



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 – Beyond The Basics

Presented by Autism Empowerment

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What is the purpose of Scouting ?

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“Scouting is a Game with a Purpose”

William "Green Bar Bill" Hillcourt (1936) 3rd addition of Boy Scout Handbook

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What is the purpose of scouting for scouts on the Autism Spectrum?

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The same as every other Scout + More!

To have fun and make friends!

Be around other kids

Learn and practice Life Skills

Be accepted

To be the best that they can be

To have time outside of school and therapy

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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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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 – Changes coming in 2013 with the new DSM V.

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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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Sensory Processing Issues

What is a Sensory Issue?

Sensory Issue vs. Behavioral Issue

Self Regulation / Over Stimulation

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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 them.
- 4) How to get the scout the accommodations that he needs.

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Behavioral Issue vs. Sensory Issue

Is it sensory? Is it behavior?

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Behavioral Issue vs. Sensory Issue

Both may seem to look the same, ie acting out, meltdown, shutdown, yelling or doing an action that is perceived as a problem issue

- Temper Tantrum vs. Meltdown

Meltdown is an emotional response from sensory challenges or needs not being met.
Assess the source of meltdown.

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Behavioral Issue vs. Sensory Issue

- A sensory overload issue triggers a Fight or Flight reaction which may look on the surface as a behavioral issue.
- Making S.E.N.S.E. of the situation (Voss)
- See handouts from Angie Voss, OTR/L
- <http://www.understandingspd.com/sensory-meltdowns.html#.UEhFArJISIQ>

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Behavioral Issue vs. Sensory Issue

- If you treat the sensory issue first, there is a high chance the “behavioral issue” will be taken away from the equation and the child will be more regulated. Communication with the child should improve.
- Behavior can be addressed at a later time after a cooldown.

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Behavioral Issue vs. Sensory Issue

- **If you treat a sensory meltdown as a behavioral issue first, the negative actions by the child will likely continue and many times get worse.**

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Behavioral Issue vs. Sensory Issue

- **Helping the child become calm and in control will help you connect with the child and will also build trust. This will show him you are coming into his world and attempting to get to know him.**

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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 (stimming) are flapping, spinning, crashing, humming, swaying, tapping a pencil, etc....

Self Regulation happen with every single 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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Self Regulation – Assistance for the Scout

The scout shouldn't be made to feel what he is doing is wrong unless it is for health or safety reasons. (Redirection okay.)

With the permission of the scouts family, stimming education for other scouts & families can and be done within the unit.

Any Bullying by other scouts should be stopped and the scout should be given counsel on what it means to be a scout.

A private area can be set up for the scout to have a sensory break. Short walks are often effective also.

A pack Disability Awareness Class or doing the Troop Disabilities Awareness Merit Badge should be considered.

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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 for the scout to respond.

Be aware of sensory triggers and try to avoid them.

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Getting into the Scout's World

By getting into the scout's world, you can unlock his world. This will enrich his scouting program and he will get more out of scouting.

By getting into the scout's world, you will learn how they learn best. Many (not all) on the Autism Spectrum are visual learners. Show them.

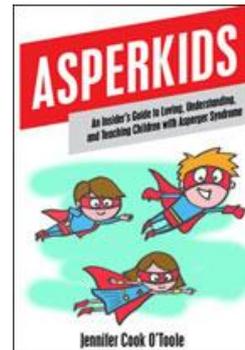
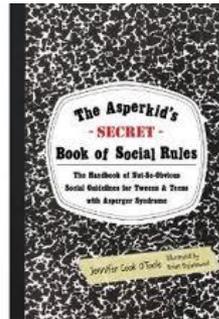
Utilize creative tools that will you will be able to use to learn. YouTube, ipad, bookshare.org etc.

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Getting into the Scout's World

Use of the scout's Special Interests



First step is to find the scout's Special Interests

Next **“Don't be a Poser”** author Jennifer Cook-O'Toole

Use the special interests to engage the scout

Use positive encouragement and special interest incentives for participation (bead necklace etc..)

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Try to integrate the scout's special interests

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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Conflict Resolution - Redirection

Be aware of warning signs: Sensory triggers, fidgety behavior, tired, hungry, changes in routine, lack of focus.

When redirection is necessary:

Do so in a calm voice unless safety is a risk.

