Autism Empowerment

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A Practical Guide to Helping Leaders Understand and Support Individuals on the Autism Spectrum and with other Related Disorders

Presented by Autism Empowerment

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"The wonderful thing about such boys is their cheerfulness and their eagerness to do as much in scouting as they possibly can. They do not want more special tests and treatment than is absolutely necessary."

Robert Baden-Powell

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Faces of Autism

Which of these individuals are on the Autism Spectrum?

It can be a hidden disability – never assume…

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What is Autism?

It is a Spectrum Disorder

Autism is defined as a *Neurological* Disorder and a complex developmental disability that affects each person differently and to varying degrees of severity.

"If you have met one person with Autism, you have met one person with Autism. "

Dr. Stephen Shore, Autism Advocate

Important take-away:

Although there are many on the Autism Spectrum who show similar characteristics, **no** two people on the Autism spectrum are the same.

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Current Prevalence Rate

Autism in the US is 1 in 88 *

(this includes Asperger's Syndrome, PDD-NOS and all ASDs)

Autism among boys is 1 in 54 (1 in 252 for girls)*

Individuals with Autism is 1 in 1

Autism Empowerment serves the 1 in 1

*** Rates are based from 2008 CDC Rates**

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There are currently three main diagnoses of Autism Spectrum Disorders (ASDs)

1. Autism
2. Asperger's Syndrome
3. Pervasive Developmental Disorder - not otherwise specified (PDD-NOS)

Autism is a *Neurological* (Brain Development) Disorder and a complex developmental disability that affects each person differently and to varying degrees of severity.

The nature of the diagnosis is complicated in and of itself.

The criteria for diagnosis is from the *Diagnostic and Statistical Manual of Mental Disorders*. 4th, text revision (DSM-IV-TR) ed. 2000. ISBN 0-89042-025-4. Diagnostic criteria for 299.00 Autistic Disorder

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Differences Among the Three

Autism – Child doesn't meet all of his or her typical milestones and many times receives a diagnosis before age three. Can include a wide range of educational aptitudes, although there appears a developmental delay when younger.

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Asperger Syndrome – Asperger or Asperger's syndrome (AS) is a developmental autism spectrum disorder (ASD). Although symptoms are present early in life, Asperger syndrome is usually diagnosed with a child is school aged.

Sometimes confused with or called “high functioning Autism”, although there are diagnostic differences. Children typically meet most youth milestones in terms of speech. May perform well and excel educationally but still has many social and/or physical obstacles.

Pervasive Developmental Disorder, Not Otherwise specified (PDD-NOS) – Psychologists and psychiatrists sometimes use the term “pervasive developmental disorders” and ASD interchangeably. PDD-NOS is often the diagnosis applied to children s who are on the autism spectrum but do not fully meet the criteria for “classic” Autism or Asperger’s.

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Similarities among the Three

Sensory Issues / Moderating sensory response

Need for some type of self regulation

Social interaction / communication challenges

Appropriate emotional responses

Having greater difficulty in the ability to understand how others perceive what they do or say

Families need extra support

There is No "Cure", there is no universal "Cause"

There are treatments and interventions for symptomology and co-conditions

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Other possible related conditions or co-conditions

ADD / ADHD - Attention deficit hyperactivity disorder

2007 CDC rates 8.8% in OR 9.5% in WA

Anxiety

Childhood Disintegrative Disorder

Depression

Dyslexia – estimated at 5 – 10%

Epilepsy / Seizures

Eating Disorders – Anorexia, Binge Eating, Bulimia

OCD - Obsessive–compulsive disorder - 1 in 50 Adults – onset in childhood

Rett Syndrome – affects mostly girls

SPD - Sensory processing disorder - 1 in 20 Children may be affected - Dr. Lucy Jane Miller, founder Sensory Processing Disorder Foundation

Tourette Syndrome - 2007 CDC rates 3 in 1000

This is not an all-inclusive list

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Get to know the Scout and the Scout's family first!

Labels do not define who someone is. Just as all boys are not the same and all scouts are not the same, all individuals on the autism spectrum are not the same. Treat the scout as an individual and get to know him.

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Get to know the scout and the scout's family first!

