# INCLUSION TOOLBOX FOR SPECIAL NEEDS AND DISABILITIES



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BOY SCOUTS OF AMERICA®



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### **MODULE A**

## INTRODUCTION

IN THIS MODULE:

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#### HOW TO USE THIS TOOLBOX

The Inclusion Toolbox for Special Needs and Disabilities is a printable website that keeps special needs and disability information accessible 24/7/365 to the BSA community. The Toolbox does not read like a novel or textbook. It is designed to allow you to jump to the topics of greatest interest and then read other sections later. Use the Table of Contents and search feature to jump to what you need.

The Toolbox is organized into four parts. The first few modules were written for BSA unit leaders<sup>1</sup> that deal directly with youth and for the parents and guardians of Scouts<sup>2</sup> with special needs and disabilities. These target audiences were combined because communication and understanding between parents/guardians and leaders is important for providing the best program and because each group needs to understand what it's like to be in the other's shoes. Leaders may want to reproduce parts of the Toolbox, especially Modules B and D, as handouts for families that are new to Scouting.

The second group of modules offers a deeper look at different classes of disabilities and special needs, to offer more insight and more specific advice for serving youth and adults with these disabilities. While the emphasis in these modules is on serving youth, please be aware that "inclusion" includes supporting adult Scouting volunteers and family members of Scouts. This

<sup>&</sup>lt;sup>1</sup> In this Toolbox a "unit" is a Scouting unit at any program level; Pack, Troop, Crew, Ship, or Post. "Unit Leaders" are registered adults at all program levels (Cub Scouts, Scouts BSA, STEM Scouts, Sea Scouts, Venturing, and Exploring) that interact directly with youth.

<sup>&</sup>lt;sup>2</sup> In this Toolbox a "Scout" is a registered youth participant at any program level and includes Cub Scouts, Scouts, Venturers, Sea Scouts, and Explorers. It also includes older people with disabilities that are allowed to participate in Scouting on a youth basis.

group of modules should be useful to Scouting volunteers and professionals at all levels that need more specific information. Please understand that an individual may have more than one special need or diagnosis. It was impractical to deal with the specifics of every possible combination of needs in this Toolbox. To assist a particular Scout or adult you may have to refer to a few different modules to address each facet of her or his disability.

The third group of modules covers topics of interest to volunteers and professionals operating above the unit level. While they may not have much direct contact with youth with special needs and disabilities, they are responsible for organizing large events, building and operating camp facilities, and recruiting and training event and camp staff. They are also the ones that have to make the difficult decisions when exceptions may be needed to support a youth or adult with a disability or special need.

The fourth group of modules is designed for program area leaders that are providing experiences as Scout camps. They may not have the luxury of focusing on a single Scout's needs, but do need to understand how to adapt their specific activities for greater inclusion.

#### PURPOSE

The purpose of this *Inclusion Toolbox for Special Needs and Disabilities* is to provide a single comprehensive reference source for disabilities information for the BSA Scouting community. The National Special Needs & Disabilities Committee developed this Toolbox to bridge the gap between more general sources of disabilities information and the Methods of Scouting. We expect that the information provided here will become the basis for other shorter publications to raise awareness of special needs and the foundation for training courses for Scout volunteers, professionals, and family members.

Suggestions for improvements can be directed to the National Special Needs & Disabilities Committee, BSA National Service Center, 1325 W. Walnut Hill Lane, P.O. Box 152079, Irving, Texas 75015-2079 or by email to SpecialNeedsChair@scouting.org.

This document is a reference for good practice and is not intended to create rigid rules to be followed, standards to be maintained, or standard operating procedures to abide by. It should be taken as good advice and it does not supersede other authoritative BSA publications.

Another aspiration for this Toolbox is that it will provide timely information for decision-making and allow any "issues" that come up at the unit or local level to be resolved at the unit or local level. In our experience, most "problems" trace back to a lack of understanding and ineffective communication between the people involved.

#### SCOPE

This *Inclusion Toolbox for Special Needs and Disabilities* builds on many historical BSA documents and has kept the best from the past while also keeping up with the times. The editors deeply appreciate the contributions of past generations of volunteers. This Toolbox replaces and expands upon BSA 34059 – Scouting for Youth with Disabilities Manual, 2007.

The information in this Toolbox is presented in lay language, with enough detail to allow you to provide a good experience for Scouts and their families. It will not train you to be a full-time caregiver or how to provide skilled therapy such as physical, speech, occupational, psychological, or medical. The descriptive information about specific types of disabilities focuses on their effects, not their causes, and is intended to help you understand and have empathy for a person with that disability.

You will find two modules about advancement. Module E is for parents, guardians, and unit leaders. Module V is for Council and District advancement volunteers. This material expands on information in the *Guide to Advancement* to show how the requirements for advancement can be met in innovative ways. We reference the 2021 edition of *Guide to Advancement* in this Toolbox. The *Guide to Advancement* is regularly updated by the National Advancement Program Team and this Toolbox defers to the mandated procedures in the *Guide to Advancement*. While we plan to regularly update this Toolbox as well, it is wise to consult the latest edition of the *Guide to Advancement* before making any critical decisions in a plan for alterative advancement.

Other than suggesting ways to provide support for a Scout with a disability while meeting BSA Youth Protection policies, health and safety are not directly addressed in this Toolbox. However, health and safety need to be considered in designing adaptations, accommodations, and accessibility features. The *Guide to Safe Scouting* outlines current BSA policies that have been adopted to keep youth safe in our program and this Toolbox defers to the *Guide to Safe Scouting*. The *Guide to Safe Scouting* is regularly updated by the National Health & Safety Committee. We encourage you to become familiar with it as well.

The writers and editors of this Toolbox have used terminology that is reasonably current at this time. Cutting edge insider terminology would leave many readers behind. Person first language<sup>3</sup> has been used to a maximum extent to underscore the importance of the person over the disability. We beg your understanding and forgiveness if any particular choice of words bothers you. As a practical matter, the language used to discuss special needs is continually changing in our culture. In our experience different terminology is used for the same thing in different parts of the country, and in different professional fields. It would be impossible to satisfy everyone's sensibilities, but we did try.

<sup>&</sup>lt;sup>3</sup> Person first language usually takes the form "person with X" rather than "X person". However, there are certain communities of people that consider their condition to not be a disability, but rather an element of their core identity. In those instances, the editors have honored the traditions of those communities.

#### BSA INCLUSION PHILOSOPHY

Since its founding in 1910, the Boy Scouts of America has included fully participating members with physical, mental, and emotional disabilities. The Boy Scout Handbook has developed Braille editions. Merit badge pamphlets have been recorded on audio for Scouts who are blind. Closed caption training videos have been produced for Scouts who are deaf. In 1965, registration of overage Scouts with intellectual or developmental disabilities became possible— a privilege now extended to many Scouts with disabilities.

The basic premise of Scouting for youth with special needs and disabilities is full participation. Youth with special needs are to be treated and respected like every other member of their unit. They want to participate like other youth—and Scouting provides that opportunity. Providing the Scouting program to those with disabilities means that we have an ongoing process to educate unit leaders how to adapt their methods and how to create healthy, safe, empathetic environments for all of their Scouts, both with and without special needs. It also means actively encouraging inclusion of Scouts with special needs and disabilities into "mainstream" or "traditional" Scout units like Cub Packs, Scout Troops, Venturing Crews, STEM Scouts, Sea Scout Ships, and Exploring Posts.

While it is usually best to include Scouts in regular units, there are situations where that is not the best solution for a Scout with a disability. BSA also supports Scout units where all the members have a similar disability—such as a Scout troop for Scouts who are blind or a Cub Scout pack for Scouts who are deaf. Many of these disability-specific Scouting units are chartered to schools or centers for youth with a particular type of disability that make the Scouting program part of their curriculum. These Scout units are encouraged to participate in Scouting activities at the district, council, area, regional, and national levels along with other traditional units.

When it comes to specific activities, our goal is to allow a youth with a disability to participate to the maximum extent possible in the same way, place, and time as everyone else. Even when adaptations or accommodations are needed, we want to have everyone sharing the experience together. In our experience, youth are often able to do more than is expected of them, when they are given a chance.

In order to encourage positive, inclusive experiences for all youth in Scouting, especially those with different abilities or challenges it is necessary to define "inclusion". It is almost as if the Scout Oath and Law created the concept of inclusion. There are several definitions of inclusion, but one that truly resonates is "An attitude and approach that seeks to ensure every person, regardless of ability or background, can meaningfully participate in all aspects of life."<sup>4</sup> Inclusion is an approach, not a program. It is an attitude, not an activity.

<sup>&</sup>lt;sup>4</sup> Paths to Inclusion: A Resource Toolbox for Fully Including Youth of ALL Abilities in Community Life

#### HOW SCOUTING BENEFITS YOUTH WITH SPECIAL NEEDS & DISABILITIES

By definition, a disability is an impairment that substantially limits one or more major life activity. A special need makes a life activity substantially harder than it is for most people. When a major life activity is impaired, a youth is at risk of being left out or isolated from our society. Some special needs make it hard to communicate or interact with others. Others create odd behavior that doesn't easily mesh with the social order. Other disabilities require equipment or assistance that makes one move slower or fall behind the group. A few disabilities make one look odd to others.

For most youth with disabilities, their primary opportunity to interact with their peers is at school. Even then, their special needs can entail many hours outside the regular classroom to give them their needed therapies and educational supports. Outside of school, there are few extracurricular opportunities for youth with special needs or disabilities to participate like everyone else. Scouting is a somewhat rare exception. In Scouting a youth with a special need can participate on an equal (or near equal) footing with everyone else.

For the most part, individuals with special needs or disabilities learn good social and life skills when they're able to bond with peers their own age. Their friends become role models of good behaviors. Their self-esteem and confidence begins to build when they feel a sense of belonging. Tasks they once felt were difficult or impossible become manageable. In Scouting, positive results can be seen as a youth with a disability starts to advance in rank and take on leadership positions. Genuine praise given to a Scout who has a special need can be very powerful.

While Scouting was not invented specifically for those with different abilities, from its founding it has been an inclusive movement and based on a belief that no matter what culture or economic class a boy came from, he had similar needs to mature into a good citizen, and that people from all classes and culture should be part of one brotherhood. Obviously as the decades have passed, our language has changed and the Scouting movement has broadened its perspective to include many other aspects of diversity. Though it was not called that in the language of the day, ability diversity was one of the earliest initiatives in this regard, though we now include gender, ethnic, economic, and orientation diversity as well.

The Scouting program provides experiences and opportunities for youth, including those with a disability, to try and experience things outside their normal life routines. They also encounter people they would not otherwise know in person. We know from experience that this builds confident, resourceful, good-hearted adults. The program is flexible enough to allow Scouts to attempt a challenge when they are ready, rather than on a fixed timetable. It also allows them to take as many tries as they need to in order to succeed. The truth is that all of us as human beings have a varying set of abilities and are stronger in some than in others. A Scout with a "diagnosed" disability could easily have an "undiagnosed" super ability as well.

Every youth should have a chance to become his or her best self. Scouting is committed to this ideal and seeks to have every youth have the opportunity to be a Scout.

#### HOW YOUTH WITH SPECIAL NEEDS BENEFIT OTHER YOUTH

"Man's mind, once stretched by a new idea, never regains its original dimensions." – Oliver Wendell Holmes

It is as important for typically developing youth to experience friendships with those with special needs or disabilities as the other way around. It is simply impossible to see a person with a "label" or a difference in the same way when you have walked in each other's shoes and shared the same challenges. The presence of those with special needs provides an opportunity for others to practice serving. Service is like a muscle. If it is exercised, it grows stronger. While Scouting is fun and games for our youth, our higher purpose is to make better people out of them when they are adults. We want that culture of cheerful service to be ingrained in them from now on. Exposing them to people who are different from themselves is part of the process.

Author : Roger B. Tate Reviewers: Midge Savage & Sandy Payne

#### **MODULE B**

## BASICS OF SCOUTING FROM A SPECIAL NEED PERSPECTIVE

IN THIS MODULE:

SCOUTING IDEALS UNIT STRUCTURE UNIT LEADERS THE PATROL METHOD THE OUTDOORS AWARDS AND RECOGNITIONS (ADVANCEMENT) ADULT MENTORING PERSONAL GROWTH LEADERSHIP DEVELOPMENT THE UNIFORM PROTECTING AGAINST ABUSE

> "But the real way to get happiness is by giving out happiness to other people. Try and leave this world a little better than you found it and when your turn comes to die, you can die happy in feeling that at any rate you have not wasted your time but have done your best. 'Be prepared' in this way to live happy and die happy—stick to your Scout Promise always—even after you have ceased to be a boy—and God help you do it." —Excerpt from a farewell letter written by Robert Baden-Powell to the Scouts of the world

This module is for parents and guardians who are new to the Scouting program and need to understand the big picture while helping their children with special needs and disabilities navigate the Scouting world. It borrows heavily from the *Scoutmaster's Handbook*, but applies to all of the Scouting programs.

The *Inclusion Toolbox* uses the term "Scout" throughout. In this context, a Scout is any member of a Scouting program, including Cub Scouts, Scouts BSA, Venturing, Exploring, Sea Scouts, and other special opportunities. Unless there is a specific explanation, the term "Scouting" applies to all program levels and options.

#### SCOUTING IDEALS

At its core Scouting is a values-based program. Those values are summarized in a group of statements. They are the:

Scout Motto: Be Prepared

Cub Scout Motto: Do Your Best

Scout Slogan: Do a Good Turn Daily

- Scout Oath: On my honor I will do my best to do my duty to God and my country and to obey the Scout Law; To help other people at all times; To keep myself physically strong, mentally awake, and morally straight.
- Scout Law: A Scout is: Trustworthy, Loyal, Helpful, Friendly, Courteous, Kind, Obedient, Cheerful, Thrifty, Brave, Clean, & Reverent
- BSA Mission Statement: The mission of the Boy Scouts of America is to prepare young people to make ethical and moral choices over their lifetimes by instilling in them the values of the Scout Oath and Law.

Inclusiveness is implicit in the Scouting values statements. The Scouting program is open to any youth within the program age ranges and to older people with disabilities who can benefit from Scouting's youth-oriented programs. While our history has not been perfect, it has been our desire to let nothing stand in the way of a youth participating in Scouting. Special needs and disabilities should not exclude a youth from being a Scout.

Scouting is primarily an experiential learning environment. Scouts should always be trying new things, taking chances to learn, becoming more capable, learning how to work with others, and how to lead. The program has an emphasis on the outdoors largely because it strips living down to the basics and provides more opportunities to learn than everyday life. Even if a person has restrictions on outdoor activity, that doesn't mean he or she cannot benefit from the Scouting program or be a "good Scout". Scouting prepares young people to live a more productive and fulfilling life.

