



Autism Support Systems

A Model for Autism Support Groups Within The Christian Community

This document addresses the primary needs of students with Autism Spectrum Disorders and their parents, and cites the most influential and prioritized group therapies, from a distinctly Christian perspective, in order to provide a model of Group Autism Support to be used in the Christian Community as an aid to families with an Autism Diagnosis.

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10/20/2008

What Is Autism?

The Basics

Autism is a developmental brain disorder that is mainly characterized by impaired or awkward social skills and repetitive behaviors, that can become restrictive. Generally, children with Autism will begin to show noticeable symptoms by age three. While Autism is just one diagnosis under the Autism Spectrum Disorders branch of Mental Disorders, there are many other diagnoses that manifest in essentially the same manner, ranging from mild to severe and each having its own specific set of challenges for both the child who is diagnosed, and the parents and family members who must learn to adapt to the diagnosis. Autism is commonly used as a blanket term to refer to the entire range of diagnoses. Research has shown Autism to have a strong genetic basis. Other theories as to the cause of Autism include everything from environmental toxins, such as pesticides and steroids, to vaccinations. Many of these hypotheses' causes are controversial in nature and lack solid scientific proof.

To illustrate the many diagnoses associated with Autism Spectrum Disorders, see the chart on page 3.

Autism has become very common and has increased exponentially since the 1980's. Though a large amount of this increase is due to better and more reliable diagnostic testing and a more in depth and accurate understanding of the brain's function in development, there is also significant research that shows an increase in the disorder itself. The cause of this increase is, so far, unknown. One in 150 children will be diagnosed with Autism, with a male to female ratio of 4:1.

Autism diagnosis can be a scary time, for both the student and the parents, but it is imperative that early diagnosis and intervention are sought out. It has been researched and proven that early intervention produces results, not only in the verbal, non verbal and cognitive skills of children with autism, but in social skills as well.

