



## Autism Empowerment Autism and Scouting Leadership Training Kit



Autism Empowerment  
Accept Enrich Inspire Empower



Written by John Krejcha and Karen Krejcha, Autism Empowerment  
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# About this Kit

**Autism Empowerment** and its **Autism and Scouting Program** provides information about autism, Asperger syndrome and ASD with the mission of helping make life better and more meaningful for individuals on the autism spectrum locally, regionally and worldwide. This includes families, friends and support networks. With this Autism and Scouting Leadership Training Kit, we share information that is meant to help scouting leaders and scouting volunteers better support youth on the autism spectrum who are interested in or currently involved within the scouting community.

Please note that Autism Empowerment and the Autism and Scouting Program do not provide medical or legal advice or services. We are also not affiliated with any scouting or alternative scouting organization. As such, the information provided in the Autism and Scouting Leadership Training Kit is not a recommendation, referral or endorsement of any specific educational or therapeutic method and does not replace advice of medical, legal or educational professionals.

The Autism and Scouting Program of Autism Empowerment is intended to **serve all scouting and alternative scouting organizations** which are interested in helping better the scouting and youth development experience for youth in their units who are on the autism spectrum.

What is alternative scouting? That would be an organization that offers a youth development program that has similarities to a program that organizations such as the Boy Scouts or Girl Scouts might offer, however their organization may or may not use terms like “scout”, “scouting” and “scout leaders” when referring to their membership or leadership base. A few examples would be Camp Fire, Navigators USA, American Heritage Girls, Trail Life USA and Royal Rangers.

You will read, see and hear real examples from scouters worldwide from varying organizations. Because each scouting or alternative scouting organization has its own program, the information in this kit is presented in a general way with the understanding that you may need to do some adaptation in order to tie in with the rules and practices of your particular scouting or scouting related organization.

**For purposes of this manual, going forward we use “scout”, “scouter” and “scouting” terminology.** Please feel free to adapt and substitute whatever term is appropriate for your group membership.

This kit has a lot of useful features. As not all of us learn the same, you will find written, audio and visual material. Part of your learning also includes connecting with other leaders in the scouting community who have been where you have before or who at the very least can “get” part of the journey that you are undertaking. This kit isn’t just meant to be put on the shelf and left there. We invite you to connect with the **Autism and Scouting Program** through our website and social media and participate in the ongoing training we will continue to offer at [www.AutismEmpowerment.org](http://www.AutismEmpowerment.org).



# Acknowledgements

Autism Empowerment, the Autism and Scouting Program and the authors of this publication hereby acknowledge Autism Speaks Family Services Community Grants as the funding agency for the project leading to this publication. The views expressed in this publication do not necessarily express or reflect the views of Autism Speaks or any other funding agency.

Autism Speaks provided a generous \$25,000 grant which allowed for Autism Empowerment to develop, produce and distribute our first 500 kits throughout the United States. We are very grateful for these project funds and look forward to the information within these kits being shared far and wide, in person and online.

Autism Empowerment and the Autism and Scouting Program is also greatly appreciative to all of the volunteers who donated their time, energy and brainpower to assist with the development and production of the Autism and Scouting Leadership Training Kit.

This kit was co-authored by John and Karen Krejcha from Autism Empowerment with the assistance of a Leadership Advisory Committee. In putting together the Leadership Advisory Committee, we included scouts, scouting leaders and volunteers from a variety of scouting organizations in the United States and Australia. We included educators, trainers and internationally known autism experts.

Autism Empowerment has a core belief that if you really want to get deeply engaged and help kids, teens and adults living with autism, Asperger syndrome or ASD, **you need to actively include men, women and youth on the autism spectrum in the conversation.** We have in the past. We do in the present. We will in the future.

Thank you to John and Karen Krejcha, our **Leadership Advisory Committee** and invaluable support from Autism Empowerment Board of Directors: **Brian Tashima, Sara Wilber, Paul Pitsenbarger and Peggy Pitsenbarger.**

Chair: **John Krejcha** - Washington – Co-founder of [Autism Empowerment](#) and the Program Director for the Autism and Scouting Program. John is also a Radio host ([Autism and Scouting Radio](#)), blogger, speaker and presenter. John is the driving force behind the Autism and Scouting Program. He has many different volunteer positions within the Boy Scouts and has received a number of adult scouting awards. He has two sons on the autism spectrum.

Vice Chair: **Karen Krejcha** - Washington - Executive Director and co-founder of [Autism Empowerment](#). Karen is also an author, Radio host ([Autism Empowerment Radio](#)), speaker, blogger and a tireless self-advocate with Asperger's. She is the winner of the 2012 GRASP Distinguished Spectrumite Medal Award and 2013 Washington State Jefferson Award for Volunteerism. Karen also volunteers with the Boy Scouts and was a Girl Scout as a youth. She has two sons on the autism spectrum, a 7 year old Wolf Scout and a 14 year old Life Scout.

**Kelly Behnke** - Illinois - Kelly is an advocate for her eleven year old son. Kelly works in public education and has taught drug prevention as well as Autism Acceptance. She not only was a Girl Scout herself, but was a leader and trainer for 8 years. Currently, she serves as a Boy Scout leader in a number of roles, including trainer, and is working hard to make sure that scouting is available for scouts of all abilities.

**Gavin Bollard** - Australia - Gavin is an advocate for his son as well as himself. Gavin works in the Technology field and is a prolific blogger with a large following at "[Life with Aspergers](#)". He has been a Joey Scout leader and has written about scouting and its benefits.

**Jennifer Cook-O'Toole** - North Carolina - Jennifer is a teacher, award winning author, creator of [Asperkids LLC](#), speaker, blogger and amazing advocate for herself, her three children and husband who are all Aspies and Asperkids. She has won many different awards including the 2012 GRASP Distinguished Spectrumite Medal Award.

**Jackie Dannemiller** - Oregon - Jackie works as a special education teacher at the high school level and believes in inclusion for youth in scouting of all abilities. She is a passionate Boy Scout leader and Scouting Trainer who has received a number of adult leadership awards.

**Lindsay Foster** - Texas - Lindsay studied special education and works in public education at the elementary level. She is both a Boy Scout and Girl Scout leader. She has three children in scouting and her daughter is on the autism spectrum.

**Linda Ann Horvath** - New Jersey - Linda is an advocate for herself and all seven of her children who are on the autism spectrum. She has created and taught a training on working with girls who are on the autism spectrum in scouting. All of her children have been in a scouting program. Linda volunteers for both the Girl Scouts and Boy Scouts.

**Justin Krejcha** - Washington - Justin is currently a BSA Life Scout and has Asperger's. He has designed and maintained scouting websites. He has worked for the past two years with Cub Scouts in the role of Den Chief for both a special needs unit and a traditional unit. He is currently an Assistant Senior Patrol Leader for his Boy Scout unit.

**Tony Mei** - California - Tony has over 40 years as a special needs advocate within the Boy Scouts. He is an Eagle Scout, co-founder and current webmaster for [Working with Scouts with disAbilities](#). He currently is Chair of the BSA National Task Force on working with Scouts with disAbilities. He likes to have a focus on the Ability vs. the disability.

**Yvonne Mikulencak** - Texas - Founder and Director of the [Asperger Women's Association](#). She is a self-advocate and former Camp Fire USA leader. She is a big supporter of inclusion and acceptance.

**Erin Nilsick** - Ohio - Erin is both a Girl Scout and Boy Scout leader and advocate for her son who is on the autism spectrum.

**Chris Parrott** - Oregon - Chris is an advocate for his son and himself and works in the technology field. He is an Eagle Scout and has provided training to his council where he resides. He has held a number of leadership positions within scouting and been awarded different scouting awards. He has three sons, one of which is on the autism spectrum. He is also the author of the ADHD training on the DVD.

**Heather Parrott** - Oregon - Heather has worked in both publishing and education and has provided training for the Boy Scouts. She has three sons, one of which is on the autism spectrum.

**Erika Schron** - California - Erika is an author, trainer, consultant, radio host, blogger and founder of Journey of Learning Academy. She volunteers with the Boy Scouts and has three sons on the autism spectrum.

**Ronda Schelvan, MsEd** - Washington - Ronda is co-author of "The Hidden Curriculum", presenter, speaker and has worked for more than 30 years in the field of special education. She was co-chair of Southwest Washington's Autism Consulting Cadre for 10 years and currently serves on the Board for the Community Autism Network.

**Richard Williams** - Illinois - Richard is an Eagle Scout and is currently a youth member of Special Needs Crew 88. He is a self-advocate with Asperger's and has been previously featured on Autism and Scouting Radio.

**Sean Williams** - Illinois - Autism and special needs advocate within Boy Scouts and locally in his community. He is the Chair of his district's Special Needs Committee and creator of the Great Race for Autism Awareness. He likes to spread the message of inclusion and acceptance for youth with all abilities no matter what challenges they may face.

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# Chapter 1 - Welcome



Welcome to the first edition of Autism Empowerment's **Autism and Scouting Leadership Training Kit**.

By ordering and receiving this kit, your unit leadership has shown a dedication to learning more about how to work with children and young adults who are on the autism spectrum. Every youth should have the opportunity to have the best scouting journey possible. **Thank you** for being proactive in making that happen with the scouts you serve in your unit.

This kit has been produced to help you to better understand autism, Asperger syndrome and Autism Spectrum Disorders (ASD). We will make mention of other common co-occurring conditions that many youth on the autism spectrum face and will provide you resources for further follow-up, however the focus in this kit is autism-based.

For purposes of educational training and simplicity in reading this manual, when we refer to "Autism" or "ASD", unless otherwise specified, we are referring to all autism spectrum disorders, including Asperger syndrome.

It is our goal to give you practical information, tools and strategies to better understand the scouts you are working with who live with autism. We hope that empowering you will help you in turn empower **all** the youth you work with to have a more meaningful and inclusive scouting experience. We invite you to take a pledge to be a unit that welcomes and encourages youth on the autism spectrum to try out scouting and enjoy the benefits that a scouting program can bring.

## **A little bit about who we are:**

**Autism Empowerment** is a 501(c) 3 non-profit organization dedicated to making life better and more meaningful for individuals and families in the Autism and Asperger communities locally, nationally and globally. We serve all ages and abilities and promote four foundational pillars of positivity: **Accept**, **Enrich**, **Inspire** and **Empower**.

The Autism and Scouting Program is a featured program of Autism Empowerment and is dedicated to following the mission of Autism Empowerment while supporting youth and adults in a wide range of scouting and scouting-like youth development programs. We are not affiliated with any scouting organization. Because each scouting organization has its own program, the information in this kit is presented in a general way with the understanding that you may need to do some adaptation in order to tie in with the rules and guidelines of your particular scouting organization.

This Autism and Scouting Leadership Training Kit had the input and support of scouters and volunteer leaders from a variety of scouting organizations. Our Leadership Training Committee includes youth and adult autism self-advocates, scouters, educators, authors and parents in a wide range of professions.

We encourage you to invite all of your unit leaders to review the information in this kit and to share the resources with others who you believe might find the information valuable. Connect with our website at [www.AutismEmpowerment.org](http://www.AutismEmpowerment.org) and make sure to give this link as a resource to families you come into contact with where one or more family member is on the autism spectrum.

We believe if your unit will become familiar with and use the tools and resources within this kit, the scouts that you have on the autism spectrum will have a more complete and enjoyable scouting journey and will help encourage other youth to check out your unit and give scouting a try. Scouting offers friendship, fun and youth development skills that boys and girls can apply throughout their lives.

We want to again thank you for having your unit take the time to order the Autism Empowerment Autism and Scouting Leadership Training Kit. To access additional copies of these materials online, you can do so at [www.autismempowerment.org](http://www.autismempowerment.org) or [www.autismandscouting.org](http://www.autismandscouting.org).

## Autism Does Not Define a Scout

Former Girl Scout and Executive Director of Autism Empowerment, Karen Krejcha wrote a poem for her two sons and herself in 2010. All three are diagnosed on the autism spectrum. In 2013, it was published in *“Chicken Soup for the Soul: Raising Kids on the Spectrum”* with the title, “Autism Does Not Define Me.”

**“Autism Does Not Define Me”** by Karen Krejcha

**A**ccept me for who I am.

**U**nderstand that I may not always get what you’re saying.

**T**rust that God has me here for a reason.

**I** am an amazing human being.

**S**ocially, I might not fit in with society’s expectations.

**M**entoring can help me along the way.

**D**on’t forget that I have feelings even if I don’t express them.

**O**pportunities for my happiness are indeed possible.

**E**ducate and encourage me without prejudice.

**S**how patience and kindness along the way.

**N**ever give up trying to “get” me.

**O**stracizing me will just shut me down.

**T**ake time to try and come into my world.

**D**efining me as my diagnosis ignores my essence and best qualities.

**E**merging talents may arise when you least expect them.

**F**riendship and honesty is valued to me more than you can imagine.

**I** am in need of love and tenderness too.

**N**ever let me give up, especially when you see my mood shift.

**E**xpect the unexpected and watch me enrich your life.

**M**any people will read this and I pray millions will act

**E**mbrace and empower someone with autism today.





Never forget that autism is just one aspect of a youth's life journey. When talking with youth on the autism spectrum about scouting, treat them with **acceptance** and **respect**. They are the sum of all of their parts and life experiences just like any other human being. Autism does not define them. It does not invalidate them. They are different but not less.

There is a famous saying in the autism community attributed to well-respected autism expert and advocate, Dr. Stephen Shore, "**If you have met one person with autism, you have met one person with autism.**" Remember that phrase!

What does it mean? Quite simply, autism is a spectrum disorder. It is not one size fits all. While many of the issues and challenges that individuals with autism face may seem similar, it is important to remember that every individual on the spectrum is different and unique. As autism is dynamic and not static, characteristics can change or morph over time. Thus, if you work with one scout with autism and then work with a second one, the learning and coping strategies that worked for the first scout may not work with the second.

## **People First Language, Autism and Disabilities**

Have you heard of People First language? If you're an educator, writer or disabilities rights advocate, you may be familiar. It is often referenced in disabilities awareness and acceptance training manuals.

The intent of **People First Language** is to show respect to individuals with disabilities. People with disabilities are first and foremost people who have individual abilities, interests and needs. They are not defined by their medical diagnosis or "label".

It is recognized often in the educational and medical community that person-first language should be used when talking or writing about somebody with a disability, including those on the autism spectrum since autism is considered a developmental disability. One national speaker who has brought this to the forefront is Kathie Snow, the parent of an adult with a disability.

Best practices literature published about People First language lists suggestions of phrases for people to use when referring to people with disabilities. Kathie Snow's website, [DisabilityisNatural.com](http://DisabilityisNatural.com) gives many examples.

For example, instead of “autistic”, say “person with autism”. Instead of “Aspie”, say “person with Asperger’s”. Instead of “he/she is autistic”, say “he/she has autism”.

As mentioned earlier, **autism does not define an individual**. That being said, when it comes to disability language and autism, we get into a very controversial area. If you have familiarity with the Autism Community at large, this has been an issue of heated debate among those who have an Autism Spectrum Disorder (ASD) as well as those who care for them.

Many but not all adults or youth with an ASD will often refer to themselves as Autistic or Aspie when talking about their neurology or diagnosis. Youth may call themselves Asperkids or Auties. Individuals identifying with these descriptors often express that autism or Asperger’s does not define them but they do consider the words as connected with who they are. These are not meant to be stigmatizing words.

The word “Aspie” was coined by Liane Holliday Willey (<http://www.aspie.com>) a woman with Asperger syndrome. Asperkid(s) was coined by Jennifer Cook O’Toole, a woman with Asperger syndrome who has an Aspie spouse and three Asperkids. ([www.asperkids.com](http://www.asperkids.com))

Parents, educators and care professionals often prefer "person with autism" language and many scouting manuals that have a “working with scouts with disabilities” component recommend this language unless you are specifically or talking or writing about the disability itself.

When visiting the Autism Empowerment website, you will find that we will often alter phrasing depending on the context in which it is being used.

**There is no “right” answer for everyone**, however Autism Empowerment asks you to keep these things in mind:

- 1) The intent of “People First” language is to show respect to individuals with disabilities. In everyday reality, “people first” philosophy applied is less about linguistic semantics (choosing just the right word to say) and more **about showing a positive and respectful tone** to the person that you are speaking or working with.
- 2) Give each scout respect and privacy when it comes to their diagnosis. Respect scouts as people first and let them decide how they wish to define themselves. Respect the preference and privacy of the parents also.
- 3) Please remember that many adults and youth proudly refer to themselves as “autistic” or “Aspie”. They see the words as descriptive character traits that are part of their neurology and not something stigmatizing. Respect the preference, respect the person.

Despite what words you choose, as a scout leader, remember:

**Treat each individual as a person first, a unique and valuable human being who is a lifelong learner with gifts to share.**

[http://en.wikipedia.org/wiki/People-first\\_language](http://en.wikipedia.org/wiki/People-first_language)

<http://autismmythbusters.com/general-public/autistic-vs-people-with-autism/>

Autism Empowerment suggests to respect the right of each individual and for each individual to use the terminology that they feel most comfortable with. When in doubt, ask someone their preference and respect that over time, this may change.

## What you will find in this Leadership Training Kit

In the following pages you will find practical information regarding how to work with youth in your unit who are or who may be on the autism spectrum. We tried to pick the most practical and useful information for this guide. Many strategies and tips that are suggested for making your unit more sensory-friendly and accepting will **benefit all scouts**, not just those with an autism diagnosis.

We suggest that you go through the kit in order but if you really have a burning question and can't wait, feel free to go to the section where you need help. We also have a **Frequently Asked Questions (FAQ)** section in Chapter 9.

Although we do cover a lot of topics in this manual, we realize it is not all-encompassing so we provide additional resources at the end for you to connect and receive more information.

We also invite you to stay connected with **Autism and Scouting** and **Autism Empowerment** through social media and through visiting our website at [www.AutismEmpowerment.org](http://www.AutismEmpowerment.org). The Autism and Scouting Program has a very active Facebook page and Facebook group. We also have an active page for Autism Empowerment and highly recommend you connect with all three.

[www.facebook.com/autismandscouting](http://www.facebook.com/autismandscouting)

[www.facebook.com/groups/121685817883439/](http://www.facebook.com/groups/121685817883439/)

[www.facebook.com/autismempowerment](http://www.facebook.com/autismempowerment)

In addition to this manual, you will have also received a DVD that includes a copy of written materials, sample visuals and forms that you can use to better work with scouts who are on the autism spectrum.

We plan in the future to have scouts speak directly to you regarding how you can help them in their scouting journey and empower them to learn new skills, make new friendships, earn recognition and have fun.

Our hope is that you will realize as you go through this kit, that you have support and tools to help promote Acceptance, Enrichment, Inspiration and Empowerment in your scouting units and that you will have increased confidence as a scouting leader in working with youth and young adults with ASD.

## What you will not find in this Leadership Training Kit

This kit was created to be used by leaders and volunteers in scouting organizations throughout the United States and worldwide. Although we periodically give examples from volunteer leaders who belong to different scouting groups, these examples are their experiences and not meant to substitute or represent official scouting policy for a particular organization. When making accommodations or adaptations to a program, please make sure that they are consistent and complementary to the unit program you work with. If you have a question as to if something is allowed, please check with your respective organization to clarify their rules and policies.

Although we will give a definition of autism, Asperger syndrome and provide some other clinical definitions, this Leadership Training Kit was not intended to go into great medical depth.

Each youth on the autism spectrum is unique. Treatments and strategies to address sensory challenges, medical conditions, learning differences and behavioral issues is not a one size fits all approach. This Kit is not meant to replace the advice of medical, legal or educational professionals that are working directly with your scouts and their families.

Health-related material is provided for information purposes only and does not represent endorsement by or an official position of Autism Empowerment. Advice on the treatment or care of an individual patient should be obtained through consultation with a physician who has examined that patient or is familiar with that patient's medical history.



# Chapter 2 - What is Autism Spectrum Disorder?

We talked about this a bit in Section #1 (see Autism Does Not Define the Scout) and are giving more detail here. We won't go into intense medical depth within this manual, however we will provide you with some references in the back of your kit and on the accompanying DVD in case you're looking for follow-up information. One such reference is the Autism Empowerment website at [www.AutismEmpowerment.org](http://www.AutismEmpowerment.org).

**Individuals with autism or Asperger syndrome are often said to be on the “autism spectrum” or have an “autism spectrum disorder” (ASD). What does this mean?**

Clinically speaking, most websites describe ASD something like this:

**Autism or Autism Spectrum Disorders (ASDs)** are a range of complex neurodevelopmental disorders often characterized by social impairments, communication difficulties, sensory input challenges and restricted, repetitive, and stereotyped patterns of behavior. These disorders are characterized in varying degrees.

Autism typically appears noticeable during the first three years of a person's life, however because of the complexity of the condition, it may not be diagnosed until later in life. It is a heterogeneous condition.

## Types of Autism

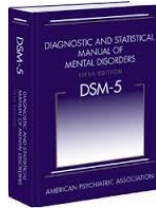
Up until May of 2013, the full range of ASDs included:

- **Autistic Disorder** (also called “classic” autism): This is what many people think of when hearing the word “autism.” People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have delays in cognitive development.
- **Asperger syndrome**: Individuals with Asperger syndrome (AS) or simply Asperger's usually have some milder symptoms of autistic disorder. It is an ASD characterized by difficulties in social interaction and nonverbal communication. Characteristics often include restricted and repetitive patterns of behavior or special interests. It differs from other autism spectrum disorders in that individuals do not have early delays with verbal language or cognitive development. Often challenges with fine and gross motor skills (physical clumsiness) and atypical use of language are reported.
- **Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)**: This is sometimes referred to as “atypical autism”. Individuals who meet some—but not all—of the criteria for autistic disorder or Asperger syndrome may be diagnosed with PDD-NOS. They will usually have fewer and milder symptoms than those with autistic disorders, with symptoms possibly including social and communication challenges.
- **Rett syndrome**: This is a postnatal neurodevelopmental disorder that affects girls almost exclusively. It is characterized by normal early growth and development followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability.

- **Childhood disintegrative disorder:** Childhood disintegrative (or disintegration) disorder, also known as Heller syndrome, is characterized by a loss of previously acquired language and social skills and results in a persistent delay in these areas. Children with this pervasive developmental disorder appear to develop normally for the first two years of life, but then lose skills in areas such as language, play, and bowel control and manifest impaired social interaction and communication associated with restrictive, repetitive, stereotyped behaviors.

The kinds of ASD referred to above are those referenced in the Diagnostic and Statistical Manual of Mental Disorders version IV (DSM-IV). This manual is published by the American Psychiatric Association and provides a common language and standard criteria for the classification of mental disorders. This is the manual referred to by clinicians and diagnosticians when diagnosing autism. The DSM IV was published in 1994 and it was the first time that Asperger Syndrome was included.

- In May 2013, an updated version of the Diagnostic and Statistical Manual was published, the **DSM-5**. In the DSM-5, **autism subtypes are merged into one umbrella diagnosis of Autism Spectrum Disorder**. Rett syndrome was removed from ASD and given its own category.



