well requires planning in advance what teaching

opportunities you are likely to encounter. If you prepare for them, it will be easy to use spontaneously arising events to teach important skills. If you hope to recognize opportunities arise on the fly without planning, you are likely to miss most of them. You can also prepare your child for such outings by showing her or him pictures of different facial expressions or various action verbs the night before the outing.

### *Household Chores*

Household chores are great vehicles for teaching the names of things (such as silverware items, napkins and dishes), places (rooms in the house), prepositions (in, on, beside, on top of), relational words (bigger, shorter, taller), color names (receptive) and labeling. Here are simple examples: "Put the fork beside the plate," "Put the towel in the bathroom," "Get the small cup," "Find the red one." Action verbs, like pour, put, fold, dump, rinse, give, hand, and help, are part and parcel of many household chores. "Pour juice in Emma's cup," "Give Donnie the spoon," or "Help Mom with the dishes." These incorporate social goals with household chores. Such household routines are also useful for teaching sequencing skills, like the order in which objects and materials are accessed to achieve a goal, such as filling a cup with juice, which involves a series of specific steps, "What should we do next?" These are called executive function activities and are usually problematic in youngsters with autism.

One of the advantages of such daily routines is that they have to be done anyway, and will eventually become functional skills that will be helpful to the child and family. When a child does helpful things around the home, parents, older siblings and friends automatically make positive comments which helps reinforce and maintain the child's activities. As the child becomes more competent in them, s/he will be able to complete many of them with minimal prompts.

A last advantage of these naturalistic household and other daily routines is that they are incompatible, to a large extent, with non-functional repetitive routines and will provide a much higher rate of positive parental contact than if the child is left to fend for her or himself. It is more likely the child will engage in some form of challenging behavior to achieve parental attention if they have nothing functional to do that gains Mom or Dad's interest.

See Chapter 6 in my book, "Straight Talk On Autism" published by Paul H. Brookes for more suggestions.

---

#### **What Are Visual Supports?**

Thoreau wrote, "The question is not what you look at, but what you see." The title of Temple Grandin's, book "Thinking in Pictures." emphasizes the importance of visual information for people with autism spectrum disorders. It isn't that speech and other auditory signals can't be useful, because they can. But on average, appropriately presented visual stimuli can not only facilitate learning, but can make the day-to-day

world more negotiable for many people with ASDs. This article provides information about a variety of visual supports that can be helpful to children and youth with autism spectrum disorders.\

The Autism Spectrum Institute of Illinois State University states, “*Visual supports are tools that are used to increase the understanding of language, environmental expectations, and to provide structure and support for individuals with autism spectrum disorders (ASD). They facilitate understanding by remaining static or fixed in the individual's environment. If verbal language, which is considered transient or fleeting, is the only method used to communicate expectations, provide support and increase an understanding of language, then individuals with ASD may have extreme difficulty.*”  
<http://www.autismspectrum.ilstu.edu/resources/factsheets/visualsupports.shtml>;  
Accessed 7-18-09 [Image: Thanks to WorkingWithAutism.Com]

### *General Information About Visual Supports*

Linda Hodgdon, MEd & CCC-SL author of “Visual Strategies For Improving Communication” (1995) Quirks Roberts Publishing Co., provides a wide array of visual support suggestions at her website: <http://www.usevisualstrategies.com/> Though a bit dated, her book is a goldmine of terrific strategies.

Another good general resource is: Marlene Cohen and Donna Sloan (2007) “Visual Supports for People with Autism: A Guide for Parents and Professionals”. Woodbine House. This award-winning book is by two behavior analysts from the Rutgers University’s Douglass Center.

### *Visual Schedules*

A series of activities extending over a period of time can seem confusing and overwhelming to a child with autism. Breaking those activities down into discrete subtasks or activities represented by pictures or printed words (with higher functioning school age youngsters) can transform a chaotic or daunting situation into one that is more manageable for a child with an ASD. McClannahan and Krantz were the first to introduce “activity schedules”, and their book is still a great introduction.

- Lynn McClannahan and Patricia Krantz (1999) Activity Schedules for Children With Autism: Teaching Independent Behavior. Woodbine House

### *Other very useful resources include:*

- The Creative Teaching CAP website, which offers an array of visual activity schedule materials for sale for children with autism  
[http://www.creativeteachingcap.com/Activity\\_Management\\_s/39.htm](http://www.creativeteachingcap.com/Activity_Management_s/39.htm)

Picture Exchange Communication System (PECS) PECS was the invention of Andrew Bondy, Ph.D. and Lori Frost, MS, CCC/SLP. See Pyramid Educational Consultants <http://www.pecs-usa.com/> PECS is a symbol or pictorial based communication system. This site lists training opportunities as well as a wealth of purchasable materials based on Bondy and Frost’s PEC System. Using PECS effectively requires being trained how to

## FAQs

introduce PECS and how use them with a child with autism. There is much more involved than posting a Velcro strip with pictures of activities, actions and consequences on the refrigerator door.

### *Visual Supports for Social Problem Solving*

- The most widely known visual support in this category is Carol Gray's "Social Stories™". The Gray Center website describes: "A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience. The goal of a Story™ should be to improve understanding of events and expectations that may lead to more effective responses. <http://www.thegraycenter.org/>
- Jed Baker's (2003) "The Social Skills Picture Book Teaching play, emotion, and communication to children with autism", Future Horizons, Publ. embraces this philosophy in this a dynamic teaching tool that engages the attention and motivation of students who need a little extra help learning appropriate social skills by using pictures of children mastering skills such as communication, play, emotion, and empathy. One Amazon reviewer wrote: "We all know that kids with Autism are visual learners, and we also know that our kids need help in the area of social skills. It only makes sense to combine the two into one book."

### *Video Modeling*

Some children with ASDs find it easier to learn to imitate from watching a video model of a specific skill than watching a parent, teacher or therapist model the same skill. In the latter situations there are often multiple distractions that make it more difficult to focus on relevant cues. Among the resources available are the following:

- Model Me Kids, <http://www.modelmekids.com/>
- Tom Bugghey's 2009 book, *Seeing Is Believing: Video Self-Modeling for People with Autism and Other Developmental Disabilities*. Woodbine House

### *Facial Discrimination Learning*

"Let's Face It", offers free computer software to assist in learning to discriminate facial features and expression. Hosted by Prof Jim Tanaka, Univ of Victoria, Canada  
<http://web.uvic.ca/~jtanaka/letsfaceit/>

There are other costly software programs available, such as Cambridge University's "Mind Reading" DVD.

The effectiveness of these facial learning programs has been called into question. In most children are able to learn using the computer programs but often do not generalize to practical situations.

### *Miscellaneous Visual Supports*

- Board Maker Software that enables you to create interactive symbol-based

## FAQs

communication and educational materials <http://www.mayer-johnson.com/>

- Do2learn, a website that offers a wide array of visual support materials and resources <http://www.do2learn.com/>

- Susan Stokes, "Structured Teaching: Strategies for Supporting Students with Autism". Website is a terrific resource for classroom teachers that includes a discussion and examples of Physical Structure, Visual Schedules and Teaching Method. Physical structure refers to the way in which we set up and organize the person's physical environment: It emphasizes where/how we place the furniture and materials (1) in the various environments including classrooms, playground, workshop/work area, bedroom, hallways, locker/cubby areas, etc. <http://www.specialed.us/autism/structure/str12.htm>

- Travis Thompson (2008) Chapter 9. Physical Setting Features, Pgs. 175- 191 in "*Freedom from Meltdowns*", Baltimore, Paul H. Brookes Publishing Co. is a discussion of physical organization and specific visual and auditory features of an intervention setting that can facilitate or interfere with learning.

---

### Non-Verbal Autism

About 25% of children with an ASD diagnosis are functionally non-verbal. They likely vocalize and may say some words repetitively, but seldom if ever use them to actually communicate.

Typically individuals who are not able to verbally communicate have been taught using various augmentative communication systems, like the Picture Exchange System or speech output devices. Many times these approaches are combined with efforts to promote spoken communication concurrently. There is interest in the fact that among a subset of such non-speaking individuals there may, nonetheless, be considerable reciprocal social interest (e.g. John Canstantio at Washington University), which may be an important source of communication motivation. Most experts believe cognitive ability and verbal communication are inter-twined, so those individuals with lesser cognitive abilities are likely to be especially challenged. Hopeful brain imaging research may shed light on subtypes of individuals with varying degrees of neurocognitive processing upon which therapists may capitalize in promoting communication development. In addition work on animal models is attempting to clarify alternative social pathways that may be beneficial in promoting socialization in non-speaking individuals.

### Bibliography:

Autism and Communication; National Institute of Deafness and Other Communicative Disorders. National Institutes of Health. NIH Pub. No. 09-4315; July 2009 <http://www.nidcd.nih.gov/health/voice/autism.htm>.

Autism Speaks (2008) Researchers Focus on Non-Verbal Autism at High Risk High Impact Meeting;

FAQs

[http://www.autismspeaks.org/science/research/grants/research\\_we\\_have\\_funded\\_hrhi\\_winter\\_2008.php](http://www.autismspeaks.org/science/research/grants/research_we_have_funded_hrhi_winter_2008.php)

Miles, JH et. al. (2005) Essential versus complex autism: definition of fundamental prognostic subtypes. *Am. J. Med. Genet. A.* 135(2): 171-80

Paul, Rhea (2010) Yale Laboratory of Developmental Communication Disorders. Yale Child Study Center, <http://info.med.yale.edu/chldstdy/autism/ldcd/>

Sallows, GO and Graupner, TD (2005) Intensive Behavioral Treatment for Children WithAutism: Four-Year Outcome and Predictors. *Amer. J. Mental Retardation* 110, 6: 417–438

Tager-Flusberg, H. et.al. (2009) Defining Spoken Language Benchmarks and Selecting Measures of Expressive Language Development for Young Children With Autism Spectrum Disorders. *J. Speech Lang Hear Res* 52: 64. Published On-line 29 April 2009.

---

#### Developmental & Behavioral Approaches

There are theoretical and practical differences. Much of the disagreement is about philosophical assumptions about the nature of what it means to be a child and how children learn best. In reality, these theoretical arguments have very little bearing on what works most effectively for most children with autism.

#### Early Learning Assumptions

Disagreements regarding optimal early learning environments for children with autism begin with assumptions arising from the theoretical writings of Jean Piaget and Lev Vygotsky who wrote about development of neurotypical children (Piaget, 1955; Vygotsky, 1978). These theorists emphasized the importance of developmental appropriateness of materials available in the learning environment and viewed the teacher, *parent or therapist as a facilitator, not an instructor or therapist*. Through exploring learning materials, it was assumed the child moves from being undisciplined to self-disciplined, from disordered to ordered, and from distracted to focused. For example, Vygotsky maintained that a child naturally follows an adult's example and gradually develops the ability to do certain tasks without help or direct assistance (Vygotsky, 1978, p. 86).

Young children with autism spectrum disorders seldom learn from watching adult models until they have been explicitly taught to do so, and even then may learn with difficulty. Moreover, if children with ASDs are left to to learn

through exploration they often lapse into repetitive, stereotyped behavior, such as rocking, flapping and repeatedly banging or twirling play materials in non-functional ways. Many children on the autism spectrum do not spontaneously perceive toys or play materials as symbolically representing actual objects (e.g. cars, houses, people), except some higher functioning children. They must be explicitly taught component play skills, which when combined in a supportive context, yield useful functional activities. The Piagetian strategy of multi-sensory experiential learning is seldom effective for young children with autism (Educating Children with Autism, National Research Council (2001) page 102).

Behavior Analysis-based interventions, such as Lovaas's UCLA Young Autism Model, are designed to provide planned exposure to a range of developmentally appropriate materials, and learning how to respond in relevant and appropriate ways to those materials. Explicit skills are taught appropriate to those situations, using principles of applied behavior analysis, including stimulus supports and external rewards (e.g. social, preferred activities or material things). Through repetition of reinforced practice, skills become increasingly independent. Groups of small mini-skills are combined to make up larger, more complex and natural skills useful in everyday life. While there are opportunities for spontaneity and creativity within learning activities, behavioral interventions are not discovery-based like Montessori early intervention. It is assumed a child will tend to learn and remember skills that are successful in achieving a goal that is meaningful to the child.

### **Emotional Self-Regulation**

A second underlying assumption of developmental approaches to early intervention are suppositions about emotional self-regulation in autism. Developmental psychologists have conducted research on how typical infants and toddlers learn to regulate his or her feelings (Calkins and Fox, 2002). They have also studied emotional dysregulation among children with emotional disturbance (e.g. borderline personality disorder) (Kernberg and Michels, 2009). Emotional self-regulation involves the child's experiencing an emotion, their thoughts in reaction to those feelings, physiological reactions within their body (e.g. heart rate, hormonal changes) and their overt behavior (e.g. laughing, crying), including facial expressions, related to emotion. Among typical children, these processes depend on the child's developing capacities to discriminate and interpret their personal experiences, such as sad, happy and angry. The process builds on emotional experiences from infancy. Gradually children become more capable of managing their own feelings. By kindergarten, typical children often have the ability to anticipate, talk about and use their awareness of their own and others' feelings, in order to negotiate everyday social

## FAQs

interactions (National Scientific Council on the Developing Child, 2004, page 2). Several autism early intervention approaches attempt to directly promote emotional self-regulation, notably SCERTS, Relationship Development Intervention® and Floortime®.

These basic skills in emotional self-regulation are typically absent or very limited among children with ASDs, such as distinguishing among one's own feelings. Generally those concepts are either meaningless to them or very vague. Their absence is among the defining features of autism. Assumptions about the optimal way to overcome these deficits in children with autism have not been tested empirically. There is little evidence from studies that it is possible to directly change emotional self-regulation among children with autism, as proposed. In other words to enable to child who is upset to change the way they feel internally and become less upset. What little evidence exists suggest changes in self-regulation of emotions by children with autism come about by learning skills that gain *control over situations that cause dysregulation* (e.g. being able to ask for help when facing a difficult task).

Most behavior analytic interventions operate on the assumption that as a child gains greater mastery of language and social skills, and makes cognitive gains, they have less reason for emotional distress since they become more effective masters of their environment. Their ability to emotionally self-regulate is thought to accompany those instrumental improvements in their ability to manage daily relations with events and development of positive relationships with people around them. This assumption is similar to that in cognitive behavior therapy, namely that cognitive (e.g. language) and other behaviorally-mediated skills gradually provide the framework within which feelings are interpreted and regulated (Thompson and Hollon, 2007, pg.145).

## References

- Calkins, SD and Fox, NA. (2002) Self-regulatory processes in early personality development: a multilevel approach to the study of childhood social withdrawal and aggression. *Dev Psychopathol.*14(3): 477-98.
- Gutstein, SE and Sheely, RK (2002) Relationship Development Intervention with Young Children: Social and Emotional Development Activities for Asperger Syndrome, Autism, PDD and NLD. Jessica Kingsley Publishers.
- Kernberg, OF and Michels, R. (2009) Borderline personality disorders. *Am J Psychiatry* 166: 505-8.
- Koegel, RL, Openden,DF, Freeden, RM, Koegel, LK (2006) The Basics of Pivotal Response Treatment. In Koegel, RL and Koegel, LK. Pivotal Response Treatments for Autism. Brookes Publishing Co.
- Lord, CE and McGee, J. (2001) Educating children with autism. Committee

on Educational Interventions for Children with Autism, National Research Council. National Academies Press, Washington, DC

Lovaas, OI (1987) Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consult Clin Psychol* 1987. 55: 3-9.

Mesibov, GB., Shea, V, Schopler, E (2004) *The TEACCH Approach to Autism Spectrum Disorders*. Springer.

Montessori, M. (1966) *The Secret of Childhood*. Fides Publishers.

National Scientific Council on the Developing Child. *Children's Emotional Development is Built into the Architecture of their Brains: Working Paper No. 2*. <http://developingchild.harvard.edu>

Piaget, J, (1955) *Construction of reality in the child*. Routledge and Kegan Paul

Prizant BM Wetherby, A. et. al (2005) *The Scerts Model: A Comprehensive Educational Approach for Children With Autism Spectrum Disorders* (2 volume set). Brookes Publishing Company, Baltimore.

Thompson, T. and Hollon, SH (2008) *Behavioral and Cognitive Behavioral Interventions*. Chapter 10. Pg. 139

\* Thompson T. (in preparation) *Blended Autism Interventions* (tentative title). Paul H. Brookes Publishing Co.

Vygotsky, L. (1978) *Mind in society: The development of higher psychological processes*. Harvard Univ Press, Cambridge, MA.

---

#### Ethical Standards in ABA Services

Most people involved in providing behavioral interventions for people with autism spectrum disorders received some or all of their training through academic departments of applied behavior analysis, psychology, educational psychology, school psychology or other closely related behavioral science disciplines.

B.F. Skinner who was the theoretical fountainhead of the field of applied behavior analysis received his PhD in psychology from Harvard University and spent all of his career in departments of psychology (Minnesota, Indiana & Harvard) and O. I. Lovaas who conducted the ground-breaking research leading to the widespread use of applied behavior analysis methods to treat young children with autism was trained in a psychology department (U of Washington) and spent all of his professional career as a faculty member in a department of psychology (UCLA).

In our work with students, clients and with fellow professionals, our actions are guided by the [\*\*Ethical Principles of Psychologists and Code of Conduct \(2010 Amendments\) of the American Psychological Association\*\*](#). It is useful periodically to remind ourselves of these basic ethical principles and take them to heart in our daily work with clients, their families and with fellow professionals.

**Principle A: Beneficence and Nonmaleficence** Psychologists strive to benefit those with whom they work and take care to do no harm. In their professional actions, psychologists seek to safeguard the welfare and rights of those with whom

they interact professionally and other affected persons, and the welfare of animal subjects of research. When conflicts occur among psychologists' obligations or concerns, they attempt to resolve these conflicts in a responsible fashion that avoids or minimizes harm. Because psychologists' scientific and professional judgments and actions may affect the lives of others, they are alert to and guard against personal, financial, social, organizational, or political factors that might lead to misuse of their influence. Psychologists strive to be aware of the possible effect of their own physical and mental health on their ability to help those with whom they work.

**Principle B: Fidelity and Responsibility** Psychologists establish relationships of trust with those with whom they work. They are aware of their professional and scientific responsibilities to society and to the specific communities in which they work. Psychologists uphold professional standards of conduct, clarify their professional roles and obligations, accept appropriate responsibility for their behavior, and seek to manage conflicts of interest that could lead to exploitation or harm. Psychologists consult with, refer to, or cooperate with other professionals and institutions to the extent needed to serve the best interests of those with whom they work. They are concerned about the ethical compliance of their colleagues' scientific and professional conduct. Psychologists strive to contribute a portion of their professional time for little or no compensation or personal advantage.