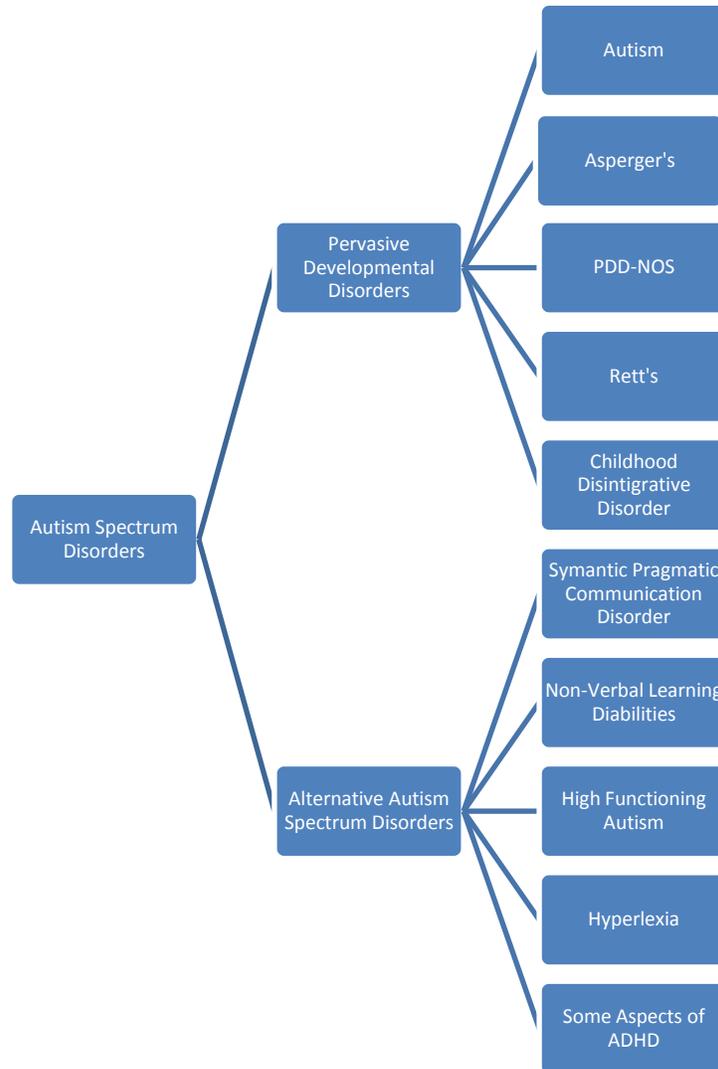


Figure 1. Hierarchy Chart representing range of Autism Spectrum Disorders

Symptoms of Autism

Symptoms of Autism

Social Interactions & Relationships	Verbal & Non-Verbal Communication	Limited Interests in Activities or Play
<ul style="list-style-type: none"> • Significant problems developing non-verbal communication skills: eye contact, body posture, facial expressions • Failure to establish friendships with peers • Lack of interest in sharing emotions, enjoyment, interests or achievements with others • Lack of empathy; a hard time seeing other's points of view. 	<ul style="list-style-type: none"> • Delay in or lack of verbal skills • Problems starting or maintaining conversations • Repetitive use of language, often repeat words or phrases they have previously heard (this is called echolalia) • Difficulty understanding sarcasm and figurative language; take language very literally. 	<ul style="list-style-type: none"> • Unusual focus on small details, often will focus on parts rather than the whole (an example would be a child playing with the wheel of a toy car, rather than the car itself). • Preoccupation and fascination with certain topics of interest • A need for routine and structure and an unwillingness/ inability to accept change. • Repetitive behaviors, such as rocking, hand flapping, etc..

Figure 2. Table representing the various symptoms of Autism.

Handling a Diagnosis – Creating the Perfect Model

Autism, generally speaking, manifests itself, at least initially, in a fairly generic manner. This means that professionals can normally perceive an Autism related disorder without much difficulty. However, just noticing it is not enough. In order for these children to receive the proper attention that they need to facilitate suitable cognitive and social functioning throughout their childhood and into their adult life, the child must receive an official diagnosis and be admitted into some kind of developmental and/or educational intervention plan. This often becomes a problem, because the thought of diagnosis seems like a death sentence to some parents, evoking an array of emotions that range from depression, to fear, to outright anger in the wake of confusion and anxiety. These emotions are all natural and appropriate, as an Autism diagnosis can be scary, confusing and is not something to be taken lightly, however, parents also need to realize that without this diagnosis, their child may develop severe learning and social disabilities in the future, leading ultimately to an inability to function independently, or even co-dependently in society.

Unfortunately, an Autism diagnosis does not always, and in fact, nearly never makes treatment and intervention neat and tidy. Though the initial symptoms are often obvious, there are many levels of functioning, ranging from extremely low to extremely high. There are also children that fall into the category of savantism, which means that, though the child is low functioning in many instances, they are nearly a genius in one particular topic, such as mathematics, or music. The disorder can manifest in a variety of different ways from one child to the next, making each individual case just as unique as a snowflake or a fingerprint.

So how then are therapists, teachers and professionals to create the perfect model of therapy and support? The truth is they can't. However, based on research and conclusions drawn from that research, and leaning on the Word of God for guidance, they can identify the most influential, imperative and useful techniques, obstacles, positions and solutions, and develop from there a constructive and valuable support system that will serve the community in their search for diagnostic assistance, emotional guidance and support, and spiritual enrichment.

Top Ten Issues that Children with Autism Face

Being Labeled "Autistic"

- Children with autism fear being labeled as Autistic, as though this is their only attribute; as if that is all they have to offer. This sets a very low expectation bar, and may give the child a "why bother trying" attitude. This kind of labeling by parents, peers or professionals creates an atmosphere of apathy in the child with autism. They want to be recognized as a child; a person, first and foremost.

Disordered Sensory Perceptions

- Children with autism do not experience senses (touch, taste, smell, etc...) the same way as those without autism. Often these senses are painful for them, in other words, they feel a sensory overload. Sometimes their environment seems hostile, and what may seem like erratic behavior to others may just be their way of defending themselves. Imagine being in the mall and having your hearing amplified to 12 times normal, or being in a restaurant where they are serving fish and having your sense of smell be 12 times stronger than normal; this is the everyday experience of a child with Autism.