#### UNIT STRUCTURE

Cub Scout Packs, Scout Troops, Venture Crews, Exploring Posts, and Sea Scout Ships are all "Scout units". A Scout unit is operated by<sup>1</sup> a local organization in your community. The local organization commits to provide the Scout unit with good adult leaders, a meeting place, and

<sup>&</sup>lt;sup>1</sup> In "Scoutspeak" – chartered by a local organization

other resources. Scout units are service-oriented and seek to pay their own way rather than rely heavily on their sponsoring organization for funding.

Each unit is governed by a volunteer committee. The unit committee does administrative work for the unit. The unit leaders (Den Leaders, Cubmasters, Scoutmasters, Advisors, Skippers, etc.) answer to the unit committee. If the unit leaders are not responding to your requests for appropriate accommodations for your Scout, approach the unit committee for additional resources.

Each unit should also have a Unit Commissioner. A commissioner is a seasoned Scout volunteer who helps the unit accomplish its goals when the unit does not have the skill or knowledge on its own. A Unit Commissioner is a member of the district<sup>2</sup> staff and is well-networked within the Scouting community. If you run into a struggle and the unit committee hasn't been able to help, reach out to the Unit Commissioner to draw on more resources.

#### UNIT LEADERS

Module C discusses the role of a unit leader, so you can find more information there. Scouting provides youth with an environment in which everyone can feel secure, both physically and emotionally. Adult leaders provide that sense of security for the youth in the unit. They set an example for others by living the Scout Oath and Law to the best of their abilities. They refuse to tolerate name-calling, put-downs, discrimination, or any form of physical aggression. They communicate their acceptance of youth by taking a real interest in each Scout. They use the Scouting programs to create a setting for learning and fun. They seek the best from each Scout and do all they can to allow him or her to achieve it.

#### THE PATROL METHOD

Within the larger community of the troop or pack, the patrol or den is a Scout's "family circle." Often made up of kids who are close in age and experience level, each patrol helps its members develop a sense of pride and identity. The youth themselves elect their patrol leader, divide up the jobs to be done, and share in the satisfaction of accepting and fulfilling group responsibilities. Patrols and dens average around eight members. This size of group is ideal for collaboration and getting tasks done. In the vast majority of situations, a Scout with a disability should be a member of a patrol or den and participate alongside everyone else.

<sup>&</sup>lt;sup>2</sup> As a parent or guardian you may hear leaders or parents use the terms "district" and "council". These are organizational subdivisions within Scouting just like states and counties are government subdivisions in the United States. A Scout council usually has its headquarters in a metropolitan area and serves several surrounding counties, sometimes across state lines. Each council will have several Scout districts. Districts can be geographically large or small and are usually sized to serve about the same number of Scouts and Scout units in each one.

Within the "Patrol Method" is the notion that Scouts should be "youth led". This means that to the maximum extent possible, decision making is delegated to the Scouts themselves. While many Scouts are naturally accepting of others, there are times when a unit leader may have to help a Scout with a disability to crack through the social shell of an established patrol or den.

#### THE OUTDOORS

Youth join Scouting for the challenge, the excitement, and the fun. Much of Scouting is designed to take place outdoors in settings where kids can find real adventure. Outdoor activities put the sizzle into Scouting. They keep kids coming back for more.

The outdoors is our classroom for many reasons, and youth with special needs and disabilities benefit from the outdoors too. While it is a natural tendency for us to compare those with disabilities to those "without", the truth of the matter is that everyone has differing abilities. Even those gifted in some ways will struggle in others. For example, a person with the physical ability to rock climb may lack the decision-making ability to do so safely. With that perspective, every youth will have something to challenge him or her in the outdoors and many of the challenges are not physical. In fact, youth who have lived with disabilities may have greater resilience and confidence to take on new challenges than most, because they have already learned to cope with so many other challenges.

For the parent or guardian of a child with a disability, the outdoors can be a scary place. It lacks the infrastructure of the home and the regular unit meeting location. It is inherently less "groomed" to make physical movement easier. The point is to accept the challenges this presents. Scouting teaches people how to turn the outdoors into "home" by the skillful use of equipment and with group cooperation. Cleverly creating comfort in the outdoors is the hallmark of good campers.

#### AWARDS AND RECOGNITIONS (ADVANCEMENT)

Advancement is "Scoutspeak" for the system of recognizing youth for their individual achievements. In Cub Scouts, Scouts BSA, and Sea Scouts, there are ranks to be earned as you go along, and there are optional awards that can be earned as well. The other BSA programs also have structured sets of award opportunities rather than ranks. These also offer a progressive challenge and are recognized with ceremonies and uniform attachments. The ranks and awards form a "curriculum" for these programs and a natural progression of skills development. In addition, advancement sets a pattern of setting positive goals and reaching them throughout life. In order to keep youth motivated to move forward we recognize them regularly to celebrate what they have already accomplished. Recognitions have two parts. One is a public ceremony within the unit so others can see and cheer on each Scout. The other is

some sort of tangible item that is worn with the uniform as a lasting recognition; like a patch, pin, or bead.

One of the challenges of Scouting is balancing fairness to all Scouts with reasonable accommodation of a disability in the advancement requirements. Whether they are recognized as disabled or not, youth are all over the map in their innate abilities and advantages. The general approach is to keep the requirements the same for everyone as much as possible. It is normal for a youth to find some requirements harder than others and for requirements that are hard for some to be easy to others. By itself, this does not disadvantage youth with disabilities because many of them will also have innate advantages over some other Scouts.

Exceptions can be made when a Scout's disabilities make it impossible to achieve ranks and awards by the normal rules. However, any system for exceptions risks being misused to benefit Scouts that don't really need them. The BSA has rigorous procedures and paperwork to complete in order to get exceptions to the regular rules. Exceptions come in two forms. One type of exception is to allow more time for the youth to remain in the program and earn awards<sup>3</sup>. The other type of exception is the substitution of an achievable requirement for an impossible one. Module E explains how to apply for and get an exception to advancement requirements.

Before leaving this topic, we should emphasize that "advancement" is a method of Scouting but it is not the mission of Scouting. Youth can benefit from the other opportunities of Scouting even if they never earn a rank. Many worthy and excellent Scouts never achieve the top rank of their program level, such as Eagle Scout.

#### ADULT MENTORING

Many youth learn a great deal by watching how adults conduct themselves. Scout leaders can be positive role models for the members of their units. In many cases an adult leader who is willing to listen to kids, encourage them, and take a sincere interest in them can make a profound difference in their lives.

Adults in Scouting are teaching youth all kinds of skills, but more importantly they show them how to "do life". We show how to honor and respect other people and we try to bring out the best in each individual Scout. Our activities set the stage for learning to be good to each other and handle aggravations, struggles, and conflicts in healthy ways.

A special feature of the Scouting movement is that our adult leaders are not trying to direct everything for the youth in our care. Rather, we seek to empower their decision making while providing enough boundaries to keep them healthy and safe.

<sup>&</sup>lt;sup>3</sup> In fact, it is possible for some people with disabilities to continue to participate as Scouts and continue to earn ranks and awards for their whole lives.

While we encourage Scouts to help and take care of each other, there are some disabilities that need more assistance than a peer should give. In these instances, extra adults are needed. They may be parents or guardians, skilled professional caregivers, or other Scouting volunteers. These extra adults become part of the social mix of the Scout unit and provide extra opportunities to mentor all of the youth in the unit. Youth Protection Training (explained shortly below) is required before any adult has access to any youth other than their own children.

#### **PERSONAL GROWTH**

Scouting-age youth are experiencing dramatic physical and emotional growth. Scouts with special needs are no different in this regard. Scouting offers them opportunities to channel much of that change into productive endeavors and to find the answers they are seeking for many of their questions. Through service projects and Good Turns, Scouts can discover their place in their community. (A Good Turn is a simple act of kindness or service to another person. Today we would call it paying it forward.) Many Scouting activities allow youth to associate with others from different backgrounds. The religious emblems program offers Scouts paths to more deeply understand their place in the world. The Scout unit itself provides each Scout with an arena in which to explore and try out new ideas. One can go on adventures with no purpose other than having fun.

#### LEADERSHIP DEVELOPMENT

Leadership is a skill that is best learned by doing it. Every Scout in a patrol and unit will find that he or she is filling positions of increasing responsibility. From the first leadership experiences on, youth learn planning, organization, and decision making. For many kids, accepting the role of Denner or Patrol Leader is the first real leadership opportunity they have ever had. Discovering that they can do the job will go a long way toward giving them the confidence and ability to take on the next job and ultimately be leaders in adult society. In Scouting, youth learn to be effective leaders . . . and to be good followers.

Like other Scouts, people with special needs or disabilities can take on leadership roles and participate in specialized leadership training. Those with different abilities spend their lives getting things done in ways that are different from most. Their leadership styles can be innovative. There is nothing wrong with a Scout fulfilling a leadership role by getting help from other Scouts where needed.

#### THE UNIFORM

Since the founding of the BSA in 1910, Scout uniforms have been a recognizable part of the American scene. Even today, Scouting programs use standardized uniforms for its members, though the uniform is more formal in some programs than in others and the uniform can be customized at the unit level in some programs. People seeing a youth in a Scout uniform expect someone of good character who is prepared to do his or her best to help others.

Wearing the uniform helps kids develop a sense of belonging and identify with their unit. It reinforces the fact that all members of the BSA are equal to one another and we are all "included". No matter how diverse we are as individuals, we are all Scouts. This is true for Scouts with disabilities too because ability is just another axis of diversity. When Scouts and Scout leaders are in uniform, they are instantly reminded of what they stand for and tend to behave in a way that brings honor to themselves and to the Scouting community.

It is important for adult leaders to be in uniform at Scout events. They set a good example for members of their units and are also seen as community leaders fulfilling a very important role.

#### PROTECTING AGAINST ABUSE

The BSA seeks to be world-class in protecting our members against all forms of abuse, to include sexual abuse, physical abuse, bullying, cyberbullying, physical or emotional neglect, exposure to violence or threat, or any form of sexual exploitation. We accomplish this through our Youth Protection Training (YPT) programs and rapid response to any situation that arises. Our training is multi-faceted in that we require every registered adult to be trained. We strongly encourage every parent to take this training as well. We also provide abuse recognition and reporting training to all our youth. The training in abuse prevention for the youth is age-appropriate, but thorough. We recognize that abuse can be either youth-on-youth or adult-on-youth.

There are two significant facets to abuse protection that relate to those with disabilities. The more obvious one is that youth with disabilities are a vulnerable population in general and make attractive targets for teasing, practical jokes, and other forms of mistreatment. This requires an extra level of vigilance from the adults at Scout events and activities to nip inappropriate behavior in the bud and create empathy in our youth so they see how an act would not be funny if you were on the receiving end.

The second aspect of abuse protection has to do with maintaining safety when a Scout needs adult help with something that ordinarily requires personal privacy. The BSA youth protection rules assume that parents and guardians are trustworthy in regards to their own children and they are allowed access that other adults are not allowed. The challenge is when a Scout needs assistance with dressing, bathing, toileting, feeding, or using medical devices. Parents and

guardians are clearly allowed to assist, while other parents and adult leaders are not ordinarily allowed to have that kind of access to a youth, whether or not the youth or parent or guardian give permission. If a Scout has a professional caregiver other than a parent or guardian, special arrangements will need to be made, and those arrangements will need to be coordinated with the leaders of the unit and camp facility. Early planning and communication are important. This is discussed in greater detail in Module C.

Author: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

## **MODULE C**

## THE UNIT LEADER'S ROLE IN SUPPORTING A SCOUT WITH A DISABILITY

IN THIS MODULE:

CAN DO ATTITUDE BECOMING AN ACCEPTING UNIT BUILDING EMPATHY BUILDING A UNIT LEADERSHIP TEAM TRAINING & SUPPORTING YOUTH LEADERS COUNTERING MYTHS ABOUT DISABILITIES HELPING VOLUNTEERS FROM OUTSIDE YOUR UNIT OUTING AND ADVENTURE PLANNING SUPPORTING SIBLINGS

#### CAN DO ATTITUDE

As a Scout leader you will continue to be challenged in new and different ways. When a situation arises, do you tend to address the problem in a certain way? If you get stuck, do you adjust tactics or strategy? Do you seek advice from someone else with more experience? When an adjustment doesn't seem to work, what happens then? The challenge is still there, and it's frustrating to the point where everything else is thrown to the side until this issue is solved. A person (Scout or Scout leader) with a disability goes through this same process when addressing a challenge, only there may be physical, emotional, or mental limitations to successfully completing the challenge in a typical way. Sometimes you, and others, have to think outside the box to find a new way. It takes a team effort for the Scout to be successful and ready to conquer the next challenge. As a Scout leader, you are the center of a team of other adult leaders, family members, council representatives, and counselors. With their help, you have the ability to ensure that the Scout has the opportunity for success while maintaining a safe and secure environment. Keep this in mind as the goal for this module.

Scouting offers youth an environment in which everyone is challenged and is having fun. They learn about themselves as well as others. A safe and secure environment is always paramount, and the responsibility to manage the environment is yours. Most Scouts don't realize they are kept safe and secure in the middle of a challenge.

For the Scout to be successful there has to be trust between a Scout, the unit leaders, and the family. At first, that trust is built by how you, as a unit adult leader, provide a role model and set an example for other leaders in your unit by living the Scout Oath and Law to the best of your ability. Through this, your unit will refuse to tolerate name-calling, put-downs, discrimination, isolation, or any form of physical aggression. Scout leaders communicate their acceptance of the youth by taking a real interest in each Scout. This is how trust is built. This provides the basic foundation for the Scout to excel and accomplish each goal and then learn from it to accomplish the next challenge. This is a "can do attitude" way of thinking.

You will find a variety of techniques for working with many types of disabilities in Module F. That information has not been repeated here even though you will benefit from it.

#### **BECOMING AN ACCEPTING UNIT**

Selecting the right Scout unit is a very big deal for all involved. By the time a family comes to your unit, they may have experienced a lot of rejection from other groups and experienced situations where their child was not accepted by others. The parents feel the same rejection as the child, so they may be nervous when seeking acceptance from a new group like yours.

Every unit has a different culture because leadership is different at each unit. The overall goals are the same, but the process of "how to get there" is different. Therefore, aligning the family's and the unit's expectations is an important part of selecting a unit. This is true for all Scouts, not just those with disabilities.