When you first learn that you have a youth on the autism spectrum in your unit, set aside private time to get to know that youth and his family.

Have a meeting with parents (separately is fine) and then later with the scout. Get information about triggers, school history, medical history and anything that will allow you to assist the scout.

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Get to know the scout and the scout's family first!

Find out what, if any accommodations may be needed

- Sensory Related Accommodations
- Physical Accommodations
- Dietary Restrictions
- Learning Support

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Get to know the scout and the scout's family first!

Find out how you can emotionally support and motivate the scout and his family

Be mindful - Families with special needs kids many times have many more things to contend with that typically developing scouts. (example: doctor visits, other types of therapy, additional economic concerns)

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Get to know the scout and the scout's family first!

Find out the level of family involvement.

- Who will be participating with the scout?
- What level of support will they have at home?
- Any scouting experience within the family?
- Will a family member be volunteering and/or involved with overnights. (Volunteering is highly encouraged.)

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Get to know the scout and the scout's family first!

Find out the scout's strengths and the way he best learns

- Visual – may think in pictures
- Audio / Verbal – note taking
- Tactile / Touching / Kinesthetic
- Combination of methods

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Get to know the scout and the scout's family first!

Find out any special interest(s) the scout has

These are great conversation starters.

You can teach using the special interest.

You can use the special interest in incentives / rewards.

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Get to know the scout and the scout's family first!

Be mindful of the privacy of the scout and his family

Not all scouts may be aware of their diagnosis.

Some families may choose to keep the diagnosis private.

Some families choose to make the diagnosis public.

(If the latter, invite them to share experiences with others within the unit. This promotes acceptance and awareness.)

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Get to know the scout and the scout's family first!

Expand your education

Beyond this class

Autism & Scouting Radio and Autism Empowerment Radio

Autism and Scouting & Autism Empowerment at Facebook

Autism and Scouting Blog

Autism Empowerment Enrichment Training Seminars

Working with Scouts with disAbilities website – www.wswd.org

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Areas to provide Support

Sensory Processing Issues

Social Issues / Communication Issues

Safety Issues

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Sensory Processing (Sensory Integration)

There are neurological issues causing difficulties with **taking in**, **processing** and **responding** to sensory information about the environment and from within the own body in the following areas:

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Types of Sensory Processing Issues

Gustatory (Taste)

Tactile (Touch)

Auditory (Sounds)

Olfactory (Smell)

Visual (Sight)

Vestibular (Body Motion/Dexterity)

Over-stimulation

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Goals of Understanding Sensory Issues

1) What to look for as far as possible sensory issues. **Each child will be different.**

2) How you can assist the child and family with self regulation issues. The child will need some type of self regulation.

3) How this will help you connect with the child and get the information that you need to assist him.

4) How to get the children the services that they need.

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Behavioral Issue vs. Sensory Issue

Leaders should know try to see the difference between what is a behavioral issue and a sensory issue.

A behavioral issue and sensory issue may look like the same thing, but they are different and should be treated differently.

Treat the Sensory issue first then after you have more of a teachable moment, address the behavioral part

In the later class we will be addressing this in greater detail. (Also see S.E.N.S.E. handout.)

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What is Self Regulation?

It is a person's ability to control his or her behavior and emotions. It develops over time and it involves many aspects of social, emotional and cognitive development.

Some examples of self regulation are, flapping, spinning, crashing, humming, swaying, tapping a pencil, etc.

Self Regulation happens with every person. It could be drinking coffee, diet soda, chewing gum, eating chocolate, twirling hair or doing that one thing that just makes you feel grounded, stable and secure.

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Taste (Food) Issues

Food Issues are some of the most common challenges with kids on the Autism Spectrum. They are not just “picky eaters”. Smell, texture, taste or temperature can cause gag reflexes and cause meltdowns / shutdowns.

It is common for a child to prefer the same foods and not want a lot of variety. (i.e. chicken nuggets, pizza, pasta, bland foods)

Children having these challenges often believe they can’t eat certain foods. Oftentimes physically they can’t eat without gagging. The mental and physical aversion to many foods is real and it needs to be treated as such.

Many can benefit from special diets because of gastrointestinal issues (gut issues). Often the diets are gluten and/or casein free, sometimes dye-free.