Having others misunderstand their actions, or lack of action.

- Children with autism want their helpers to understand the difference between them not wanting to do something, and not being able to do something. Many children with autism seem as though they are not complying with instructions, or just being defiant when the reality is that they simply do not understand what you are trying to tell them to do. Children with Autism need direct instructions that include a sequence of events. Speaking directly to the child and explaining simply what you want them to do and what will come afterward will help them to understand what is expected of them, therefore they will be much more likely to comply with your request.

Concrete Thinking

- Children with Autism are concrete thinkers, that is, they take language very literally. They can not, or at least may have a lot of trouble, understanding figurative language, such as: sarcasm, puns, idioms, or metaphors. If you tell them something is "a piece of cake" they will not understand what you are talking about, they will be looking for dessert. Just tell them that it is easy.

Limited Vocabulary

- It is hard for a child with autism to tell you what they need or want, and it is even harder for them to tell you how they feel. Because their thinking is very concrete, they often lack the ability to express emotions through words because they cannot fully grasp their meaning. Often children with autism will express their needs through body language.
- On the other side of this problem is echolalia, or "script echoing". Often children with autism have great working memories, so great in fact that they can memorize "scripts" of speech from TV, books, radio, or others around them. It is not uncommon to hear children with autism (that have language capabilities) to rattle off entire conversations in a language that seems beyond their capabilities; that is because it is. They are actually using a coping mechanism to satisfy their vocal requirements. In other words, they are saying things that they may have heard used in a similar situation, have memorized and are now using to "get off the hook" even though they do not fully comprehend what they are saying.

Visually Oriented

- Because children with autism have such difficulty with language, they often need you to physically show them how to do something, and it is often better to show them multiple times. Try to use visual representations of expectations as often as possible, rather than simply telling them.

Focusing on Disability Rather Than Ability

- Children with Autism do not want you to focus all your attention on their disability. They do not want to feel as though they need to be fixed. No human can learn in an environment where they feel as though they are not good enough. Even constructive criticism, no matter how helpful, can create discouragement and complete avoidance of an activity, if they expect only criticism. Creating an environment of acceptance and support is imperative. Focus instead on what they do well. This is not to say you should avoid things that the child is not good at, nor does it mean you can never correct the child, it simply means that you should create an environment of support, not of criticism. If the child expects criticism, they will not be open to learning and will shut down.

Awkward Social Skills

- It may look as though a child with autism does not want to be bothered with other children, however, it's more likely that they simply do not know how. Sometimes the child with autism does not understand how even the simplest of social skills work. Help them by introducing them to others, teaching them how to interact or by encouraging other children to invite them to play.
- Children with Autism also do not understand facial expressions, body language or other's emotional or appropriate social cues. Often they will laugh at inappropriate times, but this is not because they are being ignorant or rude. If a classmate falls down, a child with autism may laugh, but it is not because they think it is funny, it is because they do not understand the appropriate response. Teach them to ask "Are you ok?" and lead them to make the connection that this is the proper social protocol for this type of situation.

Meltdowns

- As a culmination of the above issues faced by children with autism, a meltdown, "mental breakdown" or "temper tantrum" is a normal and unavoidable part of their life. Frustration is a normal part of everyone's life, however, the child with autism usually does not have the mental coping skills to control their frustrations. Parents, professionals and peers should observe and identify what triggers those meltdowns. It is important to remember that these meltdowns are more disturbing and upsetting for the child than they are for any outsider, as their senses are on overload, completely flooding their system with unwanted stimuli, often even making them ill. It is helpful to log times, places, and specific situations where these tantrums occur. This will make finding the triggers, or causes easier. Once you find the triggers, you can often prevent these meltdowns. Parents and others should remember that all behavior is a form of communication. Also, keep in mind that medical causes, such as food allergies, may also be a factor. Do not dismiss behavioral changes.