Experience confirms that it is not only possible to support a youth with disabilities in any unit, but that this benefits everyone in the unit. This opportunity exposes the Scout to helpful association in a "typical" environment. This also drives home the fact that the Scout is like the others, only needing to adjust here or there for this particular "thing". "Out of the box" thinking will need to be leveraged. You usually find that this Scout will far surpass others in certain skills. Leverage those so that the Scout feels like his or her contributions are valued within the unit.

As for the unit, both the adult and youth leaders should get necessary background information on the youth's condition soon after the youth with a disability joins the unit. A systematic way to accomplish this is to have a Joining Conference<sup>1</sup> with every Scout that joins your unit. Parents may need encouragement to share information about their child. Parents or guardians are the best people to explain those conditions so bring them in to talk with your unit's leadership if they are willing. Only discuss with others what has been authorized by the family. Privacy and discretion must be upheld in these situations.

<sup>&</sup>lt;sup>1</sup> There is more information on Joining Conferences in Module F that you will want to read.

Part of becoming an accepting unit is getting your members, including the families to think of themselves as a unit/patrol/den that succeeds or fails together rather than as individuals. While American culture values individualism and meritocracy, this has to be balanced against other values like teamwork and fairness. It may seem alright to segregate out high-performing Scouts and give them more high adventure opportunities than others, based on "ability", or to discourage/exclude some Scouts from events because they may slow down the group. The danger is leaving out Scouts who would love the opportunity to try something difficult, even if they will need more conditioning than others or will simply have to move slower. Adult leaders, who may also be parents of high-achieving Scouts, can fall into the mental trap of using "safety" as a reason to avoid inconvenience and not just actual hazards. If you ask yourself "What could be the unintended consequences?" when you make major decisions, your unit can avoid getting disconnected from Scouting values.

#### **BUILDING EMPATHY**

Youth members and unit leaders should understand their responsibility to be friendly, kind, loyal, and helpful—but not overprotective of the youth with disabilities. They need to be empathetic of the Scout, not necessarily sympathetic.

**Sympathy** is feeling compassion, sorrow, or pity for the hardships that another person encounters. **Empathy** is putting yourself in the shoes of another, which is why actors often talk about it."<sup>2</sup>

Sympathy is easy. Almost everyone will be sympathetic toward a physically disabled youth, especially if the disability is obviously limiting. It is important to remember that youth with disabilities do not want someone to show them pity. We should analyze our own feelings about people with disabilities and then learn by experience in accommodating for their capabilities and limitations. In this way, we can overcome the common reactions of pity, morbid curiosity, being over-solicitous, avoidance, and even fear of people with disabilities because they are "different."

Sometimes it can be really hard to empathize because the limitation is unseen or "invisible". Most people with special needs will not have an obvious outward difference in how they look but they may really struggle with tasks others do with ease or may behave in unexpected ways in ordinary circumstances. Each type of special need or disability has its own set of limitations and challenges. Modules H through S of this Toolbox provide ample information to help you understand and adapt your unit's program to different kinds of disabilities.

An effective way to build empathy for a specific disability is to bring in a guest speaker who has the same disability. (Though tempting, don't draw undue attention to the Scout with that disability, or put the Scout on the spot to "defend" him or herself.) The guest can speak from

<sup>&</sup>lt;sup>2</sup> Footnote from Dictionary.com

personal experience about living with that particular disability. Conversing directly with people who have special needs or with others who have experienced the challenges of a certain special need can help you determine the most effective approaches for your Scout to succeed. But, if you don't have a resource person at your disposal, this Inclusion Toolbox is intended to help fill the gap and provide information when you need it.

A second way to build empathy is through first-hand experience. Most disabilities can be simulated in some way, and this simulation can be turned into a unit activity or game. Even invisible disabilities can be simulated by creating forced distractions or confusing directions. When the rest of the youth get a taste of what their fellow Scout experiences all the time, it changes hearts and minds. Though it is not available yet, a catalog is being developed with different activities that can be used on a unit outing or at a larger scale event like a camporee or jamboree. It will be added to Scouting.org when it is ready.

Pay close attention to how other Scouts absorb information about a disability. The other youth members may be very eager to help, but their assistance to a buddy must be carefully balanced. Too much help hinders the Scout's journey to accomplish the next challenge. Too little help can make a challenge impossible. Also watch for Scouts that think they are helping by "toughening up" a Scout with a disability by creating unnecessary difficulties. Closely monitor peer assistance to ensure the right balance of challenge and accommodation is accomplished.

#### **BUILDING A UNIT LEADERSHIP TEAM**

A successful unit needs a proper amount of adult leadership and involvement. Some leaders may find themselves very adept to working with Scouts with special needs and some may not. Most Scout units do not automatically have leaders with expertise working with Scouts with specific disabilities. The adult leaders, along with the families, must work together to ensure enough resources for those Scouts with disabilities. If a troop has three or more youth with disabilities, it is a good idea to seek out adults to become leaders who are already knowledgeable about these disabilities or to get disability-specific training for some existing leaders. Find out if your Council or District has a Special Needs and Disabilities Committee that can help you. In a large unit, you may want to appoint a specific adult leader a primary role to serve as the advocate for special needs for your unit. A parent or another support person may be required to attend unit activities, especially those that might require strenuous physical effort, one-on-one help, or those that occur over an extended period of time, such as a campout or summer camp.

#### TRAINING & SUPPORTING YOUTH LEADERS

Adult and youth leaders provide the example for the unit to follow in respecting one another, regardless of whether the Scout has a special need or not. The unit reflects the attitude and values of the leadership. For youth leaders, these are real world examples of what they will face

in the adult work environment and in the religious and civic organizations they will serve. This is an opportunity to learn how to properly demonstrate inclusion and acceptance, and to learn how others think. There are some key points from a leadership perspective to take into account for Scouts that have disabilities. While they apply to adult leaders as well, here are the essentials you need to share with your youth leaders.

- Above all else have patience patience will take you a long way in most situations.
- Be flexible. Understand the purpose of the activity and be willing to look for alternate ways to achieve the goal.
- Relax. People can usually tell when others are tense or stressed. Stress can be contagious within a group. (So can grumpiness.)
- Remember that Scouts with disabilities are people first and their disability is not part of their name. Ask them what words you should use if you need to talk about their challenges. Each person gets to choose how they are identified.
- Invisible disabilities will take time to understand and you may need to talk to the Scout and adult leaders about it to really understand.
- Talk directly to the Scout with a special need. Don't gossip with others about the Scout or gossip about others in front of the Scout. Don't talk behind anyone's back.
- Assume the Scout is capable of doing things. These youth are just as eager for adventure as the others, and they need challenges to have a satisfying experience.
- Realize these Scouts have the same needs as others. They want their contributions to be valued in the unit. They want to be accepted and to feel a part of the group—to have true friends.
- Be willing to give good instructions. If a Scout isn't helping when you expect it, take a moment to make sure he or she understands what is needed. You may need to break your instructions into smaller pieces.
- Practice giving genuine praise, as often as it is appropriate.
- Help this Scout when help is wanted. Offer to help, but don't take it personally if you are turned down. Be glad they want to do things themselves.
- When help is wanted, do not over help or try to do everything for the Scout. Just like with any other Scout, don't do what they are capable of doing for themselves. Ask if you aren't sure.
- Understand that some youth with disabilities will take what you say literally and won't get jokes or catch on when you are kidding or being sarcastic. You may need to protect them from being taken advantage of by other Scouts during games.
- It is **OK** to be frustrated when things don't go as they should. Don't make things worse by outbursts. Calm down, walk away, ask another youth leader to take over for a while, and go talk to an adult leader about how to handle the situation. If the problem really is

something the Scout with disabilities could control, then be sure to include him or her in the conversation, and allow this youth to also help find the solution.

• When in doubt of yourself or about what the youth needs, seek out help, suggestions, and ideas from other Scout leaders. While a youth leader should not go around a Scout to his or her parents, you may need to get an adult leader to ask the parents for more information or guidance that could help you.

#### COUNTERING MYTHS ABOUT DISABILITIES

A youth's adjustment to society depends more on how others react to him than on any special need itself. If you have only one or two Scouts with disabilities in your unit, you might see some poor reactions among the other youth. These reactions are not as common as they were a generation or two ago because many youth with disabling conditions are now mainstreamed and attend regular schools. In years past, these youth would have been in special schools or homeschooled. Even today, some are homeschooled partly because they were not treated well by peers in regular schools. The best way to overcome these negative reactions is for the leader to treat Scouts with disabilities like any other Scout, to the maximum extent possible.

Even those who sympathize with youth with disabilities may deal with them like they are seriously ill or more fragile than they really are. In many cases, aside from the effects of the disability, the youth is usually healthy. For example, a youth who was born with cerebral palsy might never have been sick a day in his life. The same holds true for youth who became disabled due to disease. Following recovery, they are disabled but are no longer sick. Youth with such conditions may have some limitations on their abilities, but otherwise they are as healthy as anyone else.

It is best not to make assumptions about a person's capabilities based on their appearance. People with physical disabilities or deformities are not likely to have intellectual limitations as well. People with intellectual/behavioral/learning/sensory disabilities may look and act much like anyone else, so it is easy to demand too much from them. There are also people with more than one disability, so they have to be understood in the context of the combined effects.

The underlying theme is not to sell a Scout with a disability short. It is fair to challenge Scouts to make their best effort, considering the disability. Remember that you want to provide as ordinary an environment as possible for all involved. In doing so, you provide a fertile ground on which fun, knowledge, experience and success can grow.

#### HELPING VOLUNTEERS FROM OUTSIDE YOUR UNIT

One of your jobs as a unit leader is to be an ambassador for your Scout with a disability when he or she needs to engage volunteers outside your unit. While these people will have important interactions with your Scout, they weren't there at your unit activities to get used to your Scout and understand his or her uniqueness. Day Camp staff, summer camp staff and merit badge counselors are obvious examples, but there are others too. If your Scout is going to a training course like NYLT, the course director and staff will want to know how to be effective and bring out the best in your Scout. If your Scout is going on an Order of the Arrow Ordeal, the OA leadership needs to know what accommodations are needed so they can make arrangements. If your Scout is hired for camp staff, the camp director and the Scout's direct supervisor will want to know about social and communication differences. If your Scout can go with a contingent to a jamboree, the contingent leaders and senior youth leader will want to be brought up to speed. When your Scout is getting ready to get an Eagle Scout project approved, there will be district advancement volunteers that want advance information about your Scout.

Module E provides detailed information for how a Scout with a disability can meet advancement requirements as they are written, how to develop alternative advancement requirements when the regular requirements are unreasonably difficult, and how to get formal approval for the exceptions. The primary responsibility for developing alternatives rests with you as the unit leader and with the family of the Scout with a disability. Even though you should have trained Scouters available at the district and council level to guide, assist, and advocate; they do not have the personal experience you have with your Scout to come up with the best alternatives for your Scout. Reach out for these experienced volunteers to help you, but understand that they cannot make decisions for you.

A unique feature of the Scouts BSA program that needs to be addressed here is the merit badge. To review, merit badge counselors (MBCs) become involved when a Scout is ready to take on a merit badge. While many unit leaders also counsel some merit badges, the MBC role is distinct from the regular unit leadership. A Scout notifies the Scoutmaster of which badge the Scout wants to pursue and the Scoutmaster helps the Scout find the right merit badge counselor. For a Scout with a disability, this means more than finding someone who is technically proficient. Remember that the trust you have built with the Scout and his or her family - is with you, and not the MBC. This means that you as the Scoutmaster will need to work closely with the MBC to ensure a smooth transition. With the permission of the family, you will need to relay to the MBC what the accommodation needs are and the best teaching strategies you have for your Scout. It's OK to discuss "out of the box" ways for the Scout to complete the requirements with the MBC. But, if you are dealing with an inexperienced counselor, there may be an issue where the MBC does not understand the scope and limits on their discretion. If they seem uncertain, you can point them to the BSA training resources for MBCs. If the MBC feels uneasy about being able to work with this particular Scout after you have talked it over, it is better to look for another counselor than to push a bad situation. You can look beyond your unit, district, and council for a counselor.

#### **OUTING AND ADVENTURE PLANNING**

The Adventure Plan (TAP) is the planning tool made available to all levels of Scouting by the National Camping Committee. It can be accessed at bsatap.org. This tool is useful for both regular unit outings as well as high-adventure excursions. What follows in this section is intended to supplement the TAP.

Scouts with disabilities should be given the same opportunities to participate in high-adventure and "regular" adventure outings as long as: (1) they are willing, (2) they have been cleared by the appropriate health professionals to do so, and (3) there are no unresolvable safety hazards. If the activity requires physical conditioning in order to be safe, the Scout should be expected to participate in conditioning activities. However, it not necessary for a Scout with a disability to perform at the same level as everyone else in the group as long as the members of the group can pick up the slack. For example, there was a Scout that completed a Philmont trek on crutches, with the support of his fellow Scouts.

Another option to consider is offering more than one track of activities on an outing. For example, if more experienced Scouts are going on a two-day one-night backpacking overnighter, less experienced Scouts could have one day learning pioneering and a day hike the next day, with an overnight at base camp. Another version is to start the day with a refresher on rock climbing and allow less experienced or skilled Scouts to have more instruction and practice time before beginning climbing in the afternoon. In keeping with the challenge by choice model, try to have something worthwhile for the Scouts to do if they opt out of the bigger challenge.

Here are some topics to think through when planning an adventure that includes a Scout with a disability. Obviously, this list covers a broad spectrum of possibilities and only a few items will apply to any particular Scout. It does not cover details about the actual activity itself, which is already addressed in the TAP.

Emergency Medical Needs (beyond usual and customary first aid and event medical provisions)

- Does the disability carry a special risk of a particular medical emergency?
- Is there any special emergency equipment that needs to be on the trek or in the camp medical facility? Is this feasible?
- Do the adults on the trek need special training to deal with such an emergency, beyond Wilderness First Aid Training?
- Could evacuation for this emergency be accomplished if needed? Can evacuation be fast enough, if required?

Toileting, Dressing, Bathing, and Feeding<sup>3</sup> (see Module R for more details)

- Is the Scout unable to do such tasks for him or herself?
- Is a personal caregiver available to assist the Scout with toileting, feeding and dressing?
- Is this caregiver both medically qualified to provide the services needed and qualified physically and otherwise to participate in the outing?
- Can a private space be created to provide the needed services to the Scout? e.g. extralarge tent, space partitioned with tarps, or "family" restroom.
- Is there any special equipment required and how can it be accommodated?

#### **Accessibility**

- Are the ordinary facilities sufficiently accessible or are special provisions needed? Does the camp need to be inspected in advance?
- Buildings?
- Restrooms in buildings? Distances to restrooms?
- Campsite tent spaces? Platform heights?
- Campsite latrines? Distances to latrines?