**Principle C: Integrity** Psychologists seek to promote accuracy, honesty, and truthfulness in the science, teaching, and practice of psychology. In these activities psychologists do not steal, cheat, or engage in fraud, subterfuge, or intentional misrepresentation of fact. Psychologists strive to keep their promises and to avoid unwise or unclear commitments. In situations in which deception may be ethically justifiable to maximize benefits and minimize harm, psychologists have a serious obligation to consider the need for, the possible consequences of, and their responsibility to correct any resulting mistrust or other harmful effects that arise from the use of such techniques.

**Principle D: Justice** Psychologists recognize that fairness and justice entitle all persons to access to and benefit from the contributions of psychology and to equal quality in the processes, procedures, and services being conducted by psychologists. Psychologists exercise reasonable judgment and take precautions to ensure that their potential biases, the boundaries of their competence, and the limitations of their expertise do not lead to or condone unjust practices.

**Principle E: Respect for People's Rights and Dignity** Psychologists respect the dignity and worth of all people, and the rights of individuals to privacy, confidentiality, and self-determination. Psychologists are aware that special safeguards may be necessary to protect the rights and welfare of persons or communities whose vulnerabilities impair autonomous decision making. Psychologists are aware of and respect cultural, individual, and role differences,

including those based on age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, and socioeconomic status and consider these factors when working with members of such groups. Psychologists try to eliminate the effect on their work of biases based on those factors, and they do not knowingly participate in or condone activities of others based upon such prejudices.

---

#### Individual Differences & Types of Intervention

##### Individual differences and choice of interventions

If we fail to appreciate these differences, it is difficult to validly assign interventions to individual children. Some of those features are more specific to autism than others, such as limited social understanding and lack of social skills, difficulties with pragmatic language, and fixed interests and repetitive behavior. Other factors are widely distributed throughout the population but interact with these three core features in autism. These include challenges with attention and activity level, anxiety problems, specific speech impairments (such as apraxia of speech), and intellectual functioning level. The particular blend of interventions that is most appropriate for a given child depends first on the profile of those three core features and, second, on how those features are moderated by the second group of factors (e.g., anxiety, attention, activity, speech impairment, and intellectual functioning). The *Autism Intervention Responsiveness Scale(tm)* described in our forthcoming book, *Individualized Autism Intervention for Young Children: Blending Discrete Trial and Incidental Approaches*, provides a concrete step toward weighing these factors collectively in predicting the type and combination of interventions that will be most helpful for a child. Though the scale is in a preliminary form, it is a step in the right direction.

#### OUTCOMES OF COMBINED INTERVENTION APPROACHES

Parents, teachers, and therapists want to know how well a combined intervention approach actually works with young children with autism. Of the first 24 children served by the Minnesota Early Intervention Project who participated in from 0.5 to 3 years of intervention (about 22 hours per week average), 75% have graduated and are currently enrolled in regular education classrooms or are continuing at progressively reduced therapy hours while making the transition to school. About one in five of those children receive some paraprofessional support, two children have been placed in self-contained special education classrooms for students with autism or communication and intellectual disabilities, and two have been placed in early childhood special education classrooms integrated with typically functioning students. One child was discharged due to lack of progress, parents of two children transferred them to other providers (e.g., center-based services), and a fourth moved away. Of those 24 children, 6 received nearly entirely Discrete Trial Intervention, 6 received largely Incidental Intervention, and 12 were provided with a blended combination of Incidental Intervention and DTI. In Blended Interventions,

Discrete Trial procedures were often used when introducing a new, especially difficult-to-learn skill, and as soon as the child began showing signs of acquisition, we made the transition to partial incidental teaching and eventually entirely incidental teaching. Supervisory staff members must be very experienced and well trained for this strategy to work. Hands-on therapists must be competent in using a range of intervention methods. This project suggests it is possible to individualize early behavioral intervention procedures incorporating elements of developmental strategies with behavioral approaches.

## MEDICATION COMBINED WITH BEHAVIORAL INTERVENTION

The future holds great promise for preventing and reversing autism symptoms for many children affected with the disability. A promising line of work combines medication to promote brain connectivity with intensive early intervention, possibly as early as 1 year to 18 months of age. Dr. Diane Chugani and her colleagues at Wayne State University have conducted very promising work suggesting that treating children diagnosed with autism at 2 years of age with low doses of a medicine (buspirone) normalizes serotonin in their brain cells, which would otherwise be deficient. Proper levels of serotonin are necessary for normal brain connectivity. Dr. Chugani and her colleagues are currently combining EIBI with medication to determine whether these interventions produce a synergistic effect, possibly preventing emergence of autism in some susceptible children (D.C. Chugani, 2010). Related work suggests it may be possible to treat youngsters with fragile X syndrome with a medication that corrects the balance of proteins that make components of brain synapses (Dolen, Carpenter, O'Carroll, & Bear, 2010; Penagarikano, Mulle, & Warren, 2007). About one quarter of children with fragile X syndrome meet the diagnostic criteria for autism. Together with EIBI, this may make it possible to reduce or eliminate many of the symptoms of autism among children with fragile X and autism.

## COMPONENTS OF EARLY INTENSIVE BEHAVIORAL INTERVENTION

The drive to contain educational and health care costs mandates employing the most effective aspects of interventions for specific students or clients. The National Research Council Report called Educating Children with Autism (Lord & McGee, 2001) and Reichow and Wolery's (2009) quantitative summary of autism early intervention studies contained two important conclusions: 1) EIBI is highly effective for many children with autism, and 2) which aspects of early behavioral intervention are responsible for these outcomes in subgroups of children is not well understood. We must be able to identify which children benefit most from specific aspects and intensities of intervention. The goal is to identify which aspects of comprehensive early interventions account for the bulk of intervention outcome, so that children optimally benefit from more focused interventions.

Individualizing autism intervention has a promising future, one that may afford the

possibility of overcoming or preventing emergence of autism symptoms in susceptible individuals.

## REFERENCES

Chugani, D. (2010) Wayne State University, personal communication, June 24, 2010

Committee on Educational Interventions for Children with Autism, N. R. C. (2001). *Educating children with autism*, C. E. Lord and J. McGee, Editors) Washington, DC: National Academies Press.

Dölen G, Carpenter RL, Ocain TD, Bear MF. Mechanism-based approaches to treating fragile X. *Pharmacol Ther.* 2010 Jul;127(1):78-93. Epub 2010 Mar 18.

Penagarikano O, Mulle JG, Warren ST. The pathophysiology of fragile x syndrome. *Annu Rev Genomics Hum Genet.* 2007;8:109-29.

Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders*, 39(1), 23-41.

Sherer, M. R., & Schreibman, L. (2005). Individual behavioral profiles and predictors of treatment effectiveness for children with autism. *Journal of Consulting and Clinical Psychology*, 73(3), 525-538.

Thompson, T and Contributors (2011) *Individualized Autism Intervention for Young Children; Blending Discrete Trial and Incidental Approaches*, Baltimore: Paul H. Brookes, Inc

---

### Effectiveness of Intensive Early Behavioral Intervention

Proponents of one early intervention approach versus another often point out that the methods they are advocating grow out of a specific theory of child development or learning. In reality, despite theoretical differences, early intervention methods often share significant features in common (e.g., following the child's lead is common to PRT, Floortime, and Incidental Intervention) but may differ widely in other respects, not necessarily having very much to do with their preferred theory. In this article I will examine some factors that have been shown to affect child outcomes of EIBI.

### Sufficient Intensity

## FAQs

The importance of intensity of a child's early experiences is not specific to ABA therapy and autism. In a landmark study, Betty Hart and Todd Risley (1995) studied language and intellectual development of typically developing preschool children growing up in poor inner-city neighborhoods and others whose parents were middle-class professional families. Although it wasn't surprising that the two groups of children displayed some language differences, what was surprising was the profound differences in the language experience of the two groups of children and the resulting differences in intellectual and language competence. In a review of the role of intervention intensity in language intervention, Warren, Fey, and Yoder (2007) noted, "Cumulative intervention intensity makes a meaningful difference in language learning." They also emphasized that it isn't always the case that massed trials, as usually occur in DTI, yield superior results to distributed practice even when they have a similar total time in intervention. However, if a child receives 30 hours per week of EIBI, it would be difficult to achieve comparable total intervention intensity by spacing intervention episodes farther apart, unless the intervention periods included weekends and evenings. In a more recent study, Steve Warren and colleagues (Warren et al., 2009) used an automated device to track all utterances of preschool children with autism and those of people around each child, such as parents or therapists. They found that during periods when children with autism were in therapy, the number of the child's total utterances, including conversational exchanges, greatly increased.

Several studies of ABA-based autism early intervention indicate that engaging in more hours per week of early intervention produces greater improvements in intellectual, language, and social functioning than fewer hours (Cohen, Amerine-Dickens, & Smith, 2006; Eikeseth, Smith, Jahn, & Eldevik, 2002, 2007; Lovaas, 1987). In comparison to the high intensity studies, several lower-intensity intervention programs have also been conducted, while reporting improvements, generally with lesser reductions of autism symptoms and skills improvement (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002; Remington et al., 2007; Smith, Buch, & Gamby, 2000; Smith, Groen, & Wynn, 2000).

Most evidence indicates that 25–30 hours per week of one-to-one intervention over the first 1–2 years is required to make significant gains in core autism symptoms for most children who are responsive to this form of intervention (Lord & McGee, 2001) with the exception of higher functioning children (e.g. Asperger disorder) who may profit substantially with lesser intensity of naturalistic intervention. Some parents prefer to begin with 10 to 20 hours of therapy per week and then increase intervention intensity later if the child's gains are judged to be insufficient. It is important to bear in mind that the majority of cognitive, language, and social gains are made in the first 18 months of early intervention. Increasing intervention intensity after 1 to 2 years may not compensate for learning that did not occur during the period when most rapid skill development and brain connectivity normally occur. Providing inadequate intensity during that early period undermines the purpose of EIBI.

## **Contextually Nested Interventions**

Skills taught out of context may not generalize to natural settings where they are ultimately intended to be displayed. Using stimuli and reinforcers that are unrelated to the context (e.g., tokens instead of natural consequences for requesting a sippy cup of apple juice) is less likely to engender generalization and maintenance once therapy is phased out. Tying a child's verbal or picture symbol requests to their natural consequences, such as a preferred activity, will make it more likely the child will make a similar req

uest under comparable circumstances in the future. Discrete trial or incidental teaching sessions embedded within normal daily routines at school or home are more likely to be adopted by caregivers and to be maintained when specialized instructional or therapy staff are not present. At times it may be necessary to conduct massed therapy or learning trials taught out of context to maintain the child's attention and to teach difficult discriminations. However, when it is possible to do so, capitalizing upon incidental learning opportunities within natural contexts can be highly effective.

## **Multiple Teachers/Therapists and Multiple Settings**

No systematic studies have been reported of the role of multiple teaching or therapy staff across several settings in early intervention programs. In the National Research Council review (Lord & McGee, 2001), conducting such a study was one of the recommendations. Based on intolerance of children with autism for changes, including interacting with different people, and in order to promote generalization across settings, this is a reasonable recommendation, and one we routinely employ in our early intervention endeavors.

## **Participation of Siblings and Peers**

Tobias, who just turned 3 years old, spends Monday, Wednesday, and Friday mornings in a typical preschool classroom. He has been diagnosed with PDD-NOS. He watches two boys playing with cars on a mat in the play area. He approaches them and hesitates. He appears to want to play with the boys, but he doesn't know how to join in. Finally, he kicks a ball so it ricochets across the floor and bangs into the boys' toy cars. They shout at him, " Stop it! Go away!" Tobias runs away crying. Few preschool-age children with autism have the skills to play interactively with same-age peers, other than very simple " chase" or " play fight" games similar to those they see on cartoons. Often siblings learn to accommodate their sister or brother with an ASD, facilitating limited play while at home, but that seldom generalizes to interacting effectively with other children who are less motivated to find ways to be helpful to the child with autism. One approach to encouraging peer-oriented social skills involves nesting intervention within an integrated setting along

side neurotypical peers.

Gail McGee's Little Walden program, at Emory University (McGee & Morrier, 2009) and Phil Strain's LEAP school-based interventions (Strain, McGee, & Kohler, 2001) explicitly combine children with autism with neurotypical peers in order to promote appropriate social interactions. Although that may be effective for some higher functioning children, in our experience more explicit teaching of basic communication and social skills is necessary to enable most children with autism to initiate and sustain social interactions with peers, including games and toy play. Interventions that explicitly teach interactive play and communication with peers are more likely to have positive outcomes. By all means, typical siblings and peers can be included in carefully crafted social interaction activities with your child or student with an ASD, but don't expect her or him to learn by osmosis to be socially competent.

### **Proactive Strategies for Preventing Behavioral Challenges**

Effective EIBI programs do not wait for behavioral challenges to arise before acting. They anticipate and prevent them. Most behavioral challenges in young children with ASDs are a result of a child's inability to communicate needs and wants, as well as being thwarted in highly preferred activities or access to desired commodities. Proactive strategies that obviate the need for tantrums, aggression, and other emotional/behavioral outbursts can be highly effective (Carr et al., 2002).

\*[Excerpted from Ch. 4. in T. Thompson *Individualized Autism Intervention for Young Children: Blending Discrete Trial and Incidental Approaches*. Baltimore: Paul H. Brookes Publishing Company]

### **References**

Bibby, P., Eikeseth, S., Martin, N. T., Mudford, O. C., & Reeves, D. (2001). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disabilities, 22*(6), 425-447.

Carr, E. G., Dunlap, G., Horner, R. H., Koegel, R. L., Turnbull, A. P., Sailor, W. et al. (2002). Positive Behavior Support: Evolution of applied science. *Journal of Positive Behavior Interventions, 4*(1), 4-16.

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Journal of Developmental and Behavioral Pediatrics, 27*(2 Suppl), S145-55.

Committee on Educational Interventions for Children with Autism, N. R. C. (2001). *Educating children with autism*, C. E. Lord and J. McGee, Editors) Washington, DC: National Academies Press.

## FAQs

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J. et al. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*, 125(1), e17-23.

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities*, 30(1), 158-178.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism. A 1-year comparison controlled study. *Behavior Modification*, 26(1), 49-68.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7: a comparison controlled study. *Behavior Modification*, 31(3), 264-278.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3-9.

McGee, G. G., & Morrier, M. J. (2009). Combining inclusion and ABA programming: The Walden Incidental teaching model and curriculum. *Autism Advocate*, 55(2), 38-42.

Remington, B., Hastings, R. P., Kovshoff, H., degli Espinosa, F., Jahr, E., Brown, T. et al. (2007). Early intensive behavioral intervention: outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation*, 112(6), 418-438.

Risley, T. R., & Hart, B. (1995). *Meaningful Differences in the Everyday Experience of Young American Children*. Paul H Brookes Pub Co.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: four-year outcome and predictors. *American Journal on Mental Retardation*, 110(6), 417-438.

Smith, T., Buch, G. A., & Gamby, T. E. (2000). Parent-directed, intensive early intervention for children with pervasive developmental disorder. *Research in Developmental Disabilities* 21(4), 297-309.

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, 105(4), 269-285.

Strain, P. S., McGee, G. G., & Kohler, F. W. (2001). Inclusion of children with autism in early intervention: An examination of rationale, myths, and procedures. In M. J. Guralnick (Ed.), *Early Childhood Inclusion: Focus on Change*. (pp. 337-363). Baltimore: Paul H. Brookes, Inc.

Warren, S. F., Fey, M. E., & Yoder, P. J. (2007). Differential treatment intensity research: a missing link to creating optimally effective communication interventions. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(1), 70-77.

Warren, S. F., Gilkerson, J., Richards, J. A., Oller, D. K., Xu, D., Yapanel, U. et al. (2009). What Automated Vocal Analysis Reveals About the Vocal Production and Language Learning Environment of Young Children with Autism. *Journal of Autism and Developmental Disorders*.

---

#### Questions for your ABA provider

Parents are told by the pediatrician and by other parents that their child recently diagnosed with autism should be receiving ABA Therapy as soon as possible. Should it be Verbal Behavior, Pivotal Response Training or "Lovaas" Therapy or exactly what? Equally important are questions about the qualifications of the therapy team. That is what this article is about. What questions should parents ask the Early Intensive Behavioral Intervention provider during your first meeting or when talking with the intake person over the phone?

**1. What degree or degrees does the person with ultimate clinical responsibility for your child have and from what institution(s) of higher education? Who was their primary mentor and what experience did that person have with autism ABA intervention, and what were their professional qualifications (e.g. PhD, MA, Licensed Psychologist, Certified Behavior Analyst, MEd?). How much experience is expected? Any other questions to think about?**

a. Professionals holding doctorates from accredited universities in behavior analysis, psychology or special-education with an emphasis on applied behavior analysis, are among the most qualified to determine your child's appropriateness for ABA services and to develop and supervise intervention plans. An academic degree alone is insufficient to determine a professional's qualifications but is a prerequisite. Most doctoral level supervisors have spent 4 or more years in graduate school and at least one year in a supervised practicum, plus often one year of post-doctoral fellowship. One would hope the supervisor has had at least 3-5 years of experience evaluating and developing intervention programs for young children with autism spectrum disorders for a significant portion of their time.

b. If the supervisor has completed only an on-line MA or BCBA in applied behavior analysis, knowing more about the person who trained them is essential information

in estimating their qualifications. An MA or BCBA who was trained by another MA or recently certified BCBA will generally have less high quality training and experience than a person with such a degree who graduated from a more traditional MA program in an accredited bricks-and-mortar university or college whose mentor had considerable academic and clinical experience. It may be helpful to look up the supervisor's mentor on the college or university website to explore their qualifications. It may also be useful to visit one of the review websites in evaluating the training of Supervisors who graduated from on-line commercial educational programs <http://www.onlinedegreereviews.org> which provides comments by program participants or graduates.

c. Ask the person with overall clinical supervisory responsibility where they did their internship or practicum training, the populations with which they worked and their clinical supervisors. Someone graduating from a bricks-and-mortar doctoral program in behavior analysis or psychology with well established clinical supervisors with extensive experience with children with autism will likely be better prepared to oversee your child's services than a supervisor lacking such training. Supervisors that worked primarily with adults or older children (rather than pre-school age children), or mainly in residential settings, or children with other developmental delays or disabilities, would have much less relevant experience. If the person supervising your child's services has appropriate academic training and gained relevant experience after completing their formal course training, they may be highly qualified, depending on the nature of that experience.

d. A supervisor who graduated with an MA/BCBA from a commercial on-line university in which part or most of their supervision was on-line, by telephone or only occasionally face-to-face is likely to be considerably less qualified and should be a cause for concern.

e. Ask the supervisor how often s/he will be in the home or at the center observing your child's therapy and providing supervision. Weekly or every other week is a minimum. Ask how often there will be team meetings including all team members including parents and hands-on therapists. Meetings less than every two weeks are usually inadequate until toward the end of therapy when less frequent meetings are appropriate.

f. Ask the provider how they provide differential services to higher functioning children with some language, versus children with more severe autism symptoms, shorter attention span and more limited skills.