Expectational Love

- Often, due to frustration, parents and others will have thoughts like "if he would just do this...." or "Why can't she do this....". Children with autism need to know that they are loved unconditionally. They do not want to be constantly reminded that they are not living up to every expectation you have of them, nor do they want to question your concern for them. Parents need to remember that the autism is happening to the child; they did not choose it, and they need to support and love the child, no matter what.

Impatience

- Children with autism need parents and others in their support system who are patient above all else. They need you to see all that they have the potential to be and to be patient with their different abilities.

Top Ten Issues that Parents of Children with Autism Face

Shock

- No parent is prepared for their child to be diagnosed with autism. If they are, they are lying. Confusion runs rampant and often parents will ignore the diagnosis all together and hope it goes away, mostly because they simply do not know what to do with it.

Sadness and Grief

- Parents who have a child with autism tend to go through a period of grief and mourning, for the hopes, aspiration, expectations and dreams that they once held for their child. This is a normal reaction, but it can be extremely painful and prolonged. Often parents have trouble facing the fact that their child may not be capable of some of the dreams they held for him or her. Parents may feel as though they've lost the ability to have a "normal " child with a "normal " life. They often fear the unknown and the worst.

Anger

- Sometimes sadness can turn into anger. Often parents direct that anger at the child, their family members, friends and even other parents who have "typical" children. They can become resentful. This is a normal response, but often parents do not know how to channel this feeling.

Denial

- Often, as a result of diagnosis, parents have to deal with involuntary denial, which is a coping mechanism that all of us experience in the wake of devastating news. This is like shock, but taken to a level of action, or sometimes inaction, as opposed to just feeling. The issue of denial cause parents to ignore or avoid information related to their child's disability and treatment. It may cause them to "shoot the messenger" and end up alienating those who are there to help them and their child.

Loneliness

- Parents of children with autism often feel a sense of loneliness. They may feel that, because of the diagnosis and interventions, they do not have time to contact friends and family as they use to. They may also feel that if they reach out, others will not understand or be supportive. They may feel that they are all alone in dealing with the aftermath of diagnosis, which is why support groups are essential.

Lack of Knowledge , Direction and Motivation

- Parents of children with autism often lack the knowledge to fully understand the disability, the direction to understand where to go and what to do next, and the motivation to do so, because they are consumed with emotional response. The key to moving forward is research (finding out what they are up against), getting the help their child desperately needs (finding out what to do post diagnosis) and getting the help they desperately need (finding support to deal with their own issues).

Social Isolation - Being their own worst enemy

- Often parents of children with autism will isolate themselves socially. They do this for many reasons. They are afraid of social stigma, they do not want to burden others, or they feel as though every second of time should be spent with their child. They are often afraid to ask for help, and sometimes, incorrectly view others as not wanting to help, when in fact it is quite the opposite. Often others do want to help, they simply do not know how. Parents need to use the resources and support they have available, but are often unsure or unwilling to ask, and cause themselves to set unrealistic goals and create unnecessary frustration in the process.

Exhaustion

- Parents of children with autism often feel overwhelmed, undernourished, and completely worn out. Between the stress, the anxiety over what to do, the appointments, the treatments, the intervention plans, etc..they completely give up time to themselves. This is recipe for disaster. One person can only take so much. They often feel as though "someone has to keep things running". They take on the load of 100 people themselves and end up running themselves into the ground.

Autism effects everyone

- Autism does not just affect the child, it effects an entire family and community. Dealing with the effects of an autism diagnosis and the uprooting it brings to your routine, your views, your emotions and your family life in general can be taxing and seem impossible. An autism diagnosis affects each member of the family differently and it is hard holding a family together when you don't even know what to do yourself. It may even feel to them, at times, that their life is over, mentally, socially, physically, spiritually and emotionally.

The Model for Success

The culmination of research on various local and state wide Autism Support groups and resources, as well as Biblical research and support, have led me to the following conclusions in consideration of the most useful and appropriate support model for the Christian Family & Children's Center.