#### Transportation and Movement

- Long distance Vehicles to accommodate wheelchairs?
- Intermediate distance Are golf carts or UTVs available to move between program areas? Will regular road vehicles work over the terrain?
- Short distance Will powered/unpowered wheel chairs work over the terrain?
- General endurance Is the amount of self-powered movement over a day reasonable for the Scout?

#### Emotional/Behavioral Support

- Is the sensory environment workable? Are earmuffs or sunglasses sufficient?
- Is respite/rest/de-stressing space needed? Can it be created?
- Can time be allowed for breaks for respite/rest/de-stressing?
- Given facilities, can youth be allowed to stay with parent at night if needed?

<sup>&</sup>lt;sup>3</sup> Note: The standard procedures of BSA Youth Protection presume that youth are capable of doing tasks that require personal privacy on their own, while allowing a parent, guardian, or sibling to be present to render assistance. If a professional caregiver has been authorized by the parents/guardians to serve their child in place of a parent for such tasks, this can be permitted on Scout outings with the approval of the charter organization and the local council. The caregiver would be expected to carry medical power of attorney documents, complete BSA Youth Protection Training, register as an adult with the unit in order to complete background screening and reference checks, and complete the BSA annual health and medical record (health form) appropriate to the event.

- Who is responsible for assisting Scout in event of a meltdown/tantrum?
- If Scout is unable to complete the outing, what provisions need to be made to get home to family?

#### **Medications**

Many camps have their own procedures for storing and administering medications for youth that will need to be followed. This list addresses situations where the unit or trekking group needs to manage their own medications.

- Is it clear who is authorized to administer medications and who is not?
- Are critically urgent medications like epinephrine autoinjectors accessible at all times?
- Do medications need special handling? (kept cold/cool/warm/dry)?
- Do any medications need to be kept secure against unauthorized use?
- Have arrangements been made to track and verify that medications are taken on the right schedule?

#### SUPPORTING SIBLINGS

The siblings of a Scout with a disability have quiet struggles of their own. Of necessity, they get a disproportionately low amount of their family's attention. They tend to feel neglected by comparison even though they are not neglected or mistreated in an objective sense.

As a unit leader, there is little you can do about this situation in general, but you can make a difference when you have two siblings in your unit. Both siblings need to be able to participate in Scouting as individuals on an equal basis. The natural tendency in a group environment is for everyone to make the more-abled sibling responsible for the less-abled one. There is a Scouting tradition where we do not ask the parent of a Scout to handle corrective action for their own child on an outing and instead let another adult leader have that responsibility. The same needs to be true for siblings.

You can push back against the natural tendency of the group by your own actions, and you can give the more-abled sibling your permission and support in resisting this tendency. For instance, if someone asked the more-abled sibling "Why does your brother act that way?" it is OK to say for the sibling to say "You can ask him yourself." Or if someone says to the sibling, "Your sister needs help." it is OK to say "It's alright if you want to help her. What do you need to know?" Good sense will tell you when only a family member knows what to do about a situation. The goal is to relieve the more-abled sibling of having to be responsible <u>all</u> of the time.

Some of this advice may seem to be contrary to the Scout Law. The more-abled sibling does need to be taught to respond **courteously** when asked to take on responsibility for their sibling.

The sibling also needs to know that allowing others to help their sibling is not a pass on being **helpful** in general. "Guilty" is not in the Scout Law. Maybe "thankful" should be.

Authors: Tony Zizak, Angela Zizak, and Julie Hadley Editor: Roger B. Tate Reviewers: Midge Savage and Sandy Payne

## MODULE D

## THE PARENT/GUARDIAN'S ROLE IN SUPPORTING A SCOUT WITH A DISABILITY OR SPECIAL NEED

IN THIS MODULE:

CAN DO ATTITUDE TEACHING LEADERS ABOUT YOUR CHILD ACCEPTING REASONABLE RISK TO PROMOTE GROWTH PROVIDING NECESSARY INDIVIDUAL SUPPORT FOR YOUR CHILD UNDERSTANDING THE ROLES OF THE LEADERSHIP OF THE UNIT ADVOCACY WITH HIGHER LEVELS OF THE BSA

This module is for parents and guardians of children with disabilities or special needs. In your role, you are already your child's primary caregiver and most committed advocate. You no doubt have encountered obstacles when interacting with schools and other institutions. Our purpose here is to help you be effective in your role as you interact with the Scouting program and BSA volunteer leaders. This discussion assumes you are already familiar with the information in Module B about the Basics of Scouting.

#### CAN DO ATTITUDE

The idea of achievable challenge is a foundation concept of the Scouting movement. We seek to give every youth in our program an opportunity to grow and become his or her best self. This is no different for a youth with a disability, even though we have to make adjustments in our techniques to ensure a successful Scouting journey.

As the parent or guardian, Scout leaders and other parents are going to look to you to try to understand the best way to work with your child. Your attitude toward your child and toward the Scouting experience may be the single biggest factor in having a successful experience for everyone involved. To begin with, take a moment to think about everything that your child can do despite the disability, because that represents where you are today, beginning the Scouting journey. Then take a moment to imagine everything your child may be able to do if given good experiences and time to grow and mature. That is your future. The Scouting experience will be better if your efforts focus on what your child can do, rather than what he or she can't do right now. If you hold a positive image of your child's future and are open to finding ways to overcome obstacles, you should find that your Scout leaders and fellow guardians/parents are willing to partner with you and go over and above to give your child chances to participate fully in the program. Similarly, if you can maintain a positive attitude toward the other adults you encounter, seeing them as partners and teammates rather than obstacles, everyone's experience will be better. That includes not only your child, but all of the Scouts your child participates with.

Please do not sell your child short. At the same time, understand that earning Scout ranks is not everything and you don't have to become an Eagle Scout to benefit and grow from your time in Scouting.

#### TEACHING LEADERS ABOUT YOUR CHILD

Did you ever wish your child came with an instruction manual? You are not alone. The Scout leaders you encounter are volunteers with great hearts for kids, but with few exceptions, they are lay people with no special background or knowledge about your child's special needs. For that matter, no single volunteer leader can be an expert on everything to do with Scouting. We seek to serve the youth of America and give them access to a world of infinite possibility. The BSA emphasizes training and ongoing learning for leaders, but our universe is too big for everyone to know everything. Considering that volunteers have limited time for training, they usually choose what is most urgent for them individually and for their unit's needs. The point of this is that empathy is a two-way street, and you can expect to be a trainer who helps the leaders be effective with your child.

Ideally, the first step in the process is a joining conference with the leaders shortly after you join the Scout unit. A joining conference is similar to a parent-teacher conference at the beginning of a school year. Ideally, the adult leader that will have the most interaction with your Scout will meet with you to get to know the Scout better. The point is to give the leaders basic information about your child's unique abilities and needs. (There is more information on joining conferences in Module F, and you may want to read that too.) If your leaders are unfamiliar with joining conferences and you have never been asked to have such a visit with them, there is no reason you cannot initiate such a conference.

As your child participates over time, you will want to keep the channels of communication open between your family and the leaders that work with your child. Feel free to give and ask for advice on how things could be done better. Share and discuss any concerns you have about upcoming events to see if they can be resolved. Encourage leaders to talk to you about their concerns and challenges too, since you may be able to help them. Bottled up frustrations can cause unexpected problems and hard feelings if not attended to.

You also have opportunities to assist with the Scouting program itself. The Scouts could always use a challenge/opportunity to experience a simulation of a disability (such as the ones your

child face). Anything can become a game with some imagination. There are also more formal options, such as counseling the Scouts BSA - Disabilities Awareness merit badge, the Webelos - Aware and Care elective adventure, or the Wolf - Cubs Who Care elective adventure.

#### ACCEPTING REASONABLE RISK TO PROMOTE GROWTH

It is in our nature as caregivers to be protective of our child. This is especially true when your child has had exceptional struggles up to this point in his or her life. The Scouting program pushes against those protective instincts in order to foster growth and confidence in young people. The Scouting approach is different from many other environments you and your child have encountered before. In Scouting, we manage risk rather than avoid it entirely. To use an old adage "A ship is safest when it is in harbor, but that is not what ships are made for."

Through the rules in the *Guide to Safe Scouting*, our rigorous training requirements for leading higher-risk activities, and our tradition to Be Prepared; the actual risk to our participants is extremely low. At the administrative levels, we analyze every incident, including near-misses as well as those that resulted in injury or damage.

On the other hand, we teach through adventure, so we would like the youth to perceive some danger even when that danger does not exist or is extremely low. This means that you may be afraid or worried if your Scout tells you about an event that seems or seemed scary, but the reality may not be what it looked like to your child. If you are ever concerned about the safety of a proposed activity, do not hesitate to contact the leader in charge and find out what the actual safety arrangements are.

We want to encourage our Scouts to take individual responsibility for their own well-being and to experience some consequences. This is especially true in the programs above the Cub Scout program. Scout leaders will let Scouts get dirty, wet, hot, cold, or otherwise uncomfortable; while at the same time protecting them from truly coming to harm from hypothermia, heat exhaustion or the like. A youth with a disability can have these same challenging growth experiences, if caregivers allow it.

So what does this mean for you? Three things, in principle. First, in your role as caregiver, you will need to carefully consider what limits you put on your child's participation, to distinguish between true safety hazards and manageable discomforts that can build confidence. Second, if the disability truly makes your child more vulnerable to something than most people, you will need to explain the risk to the leaders in charge of the activity and see if there are ways to work around the difficulties. Third, there will be some situations where you will want to attend an event in person to provide the enhanced individual attention needed while still giving your child a chance to participate.

#### PROVIDING NECESSARY INDIVIDUAL SUPPORT FOR YOUR CHILD

Some disabilities come with specific medical needs that have to be provided for daily living, whether part of the Scouting program or not. Without being exhaustive, this could include using catheters or feeding tubes, or providing direct assistance with toileting, bathing, or getting dressed. These kinds of services are beyond what volunteer Scouting leaders can or should provide.

There are also some types of disabilities where the youth needs one-on-one supervision or monitoring to prevent harmful or dangerous behaviors. The person watching over the youth may also need specific training to recognize triggers and use appropriate management methods. In traditional Scout units, there is rarely an appropriate adult available to provide such intensive supervision. The situation may be different in a specialized Scout unit that tailors its program and leadership ratios to work with that specific disability.

It is the responsibility of the parent or guardian to provide for a caregiver to deal with the unique medical, physical, and behavioral needs of their child at Scout events when those needs go beyond what the child could take care of him or herself, with ordinary adult supervision. This caregiver could be a family member, a qualified friend of the family, or it could be a paid professional caregiver. All caregivers need to take BSA Youth Protection Training to understand the protections we provide to all Scouts while at Scout events, and they need to complete their own medical forms to assure they are fit enough to participate alongside the Scouts. A non-family caregiver will also need to be registered as an adult member of BSA to receive necessary background checks and carry appropriate medical power of attorney documents.

Similarly, any special individual equipment required to meet the needs of a Scout with a disability must be arranged for by the parent/guardian.

#### UNDERSTANDING THE ROLES OF THE LEADERSHIP OF THE UNIT

Scouting is different from many other youth programs in that the kids are given significant leadership responsibility. Our adult leaders are trained to support this youth-led model during Scouting events, and our youth leaders are trained to use adult mentors as resources. From your perspective as a parent or guardian of a Scout with a special need, "youth-led" will often look chaotic because the youth are learning to lead by doing it and they are gaining experience. BSA experience is that youth leaders really can work most things out when given a chance.

There are ways for you to intervene if you need to care for your child at a Scout event, but it is important to work through the chain of command unless there is an immediate threat to a youth's health or safety. If you are a registered Scout leader, you will have been trained on how to present your advice or concern to a youth leader rather than taking over the situation yourself. If you are a guardian or parent who comes along on an outing, the appropriate way to

handle a concern is to speak to the adult leader overseeing the activity and then he or she can communicate it properly to the correct youth leader.

Though direct intervention can disrupt the program, this advice is not given just for that reason. Direct intervention can also deprive your Scout of a chance to work something out on his or her own. This is important for future life because youths with disabilities will need to be able to advocate for themselves when they are adults.

#### ADVOCACY WITH HIGHER LEVELS OF THE BSA

Before continuing, we need to reiterate a point from the BSA Youth Protection Training that any allegation of abuse, violation of BSA youth protection guidelines or policies, or inappropriate behavior by a Scout/Scout leader/parent/other person is to be immediately reported to your Council Scout Executive and to any public authorities as required in your state or jurisdiction. This is a different situation from advocacy as it is being discussed here.

There are issues that can arise with a Scout with a disability that are beyond the ability of your Scout unit to solve. The most common are difficulties related to meeting advancement requirements, special accommodations needed at multi-unit events (like day camps, summer camps, camporees, and jamborees), and overcoming objections to participating in high adventure opportunities and advanced youth leader training. Though rare, there have also been situations where a unit's leadership has created its own rules that go beyond how the Scouting program is intended to operate, or are not completely in keeping with the values of the Scout Oath and Law.

This discussion is not intended to dissuade you from advocating for your own Scout but to provide you some insight so that the best outcome can be achieved while maintaining good relationships with all involved. Most controversies begin with poor communication and/or lack of understanding by one party or the other.

Decision making in Scouting at the levels above the unit level is primarily done through committees of Scout volunteer leaders. While you may be able to call a Scouting professional at your council office during regular business hours, that professional will typically have to get you in touch with the correct volunteers to begin addressing your need. The point is that things will take time, and you should not expect a quick response and resolution if the issue is complex. You will want to allow time and get started early to resolve your issue well before you have to make a hard or unfortunate decision of your own.

While advocating for your Scout, you can expect to tell your story over and over in order to bring the Scouting volunteer leaders up to speed so they can help you. It may take a few false starts to get your issue before the right volunteer group to resolve it. You may want to recruit a unit leader to help you get connected to the right people and to support your cause.

A spirit of goodwill, or Scout Spirit, will help you a great deal. Scout leaders place high value in their personal honor and truly want to find a good solution to whatever problem is being presented. You can expect them to deal with you in good faith. It is good to think of the people you are dealing with as teammates and partners that you are working with to resolve your situation. You can also benefit by taking time to make sure you really understand the proposed solutions that come back before implementing anything.