A competent provider should be able to describe how they individualize intervention tailored to the child, using more Discrete Trial methods with children with more severe symptoms and more incidental teaching or naturalistic methods with children who are higher functioning. If you are unclear, ask for concrete examples.

## FAQs

g. Ask the Supervisor their approach to dealing with challenging behavior, such as meltdowns, aggression, repetitive stereotyped behavior, self-injury, destructiveness or other problem behavior.

If they mention “required relaxation,” “over correction,” “restitution,” squirts in the face of water mist, placing lemon juice or vinegar in the child’s mouth contingent on biting or spitting, or a spanking on the thigh combined with a stern “no,” used as a contingent aversive, placing the child alone in a locked room without direct adult observation as an aversive event, or physically restraining the child for more than a few seconds to avoid immediate injury, parents and policy makers are urged to look more carefully into the program. Any mechanical physical restraint (such as belts, straps, or posie restraints, arm guards) should never be used unless ordered by a physician for medical reasons. The first response to a child’s challenging behavior should be to attempt to understand the reasons for the behavior problem, and to make it unnecessary for the child to engage in challenging behavior through conducting a thorough functional assessment and implementing intervention accordingly. Proactive positive approaches can be combined with mild brief time outs, such as looking away from the child briefly, or placing the child on a chair away from a rewarding situation when they hit, or delaying access to a preferred item, or seating the child in their room with the door open for a few minutes, can be entirely appropriate, but more severe aversive procedures are always suspect except in specialized treatment centers.

g. Ask if they hold any elected or appointed positions in state or national ABA or autism or other professional organizations.

Having been elected an officer or appointed chair person of a state Task Force or a national Committee usually means the person is held in high esteem by their peers for their training, experience and leadership skills. After they tell you about their honorific position, ask them to explain what that post entails. That will often tell you a great deal about the person’s competence, sense of balance and humility.

**2. Ask what degree or degrees does the person with day-to-day supervisory clinical responsibility for your child has, and from what institution(s) of higher education? Where did they receive their didactic training (e.g. classroom or on-line) and who were their instructors? What were their instructors’ qualifications? What clinical supervision did they have (i.e. setting, diagnoses, age groups) and by whom?**

Most on-site ABA therapy supervisors have MA/MS degrees and some are Board Certified Behavior Analysts. Some BA/BS trained supervisors with many years of relevant experience, including experience with supervision, can also be highly qualified for on-site supervision depending on the specific training they have received. Preference is for persons trained by bricks and mortar academic institutions with established behavior analysis or psychology degree programs. It is

appropriate to ask such individuals how much of their didactic training was face to face versus on-line. Generally, face-to-face mentoring is more effective. Ask the names and degrees of their favorite instructors and where they received their academic training. If they don't recall their names, or are unaware of their instructors' qualifications, that is often a red flag. The hand-on-supervisor should have had at least 3-5 years of experience working with children with autism, at least two doing hands-on one-to-one intervention and up to three years of supervisory experience. Ask the supervisor how much experience they have had working with families and parents, the more the better. If this is their first supervisory experience that is not usually a good sign unless the top supervisor is planning to spend considerable time with them on site over the first 3-6 months.

**3. Ask what degree or degrees and experience the persons or persons who conduct your child's day-to-day hands-on ABA intervention have and from what institution(s) of higher education? If they have not had formal academic training in ABA or autism, where did they receive such training, and from whom and for how long?**

While it is possible for some high school graduates to do a credible job of hands-on ABA therapy with young children with autism, that is less likely to be effective than a person with at least 2-4 years of education from an accredited college with relevant academic training (e.g. child psychology, education, behavior analysis). While some aspects of ABA therapy are relatively routine and can be carried out by persons with less training, many skills require judgment on-the-fly, which must emanate from a combination of firmly understanding the basic principles and experience-based learning. Preferred are people with a BA or BS in psychology, child development, education, special education or speech language pathology and at least one year of experience working with pre-school age children in an educational or clinical setting.

**4. Ask the hands-on therapists' supervisors how much pre-service training hands-on therapists receive.**

If they say "none," that they learn on the job that is often not a good sign. That basically means the first month or so of your child's therapy will be spent teaching the new therapist. Ask what kind of daily data the hands-on 1:1 therapist will be recording and how much of their time will be devoted to data versus intervention. Tell the supervisor you plan to review the data at the end of shifts periodically.

**5. Ask the supervisors how they handle situations in which you as a parent or a visitor are uncomfortable with, or disapprove of interactions observed between a therapist and the child.**

If they say the problem should be resolved directly with the therapist and fail to mention that they welcome any feedback or concerns the parents may have, that is

a serious problem. Parents should never feel that they are hostages to a given therapist, and unable to report their concerns to supervisors.

---

#### School: Should Your Child with ASD Attend School this Fall?

As parents of children with autism are planning for next Fall and the start of a new school year, they are wondering whether to enroll their child in a regular school program. Nearly all parents want their children with autism to attend school alongside their typical peers. They believe that will promote social skills and help in developing friends. Sometimes it works well, but often not, depending on how much additional Early Intensive Behavioral Intervention the child receives and his/her functioning level.

Two recent studies, one in Norway and the other in the US, suggest that three hours per day of intensive Early Behavioral Intervention combined with several hours per day of participation in school led to significant improvements among the children with autism, but participating in regular school alone did not. In one study, parents also agreed to give the toddlers with autism ten hours each week of additional interventions at home that helped their progress.

A recent regrettably negative study published by McPheeters, Warren, et.al. in *Pediatrics* suggests there is little evidence any treatments are effective for autism except risperidone and aripiprazole. The review's conclusions are contrary to nearly all of the other reviews of similar research over the past 6-7 years that show unequivocally that Early Intensive Early Behavioral Intervention is highly effective for many children with autism. "I really don't like it when I see reviews that systematically say we're not looking at single-subject studies, because that's where some of the best evidence lies," notes Laura Schreibman, professor of psychology at the University of California, San Diego. There are within subject research designs that provide strong evidence according to the *Oxford University Centre for Evidence Based Practices*, which the McPheeters/Warren et. al. group unfortunately excluded from their analysis. The Institute of Medicine has published a monograph on *Small Clinical Trials* which would have been helpful to these authors. Regrettably many clinical researchers have forgotten the lesson of Claude Bernard, the father of modern physiology and medicine. Bernard introduced the within subject reversal experimental design (ABA) for demonstrating effects of physiological variables within individual subjects. Bernard's goal was to understand, by which he meant to be able to predict and control, factors affecting functioning of individual people, not the average person. (Bernard, 1865; Trans, 1927). His lesson stands as true to day as it did nearly a century and a half ago (see image below).

LEAP (Learning Experiences and Alternative Program for Preschoolers and Their Parents) is one of two evidence based inclusion models for the education of young children with ASD and implemented in public school settings. Most of the other behavioral programs with demonstrations of efficacy, children begin their

## FAQs

intervention in one-to-one intervention in the home, a clinic, or in a class with only children with ASD (Strain and Bovey, 2011). LEAP relies on incidental behavior analytic teaching strategies similar to milieu language intervention, pivotal response training and positive behavior support methods, within naturalistic school settings in which many classmates are typical peers. LEAP employs a minimum ratio of adults to children (1:5) and minimum ratio of typical peers to children with ASD (2:1), so it is not a typical regular education classroom. In a very recent study with 56 children, half receiving LEAP intervention over two years of teacher and parent training and mentoring by LEAP professional staff, and the other half only reading the LEAP manual. Children were similar on all measures at start. After 2 years, LEAP-trained class children were found to have made significantly greater improvement than their comparison cohorts on measures of cognitive, language, social, and problem behavior, and autism symptoms. The improvement in Childhood Autism Rating Scales scores (i.e. autism symptoms) were modest but significant (from 39 to 32). A CARS score of 30 is the usual cut-off for a tentative autism diagnosis. The fidelity with which teachers implemented LEAP strategies predicted outcomes (Strain and Bovey, 2011). This study suggests that moderate to higher functioning children on the autism spectrum may profit from participation in an integrated classroom structured around the LEAP model, but the gains may be less, particularly in the beginning, than one to one intervention. It also suggests that placing a child with autism in a regular education classroom without substantial support of the teacher by specialists is likely not to be helpful.

The long and short of it is that your best bet is to enroll your 2-5 year old child with autism in an Early Intensive Behavioral Intervention program for at least 15-20 hours per week, more for children with more severe disability. Emphasis should be on communication and social skills. Incorporating typical peers can be extremely helpful once the child begins making significant progress on their social skills and communication that are necessary to play with peers, participation in school can be a real plus for many children on the autism spectrum.

Bernard, Claude. *An Introduction to the Study of Experimental Medicine*, 1865. First English translation by Henry Copley Greene, published by Macmillan & Co., Ltd., 1927;

Eldevik S. et al. *J. Autism Dev. Disord.* Epub ahead of print (2011)

Institute of Medicine (2001) *Small Clinical Trials: Issues and Challenges*. Washington DC.

---

## MEDICAL & BIOLOGICAL INTERVENTIONS

---

### Epilepsy in Autism

Many children and youth with autism spectrum disorders are also diagnosed with epilepsy, also called a seizure disorder. A seizure is a disturbance in the electrical activity

of the brain. Twenty-five million Americans (1 in 10) have had, or will have, at least one seizure at some time in their lives. Among children and adolescents with autism, from 20-40% experience some form of epilepsy between early childhood and adulthood, which can be very alarming to parents.

In early childhood, many young children have one or several seizures during periods of high fever, such as a bout of the flu. They may never have another seizure the rest of their life. But for other children with autism, those initial febrile seizures may be followed by other epileptic episodes without fever, repeatedly over time. For some, epileptic seizures will be a part of their life indefinitely.

Epileptic seizures may include muscle spasms, mental confusion, loss of consciousness and/or uncontrolled or aimless body movements. Some individuals cannot remember what happened immediately before or during a seizure. There is an old myth that a person having an epileptic seizure may swallow his or her tongue. Medical experts say that is impossible, though some individuals bite their tongue during a seizure.

#### **There are two main types of seizures:**

**Generalized** involving an electrical discharge of nerve cells throughout much of the brain. They include:

*Tonic-Clonic* seizures or "grand mal" (loss of consciousness, stiffening of body, jerking of limbs) and *Absence seizures* or "petit mal" (blank spells, staring, slight twitching)

**Partial Epileptic Seizures**- begin with a discharge of neurons in just one part of the brain. They include Simple Partial seizures (uncontrolled body movements often with one hand or part of the body, brief changes in sensory perceptions) and Complex Partial seizures (confusion, loss of awareness, aimless movements). Occasionally people exhibit violent outbursts of aggression or property destruction during a Complex Partial Seizure. In the past this type of epilepsy was called Psychomotor Epilepsy. Infantile Spasms (babies have sudden, jerking seizures) are considered a type of Partial Epilepsy

Seizures may be frequent or rare. Some children have many seizures per day, and others may only have a few seizures per year. Seizure may last a few seconds or several minutes. They may be severe or mild. A person can have more than one type of seizure, and the pattern of seizures may change with time, which can be very confusing to parents. Children with autism and higher IQ are less prone to seizures than those with lower IQ.

#### **Anti-Epileptic Medications (AEDs)**

Antiepileptic medications can control seizures in about 70% of patients. However, medications won't cure epilepsy. An accurate diagnosis of the type of epilepsy is important in choosing the best treatment. *Narrow Spectrum Antiepileptic Medications*

mostly work for specific types of seizures (such as partial, focal, or absence, myoclonic seizures). *Broad Spectrum AEDs* additionally have some e

ffectiveness for a wide variety of seizures (partial plus absence myoclonic seizures). Examples of Narrow-Spectrum AEDs are Dilantin, Tegretol and Neurontin. Examples o Broad Spectrum AEDs are Depakote, Topamax and Klonopin.

### **Status Epilepsy**

Anyone who exhibits persistent seizure activity or who does not regain consciousness for five minutes or more after a witnessed seizure should be considered to have status epilepticus. For most children at highest risk, maintaining abortive therapy in the home may be a reasonable precaution. Rectal, nasal spray, or within the cheek pouch and sublingual ways of administering medication may be used. Versed (midazolam) can be given by nasal spray or inserted in the child's cheek pouch. Rectal administration of Valium (diazepam) or Ativan (lorazepam) is generally safe when under close supervision of the child's neurologist. When status epilepticus persists over an extended period on a given occasion, the child should be transported to an emergency room by emergency personnel to provide oxygen and intubation if necessary. There is some evidence of small but significant decline in intellectual functioning over a five year period for individuals with persistent Status Epilepsy.

### **Ketogenic Diet**

The ketogenic diet is a high-fat, adequate-protein, low carbohydrate diet that in medicine is used primarily to treat difficult-to-control (refractory) epilepsy in children. Some neurologists say that when 2-3 or more antiepileptic drugs have been tried and failed to reduce seizures, the ketogenic diet should be considered. The diet mimics aspects of starvation by forcing the body to burn fats rather than carbohydrates. Success rates with the ketogenic diet have been modest, in the range of 30% showing reductions of 50% in seizure frequency. Common but easily treatable short-term side effects include constipation and low blood sugar, if there is an initial fast. Cholesterol may increase by around 30% which could pose problems with long term treatment. Long-term use of the ketogenic diet in children increases the risk of retarded growth, bone fractures, and kidney stones. Supplements are necessary to counter the dietary deficiency of many micronutrients.

### **Vagal Stimulation**

Vagal stimulation is only used in individuals whose numerous seizures are unresponsive to medications and the ketogenic diet has been ineffective. An electrical lead is surgically attached to the left vagus nerve that runs along side the esophagus and windpipe, and delivers a very small electrical current that continuously cycles between on and off periods. The programmable

pacemaker is placed on the patient's upper chest. In one study, 55.08 % of treated children and youth had a satisfactory outcome (either no or minimal seizures or sizable improvement), and 44.92 %, there was no worthwhile improvement of seizures. Other

studies have reported similar results. In general, vagus nerve stimulation is the last choice of epileptologists before surgical removal of the brain tissue causing the seizures in treatment-resistant cases..

## Neurosurgery

The goal of epilepsy surgery is to identify an abnormal area of the brain's surface from which the seizures originate and remove it without causing any significant functional impairment. The primary components of the pre-surgical evaluation includes a detailed clinical history and physical examination, advanced brain imaging, video-EEG monitoring, neuropsychological testing and assessment of psychological and social functioning. If the information obtained during the noninvasive pre-surgical evaluation consistently points towards a single area of the brain as being the site of seizure onset, then surgery may be appropriate to remove that area. If the brain scan demonstrates a well-characterized lesion and is consistent with the clinical features of the seizures, then surgery may be reasonable. The most common type of surgery removes layers of scarred nerve cells within the hippocampus, two structures shaped like thin loaves of French bread running along both the sides of the brain adjacent to the underside. This surgical procedure (meticulous removal of mesial temporal sclerotic tissue) has a high success rate, often with minimal side effects. Neurosurgery always involves some risk of damage to other adjacent structures, though that is usually minimal. Surgery is nearly always the last resort after the above approaches have been tried and failed to provide relief from frequent debilitating seizures.

**Resources:** The books by Blackburn (2003) and Freeman, Vinning and Pillas (2002) are excellent starting points for parents of children with epilepsy and autism. Timely information about epilepsy diagnosis and treatment can be found at The National Institute of Neurological Disorders and Stroke web site; NINDS Epilepsy Information Page.

## Bibliography

Blackburn, LB (2003) *Growing up with epilepsy: A practical guide for parents*. Demos Health Publisher

Dodrill and Wilensky. Intellectual impairment as an outcome of status epilepticus. *Neurology* 1990;40[Suppl 2]:23-27. From Devinsky O and Tarulli A. Progressive cognitive and behavioral changes in epilepsy. In: Devinsky O and Westbrook LE, eds. *Epilepsy and Developmental Disabilities*. Boston: Butterworth-Heinemann; 2001;133-149. With permission from Elsevier

Fisher, R.S. Epilepsy.ComNewsletter. Summary of Antiepileptic Drugs  
<http://www.epilepsy.com/epilepsy/newsletter/sept09/aeds>

Freeman, JM, Vinning, EPG and Pillas, DJ (2002) *Seizure and epilepsy in childhood: A guide, 3rd edition*. Baltimore, MD: The Johns Hopkins University Press.

## FAQs

Gabis, L, Pomeroy, J, Andriola, MR (2005) Autism and epilepsy: Cause, consequence, comorbidity, or coincidence? *Epilepsy and Behavior* 7: 652-56

Gillberg, C. (1991) The Treatment of Epilepsy in Autism. *J. Autism Develop. Disord.* 21: 61-77

Kabir, SM et al. (2009) Vagus nerve stimulation in children with intractable epilepsy: indications, complications and outcome. *Childs Nerv System.* 25: 1097-100.

Malow, BA (2006) Searching for Autism Symptomatology in Children with Epilepsy—A New Approach to an Established Comorbidity. *Epilepsy Curr.* 6(5): 150–152.

The National Institute of Neurological Disorders and Stroke web site; NINDS Epilepsy Information Page <http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>

Stafstrom CE (2006) Dietary Approaches to Epilepsy Treatment: Old and New Options on the Menu. EpilepsyUSA, reproduced in Epilepsy Foundation Newsroom. <http://www.epilepsyfoundation.org/epilepsyusa/diet200607.cfm>

WebMD Medications to treat Seizures <http://www.webmd.com/epilepsy/medications-treat-seizures>

Yasuhara, A. (2010) Correlation between EEG abnormalities and symptoms of autism spectrum disorder (ASD). *Brain Dev.*

---

### Diet, Vitamins & Minerals in Autism

## Diet, Vitamins and Minerals in Autism

Many parents of children with autism spectrum disorders are concerned about their diets and whether they should receive special supplements. The following articles summarize what is known from the best available research evidence about these topics. References at the end of each article indicate the main sources of information.