1. Because parents of children with autism need to feel that they have help, support, understanding and information, I feel that it would be most beneficial to integrate a therapist/counselor directed, open forum style support system. This model would be loosely directed, in order to provide insight into specific problem areas and to provide information and guidance where it is needed, yet open forum, so as to discuss, compare and contrast emotions, ideas, feelings, experiences and advice from others who are going through the same situation, in order to relieve the feelings of loneliness in parents regarding their position. This model would function much like an AA model.
2. The need for group prayer, Scriptural reference and Biblical support concerning unconditional love, forgiveness, patience, creation, compassion, reliance on the Lord, hope and renewal are essential.
3. The presence of professionals, either therapist, counselor, or those experienced in the field of learning disabilities would be integral to the parents for informational purposes and understanding the thought processes of their children.
4. The best model for a small community such as this would be, ideally, a bi-weekly or monthly meeting.
5. In meeting training, "homework" and group assignments meant for educational purposes should be scheduled regularly. Perhaps an example of this would be a role playing activity in which the parents take turns, trying to let others know how they feel without words or facial expression, in order to better understand the difficulty their child has with these language barriers. Another exercise may be to have a different parent bring an article on autism each meeting and pass it out to the other parents.
6. Having resources readily available, such as videos, library books, diagnosis packets (such as the 100 day kit), and contact lists is essential to give the parents the direction they need to break up the confusion of a new diagnosis and to aid in the process of intervention. The earlier the intervention, the better.
7. Developing a support contact list for the parents; this would list the contact info for any and all other parents involved in the group, to serve as support and a friendly ear in between meetings.

GOALS

The key goals of a local support group would be as follows:

1. To provide a local, family oriented, faith based, inviting place of refuge, support, information, referral and assistance for parents of children with autism, in order to aid them in working through the emotional issues, informational barriers, understanding difficulties and social isolation that accompanies an autism diagnosis, so as to better equip those parents to assist their children in the most efficient, effective and loving way possible, and to create an environment of love, acceptance and possibility for those children.
2. To educate parents on the various aspects and types of treatments, therapies, and interventions available to their children, as well as to educate them on the various types of Autism Spectrum disorders, symptoms and issues their child will face due to their disability.
3. To facilitate deep understanding of their child and their child's disability through role playing, homework assignments, and educational tools.
4. To help parents understand the necessity of early intervention and the role that intervention will play in their child's future.
5. To provide a network of support, and resources, with other parents of children with autism.
6. To create opportunities for the parents to learn new ways to interact with and appreciate their children, and their special needs and abilities.
7. To broaden the ministry of the Center, and to reach out to those in the community who are in need.

Local Support Groups

**123 I Am Me Sibling Support Group for
Autism**

Marla Green
2657 Russell Drive
Lower Burrell, PA15068
724-339-0597

**ABOARD Chapter
Autism Support Group**

Carol Schrecengost
376 Hillcrest Dr.
Lower Burrell, PA 15068
724-339-4865

**ABOARD Chapter
Autism Support Group**

Mandy Welty
Sibling Support Group
Lori Mondock
Northwestern Human Services
4536 Rt. 136, Suite 5
Greensburg, PA 15601
724-836-1072

**ABOARD
Advisory Board on Autism Related
Disorders**

35 Wilson Street
Suite 100
Pittsburgh, PA 15223
412 781 4116
800 827 9385
Fax: 412 781 4122
<http://www.aboard.org/>
Contact: Marie Mambuca
info@aboard.org