#### A FINAL WORD

#### May you and your Scout have a great time in Scouting!

Author: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

## **MODULE E**

## **NAVIGATING ADVANCEMENT REQUIREMENTS**

IN THIS MODULE:

#### OVERVIEW

**KEEPING THINGS IN PERSPECTIVE** 

Advancement is a Method of Scouting, Not the Mission What is Expected of Scouts With and Without Disabilities Achievable Challenge All in Good Time Comparable Challenge Having Fun CUB SCOUT STANDARDS & ALTERNATIVES SCOUTS BSA, VENTURING, AND SEA SCOUTING PROGRAM STANDARDS STRATEGIC PLANNING WITH AN INDIVIDUAL SCOUT ADVANCEMENT PLAN (ISAP) GETTING EXCEPTIONS APPROVED - SCOUTS BSA Rank Requirements Merit Badges

Staying in Scouting Past the Program Age Range, or Registering an Adult as a Scout GETTING EXCEPTIONS APPROVED – SEA SCOUTS AND VENTURING

#### OVERVIEW

Advancement is a system of ranks, badges, and awards that recognize what a Scout has accomplished and creates incentives to strive and grow as a person. The system is intended to provide a structured sequence of tasks that provide experiences to learn, grow, and succeed.

This module is directed at parents, guardians, and unit leaders who want to help a Scout with a special need or disability succeed in advancement. Module V looks at advancement from the perspective of the district and council leaders entrusted to make approval decisions for alternative rank requirements and badges. This module does not replace the rules for advancement found in the *Guide to Advancement*<sup>1</sup> (BSA 33088), which is the authoritative document. Rather this module provides commentary and advice to assist you in using the *Guide to Advancement (2021)*. Since requirements change from time to time, you will need to look at the handbook for your program level to find the requirements that apply to your

<sup>&</sup>lt;sup>1</sup> Rules related to special needs and disabilities are located primarily in Section 10 of the *Guide to Advancement*.

Scout(s). Some classes of disabilities have their own nuances and challenges related to advancement and you will find more specific "how to" information in Modules H to S of the Inclusion Toolbox.

#### **KEEPING THINGS IN PERSPECTIVE**

Before we talk about details and forms and processes, we want to make some philosophical points.

Advancement is a Method of Scouting, Not the Mission - The mission of the BSA is to prepare young people to make ethical choices throughout their lifetime. Advancement is one of several methods for promoting the mission. Handled well, advancement creates healthy peer pressure that benefits all the Scouts in a unit. There is a danger that we may set expectations too high and expect Scouts with special needs to go to extremes in order to advance. There is also a risk that we try to bend advancement requirements too far and take away the sense of accomplishment just to check off the boxes.

There are many wonderful Scouts who never become Eagle Scouts. When we laud and honor Eagle Scouts there is a danger that we diminish the accomplishments of other Scouts and fail to appreciate the good people they are becoming. When we look at Scouts with disabilities and try to create advancement opportunities for them, let's not lose sight of the possibility that they are already good enough, just like they are. Advancement needs to serve the Scout, not the other way around.

What is Expected of Scouts With and Without Disabilities - It is easy to lose track of what is expected from others when you are an advocate for someone with a disability. A Scout rank is a multi-faceted array of challenges, and any youth will find some tasks easier than others. If a Scout with a special need finds that a few requirements are really hard to complete, many requirements are doable but take an effort, and a few requirements are really easy; he or she is effectively "typical". At the other extreme, a more reasonable alternative is needed for a requirement that a Scout could not possibly complete. We want it to be somewhat difficult for a Scout with a disability to earn a rank, like it is for everyone, but not unfairly difficult. It is important to remember that advancement is not meant to be easy for any Scout, and that is why only a very small percentage of Scouts achieve the rank of Eagle. There are no guarantees that every individual will be able to become an Eagle Scout.

Achievable Challenge - Alternative advancement requirements bring the challenge within the capability of the Scout, but the Scout must still have the will to meet the challenge. No Scout is asked to attempt an advancement challenge beyond his or her capability if that capability can be objectively determined. A Scout is never set up for failure, but a Scout should expect to be challenged. Families and leaders should prepare Scouts to be challenged and encourage them to overcome.

All in Good Time - Think about what your Scout will be able to do later that he or she cannot do today? After Cub Scouting, advancement challenges are expected to be met over a period of years. Not everything is within the capability of an 11 year old Scout nor should it be. The process for approving alternatives requires the Scout to attempt to complete all the requirements he or she can before an alternative can be approved. The Scout does not have to attempt the impossible, but the Scout should attempt the requirements that might be possible. This may sound harsh to a parent of a child with a disability, but there is a sound reason for this. As parents, our protective instincts make us wary of pushing our children too hard, but at the same time we are continuously surprised when our children demonstrate new capabilities, especially when they have a disability. In Scouting, this means that we all have a bias to sell kids short. Having a rule that asks the Scout to try a requirement first, before we decide it cannot be done, counteracts the bias and allows the Scout to achieve more than the adults initially thought possible.

**Comparable Challenge** - We want all Scouts that earn a rank to have been challenged in a way that is fair to everyone who earns that rank; past, present, and future. The honor that goes with the rank needs to be deserved, and it needs to mean the same thing over time. The challenge of advancement for Scouts with special needs is to be fair. As all parents know "fair" is not always "the same as for everyone else". Even "challenge" is difficult to measure because it could mean different things in different circumstances, such as required strength/skill, level of effort, amount of time needed, or the quality of the product made. So if we assume the objective of alternative requirements is to make a rank about as hard for a Scout with a disability to earn as it is for a typical Scout, there will always be a devil in the details. That is why we entrust the responsibility for developing alternatives to responsible people rather than to a rulebook. It is also why the advocates for a Scout with a disability and those who must approve alternatives need to be considerate and treat each other according to the Scout Law.

**Having Fun** - There is an old saying that "Scouting is a game with a purpose." A lot of the things we do in Scouting should be fun or exhilarating, whether or not they check boxes for advancement. In short, the "game" is important. A parent or guardian of a Scout with a disability may be afraid that their kid will be left behind or left out of something, and be biased in the "not fun" direction. While we want our kids to live up to their potential, we also want them to experience joy, excitement, adventure, and fun. Without fun in the mix, it is hard to stay motivated to do things that aren't fun. That is true whether you have a disability or not. The journey of Scouting will include plenty of opportunities to learn something and grow up a little, but let's never lose track of the fact that these are kids and they need to have fun too.

# **CUB SCOUT STANDARDS & ALTERNATIVES**

Cub Scout advancement is easily compatible with special needs and disabilities. The standard of performance is "Do Your Best". The Scout's "best" does not mean you have to be successful to get credit for completing a requirement, but the Scout does have to make a good faith effort. That leaves very few situations where a Cub Scout will need to have an alternative to a regular

requirement. You only need alternatives when the regular requirement is impossible to even attempt. An example would be asking a Scout in a powered wheelchair to run.

In such situations, Cubmasters and pack committees may come up with an alternative requirement and they do not need higher level approval. Ideally, they would consult the family of the Scout in the process. Perhaps a minor modification is enough, or substituting a requirement from an elective. We hope to capture the spirit and level of challenge of the original requirement.

## SCOUTS BSA, VENTURING, AND SEA SCOUTING PROGRAM STANDARDS

Things are different once the Scout graduates to the older youth programs (Scouts BSA, Venturing, and Sea Scouting). At these levels, the Scout is expected to complete the requirement **exactly as it is written, no more and no less**. The key point of this is that the requirements are not different for Scouts with special needs or disabilities and we don't lower the standards of the requirement just so a particular Scout can complete it.

With that said, **the person who judges if the requirement has been completed has more latitude than it might first appear**. (Depending on the circumstances, this person could be a unit leader, assistant unit leader, den leader, merit badge counselor, parent, or a responsible older Scout.) Most rank and merit badge requirements are written in ways that allow some flexibility in how they must be performed by a person with a disability. For example, most merit badges don't explicitly require reading, writing, or speaking. Instead of saying "Write a list of the five most visible planets," or "Recite a list of the five most visible planets," the Astronomy merit badge requirement simply says "List the five most visible planets." The form and structure of the list is not part of the requirement. It could be verbal, handwritten, or typed. For that matter, few requirements are written in a way that they require the entire task to be done in one sitting, which benefits Scouts with an intellectual disability. **It is important not to read anything extra into a requirement just because that is how most Scouts do it**.

An "accommodation" does not change a requirement but does change the circumstances under which the requirement is completed. It is best explained with a few examples:

- Allowing a buddy or lifeguard to be nearby in the water for a swimming/water rescue requirement.
- Having a quiet space or special lighting to work by.
- Allowing the Scout to complete the requirement at a different time of day than usual.
- Allowing a requirement that is usually done on an overnight campout to be done indoors or at another type of event.
- Allowing a second person to serve as the eyes, ears, or hands of the Scout.
- Allowing the Scout to use notes or memory aids.
- Allowing the task to be broken into smaller steps that are done at different times.
- Allowing unconventional tools or materials to be used for the task.

Even with flexibility and accommodations, there are certain combinations of requirements and disabilities that are just incompatible. In these situations, we develop alternative requirements or alternative merit badges that replace the original requirements. Alternatives are specifically tailored to the circumstances of one individual. The alternatives are developed by a team consisting of the unit leadership, family, and health professionals, and then are reviewed and approved by the council advancement committee.

Another challenge we run into with advancement for Scouts with disabilities is timing. In general, a Scout is expected to complete every requirement or merit badge possible for a given rank before an alternative rank requirement or merit badge can be formally approved. Further complicating matters is that in general a Scout is not allowed to attempt to complete an alternative requirement or merit badge until after the alternative has been formally approved. These procedural rules can be frustrating. They force the Scout, family, and leader to be strategic in planning the sequence of work to make sure the Scout has time to accomplish what he or she wants to.

# STRATEGIC PLANNING WITH AN INDIVIDUAL SCOUT ADVANCEMENT PLAN (ISAP)

The BSA has a planning form for families and leaders to use to jointly map out the future for a Scout with a disability. It is called the Individual Scout Advancement Plan (ISAP), and you can find it by searching for BSA Form 512-936. It is modeled on the individual education programs (IEPs) and 504 plans used in public schools for students with special needs. Unlike an IEP or 504 plan, the ISAP does not create legal rights or legal status. The ISAP can be updated as a Scout matures and moves through the Scouting program.

In Module F you will find a discussion of Joining Conferences, which will not be repeated here. Creating an ISAP will take more detailed discussion than is appropriate for a joining conference. In general, before preparing an ISAP the family will need some time to learn more about the Scouting program and the unit will need some time to understand the Scout.

Most of this section is focused on the Scouts BSA program, but before we continue we should briefly discuss **how to be intentional and planful in Cub Scouting**. If a Cub Scout has a known special need or disability, it is wise for the parent/guardian and den leader to meet at the beginning of the program or school year and review all of the rank requirements for that year (Lion, Tiger, Wolf, Bear, Webelos, or Arrow of Light). This is the time to identify the requirements that will take extra effort and those that are impossible. If there are any impossible requirements, then work together to come up with alternatives to submit to the pack committee for approval.

At the Scouts BSA level and up, **the first planning step is to figure out how to support what the Scout wants to do**. While few Scouts advance without family and leader encouragement, we don't want advancement to be driven by the parents, guardians, or leaders. Realistically, the Scout with a special need should set the goals and the rest of the adult team helps spot opportunities to make progress on those goals. It is perfectly fine if a Scout just wants to have fun, make friends, and go on outings instead of making effort to advance in rank. Even a Scout who is not trying to will get quite a few rank requirements completed just by being present when the opportunities are provided.<sup>2</sup>

The second planning step is figuring out which Scouts need an ISAP. Some Scouts arrive at a unit with an obvious disability, where some advancement requirements are very difficult or impossible, and you can start on an ISAP soon. However, many Scouts have an invisible disability<sup>3</sup> that does not draw any immediate attention. A Scout leader should not try to diagnose any Scout, but a wise leader takes a long look at the performance of each new Scout after the first year. It is important to figure out if a Scout is not performing well despite trying hard or because he or she is not really trying. If a Scout has the will to succeed but is not being effective, it is time to start developing an ISAP.

Even though the ranks of Scout, Tenderfoot, Second Class, and First Class are presented in sequence, most Scouts work on requirements for all of these levels at the same time. Scout leaders often refer to this group of ranks as the "Trail to First Class". The first round of planning is to go over these requirements and determine which ones need alternatives and which ones need accommodations. If the adult team can tell up front which are which, you can go ahead and apply for alternative requirements while the Scout works on what he or she can do. Most of the time, you will not know all of the obstacles until the Scout makes an attempt on a requirement. If there is doubt about whether a Scout can complete a task, he or she should be given a chance to complete the requirement as it is written. Be careful that you do not force the Scout to fail. Once the adult team knows what alternatives are needed, they develop them and submit them for approval. The actual process will be discussed a little later.

Scouts that need alternative requirements and merit badges often need to be efficient with their time and effort. This is very important with merit badges because **you cannot request alternative requirements for merit badge requirements. They are an all or nothing proposition.** The Scout and his or her supporting adults need to look at all of the requirements for a merit badge before starting work on it. If the Scout cannot complete all of them with reasonable flexibility and accommodations, the Scout will not be able to earn the badge even though the Scout may enjoy the activities of the badge and benefit from the socialization and participation.

There is a risk of creating hard feelings when merit badge work is done in a group setting. If a Scout is encouraged to participate alongside other Scouts in a group setting, it can create an expectation that the Scout can complete the badge, even if there are requirements that are impossible for that particular Scout. When the rest

<sup>&</sup>lt;sup>2</sup> The unofficial term for this is "stealth advancement" where leaders keep track even though the Scout does not.

<sup>&</sup>lt;sup>3</sup> An invisible disability or special need is a difference that doesn't change the way the person looks or moves, but does make learning, organizing, or demonstrating knowledge for requirements extra hard.

of the group is presented with badges, but he or she is not, it can seem unfair to the Scout and the family. It is vital that the leaders and family are on the same page about whether or not the Scout is encouraged to participate and important that the family manage the expectations of the Scout.

Currently (2021), an Eagle Scout must earn 13 merit badges out of an "Eagle-required" list of 17 merit badges, and an additional 8 badges of the Scout's choosing, for a total of 21. Ten of the 13 badges are specific badges and the other three allow a choice between two or three related badges. These badge alternatives are built into the regular advancement requirements and don't require special permission. As the Scout finishes the First Class rank, it is time to make a plan for these "Eagle-required" badges. A good target is to try to have all of the achievable Eagle-required badges completed by the time the Scout turns 16 years old. This leaves time to get alternative badges approved and to finish them before age 18.