## VITAMINS AND MINERALS

Surveys show that many parents of children with Autism Spectrum Disorders give their children vitamin supplements. While there are occasionally severely abnormal diets of children with autism, medical nutrition experts generally say that most children with ASDs receive enough vitamins through their diet for good health. However, parents often believe supplements will help with autism symptoms. Where did this idea come from, and what is the evidence?

In 1970 when Linus Pauling announced in his book “Vitamin C and the Common Cold” that taking 1,000 mg of vitamin C daily (16 times the recommended daily amount for vitamin C) will reduce the incidence of colds by 45% for most people but that some people need much larger amounts, megavitamins took the nation by storm. Pauling had

## FAQs

no background in medicine nor any evidence that what he claimed was actually true. It was a purely theoretical idea. In 1976 (Vitamin C, the Common Cold and the Flu) he suggested even higher dosages. A third book, Vitamin C and Cancer (1979) claimed that high doses of vitamin C may be effective against cancer. There is no evidence this is correct

Bernard Rimland, the parent and well know advocate for individuals with autism, obtained his PhD in experimental psychology and research design, from Pennsylvania State University. Around time Pauling was promoting mega-vitamin C dosages for colds and cancer, Dr. Rimland began suggesting parents use megavitamins and minerals to treat children with autism. He conducted numerous surveys asking parents to report treatments they were using with their children with ASDs and their effectiveness. He reported the survey results for minerals and vitamins in the Autism Research institute newsletter. In an article published by the Assn for Comprehensive NeuroTherapy in "Latitudes", vol. 1, no. 3&4, Dr. Rimland wrote, "All eighteen studies known to me in which vitamin B6 has been evaluated as a treatment for autistic children have provided positive results". The problem was that most of those studies to which Dr. Rimland referred would not pass minimum standards of a controlled clinical trial of any FDA approved medicine. The question remains, what is the evidence for vitamin or mineral abnormalities in autism spectrum disorders and to what extent do supplements overcome autism symptoms?

I recently reviewed all published clinical studies abstracted in PubMed, the National Institute of Health database, covering the period 1980 to the present searching for specific key words. PubMed is widely accepted as the authoritative source of information regarding published medical research on nearly any topic. It does not include book chapters, magazine articles, or newsletter reports that are not peer reviewed by experts in the field. I searched under "Autism" in combination with any of the following: Vitamins A, B6, B12, Bc (Folic acid), Niacin, C, D, E or K. Those vitamins include the most commonly recommended vitamin supplements recommended by individuals and groups promoting vitamin and mineral supplements in autism.

*GENERAL VITAMIN-MINERAL STUDIES:* Shearer et. al. (1982) studied calcium, magnesium, zinc, copper, lead, and cadmium concentration in scalp hair samples from 12 autistic children and 12 non-autistic controls. The only statistically significant difference between concentrations of minerals in the hair from the two groups was a 62% decrease in cadmium in the hair of autistic children. The authors concluded the cadmium difference was not medically significant. Wecker et. al.(1985) studied trace element concentrations in hair of autistic children compared with matched controls. The autistic population had significantly lower levels of calcium, magnesium, copper, manganese and chromium and higher levels of lithium as compared to sex- and age-matched controls. There have been no replications or similar studies for the past 20 years. Most experts question the validity of hair samples as measures of body minerals.

*VITAMIN A:* Two single case reports have appeared in the research literature over 20 years involving Vitamin A deficiency in autism. In both cases, visual problems were reported and in one an 8 year old also developed a limp after living on a diet composed entirely of French Fries. There have been no studies of Vitamin A supplements alone.

## FAQs

**VITAMIN B6 and MAGNESIUM:** Kleijnen and Knipschild (1991) surveyed all published studies of magnesium, Vitamin B6 and other vitamins and minerals up to 1990. In some autistic children positive results were reported with very high dosages of vitamin B6 and magnesium. Because of serious methodological problems they concluded further evidence is needed before clear conclusions could be drawn. Pfeifer et.al (1995) conducted a similar review of B6-magnesium studies and found that while many reported a favorable response to vitamin treatment, serious methodological shortcomings made it difficult arrive at a clear conclusion about the validity of the authors' conclusions. Errors included imprecise outcome measures, lack of double blind conditions, small samples and short-term measures of effects. Adams and Holloway (2004) found that autistic children had substantially elevated levels of B6 compared to a control group of typical children. They suggested high vitamin B(6) levels are consistent with reports of low levels of related enzymes in autism. Nye and Brice (2005) surveyed 33 studies dealing with Vitamin B6 and Magnesium in autism under the auspices of the highly regarded Cochrane Collaborative. Only three met minimal standards for a controlled scientific study. The Tolbert (1993) study provided insufficient data to conduct a secondary analysis. Another study (Findling 1997) yielded no significant differences between B6-magnesium and placebo groups on measures of social interaction, communication, compulsivity, impulsivity, or hyperactivity. Kuriyama (2002) (n=8) measured IQ and 'Social Quotient' and found a small but statistically significant benefit for IQ but not "social quotient". Strambi et.al. (2006) found no differences in magnesium inside blood cells between controls and children with autism; however, autistic children and children with other autistic spectrum disorders had significantly lower plasma concentrations of Mg than normal subjects. Since plasma includes serum and blood cells, that must mean serum levels are lower. The implications of this difference are unclear.

**VITAMIN B12:** Pasca et. al, (2006) reported in a sample of 12 children with autism Vit B12 blood levels were "suboptimal". There have been no published reports of effects of B12 supplements in children with ASDs.

**VITAMIN Bc (Folic Acid):** Some years ago it was suggested there may be folic acid deficiencies in Fragile X syndrome, approximately 25% of whom also have autism. Eto, (1992) studied levels of folate of children with autism and matched controls and found they were not statistically different. The benefits of folic acid supplements in Fragile X syndrome have been equivocal in controlled studies (Laxova, 1994). There have been no published studies of Folic Acid supplements in autism.

**NIACIN:** Niacin is a component of the Vit B complex. There have been no reports of niacin deficiency or supplementation in ASDs.

**VITAMIN C:** Dolske et.al. (1993) studied effect of Vitamin C on behavior of 18 children with autism in a residential school. Ratings were double blind using the Ritvo-Freeman Autism Scale (seldom used today). Total scores and also sensory motor scores indicating a reduction in symptom severity associated with the ascorbic acid treatment. There have been no replications of this study or other Vitamin C studies since then.

**VITAMIN D:** There have been no reports of Vit D deficiency or supplementation in ASDs.

## FAQs

**VITAMIN E:** Corbett et. al. (2006) studied differences in a large number of proteins in children with autism and matched controls. Apo B-100 and apo A-IV were higher in children with high compared to low functioning autism. Apos are involved in the transport of lipids, cholesterol and vitamin E. There have been no reports of Vit E supplements in ASDs.

**VITAMIN K:** There have been no reports of Vit K deficiency or supplementation in children with ASDs.

### SUMMARY:

1. There is one published study reporting elevated Vit B6 in blood of children with autism and one study reporting suboptimal Vit B12 in a small group of children with autism. One study suggested a protein related to Vit E may be abnormal in autism, but Vit E was not measured. Otherwise there is no evidence of vitamin abnormalities associated with autism.
2. There are several reports suggesting B6-magnesium supplements may improve autism symptoms in some children, though the results are difficult to interpret because of problems with the research. One study of 18 children with ASD in a residential school suggested Vit C supplements may have beneficial effects, but there have been no replications of that study in the past 14 years.
3. There have been no published reports of controlled supplement trials with children with autism spectrum disorders with Vitamins A (two single cases of children with grossly abnormal diets), B12, Folic Acid, Niacin, D, E or K.

### References

- Pasca, SP et.al. (2006) Life Sci 78:2244-8.  
Laxova, R (1994) Adv Pediatr. 1:305-42.  
Eto, I. et.al (1992) J. Autism Dev Disord. 22:295-308.

## **Autism and Diet 1: The Casein-Gluten Free Diet**

*“Though it be honest, it is never good  
To bring bad news: give to a gracious Message  
An host of tongues, but let ill tidings tell  
Themselves, when they be felt”*

Cleopatra to the Messenger in *Antony and Cleopatra*, William Shakespeare

The final details of the story linking diet and autism remains to be written, but a good deal is already known. Many parents of children with autism spectrum disorders believe such a link exists, varying from the firmly held conviction that vaccines together with diet caused their child's autism, to other parents who

subscribe to the idea that specific dietary indiscretions can cause worsening of their child's autism symptoms though they may not have caused autism. To be the bearer of the news that such a link may not exist, at least not in the sense that diet is causally related to the core symptoms of autism, may make me an unwelcome messenger. But in light of the objective scientific evidence, that conclusion seems apt. After exploring the evidence, it is worth thinking together about the reasons the idea that dietary changes may improve autism functioning is so appealing, especially to parents. That will be discussed in the second part of this report.

The idea that diet and healthy living can overcome a developmental disability isn't new. The best known early advocate of this notion was Johann Guggenbuhl, a young Swiss physician who in 1841 constructed a mountain retreat Abendberg, near Berne for children with Cretinism. Guggenbuhl claimed his diet, exercise and clear mountain air cured individuals of Cretinism (congenital hypothyroidism). Individuals born lacking sufficient thyroid hormone develop moderate to severe intellectual and physical disability, healthy diet or not. Guggenbuhl travelled all over Europe raising money for his mountain retreat, fleecing wishful parents and other donors. Eventually, however, visitors to the Abendberg discovered neglect and abuse, due in part to Guggenbühl's frequent and prolonged absences, and it was discovered that his claims of cures was false. Guggenbuhl was eventually prosecuted by Swiss authorities and the Abendberg was closed.

### **The Shot Heard Round the Autism World**

Before 1998, parents of children with autism expressed limited concern about their children's diet, other than noting their children tended to be very finicky eaters. Doctors seemed to have had a similar reaction to diet and autism. I did a thorough review of medical literature from 1988-98 and found only 4 scientific publications involving children with autism and diet. Two suggested diet may be related to autism behavioral symptoms and two failed to find any relation to autism. I have been unable to uncover any publication suggesting diet could cause autism before 1998, the year Karoly Horvath and his co-workers in Maryland, and Andrew Wakefield and colleagues in London, separately published articles in medical journals proposing a link between gastrointestinal functioning and autism. Following appearance of those two inflammatory articles pandemonium broke out within the autism parent community, with wild claims circulating the globe via the internet, literally within hours, about the cause of autism. Horvath's and Wakefield's claims suggested there was a readily preventable cause of autism, namely an immune disorder caused by Measles-Mumps-Rubella vaccination, which turned out was false. But these beliefs stick to the parent autism community wall like *al dente* spaghetti.

Horvath and Wakefield are gastroenterologists with no prior autism background. Horvath injected three children who he said had autism with secretin, a pancreatic hormone used in testing GI function, because the children had gastrointestinal

## FAQs

symptoms. Five weeks after the secretin test Horvath said their autism symptoms dramatically improved. There were no standardized independent assessments of the children by an unbiased observer before or after administration of secretin. Dozens of subsequent independent studies failed to reveal any relationship between the pancreatic hormone, secretin and autism symptoms. Horvath's results were either imagined or were a fluke.

Wakefield studied intestinal tissue and spinal fluid from children with autism who were referred to his GI clinic because they had gut symptoms. They were not referred because they had autism. On laboratory examination he found physical abnormalities in the intestinal tissue among some children with autism who had gastrointestinal symptoms. He asked the parents if their autism symptoms and diagnosis first appeared following measles-mumps-rubella vaccination, and most of the parents reported that they thought their child's autism symptoms did arise that way. In other words, Wakefield suggested to the parents that there was a link between MMR immunization and autism, and most agreed. Wakefield hypothesized that MMR vaccine damaged the gut lining making it permeable to toxic bacteria. What he didn't tell the parents, was that he was being paid by an anti-vaccine group to conduct the study. He was hardly an unbiased professional observer. There were numerous other methodological and ethical flaws in his study, that have been investigated by the UK General Medical Council, which, as a result, disbarred Wakefield from practicing medicine in the UK in 2010. Ten of the 13 authors of the Wakefield study article asked that their names be removed from the article. The journal Lancet withdrew the Wakefield article from its pages.

A large number of independent studies in several countries by unrelated groups of researchers have failed to find a relation between MMR vaccination and autism prevalence. In addition, most studies by other independent researchers have failed to find a reliable immune disorder or physical gut differences in children with autism, as reported by Wakefield. Only Wakefield and his collaborators (4-5 articles) and Jyonouchy (two articles), found such immune disorder relationships. Other independent researchers have failed to find such a relationship. It is true that children with autism tend to have more problems with constipation or diarrhea than typically developing comparison children, but not more than other children with developmental disabilities, but that may be due to many other causes unrelated to vaccines or autism.

### **Casein-Gluten Free Diet**

Caseine is the main protein present in milk and (in coagulated form) in cheese. Gluten is a protein present in cereal grains that is responsible for the elastic texture of dough. A mixture of two proteins, it causes severe gastrointestinal illness in people with celiac disease, usually of genetic origin. Celiac disease affects about 1% of Americans. Celiac disease (allergy to gluten) is not more common among individuals with autism than matched control children. A specialized diet free of

casein and gluten has been widely used by parents in the belief that it would counteract these alleged but unsubstantiated immune-related gut abnormalities. A considerable industry has emerged providing CGF dietary products for parents seeking them for their children, with total annual sales exceeding \$1.7 billion.

### **CGFD: Empirical Evidence**

It is possible the CGF diet could reduce behavioral symptoms associated with autism by another mechanism even if there are no physical gut abnormalities as Wakefield claimed, so perhaps it is worth evaluating. There have been several controlled studies of the CGF diet, mostly failing to find an effect of the diet, and one recent study from the UK that lacked a control comparison group, that reported improvements in some autism symptoms associated with CGFD. An American consensus panel of autism and GI specialists chaired by Timothy Buie, a gastroenterologist from Harvard University concluded, "that evidence-based recommendations are not yet available. The consensus expert opinion of the panel was that individuals with ASDs deserve the same thoroughness and standard of care in the diagnostic workup and treatment of gastrointestinal concerns as should occur for patients without ASDs." In other words, any child with gastrointestinal symptoms should be evaluated and treated for those symptoms, but there is no indication that those symptoms are specifically related to autism.

The Cochrane Database System Review conducted an analysis of controlled CGFD studies in 2008. They found two small Randomized Clinical Trials. There were only three significant treatment effects across the two studies favoring the CGFD diet intervention: overall autistic traits, social isolation, and overall ability to communicate and interact. Three other outcomes showed no significant difference between the treatment and control group. An example is the Elder et. al. (2006) study that tested the efficacy of a gluten and casein free diet in treating symptoms of autism in a randomized, double-blind study. Over 12 weeks the sample of 15 children showed no significant symptoms differences between being on and off the diet, though several parents reported improvements regardless of diet condition. Cornish (2002) studied nutrient intakes of children who were receiving gluten and casein free diets and a comparison group of children with ASDs that was not. Half of the children in the gluten-casein free diet group were deficient for zinc and calcium. Arnold et. al. (2003) studied dietary plasma amino acid profiles of 36 children with ASDs. Ten children were on gluten-casein free diets. No consistent amino acid profile was found across children with ASDs. Children on the GCFD had more types of essential amino acid deficiencies and lower plasma levels of the essential amino acids tyrosine and tryptophan, which are involved in serotonin metabolism. The role of dietary abnormalities in GI symptoms including diarrhea and constipation among children with ASDs was unclear.

### **Conclusions**

## FAQs

1. Prior to the Horvath and Wakefield articles published in 1998 few parents of children with autism or their doctors expressed concern about diet and gastrointestinal problems. Many parents noted their children were finicky eaters, but not that they had unusual gastrointestinal problems.
2. Horvath's and Wakefield's claims about gut abnormalities that are specific to children with autism appear to be false. Both claims (secretin cures autism) and MMR vaccine, gut problems are associated with increased autism prevalence have not been substantiated when studied by others. While some children with autism as well as those with other developmental disabilities have intestinal problems, there is no evidence there are autism-specific gut abnormalities as claimed.
3. Celiac Disease (gluten intolerance) is about as common among children with autism as among other children. The rationale for the Casein-Gluten Free Diet based on presumed gut abnormalities, including gluten intolerance in autism lacks empirical support. Recent research has indicated that proposed internal opioid chemicals are released in the gut by gluten in the diet, and are linked to GI and autism symptoms, have been found to be false.
4. There have been two controlled clinical trials with the CGFD yielding little evidence of significant improvements or gains associated with the diet. A national consensus conference held in the US in 2009 concluded there was insufficient evidence to recommend the diet. Several other studies without random assignment have failed to find autism symptom changes as a function of being on or off the CGFD.

## References

- No Authors. (1983) Dr. Guggenbühl's Hospice for cretins on the Abendberg in Switzerland (1840). *Pediatrics*. 71: 452.
- Arnold GL, et.al. (2003) Plasma amino acids profiles in children with autism: Potential risk for nutritional deficiencies. *J. Autism Dev Disord*. 33:449-54.
- Buie, T. et. al. (2010) Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics*. 125 Suppl 1:S1-18.
- Cornish, E. (2002) Gluten and caesin free diets in autism: A study of the effects on food choice and nutrition. *J. Hum. Nutr. Diet*. 15: 261-9
- Elder, JH. Et. al. (2006) The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial. *J. Autism Dev Disord*. 36:413-20.

## FAQs

Horvath, K, et. al. (1998) Improved social and language skills after secretin administration in patients with autistic spectrum disorders. *J. Assoc. Acad.Minor Phys.* 9:9-15.

Jyonouchi, H. (2005) Dysregulated innate immune responses in young children with autism spectrum disorders: their relationship to gastrointestinal symptoms and dietary intervention. *Neuropsychobiology* 51:77-85.

General Medical Council, Preliminary Proceedings Committee and Professional Conduct Committee (Procedure) Rules 1988. Date: 24 May 2010 Dr Andrew Jeremy WAKEFIELD Determination on Serious Professional Misconduct (SPM) and sanction. [http://www.gmc-uk.org/Wakefield\\_SPM\\_and\\_SANCTION.pdf\\_32595267.pdf](http://www.gmc-uk.org/Wakefield_SPM_and_SANCTION.pdf_32595267.pdf) Accessed 8-23-10

Millward, C. et.al. (2008) Gluten- and casein-free diets for autistic spectrum disorder. *Cochrane Database Syst. Rev.* Apr 16 (2) CD003498

National Institutes of Health; Celiac Disease Awareness Campaign. National Institute of Diabetes, Digestive and Kidney Disease August 18, 2009. <http://www.celiac.nih.gov/> Accessed 8-23-10 .

Sturmey, ,P. (2005) Secretin is an ineffective treatment for pervasive developmental disabilities: a review of 15 double-blind randomized controlled trials. *Res. Dev. Disabil.* 26:87-97.