**Okay. Plain English time. What does this really mean? What does it look like?**

Autism is not a single disorder, but a spectrum of closely-related disorders with a shared core of symptoms. Every individual on the autism spectrum has problems to some degree with social skills, empathy, communication, moderating sensory input and flexible behavior. The level of ability or disability and the combination of symptoms varies tremendously from person to person.

There are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms. **So in reality, two youth or adults with the same diagnosis may look very different when it comes to their behaviors, abilities and challenges.**

As a scout leader or volunteer working with youth on the autism spectrum, you may hear many different terms coming from parents to describe their children including *high-functioning autism*, *atypical autism*, *autism spectrum disorder*, and *pervasive developmental disorder*. These terms can be confusing, not only because there are so many, but because doctors, therapists, and other parents may use them in dissimilar ways.

Individuals with autism may have learning or intellectual disabilities. They may also be of average to above average intelligence. Some have an IQ at a gifted or genius level. Some have savant splinter skills meaning that they are extremely gifted in one particular area such as music, art or mathematics but may be moderately to severely impacted in other areas.

The graphic on the next page represents how one person on the autism spectrum might look in terms of these characteristics.

### MEASURED INTELLIGENCE

Intellectual disability ..... Gifted

### SOCIAL INTERACTION

(Making eye contact, enjoying interaction with others, etc.)

Not interested in others ..... A variety of friendships

### COMMUNICATION

(Using words correctly to communicate)

Nonverbal ..... Verbal

### BEHAVIORS

(Repetitive behaviors, unusual behaviors such as hand flapping, etc.)

Intense ..... Mild

### SENSORY

(Response to touch, smell, sound, taste, and feel)

Not very sensitive ..... Very sensitive

Pain ..... Sounds

### MOTOR

(Gross motor, such as walking)

(Fine motor, such as using fingers to grasp a small item)

Uncoordinated ..... Coordinated

Fine ..... Gross

#### Important things for Scout leaders to remember:

- From the get-go, assume intelligence. Children that are non-verbal may have high-IQs and children that are verbal may have learning disabilities. Don't assume based on looks!
- **No matter what doctors, teachers, and other specialists call the autism spectrum disorder, it is each scout's unique needs that are truly important.**

If a parent comes to you and says, "My child has \_\_\_\_\_", remember that no diagnostic label can tell you exactly what problems each child will have.

**Using strategies that address each scout's needs**, rather than focusing on what to call the "problem" is really one of the most helpful things you can do. It's not about the diagnosis, it's about the child.

While Autism Empowerment believes that each person on the autism spectrum **should be treated as an individual**, it is important to be aware of prevalence rates because statistically speaking, if you are volunteering in scouts, you are likely going to be working with youth on the autism spectrum, some that are diagnosed, some undiagnosed.

## Prevalence Rates

Identifying a true prevalence rate for ASD has proven to be no easy task because there are a lot of factors to be considered. That being said, there are a couple different sets of numbers that have been reported in the United States within the past couple of years.

The first is a report which came out from the Center for Disease Control and Prevention (CDC) in April 2012. In that report, the identified prevalence rate in the United States was that 1 in 88 youth have an autism spectrum disorder. These statistics which are commonly talked about are based on children who were identified with ASD by age 8 in 2008.

In boys it is 1 in 54 and 1 in 254 for girls. It is commonly believed that girls are underdiagnosed.

Here is a chart from the CDC showing the rates within the US.

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88

Statistics do not include children born after the year 2000. Looking at these reported statistics only, it asserts that for every 88 children you meet, 1 of them will be diagnosed on the autism spectrum.

In March 2013, the National Survey of Children's Health reported on an independent telephone survey taken in 2011-2012 with households who had children aged 6 – 17. Parents were asked if any of their children had or had been diagnosed with autism.

"Based on parent reports, the prevalence of diagnosed autism spectrum disorder in 2011-2012 was estimated to be 2 percent for children aged 6-17," the report reads. "This prevalence estimate (1 in 50) is significantly higher than the estimate (1.16 percent or 1 in 86) for children in that age group in 2007."



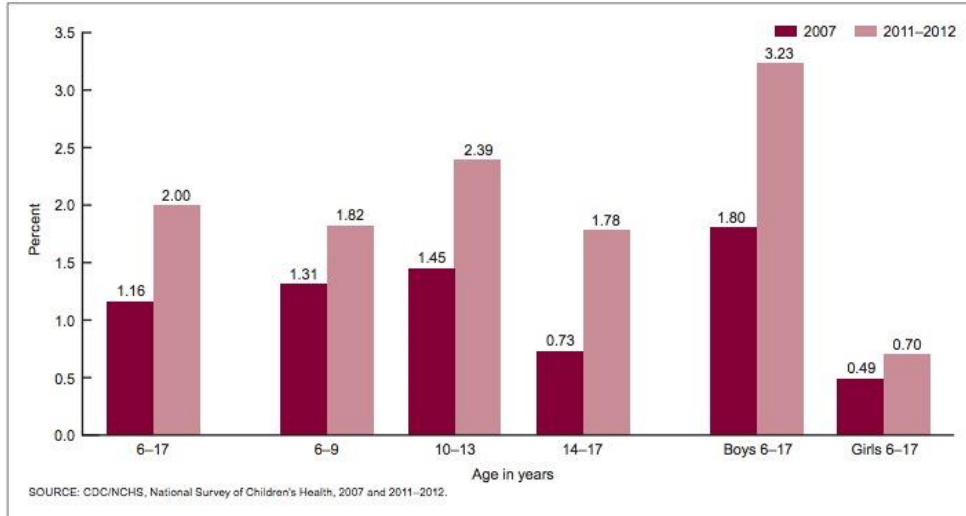


Figure 1. Percentage of children aged 6-17 years with parent-reported autism spectrum disorder, by age group and sex: United States, 2007 and 2011-2012

Statistically speaking, most scouting leaders who volunteer with medium to large size units or who volunteer in a unit for multiple years are going to end up with children on the autism spectrum at some point in time. That is why it is so important that leaders have access to information and training.

It is also why our scouts and leaders on the autism spectrum that had a huge hand in putting this kit together are so glad you are taking the time to enrich yourselves. **Thank you for caring about us and our children!**

Whatever the true prevalence rate is across the board, for an individual with ASD, their personal prevalence rate is **1 in 1** or **100%**. Autism Empowerment and Autism and Scouting **believe that is the statistic** you should focus on in working with your scouts who are on the autism spectrum.



# Faces of Autism

What does autism look like you might be asking yourself? Autism is considered by many to be an invisible or hidden disability. **Can you tell which of the following are on the autism spectrum?**



Hidden or invisible disabilities are disabilities or learning differences that are not immediately apparent and cannot be detected easily. Although the disability creates a challenge for the person who has it, the reality of the disability can be difficult for others to recognize or acknowledge. Others may not understand the cause of the problem if they cannot see evidence of it in a visible way.

**If you have not figured it out yet, *all* of the individuals above, both youth and adults are on the autism spectrum.**

As we said back in Chapter 1, if you've met one person with autism, you've met one person with autism. If you've met one scout on the spectrum, you've met one scout on the spectrum.

## **Okay, got it. But what is that DSM-5 thing? How will it relate to the scouts I work with?**

Yeah, that DSM-5 thing... lots of confusion and controversy with that publication... We won't get too much into the nitty-gritty but here are a few background details to help you understand.

In May 2013, an updated version of the Diagnostic and Statistical Manual was published by the American Psychiatric Association, the **DSM-5**.

This book is the standard classification of mental disorders used by mental health professionals in the United States and some other countries as well. It is intended to be applicable in a wide array of contexts and used by clinicians and researchers of many different orientations (e.g., biological, psychodynamic, cognitive, behavioral, interpersonal, family/systems).

## **So it's the book that doctors and psychiatrists use to diagnose autism?**

Yes. It is also the book used to diagnose Eating Disorders, Social Communication Disorder (new and is similar in some ways to Asperger syndrome), Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder, Depression, Anxiety, Alzheimer's, PTSD, Bipolar Disorder and the list goes on...

## **Autism Spectrum Disorder defined by the DSM-5**

### **Development in early childhood**

To be diagnosed with ASD, an individual must have displayed symptoms starting in early childhood, and those symptoms must impair the individual's ability to function in day-to-day life.

### **Social and Communication Deficits**

In order to receive a diagnosis of Autism Spectrum Disorder, a person must have all three of the following deficits:

- Problems reciprocating social or emotional interaction - This can include difficulty establishing or maintaining back-and-forth conversations and interactions, inability to initiate an interaction, and problems with shared attention or sharing of emotions and interests with others.
- Severe problems maintaining relationships - This can involve a complete lack of interest in other people, difficulties playing pretend and engaging in age-appropriate social activities, and problems adjusting to different social expectations.
- Non-verbal communication problems - This can include abnormal eye contact, posture, facial expressions, tone of voice, and gestures, as well as an inability to understand these non-verbal signals from other people.

### **Repetitive and Restrictive Behaviors**

In addition, the individual must display at least two of these behaviors:

- Extreme attachment to routines and patterns and resistance to changes in routines.
- Repetitive speech or movements.
- Intense and restrictive interests.
- Difficulty integrating sensory information or strong seeking or avoiding behavior of sensory stimuli.

## So does Asperger syndrome still exist? What about PDD-NOS?

Despite the fact that the new DSM-5 has removed Asperger syndrome as an official diagnosis, there is still a large group of adults and children that identify with the characteristics of Asperger syndrome and with what has become for many, a community of acceptance and understanding.

It still exists culturally and you will find a lot of books, support groups, trainings, non-profit organizations and social education organizations continuing to refer to Asperger's, Aspies and Asperkids.

### Sorry, I'm still a little confused.

Hopefully this illustration from Jennifer Cook O'Toole of Asperkids will help.

Here is what Jennifer answers when asked **how is Asperger syndrome different than autism?**

"It's not. It's part of the whole – like a state within a country or a chapter in a book. It's the "vanilla" or "vanilla with fudge on top" in this illustration:



Jennifer continues, "some people really identify with the word "Asperger's" because it explains the particular "flavor" of autism without having to further say "high" versus "low functioning." Others don't care and feel that the larger "umbrella" term "autism" is more unifying, that "hierarchies" are damaging to a community which does all share "the same ingredients...expressed in different intensities." Honestly, I see both sides clearly. And as to how the changes in naming will pan out, only time will tell..."

### So, is there anything else I should know about this change in diagnostic criteria?

In terms of serving your scouts, we hope that having this general overview will be helpful. Some scouting organizations allow for additional accommodations or alternative requirements for advancement to be allowed with youth on the autism spectrum, however they may not do so without a specific diagnosis, so if this is something that applies to the scout you are working with, check with your specific scouting organization for their policies and procedures.

Again, it's not about the "labeling" as much as it is about a person's strengths, the way they learn and process information and how you can help them through challenges.

## **What if I have a scout that now loses an autism diagnosis but would have otherwise qualified for an accommodation or alternative advancement requirement?**

The intent of the reclassification was not to have children or adults lose support services but instead to be supported properly underneath one “autism spectrum disorder” umbrella.

If a child would have otherwise qualified for an accommodation or alternative advancement requirement before based on their level of ability or challenge, they should still qualify, however check with your local scouting organization to be sure.

According to the American Pediatrics Association, “because almost all children with DSM-IV confirmed autistic disorder or Asperger syndrome also meet diagnostic criteria under DSM-5, **re-diagnosis is not necessary**. Referral for reassessment should be based on clinical concern. Children given a PDD-NOS diagnosis who had few DSM-IV symptoms of autism or who were given the diagnosis as a “placeholder” might be considered for more specific diagnostic evaluation.”

So in a nutshell, individuals that were properly diagnosed with autistic disorder or Asperger syndrome should still classify as being on the autism spectrum with “autism spectrum disorder.” Youth that were diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) may find a different diagnostic classification: **Social Communication Disorder**.

### **Is Social Communication Disorder autism?**

No. By definition, **Autism Spectrum Disorder has to be ruled out** before Social Communication Disorder (SCD) is diagnosed. You may see some overlaps just as you will see overlaps with many children who have learning disabilities or attention deficit issues.

SCD is characterized by a persistent difficulty with verbal and nonverbal communication that cannot be explained by low cognitive ability. Symptoms include difficulty in the acquisition and use of spoken and written language as well as problems with inappropriate responses in conversation. The disorder limits effective communication, social relationships, academic achievement, or occupational performance. Symptoms must be present in early childhood even if they are not recognized until later when speech, language, or communication demands exceed abilities.

<http://www.dsm5.org/Documents/Social%20Communication%20Disorder%20Fact%20Sheet.pdf>

### **Important things for scouting leaders to remember:**

- **Using strategies that address each scout’s needs**, rather than focusing on what to call the “problem” or “disorder” is one of the most helpful things you can do. It’s not about the diagnosis, it’s about the child.
- **It is each scout’s unique needs that are truly important. Practice acceptance.**
- Strong scout leaders stay educated, informed and trained. Refer to this kit and the Autism and Scouting Program to keep up-to-date.

### Some other autism facts to think about:

- ✓ ASDs occur among all racial, ethnic and socioeconomic groups.
- ✓ Autism is the fastest-growing serious developmental disability in the U.S.
- ✓ ASDs are almost five times more common among boys than among girls.
- ✓ Referrals for diagnosis for girls however are closer to 10 to 1. (Meaning many girls are not getting referred early enough to benefit from early intervention.)
- ✓ While there is no medical detection or known cure for autism, many children have shown significant improvement resulting from early diagnosis and use of effective interventions.
- ✓ In addition to medical costs, intensive behavioral interventions for children with ASDs can cost \$40,000 to \$60,000 per child per year.
- ✓ Medical costs for children with ASDs are estimated to be six times higher than for children without ASDs.

### Autism Myths

- Autism is a result of bad parenting or what many years ago were called “refrigerator moms”.
- Autism is contagious.
- Individuals with autism have no sense of humor.
- Individuals with autism have no empathy or lack feelings.
- Individuals with autism do not want to communicate.
- All individuals on the autism spectrum who are non-verbal are intellectually disabled.
- Most individuals on the autism spectrum are autistic savants like Dustin Hoffman’s character in the movie, Rain Man.

### Autism Truths

- Individuals on the Autism Spectrum are not defined by their diagnosis. They are people first and should be treated as such (they are 1 in 1).
- Autism is a spectrum disorder and neurological difference that affects each person differently. Symptoms can range from mild to severe.
- Autism affects all social, ethnic and economic classes worldwide but not all boys and girls in each culture are referred at the same ratio.
- Some individuals with autism prefer being called Autistic. Some prefer Aspie. Some prefer “person with autism”. Respect individual preference.
- Individuals on the autism spectrum do have feelings, they do show emotion and they do have a sense of humor.
- There is no one known **cause** of autism. Medical professionals are working to understand the neurological disorder.
- There are many treatments and therapies that work to help improve many of the conditions associated with autism. Effectiveness varies from person to person and is not “one size fits all.”
- Individuals on the autism spectrum need awareness but they **especially** need **acceptance**.

## Co-occurring conditions with Autism

Now that you have received an overview of autism, there is something else to consider when working with scouts and the families of scouts in your unit. **Get ready because this is actually pretty big.**

**Differentiation between the core features of an autism spectrum disorder and other co-occurring neurodevelopmental and psychiatric conditions can be really challenging for clinicians.** Diagnostic confusion may and often does delay appropriate diagnosis and subsequently leads to missed opportunities for early intervention, educational services and the treatments that may accompany an ASD diagnosis.

Reference: <http://pediatrics.aappublications.org/content/129/2/e305.full.pdf>

There is no medical test for autism so in simple terms, doctors don't always figure out what's going on. Diagnosis of adolescents involves personal observation and interviews with a trained specialist or team of professionals. Unfortunately sometimes clinicians that are unfamiliar with diagnosing autism don't know what questions to ask and may dismiss parent concerns, therefore delaying diagnosis.

It is quite common for individuals on the autism spectrum to be diagnosed with co-conditions first.

### Now what does that mean to you as a leader?

Pretend that a family comes to your unit, eager to have their child join scouts but nervous because they're afraid their child won't fit in.



Being the proactive leader that you are, the family received a Scout Information Profile as part of their welcome packet (we'll talk about this form later) and you are sitting down to meet with them to get to know the family and the new scout. Although many parents don't always feel comfortable sharing a child's diagnosis, this family made the decision to disclose.

On the form you see that Chris has: Sensory Processing Disorder (SPD), Oppositional Defiant Disorder (ODD), Obsessive Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD), Anxiety Disorder and just to top it off, maybe an eating disorder too. Oh... and they think, maybe that their child might also have autism but the doctors haven't yet made the diagnosis.

With all this alphabet acronym soup, you might be thinking **O.M.G!** I'm this kid's leader? **H.E.L.P.**

Hey, we understand! The ones creating this manual for you, we get it. We live it. We are on the spectrum, parents to children on the spectrum, scouting leaders on the spectrum, and in some cases, all of the above!

That's why we've written this manual for you and created this kit. Scouting has so many amazing opportunities for youth and adults, including those of us diagnosed on the autism spectrum as well as those of us that probably should be diagnosed on the spectrum but are currently wearing another label or two around our neck.

We have confidence that you have the capability to be a great leader for our son or daughter, our brother or sister. We believe whole-heartedly that if you're reading this manual that you have what it takes.

### **It starts with Acceptance.**

That means accepting we are the sum of our parts but are **so much more** than labels.



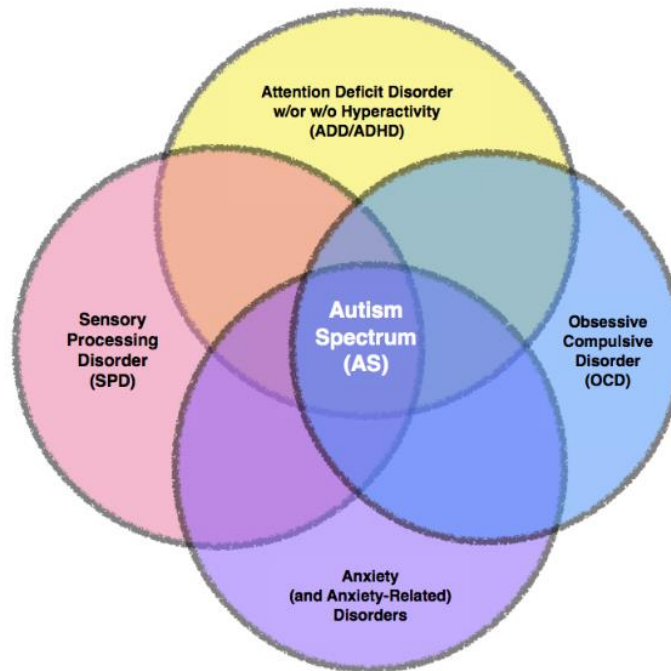
**We want to have fun.** We want to make friends. We want to learn. We want to have adventure. We want to earn badges and patches and go camping and learn about nature and volunteer to serve others. We may not be a “typical” scout... but we'd be happy to be a part of your unit if you'd have us. Deal?



Okay... deep breath. Back to those alphabet soup acronyms above. Rather than looking at all of those “disorders” independently, understand that individuals on the autism spectrum have a wide range of signs, characteristics and symptoms which co-exist and overlap. Remember the earlier “Autism illustrated in Ice-Cream” photo from Jennifer Cook O’Toole of Asperkids?



For illustration purposes, she has created a Venn diagram to give a visual example of how many of the symptoms of being on the autism spectrum *might* overlap. This will look different from person to person.



Not everyone with SPD or ADHD or OCD or Anxiety is on the autism spectrum. However, to varying degrees you are very likely to find characteristics or “symptoms” of those “disorders” in individuals on the autism spectrum. As mentioned earlier in this section, there are distinctive symptoms of ASD.

Here are a few of the more commonly reported co-conditions that can co-exist with autism spectrum disorder. This is not an exhaustive list and going into depth about each of these conditions is beyond the scope of the Autism and Scouting Training Manual.

We have included references and citations in the back of this kit and also on your DVD.

- ADD / ADHD – Attention Deficit Disorder / Attention Deficit Hyperactivity Disorder
- Allergies / Immune system deficiencies
- Anxiety, Bipolar Disorder, Depression and other mental health issues
- Dyslexia, Dyspraxia and other learning differences
- Eating Disorders – Anorexia, Binge Eating, Bulimia, Compulsive Overeating
- Epilepsy / Seizures
- Executive Function Disorder – Planning, Organizing, Managing Time
- Gastrointestinal issues, Chronic Constipation, Diarrhea
- OCD – Obsessive Compulsive Disorder
- Sleeping disorder
- SPD – Sensory Processing Disorder / Sensory Integration Disorder
- Tourette syndrome

We know this can be a lot to take in which is why we have put this information for you in a manual that you can refer back to as needed.

Before we end this section, we want to reinforce a few important points:

- **Scouts on the autism spectrum want to have fun, make friends, learn and have adventure.**
- **Scouts on the autism spectrum do not want to be pitied and thought of as a label or series of symptoms and co-conditions.** They are people first.
- **Scouts may have more “going on” than just autism but that’s okay!** (We’re going to share with you quite a few strategies and tips that can help!)
- **Use the Scout Information Profile (or an adaptation thereof) to get a better idea what challenges a youth might be facing while in your unit.**
- **Focus on each scout’s needs.** It’s not about the diagnosis, it’s about the individual.
- **Acceptance and inclusion of all abilities** in your unit includes leadership, scouting members and all scouts.

*We’ll get into that last part in the next section!*



## Chapter 3 - The Scout Family and Inclusion

An important part of helping a youth on the autism spectrum be more successful in scouting is to positively connect with his or her family and encourage them to take an active role in their son or daughter's scouting journey. In this section we will explore reasons why you should get to know the family and try to understand some of the challenges that families may have to experience on a daily basis.



Ideally, it would be great to connect with each family before their son or daughter joins scouting so that questions can be asked and answered and each party involved will have a better idea of what to expect. When talking about “family”, we include any parent or extended family member who may accompany a scout to meetings or outings. In some cases this includes siblings if they are involved in scouting or may be accompanying a scout to extracurricular scouting functions. In some cases this may be a legal guardian or foster parent. For purposes of this discussion we refer to all caregivers as family.

Connecting with families in a meaningful way in advance to a youth joining scouts is not always possible. Even though autism is often being recognized at a younger age, especially with children whose symptoms or characteristics are more pronounced, there are many youth whose signs might be overlooked or attributed to another cause. It is not uncommon for youth with an Asperger syndrome diagnosis to have been diagnosed in 4<sup>th</sup> or 5<sup>th</sup> grade, perhaps even as a teenager.

Many parents who are also on the autism spectrum share that they weren't diagnosed until after their children were diagnosed. Quirky, techie, geeky, nerdy, socially awkward, eccentric, brilliant, clumsy, disorganized, absent-minded professor, introverted, misunderstood creative genius? These are some of the terms that many adults on the spectrum have used to describe themselves while they were growing up undiagnosed.