When planning for the Eagle-required badges, we want to avoid false starts and wasted effort for the Scout while giving the Scout a chance to strive, succeed, and surprise the adults. Like before, the planning review needs to look at all of the requirements for all of the Eagle-required badges and determine which badges cannot be completed due to the Scout's disabilities. Some borderline requirements may have to be attempted in order to be sure. **Alternative merit badges need to be selected to provide similar challenge and learning experiences** to the originals. There is a special form (BSA 512-730) for requesting alternative merit badges for the Eagle rank. This form includes lists of possible alternative badges to consider for some of the badges. The exact badge to pick will depend on the individual and the details of his or her disabilities.

# GETTING ALTERNATIVES APPROVED FOR SCOUTS BSA

There are four types of special exceptions available to Scouts with disabilities. They are:

- Substituting alternative requirements for regular requirements for the Scout through First Class ranks
- Substituting merit badges for badges on the Eagle-required list
- Getting to remain in Scouts BSA indefinitely (and continue to work on advancement)
- Getting to register as a Scout when you are already too old to ordinarily register

The people reviewing the applications for exceptions have difficult work because they have to assess the necessity of the exceptions and protect the advancement system from abuses. It creates problems when the reviewers receive requests at the 11<sup>th</sup> hour. It forces the reviewers to act quickly and denies them chances to ask follow-up questions and gather more information before making a decision.

For all of the exceptions, a packet of documents will need to be assembled to support the request. The council advancement committee can give you specific requirements for your situation. These documents typically include:

- A completed request form. Some types of requests do not have an official form, so this is not always required. Requests need to spell out the specific alternatives requirements or badges that are being requested. There are no general waivers to be granted for these.
- A letter from a parent, guardian, or Scout petitioning the Scout council for the exception. The letter needs to describe the disability in some detail so the reviewer understands the nature and severity of the disability, and how long the disability may last.
- A supporting letter from the unit leader that endorses the request for an exception. This is a place for the unit leader to put the Scout's disabilities into a Scouting context and further explain how the Scout's disabilities interfere with advancement tasks.
- A letter of explanation from the Scout directly (when possible). It is good for the Scout to be his or her own advocate in this process, and it is good for the reviewer to get the Scout's perspective on the disabilities in his or her own words.
- A completed medical form, or more precisely, the BSA Annual Health and Medical Record form. Parts A, B, and C need to be completed just as if the Scout was going to summer camp. This establishes that the Scout is healthy enough to participate in Scouting and is primarily used in this process for people who remain or become Scouts at an advanced age. There is not enough detail on this form to explain a disability.
- A written statement from a qualified health professional. This is not always a medical doctor. Depending on the nature of the disability, the appropriate professional might be a physician, neurologist, psychiatrist, psychologist, speech therapist, special education diagnostician, or special education administrator. The statement needs to explain the disability and the Scout's capabilities and limitations. It needs to explain whether the limitations are permanent, or if not, how long they can be expected to prevent the Scout from fulfilling the typical requirements. The health professional should be shown what alternatives are being requested, to assure that there is no medical/health obstacle to completing the alternatives if they are approved by BSA.
- Copies of existing plans for treatment or accommodations are not mandatory, but can help the reviewers get a better picture of the Scout. For example, an Individualized Education Plan (IEP) or 504 plan from the Scout's school can provide extra information. Diagnostic test results, treatment summaries, and reports from health professionals can help. It is important to recognize that these documents are generally confidential in one way or another. It is the parent or guardian's choice whether or not to disclose them and these documents should not be copied, distributed, or permanently archived by anyone in the review process. They are to be returned once the review is complete.

**Rank Requirements** – Alternatives for rank requirements are only available for the ranks up to and including First Class. There is not an official application form for alternative rank requirements, so an ISAP or written letter can be used for this purpose. This request is submitted to the council advancement committee. The committee may want to talk to the Scout, the family, and/or the unit leader. The BSA Annual Health and Medical Record form is not typically required for this kind of request.

**Merit Badges** – BSA 512-730 is the official form for requesting alternative merit badges for the Eagle rank. It is submitted to the <u>district</u> advancement committee and forwarded to the council advancement committee. The BSA Annual Health and Medical Record form is not typically required for this kind of request. Merit badges are substituted on a badge-for-badge basis. There is no provision to earn part of an Eagle-required badge and part of another badge to make a whole badge. There is no provision to modify or replace single requirements within a merit badge.

The Scout should request all of the alternative badges that will be needed at one time. While a Scout should earn as many of the Eagle-required badges as possible before making a request, there is an exception for situations where the need for an alternative is obvious. In that situation, you wait until the Scout is working on the Star rank to make the first request for the obvious needs, and then if needed make a second request later, after maximum progress has been made.

A Scout is not allowed to use a merit badge that has already been earned as a substitute for an Eagle-required merit badge. If a Scout anticipates needing alternative badges, but needs to wait until the maximum number of Eagle-required badges are completed before making a request, the Scout needs to be careful about earning merit badges that might make good alternatives. You may want to put off working on your first choice for an alternative badge until you have received approval for the alternative badges, even if you could complete the badge earlier.

**Staying in Scouting Past the Program Age Range, or Registering an Adult as a Scout** – These are actually the same process. A person that wants to be a Scout but has a permanent and severe disability can be granted a special status that allows him or her to join Scouting and participate indefinitely on a youth basis, regardless of calendar age. In Scoutspeak this is called Registration Beyond the Age of Eligibility or RBAE. A Scout that enjoyed the program while younger than 18 can continue on as a physical adult, and a person that is physically an adult can become a Scout even if he or she was never a Scout when younger.

In order to qualify, the combined effect of the disabilities has to be great enough that the person can only advance at much slower rate than other Scouts. A person with more than one type of disability can qualify for this special status based on the combined effects of all the disabilities, even if each of the individual disabilities is not that severe. With this special status, there are no longer time limits on advancement. As a practical matter, such people usually live

in some kind of supported situation (living with family or at a group home). The Scout unit they join may be a special program of a group home or support agency that is tailored to their needs.

BSA 512-935 is the official form for requesting Registration Beyond the Age of Eligibility. It is submitted to the council Scout executive<sup>4</sup> rather than the council advancement committee. In addition to the usual documents, either a completed "youth" application form or proof of current BSA membership needs to be attached to the request. RBAE status can be requested before the Scout ages out under the regular rules so that there is no interruption in membership.

# **GETTING EXCEPTIONS APPROVED – SEA SCOUTS AND VENTURING**

A Scout registered as a Venturer or a Sea Scout may work on Scouts BSA advancement as long as he or she meets the age requirements for Scouts BSA or has been granted RBAE status. The procedure for approving exceptions is the same as described in the section above.

Like with other Scouting programs, Venture crew Advisors and Sea Scout Skippers have a degree of flexibility that is built into the regular advancement requirements that may be enough to accommodate a disability. In situations where Venture and Sea Scout advancement requirements cannot be met because of a disability, it is possible to apply for alternative requirements. The process for this is the **same process used** to apply for alternative requirements for the First Class and under ranks **in Scouts BSA**.

Author: Roger B. Tate Reviewers: Mark Chilutti, Midge Savage, and Sandy Payne

<sup>&</sup>lt;sup>4</sup> The council executive board is responsible for reviewing RBAE applications, but they can delegate that responsibility to another council committee. Most often that is the council advancement committee, but not always. That is why the instructions are to send the application to the council Scout executive.

# MODULE F

# METHODS THAT APPLY TO MANY TYPES OF SPECIAL NEEDS AND DISABILITIES

IN THIS MODULE:

OVERVIEW THE "REACH" MODEL JOINING CONFERENCES COMMUNICATION CORRECTIVE ACTION AND ADDRESSING CONFLICT SELF REMOVAL ACCOMMODATIONS ADAPTATIONS PEER BUDDIES ABOUT MEDICATIONS ABOUT SERVICE ANIMALS

#### **OVERVIEW**

Fundamentally, supporting a person with a disability is very individualized, taking into account what the person can do and what the person struggles to do. However, there are some methods that apply to disabilities in general or cover a wide range of disabilities. This module covers these methods, and you will find that all Scouts can benefit from them, whether disabled or not. When you develop a plan to support a specific individual, you can use the general information here along with the more specific information and methods you will find in Modules H through S.

About 15% of Scouts have an acknowledged special need or disability<sup>1</sup> and the majority of those that have a need have one that is "invisible". That means that there is little about the person's physical appearance or behavior that indicates that they have a disability or special need. Their needs are not obvious to all, so it is essential to communicate and build a trusting supportive relationship in order to understand what is needed for the Scout to grow.

<sup>&</sup>lt;sup>1</sup> The numbers are almost certainly higher as many moderate disabilities are not formally diagnosed by professionals and others are kept secret by the family.

## THE REACH MODEL

The REACH model represents both an acronym for how we interact with all Scouts, including those with disabilities, and a conceptual model for what we hope to do for those with disabilities. The acronym represents:

RESPECT all Scouts as stated in the Scout Law. ENCOURAGE all Scouts to become their best, to improve, and to achieve their goals. ACCEPT where each Scout is on his or her journey through Scouting and show tolerance. CARE and show concern for all. HONOR each other's differences and help to grow all Scouts' abilities.

The REACH model is an attitude that applies to all Scouts. "Reach" is also a good way to look at how we implement the Scouting programs. The Scouting curriculum is designed to give youth opportunities to strive and reach out to experience and do new things. Often they do not know what they are capable of until they try. Youth with disabilities have the same need to be successful and accepted as others do, both socially and emotionally. Scouting is designed to present some difficulty, but should never be impossible. When we look at adaptations, accommodations, and methods of supporting Scouts with special needs, our goal is to be creative and bring things that are impossible within the <u>reach</u> of the Scout. All Scouts build confidence from accomplishing the difficult. All Scouts benefit from the encouragement and support of their fellow Scouts.

# JOINING CONFERENCES

There are many factors that may cause difficulty for a Scout, with or without a special need. By knowing these factors in advance, you can prevent unnecessary hardships. Triggering factors may include loud abrupt noises, whistles, PA systems, bright lights, changes in tones, changes in routine, and so forth. As you begin to understand a Scout's special needs, you may observe behaviors you should discuss with the Scout's family. Reach out and talk to the family. Building an initial foundation of trust will help later.

It is essential to learn what each Scout needs in order to have an opportunity to be successful and this begins with building a line of communication with the Scout's parents or guardians. It is highly recommended that a unit have an organized effort to have a **joining conference** for every new Scout joining a unit, before the first overnight outing<sup>2</sup>, within the first couple of months.

A joining conference is similar to a parent-teacher conference at the beginning of a school year. Ideally, the adult leader that will have the most interaction with the Scout will meet with the parents or guardians to get to know the Scout better. In Cub Scouting where new leaders and

<sup>&</sup>lt;sup>2</sup> Long and overnight events are more likely to have triggering situations than a typical Scout meeting.

new youth often arrive at the same time, experienced leaders in the Pack will need to provide some "quick start" mentoring for new leaders to do joining conferences.

Remember, Scouting is open to all youth, so the joining conference happens after the youth has been accepted. It is not a "job interview" and it is not a condition of accepting the youth into your unit. The youth has nothing to prove. It is good to share these words with the family and Scout at the first opportunity to reduce stress and anxiety.

Keep the tone of the conference relaxed and friendly. During the joining conference you want to learn:

- (1) What are unique strengths and struggles of this youth?
- (2) What accommodations/adaptations are being made at home and at school?
- (3) Does anything trigger emotional or behavioral struggles?
- (4) How does he/she act when things are getting overwhelming?
- (5) What concerns do the parents have about putting their child in Scouting?

The parents/guardians will decide how open they will be with you. Until they trust you, they might not share their child's diagnosis. If they confide in you, ask their permission before telling anyone else about a diagnosis. Practically speaking, it is more important to know the behaviors the Scout may exhibit than the name of the special need or disability. Asking parents for suggestions on how to handle disruptions will help you know which appropriate action to take. This also shows parents you are willing to listen and work with them on what's best for their son or daughter. If you believe the Scout will benefit from other key adult and youth leaders being brought into the loop, you may ask the family if you can brief others.

If appropriate to do so, include the Scout in the joining conference with their parents. For Cub Scouts, meeting just with the parents is fine. For Scouts BSA and older programs, the Scout is often included in the meeting, but good sense should prevail when deciding whether or not to include the Scout.

This is a candid and private conversation with the family, so the meeting needs to be out-ofearshot of others. It is OK to do this off at the side of a regular unit meeting, but you might have to hold the conference at a different place or time to get privacy.

Here is a **SAMPLE SCRIPT** for a Joining Conference:

Hi. I'm <u>name</u> and I'm the <u>leader position</u> of <u>unit type ###</u>. I'm glad you and <u>youth name</u> have joined our unit. The other leaders and I want to give your child the best experience we can. I know we have told you what our unit is like, and it will help if you can tell us what makes your son/daughter unique. Can we have a few minutes? – To start with, is there anything you are concerned about with joining Scouting? What are his/her strengths? Is anything harder for him/her than for others? Is there anything that helps him/her be successful at home or at school? Is there anything I need to

watch out for or avoid doing with your son/daughter? Is there anything I need to make sure I do for your son/daughter? When he/she is struggling, how do you help him/her? ......

Depending on how the conversation goes, this may be a good time to mention how the Individual Scout Advancement Plan works. There is more information on this in Module E.

## COMMUNICATION

Ongoing communication goes in three directions, which we will address in turn. The first direction is communication between the leaders and the family. The second direction is communication between leaders and a Scout with a special need, and the third direction is communicating between Scouts (peer to peer). Good communication allows needs to be met and minimizes future conflict.

Before we begin, there is one overarching thing to remember: Confidentiality is required. You cannot take it back if you gossip or complain about a Scout with a disability around the Scout, his or her peers, parents or guardians, or other leaders. That includes electronic communication.

<u>Parents and Guardians</u> - Conducting a joining conference is the beginning of a regular dialog with parents and guardians. Ideally you will continue to communicate with the parents on an ongoing basis. While all leaders are busy, it is very helpful when you can give honest praise to the parents about their children, even when you don't have to. If you need to talk to parents or youth about a specific situation, it helps for you to "own" the difficulty rather than put in on others. This way no one feels antagonized. A positive approach would be to say, "I want to make sure the Scout is experiencing all that Scouting has to offer" or "How can I make it a success for the Scout?" Focus on the behavior you want to change, not the person.

In general, do not rely on a parent always being able to attend meetings or outings because this tends to be seen by others as a requirement that the parent must be present for the Scout to participate. Requiring a parent to be there places a burden on the parent to handle inappropriate behavior instead of allowing leaders and Scouts in the unit to learn how to do this. It also presents a risk of creating conflict when the parents' natural protective instincts cause them to interact poorly with other Scouts. The need for a parent will need to be addressed on an individual basis however, because there are rare situations when only a parent or caregiver can provide what the Scout needs. When parents attend regularly, it is important to monitor the interaction so that the Scout's independence can grow rather than be hindered.