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"Just let me have them for a few days on a trail; if they get hungry enough they will eat what we have." - unnamed Assistant Scoutmaster

NO – More than likely most will not eat and there is a chance they might get dehydrated and sick. **They will just not eat.**

Chances are the scout will become embarrassed, resentful and will then not want to take part in unit events. In some cases the emotions may be so overwhelming that they will drop scouts altogether.

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How to assist scouts with this issue

Be a role model and **"Be Prepared"**

Give encouragement to try the foods being offered.

Do not make fun of the scout or belittle in any way.

Know of any special dietary concerns or restrictions by talking to the family and scout in advance.

"Do Your Best" to have foods that will work at campouts, meeting and special events

Get the scout involved in helping plan and prepare the food.

Communicate with the family and scout about special events, camps or outing to make sure that basic needs are met.

Test out foods in advance to see what works – then make a list of what will work for future reference.

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Touch and Contact Issues (Tactile)

Certain fabrics, materials, feels or touches can be painful, itchy or uncomfortable (**Touch-sensitive)**

- Clothing tags, long sleeves, long pants
- Grass, sand, snow, rough concrete, etc…
- Hats or head gear

Be aware of any issues and possible reactions.

With some children, physical contact like a high five or a handshake may cause an emotional reaction. Avoid these things if you sense it may be an issue. Smiling, eye contact and positive reinforcement however are encouraged even if not reciprocated. - These issues may be compounded by emotional issues the child has experienced.

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Sound Issues

Some children will be bothered by loud or sudden sounds or very high pitched sounds. Senses are often heightened and a child may be distracted by multiple conversations simultaneously.

Tips to help with Sound Issues

If possible, give a warning in advance of events with loud noises.

Practice desensitizing in advance. (Tape-record noise in high fidelity, practice with increased volume, practice muffling noise.)

Provide a real-time visual and verbal Social Story in advance of the event

Ear protection to reduce noise or sounds. A simple pair of noise-cancelling headphones or earplugs goes a long way to help. (i.e. school fire drills)

Take them away from the loud noise and give them a place to recover and go in case it gets too overwhelming

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Smell Issues

Sensitivity to smells can be difficult to avoid (again, senses may be heightened)

How to assist Scouts with this Issue

- Be aware of excessive smells –any warnings ahead of time can be helpful to **Be Prepared**

  (Camp smells, cooking smells, hospital smells, KYBO, bug sprays can be talked about in advance. Practice desensitizing.)
- If going on field trip to some place like a hospital, Dr. Office, Vets office etc. provide a Social Story in advance.
- Provide a small mask to help assist the scout.

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Sight Issues (Can you read this text?)

Light Sensitivity is very common. Sensitivity to fluorescent lights or sunlight or bright lights often bother those with ASD.

Tips to help Scouts with Sight Issues

Utilize reduced lighting or incandescent lighting (keeping mindful of safety).

Ensure that any sight challenges are included in the child's sensory profile.

Try to avoid sudden changes in lighting if possible or provide a warning.

Give transition time for the child and the use of social stories if needed.

Consider eye protection. (Sunglasses or tinted glasses)

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Over-Stimulation Issues

Over-stimulation happens when one or more of the senses are strained and it becomes difficult to focus on the task at hand. It is a sensory overload.

How to assist Scouts with this Issue

Allow for Sensory Breaks

If possible have a quiet, non-cluttered area set aside for breaks or take a 5 minute walk.

Camping, bring an extra tent for these breaks.

Allow for Processing time.

Give extra time to respond.

Be aware of sensory triggers and try to avoid them.

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Vestibular (Body Motion)

Relates to the body and its relationship in space

How to assist scouts with this Issue

Games where eyes need to be blindfolded, the scout may want to avoid, let them opt out

Be aware of games with excessive motion and monitor.

-Work with the scout one on one – **remember guide to safe scouting**

Provide positive encouragement and support.

Provide extra supervision when doing obstacle courses or anything that is above the ground.

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Vestibular (Body Motion)

-Some scouts may appear clumsy or uncoordinated – this is due to the inability to process their relations to their bodies in the space they occupy.