When you make a genuine effort to build a relationship with **each** scout and his or her family, then should a situation arise, that family is more likely to openly share challenges their youth may be having. Families that feel respected are also more likely to invest more time in the scouting journey. That helps with scouting retention and overall satisfaction for scouters, families and leaders. **Win-win-win!**

**When meeting with ANY scout and his or her family, we recommend five Ps:**

- Be Polite
- Be Professional
- Be Positive
- Be Patient
- Be Proactive

## **Is it really necessary to get to know the family? Isn't getting to know the youth good enough?**

We realize you're not going to become best friends or personally relate with every family you meet, however establishing a positive connection with each scout's parents or caregiver shows that you care about their son or daughter and want him or her to succeed in scouting. That is something you should always have in common.

Other benefits of information gathering and family connection-building:

- Parents are going to know their children the best and know what routines they may be accustomed to.
- Learning and mirroring coping strategies that are already successfully being used at home or school provides consistency. You can also learn from parents if they have tried something that hasn't worked.
- Families with children on the autism spectrum may be feeling isolated or overwhelmed. Making a connection helps them feel supported and helps you understand some of what they are contending with beyond typical life challenges.
- You will get to see a better overall picture of where the scout is coming from culturally.
- You will often get a sense of if the youth has a supportive family or one that does not support the scout in their scouting journey. This will give you a chance to build on the scouting support or encourage the family to be more positive about scouting.
- You will find out what level of involvement the scout's family may be willing to take on. Some family members will want to jump in and help lead and others are hoping that Scouts might provide a break (respite care) for the challenges they face.
- In many families there is a genetic component tied in with autism. What this means is that your scout may have a brother, sister or parent that is also on the autism spectrum. Some will disclose this. Some will not. Some will not yet be aware. In any case, be mindful, accepting and respectful.

## **Okay. Got it! What is a good way to make that first contact?**

I'm glad you asked! When a family first joins scouting (or renews), they fill out an application packet. The contents will vary from one scouting organization to another. This is an opportunity for you to show parents that you and your scouting unit are dedicated, caring and responsible.

## **Who makes the contact and what should they say?**

This will vary depending on a variety of factors including the age of your members, your unit structure and Scouting level.

With scouts in Pre-K through elementary school or in programs that are primarily adult led, this may be a **den / group leader**. With scouts that are middle school age or older in programs that are intended to be youth led such as Girl Scouts or Boy Scouts, this may be a Troop Leader, Scoutmaster or Assistant. Middle school age children may fall into "adult led" or "youth led" categories, so choose an adult that is going to be directly involved in leadership or mentorship.

**Focus on the positive.** For example when handing out application packets, "we're interested in getting to know more about your son/daughter so he/she can make a smooth transition into our group and we can learn his/her interests, strengths and learning style."

## Individual Scout Profile (ISP) and S.M.I.L.E. Worksheet

The **Individual Scout Profile** is a two part worksheet developed by Autism Empowerment and the Autism and Scouting Program to help you better learn a scout's strengths, challenges and learning style. The first part is for the parents or caregivers to fill out. It provides clues to potential sensory challenges and also alerts you to medical, health and safety issues that will help you better serve each scout in your unit.

It is best practice to have **ALL scouting families** fill out this form and to have it updated annually, preferably at the start of your scouting season.

- Many disabilities and learning differences are hidden or invisible. A youth may not have an autism spectrum diagnosis but he or she may still have sensory, learning or emotional challenges that are helpful to be aware of. Many of the strategies we suggest throughout this guide are beneficial to ALL scouts.
- You are proactively showing families from the start that you care about a positive experience for their children.
- You do not hurt feelings, assume disability or alienate any family by singling them out.



The second part of the **Individual Scout Profile** is the **S.M.I.L.E. worksheet**. This is a “get to know you” worksheet for the scout to fill out. It asks questions about their interests, likes and dislikes and is similar to what many teachers use in school when they're getting to know new kids in their classroom.

Answers can be used as conversation starters and will help you with the bonding process. Information can also be used to help find buddies or peer mentors already in your unit with similar interests.

*Please see a copy of these forms on your Autism and Scouting Leadership Training Kit DVD.*

**We've never done this before and I'm a bit concerned about privacy push-back from new parents and families that are already in our unit. Any suggestions?**

We understand your concern. Before introducing these forms into your unit, we recommend sharing them with your group leadership committee so that everyone is on board with the concept and understands the reasoning behind gathering this information from ALL scouts. (Make sure to show them a copy of this kit if they have not been through Autism and Scouting Leadership Training!)

If you're worried that you might receive a negative reaction from parents, we have some help here too.

At the top of the **Individual Scout Profile** is a paragraph that explains the purpose of the profile and the potential benefits. Caregivers are informed that the intent is for leadership to better serve each youth and create a more positive scouting experience that is tailored to the needs of the group.

Here are some additional points to share:

- Your unit leadership recently went through training to better serve all scouts within the unit.
- The Individual Scout Profile is not the same as an annual medical form which a scouting organization may require for participation in events and camping activities. Filling out the information in the ISP is strongly encouraged but it is **optional**. Parents and caregivers can fill out as much or as little of the profile that they wish.
- All records will be handled by staff or volunteers whose job includes processing or using this information for the benefit of the participant.
- Minimal necessary information may be shared with selected staff or volunteers in order to provide adequate participant safety and health care.

If you give the **Individual Scout Profile** out as part of your Welcome Packet, new families are probably not going to know you haven't done this before and will just fill the information out as part of their registration.

With returning families, you might say that unit leadership has decided as a team to help strengthen the unit to better serve all scouts and gathering this information is intended to be for everyone's benefit.

**Finally, these forms are meant to be used as a template.** You are allowed to adapt them to suit your unit's needs. Please send a copy to Autism Empowerment so we can see the great work you are doing!

### **Who gives these out and who receives the forms after they are complete?**

Most units will give these out as part of a welcome or rejoin packet. In units that are primarily leader-led, the person handing out the forms should be the direct leader, someone who will be working closely with the scout. In units that are primarily youth-led, it should be an adult leader that will have a connection with that scout and his/her family.

Be aware that these forms will often require some time for thought if you want meaningful answers. To take away pressure and to increase the likelihood that forms will be filled out in greater detail, the leader handing out packets may suggest a family take the ISP and S.M.I.L.E. forms home and fill them out sometime before the next meeting.

- **IMPORTANT!** Have the person who is **handing out the forms** mention that at a mutually convenient time that he/she or another leader in the unit would like to spend 15 - 20 minutes with each family to get to know them, review their profile and get their scout off to a positive start.
- With returning families, you're going to already know them and their scouts to varying degrees but we strongly suggest you still meet and review the form. It may not take as long as with a new family. If you expect push-back, you might wish to phrase it as a short meeting to check-in, review the form, check a scout's current progress and answer any questions.

In some units a Medical Records Coordinator or Committee Chair may initially collect the forms. In some cases it may be a direct unit leader or closely connected unit volunteer. The forms need to be accessible to the Scout Leader that will be facilitating the **Caregiver and Scout Leader meeting** or “**check-in.**”

### **The Caregiver and Scout Leader Meeting**

As mentioned earlier, the Autism and Scouting Program of Autism Empowerment promotes that strong leadership includes making **positive and meaningful connections with each scout and his or her family**. For purposes of this discussion we’re going to talk about meeting with families or care providers where you have been made aware from the questionnaire or prior discussion that the family has a child on the autism spectrum. This can be adapted to other diagnoses and co-existing conditions.



Parents of children with autism have likely spent quite a bit of time in meetings with medical professionals, educators, therapists and other providers. A 15 - 20 minute meeting request shouldn't seem that out of the ordinary. **If you have prefaced it by letting them know you're interested in helping their youth succeed, parents or other caregivers should be receptive.**

If you're getting a sense of push-back, this may be a warning sign that other things are going on in the home environment. You will want to tread carefully and see if you can find out the concerns. **Assume that the family does want to work with you** but may be anxious or apprehensive with someone they do not know. Some people are naturally more open with sharing while others are reserved. Sometimes there might be a language or cultural barrier with the family. Showing acceptance and respect builds trust.

By asking for a short meeting to go over forms and “get to know you”, it keeps the initial discussion time reasonable but still allows bonds to begin to be formed. In reality, what you will be discussing may need to take longer but try and keep this initial meeting to a reasonable timeframe.

Here are some guidelines for this “get to know each other meeting” in order to get you started.

- Have a meeting between the direct scout leader and the parent(s) or caregiver first. This way you as the scout leader can ask questions of the caregiver without the scout present. The scout may or may not be aware that they are on the autism spectrum and the wishes of the scout's family need to be taken into consideration.
- Remember that the youth is a person first. If they are on the autism spectrum, autism is just one part of them, just like the color of their hair or if they are left handed or right handed.

- Give the parents and caregivers a chance to ask questions about you and your unit. Remember that Scouting exists for the youth and not for leadership or egos. Be open with them. Depending on the needs of the child and the ability for support within a unit, a parent or caregiver may need to more actively participate at events or overnights so if there is an expectation or policy in that area, try and make it clear.
- When going over the **Individual Scout Profile**, try to phrase things in the positive, talking about strengths first. Do assume intelligence. Parents and clinicians sometimes become so focused on the deficits and the negative issues that a child is having that they aren't able to notice what a child does well. By asking about what a child is good at and what his or her positive traits are, you have information for teaching, modeling and positive reinforcement.
- When going over the parts of the form where challenges with sensory, emotional, social, dietary restrictions or allergies may be checked, make sure you verbally clarify each area.
- Bring up to the caregivers any concerns that you may have about a scout's sensory issues or emotional triggers as these may cause meltdowns or shutdowns.
- Listen non-judgmentally. Families do not want to be pitied or be made to feel that their child is going to be a burden.

**Example:** I see that you mentioned Johnny doesn't like loud noises. Would you tell me a little more? How does he react and what do you do to help calm him afterwards?

**Example:** I noticed that Susie has trouble staying focused. What are some of the strategies at home or school that have been most effective?

**IMPORTANT NOTE!** Although you may have an urge to give guidance or "fix" an issue, this is a time for listening. If your unit has certain tools already in place (i.e. visual schedules, sensory break area, noise-cancelling headphones), it's okay to mention them but be humble and realize that you are just getting to know the family and chances are, they are giving you a softer version of what their reality is. Families who have children with autism often get plenty of unsolicited advice. Your goal here is to build an authentic bond so that you can be a better leader and help empower their son or daughter through their scouting journey.

- Find out what accommodations the scout may need if applicable.
- Ask what level of privacy they prefer. See the next section on Privacy.
- Getting parents or caregivers involved in the scouting journey can benefit the entire family, however in the beginning, realize that families may be hesitant to jump right in. In addition to exploring the strengths of the child, it can also be useful to ask a question or two about family strengths and interests. Is Dad a chef? Is Mom a musician? People are more likely to volunteer in areas they feel confident.
- If a parent or caregiver doesn't seem to want to get involved right away and their child is old enough and has the ability to participate in most activities without a parent by his/her side, be mindful that scouting can serve as well-appreciated break time (respite care) for the caregiver. We do not suggest parents ever get the impression that scouting is a "drop-off" only activity. You



may still need them to be close depending on the ability level of the scout but this can give the family member a needed break.

**Note:** Well-meaning scouting leaders are often eager to recruit parents into volunteer roles, especially if a unit is young or experiencing transition. This “get to know you” meeting is not the time to soft pressure a parent or caregiver into a leadership or committee role. That may come in good time but it is much more likely that they will step up when they see their son or daughter happy and excited about scouting.

- After you talk with the caregivers, bring in the scout to get to know him or her using the **S.M.I.L.E. Worksheet** - Scouting Makes Inspired Leaders Exceptional.
- Build the bond. Create the connection. Invest in the family and watch for dividends.

### Meeting Follow-Up

Now that you’ve established a connection at the initial **Caregiver and Scout Leader Meeting**, you want to keep that connection going. Here are some suggestions:

- Send a thank you follow-up note after the meeting, letting the family know that you will do your best in working with their son or daughter and offering an open door policy if they have any future questions or concerns. (This shows continuing acceptance of the scout and his/her family.)
- Now that the family and scout have shared strengths, learning styles, challenges and any concerns, incorporate that information into your scouting plan.
- Periodically check-in with the family and give a progress report on how their scout is doing, emphasizing strengths and positives. If talking about challenges, try to frame in a positive way, “opportunities for growth” rather than “bad” or “wrong”. Even if there are problems and challenges, you want to partner with the family to find solutions, not be their adversary.
- Some units establish an “Accommodations Coordinator”, “Sensory-Friendly Coordinator” or “Special Needs Coordinator” who acts as a liaison between families, scouts and leaders. If your unit has a position like this and they were not at or leading the Caregiver and Scout Family meeting, make sure they connect with the family.
- Offer opportunities for the family to help participate or get involved in some way so that they have a chance to help see their scout thrive and be more invested in the scouting experience.



## Privacy

Disclosing a hidden disability such as autism or Asperger syndrome is often a fearful task for parents and youth, especially since one doesn't know how others may respond. Often people that are unfamiliar with autism or ASD are operating under false assumptions, fear or lack of accurate information.



When a family does share, it is respectful to **acknowledge that disclosure** and get a feel for what their preferences may be when it comes to who else in your unit should know and what should be known.

If a scout is less outwardly affected, often no disclosure outside the unit leader and direct unit contact leader may be desired in order for the scout to have a better opportunity to feel full inclusion and not be singled out.

Your level of disclosure to other leaders, volunteers or in some cases other scouts is often in direct relationship to the challenges that youth may be facing.

**Example:** When it comes to safety, there are many children on the autism spectrum who are prone to wandering, something that could be a big concern on field trips or campouts. Some youth have a high tolerance for pain and may not indicate or even know when they have been hurt. Because almost all youth on the autism spectrum are prone to challenges with communication, you need to be extra mindful to their vulnerability when it comes to health and safety issues.

Autism Empowerment holds the position that when a person discloses a diagnosis, they have an opportunity to promote acceptance for not just themselves or their child on the spectrum but for others as well. When one is willing to talk about autism in a meaningful and open way, they help to demystify autism and reduce the chance for stigmatization that others may feel.

Your unit should have policies and procedures in place when it comes to the safekeeping of medical records but if you're not sure, then do ask. Often they are held by a medical records coordinator for the unit. If your group is small, a leader may be taking on dual roles.

Disclosure and the amount of disclosure should be discussed in **The Caregiver and Scout Leader Meeting**. This should be without the youth present in case he or she is unaware of a diagnosis. It is better to err on the side of privacy.

If a family is very open about disclosure, which is more likely to be the case if their son or daughter has more obviously seen challenges, this is an opportunity to offer them the chance to present to other leaders or scouts about what autism may look like for their son or daughter.

## Inclusion

Inclusion defined in the dictionary is the act of including or being included. So what do we mean when talking about inclusion in a scouting environment?



Think of a time when you felt like a real outsider, when you felt really **excluded**.

**How did that make you feel?** Sad, mad, lonely, depressed, angry, withdrawn, embarrassed, ashamed?  
Not so good...

Now think of a time when you felt like you really belonged, when you were welcomed, when you were **included**.

**How did that make you feel?** Happy, warm, loved, self-confident, positive, accepted?  
Much better!

***Which experience would you want to give your children? Which experience do you want to provide and teach to scouts under your care?***

A big reason why parents may choose a scouting program for their youth is because scouting at its core is about inclusion, embracing humanity and offering the opportunity for individuals of all abilities to learn new skills, build friendships and have fun in a cooperative and accepting environment.

**Parents of children with autism want their kids to have friends, learn new skills and have fun just like their typically developing peers**, however it can sometimes be difficult to find inclusive minded extracurricular activity programs that allow each person to shine and be successful.

Families of children with autism often report feeling isolated and overwhelmed by schedules which don't leave much time for building peer relationships and having fun. If a family is in a situation where their schedule revolves around school, medical appointments and therapies, they often don't feel like they're having a great quality of life. Scouting often helps fill that gap and gives a youth something to look forward to.

*"When children take part in a camp or other activity without exclusion or discrimination based on disability, they learn skills of vital importance in today's multicultural world -- to appreciate one another's diversity, to understand and accommodate differences, and to develop friendships based on genuine respect and equality."* Meg Evans, Autistic Self Advocacy Network

Having a youth being included in a positive values-based program that promotes honor, integrity and doing one's best allows the scout and family a feeling of being included both in scouting and as a part of a larger community.

There are many positive outcomes to inclusion for not only the scout and the scout's family but for the whole scouting program and the community at large. Here are just a few:

- The scout builds confidence and feels like they belong to something larger than themselves.
- The scout is able to try new things in a safe and accepting atmosphere. A common saying in the scouting community is "scouting is a safe place to fail."
- If a scout fails in something, the safe atmosphere allows the chance to learn from mistakes and grow with leaders that have that young person's well-being in mind.
- It gives the parents a place to bring their youth to feel included and earn recognition for their progress.
- Having a youth with autism in their unit teaches scout leaders about working with children with different abilities and makes them stronger leaders when supporting all youth.
- It gives a chance for unit leaders to become stronger and provide a more comprehensive program for all scouts.
- Scouts without autism and their families have a chance to grow in their understanding and acceptance of autism, neurodiversity and differences.
- This better understanding and acceptance of individuals with autism and other differences will often be transferred to other settings such as school or work.
- Including the family in scouting as well can allow them to feel less isolated and alone within the community.
- Inclusion of youth with autism in scouting promotes acceptance within the community at large.  
**Accept, Enrich, Inspire, Empower!**

As a scouting leader or volunteer, remember that acceptance and inclusion need to be promoted by all leaders and volunteers within your unit.

One way to do this is to have a pack, troop or unit meeting at the beginning of every scouting season that has a theme of **Acceptance of All Abilities**. This is a form of disabilities awareness training, however the primary theme is Acceptance. Autism Empowerment's Autism and Scouting Program has ideas for you to use to create this Acceptance of All Abilities day. See Appendix sheet for ideas on hosting this kind of event.

Remember that we are ALL ambassadors for acceptance of all abilities. The youth we lead will look to adults to be role models that guide them. There is a saying that goes, "don't just talk the talk, walk the talk!" **Make sure you are living by the principles that you teach.**



## Chapter 4 – Different Ways of Thinking & Learning

One of the most baffling things for leaders, parents and teachers to understand is how some children on the autism spectrum can be **extremely gifted** in one area but **seemingly clueless** in another. These particular children are often very smart academically but socially very behind with interpersonal difficulties that can lead to loneliness and anxiety. It is an autism paradox.

In scouting this may take the form of:

- Children that are virtual encyclopedias in subjects they are interested in but can't tie their shoes, pack their own bags or remember to bring their scout book, hat, sash, etc.
- Someone who is very happy-go-lucky UNTIL someone breaks a rule or veers off schedule.
- A youth able to laser focus on one activity with extreme intensity one meeting but unable to focus, keep their hands to themselves and sit still at the next meeting.
- Youth that get so stuck on how to **begin** a timed project or craft that they never complete it.
- Someone who can verbally recite the instructions on how to tie a knot, sew a badge, cook a meal or put up a tent but they can't physically do these skills without a lot of help.
- Even though you know that a scout can demonstrate how something is done because you've seen her do it, she struggles to "connect the dots" between thoughts and words to explain it.
- The youth can hear a cricket chirping or an owl hooting from a distance but you need to call his name five times before he will respond.
- The kid that must be first in line every time... or last... but never in the middle.
- Failing to notice that despite having perfect pitch, people around them are not interested in hearing the same camp song 49 times in a row.

### What is going on in the brain which is causing the challenges you may be seeing above?

We could write a library of books about this subject but since many have before us, we're not going to try and reinvent the wheel. We'll give an overview below of some of the core challenges individuals on the autism spectrum face and then in your reference section, we'll provide links if you'd like to find additional information.

- **Executive Function:** Executive functioning challenges are associated with a variety of different disorders including autism and ADHD. It is a set of mental processes that help you connect your past experience with present action.

It may help to think of executive functioning in terms of having a Chief Executive Officer or Chief Operating Officer of your brain. This **head honcho** is in charge of all the high-end mental processes that allow you to get things done: analyzing, planning, organizing, developing timelines of completion, adjusting and adapting to change and completing your tasks in a timely way. If that wasn't enough, the Chief helps you self-regulate your behavior and impulses too.

It's like the executive function center in your brain is the air traffic controller at a busy airport, managing arrivals and departures of dozens of planes on multiple runways.

- **Theory of mind / Mind blindness:** This refers to the ease at which someone is able to put themselves in someone else's shoes, to correctly imagine and understand their thoughts, feelings, motives and intentions.

As no-one can “read minds” or see what's going on in another's brain, we all are “mind blind” to a degree. Adults on the autism spectrum when referring to their own theory of mind may refer to it as the level of ability for someone on the autism spectrum to create a functional representation of the thinking of someone not on the spectrum.

- **Understanding Social Rules or the “Hidden Curriculum”:** This is an impairment in ability to learn, understand and demonstrate the implied, unspoken, often changing rules and routines of a situation, game, or event. These are usually seen as common-sense items that don't need to be directly taught but should somehow be intuitively known.
- **Concrete thinking:** Most individuals on the autism spectrum have a tendency toward concrete versus abstract thinking. They may take the words you say very literally and may have trouble initially understanding sarcasm, euphemisms, slang and idioms. Concrete thinking is thought derived from the senses, which reflects experience rather than abstract reasoning.

## Learning Styles and Multiple Intelligences

A learning style is defined as a person's natural or preferred way to acquire and process information when in learning situations. It is also the way in which people gain information about their environment.

The most commonly referred to learning styles are **Visual**, **Auditory** and **Kinesthetic**.

There is also a theory of multiple intelligences developed by Howard Gardner that extends beyond the traditional view that there is a single kind of intelligence that can be measured by standardized tests. It extends well beyond the “learning styles” listed above.

### These 7 intelligences include:

- **Visual / spatial learning** – learning through pictures, images and spatial understanding
- **Aural / auditory-musical** – learning through sounds and music
- **Verbal / linguistic** – learning through using words, both in speech and writing
- **Kinesthetic / tactile** – learning through your body movement, hands and sense of touch
- **Logical / mathematical** – learning through logic, reasoning and systems
- **Social / interpersonal** – learning in groups or with other people
- **Solitary / intrapersonal** – learning by working alone, self-study



Most people learn through a combination of ways but they often have one or two dominant or preferred ways of being able to learn and process information.

Arguably the most well-known person on the autism spectrum in the world is Temple Grandin. You may have seen the HBO movie made about her life, heard her speak or read one of her multiple books.

*"I THINK IN PICTURES. Words are like a second language to me. I translate both spoken and written words into full-color movies, complete with sound, which run like a VCR tape in my head. When somebody speaks to me, his words are instantly translated into pictures. Language-based thinkers often find this phenomenon difficult to understand, but in my job as an equipment designer for the livestock industry, visual thinking is a tremendous advantage." Temple Grandin, Thinking in Pictures*

Although many on the autism spectrum may be visual thinkers and learners, it is important to assume that this is **not the case** for everyone on the spectrum.