<u>The Scout with a Special Need or Disability</u> – You don't have to worry about what specific words you use to describe the disability. For example, you can use ordinary phrases like "See you later!" or "Give me a hand!" even when talking to someone with a vision or physical disability.

As a matter of dignity, it's best to speak directly to the Scout, not to his or her companion. Let the companion overhear your discussion with the Scout, not the other way around.

It is our goal to help Scouts develop into people who can solve their own challenges in an adult world. A Scout with a disability may need opportunities to practice self-advocacy skills even more than others do. **Remember every Scout with a disability will eventually be an adult with a disability.** These youth may also need more guidance in exercising self-advocacy than others. Involve the Scout in problem-solving discussions. The more you include the Scout in the process, the more ownership the Scout will take in his or her behavior. Encourage all your Scouts to ask for help, speak up when they don't understand something, and ask when they need extra help. With all this said, there are some Scouts who will struggle with self-advocacy because of the nature of their individual disability. These Scouts will need extra attention and you may have to reach out to them for a while, actively offering help, while you coach them to be more effective advocates for themselves.

<u>Other Scouts</u> – It is healthy and appropriate for other Scouts to want to advocate for and to assist a Scout with a disability. They can be a resource to help leaders understand what the Scout needs. Sometimes peers know the Scout from other situations like school, other extracurricular activities, or religious activities and know how teachers and leaders in those environments have adapted programs to help the Scout with a disability. You certainly should use the information you receive in this way, but **you should not ask or probe for information from fellow Scouts.** 

Youth leaders in the Scouting program may need extra information that others do not and experience frustrations with a Scout with a disability that other Scouts do not. You can partner with the parents of the Scout with a disability to decide what additional information to share with youth leaders that will be to everyone's benefit. When a youth leader is struggling with a Scout because of a disability, it is OK to give the youth leader extra advice and encouragement.

#### CORRECTIVE ACTION AND ADDRESSING CONFLICT

A disability may cause poor impulse control, but it is not an automatic excuse for poor behavior or failure to obey rules. Keep in mind that certain types of youth behavior may be a way of communicating needs or distress in a non-verbal manner. One should also understand that all youth, whether disabled or not, grow into maturity, and their behaviors change along the way. Most difficult behaviors improve with maturity, but in some instances they become more extreme.

<u>Addressing Safety</u> - In the rest of this section, we will talk about how to improve behavior, but at the outset we must acknowledge that maintaining the health and safety of our members takes a priority over managing people's feelings. If a Scout's actions are placing anyone in danger, including him or herself, immediate action is needed to address the danger, and any consequences will be dealt with later. Along these lines, we need to keep watch for possible bullying situations. By definition, bullying is unfair and one-sided behavior, characterized by continued hurting, intimidation, threatening, or leaving someone out on purpose. A more subtle form of bullying is taking advantage of another person's inexperience or naiveté to embarrass or humiliate him or her. Confront these behaviors if you see them. Be alert when Scouts are engaged in competitive games. Games can be used to camouflage bullying. Scouts with special needs are not always competitive in spirit, or capable of performing the game, and this may lead to a situation where the Scout becomes frustrated. Having a planned alternative activity may head off difficulties.

<u>Addressing Conflict</u> - A youth with a disability may see the world differently from everyone around him or her. For this reason, some unanticipated events may result in a conflict and the source of the conflict may not always be obvious. As with any conflict between youth, you will first want to separate the participants. Then begin asking questions to find out each youth's viewpoint. It is important to handle situations carefully and take the time you need to gain a good understanding. At that point you can choose a course of action. It may be that all that is needed is for each youth to come to understand the other's perspective on the situation. It may be that one or both need some space and time to regain control of their emotions.

<u>Corrective Action</u> - Our overall goal in dealing with youth who are misbehaving is to improve the behavior. This is true with Scouts regardless of whether a disability is a factor. We never use corporal punishment. In fact, neither the carrot nor stick approach creates the selfawareness and self-control that youth with a disability may need to develop. Feedback and redirection should always be given in a **respectful** manner, allowing the Scout to save face. When Scouts are treated with respect, they are more likely to respect the authority of the Scout leader.

With some disabilities, social activities may cause Scouts with special needs to get more and more anxious and uneasy. It may be best to remove them from participating in the activity before losing control. However, if you have to intervene, it is important to emphasize that this is to give them a chance to regroup and is not a "time out" (punishment by isolation) for misbehavior. In fact, you should encourage the youth to learn to monitor themselves and let an adult know they need to excuse themselves from the activity or game if they feel anxiety coming on. Agreeing on a place he or she can go to "chill-out" helps. This empowers Scouts to take control of their actions, which fosters independence and self-esteem.

In other situations, an adult may need to help guide the youth in introspection. Some selfawareness questions a leader can ask a youth include: "What was I feeling before I acted out?", "What exactly triggered my anxiety?", "Was the other person trying to bully me or did I misunderstand?" and "What could I do differently if this happens again?" A responsible adult mentor can help a youth develop personalized strategies for coping in his or her environment. The youth may have to live with the disability, but you can help him or her discover an inner strength despite the disability and develop his or her full potential.

#### **SELF REMOVAL**

Self-removal is a great resource for a Scout to use when getting too overwhelmed, building up anger, or just needs to pull him or herself together. The basic idea is that you and the Scouts have some prearranged places and times where they can go during a meeting or event if they need to escape a stressful situation. This empowers the Scout to manage his or her own stress. Self-removal represents a partnership between the responsible adults and the Scout with a disability. Refuge (chill out) spaces can be helpful for many Scouts, not just those with special needs.

The specifics of where the "refuge" is and what the youth does there will need to be tailored to the age and disability. For example, at summer camp you could have a tent set up with coping tools in it, like a book or playing cards or something that might help settle him or her down. It is also OK for a Scout to go to bed earlier than most or catch a nap if needed, as long as that is not disruptive.

The Scout still needs to be supervised. The place of refuge cannot be so far away that a buddy should go along. This system will not work if the Scout has a propensity for mischief or for wandering off. Although the Scout may feel "alone" during self-removal, the adults monitor at a distance. It is important that the Scout knows to make sure the appropriate adult knows where he or she is going, so no one is worried or goes searching for a "lost Scout". A period of self-removal could extend to the end of the regular meeting time, but it needs to have reasonable time limits during an outing.

During a meeting, it may be impractical for the Scout to ask out loud for permission to go, and it may be disruptive to the meeting as a whole to let one person go because they will all want to abandon the planned activity. There are ways to avoid the appearance of "special treatment" or drawing harmful attention to the struggling Scout. You can establish a sign language that allows the Scout to ask permission with one sign and you to agree with a sign of your own. You could also use a particular sound from your cell phone to acknowledge the Scout is exiting the area.

#### ACCOMMODATIONS

Accommodations are procedural changes that make it possible for Scouts with disabilities to have a more normal life. An accommodation is just a different way of doing things and it is tailored to the individual needs of a person with a disability. While accessibility features are easy to see and provide opportunities for those with physical disabilities, accommodations also provide opportunities for those with invisible disabilities. Accommodations may not be obvious to others because they don't change the environment for anyone else. An accommodation that works for one person with a disability may not work for everyone else, so it isn't always possible to make everyone happy or to have everyone work in the same space.

Here are some ideas and examples:

## Timing

Allow extra time for completing a task, like a test at school Do the hard thinking work in the morning or afternoon, or whenever it works best Break a task into smaller pieces and take breaks in between Slow down or speed up the pace Allow time for physical activity or movement

## <u>Sensory</u>

- Move to a place in the room where there are fewer visual distractions from other people or objects in your field of view
- Change the type of lighting to adjust the brightness or color of the light, or eliminate flickering effects of the light source
- Use earplugs or noise-cancelling headphones to reduce noise, or perhaps have intentional sources of background sounds or music.
- Adjust sound louder or softer to a comfortable and functional level
- Provide special ventilation to eliminate distracting odors
- Hold or squeeze an object to provide something to do with your hands for needed tactile stimulation

#### Presentation & Communication

Change the group size when teaching Use technology to interact and communicate instead of verbal or face-to-face Provide captioned screens or captioning glasses for video presentations Change the method of communication - verbal to visual to written as needed Provide a sign language interpreter for meetings, performances, ceremonies, etc. Use hands-on activities or demonstrations instead of words

#### Organization, Memory, and Attention

Provide an assistant to keep tasks in order or keep the scheduleUse electronic devices, or paper and notes to retain important informationHave an aide redirect a person's attention back onto the topic when they drift off or become distracted by another idea

#### <u>Social</u>

Use a peer buddy Supplemental social skills coaching

#### ADAPTATIONS

In Scouting we want to avoid Ableism. Ableism (or Able-ism) is a belief or attitude that leads to discrimination and denial of opportunities, much like racism or sexism. It begins by making assumptions about what people with disabilities cannot do, and then making no effort to give them an opportunity to try. Ableism is harder to spot than other forms of discrimination because the person doing the discriminating appears to be looking out for the best interests of the person with the disability.

Adaptations are physical adjustments to ways of doing things so that people with disabilities can participate in activities that others do. Adaptations differ from accommodations in that the focus is using technology to enhance a person's physical abilities or to make an activity doable.

The key point for Scout leaders is to make an effort to make the same activities that you would do with any other Scout available to those with disabilities. Yes, there will be situations where it is not possible, but if a Scout is willing to try, there is almost always a way to make something possible.

Here are some examples:

#### **Mobility**

Wheelchairs Motorized Chairs Utility Task Vehicle Golf Cart

#### <u>Hearing</u>

Text to Voice Devices or Phone Apps Voice to Text Devices or Phone Apps Video Displays Flashers in place of Alarm Sounds

#### <u>Vision</u>

Text to Voice Devices or Phone Apps Tactile Signage and Braille Resources Voice Messaging in place of signal lights Spelled out signs along with color coding (for color-blindness) Sighted guides

#### Fine Motor

Pointing and typing with eye or mouth controls Use of tools to enhance grip Modifying tool handles for easier control <u>Sports</u>

Hand crank bicycles Sit-down skis and in-line skating Swimming flotation aids Beep baseball Wheelchair sports (basketball, road racing, soccer, etc.) Seated volleyball

#### PEER BUDDIES

A peer buddy can be a useful accommodation for a Scout that struggles with social behavior, navigating from place to place at camp, or with self-organization. Since the concept is new to most Scout leaders, we explain it here. It is not the same as the Buddy System we use for safety in the Scouting program. A peer buddy is a volunteer Scout providing ongoing support for another Scout with a special need. It is a position of responsibility where one Scout is committed to helping another Scout for an extended period of time or in special situations. (Note that while this service may be used for some advancement credit, it is not one of the listed positions of responsibility for the Eagle Scout rank.) A peer buddy can be thought of like a youth leader and needs to be supported by adult mentors in that role. A peer buddy will need to be matched well in maturity and temperament to the person being aided. The parents and guardians of both Scouts should be aware of and agree to this arrangement.

#### ABOUT MEDICATIONS

Medications are useful tools for helping with the symptoms of some disabilities. In this context, medications may include non-prescription medications and dietary supplements along with prescribed medications. They do not take the disability away and they won't make all of the difficulties go away. There are many laws and rules that limit how medications can be used, especially for youth. If a youth takes a medication, there needs to be a responsible adult keeping track of when and how much medication is given. Depending on the medication and what it does, a person with a disability may have to plan to do some activities at certain times to get the most benefit from the medication. Scout Leaders should refer to the *Guide to Safe Scouting*, *Medication Use in Scouting* (BSA 680-036), and the Personal Health and Annual Health and Medical Record section for BSA guidance about handling prescription medications for Scouts. Camps may have their own rules for medication handling, and state and local laws vary. Some local councils offer additional training on this topic.

As a matter of good manners, you should never talk about a Scout's medications with anyone other than the Scout or the Scout's guardians/parents. Whether a person is "on his meds" or "off his meds" is never a joking matter. If you are truly concerned about a Scout not receiving the medications he or she is supposed to have, talk to the Scout directly, the parent or caregiver, or the adult responsible for the outing or event.

#### ABOUT SERVICE ANIMALS

For a long time, "seeing eye dogs" and "helper monkeys" have been used to support people with disabilities. In recent years, the use of trained animals to support different types of disabilities has broadened and more and more productive uses for trained animals are being found. As of the time of this writing, it is hard to anticipate which additional uses may be found and what species of animals might be included as service animals.

Just as in other public venues, it is necessary to distinguish between pets and trained service animals<sup>3</sup>. Where councils have made rules restricting or prohibiting pets from events or facilities, those rules need to make exceptions for trained service animals. In facilities belonging to charter partners, the unit will have to abide by their rules, however Scout leaders may need to advocate with a charter partner so a Scout that makes effective use of a service animal is not denied this aid.

Author: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

<sup>&</sup>lt;sup>3</sup> As of this writing (2021) current federal regulations are found at: <u>https://www.ada.gov/regs2010/service\_animal\_qa.html</u>

# MODULE G

# OTHER ORGANIZATIONS THAT SUPPORT SPECIAL NEEDS & DISABILITIES

IN THIS MODULE:

CAUTIONS GENERAL/COMPREHENSIVE ADAPTED SPORTS ATTENTION DEFICIT HYPERACTIVITY AUTISM BLIND/VISUALLY IMPAIRED DEAF/HARD OF HEARING FOOD ALLERGIES INTELLECTUAL/COGNITIVE LEARNING DISORDERS MENTAL HEALTH/BEHAVIORAL PHYSICAL/MOBILITY SPEECH/LANGUAGE

#### CAUTIONS

As you seek to serve a Scout with a disability or a family member, you may want to look at outside sources beyond the BSA Inclusion Toolbox. If you reach out to others to discuss a specific situation, do not provide the name of the person you are discussing, or any personally identifiable information.

It is nearly impossible to assemble a list of organizations that is complete for every purpose. The organizations and websites in this list have a national or international presence. Many of these organizations also have local or state affiliates or chapters that may be able to provide additional local resources. There are also countless local organizations that serve people with special needs and disabilities that are not connected to a national organization. If you are not able to find them on the internet, we suggest you network with the special education department of your local public school system or the local office of the rehabilitative services agency for your state or jurisdiction.

You may feel we made some omissions here. There are many well-known organizations that primarily serve professionals in the medical, therapeutic, or educational communities. To be included in these lists, the organization's web presence needed to show that they made a public education effort as well as a professional education effort.

These lists have been sorted (imperfectly) into categories. When an organization serves needs in more than one category it has been listed in more than one category.