Thompson, T, (2007) Caveat Emptor: Cautionary Consideration for Parents and Practitioners. Chapter 10. In T. Thompson, *Making Sense of Autism*. Pg 187-203. Baltimore: Paul H. Brookes Publishing Co.

Wakefield, AJ et. al. (1998) Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet* 351: 637-41.

Whiteley P, et. al (2010)The ScanBrit randomised, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders. *Nutr Neurosci.* 13:87-100

---

### Diets and Parent Beliefs

#### **Why Autism Parents are Drawn to Special Diets**

Behavior of many children with autism fluctuates from hour to hour and day to day due to numerous factors. Some mornings when the child slept poorly the night before, the youngster may be more irritable. For an hour or more after a child was involved in a fracas with her sibling she may be prone to a meltdown. If the child's school had a fire drill earlier in the day, s/he may be upset the remainder of the day.

## FAQs

If a child is frustrated because there has been a change in his daily routine she may also have a meltdown. This morning your daughter has had two sippy cups of apple juice and some fresh pear for a snack, and has experienced a tummy ache and loose stool. Oh, and I almost forgot, she inadvertently ate an oatmeal cookie that contained gluten last night before bed. Which is the cause of their child's behavioral irritability and bowel problem? It is impossible to know since many things change from day to day that can contribute to similar symptoms. Parents focus on what they think is most likely to be causally important. If they believe the gluten in her diet contributes to her behavior problems and loose stools, that is what they will remember and they may disregard the rest.

### **Typical Dietary Habits of Children with Autism**

Most studies show children with autism are finicky eaters and seldom have a balanced diet. I have summarized here findings from several studies: "ASD children tend to consume less vegetables, salad and fresh fruit. Nutrients least likely to be consumed in their diets in recommended amounts were vitamin A, vitamin E, fiber, and calcium." "Intake of total calories, carbohydrates, and fat are typically in the average range; protein intake was increased (211% of RDA). Reported frequency of GI abnormalities, including abnormal stool consistency (e.g., bulky or loose), was increased (54%), but there is no statistically significant relationships between stool consistency and dietary intake." In one study of enlarged colon among some children with autism, increased constipation and colon size was associated with excessive cheese and milk consumption. In another study, constipation or diarrhea were as common among children with other developmental disability as among children with autism, suggesting GI problems are not autism-specific.

### **Importance to Parents of Identifying a Tangible Autism Cause**

If parents believe their child's autism was caused by a vaccine that had been administered by the child's doctor, that makes it possible to point to a single, visible, tangible cause of their child's condition, much as they might point to eggs tainted with salmonella causing food poisoning. It is comforting to know what causes a person's symptoms. From the day their child was first diagnosed, parents want to know what caused their child's disability. To be told autism is usually of genetic in origin seems ethereal to parents, conjuring up images of squiggles of DNA too small to be seen by a microscope, which might as well be black holes in a distant galaxy. In fact, DNA is no less real, but it may seem less tangible to parents because they are unable to see it and hold it in their hands.

If parents can say, "That thing over there (*pointing with their index finger to the vaccine vial in the doctor's office*) caused my child's autism," that means their feelings of guilt and blame regarding their child's diagnosis are diminished because they can hold accountable the doctor who injected the MMR vaccine, or the pharmaceutical manufacturer who created the vaccine that placed it into injection

vials. "There is nothing I did that caused my child's autism. I trusted the doctor and now see what has happened!" the parent thinks. It makes sense that this scenario is highly appealing to parents, but it appears the link between vaccine and autism is false.

### **Diet: Something Fairly Simple Parents Think Might Help**

A child's bowel problems and tummy ache are tangible to parents. The notion they are produced by diet or a vaccine is appealing. There is a clear causal arrow between A and B. Bowel movements are something real, to which anyone who has been parent of a young child in diapers can attest, me included. Parents can see and point to signs of the problem, and more importantly, there are specific things they can do that they think will improve the child's autism symptoms, or at least they believe they can. They can switch their child to a casein-gluten free diet, which is far simpler than taking part in many hours per week of home-based early intensive behavioral intervention. The fact that their child's autism symptoms resulted from differences in the way several of his brain structures developed, that one can only see with a brain imaging scan (if then), makes the causes intangible and less real to parents. Parents wonder, "But what can I do to fix my child's brain?" They can usually do a great deal, by implementing an intensive early behavioral intervention program that promotes new connections in those dysfunctional brain structures. But to skeptical parents, that all seems very abstract with results very far off in the distant future. They think, "Perhaps a CGFD will produce immediate improvements."

### **Should Parents Try The CGFD?**

If, as has been reviewed above, there is limited evidence of the effectiveness of a CGFD, should parents give it a try anyway? In my own conversations with parents I find some who are convinced the CGFD diet has been helpful and others who report they could see no difference and stopped using the diet. Are there reasons parents should not try the CGFD for their child? There are things to consider in deciding to try the diet.

- Many children dislike the flavors and consistency of CGFD, foods and it can be a struggle to induce them to eat it. Some parents eventually give up.
  - It can be costly, especially if parents purchase mostly prepared foods.
  - It is inconvenient when their child's peers may be consuming far more appealing foods at school and in the community than the child with autism is allowed to have.
  - The CGFD and most other alternative interventions are not evidence-based.
- Parents often feel compelled to defend their use of the diet, even when they realize there is little objective evidence they are helpful. That leads them down the path of untested treatments.
- Emphasis on the diet tends to diminish the importance parents place on effective early behavioral intervention. If parents believe the diet will take care of their child's

autism symptoms, why waste their time and money on early behavioral intervention. A study by Corina Grindle and colleagues in the UK indicated lack of commitment to an effective early ABA program while parents tried various other interventions was a strong predictor of an unfavorable child outcome.

### **Evidence-Based Enemies**

Some parents view as enemies, professionals like me who point out there is very little evidence from controlled studies supporting the use of the CGFD in autism. If immunization did not trigger the gut changes that require the CGFD, then what are parents to believe? That raises the possibility that the special diet they have been giving to their child isn't really necessary or helpful. That leads them to think that perhaps they should be trying something altogether different. Maybe it was something else we did that caused our child's disability. The answer is almost certainly that IT IS NOT something else a parent did that led to autism. Some types of autism are caused by unpredictable, chance genetic mutations, and it appears other factors may play a role among some susceptible people. But false prophets (Offit, 2008), like Johann Guggenbuhl, do not give up their claims easily, especially when large amounts of money and personal prestige are at stake. But because a nostrum is ineffective, should not lead parents to despondency, because there are other highly effective, albeit more demanding, alternatives. It is just that there is unlikely to be any quick fixes.

### **Conclusions: Diet and Autism**

1. Most children with autism are finicky and do not eat a balanced diet. They tend to avoid vegetables and fruit and eat twice as much protein as recommended. Vitamin A, E and calcium deficiencies are common. Despite these dietary indiscretions, most children with autism are healthy.
2. Parents' preparing specialized meals that the child will eat with minimal resistance may inadvertently contribute to dietary deficiencies and aggravate the child's rejection of a range of foods. Parent cajoling and attention to food resistance may inadvertently reward rejecting new or differing foods.
3. Excessive fruit juice (apple, pear, apricot, cranapple) can cause diarrhea. Excessive milk, meat and cheese can contribute to constipation.
4. Parent surveys indicate 40-60% of children with autism experience gastrointestinal problems (diarrhea, reflux or constipation). Surveys of typical children report smaller percentage of GI problems, but these autism percentages are similar to those of children with other neurodevelopmental disabilities.
5. Many parents of children with autism report their children have food allergies, but when actually tested about the same percentage have food allergies as typical

peers (9%).

6. Gluten sensitivity (celiac disease) among children with autism is about the same prevalence as same age children without autism (1%). A much larger proportion of children with autism are given the CGFD by their parents.

7. There have been 3 randomized clinical trials with a CGFD in autism revealing some improvements in several subscales in two of the three clinical trials, none in the third trial and no improvements in other subtests. An American Consensus Panel convened in 2009 concluded there was insufficient evidence to indicate the CGFD was effective.

8. Parents may conclude specialized diets, like the CGFD are useful for their children because it is something concrete they can do that might improve their child's functioning. Since no data are maintained regarding diet in most families, GI and behavioral symptoms, there is generally no way of knowing whether the diet is helpful, and therefore cannot be easily disproved. In such cases, parents have to decide whether it is worth the cost and effort to feel they are at least "doing something."

9. Most other effective interventions, such as intensive early behavioral intervention, require long term commitments with gradual improvements in child symptoms over time, making dietary treatments appealing because they seem to promise more immediate gains with less effort and time commitment.

## References

Buie, T. et. al. (2010) Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics*. 125 Suppl 1:S1-18.

Carroll, L (1914) *The hunting of the Snark: An agony in eight fits*; with Illustrations by Henry Holiday. New York: McMillan & Company.

Cass H. et. al. (2008) Absence of urinary opioid peptides in children with autism. *Arch Dis Child* 93:745-50

Elder, JH. Et. al. (2006) The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial. *J. Autism Dev Disord*. 36:413-20,

Elder, JH (2009) The gluten-free, casein-free diet in autism: an overview with clinical implications. *Nutr Clin Pract* 23:583-8.

Emond, a. et.al. (2010) Feeding symptoms, dietary patterns, and growth in young children with autism spectrum disorders. *Pediatrics*. 126(2):e337-42

## FAQs

Hendy, HM (2010) Parent mealtime actions that mediate associations between children's fussy-eating and their weight and diet. *Appetite*. 54: 191-5.

Horvath, K, et. al. (1998) Improved social and language skills after secretin administration in patients with autistic spectrum disorders. *J. Assoc. Acad.Minor Phys.* 9:9-15.

Jyonouchi, H. (2005) Dysregulated innate immune responses in young children with autism spectrum disorders: their relationship to gastrointestinal symptoms and dietary intervention. *Neuropsychobiology* 51:77-85.

Levy, SE et. al. (2007) Relationship of dietary intake to gastrointestinal symptoms in children with autistic spectrum disorders. *Biol. Psychiatry* 61:492-7.

Offit, P.A. (2008) *Autism's false prophets: Bad science, risky medicine and the search for a cure*. NY: Columbia University Press.

Lockner, DW et.al. (2008) Dietary intake and parents' perception of mealtime behaviors in preschool-age children with autism spectrum disorder and in typically developing children. *J. Am. Diet. Assoc.* 108:1360-3.

Millward, C. et.al. (2008) Gluten- and casein-free diets for autistic spectrum disorder. *Cochrane Database Syst. Rev.* Apr 16 (2) CD003498

Smith, RA. Et. al. (2009) Are there more bowel symptoms in children with autism compared to normal children and children with other developmental and neurological disorders?: A case control study. *Autism*. 13:343-55.

Sturmey, ,P. (2005) Secretin is an ineffective treatment for pervasive developmental disabilities: a review of 15 double-blind randomized controlled trials. *Res. Dev. Disabil.* 26:87-97.

Thompson, T, (2007) *Caveat Emptor: Cautionary Consideration for Parents and Practitioners*. Chapter 10. In T. Thompson, *Making Sense of Autism*. Pg 187-203. Baltimore: Paul H. Brookes Publishing Co.

Wakefield, AJ et. al. (1998) Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet* 351: 637-41.

Whiteley P, et. al (2010)The ScanBrit randomised, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders. *Nutr Neurosci.* 13:87-100

#### DAILY LIVING

Nearly every parent of a child with an autism spectrum disorder encounters practical situations in daily life that are confusing and frustrating. The following articles discuss problems with toothbrushing, falling asleep, remaining asleep and how to use visual schedules to encourage regular daily routines.

---

#### Finding Lost Children with Autism

Television station WITN in Eastern Virginian recently reported, *"A missing autistic 3-year-old girl is safe after wandering off at a family reunion in Halifax. The Halifax County Sheriff's Office says April Eubanks had been missing since around 9:30 Friday morning. The Halifax County Sheriff's Office, firefighters, and volunteers searched the area near Andrew Jackson School for the girl and found her around 2:00 p.m. along the banks of the Roanoke River, just a few blocks from where she disappeared."*

This near tragic story reminds us of the importance of taking precautions to prevent your child from wandering off, and if that happens, quickly finding her or him before the worst happens. There are also avoidable dangers at home and in the neighborhood that deserve your attention.

Very little work has been done in abduction safety training for children with autism. One study by Gunby et. al. (2010) Teaching abduction prevention skills to children with autism. In [J. Appl. Behav. Anal. 43:107-112](#) demonstrated one method that was effective with three 6-8 year olds who had a history of having been previously trained to follow adult verbal instructions.

At the very least, every child with autism should wear a Medical Alert Bracelet or tag woven into their shoe laces with their name, diagnosis and phone number to be called if they are found. There is a large number of such sites on line, such as Hope Paige <https://www.hopepaige.com/>

At the high end there are several GPS child locating devices, usually similar to a wrist watch, which can cost as much as \$200 plus a yearly service charge. It may be possible to use Waiver funds for such purposes in some localities. <http://www.locationbasedgps.com/categories/Autism/>

Some states provide Amber Alert announcements for lost children with autism <http://autismamberalert.blogspot.com/2011/06/emfinders-bracelets-for-missing-ohio.html>

Around home or the park, the Safety Turtle is a good idea which sets off an alarm if the child falls into water, such as a swimming pool. <http://www.safetyturtle.com/>

*Autism Speaks' Autism Safety Project* website contains numerous resources to help in planning you're your child's safety.

<http://www.autismsafetyproject.org/site/c.kuIVKgMZIxF/b.5058283/k.BE40/Home.htm>  
*The Autism Society of America has a Safe and Sound Task Force* chaired by Judge Kimberly S. Taylor is a good resource for autism safety suggestions.  
<http://www.autism-society.org/living-with-autism/how-we-can-help/safe-and-sound/safe-and-sound-task-force.html>

Better safe than sorry. Have fun, but asy they say, An ounce of prevention is worth a pound of cure.

---

#### **Feeding Problems in Autism**

The mother of a two year-old boy diagnosed with an ASD for whom we had been providing early behavioral intervention services, reported that he rejected most foods and gagged when a spoon with food was brought near his mouth. He was participating in a feeding clinic that attempted to desensitize him to food in his mouth, and particularly certain textures. A swallowing study conducted by the clinic revealed no physical or mechanical reason he was having difficulty swallowing food, which is a common finding among children with autism who have feeding problems. The boy's parents were very apprehensive about his feeding difficulty and devoted several hours per day working with him on his food refusal under the direction of the staff at the feeding clinic. Gagging was a conditioned response to the sight and smell of food in the spoon which in the past had been associated with choking when trying to swallow.

Around 2/3ds of parents of children with autism report their child is a finicky eater and report meal time difficulties, but only around 6-7% consider their child to have a "feeding disorder." Feeding disorders affect a child's ability to properly function at home, school and other social settings, impacting physical, social and psychological development.

#### ***Common signs and symptoms of a feeding disorder include:***

- Poor weight gain
- Feeding tube dependence
- Bottle or formula dependence
- Mealtime tantrums, or mealtimes exceeding 40 minutes
- Distress and anxiety with new foods
- Inability to increase textures
- Inability or refusal to feed oneself
- Extreme pickiness (eating fewer than 12 foods)

**Causes:** Several reasons have been suggested for the prevalence of feeding problems in children with ASD, including compulsivity, impulsivity, fear of novelty, exaggerated sensory responses, deficits in social compliance, and biological food intolerance (Cumine, Leach, & Stevenson, 2000). Parental anxiety, reinforcement of negative feeding patterns, and communication difficulties have been suggested as social factors that contribute to the maintenance of maladaptive feeding behaviors.

A very common scenario occurs when a child who eats only a few foods is given access

to his favorite foods when he rejects non-preferred foods, the child is being positively reinforced for food refusal. In treating feeding problems, the behavior that is reinforced is generally acceptance or swallowing of food. Hoch et al. (2001) suggested that reinforcement alone is effective only when food refusal occurs solely because of insufficient positive reinforcement for eating foods.

**Testing:** Evaluating food refusal in autism begins with a physical examination for oral motor apraxia (inability to coordinate tongue, mouth and swallowing) and ruling out other physical problems such as gastroesophageal reflux disease (GERD) and constipation, diarrhea, or other symptoms resulting from food allergies (Volkmar & Wiesner, 2004). A small percentage of children with autism are diagnosed with dysphagia, who have difficulty swallowing and may experience pain while swallowing. Some may be completely unable to swallow or may have trouble swallowing liquids, foods, or saliva. Eating becomes a challenge. Often, dysphagia makes it difficult to take in enough calories and fluids to nourish the body. Such children are usually underweight and may have lost their appetite almost entirely. Physicians and speech-language pathologists who test for and treat swallowing disorders tests that allow them to view parts of the swallowing apparatus. One test, called a fiber optic laryngoscopy, allows the doctor to look down the throat with a lighted tube. Other tests, including video fluoroscopy, which takes videotapes of the child swallowing, and ultrasound, which produces images of internal body organs, can painlessly take pictures of various stages of swallowing (Ledford, and Gast 2006; Twachtman-Reilly, Amaral and Zebrowski, 2008).

**Behavioral Treatment:** If physical causes can be ruled out or treated medically, the most effective treatment is generally Escape Extinction. Escape extinction is designed to treat feeding problems based on the principle of negative reinforcement. Negative reinforcement for food selectivity is usually the removal of non-preferred foods after the child exhibits refusal behavior. When escape extinction is implemented, the child is not allowed to escape from eating. One form of escape extinction is non-removal of the spoon, in which an adult holds the spoon in front of the child's mouth until he or she takes a bite of food. Upon acceptance, positive reinforcement is usually provided in the form of descriptive praise or tangible items (Ahearn, Kerwin, Eicher, Shantz, & Swearingin, 1996). Another form of escape extinction is physical guidance, in which an adult physically guides the spoon into the child's mouth and physically assists him or her in opening the mouth. Again, acceptance of the spoon results in positive reinforcement. Parents often prefer escape extinction involving

physical guidance, and empirical findings showed that physical guidance resulted in shorter meals and fewer behavior problems. Cathleen Piazza, Director of the Feeding Clinic at the University of Nebraska Medical Center is shown in this embedded image.

Several studies have shown differential reinforcement involving escape extinction is effective in improving feeding in young children with varied cognitive abilities and medical problems who were dependent on tube feedings (Coe et al., 1997; Didden, Seys, & Schouwink, 1999). Additional studies have also indicated the usefulness of differential reinforcement for a variety of children, including those with gastrointestinal problems and total food refusal, language delays and failure to thrive. Patel, Piazza, Martinez, Volkert, and Santana (2002) demonstrated the effectiveness of escape extinction--regardless of

the presence or absence of differential reinforcement--with children from 15 months to 4 years of age who had various medical conditions and limited food intake.