The **Individual Scout Profile** includes a section where parents / caregivers indicate how their child learns best. The **S.M.I.L.E. sheet** also asks learning preference questions so please use the information on these forms. Sometimes people are unsure so you might be able to tell through observation. There are also a lot of free online tests at:

[http://kids.lovetoknow.com/wiki/Learning\\_Style\\_Test\\_for\\_Children](http://kids.lovetoknow.com/wiki/Learning_Style_Test_for_Children)

A useful article about Multiple Intelligences can be found at:

<http://www.ldpride.net/learningstyles.MI.htm#is%20Multiple%20Intelligence>

### **What about scouts with autism who are non-verbal? How do they communicate?**

Individuals on the autism spectrum who are minimally verbal or non-verbal still communicate, however they do so in a variety of different ways including sign language, writing, art, keyboarding and using **Augmentative and Alternative Communication (AAC)** devices.

"AAC is a set of tools and strategies that an individual uses to solve every day communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices, etc. Everyone uses multiple forms of communication, based upon the context and our communication partner. Effective communication occurs when the intent and meaning of one individual is understood by another person. The form is less important than the successful understanding of the message." *Linda J. Burkhart, Technology Integration Specialist*

If you have a scout in your unit who is non-verbal, be sure to find out from the parents, caregivers and youth the ways in which the youth communicates. Often with younger scouts who are non-verbal, a parent or educational aide will accompany the scout to and from activities.

Some leaders may be anxious to have a non-verbal scout in their unit, however it really is a benefit to the scout and that scout's family for this youth to be included. It is an opportunity to promote inclusion and acceptance and it also gives the family a teaching opportunity to advocate for their child and if old enough, to empower the scout to advocate for him or herself.

### **A few things to remember with scouts who are non-verbal:**

- Unless you have been told otherwise, trust that the non-verbal scout can hear, see, smell, taste, feel, think, formulate ideas, understand what he/she hears, understand what he/she sees (including reading), question what he/she does not understand and be successful.
- It is always better to **assume competence** and intelligence than the opposite.
- Do your best to make a genuine connection with the scout. So many times, people are nervous or afraid to communicate with people that are different from themselves. Make sure to address the scout directly. This is an opportunity to really show another human being that he or she is welcome and accepted. Wouldn't you want the same if it were your son or daughter?
- Everyone communicates! <http://www.everyonecommunicates.org/index.html>

### **Suggestions when working with ALL of your scouts:**

- Understanding and accepting the ways that a scout learns helps you get into their world effectively and instruct them in ways that include them rather than exclude them.
- Individualize your teaching when possible. Instead of "one size fits all", learn as much as you can about each scout, and teach each person in ways that they find comfortable and learn effectively.
- Teach important tasks several ways, not just one (e.g. through role play, visual examples, stories, peer modeling, diagrams, music). By doing this, you promote what it means to understand something well.
- Augmentative and Alternative Communication (AAC) tools benefit verbal and non-verbal scouts.
- When explaining a new skill, demonstrate how it is done in concrete language.
- When giving choices, try to be clear rather than open-ended. For example, "Would you like to go to the archery station or the arts and crafts station?" rather than "What would you like to do next?"
- Avoid overstimulation by structuring your meeting environment to be organized with minimal distractions.
- Have written rules for meetings, outings and campouts and provide a copy to parents so that they can prepare a scout at home for what to expect.
- Use visual supports to make the sequence of activities predictable and understandable.

### **Visual Supports**

A visual support refers to using a picture or other visual item to help communicate with a child who has difficulty understanding or using language. Examples of visual supports include photographs, drawings, objects, written words or lists. This teaching tool can be done in a very simple way with stick figures or you can draw out a whole situation.

You may want to use a visual support for:

- 1) Explaining upcoming situations where there may be sensory challenges or obstacles.
- 2) Modeling correct behavior choices in a certain scenario.
- 3) Recreating a situation that turned out successfully as a tool to reinforce the positive choice.

A free 4 page Visual Supports and Autism Spectrum Tool Kit can be downloaded from Autism Speaks.

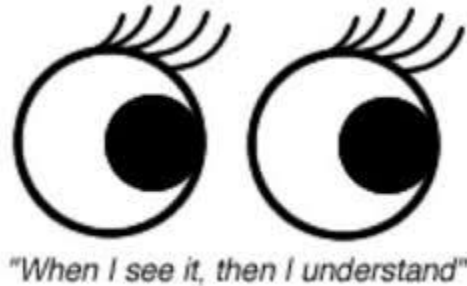
[http://www.autismspeaks.org/docs/sciencedocs/atn/visual\\_supports.pdf](http://www.autismspeaks.org/docs/sciencedocs/atn/visual_supports.pdf)



## Schedules

Imagine you are called into a meeting at work by either a co-worker or an employer. You are not told what the meeting is about and you are not told how long the meeting is going to be. How would you react? Would you feel stress or anxiety? For most people this would be a common reaction.

A common trait for those who are on the autism spectrum is the **desire for structure, order and predictability**. It is also common to have a challenge with the abstract concept of time and to be able to correctly predict, plan or understand how long a task will take to complete.



When having unit meetings, going on outings or attending camp, **having a written or visual plan and schedule** for a scout on the spectrum is extremely helpful. It allows that individual to understand the sequence of expected tasks or events. By knowing the order of activities and what is coming next, it helps that person be prepared for anything that may be a challenge.

Schedules can be used for meetings, outings and even longer multi-day events such as summer camp. Having structure and a sense of routine will often reduce stress and minimizes the likelihood for a meltdown or shut down. It also allows for better communication among the scout, parents and leaders.

Some of the positive things that come from using a schedule.



- Scouts on the spectrum don't have to guess or try to predict what is supposed to happen. They can look at the schedule and see the sequence of events.
- Scout families can share the schedule in advance and can prepare the scout for possible challenges. (For example, when we practice a fire drill, there may be loud noises so you will want to have your noise-cancelling headphones or arrange to be in another area.)
- Scout Leaders can become more organized and on track with their meetings.
- All scouts will benefit from having a schedule and should be accustomed to schedules if they attend public or private schooling.

A **visual schedule** is a visual / concrete system used to tell a scout what, where and when activities will occur throughout the day or within a task or activity. It can be used across all environments (home, school, scouting, community), ages and functioning levels.

There are many ways you can create a schedule. We have provided you two examples. The first example is with a schedule that can be used with a visual timer clock and is based in sections by minutes.








Den Meeting Schedule

Wednesday, November 7th

Opening Flag		5 Minutes	
Station 1	Sewing		15 Minutes
Station 2	Card Making		15 Minutes
Station 3	Games		15 Minutes
Awards		5 Minutes	
Circle time		5 Minutes	

The second example is based on time and should be used with a clock. This is with the understanding that your scouts can read time. You can always opt for a digital clock while scouts are still learning.

Friday Schedule

Arrival		11:45 pm
Opening Flag		12:00 pm
Wolf Den Time		12:30 pm
Station 1		1:10 pm
Station 2		1:50 pm
Snack Time		2:30 pm
Station 3		3:15 pm
Station 4		4:00 pm
Wolf Den Site Clean- up		4:45 pm
BBQ Time		5:15 pm
Campfire		6:15 pm

*Example of a schedule for a summer day camp*

**Other things to remember about schedules:**

How many times have you been to a meeting that lasted **exactly** the time that was allotted?

You may not want to put an exact time on the schedule unless you KNOW that the schedule will be strictly adhered to because many youth on the autism spectrum struggle with flexible thinking and will get upset if an activity is supposed to start at 6:00 p.m. and it is 6:01 p.m.

When you give a schedule to scouts on the spectrum you need to also sit down with them and explain that this is the best estimate and that things may happen that cause us to get off schedule.

Letting your scouts know upfront that the plan is to keep on the schedule as best you can but things may change slightly can help minimize the “we are past the time” or “we are not following the schedule” commentary. This also gives the scout a chance to grow and be more flexible.

Using the schedule with the minutes on the right side gives each scout a time expectation and also allows you to use your visual timer clock to start and end each activity.

### **Staying on Task / Transitions**



Moving from one activity to another can be a challenge for many on the autism spectrum. This ties in with the executive functioning challenges that we referenced earlier in this section. Helping your youth with transitions can many times not only benefit scouts on the spectrum but all of the youth in your group.

#### **Here are some ways to help with transitions:**

- Have a printed schedule sent to the families ahead of time so the families can prepare the youth in advance for what to expect at the meeting. If this is not feasible, have copies of the schedule at your meeting for each youth. This is a good tool for any scout to be prepared.
- During the meeting use a **visual timer clock** so the scouts will have a visual to see when they will be making a transition to the next portion of the meeting. You can see what one looks like in **Chapter 7, “Making Your Unit More Sensory Friendly.”**
- Give reminders of the transitions coming up. “Just a reminder that we will be moving to the next activity in 5 minutes” or something to that effect.
- Stick to your schedule as much as possible. If you are going to make a change to the schedule, make sure you provide a warning to the youth and let them know of the upcoming change. Have strategies in place in case this will be upsetting for the scout. (Encourage flexible thinking.)
- When possible, provide a choice. “It’s time to clean up the craft project. Do you want to do it by yourself or do you want me to help?”
- If a scout gets upset, first listen and acknowledge the concern and feelings. Then try to help him or her focus on the next activity. Provide understanding and empathy.
- Use other peers as role models, providing positive reinforcement for the whole group. Avoid singling out or comparing the youth to others. When you praise the whole group, you are reinforcing everybody's success and making all feel they are important parts of the unit.

## Building Connections and Promoting Learning through the Use of **Special Interests**



In the autism world, “**special interest**” is code for what a person on the autism spectrum is **really into** at any particular point in time, even to the point of perseveration. **Perseveration** in this case would refer to an uncontrolled response such as a word, phrase, thought or gesture perpetuated to an exceptional degree despite there being no apparent stimulus. So keeping this in mind, if a person was to have your full undivided attention for hours on end, what would they most likely communicate with you about?

Minecraft? Dinosaurs? Horses? Baseball statistics? Cars? Greek mythology? Roman Numerals?

### Finding out the Scout’s **Special Interest**

When you first meet a youth on the autism spectrum and start to spend time with him or her, you may quickly find out that person’s special interest. Those that are verbally expressive may come up to you and start to talk about their favorite topic non-stop. Others will be less inclined to share but if they see that you have a genuine interest in their interest, it opens the door for communication and bonding.

If you don’t know a person’s special interest, check the **S.M.I.L.E. sheet** that was filled out with their **Individual Scout Profile**, ask the scout what he or she likes to do when outside of school or check with the parents.



### Why is this important?

If you can find out what a scout’s special interest is, then you have found the key to unlocking a treasure chest of potential!

- Talking about a special interest helps get communication going.
- It shows the youth that you have an interest in learning about him or her.
- It sends a signal to the scout that he or she is worth being heard and recognized.
- You have a window into their world and what is important to them.
- You can use that special interest for teaching and helping them stay focused.

## Steps to take to help access their world.



- Observe them regarding their passions and what they are engaged in.
- When you are talking to them about their special interest, be authentic. **Don't make things up** or pretend to know more than you do. Honesty and loyalty are extremely important. The youth will likely see through your facade, call you on your inaccuracy and may not trust you in the future because you have lied about something so very important to them.
- Oftentimes the scout is going to know more about the special interest than you! If you don't know much about their special interest, ask them! This will help show that you are still interested in them and their world and remain the integrity of the bonds made. An example "I don't know much about \_\_\_\_\_, what can you tell me?"

## Using the Special Interest to Help a Scout Learn New Skills

One of the best things about having a scout who is really into a special interest is that you can utilize that special interest to willingly engage them in learning other skills or subjects they don't know. You can also use it as an incentive or reward system. You may need to get creative in the process but having an engaged and happy scout that is learning new life skills and making new friendships is well worth it!

**Example 1:** Johnny is really into birds and bird study, however your unit is trying to teach about citizenship. Let Johnny know you are going to talk about citizenship but that at some point you are going to talk about birds. During the talk, bring up information about the Bald Eagle and why it represents the United States.

**Example 2:** Julie loves talking about the Medieval period of history. You are working on a food unit or badge. You ask each person to bring in something to represent a different time period and then fit those foods on a plate using the current FDA food guidelines. This gets everybody involved and Julie gets to bring in something from her favorite era and create a "Medieval Times" meal.

Points to remember:

- Integrate special interests into how you interact with scouts on the autism spectrum.
- Use a special interest to help teach unfamiliar topics or skills.
- Use a special interest to help a person through a challenging moment and turn it into a teachable moment.
- Harness the power of the special interest to get them passionate about learning.
- Have the youth help teach at a meeting about their special interest if they feel comfortable. This is a great way to introduce and reinforce the concept of leadership.

**I see the benefits of tapping into a youth's special interest but I'm concerned it may be a bit of an obsession and distracting to others. Is there any way to redirect and help them become more engaged in other topics?**

We get it! As fascinating as our special interests are to us, you may not feel the same way. Those of us on the spectrum get distracted by others' special interests too! Imagine everyone in a room all trying to talk about their favorite hobbies, interests, books, TV shows or sport teams at the same time! Sometimes **we all** need a break from the chatter so that we don't feel like we're going bonkers!

As a leader, we don't want to quell the enthusiasm and miss out on a chance to genuinely connect with a scout. Also, sometimes youth on the autism spectrum will engage in repetitive behavior as a comfort mechanism for anxiety or as a way to self-regulate from being overstimulated.

Before you try and stop or redirect, try and understand if there is anything external going on that might be prompting the behavior. **Play detective and look for the clues!** If Ryan starts sharing addition facts with Roman numerals every time he hears loud clapping, he may be trying to block out the noise and is using this as a calming technique to block sensory input. This is a time to try and help him with his sensory issues and not redirect him from mathematics.

However, if there doesn't appear to be anything out of the ordinary going on and Ryan is joyfully chattering about  $IV + VI = X$  and  $X + X + X = 30$  or a turkey if you are bowling, there are some techniques that can be used to turn his fascination with numbers and number connections into a positive.

- ✓ Acknowledge to the scout that what he or she is talking about is important but the group needs to stay on schedule so they have 1 or 2 minutes to finish the thought they are currently on.
- ✓ Let the youth know that you would be willing to hear more (be authentic) and let them know that if they do their best to stay focused during the rest of the meeting or at a time when there is a break, that you will give them 10 minutes (or X minutes) afterwards where you will pay full attention to them. Remember your program's rules when interacting with youth and make sure that they are followed.
- ✓ If the youth veers back to talking about the special interest, give kind reminders that they will have time afterwards to share.
- ✓ Then when it is the time to listen, listen to them asking questions about their topic. It is very important that you follow through or you will lose trust and risk a meltdown.
- ✓ Give the scout "extra credit" work that he or she can complete during the week regarding the special interest and try and tie it into a patch or badge or recognition system.

These techniques can be effective in helping a scout practice taking turns, sharing and learning about other people's perspectives.

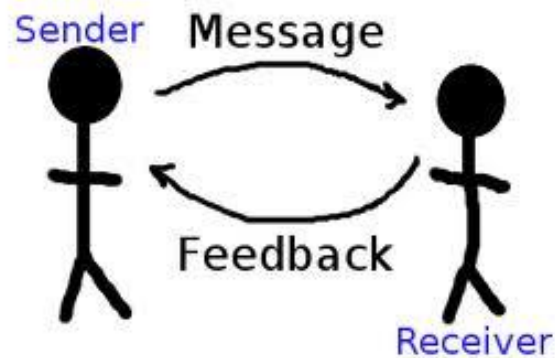
Allowing a scout to share or incorporate his or her special interests into scouting also makes a great incentive or reward system. If a youth knows that he or she is going to have an opportunity to share special interests with others, it often helps them stay focused during other parts of the meeting.

## Chapter 5 – Social Communication Challenges

In order for someone to receive an autism spectrum diagnosis, a person needs to have persistent challenges in social communication and emotional interaction across multiple contexts.

Here are a number of ways challenges may appear when observing scouts on the autism spectrum:

- Difficulty in making and keeping friendships with youth the same age. (May get along much better with adults or younger children.)
- Trouble initiating or maintaining back and forth conversations. May appear shy, aloof or detached.
- Problems understanding other people's feelings or point of view.
- Unusual or inappropriate body language, gestures and facial expressions. (e.g. laughing if someone is hurt, looking solemn if one is happy)
- Struggling to read nonverbal body language or understand social cues or norms.
- Resistance to being touched. Conversely, very clingy.
- Challenges taking language very literally. May have trouble understanding sarcasm or idioms.
- Challenges with impulsivity and control of emotional outbursts. (e.g. having difficulty controlling excitement, anxiety or rage)
- Difficulty responding to questions. This may take the form of needing extra time to process and formulate a response. It may also take the form of mimicking other's behavior or using memorized social scripting or rules to respond.
- Voice modulation challenges. (Too soft or too loud.)
- Struggles with telephone conversation, would prefer to text or email.



**Communication can be one of the biggest challenges for people with autism.** To engage in conversation with someone on the autism spectrum, you may need to shift your expectations a bit. Meet them halfway or better yet, meet them in their own world. (All the travel that individuals on the autism spectrum do on a daily basis to try and meet you in your neurotypical world can be **quite exhausting**.)

Here are a few areas to think about when communicating with individuals on the autism spectrum:

**Absolutes** - For those that think quite literally, absolute statements are often taken at face value, meaning exactly what they say. In other words, if you say, "We are **always** going to meet in the conference room. We are **never** going to meet anywhere else" and then one week you hold your meeting in a gym, anticipate being called on what you said so that you are suddenly not deemed "a LIAR".



Here are words that have no exception. They are either 100% correct or 100% wrong. Watch for accuracy when saying, “all, always, every, must, never, none, only.”

- Using absolutes when it comes to **safety of the youth** or others is understandable.
- It can be difficult to remember not to use absolutes, so if you use one and a situation changes, be prepared to explain what has changed or admit that you should have used a more accurate word.

**Compassion and Empathy** – It is often implied that individuals on the autism spectrum lack empathy, sympathy and compassion for others. Although it can be true that we may not empathize with your particular situation if we have never experienced a similar situation, the same is also true for individuals not on the autism spectrum. Many of us are introverted. Others are extroverted. That’s also true for society as a whole.



Scout leaders need to unequivocally know that **individuals with autism have feelings just like anyone else**. We may not always show them outwardly but we each experience emotion in our own way and a lot of it comes as a result of our age, maturity, cognitive ability and life experiences. Society tends to place a higher value on the outward expression of emotions, especially with women, so if a sad situation happens and someone does not “look” sad enough or isn’t crying, it may be falsely assumed that a person is ambivalent, not sad or simply uncaring.

Karen from Autism Empowerment shares, “Those of us on the autism spectrum are often very compassionate and sympathetic. Just as we live with our sensory dial turned up to full volume, so it may be the case with our emotional dial. We don’t always use coping mechanisms that a neurotypical society would expect. We may cry in excess or not at all, we may express extreme passion or keep it inside. We may meltdown or shutdown. Autism isn’t the only spectrum condition. All of us experience our emotions on a spectrum too.

It can be very hurtful to children, teens and adults on the spectrum when we read or hear that people with autism or Asperger’s don’t have feelings or don’t make good friends or parents. Sadly it often happens right in front of us, like we’re not in the room. Imagine being told **you** needed to adjust your neurological wiring and learn compliance or else you couldn’t be happy or exist as a productive member of society? When I read online or hear on the news how as a collective group, those of us with autism are “a burden on our parents”, “a drain on society” and “an epidemic” that somehow needs to be controlled and cured, I wonder who it **really is** that needs compassion lessons and perhaps a social skills lesson or two.”

“My children on the spectrum don’t need to hear that negativity so we promote positivity and acceptance instead. I can’t speak for all of us. No-one can. We are each unique with our own gifts to give and our own life journey. It’s true that individuals on the spectrum may not always read body language correctly or pick up right away on a sad situation but oftentimes, once we have been shown and are cognitively aware of another’s circumstances or feelings, we are very capable of showing compassion.

Many autistic and Aspie advocates say that they have an overabundance of feelings. Sometimes it is just so overwhelming to process our feelings that we might not be able to deal with them at the present moment and so that might manifest itself in awkward or inappropriate behavior.

What that looks like to others varies from individual to individual. But we laugh, we cry, we celebrate and we grieve, each in our own very human ways. We can also **Accept, Enrich, Inspire & Empower.**”

- Understand that individuals on the autism spectrum may show empathy, sympathy or compassion in actions and not in words.
- Allow scouts on the spectrum time to process their emotions. They might not be able to define them for you verbally or quantify them in a way that makes sense to you.
- If you are able to recognize an emotional response, try to validate it.
- Do not talk negatively about people with autism, especially in front of a child or adult with autism. Assume that we understand everything you’re saying.

**Conflict Resolution and Challenging Behaviors** – One of the most challenging tasks and least fun tasks that a scout leader faces is trying to resolve conflict between scouts that aren’t getting along. When you throw communication challenges, different levels of social maturity and sensory stimuli into the mix, emotions can get heated VERY quickly and misunderstandings get easily blown out of proportion. How did that super fun, productive, “best outing ever” turn into a screaming, crying, “UNFAIR, I HATE YOU” fight-fest so quickly?



Fortunately, many of the conflict resolution skills that they teach leaders in scouting can be applied and adapted to children on the autism spectrum. For example, many groups use the EAR acronym for Express, Address and Resolve.

- **Express** – each person should be given the opportunity to tell their side and express how they view the situation. Equal time is given to all sides and no jumping to conclusions or prejudging should happen.
- **Address** – after listening to the involved parties, the leader voices the concerns so everyone understands the issues to be resolved. This ensures that everyone is trying to work through the **same problem**, even though from different views. Acceptable changes to the situation that will ease concerns are discussed.
- **Resolve** – a plan evolves that will effectively resolve the conflict. This may be an obvious decision or may require each party giving up something to meet a compromise for complex issues. The leader needs to work so each side feels as good as possible about the solution.

When the situation is calm, it's often helpful to also try a **Role Reversal**. This is where you ask each scout to state the point of view of the other person. This can be difficult for individuals on the autism spectrum but actually provides for a good learning experience for all parties involved.

There is also another EAR acronym that helps with conflict. It is called an E.A.R. statement and was developed by Bill Eddy, LCSW, Esq. **The E.A.R. Statement** is a statement that includes **Empathy**, **Attention** and **Respect**.

It is used to help calm an aggravated situation and help a person who is feeling very agitated be heard and understood. At moments of sadness or anger, meltdown or shutdown, it can really help to have a human connection, knowing that someone has empathy for us, is paying attention and still has respect for us.

If you're being attacked, Empathy, Attention and Respect may be the **OPPOSITE** of what you feel like giving, however when you can stay calm and practice this, you can often defuse a situation despite how counter-intuitive it may feel.