-Some scouts may get car sick due to motion and taking precautions would be advised. Allow time for extra stops.

-Some scouts may be thrill seekers and enjoy and seek out motion for self regulation. Make sure they are monitored for safety.

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Social and Communication Issues

Lack of Engagement/Advancement

Staying Focused on a Task/Routine

Communication / Relating to Peers and Adults

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Lack of Engagement /Communication

Many on the Autism Spectrum have issues with lack of engagement with peers or adults.

How to work around this Issue

Try to get into the child's world by finding out what their special interest is. This will help in communication issues as well.

Special Interests are something that the child spends a large portion of them their time focusing on. It could be cars, dinosaurs, whales, bridges, computers, Minecraft, Angry Birds, horses (animals are very common) etc…..

Use Positive encouragement for participation customizing an incentive program relating to their special interest. (Stickers work great for younger scouts)

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Try to integrate the scout's special interests into den or troop activities.

Computers – Computer Belt Loop, Communications Activity Badge, Computers, GeoCaching, Robotics Merit Badge, tour at a computer company.

Dinosaurs – Wildlife Conservation or Geology Belt Loop, Geologist Activity Badge, Geology Merit Badge, tour at a Museum or hike at someplace like the Ape Caves

Bridges – Science Belt Loop, Engineer or Scientist Activity Badge, Engineering or Architecture Merit Badge

For all Subjects – Art Belt loop, Communicating Belt Loop, Reading and Writing Belt Loop, Artist or Showman Activity, Reading or Theater Merit Badges

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Lack of Engagement in Meetings/Games/Outings

Work with parents to create a positive reward system

Use positive encouragement for participation and focus.

- Use of an instant Bead System – can work well for all scouts

Give options - Find a place they will fit or encourage them

Example - you can take part **or** you can be a judge

- you can take part **or** be my shadow

- you can watch first, then take part

Let them sit on the sidelines to watch and check in with them.

Build their special interest into the meeting, game or outing.

Many times it is best that a leader encourages and not the parent. This protects the Parent/Child relationship.

Encourage inclusion whenever possible, not to the point of embarrassment or singling out.

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How the Scout can Learn Best

Find out which way they learn best and use these formats to learn and take part : From a book, YouTube, ipad App, hands on, audio, visual

If they are not taking part, explain the reason or the goal of the activity to the scout. Often **just knowing why** will help them take part because they will see a value for them.

Find out why they do not want to take part.

Fear, embarrassment, sensory issue, not seeing value

Find out how they express themselves best (Explain)

writing, verbal, drawing, building

Never add or take away from a requirement but you can adapt it.

Recite – can be done verbally, through signing or in writing

In advanced class we will talk more about advancement.

Find a buddy to work with them or a peer mentor.

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Staying on Task / Routine

Some scouts with ASD may seem inflexible if not adhering to a strict routine.

How to assist Scouts with this Issue

If you give the scout a routine, try to stick to it as much as possible . He will look to you as an example of accountability and integrity.

Use of visual Timer Clocks

Use of Picture Schedules

If you are going to vary from routine, try to prepare the scout in advance if possible. (Superflex powers)

Allow time for transitions from one portion of the meeting/outing to the next.

Oftentimes scouts on the spectrum are rules-oriented and want things to be “fair” and just. Explaining why something is not equal may need to be addressed.

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"Scouting helps them by associating them in a world-wide brotherhood, by giving them something to do and to look forward to, by giving them an opportunity to prove to themselves and to others that they can do things – and difficult things too – for themselves."

Robert Baden-Powell

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Communication and Relating to Peers and Adults

Encourage Leadership positions

- Finding the right fit or starter position is important.
- In Cubs, promote the use of the Denner System.

Encourage participation in service projects or Eagle Projects.

Encourage them to join hikes and outings.

Encourage Team building and Patrol or Den building.

Be careful of using sarcasm either directly to or around the scout.

Don’t talk down to them and make sure to monitor your tone.

Try to avoid absolutes unless it is called for: all, never, none

Some scouts will take what is said literally and not understand the difference. Example: It’s raining cats and dogs.

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Relating to Peers and Adults

Bullying & harrassment does happen in Scouting units.