**Conclusion:** A child with an autism spectrum disorder and a significant consistent feeding problem should be evaluated by a pediatric gastroenterologist, a speech pathologist, nutritionist and a behavioral specialist to rule out a physical causes, evaluate nutritional status and possible psychological contributions. Many children with autism and feeding problems have Gastroesophageal Reflux problems, which can be treated with medication. The research literature reveals predominant feeding problem in autism is food selectivity, not dysphagia. Around 2/3rds of children with autism exhibit some food refusal but less than 10% have physical causes for their feeding difficulties. A subset of children, usually with multiple developmental and health challenges (e.g.cerebral palsy, epilepsy), may also have oral motor difficulties. Which can often be treated by speech pathologists working in feeding clinic. Some severe mechanical problems are treated surgically.

Parental reactions to their child's food refusal, motivated by anxiety, often make matters worse. Parents usually coax, cajole, plead and threaten, and eventually offer the child his/her most preferred food items in lieu of typical health foods consumed by most children. Parents are often very concerned their child will go hungry and perhaps be malnourished. Parental attention to food refusal positively reinforces the very behavior they wish to eliminate, and providing an alternative preferred food negatively reinforces food refusal, making matters worse.

If physical causes can be ruled out or treated medically, the most effective treatment for food refusal is Escape Extinction combined with positive reinforcement for food acceptance, and planned ignoring of behavioral outbursts. Children with autism thrive on routines, so once the following procedure is in place, many children begin to accept it as part of their everyday schedule. In its simplest form, this involves presenting a very small amount of finely blended typical food on a spoon and physically guiding the spoon into his/her mouth. Begin by creating a smooth blend of a food item (to minimize a texture the child will not accept). Select a food with mild flavor and minimal food fragrance, such as mashed potatoes blended with diluted chicken broth or milk (if lactose isn't a problem). Some parents and feeding clinic staff members use a Nuk Brush to present food, that is often easier to manipulate and deposit the food in the child's cheek pouch. As soon as the child has accepted a small amount of a non-preferred food item and not spit it out, an equally small amount of a preferred food is made available. Over successive repetitions (usually several times daily over weeks), larger amounts of the non-preferred food item are presented, and usually multiple spoons of non-preferred food before a preferred food item is offered.

The greatest mistake parents or other caregivers make with this procedure arises from becoming impatient, and increasing the amount of the non-preferred food too rapidly or changing the texture prematurely. During this escape extinction procedure the child will likely cry, turn away, may hit and scream, which should all be ignored. The child will try all of the negative behaviors that have worked in the past. Such behavior is very difficult to ignore, but with support most parents can tolerate the tantrums, which will eventually wane and stop. Wait until the child turns facing the parent or caregiver again and repeat

this procedure. Over time, the oppositional behavior will slowly decrease and food acceptance will increase. Parents should assume this process will take weeks, not days to be successful. For some cases of extreme food refusal, overcoming the problem requires months of consistent follow through.

Throughout this process, the child should be weighed regularly to make certain weight is either constant or gaining. Often physicians prescribe vitamin and mineral supplements to assure the child is receiving adequate nutrition. Because this procedure is very difficult for most parents, I encourage caregivers to work closely with a behavioral practitioner, speech pathologist and nutritionist who can provide support and encouragement when the task becomes too difficult to do alone.

## References

Ahearn, W. H. (2002). Effect of two methods of introducing foods during feeding treatment on acceptance of previously rejected items. *Behavioral Interventions*, 17, 111–127

Ahearn, W. H., Kerwin, M. E., Eicher, P. S., Shantz, J., & Swearingin, W. (1996). An alternating treatments comparison of two intensive interventions for food refusal. *Journal of Applied Behavior Analysis*, 29, 321–332.

Coe DA et. al (1997) Use of extinction and reinforcement to increase food consumptions an reduce expulsion. *Journal of Applied Behavior Analysis*. 30: 581-3.

Cumine, V, Leach, J. & Stevenson, G.(2000) *Autism in the Early Years: A Practical Guide*. David Fulton Publisher.

Didden, R., Seys, D. and Schouwink, D. (1999), Treatment of chronic food refusal in a young developmentally disabled child. *Behavioral Interventions*, 14: 213–222.

Field, D., Garland, M., & Williams, K. (2003). Correlates of specific childhood feeding problems. *Journal of Paediatric Child Health*, 39, 299–304

Hoch, TA, et. al. (2001) Empirical Examination of a Multicomponent Treatment for Pediatric Food Refusal. *Education & Treatment of Children* | May 01, 2001 |

Ledford, JR and Gast DL (2006) Feeding problems in children with autism spectrum disorders: a review. *Focus on Autism and Other Developmental Disabilities*. Sept 22, 2006.

Kerwin, M. E., Eicher, P. S., & Gelsing, J. (2005). Parental report of eating problems and gastrointestinal symptoms in children with pervasive developmental disorders. *Children's Health Care*, 34(3), 217–234

Kodak, T., & Piazza, C. C. (2008). Assessment and behavioral treatment of feeding and sleeping disorders in children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America*, 17, 887–905.

Patel, M. R., Piazza, C. C., Martinez, C. J., Volkert, V. M., & Santana, C. M. (2002). An evaluation of two differential reinforcement procedures with escape extinction to treat food refusal. *Journal of Applied Behavior Analysis*, 35, 363–374.

Piazza, C. C., Fisher, W. F., Brown, K. A., Shore, B. A., Patel, M. R., Katz, R. M., et al. (2003). Functional analysis of inappropriate mealtime behaviors. *Journal of Applied Behavior Analysis*, 36, 187–204.

Twachtman-Reilly, J, Amaral, SC and Zebrowski, PC (2008) Addressing Feeding Disorders in Children on the Autism Spectrum in School-Based Settings: Physiological and Behavioral Issues. *Language, Speech, and Hearing Services in Schools*. 39: 261-272

Volkert, VM and Maz, PCM (2010) Recent studies of feeding problems in children with autism. *Journal of Applied Behavior Analysis* 43: 155-59

Volkmar, F. R., & Wiesner, L. A. (2004). *Topics in autism: Healthcare for children on the autism spectrum: A guide to medical, nutritional, and behavioral issues*. Bethesda, MD: Woodbine House.

---

#### **Toothbrushing; How to Deal with Resistance**

### **Toothbrushing**

**A DAILY CRISIS:** Tooth brushing is a daily crisis for many families who have a child with autism. A mother of a 4 year old told me she dreaded brushing her child's teeth more than any other daily activity. Her son cried, screamed and fought the toothbrush. He clamped his mouth shut, turned his head sideways and refused to cooperate. Another told me that her daughter "had a conniption" as soon as he saw her putting the toothpaste on the brush. But tooth brushing can become an accepted daily routine like any other activity if approached the right way.

**CREATE A ROUTINE:** According to the American Dental Association, tooth brushing should be a regular daily routine by the time a child is 2 years old and by 6 or 7, children should be able to brush their own teeth twice a day with supervision. Children with ASDs are creatures of habit, and are more likely to cooperate if tooth brushing is always done at the same time and the same routine is followed. Brushing after breakfast and before bedtime are usually good times because they are invariable parts of every day's routines.

**CHILD'S PERSPECTIVE:** If we consider tooth brushing from the child's vantage point it makes no sense. Why would they put something in their mouth, move it around and then spit it out. The only things they put in their mouths are food or beverages, which they swallow, or their thumb or pacifier that they suck. Toothpaste doesn't taste like food and a toothbrush isn't very much like a pacifier. To the child it is a weird activity that doesn't feel right, and we all know how children with ASDs react to things that don't feel right.

**INITIAL GOAL:** The initial goal is to help the child accept placing the a toothbrush with a

## FAQs

small amount of appealingly flavored toothpaste his or her mouth, swish it around, and then spit it out in the bathroom sink.

**SOFT TOOTH BRUSHES:** Children who resist tooth brushing either dislike the feeling of the brush on their teeth and gums, or they dislike the taste of the toothpaste. Several companies manufacture soft or ultrasoft toothbrushes. Amazing Products Store <http://www.pacwestserv.com/index.htm> sells ultrasoft tooth brushes for children and flavored toothpastes and gels. Soft toothbrushes have nylon bristles of 0.007" diameter or less. These bristles are soft enough to remove sticky plaque but not so hard that they cause damage to the soft tissues of the gum. The Biotene Toothbrush Super Soft with 0.003 diameter bristles is even softer. All bristles should be end-rounded, which means that the toothbrush maker has run the bristle tips through a polishing machine to round the rough cut ends of the filaments. Some companies advertise their toothbrushes as being soft, but really aren't, so consumers must check with the company to make certain the bristles are under .007 inches (preferably smaller).

**FLAVORED TOOTHPASTE;** For a 2-3 year old child a pea-sized amount of toothpaste is sufficient. Flavored toothpastes usually overcome the dislike for the stringent mint taste of most toothpastes. While several toothpastes sold by the Amazing Products Store (above) are mint flavored, they also offer strawberry, strawberry-banana, cherry, herbal bubble-gum, and mango flavored toothpastes or gels. Breath Palette.Com sells a variety of flavored toothpastes, such as Fresh Yogurt, Monkey Banana, Kiwi Fruit, Strawberry, Blueberry, at least one of which is likely to be appealing to your child. The toothpaste is sold in the US by Bravo Port, Inc., P.O.Box 1712, Sausalito, California.

**REWARD PROGRESS:** Before beginning tooth brushing training, figure out how you are going to reward your child for cooperating. If they have a favorite short video, allow them to watch it immediately after breakfast tooth brushing. In the evening, if they enjoy playing a specific game, plan to play the game with them as soon as their bedtime brushing routine is complete. If you are inconsistent, the procedure won't work.

**DESENSITIZE TO BRUSHING:** Begin by placing a very small amount of flavored toothpaste on the child's finger and encourage them to taste it by placing it in their mouth. Because the child has control over what they put in their own mouth this tends to work better than it being placed there by a parent. Once the child discovers they like the taste, the next step is to place a small amount on a child size soft bristle tooth brush, and allow them to place the brush in their own mouth with manual guidance. Say "Brush your teeth". They will usually suck or chew on the bristles. That's OK for now. This should be repeated for at least 3-4 days.

The next step is to manually guide their hand so the bristles brush lightly across their tongue once or twice. Encourage your child to spit out the toothpaste rather than swallowing it, but that is often difficult to manage with younger children with ASDs. For the first few days, the child may spit out other things, like broccoli at the dinner table, but with practice that will stop. Next, guide the child's hand so they feel the bristles brushing lightly once over the outside of upper teeth and lower teeth. If they resist, say "OK, were almost done", and stop as soon as possible. Remember, always reward them immediately after they have spit out the toothpaste and wiped their face. Within a week or

## FAQs

two most children will tolerate brushing upper and lower teeth on the inside and outside surfaces. Over the next two weeks gradually increase the length of time you brush, from 15 seconds to 30 seconds, to one minute, and so on.

*FADING TO NORMAL TOOTHPASTE*; Parents may decide to continue using the exotically flavored toothpaste or eventually fade in the more conventional toothpastes, selecting one with the least flavoring. Specialty stores often sell very mildly mint flavored toothpastes that can be gradually mixed with one of the fruit flavored toothpastes or gels, and then fading from one of the exotic flavors to standard flavor most children will accept over several weeks.

**SELF SUFFICIENCY**: At some point most children indicate they want to brush their own teeth, and all you have to do as a parent is observe and assist with rinsing the toothbrush and making certain they have wiped the excess toothpaste off their face. Children should be able to brush alone by age seven.

*HYGIENE*: Do not allow your child to share her/his toothbrush with a sibling. Sharing a toothbrush can result in risk for transferring colds or other infections. Thoroughly rinse toothbrushes with a strong stream of tap water after brushing to remove any remaining toothpaste and debris. Store the brush in an upright position and allow the toothbrush to air-dry until used again. Do not cover toothbrushes or store them in closed containers. A moist environment such as a closed container is more likely to lead to growth of microorganisms than the open air. Replace toothbrushes every three to four months. Some of the softer toothbrushes need to be replaced more frequently, especially if a child chews on the bristles during the first few weeks of learning to brush.

Patience, patience, patience!!!

---

Falling and Remaining Asleep

### **Falling Asleep & Remaining Asleep**

Parent reports and clinical studies indicate individuals with ASDs very often have sleep problems. In one study parents reported 64% had sleeping problems, and in another clinical study 80- 85% of children and youth with ASDs had trouble falling asleep or remaining asleep. Not surprisingly, children with ASDs who sleep poorly also have daytime behavior problems.

**SLEEP STAGES**: When your child curls up under his or her favorite blanket with their head on their pillow, falling asleep is a gradual process divided into two phases. The first phase is called Non-REM (rapid eye movement) sleep lasting about 80 minutes, and the second is REM sleep, lasting about 10 minutes. When a child first closes their eyes they are drowsy and start dozing off, but are easily aroused if their name is called quietly or they hear a sound outside their room. During the next stage, they breathe regularly, make few movements and are more difficult to arouse. The next two stages involve the deepest sleep. A loud sound may

## FAQs

be required to awaken them, and some children even need to be physically shaken to awaken during Stage 4 sleep. During the 10 minutes of Rapid Eye Movement Sleep (REM) sleep, eye muscles are moving rapidly and the child is often dreaming. REM and Non-Rapid Eye Movement Sleep (Non-REM) alternate in roughly 90 minute cycles throughout the night.

Parents report most children with ASDs either have difficulty falling asleep (Non-REM Sleep) or wake up during the night and can't fall asleep again. Problems with initially falling asleep can be due to medications being taken during the day, or foods or beverages consumed, usually from around dinner to bedtime. Coke, Mountain Dew, and Sunkist Orange Drink all contain caffeine and should be avoided beginning mid-afternoon.

Over the counter medicines can cause difficulty falling asleep, such as Anacin and Excedrin that contain caffeine, and nasal spray decongestants and should be avoided. Prescription medications such as Ritalin or Adderall and other stimulants, Prozac and related SSRIs, Beta blockers (e.g. Tenormin, Inderal) and some steroids can prevent children from falling asleep. Talk to your child's doctor about changing the time these medications are taken.

**NAPS:** Difficulty falling asleep can also be due to the child's daily schedule or behavioral factors. An average 2 year old naps about 90 minutes during the day. A child who is 4-5 years old or older usually doesn't require a nap. Allowing an older child to regularly nap during the day will decrease their ability to fall asleep and remain asleep at night.

**DAILY ROUTINES:** Children with ASDs respond favorably to regular routines and have difficulty when daily routines are unpredictable. All children need regular, specific bedtimes, but children with ASD even more so. About one hour before bedtime the child should be bathed and gotten ready to begin settling for sleep. Large snacks should be avoided within 1-2 hrs of bedtime, and those that are permitted should not include high fat or spicy ingredients (e.g. such as pizza) which causes night time indigestion. After the child's bath and their pajamas are on they can be given a light snack consisting of a small non-caffinated beverage (4 oz) or food that is high in tryptophan content, such as cottage cheese, cheese, soy milk (e.g. Silk), tofu, chicken breast, oatmeal cookie with milk, half slice of whole wheat bread with peanut butter and a 4 ounce glass of passion fruit juice. These foods will not cause the child to fall asleep, but they will prepare them for falling asleep by making them relaxed and slightly sleepy.

**BEHAVIORAL FACTORS:** During the last 20 minutes or so before putting the child down for the night, read her/him an age appropriate book or picture book, but nothing too exciting or scary, and if they enjoy music, put on a CD with calming instrumental music (avoid prominent rhythms or loud music with lyrics). Encourage the child to sit quietly and look at the pictures in the book and relax. It's a great time

for expressing warmth and affection. Once its time for bed, turn down the volume on the TV in the family room, avoid loud conversations anywhere near the child's room, and turn off the Heavy Metal music coming from his older brother's bedroom. In other words, keep things quiet for the first half hour or so the child has been put down for the night. When the child is placed in their bed, make certain they have their favorite blanket and stuffed animal, turn on a CD of quiet, calming music for no more than 15 minutes that shuts itself off automatically (see Sleep Problems: Remaining Asleep for suggestions). This can be accomplished by plugging the CD power cord into an inexpensive timer purchased in an electronics or home supply store that automatically shuts off a power source after a specified time. Turn on their night-light, cover them with their blanket, kiss them good night, turn out the room light and leave the room. The music will provide a transition cue beginning a minute or two before the bedroom light is turned off until 10-12 minutes after the light has been extinguished.

**ARE THEY AFRAID?** Many parents are convinced the reason their child is crying at bedtime is because they are terrified of being alone in the darkened bedroom, so they coax and cajole them and sit alongside their bed talking with them, attempting to reassure them. In most instances the child isn't afraid, they prefer to stay up rather than go to bed. They do whatever has been effective for them in past, from melt downs, screaming and threats of self-injury (e.g. they may slap their face or bump their head against the headboard) to convince their parents to allow them to stay up rather than going to bed. Parental coaxing and cajoling will nearly always make matters worse. If the child fusses, cries, calls for Mommy, it is best to ignore them.

Children with ASDs who have a history of resisting bedtime often cry and fuss for 30-45 minutes the first night. It is important that parents agree BEFORE beginning this procedure that they will not allow their child to get up no matter how much they carry on. If one parent begins to feel they have to "give in" to their child, they should go for a walk or take the car out for a drive and allow the other parent to handle the situation. Parents need to support one another through this difficult and trying experience, and taking turns sitting through the child's crying is a good way to do that. In most instances, by the second night the child's crying is about half to two-thirds the duration of the first night. By the fourth or fifth night most children fuss a little and then fall asleep. Within a week to 10 days most children fall asleep within a few minutes of turning off the light in their room. If parents go into the child's room "to make certain the child is really all right" in the midst of a crying outburst, even once, the whole cycle will resume and then the procedure will have to start over again, beginning with 45 minutes of crying or possibly longer.

Suppose you just can't stand the feeling your child is really afraid and you need to do something to reassure her/him. The best alternative option is as follows. Once the child is in bed with the light out, sit in a chair in the child's room half way between the child's bed and the doorway and listen to music on your iPhone. Do

## FAQs

not sit directly by the bed. Try to avoid looking at the child. Alternatively, if you have an e-book reader, read a book while the child is falling asleep. If the child comes over to you and seeks your attention, point to the bed and say, "Time for bed," and resume listening or reading. Often this will also require 30-45 minutes and multiple "It's time for bed," prompts, but usually with less crying. Once the child is falling to sleep in less time, move the chair closer to the door a foot or two each night until you are in the hallway so your child can see you through a crack in the door. The next step is to disappear altogether. Tedious? Yes, but better than feeling guilty about your child's being terrified.