**Example:** Casey has some motor skill challenges and often gets frustrated when he doesn't do a task to perfection. In the past, you've left him alone or tried to redirect him to another task to avoid a negative situation. In each case, Casey has gotten worked up to the point where he's gotten very upset, blurted out comments like, "I'm stupid" or "this is a stupid activity" and has even snapped at scouts around him. You're worried that Casey may alienate himself so this time, you see the signs of agitation and walk over to try and see how you can help. **"Wow, I can hear how upset you are. I've been upset before too and it doesn't feel good. Tell me what's going on. I respect your efforts and want to work with you to help make this better."**

This statement included:

**Empathy** – "Wow, I can hear how upset you are. I've been upset before too."

**Attention** – "Tell me what's going on."

**Respect** – "I respect your efforts and want to work with you to help make this better."



**Using your EARS** by utilizing the methods above doesn't mean that you're taking sides. Giving your empathy, attention and respect helps you connect with an upset person as a human being. Too often, people get stuck on arguing about an "issue" that isn't the real challenge at all. It is often up to you to be proactive, professional and put on your brain detective hat to try and figure out what is **really going on** and try to resolve the conflict in a way that allows the scouts to maintain their dignity and learn problem-solving skills that they can use in the future.

## After the Conflict or Situation

After time has elapsed, everyone is calm and the conflict is over, it is time to take a look back at what happened and assess if a situation was handled appropriately or if there are things that could be changed in the future to minimize or avoid conflict when issues might come up again. Look for teachable moments with all scouts in your unit. Role play is often a great group activity to practice perspective taking.

**Observe the antecedent to behavioral challenges.** Do behavioral reactions seem random or is there some underlying theme tying them together? Try to determine the trigger or root cause of the conflict.

Many find it helpful to write these observations in a notebook so that if a consistent pattern is noted, proactive and preventative measures can be taken. (e.g. if behaviors happen every time your group meets in a gym as opposed to a quiet classroom, it may be a noise and sensory issue that is aggravating the situation.) If you have these observations recorded, it makes it easier to strategize with parents, caregivers, other leaders and the scout(s) on ways to help resolve the challenge.

Some additional points to take into consideration:

- **Remember that all behavior serves as some form of communication.**
- Behavior also serves a function and is related to the context of a situation.
- Do your best to keep your cool and realize that the vast majority of the time, youth on the autism spectrum are not trying to disrespect you. (We all may have our moments!) Assume the best.
- Sit down with the youth and/or a family member to assess the situation in a non-threatening atmosphere.
- Offer feedback and redirection strategies in a respectful way that allows the scout to save face.
- Try to identify something positive from the situation. You can view this as a learning and growth opportunity.
- Collaborate! If a scout is showing consistent behavioral challenges, chances are that these issues may also be showing up at school and home. Maybe the parents or teachers are doing something that you could mirror or maybe you're doing something pretty awesome that they could use too.
- Try to mirror what is being done in their IEP or 504 plan in relation to behavior, if applicable. It helps scouts on the spectrum to have a consistent approach across multiple environments.
- SHOW what correct behavior looks like. (Visually and/or through Role Play)
- Oftentimes, when you see a meltdown or shutdown with children on the autism spectrum, it is related to a sensory issue. We'll be talking about this in Chapter 6.
- The use of social narratives can also help, especially with less socially mature children. We talk about these later in this chapter.
- Brainstorm together ways to change the outcome in the future. Write down an action plan for improved performance and offer incentives to the youth based on his or her special interest.

**Echolalia** - From time to time you may have a person in your group with echolalia. This is the repetition of phrases, words or parts of words. There are a couple kinds of echolalia, immediate and delayed. An example of immediate echolalia would be if you said to your scout group, "It's time for flag ceremony" and one of your scouts repeated back as soon as you finished, "Time for flag ceremony."

An example of delayed echolalia would be the repetition of a saying or phrase after a period of time. It could be five minutes, it could be months or even years after the phrase was originally heard. The

phrases may pop up at any time or any place. It could be lines from a movie, directions that a teacher gave in class, a catchy jingle or almost anything. When in context, echolalia is socially accepted, however when out of context, it seems a bit random.

When repeating conversations, videos, songs or phrases, youth with echolalia will often use the exact rhythm and tone of the original message. He or she often doesn't understand the meaning of what he or she is repeating. This can prove particularly uncomfortable if a youth is repeating something he or she should not have been listening to!

A few instances where echolalia might occur is if a scout wants to:

- Express that he or she has heard what you have said.
- Self-regulate. Repetition may come if a youth is feeling anxious or sensory overloaded.
- Show emotion about the content. (Repeating "time for flag ceremony" over and over in a gleeful tone would be a way of showing that this is an activity the scout might enjoy.)
- Try to cope in the moment but might be having trouble effectively processing a situation.

When working with a youth that has echolalia, here are some suggestions:

- Model age-appropriate language from the child's point of view. Model words and vocabulary that he or she can imitate and understand.
- Make sure that others do not make "fun" of the scout or call him or her a "copycat". The scout is not trying to be disrespectful.
- Remember that anything you say may end up being repeated, tone and all.
- Try not to ask "Do you want..." questions since the scout will then initiate requests by saying "Do you want..."
- Read "Echolalia... what to do about it" at <http://teachmetotalk.com/2008/06/02/echolaliawhat-to-do-about-it/>

**Eye Contact** – Making and holding sustained eye contact can be difficult for many individuals on the spectrum. If you are engaging with a scout and he or she is not directly looking at you, don't force eye contact or assume a lack of respect. Just because a scout is not looking at you when you are talking, doesn't mean he or she is not paying attention.



Here are some additional suggestions from Gavin Bollard in Australia, popular blogger from [Life with Asperger's](#), Aspie, and father to scouts on the spectrum.

- Place less emphasis on eye contact and more on "participation in conversation."
- Explain how some people need to see you looking in their direction before they think you're listening.
- Give children a few options for controlling gaze avoidance. (suggest looking at cheeks, bridge of nose or higher)

- Encourage “looking at my face” but don’t push it – it’s really uncomfortable for us.
- Be understanding when we don’t feel like looking – we’re not being rude, just feeling insecure. (We might be feeling overstimulated too.)

**Hidden Curriculum** – We are surrounded every day by unstated rules, social expectations and customs that can make the world a very confusing place, especially for those on the autism spectrum.

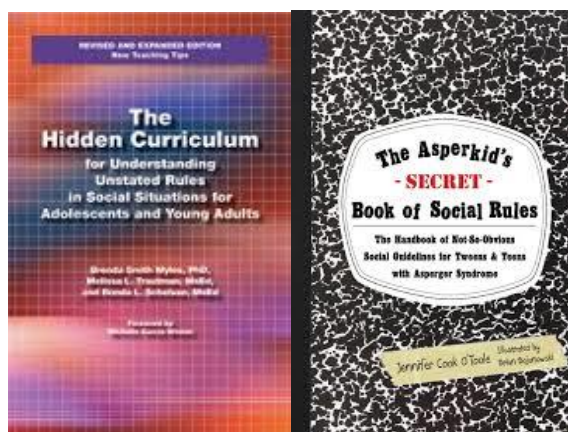
This is what is known as the “hidden curriculum”, a set of rules or guidelines that are often not directly taught but are assumed to be known.

“The hidden curriculum contains items that impact social interactions, school performance, and sometimes safety. The hidden curriculum also includes idioms, metaphors and slang – things most people “just pick up” or learn through observation or subtle cues, such as “get off my back” and accompanying body language (frowning, looking irritated, raising voice) communicates that the speaker wants to be left alone, but to somebody who has social-cognitive challenges and predominantly interprets language literally, the term will have a totally different meaning and be very confusing.” *The Hidden Curriculum for Understanding Unstated Rules in Social Situations for Adolescents and Young Adults* by Brenda Smith Myles, Melissa L. Trautman and Ronda L. Schelvan (AAPC Publishing, 2013)

The hidden curriculum affects individuals of all ages on the autism spectrum. When youth and adults don’t understand slang, idioms, social rules or sayings that everyone is already “expected to know”, it can lead to embarrassing situations, social goofs and miscommunication. It can also come across to others that one is being rude, ignorant or disrespectful even if not intended. These mishaps are often a precursor to teasing, taunting, bullying and feelings of inadequacy and incompetency for individuals on the spectrum.

It is very important as a scouting leader to understand this, so that you can help incorporate the hidden curriculum and social rules into your scouting program.

So how do you teach these rules? These two books are an excellent start and each provide lots of examples of rules that you can teach.



**For you and the parents:** “*The Hidden Curriculum for Understanding Unstated Rules in Social Situations for Adolescents and Young Adults*, Brenda Smith Myles, Melissa L. Trautman and Ronda L. Schelvan (AAPC Publishing, 2013)

**For the scout with higher-functioning autism, the parents AND you:** “*The Asperkid’s Secret Book of Social Rules – The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome*” by Jennifer Cook O’Toole

Although geared toward children and teens with Asperger syndrome, affectionately called “Asperkids”, this social survival guide written by an Aspie resonates with children and adults who have trouble with the secret rules they never taught us in school.

### **What else can you do?**

There are hidden curriculums and social rules for a variety of situations and environments including scouting! Teaching the hidden curriculum of scouting is one of the best ways you can help a scout on the spectrum fit in with his or her peers.

- Each person is going to have a different level of understanding so when teaching one-on-one, teach to the level of maturity.
- Everyone can benefit from reaffirming social expectations. Every unit meeting, outing or activity, make it a point to teach or reaffirm a rule or social expectation that is age-appropriate. Here are a few examples:
  - “When another scout receives an award or recognition, it is polite to clap, smile or congratulate that person and let them enjoy that moment.”
  - “If at an outing where there is food, someone offers you a food you do not like, say “no thank you” politely rather than “yuck” or “ewww, I hate that.”
  - “It is okay to have different opinions than other scouts. Sometimes friends don’t agree with each other but it doesn’t mean that one person’s opinion is better than the other’s.”
- Try to encourage flexible thinking through examples. Although you are setting up your unit to be more sensory-friendly and accommodating to scouts on the spectrum, there are still going to be challenges, mishaps and mistakes. That’s part of life. Scouts with a higher level of maturity will appreciate you sharing with them that sometimes accommodations may be very difficult (e.g. a sensory-friendly outhouse or a quiet bus ride to camp) but you will work with them to make the best of it.
- Literal thinkers will often blurt out EXACTLY what they are thinking and not realize that their internal voice was meant to be internal and not external. Know that this WILL happen and be prepared for how to respond in a calm tone the next time, “You farted and it STINKS” is shared in a scout’s loud outside voice while your group is enjoying an excursion to the library.
- Consider creating **as a group**, an age-appropriate list of “Best Practices”, expectations and courtesies for your unit, making sure to include hidden curriculum rules that may be currently unfollowed. Make it fun. You could have the activity be under the theme of “friendship”, “getting along”, “citizenship” or something of the sort that ties in with one of your unit’s badges or awards. Provide a copy of the group rules to each scout and then at each subsequent meeting, give out a bead, sticker or other incentive as the rules are being followed. Repeat yearly and reinforce or add to the list as needed.

**Humor:** One of the silliest autism myths out there is that people on the autism spectrum lack a sense of humor. Good grief!

While many individuals on the autism spectrum have tendencies at times toward black and white thinking and may miss some of your sarcasm, idioms or metaphors the first time around or even the second or third, it doesn’t mean they don’t have a wonderful sense of humor. It may just be a different brand. In fact, it is often the history of our own experience learning idioms such as “it’s raining cats and dogs”...that allow us to come up with groan-worthy comebacks such as “watch out, you might step on a poodle!” or

“Gee, I thought it was raining chickens and ducks”... “?????”because of all the “fowl” weather!” (Badda bing, Badda boom!)

Humor can be goofy, it can be offbeat and it can also be rather sophisticated. As an older scout on the spectrum shares, “You may not always get our humor. We don’t always get yours. There are many creative types on the spectrum in Hollywood writing comedy, however it may not be where you expect. They’re working on sci-fi shows that have more longevity and humor than the average canned laughter sitcom. If I’m attempting to share humor with you, then I feel comfortable enough with you to try and connect. Your reaction will often determine whether I try to connect again.”

When you share humor with your scouts, whether it be cornier than corn on the cob or rimmed with situation defusing wit, you’re sharing an opportunity to laugh and bond. Remember this when you find yourself in exasperating or precarious situations. **Teachable moments are much more likely after sharing a genuine laugh than a loud lecture or gritty grimace.**

### **Idioms, Euphemisms, Slang, Sarcasm & More:**

As a follow-up to the sections above concerning humor and the hidden curriculum, it is no joking matter that many of the scouts on the spectrum you may come across, **do struggle** to learn and appropriately use idioms, euphemisms, slang, sarcasm, similes and metaphors. The speed and ability to pick up on these things is brain based and for some very literal thinkers, it may be difficult to alter.

This can be especially true with scouts that are younger in age, scouts that may be only children (not around a lot of other children) and scouts that have more challenges with processing and reasoning.

Imagine trying to learn a foreign language from a textbook but never spending any time immersed in that foreign culture. You memorize the vocabulary and conjugation of verbs and commend yourself on being bilingual. Truthfully, you might be able to “get by” with your literal language but you would soon find when engaging in conversation with your new foreign friends that many phrases would fly over your head and the speed and tone which others used could be quite confusing. Slang and social nuances? Those things aren’t taught in textbooks.

So how would you learn? Through exposure, through practice, through making connections with that culture... it would likely not come naturally unless you were linguistically-inclined or started learning multiple languages at an early age.

So how do you help children on the spectrum whose native language appears to be almost foreign? You work with the age level, the cognitive level and the social level and do your best to teach the idioms. Explain the slang. You teach those hidden curriculum social rules and be prepared to kindly translate when confusion arises or an expression is inappropriately carried over from one context to the next. **The worst thing you can do is to assume that your scouts on the spectrum can’t learn.**

Although many individuals on the spectrum do lean toward concrete, black and white thinking, that does not mean they can’t think abstractly. There are many adults on the spectrum who are engineers, computer scientists, game designers, mathematicians, actors, artists and writers who can reason in highly symbolic and abstract ways. That doesn’t mean that there may not have been challenges when younger or that slang, idioms or sarcasm may not sometimes sail over their heads but individuals on the spectrum with higher cognitive function often learn these phrases over time.



### Here are a few other suggestions:

- When teaching skills or concepts such as tying a knot or pitching a tent, use concrete words to name and describe things in detail. Concrete language provides clear direction.
- Avoid verbal overload and allow time for language processing. If you perceive a scout isn't understanding you, use short clear directions.
- If learning a task is difficult, break it down into smaller steps and teach the task in multiple ways. (e.g. visually, verbally, physically, musically)
- Tone matters and it may be difficult for scouts to understand a sarcastic or cynical tone.
- If a scout doesn't understand something, let him or her know that it is okay and try to explain or redefine in a positive way. (Don't tease, belittle or assume that he or she should have "understood that" because "everybody does.")
- If other scouts are making fun of the youth who is struggling, make sure this negative behavior is stopped.
- When teaching the scout, put yourself in the position of a foreign language student visiting another country for the first time but not knowing any of the social mores, customs, slang or nuances. How would you want to be taught these things?
- If you notice that a scout may be consistently missing some hidden curriculum items, jot them down on paper and share them with the family, so they can be practiced at home in a non-threatening or embarrassing way.

### Lack of engagement

Lack of willing engagement is a common challenge with youth who are on the autism spectrum and can be a challenge for any volunteer leader. A good leader wants all of the youth in their unit or program to be successful and to at least attempt to take part in the activities they have planned. So how does one get engaged to do their best?

First, understand that just because a scout is not choosing to engage in an activity does not mean they are not paying attention to what is being said or what is going on around them. You're going to need to put on your brain detective hat and try to figure out what might be holding him or her back.

Here are some tips to help try to get scouts engaged in an activity, game, discussion or other function.

- Ask the youth if he or she understands the rules and expectations. It may be as simple as explaining what is going on during the game / activity / meeting and demonstrating. Don't assume that the scout will ask for help but do practice teaching self-advocacy.
- Show patience. Some youth may be naturally shy and introverted. Some may be withdrawn for a variety of reasons including the fact they may be anxious and stressed because they struggle with communication in social settings.
- Try to find out why they are not taking part. Many times there is a root cause to the lack of engagement. It could be embarrassment (this tends to be a common trigger), fear or some other emotion or it could be a sensory issue such as noise or light.  
**Example:** Kayleigh would not participate in a relay game where each team had to take a balloon and sit on it to pop it. In talking to Kayleigh, we learned she did not like the noise so she was able to choose to wear noise-cancelling headphones, take a sensory break or do a different activity.
- **WIIFM** – What's in it for me? The scout may not see a personal benefit to doing an activity. "Boring!" If they ask "why", try not to say "because I said so" or "because that is the rule" because that is not meaningful. Explain why the group is doing what they are doing.

**Example:** We are learning to do a relay race because it teaches teamwork.

**Example:** We are making Veteran's Days cards so we can show support for our veterans as we march in the parade to show honor to those who served our nation.

- Encourage inclusion whenever possible but not to the point of embarrassment or singling out. Sometimes it's okay to let a scout sit on the sidelines.
- Give guidelines regarding how long the activity will be taking place. If you have a visual schedule, you should show them the schedule so they have expectations as far as time is concerned and it is not open ended.
- If a scout is having issues staying focused or is getting overly excited and this is perceived to be the cause for the lack of engagement, something like a **fidjet** (see Chapter 6) is helpful to have.
- If it is a game or activity, let them watch first. This might help spark interest.
- Put them into a different role such as a judge or referee.
- Have them shadow another person or assign a buddy to work with them.
- Try to build the youth's special interest into the game or activity if possible.

**Power of positive reinforcement** - Use positive encouragement for participation, customizing an incentive program relating to their special interest. You could have time where the scout talks about their special interest as a reward.



Pictured here is an example of a **bead reward system** used by many scouting units around the country. When a youth joins a unit, he or she gets a welcome necklace with an arrow, special bead or other symbol. Then at each meeting, outing or event, he or she can wear the necklace with the uniform and earn colorful beads as recognition and positive reinforcement.



**Examples include:** Coming to the meeting prepared, doing their best to stay focused, doing a kind deed, etc. If a necklace or bead system doesn't work, you could use stickers or "**Scout Bucks**" which can be earned and turned in later for small rewards.

## Relating to peers

One challenge that you as a volunteer leader will face when working with scouts who are on the autism spectrum is how scouts relate to their peers. It is common to have youth on the spectrum relate better to adults or younger scouts than their peer group.

The hidden curriculum and secret social rules come into play here but there may be other factors that come into play that affect a scout's level of confidence and willingness to try and relate with peers.

Younger children and adults are often more inclusive and accepting of the challenges that a person on the spectrum may face. If scouts on the spectrum are getting to a developmental stage where they are more self-aware, some of their challenges may negatively affect self-esteem and may also be areas where they are teased or bullied by peers.

### Examples include:

- Others trying to force eye contact.
- Others making negative comments toward what may seem as inappropriate social responses.
- Past rejection from peers.
- So much focus on a special interest that they appear in their own world.
- Embarrassment over not understanding slang, idioms and stuff that others around them seem to understand intuitively
- Feeling like no-one "gets them" or can relate.
- Loneliness, anxiety, depression.

### Here are some ways to assist scouts on the spectrum relate better to other youth:

- Have games with a social non-competitive aspect that will help scouts better relate and get to know other members.
- If your unit or scouting group has helper or leadership positions, encourage the youth to take an active role. If the youth doesn't want to take part directly in leadership, have them act as a shadow or assistant to a person in a leadership role.
- Encourage each scout to take part in team service projects where they will be doing good for others and taking the focus off themselves.
- Encourage them to take part in hikes or campouts. This can be a good place for the scout to have a chance to practice building relationships.
- Encourage team building activities that include all.
- Assign a buddy that serves as a positive peer role model.
- Provide positive reinforcement to the whole group when doing positive social interactions. This must be authentic and not canned because it will be picked up by both the youth, other leaders and other adults.
- Model positive social interactions with the youth and other adults. Assume the scout will be paying attention even if they are not directly watching you.
- If you have more than one scout on the autism spectrum, often they may gravitate toward each other. Try to connect scouts with other scouts that you think may share similar interests.

## Social Narratives

Social narratives are visually represented stories, snippets or cartoons used as educational tools to help describe social situations to individuals on the autism spectrum. The idea is to visually represent the story in a way that the person can understand and to show or model a sequence of events and what would be an appropriate and expected response.

In other words, it's a visual way to help teach expectations, problem-solving, decision-making, self-management and positive peer relations.

In scouting, social narratives could be effectively used in a variety of circumstances including:

- Prior to a transition or new experience (e.g. going to camp, changing units, visiting a fire station with your unit).
- As an educational tool or intervention to reduce existing recurring behaviors (e.g. blurting out during a meeting, snot-eating, not showering at camp).
- After a social mistake or inappropriate behavior has occurred (e.g. saying something rude to another scout, yelling, taking too many snacks).
- To assist with conflict resolution.

On the DVD included with your **Autism and Scouting Leadership Training Kit** is a PDF called "**Social Narratives.**" This is the work of Annette Wragge (2011) and is part of an online training module from the Ohio Center for Autism and Low Incidence (OCALI) at [www.autisminternetmodules.org](http://www.autisminternetmodules.org)

This PDF will outline, describe and give examples of many different kinds of social narratives that you can use and adapt to your scouts including:

- Social Stories™ - [www.thegraycenter.com](http://www.thegraycenter.com)
- Cartooning and Comic Strip Conversations
- Power Cards
- Social Scripts
- We'll also add information about *The Incredible 5 Point Scale* by Kari Dunn Buron and Mitzi Curtis

We have found that the time you invest to build an authentic relationship with a scout on the spectrum will really pay dividends when it comes time to teaching expected scouting behavior.

Are you more willing to learn from someone who respects you or berates you? Are you more willing to be receptive to someone who gives you attention and acknowledges your challenges or takes pleasure in pointing out your shortcomings?

Finally, to end this section, we're going to go back to give you a reminder from **Chapter 3, The Scout Family and Inclusion.**

Just as you teach your scouts to do their best, be prepared and live by the scout oath and law, so you must remember to live by it too and realize that all of us are lifelong learners. No-one expects you to be perfect or know all the answers. If you have taken genuine time to build a relationship with the scout and his or her family, then if conflict arises, an embarrassing situation occurs or you just want to share something positive and uplifting, it will be much easier to do so and you will be coming to the family from a proactive position of caring, something all scouts need to have positively modeled in their lives.

**Thank You so much for caring about your scouts!**

# Chapter 6 – Sensory Challenges

Almost everyone you meet on the autism spectrum has some form of sensory integration dysfunction. Having difficulty processing or tolerating sensory information is a characteristic that is also seen in many other developmental disorders including **Sensory Processing Disorder (SPD)**, Attention Deficit Hyperactivity Disorder (ADHD), Developmental Coordination Disorder and Childhood Anxiety Disorder. The conditions may be co-existing or they may be independent.

Studies from the Sensory Processing Foundation suggest that more than 75% of children with ASD have significant symptoms of SPD. However the reverse is not true.

Everyone can be negatively impacted by too much sensory stimulation, however for many individuals living with Sensory Processing Disorder or sensory integration dysfunction, the difficulties adversely affect daily life. It's like living life with an amplifier, the volume of the senses may be very high.