Watch out for bullying and stop it where it happens.

Be mindful of the privacy of the scout.

Misunderstanding and lack of education can lead to intolerance and insensitive behavior by scouts or leaders.

Run a Disabilities Awareness Merit Badge or Belt Loop program

Bring somebody in from the local ARC, law enforcement or other agency or you can request Autism Empowerment to help

Do not tolerate poor or insensitive behavior from **anybody.**

All scouts and scout leaders should live by the Law and Oath.

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Other possible Safety issues to be Aware of

Wandering

92% of those with Autism are reported to have issues with wandering at some point in time*

* a 2007 NAA online poll

Reinforce the rules of the buddy system

Have extra vigilance

Campouts and hikes check in more often

Have the parents fill out an Autism Elopement Form from the National Autism Association (see resources)

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Other possible Safety Issues

Seizures - Roughly 25-30% of adolescents with Autism have been reported to develop seizures at some point in time.

Make sure all contact information is updated.

Make sure leadership leading an outing is aware

Depression and Anxiety - increased rates of being bullied in other peer groups, feelings of not fitting in lead to greater rates.

Be a good Mentor.

Learn about the signs of depression and anxiety.

Provide support for the family.

Remember the guide to Safe Scouting.

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Autism Empowerment

Accept Enrich Inspire Empower

Accept the scouts for who they are, where they are.

Enrich their lives by teaching them lifelong skills.

Inspire them to be Exceptional. Chances are that they'll inspire you too.

Empower them by giving them the tools to be self-sufficient and successful.

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Additional Resources included on your CD

Autism and Scouting Contact Information

Autism Empowerment Sensory Profile

BSA “Scouting for Youth with Disabilities” no. 34059

World Scouting Organization’s Guidelines, Scout Disabled

Working with Scouts with disAbilities (ISAP) Document

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Supplemental Resources

http://autismempowerment.org - Autism Empowerment – Founded in Vancouver, WA in 2011
Accept, Enrich, Inspire, Empower. – http://www.facebook.com/autismempowerment @AutismEmpowermt

http://www.facebook.com/autismandscouting - Autism and Scouting Facebook Page & Online Support

http://www.blogtalkradio.com/autismandscoutingradio - Autism and Scouting Radio (free broadcasts)

http://itunes.apple.com/us/podcast/autism-scouting-radio-blog/id550043079 Radio show on iTunes

http://www.blogtalkradio.com/autismempowerment - Autism Empowerment Radio (also on iTunes)

http://www.scouting.org/filestore/pdf/34059.pdf - BSA Special-Needs **Scouting**

http://scout.org/en/information_events/library/diversity/guidelines_on_scouting_for_people_with_disabilities
World Brotherhood of Scouting People with Disabilities

http://scout.org/en/information_events/library/diversity/scouting_with_the_disabled - World Brotherhood of Scouting

http://www.wwswd.org/ - Working with Scouts with Disabilities

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http://autismandscouting.blogspot.com
Autism and Scouting Blog – Helpful information on supporting scouts

http://asperkids.com/ Asperkids website – educational resources and learning tools

http://www.pacer.org/ - PACER supports families of all disabilities
http://www.pacer.org/bullying - PACER National Bullying Prevention Center

http://www.scouting.org/filestore/pdf/bks-scout.pdf - Books from Bookshare

http://www.autism-society.org/ - Autism Society of America

http://www.autismspeaks.org/ -Autism Speaks

http://usautism.org/
US Autism and Asperger Association

http://www.nationalautismassociation.org/pdf/AUTISM%20ELOPEMENT%20ALERT%20FORM.pdf
National Autism Association Elopement form

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http://www.sinetwork.org/
The Sensory Processing Disorder Foundation

http://www.understandingspd.com
Understand Sensory Processing Disorder – Free printables and educational resources from Angie Voss

http://www.help4adhd.org/
National Resource Center on ADHD

http://www.tsa-usa.org/
National Tourette Syndrome Association

http://www.rettsyndrome.org/
International Rett Syndrome Foundation

http://www.dyslexia-parent.com/
Dyslexia Parents Resource

http://www.cdc.gov/ncbddd/autism/index.html
Center for Disease Control and Prevention