**MEDICATIONS:** Some children continue to have intermittent problems falling asleep even after parents have regularized their schedules and established a sound nighttime sleep routine. Parents should consult their child's pediatrician about sleep medication options. A recent study by Dr. Gianatti and colleagues in Rome examined effectiveness of controlled-release melatonin for autistic children with chronic sleep disorders and found it effective with minimum side effects. Atarax (hydroxyzine) an antihistamine, is often prescribed to promote sleep (0.5-2mg) for children with ASD though it is not specifically recommended by the FDA for this purpose. Finally, Catapres (clonidine), a blood pressure medicine has mild sedation as a side effect and is also used to assist with sleep. Occasionally children may have other emotional or health problem that interfere with sleep, and an overall sleep hygiene strategy may require targeted treatments for those conditions as well. Talk with your child's pediatrician before beginning an over the counter medication.

## REFERENCES

Couturier, JL et. al. (2005) Parental perception of sleep problems in children of normal intelligence with pervasive developmental disorders: Prevalence, severity and pattern J. Am Acad Child Adolesc Psychiatry 44: 815-22

Gianotti, F. et. al. (2006) An open-label study of controlled-release melatonin in treatment of sleep disorders in children with autism. J. Autism Dev Disord 36: 741-52

Polimeni, MA et. al. (2005) A survey of sleep problems in autism, Asperger's disorder and typically developing children. J Intellect Disabil Res 49: 260-8

Schreck KA and Mulick JA (2000) Parental report of sleep problems in children with autism: J Autism Deve Disord 30: 127-135

Zhdanova IV, et al. (1995) Sleep-inducing effects of low doses of melatonin ingested in the evening. Clin Pharm Ther. 57:552-558.

See: Sleep Problems: Remaining Asleep

## REMAINING ASLEEP AND FALLING ASLEEP AGAIN

Many children with ASDs not only have problems falling asleep, but they often awaken during the night and have difficulty falling asleep again. Sometimes they play quietly in their bed until they become drowsy and fall asleep. One mother reported peeking in her son's bedroom late at night, and seeing him rocking with his eyes closed for nearly 10 minutes, then slumping to one side and resuming sleep. At other times children begin crying and screaming in the middle of the night until a parent comes to their room to see what is wrong, and they usually promptly stop crying. The problem from the child's vantage point is that they don't understand how long it will be until morning and they dislike being alone in their room. Children with ASDs have little sense of time. They have no idea how long it will be until the next event happens, such as when her mother is going to come into her room and get her up for breakfast. Let's explore the options.

*LIGHT SLEEP PERIODS:* In "Sleep Problems: Falling Asleep", I noted that the typical 90 minute cycle of light and deep sleep that is followed by 10 minutes of REM sleep. During the first stage of each 90 minute cycle the child's sleep is light, and the slightest noise or discomfort is likely to awaken them. A dog barking next door, pain caused by sleeping in an awkward position, or indigestion may be sufficient to awaken them. If a child falls asleep at 9pm, the next sleep cycle is likely to begin around 10:30pm, when they are especially likely to awaken. This happens again around midnight, at 1:30am, 3:00am, 4:30am and 6am. So a typical child will have 5 or 6 light sleep periods per night when they are particularly likely to awaken. There is nothing unusual about having light sleep episodes.

*MUSIC TRANSITION CUE TO SLEEP:* The main problem is not so much whether a child arouses briefly, but how to help them to fall asleep again. Most typical children are able to fall asleep again on their own. In "Sleep Problems: Falling Asleep" we suggested using a CD that plays relaxing bedtime music to the child as a sleep cue. Older children who have problems awakening can be taught to turn on the CD player again, that will provide the falling asleep cue, that facilitates resuming sleep. Another aid is a Progression Wake Up Clock sold by Hammacher and Schlemmer, which can also be set to operate in reverse, gradually diminishing light, producing a distinctive scent, and sound to transition the child into a relaxed slumber. Several nature sounds can be selected that become softer and turn off after 15 minutes. Either of these approaches will work, but the child needs to be taught how to turn the music or the clock on so the sequence begins. Most 4-6 year old children can learn to do this with several repetitions.

*BEHAVIORAL APPROACHES:* Some therapists conduct falling asleep exercises with 3-6 year olds to teach self-quieting. It is often difficult for children with ASD to engage in pretend play, but some children enjoy playing with dolls or action figures that can be a vehicle for "putting the baby to bed" exercises. Sleep preparation may be more effective if used in conjunction with one of the commercially available heart beat musical CDs, such as that available from BabyGotoSleep.Com which superimposes calming children's songs on top of the rhythm of the human heartbeat. Controlled studies have demonstrated the heart beat-music combination can effectively calm some infants and promotes restful sleep.

## FAQs

By practicing "putting the baby to bed" and then asking the child to lie down as well and listen to the CD, the music becomes a cue associated with falling asleep. Once the child has had 3-4 practice sessions preparing for nap time using the putting the baby to bed routine while listening to the CD, they can be asked to push the ON button on the CD player when they go to bed at night. After several repetitions demonstrating that they can turn on the CD player, they can then be encouraged to push the button if they wake up during the night.

Though the music is very quiet, if parents are concerned about awakening a sibling who shares the same bedroom, under the pillow speakers are available so only the child with ASD hears the music and heart beat. Older high functioning children can take advantage of relaxation therapy exercises similar to those used with typical children. Books and CDs are available from commercial distributors such as Barnes and Noble or Amazon. A child who successfully sleeps through the night or awakens but does not cry or scream should be rewarded in the morning with a favorite treat for breakfast.

*MEDICATIONS:* Most sleep medications are designed to encourage falling asleep but are not intended to maintain sleep throughout the night. Long acting melatonin appears to produce longer lasting sleep, but there have been insufficient studies to clearly demonstrate that. Atarax is an antihistamine with sedative properties with effects that typically last 4-6 hours, which may make it better choice for a child who awakens during the night, though no controlled studies are available. After several months, many pediatricians taper or discontinue sleep medications for young children assuming they have established more regular sleep patterns.

## References

Gerkenmeyer J. & Keck J. F., (1999) Evaluations for Neonatal Procedural Pain. American Pain Society, 18th Annual Meeting Abstract: 157).

Weiskop, S. et. al. (2001) Treatment of sleep problems in a 5-year old boy with autism using behavioural principles Autism 5: 209-21

Weiskop, S, et.al. (2005) Behavioural treatment to reduce sleep problems in children with autism and fragile X syndrome. Dev Med

---

## SPECIAL CHALLENGES

### **Behavioral Challenges in Autism: Prevention and Management**

The single most common cause parents, practitioners and school personnel seek assistance with youngsters with autism is because of various behavioral challenges: aggression, meltdowns, hyperactivity and attention problems as well as other more severe difficulties, such as self-injury, which will be discussed later. The articles in this section address some of the most common problems encountered focusing on ways of preventing them, but if that isn't always possible, strategies for managing difficult situations.

## **Aggression, Prevention & Management**

### **How to prevent & Manage Aggression**

A common complaint of teachers and parents regarding children with autism spectrum disorders is that his aggression came out of nowhere, unexpectedly like a storm, and

for no apparent reason. Aggression is more common among boys than girls, but can happen with both. It occurs more commonly among people with limited cognitive ability and who lack spoken language. Most of the time children and youth with an ASD are aggressive there is a pattern, but it may be difficult to discover. Effective behavior management strategies require understanding health conditions contributing to outburst, situations that trigger aggression and the functions aggression serves ,i.e. the consequences.

#### *HEALTH SETTING EVENTS*

A setting event is something that happens earlier in the day or even the night before, that makes a behavioral outburst more likely. After a night of little sleep, the slightest request or demand by a parent or teacher may trigger aggression. For other children, a flare up of gastroesophageal reflux may set the stage for aggression. Other problems, like an earache, toothache, a bad cold, or constipation are setting events that make aggression likely. As with other children, youngsters with autism can have food allergies. The most common childhood food allergens are eggs, milk, and peanuts. Other less common food allergies include wheat, soy, and tree nuts. Children with food allergies usually experience intestinal cramps, gas and diarrhea. Though many parents believe their children with ASDs have gastrointestinal problems, a study conducted in England evaluated indications of chronic inflammation of the gastrointestinal tract, coeliac disease, food intolerance, and recurrent gastrointestinal symptoms recorded by doctors treating children under the National Health Service. Nine percent of children with a diagnosis of autism and 9% of children without autism had a history of gastrointestinal disorders, suggesting GI problems are roughly equally common. Most of health problems children with ASDs experience are “invisible” and parents often don’t think of them as events that lay the foundation for seemingly “random” aggression, which isn’t really random. Often treating the underlying health condition will reduce aggression.

#### *TRIGGERS*

Things that happen immediately prior to an aggressive outburst, like a parental request to “Put on your shoes”, may be followed by aggression. They are called Triggers. Half to two-thirds of aggressive outbursts are a way of avoiding an activity or situation that is too difficult or unpleasant to the child. To identify triggers, one must keep track of what happened immediately prior to aggressive outbursts, usually for at least a week. At first it may appear there is no pattern. On one occasion the child was eating his breakfast and had an outburst. On another he was watching TV and hit his brother. On another he bit another child in the classroom while playing on a swing. But if we look more closely we discover in each case someone told him to stop what he was doing, and to do something different (e.g. stop eating breakfast and get ready for school, stop watching a preferred TV program, stop swinging so the other child could swing).

Sometimes adult requests may seem too difficult for the child. He may lack the skills to do a task, such as “put on your shoes”, and aggression is a way of avoiding the task. Teaching

## FAQs

prerequisite skills or making the task easier (e.g. by using shoes with Velcro strips) may eliminate the problem. Teaching the child to request "help" verbally or with a picture icon can avert many outbursts. Another alternative involves teaching the child to request to do a task later, using either a verbal or icon card to request a delay. That gives the child the feeling they have some control in a situation that they otherwise find impossible.

Sometimes aggression is triggered by requests to enter a place that is frightening to the child, like a crowded shopping mall, a room full of strangers or a doctor's office. An outburst may occur well before the actual event if the child anticipates it is going to happen, which makes it difficult to connect the outburst with what she or he fears. Alerting the child to the forthcoming activity 3-5 minutes prior to the actual event, combined with explaining s/he will receive a treat as soon as they enter the mall, or leave the doctor's office may help. Some parents who identify specific situations that cause problems go on practice runs to those locations when there are few other people present (e.g. Tuesday morning at 10am to the shopping mall) to desensitize the child so they will be less fearful. ,

Aggressive outbursts may be triggered by a change in routine that may seem inconsequential to adults but represents an intolerable change to the child. If a child's usual teacher is out due to illness and a substitute teacher appears, or speech therapy is after lunch rather than before lunch as usual, or if where the child sits at the table during mealtime is changed, that can trigger an outburst. A child with an ASD should always be alerted to any forthcoming change, such as "Miss Jones is going to work with you after lunch today instead of before lunch", pointing to a picture on the child's Visual Schedule. Saying, "Miss Jones will have a treat for you when you finish your lesson", often helps.

## CONSEQUENCES

Many teachers and parents think that if they explain to a child who has just had an aggressive outburst why they must do a non-preferred task even if they don't want to do it, that it will somehow help. It almost never helps and usually makes matters worse, because while the adult is "explaining", the child is receiving undivided attention, which reinforces the behavioral outburst. Other adults believe scolding will help. It rarely helps and for the same reasons may make things worse. For younger children who have engaged in physical aggression, requiring the child sit in a specific chair in the corner of the room facing away from others (a form of time out) for 3 minutes can help. But it will only help if the situation from which they have been removed have lots of opportunities for rewarding activities. It gives the child time to calm down, and secondly, it assures no positive consequence occurs as a result of aggression. After the child has been quiet for 3 minutes, they should be returned to the same activity, but it should be made much easier so they almost immediately succeed.

Depending on cognitive level, it may be useful to contract with the child so they have an incentive not to have aggressive outbursts. For example, if the child successfully makes it through the morning at school without an outburst, they might be given 10 minutes to engage in a highly preferred activity before lunch.

Physical punishment methods, such as Positive Practice, Over Correction or other punitive methods usually backfire. In addition to providing the child with attention while being carried out, they create a coercive relationship between the adult(s) and youth. With older children and youth, ferreting out the Setting Events and Triggers is usually necessary to solve the problem.

## SEIZURES

Some types of seizures can involve physical assault. They are difficult to detect because the person may appear conscious, they may engage in what appear to be purposeful movements, but are actually not conscious and not aware of what they are doing. Temporal Lobe Epilepsy is fairly common among individuals with autism. It can only be diagnosed through using an Electroencephalogram conducted by a neurologist. Some doctors prefer to conduct the EEG after the child has been deprived of sleep, which makes it EEG abnormalities more obvious. Other doctors have the child wear a recording device connected to electrodes that track EEG abnormalities as they go about their daily routines. This is called an Ambulatory EEG. Whichever approach is used, if the young person with ASD has Temporal Lobe Epilepsy, there are several anti-epileptic medicines that often control the brain seizure activity as well as behavioral outbursts. While epilepsy is common in autism, it is seldom that behavior outbursts, such as aggression, is caused by undetected epilepsy.

### *COMPULSIVE DISORDER*

There is evidence some individuals with ASDs have differences in the same brain structures as psychiatric patients with Obsessive Compulsive Disorder (OCD). People with autism often respond favorably to the same medications as those used to treat psychiatric patients with OCD. Children or adolescents who have numerous fixed routines, are highly intolerant of changes in routines, and who engage in repetitive, anxious speech (e.g. asking the same question repeatedly, or reciting television ads verbatim, over and over), may be candidates for treatment with Selective Serotonin Reuptake Inhibitor medications, such as Prozac, Luvox, Paxil, Celexa or similar medicines. There is evidence higher functioning individuals may be especially responsive to these medicines.

### *ATYPICAL ANTIPSYCHOTIC DRUGS & AGGRESSION*

Older aggressive children and adolescents who are lower functioning cognitively, with little or no language, and who have not been responsive to a functional assessment based behavioral intervention strategy are often treated with atypical antipsychotic medications, such as Risperdal or Zyprexa. These medications have broad effects on brain chemical systems, and have been shown to reduce aggression, self injury and irritability (esp. Risperdal). This class of drugs often cause sedation, and very occasionally cause a movement disorder (dyskinesia). With the exception of Abilify, nearly all atypical antipsychotic drugs cause weight gain and pose a risk for developing Type II Diabetes. Atypical antipsychotics may be an important form of treatment in order to gain control over serious aggression, but because of the weight gain side effect, are often only used for 3-6 months.

---

### **Metdowns: Preventing & Managing**

Most of the time children with ASDs have melt downs it is in response to an unexpected change in routine or interrupting a highly preferred activity. If you have ever watched the behavior of the television inspector Adrian Monk, you will understand more about why your child does what s/he does. There is no single remedy for tantrums, aggression or self-injury in ASD. One needs to determine what is leading the child to behave the way they do in order to reduce these problems. Behavior management approaches depends on reaching an understanding of the reasons the child his having repeated meltdowns.

Most "melt downs", aggression and self-injury by a child with ASD causes adults to stop making demands or requests. In other words its away of escaping or avoiding a situation

## FAQs

they don't like or don't understand, or for which they have no other coping mechanism. The solution depends on the reason.

1. The child doesn't really understand what you are saying to them.

- a. Teach more adequate receptive communication
- b. Teach them a way of asking for help
- c. Use visual rather than verbal requests, such as pointing to a visual schedule

2. The child lacks the skill to do what you're asking them to do, or it is very difficult for them to do it (e.g. put on your shoes)

- a. Teach them to ask for help
- b. Teach them how to improve their skill in doing what you are asking them to do in a series of small steps; use lots of reinforcers for small gains.
- c. Don't ask them to do it in the first place. Maybe it's not important, at least not right now,

3. The adult request comes at a time the child is occupied with a preferred routine (e.g. playing a video game, spinning objects, other repetitive routine)

- a. Wait until they stop the routine before asking them
- b. Give them a warning 10 seconds before you are going to make a request. Count to five holding up your fingers one at a time, 2 seconds for each finger. When the last finger is up, say "Now we're going to..." Some people use a visual count down clock the same way that turns a different color when it's time to stop one activity and start another.
- c. Negotiate
  - C1. Offer to collaborate i.e. I'll do one then you do one
  - C2. We'll do it this way this time, and your way next time
  - C3. Tell the child they can return to their preferred activity as soon as X is done.
- d. Try to make requests only before a highly preferred activity, such as meal-time, watching a preferred video, etc. or another activity which is part of your normal daily routine.

4. The child lacks the ability to request that they be allowed to do it later.

- a. Teach them to make a "Later" request, either verbally, gesturally or with a picture icon (e.g. a clock icon)
- b. Always follow through by providing a delay, and then gently returning to the requested activity
- c. Lavishly praise and reward the child for starting the activity you have requested them to do after the delay, "Great job, you're a good helper!"

Some "melt downs" are maintained by parental attention. *Remember, scolding or negative attention is still attention.*

## **MEDICATIONS for MELTDOWNS**

## FAQs

Some doctors prescribe medications that have been helpful in adolescents and adults with ASDs for reducing emotional outbursts younger children (off label) in response to changes in expected routines, or task demands that exceed their tolerance. For some children, the intensity and duration of outbursts can be reduced by treating them with Beta Blockers (e.g. Atenolol) or Catapres (clonidine). Younger children and school age youngsters often respond favorably to SSRI antidepressant medications (e.g. Luvox or Zolft). and older youth are occasionally given tricyclic antidepressants (e.g. Tofranil) or atypical antipsychotic medications (e.g. Risperdal). There have been no well controlled studies with younger children with ASDs with these medications however, and they have considerable side effects. Medications are seldom sufficient alone.

### *NO SINGLE SOLUTION*

Parents and teachers often ask what is the best medication or behavioral treatment for meltdowns. In our experience there isn't any single best treatment. Solving the problem requires understanding the reasons for the emotional outburst, and methodically teaching the missing skill or changing the conditions giving rise to it. Some medications can help but they rarely solve the problem alone.

### **FREQUENT ISSUES PUBLIC MELTDOWNS**

A mother of a child with autism reported “dying a thousand deaths” as people around her in the large discount store stared disapprovingly at her daughter on the floor screaming, kicking and carrying on as though the world was about to come to an end. The meltdown seemed to come out of the blue. Mom said the screaming began as they passed from the Dora The Explorer display and entered the kitchen implements section. She said they had been shopping for about an hour when her daughter descended into a “tizzy.”