## How is sensory integration dysfunction defined?

According to the Sensory Processing Disorder Foundation at [www.spdfoundation.net](http://www.spdfoundation.net), sensory processing, sometimes called "sensory integration" or SI is a term that refers to the way the nervous system receives messages from the senses and turns them into appropriate motor and behavioral responses. Whether you are biting into a hamburger, riding a bicycle, or reading a book, your successful completion of the activity requires processing sensation or "sensory integration."

Sensory Processing Disorder is a condition that exists when sensory signals don't get organized into appropriate responses. Pioneering occupational therapist and neuroscientist A. Jean Ayres, PhD, likened SPD to a neurological "traffic jam" that prevents certain parts of the brain from receiving the information needed to interpret sensory information correctly.

"When their central nervous systems are ineffective in processing sensory information, children have a hard time functioning in daily life. They may look fine and have superior intelligence, but may be awkward and clumsy, fearful and withdrawn, or hostile and aggressive. SPD can affect not only how they move and learn, but also how they behave, how they play and make friends, and especially how they feel about themselves." *Carol Stock Kranowitz, The Out of Sync Child*

**One tech-loving scout living with sensory challenges shares an analogy**, "Think of a computer. You need to have your software and hardware compatible in order for your computer to function properly. For individuals experiencing sensory processing challenges, their computer is trying to process too much data at once."

## Sensory challenges are also on a spectrum.

The degree and level of how a scout takes in sensory stimuli is different and varies from person to person. It can also change over time. In this section we will cover types of sensory processing challenges, the difference between a sensory issue and a behavioral issue and techniques you can use to help scouts. Being aware of potential sensory challenges and working to make your unit more sensory-friendly will benefit all scouts.

## Types of Sensory Processing Challenges

- Gustatory (Taste)
- Tactile (Touch)
- Auditory (Sound)
- Olfactory (Smell)
- Visual (Sight)
- Vestibular (Body Motion / Dexterity)
- Overstimulation (Sensory Overload)

We will be talking about challenges in these areas below but first we wanted to cover the concepts of self-regulation and stimming and what that might look like in individuals on the autism spectrum.

## Self-Regulation

Self-regulation, often also referred to as emotional self-regulation (or dysregulation) is a learned process that begins in infancy and develops over time. It refers to the way that the mind organizes its own functioning to achieve control over behavior and emotions. It involves many aspects of social, emotional and cognitive development.

Individuals on the autism spectrum or with other neurological conditions such as Attention Deficit Hyperactivity Disorder (ADHD) will almost always have challenges in this area.

Angie Voss, OTR from [ASensoryLife.com](http://ASensoryLife.com) explains, “Self-regulation is the ability to adjust or regulate the level of alertness depending on the time of the day and the stimuli presented. For instance the ability to wake up in the morning, become alert and adapt to the school environment and demands placed on the nervous system in the school setting...including attention to task, cognitive demands, communication, social and emotional demands, and motor tasks (gross, fine, and visual motor). Then returning home for the evening and preparing the nervous system for rest and sleep. The ability to self-regulate the nervous system involves all these components, including the sleep/wake cycle.”

### What does that mean in terms of the youth I'll be working with?

In terms of self-regulation, think of **coping strategies**. When a person is starting to feel a bit out of sync, emotionally overloaded (happy or sad) or begins to get upset, what does that person do in order to help them feel more in control of their behavior, emotions or environment? Are those choices proactive or reactive? Healthy or destructive? Compulsive or impulsive?

### Examples please!

All people use some sort of self-regulation strategies whether or not they are on the autism spectrum. Some of these strategies are healthier and more effective than others. Here are some you may not even be realizing you're doing:

Do you drink coffee in the morning? Do you chew gum to help you concentrate? Twirl your hair? Tap your pencil, click your pen, doodle while listening, pace back and forth?

For many adults, self-regulation might look like drinking coffee, diet soda, chewing gum, eating chocolate, meditating or doing an intense workout. Many people get into a habit or ritual of doing that “one thing” that makes them feel grounded or secure. You may hear things like, “I need \_\_\_\_\_ first thing in the morning in order to function.” or “I can’t concentrate on this project unless I have \_\_\_\_\_ first.”

For individuals on the autism spectrum, self-regulation may take on a form that looks or sounds strange to someone who doesn’t understand it.

You may see flapping, spinning, crashing, humming, swaying, fidgeting, conducting (waving arms as if they were a conductor), bouncing or doing some other activity that includes motion. These self-stimulatory and self-regulating behaviors are sometimes called “stimming” or “stim” for short.

### **Is this behavior okay? Should I allow it?**

Everyone needs to self-regulate in some way. Although most stimming behaviors are fairly innocuous, parents and caregivers are often concerned by stimming in public because they fear it may bring unwanted attention to the youth where people will pass judgment without understanding. Unfortunately misunderstandings sometimes lead to teasing, bullying, school detention, exclusion and lost friendship opportunities.

So it can be a tricky situation. **On one hand, you want to show acceptance** to the youth and let him or her be safe to calm themselves without embarrassment. Come as you are, let your light shine! On the other hand, you may be able to substitute other self-regulating techniques that have the same or similar calming effect without as many stigmatization risks.

**Common substitutions** that may grab less attention from others but still be self-regulating include the use of hand fidgets such as stress balls, soft foam blocks or sensory balls, chewing gum, pretzel sticks, ice chips, chewable jewelry, sugar-free hard candy, weighted vests, weighted blankets, plastic straws, play dough or good old-fashioned exercise.

### **Things to remember about Self-Regulation**

- Check the **Individual Scout Profile** to identify any self-regulation / coping methods that the scout currently uses.
- Remember that we all have something that keeps us grounded. Be accepting that this will look different for each person.
- Fidgets can help with anxiety, calming, hyperactivity and focus, however if perceived by others as a “toy”, they can be distracting to others.
- For scouts whose stims are more apparent, stimming education for other scouts and families can be done within the unit or group with the permission of the family.
- Host an annual Sensory Acceptance Party where you bring in fun sensory-friendly items for each scout in your unit to try. Medicine balls to bounce on, fidgets to play with, rice bins, shaving cream, etc. The benefit to this is that you can observe first-hand what items appeal to which youth. You may be surprised at how this activity can benefit everyone.
- If a person’s self-regulatory behavior turns out to be something that is a health or safety issue for the scout or others, redirection and a self-regulation substitute should be given.
- Try not to embarrass the scout as this could lead straight to a negative situation. (If you’ve seen a child’s temper go from 0 miles an hour to 60 in less than 3 seconds, this is what you want to avoid!)

- If the scout needs to take a sensory break for self-regulation or calming, make sure you have a quiet and safe place for him or her to go.
- If you see a youth flapping or humming or flicking or spinning, please never make them feel what they are doing is “bad” or “wrong” because they often internalize this **they are bad or wrong**. Whatever is affecting the scout feels very real to them.

We’re now going to go over sensory issues in more detail as they relate to each of our senses.

### **Gustatory (Taste)**

Food issues are some of the most common issues you’ll hear about with youth who are on the autism spectrum. Do you know of a child who always prefers his food plain or wants to eat chicken nuggets from just ONE fast food restaurant? Maybe you know of a girl who wants her food separated because she doesn’t want it touching other food. Ever seen a child who will eat paste, snot and other non-food items but doesn’t want anything to do with condiments? Perhaps you’ve met a scout that will not drink anything carbonated or who will not touch caffeinated or hot drinks?



People will often label these children as “picky eaters” or “selective eaters.”

Challenges vary and can include issues with food smell, texture, taste and temperature (too hot or too cold). Gag reflexes and gastrointestinal issues may occur. Some children have food allergies. Meltdowns and shutdowns can easily occur if a scout is feeling forced to eat a food he or she does not want.

Taste preferences may change over time and become less restrictive, however many selective eaters will remain as such well through their teenage and even into their adulthood years. Some will say that special diets work well for their children. Others have different experiences and struggle to get their children to take nutritional supplements.

Medical conditions can also affect a scout’s eating habits and eating habits impact health. The mental and physical avoidance of many foods and drinks is real and it needs to be treated as such.

### **Tips and Strategies to remember about Taste Issues**

- Make sure food challenges are listed on the **Individual Scout Profile**.
- Check with the scout’s family to see about any dietary restrictions. (Some scouts may be on special diets like gluten-free, casein-free or dye-free). Make sure that these are respected and get suggestions from the family regarding what snacks and foods are okay.
- Give encouragement to try new foods in a positive manner.



- Do not tease or embarrass the scout. If the scout is a really selective eater, watch to make sure that no-one harasses or bullies.
- Do not assume that if they go long enough without eating that they will eat a certain food.
- Even if they're not eating on a hike or campout, make sure they stay hydrated.
- Assume intelligence. Trying to "trick", use peer pressure or force a scout to eat a food will likely backfire and the scout may feel long-lasting resentment toward you.
- Have the scout be actively involved in the planning of the meals.
- Describe the taste of a new food to a scout comparing the positive attributes to something else she already likes.
- If special foods or other foods are required at an outing, plan ahead on how cooking will be done with minimal embarrassment to the scout.
- If the scout has different food, still have him or her eat together with other scouts at meal time.
- Be prepared ahead of time and be a good role model.
- A scout with food challenges may also have weight challenges. Be very sensitive to this.
- If you suspect or witness eating disorder behavior (anorexia, bulimia, compulsive over-eating), talk about it with the parents.
- Mealtime and Children on the Autism Spectrum: Beyond Picky, Fussy, and Fads - See more at <http://www.iidc.indiana.edu/?pageId=476#sthash.iZNbkHpc.dpuf>

## **Tactile (Touch)**

Certain fabrics, feels or points of pressure to the skin can be painful, itchy or uncomfortable. This is sometimes known as being touch-sensitive. In scouting, this issue may present itself in a number of ways, most commonly when uniform items are required to be worn or expected to be worn in a certain way.

Some scouts may not want any contact including "high fives" or handshakes while others may be the opposite and want or crave things that will give them more pressure such as hugs. Having a completed Scout Information Profile helps determine if a scout may need accommodations in this area and provides information you may require if your unit requires you fill out paperwork to make an exception to the organization's uniform policy. (Each organization has different rules, so be sure to check with yours.)

If you find out that you have a scout that craves lots of touch and additional pressure or tends to be the type that gives big hugs or tries to wrap his or her body around another, make sure you have a conversation with the scout's parent and if possible the scout and set ground rules. You do not want to make the scout feel rejected but Youth Protection policies are in place to protect the scout. They are there to protect leaders as well. If the scout is younger, you may come up with some other option like doing "knuckles" or having the scout have a sensory blanket at their disposal.

## **Tips and Strategies to remember about Touch Issues**

- Have a filled out **Individual Scout Profile** to identify any tactile issues (touch-defensive, touch-sensitive).
- Suggest parents cut tags out of shirts or hats. If the uniform fabric is scratchy, have the scout wear a soft shirt underneath. Wear seamless socks.
- Lycra or spandex underneath a uniform often may have a calming effect because deep pressure is distributed throughout the body.
- Be flexible when it comes to a uniform requirement such as hats, socks, collars, clothing being tucked in etc... (The important thing is that the scout attends.)

- Consider having a compression vest, weighted vest or weighted blanket to help a youth self-regulate. (Ask parent or caregiver permission first. They might have one at home to use.)
- Understand the scout and don't take it personally if he avoids high fives or she gives you a super hard handshake.
- For clingy scouts, use eye contact, smiling and voice to show approval but make sure "touch" limits are set for the protection of the youth and scout leader.

### **Auditory (Sounds)**

We live in a world filled with sounds. Some people with autism have difficulty processing intense multiple sensory experiences at once. Challenges can come from many places including loud or sudden sounds, high pitched sounds, the buzz and flickering of a fluorescent light or trying to carry on a conversation while hearing a familiar voice in a distance.

This animation and 2:16 video gives the viewer a glimpse into sensory overload and how often our sensory experiences intertwine with daily life. The video is directed by Miguel Jiron and created as part of Mark Jonathan Harris' and Marsha Kinder's "Interacting with Autism" project.



<http://vimeo.com/52193530>

Being an effective leader to a scout that has this issue will go a long way to making their scouting journey a successful one.

### **Tips and Strategies to remember about Sound Issues**

- Make sure any auditory issues are noted on the **Individual Scout Profile**.
- Try to reduce the noise when possible, have speaker systems turned down.
- Practice desensitizing in advance. (Record noise in high fidelity, muffle noise and practice with gradually increased volume.)
- Have the scout sit away from the source of the noise (speakers, amps etc.).
- Hold indoor meetings in carpeted rooms rather than noisy cafeterias or gymnasiums.
- Scouts with sound challenges may make loud noises to block out other auditory input.
- Provide ear protection such as noise cancelling headphones or soft foam earplugs.
- Prepare the scout and his family ahead of time when going on an outing or field trip that will be near high noise (such as an Airport, Seaport, Train station, Fire Station, etc.).
- Consider allowing the scout to have an mp3 player with music (good for sensory room).
- Provide a Social Narrative for what the scout can expect (see chapter 5).
- Plan ahead and give the scout a place to go to get away from the noise if too overwhelming.

## Olfactory (Smell)

Sensitivity to smells is one of those senses that can be a difficult one to avoid or prepare for since smells can come up at any time in all different settings. Having an understanding that a scout might have an issue can go a long way for you to prepare for any negative possible responses by the scout if this issue arises.

Sometimes these scouts will be known as the ones with a nose like a bloodhound or with a “super sniffer”. Some may seek out smells and sniff everything around them. Others may have a real aversion to smells. Understand that challenges with smell will commonly tie in with a desire to eat certain foods.

### Tips and Strategies to remember about Smell Issues

- Make sure any olfactory issues are noted on the **Individual Scout Profile**.
- Strong smells can bring about nausea, gagging, headaches and meltdowns in some people.
- Some may be hyperaware of body odor. Others may be oblivious. Don't be surprised if the scout who is hyperaware lets the scout who is oblivious know in a less than tactful way. (e.g. “YOU STINK!”)
- Bring extra deodorant on a camping trip with older scouts who might forget to pack their own. Choose an unscented kind.
- Try not to wear cologne, perfume or heavy scents around children with scent aversion and ask other leaders to do the same.
- Realize though that some scouts may recognize you by your smell so if you wore cologne or perfume before and stopped, some on the autism spectrum might not recognize you.
- Provide a small surgical mask to help reduce smells (see picture in Chapter 8).
- Allow scout to pinch or hold their nose and cover their mouth if something is “too stinky”.
- Although hand-sanitizer is commonly used in camping, sometimes these scents are too strong for scouts with olfactory issues.
- Rubbing a little Vicks vapor rub in the nose can help block out bad smells.
- Prepare the scout and his family ahead of time when going on an outing or field trip that might include strong smells (hospital, dentist's office, factory, fish hatchery, etc.).
- Prepare the scout ahead of time for camping with a social narrative (see Chapter 5). Outhouse, bug sprays and cooking smells can be a huge challenge which may also make it difficult for a scout to use the restroom.

## Visual (Sight)

Visual challenges related to sensory processing can take on many forms. It's more than just issues involving sight or the sharpness of vision. Individuals with visual processing challenges have a reduced ability to make sense of the information taken in with their eyes. They may have 20/20 vision but difficulties in discriminating forms, size, foreground, background and position in space. For example, they might not be able to find their jacket in a large pile.

It could affect visual memory or visual integration and processing of signs and symbols. Some children with visual challenges will also have challenges reading and correctly copying information down from a board.

A scout may seem visually distracted when there is too much going on in a room. Writing may appear hard to read and a youth may have difficulty staying on a line and spacing out his or her work. There can be sensitivity with lighting which can include bright sunlight and quite commonly fluorescent lights. Conversely, if a child craves visual stimulation and is a sensory seeker, he or she might like watching spinning bright objects, flick lights on and off and enjoy watching repetitive movements.



### Strategies and thoughts to think about concerning Visual Issues

- Make sure any visual issues are noted on the **Individual Scout Profile**.
- There are times when a scout may be overstimulated and need calming down or there may be a time when a child is too calm and need visual stimulation.
- Have the scout sit away from bright windows, bright posters and fluorescent lights unless they need and prefer visual stimulation.
- Reduce lighting inside when possible by turning one section of lights off when safe.
- If you have windows, put something like plastic on the windows to reduce the light.
- Prepare the scout in advance when possible with a social narrative (see Chapter 5).
- Provide eye protection such as sunglasses or a hat for either outside or inside use.
- Suggest bringing an eye mask for sleeping while camping.
- Some scouts will wear tinted glasses or Irlen lenses. Allow this accommodation.
- Understand that some scouts may struggle to follow instructions on a poster or might not do as well responding to gestures so teach in different ways.

### Vestibular (Body Motion / Dexterity)

The **vestibular system** which is located in the inner ear contributes to detecting our movement through space and the position of our head. It sends signals to the brain that control our eye movements and to the muscles that help keep us upright.

It helps us to know what direction we're facing and helps give us a sense of spatial orientation and balance. Many youth with vestibular dysfunction are **sensory seekers** and crave a LOT of motion. This is called hyposensitive and are your thrill-seekers who have trouble sitting still. Others are **sensory avoiders**, may lose balance quickly and tend to prefer sedentary activities versus ones with a lot of movement. This is called hypersensitive.

If you were at an amusement park, the sensory seeker would be the one craving the fast, intense scary rides that go in circles and upside down. The sensory avoider would be one who gets an upset stomach on any ride that had a rapid or rotating movement.

**It's important to note that youth sensory processing challenges can be hyposensitive in one area and hypersensitive in another.** A child who craves sensory stimulation in certain areas may avoid sensory input in other areas. For example, the child who loves fast rides might get really upset if clothes were to get wet on a water ride.

### **Strategies and thoughts to think about concerning Vestibular Issues**

- Make sure any vestibular issues are noted on the **Individual Scout Profile**.
- If you play games where the eyes are closed or blindfolded, be aware some may have challenges. If they want to, let them try but if they are fearful, either have a helper or allow them to sit out.
- Provide extra supervision when doing obstacle courses or anything that is elevated.
- If watching a sporting event, sit the scout at one end of the field rather than on the sidelines. This helps avoid turning the head back and forth as the team travels up and down the field.
- Beware that some scouts may have motion sickness, so if you're driving to an outing, let them sit in front and allow extra time for stops. If someone does have a tendency to have motion sickness issues, fresh air and saltine crackers may also help. Do not expect them to read a book or map while in the car.
- Conversely some scouts may be thrill seekers and seek extra motion which could lead to safety issues. Sometimes they are also under-sensitive to pain and won't be able to tell you when obviously hurt.

### **Overstimulation or Sensory Overload**

Overstimulation happens when one or more of the senses are strained or overwhelmed and it becomes difficult to focus on what you are doing. An abundance of sensory experiences may enter your nervous system all at one time or build up throughout the course of an activity. For scouts on the autism spectrum, this may lead to **shutdown**, **meltdown** or other negative behaviors.

Suppose for example that you decided to take your scouting group to the county fair. What are a few of the sensory stimuli your scouts might need to contend with?

**Taste / Texture:** greasy, sweet or salty food, cotton candy, elephant ears, slushies

**Smells:** barn animals, hand-sanitizer (after touching animals), food, sweaty people

**Sound:** carnival games, rides, screaming children, people around constantly talking

**Visual:** input of fast moving rides, blinking lights, lots of people

**Touch:** bumping into people within a crowd, clothes getting wet on a water ride

**Vestibular:** carnival rides, trying to wait in line

It's enough to have people without sensory issues overloaded but for people who have a lot of sensory problems, what should be an exciting adventure at the fair turns into a fun-house nightmare.

What is even more difficult to understand is that most youth with sensory processing issues have times when they display elements at both extremes. Sometimes they will be seeking stimulation and sometimes they will be avoiding it. **A scout can be both a sensory seeker and sensory avoider.**

Of course you don't need to take a group to the fair to have sensory overload. It is a common occurrence at camp, on outings or in big group meetings where there are a lot of scouts gathered together and multiple things going on at the same time in a relatively small area.

Here are some possible signs of sensory overload to **watch out for**:

- Scout complains of bad headache.
- Scout complains of dizziness or nausea.
- You notice a scout getting very hyperactive.
- You notice a scout getting very withdrawn, like a turtle drawing into her shell.
- You notice a scout stimming more often than usual or doing a repetitive stim that he doesn't do when he is happy. (Covering ears and rocking back and forth. Banging head.)
- You see what looks like hyperventilation or an anxiety attack.
- The scout starts to cry, scream or become aggressive.
- The scout appears to have lost some of her abilities like the ability to speak.

At this point a scout may be feeling increased stress and extra chemicals are released into the brain which may lead a scout to a **Fight or Flight Response**.

**What is Fight or Flight? Doesn't that relate somehow to survival instinct?**

Yes. The fight or flight response is a physiological reaction that occurs in response to a perceived harmful event, attack, or threat to survival.



Non-emergencies allow our nervous system to relax, rest and digest, however when we feel threatened and our body senses an emergency, then fight or flight kicks in. Our blood pressure increases, our heart beats faster and our digestive process slows down.

**What does that look like in terms of a person experiencing sensory overload?**

There are a lot of possibilities, many of which will look like "behavior issues" but are instead really sensory issues. According to Angie Voss, OTR and author of "Understanding Your Child's Sensory Signals", here are a few **meltdown** or **shutdown** behaviors you might see a youth doing during **Fight or Flight**:

- Hitting, kicking, biting, spitting, pushing (especially while standing in line or in new challenging/overwhelming situations or activities).
- Trying to run or escape from the situation.
- Trying to hide under something like a desk, table, or chair.

- Burying themselves in an adult's arms, avoiding all eye contact, or trying to curl up in a ball on the floor or at their desk.
- Covering ears or eyes.
- Crying or screaming.
- Hiding in the closet, under couch cushions, or under covers in bed.
- Shutting down completely and not speaking or responding.
- Even falling asleep unexpectedly.

These negative reactions are often perceived by adults to be **behavioral issues** when in all reality it is a reactive response to a sensory issue. In order to get the behaviors to stop and to later address them, you **must treat the sensory issues first**.

### **Strategies to help reduce and prevent overstimulation and Fight or Flight**

- Know your scouts and what sensory issues they have.
- Make sure you are familiar with signs of sensory overload.
- Before you have a meeting, special event or outing, imagine what triggers could cause sensory issues and have strategies in place to make the environment more sensory-friendly.
- If you are in a position to immediately reduce noise or eliminate the trigger(s), try to do so.
- Have items on hand and use strategies to help the scout with self-regulation.
- Give the scout extra time to process questions and respond because overload tends to slow mental processing.
- When overloaded, most scouts do not like to be touched or crowded.
- If you start to notice what look like poor behavior choices, ask yourself if this could be sensory-related instead? What is the antecedent? Is there a pattern that goes with this behavior?
- Allow for Sensory Breaks in a sensory friendly area (see chapter 7).

### **Sensory Issues versus Behavioral Issues**

Knowing and recognizing the difference between a sensory issue and a behavioral issue is often the difference between a successful scout meeting or outing and one that could lead to an embarrassing incident where a scout or a scout's family gives up and leaves the program.