African American & Autism Support

Group

233 Edgewood Ave.
Apt. 7A
Pittsburgh, PA 15218
412 242 5596

**Alle/Kiski family Support Group For
Autism Spectrum Disorders**

Marla Green
2657 Russell Drive
Lower Burrell, PA15068
724-339-0597

Alle/Kiski Asperger's Association

Marla Green
2657 Russell Drive
Lower Burrell, PA15068
724-339-0597

Autism Support Group

Susan Jennings
1100 College Ave.
Jeanette, PA 15644
724-522-1530

AutismLink

376 Wagon Wheel Trail
Wexford, PA 15090
412-377-8778
info@autismlin.com
www.autismlink.com

Bedford County Family Support Group

159 Smithfield Street
Bedford , PA 15522
814 932 4967
Contact: Beth Gable
egable11@hotmail.com

Bedford County Family Support Group

3936 Cortland Dr.

New Paris , PA 15554
814 839 4442
Contact: Amy Howsare
s_howsare@yahoo.com

**Cambria & Somerset County
Parent Support Group**

3125 Somerset Pike
Johnstown, PA 15904
814 288 1659
Contact: Jennifer Gindlesperger
jennifermbm@verizon.net

Cambria County Support Group

384 Ridgeview Lane
Conemaugh, PA 15909
814 322 1862
Contact: Pauline Springer
Paulie318@aol.com

**FBR/ABOARD North Huntingdon Family
Support and Social Skills Play Group**

Cathy Highes
724-861-9200
Rick Murray
8960 Hill Drive
North Huntingdon, PA 15642
724-861-4700

**FBR/ABOARD New Kensington Family
Support and Social Skills Play Group**

Kara Kaylor
943 4th Ave.
New Kensington, PA 15068
724-335-9733
FBRAutism@aol.com

FBR Monroeville Family, Social & Play Group**Family Behavioral Resources**

2526 Monroeville Blvd.

#200A

Monroeville, PA 15146

412 788 4224

www.familybehavioralresources.com

Contact: Christine Sheffey

monroeville@familybehavioralresources.com

Ligonier Support Group

1007 Canterbury Rd.

Ligonier, PA 15658

724 238 2325

Contact: Mary Jo Sell

mjsell@valleydairy.net

Love Our Children

1081 Valley View Dr.

Scottsdale, PA 15683

724 887 7742

Contact: Lisa Rizza

lrizza2001@yahoo.com

Parent Support Group NHS Twin Lakes

4536 Rt. 136

Greensburg, PA 15601

412 554 7361

Contact: Colleen Patrick-Evans

cevans@nhsonline.org

Parents of Asperger Teens

1010 LaClair Ave

Pittsburgh, PA 15218

412 247 0599

Contact: Rebecca Klaw

rebeccaklaw@aol.com

SharpVisions

4813 Jonestown Road
Suite 203

Harrisburg, PA 17109

717 651 5500

Fax: 412 456 2145

www.sharpvisions.org

Contact: Gwen Arbuckle

garbuckle@sharpvisions.org

SharpVisions

1425 Forbes Avenue

Third Floor

Pittsburgh, PA 15219

412 456 2144

www.sharpvisions.org

Contact: Gwen Arbuckle

garbuckle@sharpvisions.org

**SIA – Strength in Autism
Group for Those Affected By Autism**

Excela Health

Westmorland Hospital

Greensburg, PA

1-877-771-1234

Sibshop**FRNS**

20 W Tacoma Ave.

Latrobe, PA 15650

724 837 8159 ext. 130

Our Sibshops are for sibs ages 6-12 and are

held 8 times per year. We also have teen

Sibshops which are held monthly.

Contact: Regina Sciuлло and Ida Hower

FRNS1@verizon.net

Somerset County Parent Support Group

681 Cherry Lane Rd.

Central City , PA 15926
814 267 6095
Contact: Michelle Miller
maxinejm@stargate.net

**Starfish Advocacy Association
Internet Community**

216-283-2377

www.starfishadvocacy.org

starfish@starfishadvocacy.org

Starfish Advocacy Assoc.

3341 Warrensville Center Road

Suite 203

Shaker Heights, OH 04412

**Support Group for Adults with
HFA/Aspergers**

353 Spahr Street

Pittsburgh, PA 15232

412 848 9355

Contact: Carolyn Komich-Hare

carolynkhare@yahoo.com

Resources

www.autismspeaks.org

www.wikipedia.com

www.austism-society.org

www.ninds.nih.gov/disorders/autism/detail_autism

<http://groups.msn.com/theautismhomepage/autismandthebible.msnw>

www.nationalautismassociation.org

www.webmd.com/brain/autism/autism-symptoms

Facing Autism: Giving Parents Reason for Hope and Guidance for Help by Lynn M. Hamilton

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