Try to redirect privately. Never publicly humiliate or taunt.

Consider a private, non-verbal signal.

Desensitize the environment.

Redirect to a calming activity, bring to a sensory break area or get the scout engaged in something else.

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Conflict Resolution Reminders

Keep your cool!

It is hard but in the middle of a meltdown / tantrum, this is not the time to teach. Remove the Scout if he is posing a safety risk to himself or others.

When it is a teachable moment:

Support, give positive feedback and clear limits.

SHOW correct behavior. (Visually and/or through Role Play)

Offer feedback and redirection in a respectful way that allows the Scout not to be embarrassed and save face.

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How to make your Unit Sensory Friendly

It starts with Leadership

Knowing the Scouts

Changing the way things are done

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Sensory Friendly ?

Means that the unit is aware that sensory issues affect everybody, both youth and adults. Scouts do not need to be on the Autism Spectrum or have Sensory Processing Disorder to have sensory issues.

All scouts can benefit!

Means that Leaders are sensitive and willing to provide support and put into practice best practices to prevent over stimulation of the scout's senses.

Means Leaders and unit volunteers will **Be Prepared** for issues that arise when a scout needs a sensory break.

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Sensory Friendly ?

Any Unit can become Sensory Friendly and welcoming to all scouts. This is not just reserved for Special Needs units. There is a strong chance that there will be scouts on the spectrum in your unit undiagnosed.

So, Sensory Friendly policies benefit all!

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Making your Unit Sensory Friendly

It Starts with Leadership

Have Leaders willing to receive initial training.

Have Autism Empowerment or another agency provide training to your group

Be receptive to ongoing training through Autism and Scouting Radio and Blog
as well as the Autism Empowerment Website / Radio Station / Blog

Leaders follow and live the Scout Oath and Law.

Accept each scout for who they are.

Enrich each scout with Love and Caring.

Inspire each scout and each family to be their best.

Empower the scout by giving him the tools to be successful.

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Making your Unit Sensory Friendly

Knowing the Scouts

Have each family fill out a **Sensory Profile** to be shared with direct leadership including Den Leader, Cubmaster, Scoutmaster and Committee Chair. (See CD or our website)

Have a meeting with the scout and his family prior to the scout joining to talk about the scout's strength and challenges.

Find out how the scout learns best and be aware of that.

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Knowing the Scouts

Find out the scout's special interests. Speaking their language is the key to opening up their world and having them be more successful and feel integrated and accepted.

Find out how the unit can support the family and to what degree the parent or caregiver will be involved.

Keep an “extra” eye on the scout and watch out for any signs of bullying or harassment, depression or anxiety.

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Simple ways to Change your Unit – Sensory

Choose a meeting place without fluorescent lighting or bad acoustics (if possible). It is understood that many times Pack meetings take place in school or church gyms and this might not be possible to have the ideal setting.

Sensory Room – Set up a room where a scout can go to have a sensory break. Always remember the **guide to safe scouting and two deep leadership**. It would be ideal if this room is free of distractions and where lights can be dimmed.

Sensory Tent – On campouts, this is where scouts can have time to have a break.

Sensory Supply Box - Have your unit purchase a bin, noise reducing headphones, small fidgets, some sun reducing glasses, small nose mask and/or nose plugs. Optional items could be a bean bag chair, some scout books, a big pillow, weighted blanket or sensory disc or sensory seat.

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Simple ways to Change your Unit – Visuals

Visual Timer Clocks – In Den meetings, use them to show changes between different activities. In Pack/Troop Meetings they can be used in the front of the room to show when changes will be made. (Time Timer Clock brand.)

Visual Schedules – Having a visual picture schedule will help all Scouts keep focused and know the expected sequence of events.

Visual Tools & Rewards – Many on the Autism Spectrum are visual learners. Having visual tools and rewards can provide you another level of teaching. Again, many will benefit from this type of learning.

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Advancement

Cub Scouts

Boy Scouts / Venturing / Sea Scouts

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Cub Scouts



BSA Policy in advancement manual states

4.1.04 “Do your Best” – Advancement performance in Cub Scouting is centered on its motto “Do your best”. When a boy has done this – his very best – then regardless of the requirements for any rank or award, it is enough; accomplishment is noted.