The trouble is that sensory and behavioral issues may sometimes appear alike. You really have to channel your inner Columbo or Nancy Drew and **be the best brain detective possible** to try and figure out what might be going on. **Put on your detective hat and assess the following scenario:**

Jamie is a scout in your unit on the autism spectrum. She's a relatively happy-go-lucky child who is a big rule-follower. You normally meet as a unit in a quiet carpeted room but tonight all the smaller units within your group are meeting in the school cafeteria, a larger open area with fluorescent lighting and tiled floor that also serves as the school assembly area. There is a magician coming and everyone is excited.

Jamie gets to the meeting while people are setting up metal chairs. The buzz in the room is high with lots of different conversations going on. There is popcorn in the back for the scouts to enjoy during the show. While setting up his act, the magician blows up a balloon but it accidentally pops.

The show is about ready to start. Kids are asked to take their popcorn up front and sit on the floor while parents and leaders sit on chairs in back. There are a lot of kids so everyone is asked to scoot in. Jamie is sandwiched between two children. She starts to squirm. Everyone is told to sit still.

Jamie gets up to try and take a chair but is asked to sit down with the rest of her group. Jamie tries to watch the show but is distracted by one of the fluorescent lights that is flickering and buzzing. She is feeling extreme discomfort. No matter what Jamie does to protect herself from what she perceives is an attack to her senses, the input keeps coming in. She starts to rock. The scout behind her tells her to stop.

She starts to hum but is scolded for being disruptive. She covers her eyes and then her ears but no-one is paying attention. Finally she gets up, screams, runs, tips over a chair and dashes out of the room. A parent quickly exits the room after her and reprimands her for embarrassing behavior. You go out to check and see if everything is okay and when Jamie sees you, what ensues is a five minute meltdown of screaming, crying and aggressive behavior. The parent who is extremely embarrassed and noticed scoffing from other adults apologizes profusely and says that maybe scouting just isn't the right fit for Jamie.

Jamie wasn't trying to be naughty or exhibit bad behavior. She was trying to protect herself from sensory overload and once it got to be too much, she went into a fight or flight mode and was past the point of no return. Unfortunately no-one noticed or understood. What could have been avoided ended up turning into a negative experience. **Unfortunately, this happens all the time to children on the autism spectrum at school, at home, in the grocery store and yes, in scouting too.**

Fortunately leaders like you can help the misunderstood Jamies of the scouting world.

What were the possible contributing factors to provide sensory overload?

- Different meeting environment than normal (quiet carpeted room vs. uncarpeted noisy cafeteria)
- More scouts together meeting at one time (more noise, more visual input, different faces)
- Metal chairs being set up (noise, likelihood of scraping and squeaking on floor)
- Popcorn (smell, taste, texture)
- Balloon popping (sudden loud noise)
- Sitting on the floor (surface may be uncomfortable)
- Scooting in and sandwiched between two children (no personal space)
- Fluorescent lights flickering and buzzing (visual / audio)
- Not being allowed to try and regulate (senses heightened, fight or flight kicking in)



## **Figuring out a Sensory Issue vs. Behavioral Issue with S.E.N.S.E.**

Angie Voss, OTR has come up with a very simple strategy to help understand and address most challenging moments and when the question comes to your mind...is this sensory or behavior? How can I help the scout? She calls this "Making SENSE out of the Situation!"

- S.** Stop, assess the situation, do not assume it is "behavior"
- E.** Environment change
- N.** Note the child's response to the environment change
- S.** Sensory strategies and Tools
- E.** Embrace the positive and learn from the moment

This is a simple strategy that can be used and applied to moments you have questions. To learn more in depth about this issue visit, [www.asensorylife.com](http://www.asensorylife.com). S.E.N.S.E. has been adapted by Autism Empowerment's Autism and Scouting Program to fit within a scouting context.

**S.** Try not to simply react, it is important to analyze the situation to determine if there is a sensory trigger. Do not force a scout through the situation, this can create further negative reactions from the nervous system. Also, maintain a calm and objective state of mind, this will only benefit the situation. A person with sensory challenges co-regulates via the people around them...if you are stressed or angry or panicked...this will create further dysregulation.

**E.** Change the environment, even if only briefly, this can help you determine if there is indeed a sensory trigger. It will also give yourself another minute to assess the situation. Taking the scout to another room outside the building in a meeting situation or away in a different part of the campsite for outside situations.

**N.** Notice how the Scout responds to the change...watch closely for body language, pattern of breathing, tone of voice, etc...This will tell you so much about the state of the nervous system. If you see a positive change...then you are on the right track, if not, change something else.

**S.** Implement sensory strategies right there on the spot (many have been taught self-regulation techniques such as Dots and Squeezies) or offer a sensory retreat, a squish box, a weighted blanket or noise cancelling headphones. The sensory tool and strategy may also be something as simple as a Camelbak water bottle or encouraging deep breaths. It may also have something relating to their special interest.

**E.** Embrace the moment as a learning experience and developing more understanding and respect for the scouts sensory needs and differences. Do not let frustration get in the way, get stuck on thoughts like "how do I fix this?" or write it off as another bad experience. Learn from it...respond with respect....and accept the scouts for who they are and will become, and remember that they simply want to be cared for and understood.

### **Things to remember when determining if it is a Sensory Issue versus a Behavioral Issue**

- Be aware that on the surface, both may look the same.

- Treat the sensory issue first (unless there is a safety issue).
- During sensory overload, the scout is not thinking at this point in a cortical manner (thinking, judging and reasoning). Treating the issue from a behavioral standpoint will often be fruitless or will backfire. In “fight or flight mode” a different part of the brain (sympathetic nervous system) is called into action.
- When sensory issues are prevented or removed from a situation, often the “behaviors” go away.
- Behavior choices during a meltdown or shutdown should only be addressed once the scout has a chance to recover and is in a teachable moment. This may not be for hours.
- Helping the scout with the sensory issue will help build connection and trust.
- If it is a behavioral issue, try using the strategies in Chapters 3, 4 and 5.

**What if the “meltdown” or “shutdown” is really a temper tantrum? How can I tell the difference?**



While physical aggressions and behaviors associated with escalation and meltdown appear similar to a temper tantrum, they are really quite different.

A **tantrum** is a **manipulative fit** (crying, screaming, hitting, etc.) that is “**want**” directed. The goal is for the child to get what they want from you or another person and requires an audience. The child is taking action to accomplish a goal. The child will watch for your responses. If he gets what he wants, the tantrum will often immediately stop. It may also stop with redirection or discipline. Treat as a behavioral issue.

A **meltdown** is a reactive mechanism and “**need**” directed **emotional response** (crying, screaming, hitting, etc.) to feeling overloaded. It’s a loss of control that does not require an audience. A person in meltdown mode isn’t looking for a reaction. More stress factors = a more rapid escalation. Behavior is an automatic response and the person isn’t choosing their behavior. Treat as a sensory issue.

A **shutdown** is also a reactive mechanism and “**need**” directed **emotional response** (retreating, closing oneself off, not responding, etc.) to feeling overstimulated by external sources. It’s a loss of control that does not require an audience. A person in shutdown mode isn’t seeking a reaction. Behavior is an automatic response and the person isn’t choosing their behavior. Treat as a sensory issue.

### **Final Thoughts**

One good rule of thumb is that if the scout appears to be melting down and is stopping periodically to see what kind of reaction they are getting, it is a behavioral issue. If they don’t appear to care about a reaction, it is more than likely an issue that is sensory related and should be treated as such.

**We’ve included a copy of S.E.N.S.E. and other helpful sensory handouts on the DVD** you received with your kit. These are useful to share with everyone in your unit who will be working with scouts.

## Chapter 7: Making Your Unit More Sensory Friendly

Now that we've talked about sensory overload and learned how uncomfortable that can make scouts feel, this section was written to share some ways that you can make your unit meetings, events and outings more sensory friendly.

### What does “sensory friendly” mean?

The term sensory friendly was first widely spread within the autism community a few years ago when the Autism Society collaborated with local AMC theatres to host special film screenings that would allow families who have a member with sensory issues to enjoy the films in a safe and accepting environment. An example would be a theatre that offers a special showing where the lights are up, the sound is turned down and audience members are allowed to get up, walk around and be themselves without shushing or looks of disapproval.

This concept has been met with wide approval by families and can now be found around the country with a variety of organizations collaborating with different theatres to host special viewing parties. The concept has also been adapted to concerts and stage performances.

### So what would sensory friendly scouting look like?

People ask, how is it possible to have “sensory friendly” scouting? By definition, wouldn't things like camping, fishing and big group gatherings in uniforms be inherently challenging to the senses?



Yes, that's true! In terms of this context though, we're talking about making your scouting group more “friendly” to people with “sensory” challenges. By that, we mean:

- Educating your leaders and scouts to show **acceptance, respect, patience and tolerance** to scouts who have sensory challenges.
- Showing scouts ways that they can help themselves self-regulate and advocate for help.
- Having a safe place scouts can go if they need to take a break from sensory stimulation.
- Knowing the scouts in your unit and what sensory challenges or triggers they may have.
- Preparing scouts in advance with social narratives, schedules and routines.
- Reviewing the environment of meetings, events and outings and checking to see how you can provide a better scouting experience to all the scouts in your unit.
- Keeping an accessible bin, bag or box with leadership training essentials.
- Bringing a sensory bin to all meetings and outings.

## Leadership Training Bin

Being prepared means having training tools accessible to all leaders and volunteers. Include in here your Autism and Scouting Leadership Training Kit Manual, notepad and pen, mini first-aid kit, a stress ball or fidget and something related to your own hobbies and interests. Leaders need self-regulation too!

## Scout Sensory Bins

A scout sensory bin is a portable bin or container that you can use to store small sensory items that can be used at unit meetings or field trips for calming and self-regulation. Think of it as a **First Aid Kit for sensory challenges**. Every unit and sub-unit (such as a den, grade level, rank) should have one.

Here are some of the items that you should consider having in each bin:



**Noise Reducing Headphones** - These are to help with loud or high pitched noises. They don't block hearing completely but reduce it. This should be the first thing that goes into the bin since this is one of most common sensory issues that occurs when on outings and at camp. These can be purchased from a variety of places including big box stores or hardware stores with not much cost. If you go to a larger box store, you can check out the area where they sell firearms. Typical cost for the headphones ranges from \$8.00 to \$25.00 but you should be able to get a decent pair for around \$14.00.

**Ear Plugs** are more cost effective and less noticeable but they do have some drawbacks including they can only be used one time and some may not like the feel of them and this could cause a different sensory issue. They are soft squishy foam. Cost should be about \$1.00 per set or less.



**Sunglasses or Eye Protection** - Another very common sensory issue is light. If this is an issue for the scout they may already have a pair of sunglasses or something to reduce the light. Some individuals wear tinted lenses or Irlen® lenses to help them with visual processing, so if a youth in your unit has this type of eyewear, be sure to allow him or her to use it. To be prepared, you might want to have a few inexpensive pair of sunglasses on hand. Scouting hats also help with the light.



**Surgical Mask** – The best solution for olfactory (smell) issues is to move away from the smells. That isn't always possible but bad or strong smells can bring on headaches, nausea and lead to sensory meltdowns. When pinching one's nose and covering one's mouth isn't practical, a small surgical mask can help. These can be found reasonably priced in drugstores or you can try the painting department of a big box store. Pick up multiples and don't be afraid for you to model wearing this as a leader so scouts don't feel singled out.



**Fidget or stress ball** - Having these on hand for scouts that have sensory or attention issues are very helpful because if they have something in their hands, many times it helps to stay focused.

**Warning** - For younger scouts, others in your group may see these as toys and not understand why one scout can have one and others can't. In this case, education of the whole group will need to happen or the use of this option can be limited to a sensory place outside of the normal meeting area. An alternative is mini squeeze balls for everyone who needs one.



**Swivel Disc** - This can be a bit more of an expense but can be well worth it for those scouts that are doing a great deal of work seated. **Swivel discs** are used to strengthen the body's core while promoting balance and flexibility. They are commonly used for youth who have attention and dexterity challenges.



**Visual Timer Clock** - This is something that **SHOULD** be in every Sensory Bin as well as in every unit meeting. Many youth on or off the autism spectrum have challenges understanding the abstract concept of time. Timers gives the scout a visual and they are better able to process when the next change is going to happen. The **TimeTimer™** brand of clock (pictured below on the left) is used in many elementary school classrooms so children may already be familiar with it. Use this in conjunction with a picture schedule or meeting agenda.

The cost of these can range from \$25 - \$35 but have been reported by many scouting leaders to be well worth it. A timer clock will not only help out those on the autism spectrum but will help all of the scouts. It also helps a leader stay on track.

For older self-aware scouts that may not want to be seen as different or want to be embarrassed, the family can get a timer clock that looks like a watch. The prices for these items are more but can be a valuable asset.



**Paper, pens, pencils and crayons** – Drawing and coloring can be very calming, especially if one is drawing their favorite item. Also have spare paper on hand for producing visual social scenarios.

**Books, magazines and items with Special Interest topics** – Find out what special interests and hobbies your scouts are really into. With many children, this will be very obvious as you get to know them. Get old magazines, coloring books or books that have the scout's special interest (appropriate with the ideals of scouting) and keep them in the bin and if the scout needs to take a sensory break, they can go to the place that is designated as a sensory area and read about what they love. This should help reduce the stress they are feeling and recover faster.

To make sure that items are not lost or accidentally removed from your sensory bin, keep a laminated checklist affixed to or inside the box lid and label the items with your unit #.

### **Recovery and the Sensory Recovery Area**

Having a recovery plan and sensory recovery area available for scouts who are feeling overwhelmed or who are having a sensory overload will help prevent further escalation. This allows for a scout to recover faster in a safe and accepting environment so that he or she can get back into the mode of enjoying the scouting journey.

It does not matter if you are at an inside meeting or you are outside at a campout, a recovery area or sensory area should be part of your planning and should include the items that are in your sensory bin.

### **Setting up your Sensory Recovery Area**

Setting up a recovery area can be done with little effort and in a way that helps to keep unwanted attention from the scout. The idea is to create a **safe and supportive place** for scouts to go when they need to take a break to calm down.

These are often utilized at larger troop or pack meetings or outings where there are usually more scouts around, more noise and more distractions. Make sure you have your sensory bin!

### **In addition to the sensory bin items, here are a few other suggestions for your recovery area(s)**

- Weighted blankets, weighted vests, compression vests
- Beanbags with a soft blanket to cuddle in
- Soft stuffed animals
- Big pillows
- Ice water / crushed ice (if available)
- Mp3 Player
- iPad or Tablet - If a scout has one that is used for calming, allow him or her to have access in this area. Scouts that are non-verbal or who use an iPad or AAC device for communication should be allowed to have their device with them at all times.
- Inflatable swimming pool with balls to use as a makeshift ball pit for crashing.

### **Here are a few suggestions for setting up your area**

- Try to select an area or a room that is away from the main hub of noise and distractions. If you can, find an area that has minimal things that will distract the scout and a place where the scout can be monitored safely.
- As you're setting up for your unit meeting, make sure to place your sensory bin in the area and assign a volunteer to lay out some of the items.
- Try to have a few things that include the scout's special interest but not so many that the scout will not want to leave. You might want to include a scouting book or magazine so that the focus is still on scouting.
- If space is limited, you can also use a section of a hallway that is still away from the noise and/or distractions.
- When camping, set up a tent that has just a pad, sleeping bag or pillow in it. The scout can use this as a place to go and recover while still fitting in.
- For outings when the group is going to go on a field trip, come up with a plan on where the scout can go in case there is a sensory challenge.
- If you are doing a parade event, know the route and try to find places along the route that could be used to step out of the event in case of sensory issues.

### **What if a sensory bin or sensory recovery area isn't available? How else can I help?**

Make sure you know how to look for the signs of a sensory overload and also make sure you're familiar with the differences between a sensory issue and a behavioral issue. Familiarize yourself with terms like meltdown, shutdown and tantrum and know the characteristics of each. If you don't feel confident in your knowledge in this area, be sure to review Chapter 6 and get familiar with the S.E.N.S.E. strategy created by Angie Voss.

We are also listing some calming strategies below. It is important to note that most calming strategies should be first introduced and explained to scouts during a calm teachable moment. You want to introduce them before they are ever upset so they know what the strategies are and how they work.

Strategies will likely be the most effective when given to the child **before** he or she *completely* escalates and is *totally* inconsolable. Most calming strategies will be most effective when implemented *before* kids get to that "point of no return."

## A reminder about Individual Scout Profiles

In **Chapter 3**, we talked about the importance of getting to know each scout and his or her family. In that chapter we introduced the **Individual Scout Profile** (a copy of which is on your DVD) and **S.M.I.L.E. worksheet** for your unit to use with each scout in your unit. A big chunk of the ISP includes questions regarding sensory challenges, preferences and sensitivities.

As mentioned earlier, these forms are meant to serve as a template and are allowed to be adapted to your unit's requirements. They are useful in creating a **better environment and program for ALL scouts in your unit.**

Here are some tips to help the scout recover once you notice they are starting to become overwhelmed.

- Stay calm. You've got this!
- Make sure you are familiar with a scout's **Individual Scout Profile** (Chapter 3).
- Use the **S.E.N.S.E.** method as outlined in Chapter 6.
- Check around to see if there is immediate action you can take to reduce noise, reduce lighting and make the environment more sensory-friendly.
- If they are not in a meltdown mode and can carry on conversation, empathize with their situation, showing them attention and respect. Use an **E.A.R. statement**. (Chapter 5)
- Take them aside and have them practice deep breathing.
- If near a wall, try wall push-ups.
- Have them take a walk outside the room or a walk about the building they are meeting in with adult supervision, being sure to take into consideration youth protection policies.
- Teach them to do "**Dots and Squeezies**" to help themselves calm, focus and self-regulate:

**Dots:** Gently but firmly press your thumb into the palm of your opposite hand and move it around the palm. Dots can also be done on the feet but avoid fingers and toes.

**Squeezies:** Start at the wrist and move up to the shoulders. Take your opposite hand and gently but firmly squeeze all around as you move up. This can also be done on the legs.

Once the scout is calm, introduce him or her back into the routine of the rest of the meeting. It takes time for the human body to fully calm after becoming excited or upset. With stress, sensory overload or an emotional breakdown, it may take longer if an incident has fully escalated before a person is removed from that stressful situation. Recovery time will vary from person to person but try not to introduce the scout back into an activity before he or she expresses being ready.

Make sure to keep the family in the loop if there are issues of concern but try to frame it in such a way that also includes positive progress the scout is making. Including parents in the conversation is a sign of respect and acceptance and gives them an opportunity to see how much you value having their child be a part of your unit.



# Chapter 8 - Safety & Mental Health Issues

## Wandering and Elopement

According to a 2007 online poll from the National Autism Association, 92% of individuals with autism are reported to have issues with wandering at some point in time.



**Wandering is the tendency for an individual to leave the safety of a responsible person's care or a safe area, which can result in potential harm or injury.** This might include running off from adults or leaving a scouting area without permission or when no-one else is looking. Other terms you might hear associated with wandering include elopement, bolting, running or fleeing.

We have included a copy of an Autism and Wandering safety brochure from [awaare.org](http://awaare.org) on the DVD that comes with your Leadership Training Kit. You can also find this brochure and other information at the following links:

<http://awaare.org/docs/wanderingbrochure.pdf>

<http://awaare.org/index.htm>

Here are important things to remember to help prevent or catch wandering when it happens:

- Ask parents to fill out an Autism Elopement Form and make sure that all leaders are aware of this safety issue. A free copy can be downloaded from AWAARE.org at: <http://www.awaare.org/docs/AUTISM%20ELOPEMENT%20ALERT%20FORM.pdf>
- Make sure everyone in your unit knows the rules of the buddy system.
- Check in frequently at campouts and hikes.
- There can be a lot of exciting new things to see when hiking or camping. It doesn't take long to be distracted.
- Be mindful of a scout's special interests because these are areas they may wander to (e.g. water areas such as ponds, lakes, rivers or streams).
- If you're camping in tents, attach a bell to the tent zipper so that someone is alerted when the youth enters or exits the tent. Try to assign a tentmate that is more mature to keep an extra set of eyes on them.
- Even if a scout has never wandered away before, doesn't mean he or she is not at risk. **The first time is often the worst time.**

- If a scout used to wander, run away or bolt when younger and has stopped, still be vigilant because it only take a few seconds for someone to wander away.

### **High Threshold for Pain / Thrill Seekers**

You may witness scouts in your group actively seeking very intense sensory experiences. These may be your thrill seekers of the group, the active children who always seem to be on the go.

You may notice excessive body whirling, jumping, crashing and/or spinning in younger children. In older children, these may be your high-adventure seekers, ready to participate in any extreme sport or activity. These are also youth who are at risk for getting hurt but not realizing it. These individuals are hyporeactive to sensory input and are trying to stimulate their vestibular systems.

- Encourage activity in a safe, planned environment.
- Clearly explain rules and guidelines when engaging in physical activities.
- Always make sure to have leaders and scouts nearby trained in First Aid. (Something you will want to do anyway!)

### **Epilepsy & Seizures**

Epilepsy is a brain disorder marked by recurring seizures or convulsions. It has been estimated that as many as 1/3 of individuals on the autism spectrum have been reported to develop seizures at some point in time.

The following is a link to a brochure from the Daniel J. Fiddle Foundation: **Autism, Epilepsy and Seizures: How to Recognize the Signs and Basic First Aid When You Do.**

<http://www.djfiddlefoundation.org/news/attach/DJF-EpilepsyBrochure.pdf>

### **Bullying**

**Autism Empowerment** has collaborated with **PACER.org** and **PACER's National Bullying Prevention Center** as one of their community champions since 2012. We gladly share during Unity Day, Bullying Prevention Month in October and throughout the year the bullying prevention resources on their website to help engage, educate and empower individuals and their families.



**We have included a number of these downloadable resources in PDF form on the DVD that is included with your Leadership Training Kit.** We have a Bullying Prevention Center on the Autism Empowerment website and have also done Bullying Prevention shows on our Autism Empowerment Radio and Autism and Scouting Radio podcasts.

<http://www.autismempowerment.org/resource-center/bullying-prevention/>

<http://www.pacer.org/bullying/>

While any child can be a target of bullying, individuals on the autism spectrum can be especially vulnerable. It may be difficult for them to communicate that unwanted behavior is taking place.

Scouting should be a safe and welcoming environment for all scouts and leaders. As leaders, you are tasked to create an anti-bullying culture in your scouting units and to empower scouts to assist those targeted by bullies wherever it occurs. This means creating a culture that does not condone bullying or harassment by scouts, leaders, parents or other volunteers.

It also means modeling kindness, acceptance, mutual respect and inclusion and not solving a problem with aggressive behavior.

#### **A few key points:**

- Bullying is any behavior that is deliberate, hurtful and repeated over time. It is usually characterized by a relationship involving an imbalance of power, such as size or popularity.
- Bullying can be physical, verbal, emotional, social, psychological or any combination thereof.
- It may also involve relational aggression, name calling and exclusion from people you thought might be friends. Girls often bully using emotional tactics rather than physical ones and if not addressed, may follow girls into adulthood.
- Bullying can take place almost anywhere – at school, on a bus, online, even unfortunately in scouting.
- Targets of bullying have difficulty stopping the behavior directed at them and struggle to defend themselves or to communicate to others that they are being bullied.