Public meltdowns are especially difficult for several reasons. The most obvious is that your child's screaming and flailing draws unwelcome attention to you and your child. Second, you think you should be able to make her or him stop their outburst, but you can't. Third, you suspect that maybe you did something wrong that led to the outburst. Finally, you are aware that people around you think you are a lousy parent because you are “coddling” your child instead of putting your foot down. Little do they know! *[Image courtesy of eHow.com]*

#### *Rules of Thumb About Outings*

- Don't take your child out during naptime
- Don't stay out too long at a stretch. Usually an hour is plenty.
- As you are about to leave home on your way to the first store say, “No crying today. If you don't cry, you can have an X when we leave the store (e.g. Cub, Kroger, Target or Walmart).” X should be a

## FAQs

favorite beverage or edible.

- If your child reads, make a list of places you are going to visit on your outing in order. If not, prepare a visual schedule by downloading images from the internet and inserting them in plastic sleeves in visual schedule board.

Keep the pictures because you'll need them later on another outing.

- As you are about to complete shopping in one store and are move on to the next, ask your child what is next on the schedule. The idea is to keep the child engaged and creating a feeling of having some control over decision-making.

- When shopping in supermarket or discount store, plan your route through the store in advance, with transit through toy or candy departments last, immediately before checkout. If there are any other high risk sections, avoid them altogether or enter them last before leaving the store.

- Plan frequent breaks for snacks or running around in a mall play center or area.

- Give your child choices from time to time during breaks, such as having some pieces of fresh fruit or an Orange Julius.

### *What Do I Do if She Has a Meltdown Anyway?*

Push your cart to the Support Services Desk and tell the clerk you have to leave the store for a few minutes and will return to check out shortly. You may need to show the clerk a driver's license or other ID. Leave the shopping cart with the clerk, and then, pick up your child (who will likely be yelling and screaming) and carry him or her out to the car. Put the child in the back seat and buckle them in their car seat. Get in the car on the driver's seat side, pick up a newspaper and proceed to read the newspaper while saying absolutely nothing to the child. It will be tempting to threaten or cajole. Don't do it! Don't promise the child a treat if s/he stops crying. That is a big mistake. When s/he stops their tantrum, tell her/him you are going to return to the store and get your groceries and then both of you are going to go home. No treats today.

Most of the time, no more than 2-3 such "car time outs" are necessary to put a stop to occasional meltdowns you are unable to prevent.

By the way, the child described above probably thought she was going to be able to play with a Dora the Explorer doll, and when Mom passed on by without offering that opportunity, that set off her emotional outburst. It would help if the child were told in advance that she is NOT going to be given a Dora doll, but she will receive a Dora sticker if she doesn't cry. She was also probably tired from staying out too long.

### ADHD In Autism

Attention difficulties are an inherent aspect of autism spectrum disorders. According to DSM-IV TR criteria, Attention Deficit Hyperactivity Disorder (ADHD) is not supposed to be diagnosed separately among individuals with Autism Spectrum Disorders. However, a recent study concluded "ADHD symptoms are pervasive in clinically referred children and adolescents with ASD" (Lee and Ousley, 2006). Holtmann et. al. (2007) examined co-morbid measures of psychopathology among 182 subjects diagnosed as having PDD, who were divided into high and lower attention problem groups using

the median of the Child Behavior Checklist (CBCL). The PDD subjects with more severe attention symptoms exhibited more general psychopathology than those in the PDD subgroup having fewer attention problems. In addition, the PDD-hyperactive subgroup exhibited more impairments on the social interaction scale of the ADI-R as well as more internalizing and externalizing problems.

As a practical matter, not all youngsters with ASDs present the true profile of ADHD, either Inattentive or Hyperactive Type, but some clearly do. There is some evidence that medication treatments that are effective for treating ADHD symptoms among children who do not have ASDs, can also be effective for some youngsters with ASDs who meet ADHD diagnostic criteria. But the question is, "How good is the evidence that ADHD medications are effective in autism, and what are their side effect profiles?"

In routine clinical practice, three groups of ADHD drugs are used in treating children with ASDs who also present with ADHD symptoms: (1) Antihypertensives, such as atenolol or clonidine (2) Stimulants, such as methylphenidate or amphetamines, or (3) Atomoxetine, a norepinephrine reuptake inhibitor originally developed as an antidepressant. Though these medications are widely used, there have been very few controlled clinical studies of their effectiveness and safety in this population. Summarized below are studies of the effects of these medications between 1992 and the present in children with ASDs and ADHD symptoms.

CLONIDINE (Catapres®) is a commonly prescribed medication for symptoms of hyperactivity and inattentiveness of children with ASDs. It is an alpha adrenergic agonist that was originally approved for treating hypertension, which has mild calming effects as well as producing some sedation. Frankenhauser et. al. (1992) evaluated effectiveness of a clonidine transdermal skin patch using a double-blind, placebo-crossover design in nine children and adults with ASDs (aged 5 to 33 years). Subjects received either clonidine (approximately 0.005 mg/kg/day) or placebo by a weekly transdermal patch. Each trial lasted 4 weeks with a 2-week washout period between treatment phases. During clonidine treatment improvements were observed in social relationship to people, affectual responses, and sensory responses of the Ritvo-Freeman Real Life Rating Scale. A patient global rating scale showed clonidine treatment resulted in significant improvement in comparison with placebo. Adverse effects included sedation and fatigue during the first 2 weeks of clonidine treatment. Jaselskis et. al. (1992) tested oral clonidine on 8 male children (8.1 +/- 2.8 years) with autistic disorder, diagnosed by DSM-III-R criteria, using a placebo-controlled, double-blind crossover design. Subjects were included in the study if they had inattention, impulsivity, and hyperactivity that was

## FAQs

excessive for their developmental level. Teacher ratings on the Aberrant Behavior Checklist (irritability, stereotypy, hyperactivity, and inappropriate speech) were lower during clonidine treatment than during placebo. Comprehensive Teacher's Rating Scale ratings on hyperactivity were not significantly improved during the study, except for oppositional behavior. Parent Conners Abbreviated Parent-Teacher Questionnaire ratings significantly improved during clonidine treatment. Clonidine led to increased ratings of the side effects of drowsiness and decreased activity. Clinician ratings of videotaped sessions were not significantly different between clonidine and placebo. The researchers concluded clonidine was modestly effective in the short-term treatment of irritability and hyperactivity in some children with autistic disorder.

METHYLPHENIDATE (Ritalin®) is the most widely used drug to treat ADHD symptoms in non-autistic children. Quintana et. al. (1995) examined effects of placebo and 10 mg or 20 mg twice daily of MPH on 10 children ages 7-11, with a DSM-III-R diagnosis of autistic disorder using a double-blind crossover study using. Subjects showed modest but statistically significant improvement on MPH over placebo. No significant side effects including occurred on either dose. Handen et.al. (2000) tested effects of MPH (0.3 and 0.6 mg/kg) on thirteen children (ages 5.6 to 11.2 years) with autism and symptoms of attention-deficit hyperactivity disorder (ADHD) in a double-blind, placebo-controlled crossover study. Eight (of 13) subjects decreased their Conners Hyperactivity Index by at least 50%. Ratings of stereotypy and inappropriate speech also decreased. However, no changes were found on the Child Autism Rating Scale. Social withdrawal and irritability, especially at the 0.6 mg/kg dose were observed in some children. Di Martino et. al. (2004) used a two phase protocol to examine effects of methylphenidate in children with ASD and ADHD symptoms. Participants included 13 subjects (mean age of 7.9 years) with PDD and moderate to severe hyperactivity/ impulsivity. One hour after a single oral MPH dose (0.4 mg/kg), 5 (of 13) subjects exhibited increased hyperactivity, stereotypes, dysphoria, or motor tics and were rated as minimally or much worse on the CGI Global Improvement Scale. They received no further treatment with MPH. Four of the remaining 8 subjects were rated as improved, and four as unchanged; they proceeded to a 12-week open trial of MPH. Two (of the remaining 8) children remained unchanged: they discontinued treatment after 1 week. Measures of hyperactivity and impulsivity improved significantly, while autism core symptom measures were unaffected. No significant adverse effects were observed in any of the 8 subjects. Santosh et. al. (2006) administered methylphenidate (Ritalin) to 226 children with ASD and attention deficit hyperactivity disorder (ADHD), and children with ADHD without ASD. They found statistically significant improvements in 'hyperactivity', 'impulsivity', 'inattention', 'oppositonality', 'aggression' and 'intermittent explosive rage' in both groups. Neither tics nor repetitive behavior worsened in either group. Children in the 'ADHD-only' experienced significant 'nausea', 'giddiness', 'headaches' and 'sleep difficulties', while sleep difficulties were the only side effect in children in the ASD with ADHD group.

ATOMOXETINE (Strattera®) is another widely prescribed drug for treating ADHD symptoms in non-autistic children. Posey et.a. (2006) examined effects of atomoxetine (1.2 mg/day) on 16 children and adolescents (mean age 7.7, range 6-14 years) with autistic disorder (n = 7), Asperger's disorder (n = 7), or PDD not otherwise specified (n = 2). Twelve (of 16) participants were rated as "much" or "very much improved" on the Clinical Global Impressions-Improvement scale on ADHD symptoms. Improvements of

## FAQs

lesser magnitude were seen in irritability, social withdrawal, stereotypy, and repetitive speech. Atomoxetine was well tolerated with the exception of 2 participants (13 %) who stopped medication due to irritability. Weight decreased by an average of 0.8 kg during the 8-week trial. Arnold et. al. (2006) evaluated effects of atomoxetine on children ages 5 to 15 with ASD and prominent ADHD symptoms. Children were randomly assigned ATX and placebo first, 6 weeks each, separated by 1-week washout, and then 6 weeks of the opposite treatment. 12 boys and 4 girls (7 with autistic disorder, 1 Asperger's, 8 pervasive developmental disorder not otherwise specified) completed at least 3 weeks of each condition (i.e. 3 of 6 weeks). On the primary outcome, the Hyperactivity subscale of the Aberrant Behavior Checklist, ATX was superior to placebo. It was also superior on nine DSM-IV ADHD hyperactive/impulsive symptoms, but did not produce significant improvements in nine inattentive symptoms. One youngster was re-hospitalized for recurrent violence on ATX. Adverse events were otherwise tolerable, with no tendency to stereotypy.

Summary: ADHD symptoms can co-exist with autism spectrum disorders, including a range of emotional and behavioral symptoms often associated with ADHD. Evidence for effectiveness of FDA approved medications for treating ADHD within ASD is limited. The best evidence is for methylphenidate, which appears to reduce ADHD symptoms (but not core autism symptoms) for some children. Methylphenidate appears to have side effects for some children and youth with ASDs, including increased irritability, social withdrawal and sleep problems. Benefits of atomoxetine and clonidine appear less clear and are limited. In a recent review, Hazell (2007) concluded atypical antipsychotics such as risperidone and quetiapine can be beneficial, however, most of the evidence is from uncontrolled studies or studies with inadequate standardized measures of ADHD symptoms. Moreover, atypical antipsychotics can have serious side effects, including inducing Type II diabetes, raising questions about their appropriateness for long term treatment of children.

## REFERENCES

- Arnold, L.E. et.al. (2006) Atomoxetine for hyperactivity in autism spectrum disorders: placebo-controlled crossover pilot trial. *Amer. Acad. Child. Adolesc. Psychiatry.* 45:1196-205.
- DiMartino, A. et. al. (2004) Methylphenidate for pervasive developmental disorders: safety and efficacy of acute single dose test and ongoing therapy: an open-pilot study. *J. Child Adolesc. Psychopharmacol.* 14:207-18.
- Frankhauser, M.P. et.al. (1992) A double-blind, placebo-controlled study of the efficacy of transdermal clonidine in autism. *53(3):77-82.*
- Handen, B.L. et. al. (2000) Efficacy of methylphenidate among children with autism and symptoms of attention-deficit hyperactivity disorder. *J. Aut. Develop. Disord.* 30: 245-55.
- Hazell, P. (2007) Drug therapy for attention-deficit/hyperactivity disorder-like symptoms in autistic disorder. *J. Paediatric Child Health* 43:19-24.
- Holtmann, M. et. al. (2007) Attention deficit hyperactivity disorder symptoms in pervasive developmental disorders: association with autistic behavior domains and coexisting psychopathology. *Psychopathol.* 40(3):172-7

## FAQs

Jaselskis, C.A. et. al. (1992) Clonidine treatment of hyperactive and impulsive children with autistic disorder. *J. Clinical Psychopharmacol.* 12:322-7.

Lee, D.O. and Ousley, O. (2006) Attention-deficit hyperactivity disorder symptoms in a clinic sample of children and adolescents with pervasive developmental disorders. 6:737-46.

Posey, D. J. et.al, (2006) Open-label atomoxetine for attention-deficit/ hyperactivity disorder symptoms associated with high-functioning pervasive developmental disorders. *J. Child Adolesc. Psychopharmacol.* 16(5):599-610.

Qunitana, H. et. al. (1995) Use of methylphenidate in the treatment of children with autistic disorder. *J. Aut. Develop. Disord.* 25:283-94.

---

### **Boredom in High Functioning ASD**

A parent may report their child with Asperger Disorder or High Functioning Autism is reading chapter books above grade level, and has a full scale IQ of 112. They think he seems bored in school, especially with listening to other children's reading or asking their questions, or providing answers to questions. He dislikes reading poems and keeping a journal. He also dislikes cursive writing. He dawdles and says he's bored. Mom wonders, "How can we get his teachers to challenge him with more interesting educational activities?"

I've heard this question dozens of times in slightly different versions for both boys and girls with high functioning autism spectrum disorder. This concern confuses school adjustment with academic achievement. School adjustment is the number one priority of children with autism, academic achievement will follow for bright students like this child. Whether children on the autism spectrum do more or less well in school generally depends on how well they can communicate with their peers and teachers and their social skills. For some, it also depends on any interfering compulsive routines or other behavior difficulties, like tantrums. To adjust well, a child also has to display some school readiness skills, like remaining in their seat and following directions.

School adjustment rarely depends on providing students on the autism spectrum with a more academically demanding curriculum. The child in the above example is probably "bored" because he doesn't enjoy socially interacting with his peers, especially listening to them talk. Poems are boring because they involve abstract ideas that he doesn't grasp. Keeping a journal involves writing down how he feels about things, which is difficult for most children on the autism spectrum, and it doesn't interest him. Many kids with ASDs have poor fine motor skills, which makes printing and writing difficult. He is not bored because his curriculum is too easy, it is actually too difficult for him in some specific respects and not interesting in others.

It is a good idea to determine a child's specific interests, such as science, math or computer activities, and provide the youngster with supplementary guided opportunities to explore more advanced material, but it is usually unwise to push them into curricular subject matter that is beyond their developmental level, such as interpreting motives of characters in stories before they are ready.

Some children with Asperger Disorder or High Functioning Autism are gifted and can transition to a high potential group or classroom as their communication and social skills improve. A minority of children with Asperger Disorder fall within the gifted range. We often recommend children with autism participate in Cub Scouts or Campfire Girls or other similar small group activities, such as science or computer clubs, especially if one of the target child's parents assist with activities. These small groups participate in loosely structured activities with predictable routines. Often friendships develop out of such participation, and social skills almost invariably improve.

---

#### FUTURE PLANNING

---

##### What Does the Future Hold in Autism?

Catherine the Great of Russia is claimed to have said, "A great wind is blowing, and that gives you either imagination or a headache" (As quoted in *Daughters of Eve* (1930) by Gamaliel Bradford, p. 192). That is the way I often feel about the future of autism research and practice. In the past we experienced more headaches than imagination, but increasingly our field is guided by remarkable empirical inspiration.

##### *Epigenetics: Activation and Inactivation of Genes*

An especially promising research area concerns factors that can turn genes on and off, called epigenetics, that means factor changing the way some genes work (Lederberg, 2001). Epigenetic factors can be biological or due to a child's experience.

Biological factors may turn genes on or off: It is possible, but unproven, that the developing brain tissue of some individuals may be susceptible to another biological stressor, such as an infection, hormonal condition, or exposure to a brain toxin (such PCBs or high levels of prenatal alcohol), which together may cause genetically susceptible children to develop autism. This is called the

“two hit” or “double hit” hypothesis of autism susceptibility (Gillberg and Coleman, 2000, page 253). It is unlikely all children are equally susceptible to the same injury. The future lies in identifying subtypes of autism with differential susceptibilities to various “second hits”. That is important for two reasons. It leads to a more refined search for causes of some types that may be different from others, and ultimately possibly preventing autism among some subtypes. It also opens the way for clinical and educational research on differential interventions for various autism subtypes.

Social Factors Turn Genes On or Off: Not all epigenetic factors are chemicals or biological factors, like hormones or infections. Some factors that can effect gene activity are the child’s experiences, as the Morrow et. al. (2008) study showed. Rutter and co-workers have found quasi-autistic patterns following severe early global privation among children reared in some orphanages (Rutter et. al. 1999; Rutter et.al 2001). This suggests some forms of social deprivation at vulnerable developmental periods may have lasting effects not previously recognized. This notion is similar to Paul Meehl’s theory of schizophrenia (Meehl, 1962) which hypothesized that only genetically susceptible people subjected to certain life stressors actually developed schizophrenia. Enhanced early intervention among siblings and other relative of children with autism, even before significant autism symptoms emerge, may make it possible to compensate for this social vulnerability, preventing autism in some children.

#### *Combining Medication and Early Behavioral Intervention:*

Another promising line of work combines medication to promote brain connectivity with intensive early intervention, possibly as early as one year to 18 months of age. Dr. Diane Chugani and her colleagues at Wayne State University have conducted very promising work suggesting that treating children diagnosed with autism at two years of age with low doses of a medicine (buspirone) that normalizes serotonin in brain cells of children with autism, which would otherwise be deficient (Edwards, Chugani, Chugani, Chehab, Malian, and Aranda, 2006). Proper levels of serotonin are necessary for normal brain connectivity. In addition, she and her colleagues found improvements in autism symptoms of youngsters treated with burspirone. Dr. Chugani is currently combining intensive early behavioral intervention with medication to determine whether they produce a synergistic effect, possibly preventing emergence of autism in some susceptible children (Chugani, personal communication, 3-15-2010). Related work suggests it may be

## FAQs

possible to treat youngsters with Fragile X syndrome with a medication that corrects the balance of proteins that make components of brain synapses (Dolen, Carpenter, O'Carroll and Bear, 2010). About one quarter of children with Fragile X syndrome also have autism. Together with intensive early behavioral intervention, this may make it possible to reduce or eliminate many of the symptoms of autism among children with Fragile X and autism .

---

## MISCELLANEOUS

---