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Boy Scouts / Venturing / Sea Scouts



Advancement Policy

Modifications/Accommodations vs. Alternative

ISAP (Individual Scout Advancement Plan)

Extensions

Additional Resources

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Advancement Policy for working with scouts with Disabilities

Policy for advancement for those with disabilities can be found on page 60 of the Guide for Advancement.

Section 10 starts:

“Youth with physical disabilities and youth and adults with developmental or cognitive challenges are welcome in the Boy Scouts of America. As outlined in this section, various accommodations exist to facilitate advancement.”

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Advancement Policy for working with scouts with Disabilities

10.2.2.0 – Advancement for Boy Scouts and Varsity Scouts with Disabilities. “ Members must meet current advancement requirements as written for merit badges, all ranks and Eagle Palms, although some allowable substitutions or alternatives are specifically set forth in official literature. The member is expected to meet the requirements – no more and no less – and he is to do exactly what is stated. “ and “Requests for alternate requirements for Tenderfoot, Second Class, First Class ranks can be made using the information outlined below”. This is done in 10.2.2.1 - 10.2.2.4.

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Alternative Requirements vs. Accommodations / Modifications

An Alternative Requirement is when you are requesting a change in advancement and go through the process outlined in 10.2.2.0 – 10.2.2.4.

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Guidelines for Alternative Requirements

1. All or as many as possible rank requirements need to take place.
2. A request needs to be filed with the Advancement Committee. In many areas the Council Special Needs Committee may help assist . You will need documentation including a written request and a qualified medical professional report.
3. Provide a scout's IEP (Individualized Education Plan) or any other documentation that will support the need for a change in requirements.
4. Provide an ISAP (Individual Scout Advancement Plan) from the Working with Scouts with disAbilities website. www.wswd.org This will help the committee to see what kind of change is requested.
5. Advancement Committee reviews the request.
6. In some cases the Committee may request to interview the scout and parents.
7. The Committee will make a decision and then let the scout and leadership know if the Alternate Requirement has been approved or denied.

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Modifications (Accommodations)

A modification (accommodation) is the act of adding an aid or support in order to complete the task or requirement. Modifications are allowable under BSA Policy without prior approval outside the unit.

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10.2.2.1 -"Simple modifications very close to existing requirements need **NOT** be approved." ... "A Scout in a wheelchair for example, may meet the requirement for hiking by "wheeling" to a place of interest. Allowing more time and permitting special aids are also ways leaders can help scouts with disabilities make progress. Modifications, however, must provide a very similar challenge and learning experience. "

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Examples of Modifications / Accommodations

First Class - 9b. Successfully complete the [BSA swimmer test](#).

Have the scout use a kick board or swim noodle.

Story from Scoutmaster Karen Mansfield (on Autism & Scouting Radio)

First Class - 8c. Show how to transport by yourself, and with one other person. Simulate to help a person from a smoke filled room and a person with sprained ankle is the intent of requirement.

If the scout does not like physical contact with other individuals, then this could be something that stops the scout.

The requirement does not say demonstrate. How else could they show it?

Drawing

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ISAP (Individual Scout Advancement Plan)

Produced by Tony Mei who is currently the BSA National Special Needs Chair and the Working with Scouts with Disabilities webmaster: www.wwswd.org

Similar to an IEP (Individualized Education Plan)

Used when scouts need to have an Alternative Requirement

Is accepted as a common document to record requests for Alternative Requirements.

To be used by Boy Scouts / Venturing or Sea Scouts

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Extensions

BSA allows youth to continue past age 11 (Cub Scouts) 18 (Boy Scout) or 21 (Venturing)

Extensions can be found in the Advancement manual, 10.1.0.0 to 10.1.0.2 (page 60 and 61)

Who may qualify?

10.1.01 “Examples of conditions that, if severe, may be criteria for registration beyond the age of eligibility include these: 1. Autism Spectrum Disorders 2. Blind or sight-impaired 3. Deaf or hard of hearing 4. Developmental cognitive disability 5. Developmental delay 6. Down Syndrome 7. Emotional or behavioral disorder 8. Physically impaired 9. Severely multiple impaired 10. Traumatic brain injury”

Who does not qualify?

10.1.0.0 “This is often the case with moderate learning disabilities and such disorder as ADD/ADHD. If ranks can be earned, but it just takes somewhat longer, the option is not warranted.”

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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.wswd.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