Your scouting organization may already have bullying prevention and peer advocacy models in place and we have also included some resources below and on your DVD. **We recommend offering Bullying Prevention education and training to your unit in October of each year** during National Bullying Prevention month. (Of course, you don't have to wait until October to do so!)

#### **A couple Scouting Related Anti-Bullying resources to note:**

The **Girl Scouts of Colorado** developed a **Power Up** program that is used by units supporting girls around the United States. Power Up encourages the 85 percent of the population who are bystanders to bullying (rather than targets or bullies) to recognize the strength in those numbers and use it to intervene when they see something wrong. An all-girl program, Power Up is focused on preventing the unique verbal and relational bullying prevalent among girls.

<http://www.girlscoutsofcolorado.org/power-up>

There is a Facebook Group based out of Australia but with international resources called **Breaking The Cycle – Bullying, It's Not Part of Scouting** - <https://www.facebook.com/ScoutsBreakingtheCycle>

## Depression, Anxiety & other Mental Health Issues

Individuals on the autism spectrum are vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life. It is often difficult for youth on the autism spectrum to communicate feelings of depression, anxiety and distress in meaningful ways that resonate with caregivers.

According to the National Institute for Mental Health, these are a few of the warning signs for depression. As a leader, if you see these signs during scouting, please express your concern to a parent or caregiver.

- Persistent sad, anxious, or "empty" feelings
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Irritability, restlessness
- Loss of interest in activities or hobbies once pleasurable, including scouting
- Fatigue and decreased energy
- Difficulty concentrating, remembering details, and making decisions
- Insomnia, early-morning wakefulness, or excessive sleeping
- Overeating, or appetite loss
- Thoughts of suicide, suicide attempts
- Aches or pains, headaches, cramps, or digestive problems that do not ease even with treatment

Parents and caregivers of children with autism often need help in understanding the mental health challenges their child is going through and how to address the needs that arise.

Help is available from psychiatrists, psychologists, and other mental health professionals that work in the public or private sector. There is also a network of mental health support operating in every state as well as locally. To locate systems of support in your community or state, we have listed a few national organizations below. They can connect you with local resources, including support groups that provide connection and understanding, information, referral, and advocacy for those living with emotional and mental health challenges.

**Mental Health America** | 1.800.969.6642

<http://www.mentalhealthamerica.net/farcry/go/searchMHA>

**NAMI** | National Alliance on Mental Illness | 1.800.950.NAMI

[http://www.nami.org/template.cfm?section=Your\\_Local\\_Nami](http://www.nami.org/template.cfm?section=Your_Local_Nami)

**National Mental Health Consumers' Self-Help Clearinghouse**

1.800.553.4539 - <http://www.cdsdirectory.org/>

Also look for support on the **Autism Empowerment website:**

<http://www.autismempowerment.org>

## Chapter 9: Frequently Asked Questions and Answers



**Got Questions?** Of course you do! In this chapter, we have compiled some of the most common questions that we have received at Autism and Scouting and done our best to answer them for you. Responses are from Autism Empowerment staff and the advisory panel that helped put this kit together. Our advisory panel includes autism self-advocates, authors, educators, parents, scouts and scouting leaders from a variety of scouting organizations. (See Acknowledgements to get to know these fine folks.)

### **1) The youth is a picky eater and will eat nothing or little to nothing on a campout. What should I do?**

**Response:** It is best to understand the underlying reasons behind the youth's pickiness when it comes to eating. Rarely is the youth out to make life difficult for everyone. More often than not, he or she may have some food sensitivities or sensory challenges involving eating that are not being addressed. It would be a good idea to have a conversation with the youth and his parents in a non-threatening environment about this. Does the youth have sensitivities to the way some foods taste or smell? Do particular food textures bother him or her? Does the youth have allergies or food sensitivities, such as gluten?

Once you understand the underlying reasons behind the dietary issues, you can generally work out some solutions that will be a win-win for all involved. If the youth is staying at a resident camp, you can often fill out a special needs form ahead of time, alerting them to special dietary needs. This way, the kitchen staff can prepare a meal or a meal variation that will be acceptable to the youth. If the camp does not have a special needs form, perhaps you could work with the camp staff in advance to mitigate any dietary concerns.

If the youth is participating in a weekend campout where the unit is responsible for preparing its own meals, it would be a good idea to teach the youth to recognize his or her own dietary restrictions, and then be able to advocate for them. Teach the rest of the unit to be inclusive about dietary concerns, and work out menus or menu variations that will allow everyone to enjoy the meal, as much as possible. We have to recognize that every individual is unique, but we can still maintain a spirit of unity when it comes to sharing a meal in a scouting function.

**Response:** Perhaps have the parents pack his favorite foods for the weekend. Be careful not to fall into the thought "he will eat when he's hungry enough"...kids who are "picky" eaters are more complex than just eating or not eating food because they "don't like it". Often times the "pickiness" comes from past experiences and/or sensory issues (taste, smell, texture, appearance, etc.).

## **2) We have a Scout that doesn't want to take part in a game or activity. What should we do?**

**Response:** Allow the Scout to help the Leader by being a judge or scorekeeper or timekeeper. Find out what in particular they are afraid of. If they are afraid of the noise, allow them to wear noise reduction headphones or earplugs. Have the Scout partner with an understanding older buddy so the Scout can try the activity. Have a practice round so the Scout knows what to expect beforehand. Give the Scout the agenda for the event/meeting with times listed ahead of time. Allow them to know what to expect and maybe the planning will help them transition and want to join in the activity.

**Response:** You should engage the Scout and understand why he does not want to participate. Is he simply not interested in the activity? Is there a sensory issue involving the game or activity? Is he afraid of being bullied or feeling embarrassed about participating in the activity? Once the underlying reasons for not participating in the activity are established, you can then work to mitigate those concerns.

I had a Scout once who was diagnosed with Oppositional Defiant Disorder. He simply did not like to do things because he often got negative attention by not participating in whatever activity was going on at the time. In that case, I simply did not require him to participate – I felt it was best to de-escalate the situation. One interesting thing I found was that if there was an activity he was REALLY interested in (e.g. aquatics) - he would often choose to participate of his own free will, no prodding necessary. The trick is that you have to keep digging and find the things that youth such as these are really into. It can be a very challenging quest, no doubt.

If you find that a lot of Scouts are not really interested in a given activity, then it may be time to examine the activity and understand why. Are the Scouts not mature enough to handle it yet? Does the activity involve more sitting and listening, and less watching and doing? (i.e. They will tell you the activity is “boring.”) Do not take it personally, but use it as an opportunity to learn from it, and revamp your program to better tune in to the needs of your Scouts. You will often find that you will come up with new ideas that both you and the Scouts will really enjoy.

## **3) I have two scouts in my unit who are both on the autism spectrum. They tend to push each other's buttons, please help?**

**Response:** Set the boundaries of proximity...in that you make sure they don't sit by each other if possible YET see if you can figure out what they have as a common interest and see if they can work together on a project. Remember kids are kids first and then experience autism...so it might be that their personalities are going to clash or it might be they'd like to be friends and have no clue as to how to develop the friendship without “pushing buttons”. You might try creating an actual list of “expected behaviors” for the group to follow then give feedback at the end of the meeting or activity.

## **4) I think I have a youth who is on the autism spectrum in my group. Should I ask their parents?**

**Response:** Do NOT diagnose a Scout (or anyone for that matter). Use “I” messages to let the parents know you are in need of their help in knowing how to reach their Scout. “I am having a difficult time trying to get Johnny to focus on what I am saying. What method works well at home that maybe I can try here?” “Johnny seems confused whenever I give him directions. Do I speak too fast for Johnny or would he understand easier if I told him one step at a time?”

**Response:** I would not come right out and ask but I would approach it from the perspective of, “I noticed Teddy is really good at \_\_\_\_\_ and \_\_\_\_\_ yet he seems to struggle with \_\_\_\_\_... Are there any ideas or ways you help him at home that I might be able to put in place for him?” This type of approach opens the door in a positive way and allows the parents the opportunity to share (or maybe they haven’t noticed anything and you have just given them some food for thought).

**5) I have a scout who seems to always be withdrawn. How do I get him / her out of their shell?**

**Response:** Do you? That is the question. They may be shy when meeting new people or just nervous.

**Response:** Show patience. It might be that the person is naturally shy or is anxious/stressed in certain types of situations. It could also be that they struggle socially and aren’t sure what to do or how to communicate outside of their home/family. Find out the scout’s interests and pair them up with someone who is quieter, has similar likes and who demonstrates more predictable behavior; someone that can explain things “on the side” as to what to do or why.

**Response:** Ask their parents what the Scout’s interest is and incorporate the interest in activities or conversations. Gain the Scout’s trust and be patient. It may take a while to get them out of their shell.

**6) I have a youth that doesn't want to go hiking or camping. Any suggestions?**

**Response:** First, does the scout like to hike or camp? If not, is there a different activity he could participate in? If he is expected to participate as part of the scouting experience/badge acquiring, etc. then “make it visual for them”. Help him understand the purpose he is participating (just saying, “Because it is fun” – ISN’T going to fix it!!!). When thinking of the activity think, “how can I answer these questions for him –in a visual format (i.e. lists, illustrations, first \_\_\_\_ then \_\_\_\_, etc.):  
What do I do? How long do I do it? How will I know I am finished? What will I do next?  
Remember to start small...a short simple hike with something positive the scout likes to do after.

**Response:** Don’t make them. Forcing them to do so detracts from the experience and if they feel forced to go camping or hiking, they won’t want to stay in the program as much, if at all.

**7) We have had looks from other parents when my son / daughter has acted up in the past and we feel that our child is being treated differently. Can you help?**

**Response:** Communicate your child’s challenges to where you feel comfortable. Explain the difference between a meltdown and a temper tantrum. Train the Pack/Troop/Crew/Leaders and Parents on whatever challenge is present. With awareness and understanding comes acceptance and patience. Being treated differently is not bad if you have different needs to be met. Teach Scouts what to do if another Scout acts out so the Scout in control of themselves can be a buddy or friend to the Scout acting out. This role modeling by peers is helpful.

**Response:** By whom? If it’s by adults, talk to them. Try making them understand. If it’s by the youth, it becomes a lot tougher. If it’s a large group (like 10+) then it’s really hard to make everyone understand. You can’t really just banish everyone from the group. It’s also much easier if the “acting out” was in an environment with less people and/or on a smaller scale. But if it is a large thing that happened with behavior, the remembrance that the scout “acted up” will still exist and you may need to educate the group.

**Response:** If you are willing to share that your child has autism you can develop a business card with facts about autism that you can give to people that will help them understand your child's needs.

**8) We have a couple of scout leaders who have been around awhile and it seems they don't want to learn about working with kids who have autism. Any suggestions?**

**Response:** Patience! Acceptance is about understanding and while it can be frustrating when it appears someone isn't "interested" in learning about supporting kids who struggle, especially if the kids seem to look "normal", hope is not lost. If you can find out what is "holding" the leader back or why they are reluctant (it could be their mindset or attitude or past experiences...it could be fear of not knowing what to do...) then slowly give them "snippets" to read or have conversations about. Don't despair and don't give up...supporting kids with autism is challenging and yet VERY rewarding!

**Response:** Usually that is because they don't understand or care. The former is **much more** likely. In that case, it may be best to sit down and talk with that leader, if possible. The latter is a more rare case and even though it's usually *thought* to be the latter, most cases it's actually the former.

**Response:** Bring it up at a Committee Meeting. Have a Committee Wide Training so the one leader is not singled out. Ask a guest speaker, such as Autism Empowerment or Autism Society, to come to a meeting for a 20 minute training session. Let them know awareness makes our jobs easier.

**9) Any suggestions on working with other leaders on the autism spectrum?**

**Response:** If the leader has self-disclosed that he or she is on the autism spectrum and is receptive to a conversation, you have an amazing opportunity to learn first-hand about autism from a person who has a lifetime of experience. Treat the person with respect and acceptance. Authenticity is key. Show in a genuine way that you're interested in better working with youth on the autism spectrum. Make sure they are aware of Autism Empowerment and the Autism and Scouting program. Let them know that the organization was co-founded by a woman on the autism spectrum and are proactive autism allies and direct them to the AutismEmpowerment.org website.

**Response:** Get to know that person, what their interests are...it's all about relationships.

**Response:** Assume intelligence and competence. Treat that leader the way you would wish to be treated. Understand he or she may need accommodations as well for sensory challenges.

**Response:** Plan meetings ahead of time and be specific with the goals of the meeting.

**10) When we are on a field trip or camp, we run into people that have not worked with scouts on the autism spectrum. How do I handle disclosure and privacy issues? What can I say?**

**Response:** Rather than disclosing private information or "labeling" someone, approach it from the standpoint of a person's strengths, the way they learn and process information, such as "Teddy is really good at \_\_\_\_\_; he likes to participate with \_\_\_\_\_". Sometimes it takes him a little bit longer to respond to questions or you might want to rephrase a question or direction if it doesn't seem like he is giving you enough information. OR Teddy likes things to be a certain way and might show frustration at \_\_\_\_\_; if so, it is helpful to \_\_\_\_\_.



It might be helpful to make a list for him of the steps you want him to take or things he needs to do.”

**11) My unit has kind of a strict uniform policy and I have one child that has sensory issues around the clothing and hat. What should I do?**

**Response:** Relax the policy for the sensory issues. Try liners under clothing and in hats but allow for a Scout to deviate from the strict policy. Remember the purpose and intent of Scouting.

**Response:** Sensory issues related to clothing can be huge. Several ideas come to mind, the first being continue to allow the scout to wear his uniform the best he can and explain to the other scouts (and their parents) that each of us have a sensory system and we each have different sensory needs. I would suggest having an occupational therapist or someone else with knowledge of the sensory system come to a scout meeting and present/explain (even doing awareness activities) how our systems work. **OR** Perhaps the scout with the sensory issues can earn one of his badges by doing a presentation to the group about the sensory system...As a last resort it could come down to an ADA accommodation issue...

**12) I am a new parent to scouting. Who should I tell and what should I tell about my child's challenges? Should I tell the leaders my child has autism or Asperger's?**

**Response:** It depends on the leaders. If you think they would understand, go right ahead. If not (which isn't usually the case), then it's probably going to be harder for the leaders, as they might think that they may need to give your child special treatment.

**Response:** Yes, but tell them in a way they can see your child's strengths first! Frame it something like: My son likes \_\_\_\_\_, \_\_\_\_\_ and \_\_\_\_\_. He is really good with \_\_\_\_\_, \_\_\_\_\_ and \_\_\_\_\_ yet he sometimes struggles with \_\_\_\_\_ or is challenged by \_\_\_\_\_. With these types of supports \_\_\_\_\_, \_\_\_\_\_ and \_\_\_\_\_ he can be successful.

**Response:** Communicate your child's challenges to where you feel comfortable. Explain the difference between a meltdown and a temper tantrum. Train the Pack/Troop/Crew/Leaders and Parents on whatever challenge is present. With awareness and understanding comes acceptance and patience. Being treated differently is not bad if you have different needs to be met. Teach Scouts what to do if another Scout acts out so the Scout in control of themselves can be a buddy or friend to the Scout acting out. This role modeling by peers is helpful.

**13) Any suggestions for a youth who refuses to shower when we're at a week-long camp?**

**Response:** This is a situation where I feel you just need to tell the scout. "Either you can take a shower and you'll be good or if you don't, you'll probably get criticized by other scouts."

**Response:** Pack extra deodorant! But seriously, ask his parents if he has a specific shower routine he does/follows at home. Any sensory concerns? Then when thinking about showering at camp, step back and look at the scenario from his perspective...default on the side of anxious thinking and all of the questions it brings up: Why do I have to take a shower at camp? When do I take my shower? How many times this week will I take a shower? Am I going to shower with other people around? How does the shower work? Is the room colder than I am used to? Where do I put my things? Are other people going to use my soap or towel? The list might go on and on...

As a leader, how can you reduce the stress and anxiety while building in the visuals? Maybe have the scout look at the facilities when no one else is around and walk him through the routines; showing him exactly where he would dress/undress, put his towel, soap, etc. Show him how the shower controls work (which way it turns on/off – MAKE SURE the controls are labeled so he can easily read them). Instead of taking his shower when everyone else is, could he take it earlier in the day or at a different time?

**14) We only have two leaders in our group and have a two-deep leadership requirement. One of the children in our group often melts down in a very loud way. I would like to be able to give him a sensory break but how can I take him away privately without violating the two-deep leadership rule or leaving the other children alone?**

**Response:** This is a challenge, yet THANK YOU for realizing the need for a sensory break! Is there a place in the room that might have a way to create a “safe spot” or “cool down zone”? Even if it is in the back of the room where you have a “sensory tool kit” with items that he or she has picked which assist in reducing stress. Items such as a weighted blanket, a small squishy ball, pencils and paper, etc. - TALK with the parents for sensory calming ideas. Plus you might want to invest in a bunch of inexpensive headphones (Harbor Freight has good ones) for the rest of the boys or girls to use when a meltdown occurs. Also, try to figure out what things or activities trigger his or her meltdowns then put supports in place to help prevent them (ask yourself, “Why does (s)he need to \_\_(insert behavior)\_\_ to get needs met? It helps to remember that behavior is about unmet needs AND “ALL behavior is communication.”

## Chapter 10: Next Steps & Supplemental Resources



The **Autism and Scouting Leadership Training Kit** is a healthy starting point to build your knowledge of better serving and empowering scouts on the autism spectrum. We want to provide you with supplemental resources to help you in your continuing education.

### Information on the DVD

On the DVD included with your kit you will find the following information that you can print out and put in the Leadership Training Kit so everybody will have access to it. Alternatively, you can review much of this information online. There are over 100 pages of additional information to help support you when working with youth who are on the autism spectrum in their journey in scouting.

### Copies of Autism and Scouting Training Materials

**The full PDF for the Autism Empowerment Leadership Training manual** (what you're reading now)  
Autism and Scouting Training (Powerpoint to be shared or taught to others)  
Autism and Scouting Advanced Training (Powerpoint) – version adapted for BSA  
ADHD / SPD Training from Chris Parrott (Powerpoint to be shared or taught to others)

Here is what is included on the DVD with suggestions where you might like to include the information within your Autism and Scouting Training Manual. Feel free to keep it wherever you'd like.

23 Scouting Tips	Chapter 10
Acronyms you will find around Autism and the special needs community	Chapter 10
Autism-Friendly World Unit Locator Commitment	Chapter 10
Autism and Scouting Award (Youth and Adult)	Chapter 10
Autism and Scouting Helps Families Connect & Stay Plugged In Sheet	Chapter 10
Autism and Scouting Program Information Sheet	Chapter 10
Autism and Scouting Webinar Series for 2014	Chapter 10
Autism Does Not Define Me poem	Chapter 1
Bullying Prevention Resources (including PACER)	Chapter 8
Elopement / Wandering Emergency Plan	Chapter 8
Glossary of Terms related to Autism Spectrum Disorder	Chapter 10
Help Spread Autism and Scouting Leadership Training Worldwide	Chapter 10

Individual Scout Profile (Worksheet)	Chapter 3
Order form for Additional Kits	Chapter 10
Recognizing Autism / ASD Symptoms, Signs and Characteristics	Chapter 2
S.E.N.S.E. (Angie Voss)	Chapter 6
Sensory Friendly Unit Checklist	Chapter 7
S.M.I.L.E Worksheet (use with Individual Scout Profile)	Chapter 3
Social Narratives	Chapter 5
Supplemental Resources (Websites, Books, Materials, etc.)	Chapter 10
The Great Race to Autism Acceptance	Chapter 10
The Incredible 5 Point Scale	Chapter 5
Visual Schedule with time	Chapter 4
Visual Schedule without time	Chapter 4
Working with Scouts with disAbilities - Individual Scout Advancement Plan (BSA)	Chapter 10

**It doesn't stop there! Autism and Scouting is dedicated to providing you with ongoing training through our website, social media, podcasts and webinars.**

**Customized trainings available – email [scouting@autismempowerment.org](mailto:scouting@autismempowerment.org) for details.**

#### **Autism Organizations referenced in Autism and Scouting Leadership Training Manual**

**Autism Empowerment** - [www.AutismEmpowerment.org](http://www.AutismEmpowerment.org)

#### **Autism and Scouting Program**

Contact: John Krejcha, Autism and Scouting Program Director

P.O. Box 871676, Vancouver, WA 98687 - (360) 852-8369

[scouting@autismempowerment.org](mailto:scouting@autismempowerment.org)

[www.facebook.com/autismempowerment](http://www.facebook.com/autismempowerment)

[www.facebook.com/autismandscouting](http://www.facebook.com/autismandscouting)

@autismempowermt (Twitter)

@autismscouting (Twitter)

**Autism and Scouting Radio** – [www.blogtalkradio.com/autismandscoutingradio](http://www.blogtalkradio.com/autismandscoutingradio)

**Autism Empowerment Radio** – [www.blogtalkradio.com/autismempowerment](http://www.blogtalkradio.com/autismempowerment)

Autism Empowerment is the only national autism organization that has an Autism and Scouting Program dedicated to making the lives of scouts better by providing tools, training, support and special events for unit leaders, volunteers, parents and scouts around the world.

**Autism Speaks** - <http://www.autismspeaks.org/>

1 East 33rd Street, 4th Floor, New York, NY 10016

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

4340 East-West Hwy, Suite 350, Bethesda, Maryland 20814 - (800) 328-8476

## **Books, Materials and Websites Referenced in the Autism and Scouting Leadership Training Kit**

**A Sensory Life** - <http://asensorylife.com/> - Angie Voss's Sensory Strategies Website

**Understanding Your Child's Sensory Signals: A Practical Daily Use Handbook for Parents and Teachers** by Angie Voss, OTR/L (2<sup>nd</sup> edition)

**Asperkids** - <http://www.asperkids.com> – Jennifer Cook O'Toole

Through internationally-celebrated books, private consultations, public presentations, and carefully-selected resources, the goal will always remain the same: to unlock the precious, precocious potential of Asperkids everywhere.

**Asperkids: An Insider's Guide to Loving, Understanding and Teaching Children with Aspergers Syndrome** by Jennifer Cook O'Toole

**The Asperkid's Secret Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome** by Jennifer Cook O'Toole

**Cabins, Canoes and Campfires – Guidelines for Establishing a Summer Camp for Children with Autism Spectrum Disorders** by Jill Hudson

**Life with Aspergers** - <http://life-with-aspergers.blogspot.com/>

Written by Gavin Bollard, this is the blog that goes along with his Facebook page. A blog about living with Asperger's Syndrome and Parenting Children with Asperger's Syndrome.

**PACER Bullying Prevention Center** – <http://www.pacer.org>

**The Hidden Curriculum for Understanding Unstated Rules in Social Situations for Adolescents and Young Adults** by Brenda Smith Myles, PhD, Melissa L. Trautman, MsEd and Ronda L. Schelvan, MsEd

**The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder** by Carol Stock Kranowitz, M.A

**Thinking In Pictures** by Temple Grandin