The website addresses were last verified in August 2019.

## GENERAL/COMPREHENSIVE

AbleData Administration for Community Living 103 W. Broad Street, Suite 400 Falls Church, VA 22046 800-227-0216 TTY: 301-608-8912 abledata.com

American Academy of Pediatrics aap.org healthychildren.org/english/health-issues/conditions

Center for Parent Information & Resources c/o SPAN 35 Halsey St., 4<sup>th</sup> Floor Newark, NJ 07102 973-642-8100 parentcenterhub.org/resourcelibrary

Centers for Disease Control National Center on Birth Defects and Developmental Disabilities (NCBDDD) 800-232-4636 cdc.gov/ncbddd/index.html Disability Is Natural BraveHeart Press P.O. Box 39076 San Antonio, TX 78218 210-320-0678 disabilityisnatural.com

Easter Seals 233 S. Wacker Drive, Suite 2400 Chicago, IL 60606 800-221-6827 easterseals.com

Office of Disability Employment Policy U.S. Department of Labor 200 Constitution Avenue NW Washington DC 20210 866-487-2365 dol.gov/odep

Office of Special Education Programs U.S. Department of Education 400 Maryland Avenue, SW Washington, D.C. 20202 800-872-5327 www2.ed.gov/about/offices/list/osers/osep/index.html

TASH (Disabilities Advocacy) 2013 H St. NW, Suite 404 Washington, DC 20006 202-540-9020 tash.org

National Center on Health, Physical Activity, and Disability 4000 Ridgeway Drive Birmingham, AL 35209 800-900-8086 nchpad.org National Organization on Disability 77 Water St., Suite 204 New York, NY 10005 646-505-1191 nod.org

National Rehabilitation Information Center National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) 800-346-2742 TTY: 301-459-5984 naric.com

World Institute on Disability 3075 Adeline Street, Suite 155 Berkeley, CA 94703 510-225-6400 wid.org

#### **ADAPTED SPORTS**

BlazeSports America 1670 Oakbrook Dr., Suite 331 Norcross, GA 30093 404-270-2000 blazesports.org

Disabled Sports USA 451 Hungerford Drive, Suite 100 Rockville, MD 20850 301-217-0960 disabledsportsusa.org

International Blind Sports Federation Nijenheim 2419 3704 VJ Zeist The Netherlands ibsasport.org Special Olympics International 133 19<sup>th</sup> St. NW Washington, DC 20036-3604 202-628-3604 800-700-8585 specialolympics.org

United States Association of Blind Athletes 1 Olympic Plaza Colorado Springs, CO 80909 719-866-3224 usaba.org

USA Deaf Sports Federation P.O. Box 2011 Santa Fe, NM 87502 usadeafsports.org

U.S. Paralympics Team United States Olympic Committee One Olympic Plaza Colorado Springs, CO 80909 888-222-2313 teamusa.org

Wheelchair and Ambulatory Sports USA P.O. Box 621023 Littleton, CO 80162 720-412-7979 adaptivesportsusa.org

#### ATTENTION DEFICIT HYPERACTIVITY

Children and Adults with Attention-Deficit/Hyperactivity Disorder 4601 President Dr., Suite 300 Lanham, MD 20706 National Resource Center on ADHD 800-233-4050 chadd.org

Attention Deficit Disorder Association P.O. Box 7557 Wilmington, DE 19803-9997 800-939-1019 add.org

#### AUTISM

The Autism Society 4340 East-West Highway, Suite 350 Bethesda, MD 20814 800-328-8476 autism-society.org

Autism Speaks 1 E. 33<sup>rd</sup> S., Fourth Floor New York, NY 10016 888-288-4762 autismspeaks.org

Autism Empowerment P.O. Box 67167 Vancouver, WA 98681 360-852-8369 AutismAndScouting.org

#### **BLIND/VISUALLY IMPAIRED**

American Printing House for the Blind Inc. P.O. Box 6085 1839 Frankfort Ave. Louisville, KY 40206-0085 502-895-2405 aph.org

Bookshare 480 S. California Avenue Palo Alto, CA 94306 650-352-0198 bookshare.org

Guide Dogs for the Blind P.O. Box 151200 San Rafael, CA 94915-1200 800-295-4050 guidedogs.com

International Blind Sports Federation Nijenheim 2419 3704 VJ Zeist The Netherlands ibsasport.org

National Federation of the Blind 200 E. Wells Street at Jernigan's Place Baltimore, MD 21230 410-659-9314 <u>nfb.org</u>

National Library Service for the Blind and Physically Handicapped 1291 Taylor St. NW Washington, DC 20542 800-424-8567 TDD: 202-707-0744 www.loc.gov/nls United States Association of Blind Athletes 1 Olympic Plaza Colorado Springs, CO 80909 719-866-3224 usaba.org

American Foundation for the Blind 2 Penn Plaza, Suite 1102 New York, NY 10121 212-502-7600 afb.org

American Council of the Blind 1703 N. Beauregard St., Suite 420 Arlington, VA 22201 800-424-8666 acb.org/blind-low-vision-resources

#### **DEAF/HARD OF HEARING**

Alexander Graham Bell Association for the Deaf and Hard of Hearing 3417 Volta Place, WW Washington, D.C. 20007 202-337-5220 agbell.org

American Society for Deaf Children PO Box 23 Woodbine, MD 21797 800-942-2732 deafchildren.org

American Speech-Language-Hearing Association 2200 Research Blvd Rockville, MD 20850-3289 800-638-8255 ASHA.org Described and Captioned Media Program National Association of the Deaf 1447 E. Main Street Spartanburg SC 29307 800-237-6213 DCMP.org

Hearing Loss Association of America 7910 Woodmont Avenue, Suite 1200 Bethesda, MD 20814 301-657-2248 hearingloss.org

Laurent Clerc National Deaf Education Center Gallaudet University 800 Florida Ave NE Washington, DC 20002 202-651-5855 www3.gallaudet.edu/clerc-center.html

National Association of the Deaf 8630 Fenton St., Suite 820 Silver Spring, MD 20910-3819 301-587-1788 TTY: 301-587-1789 nad.org

National Deaf Center on Postsecondary Outcomes The University of Texas at Austin College of Education SZB 228 1912 Speedway D4900 Austin TX 78712-1284 512- 471-8283 nationaldeafcenter.org

National Institute on Deafness and other Communication Disorders 31 Center Drive, MSC 2320 Bethesda, MD USA 20892-2320 800-241-1044 www.nidcd.nih.gov USA Deaf Sports Federation P.O. Box 2011 Santa Fe, NM 87502 usadeafsports.org

#### **FOOD ALLERGIES**

Food Allergy Research & Education 7901 Jones Branch Drive, Suite 240 McLean, VA 22102 800-929-4040 Foodallergy.org

#### INTELLECTUAL

American Stroke Association (div. of American Heart Association) 7272 Greenville Avenue Dallas, TX 75231 800-242-8721 stroke.org

The ARC 1825 K Street NW, Suite 1200 Washington, DC 20006 202-534-3700 800-433-5255 thearc.org

Brain Injury Association of America 1608 Spring Hill Road, Suite 110 Vienna, VA 22182 703-761-0750 biausa.org

United Cerebral Palsy 1825 K Street NW, Suite 600 Washington, DC 20006 800-872-5827 ucp.org National Multiple Sclerosis Society P.O. Box 4527 New York, NY 10163 800-344-4867 nationalmssociety.org

National Down Syndrome Society 8 E. 41<sup>st</sup> Street, 8<sup>th</sup> Floor New York, NY 10017 800-221-4602 ndss.org

National Down Syndrome Congress 30 Mansell Court, Suite108 Roswell, GA 30076 800-232-6372 ndsccenter.org

#### **LEARNING DISORDERS**

Bookshare 480 S. California Avenue Palo Alto, CA 94306 650-352-0198 bookshare.org

International Dyslexia Association 40 York Road, Fourth Floor Baltimore, MD 21204 410-296-0232 dyslexiaida.org

Learning Disabilities Association of America 4156 Library Road Pittsburg, PA 15234-1349 412-341-1515 Idaamerica.org National Center for Learning Disabilities 32 Laight St., 2<sup>nd</sup> Floor New York, NY 10013 888-575-7373 ncld.org understood.org

#### MENTAL HEALTH/BEHAVIORAL

Child Mind Institute 101 E. 56<sup>th</sup> Street New York, NY 10022 212-308-3118 childmind.org

National Alliance on Mental Illness 3803 N. Fairfax Drive, Suite 100 Arlington, VA 22203 703-524-7600 nami.org

Mental Health America 2000 N. Beauregard St., Sixth Floor Alexandria, VA 22311 800-969-6642 TTY: 800-433-5959 mentalhealthamerica.net

Mental Health First Aid National Council for Behavioral Health 888-244-8980, ext. 5 nationalcouncil.org mentalhealthfirstaid.org

Therapy Dogs International 88 Bartley Road Flanders, NJ 07836 973-252-9800 tdi-dog.org

#### PHYSICAL/MOBILITY

American Stroke Association (div. of American Heart Association) 7272 Greenville Avenue Dallas, TX 75231 800-242-8721 stroke.org

BlazeSports America 1670 Oakbrook Dr., Suite 331 Norcross, GA 30093 404-270-2000 blazesports.org

Brain Injury Association of America 1608 Spring Hill Road, Suite 110 Vienna, VA 22182 703-761-0750 biausa.org

Helping Hands 541 Cambridge St. Boston, MA 02134 617-787-4419 monkeyhelpers.org

International Ventilator Users Network 4207 Lindell Blvd. #110 Saint Louis, MO 63108 314-534-6475 ventusers.org

Spina Bifida Association 1600 Wilson Blvd., Suite 800 Arlington, Virginia 22209 800-621-3141 spinabifidaassociation.org United Spinal Association 120-34 Queens Blvd. #320 Kew Gardens, NY 11415 718-803-3782 unitedspinal.org

United Cerebral Palsy 1825 K Street NW, Suite 600 Washington, DC 20006 800-872-5827 ucp.org

National Multiple Sclerosis Society P.O. Box 4527 New York, NY 10163 800-344-4867 nationalmssociety.org

Muscular Dystrophy Association-USA National Headquarters 222 S. Riverside Plaza, Suite 1500 Chicago, IL 60606 800-572-1717 mdausa.org

National Library Service for the Blind and Physically Handicapped 1291 Taylor St. NW Washington, DC 20542 800-424-8567 TDD: 202-707-0744 loc.gov/nls

## SPEECH/LANGUAGE

American Speech-Language-Hearing Association 2200 Research Blvd Rockville, MD 20850-3289 800-638-8255 ASHA.org

American Stroke Association (div. of American Heart Association) 7272 Greenville Avenue Dallas, TX 75231 800-242-8721 stroke.org

Brain Injury Association of America 1608 Spring Hill Road, Suite 110 Vienna, VA 22182 703-761-0750 biausa.org

National Down Syndrome Congress 30 Mansell Court, Suite108 Roswell, GA 30076 800-232-6372 ndsccenter.org

Author: Michael Bradle Editor: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

# MODULE H

# UNDERSTANDING ALLERGIES AND FOOD ISSUES<sup>1</sup>

IN THIS MODULE

OVERVIEW WHAT ARE ALLERGIES? ALLERGIC REACTIONS ANAPHYLAXIS ALLERGY & ANAPHYLAXIS EMERGENCY CARE PLANS EMERGENCY MEDICATIONS MANAGING ENVIRONMENTAL EXPOSURES FOOD SELECTION FOOD PREPARATION SWALLOWING DISORDERS FOOD AVERSIONS MEDICALLY RESTRICTED DIETS RELIGIOUS DIETS

#### **OVERVIEW**

This module focuses on prevention of serious allergic reaction incidents. We will discuss environmental allergies for thoroughness, but most of this module will focus on food allergies (see also BSA 680-063 Food Allergy Guidance<sup>2</sup>). Several other special food considerations are also addressed in this module because the accommodations for them are similar to those for food allergies.

First aid treatment for general allergic reactions is covered in a number of other BSA resources so those details are not being repeated here. However, **anaphylactic reactions are a serious concern** and are discussed in this module.

Perhaps more so than with other special needs, there needs to be good communication with the family of a Scout with high-risk allergies. All the communication information in Module F applies here. The leaders will need to check in with the family before and during most outings

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank Food Allergy Research and Education (FARE, foodallergy.org) for reviewing the contents of this module for accuracy and usefulness.

<sup>&</sup>lt;sup>2</sup> This document was produced by the Risk Management department of the Boy Scouts of America and clarifies the responsibilities of the family, Scout, and adult Scout leaders.

to address risks. It is also common for an adult family member to want to be present on outings to monitor food intake or preparation.

#### WHAT ARE ALLERGIES?

In simple terms, an allergy is a condition where a person's immune system responds too aggressively when the person is exposed to a substance. Allergic reactions can be mild or extremely serious. While we can take some preventive actions for people with known allergies, everyone is at risk of a reaction from something they are not yet aware they are allergic to, or from a common allergen that is very difficult to avoid.

Allergens are substances that cause allergic reactions. Common allergens that are found in the environment or in foods include: pollens, molds, house dust mites, animal dander and saliva, chemicals, latex, milk, fish, peanuts, tree nuts, shellfish, medicines, and venom from insect stings. Allergens have to come in contact with the body to provoke a reaction, but that contact could be inhaling particles (which stick to sinus tissues), touching the skin, touching the mouth and gastric tissue by eating, or being injected by stinging insects.

## ALLERGIC REACTIONS

Allergic reactions occur when your immune system mistakes a harmless substance as a dangerous invader. Your immune system plans a response to the invader (allergen) by building antibodies. These antibodies are always on the lookout for the specific allergen and cause a chain reaction when you are exposed to the allergen again. This reaction causes strong chemicals such as histamine to be released into the body. These chemicals cause allergic symptoms. Any allergic reaction can be mild to extremely serious. Just because you had a mild reaction when you were exposed to the allergen before does not mean it will be a mild reaction the next time. However, **if you had a severe reaction before, there is a good chance that the next one will be as bad or worse**.

Since your body's immune system is active from head to toe, inside and out, allergies can cause many different symptoms. There are many different ways the body can react, and the exact symptoms can vary from person to person and from allergen to allergen in any one person. Below are the symptoms of an acute allergic reaction:

- Skin itching, redness, hives, and swelling
- Nasal drainage, congestion, sneezing
- Eyes itching, watering, redness
- Respiratory wheezing, difficulty breathing, cough
- Gastrointestinal nausea, cramping, vomiting, diarrhea
- Cardiovascular- dizziness, fainting, drop in blood pressure, chest pain

- Generalized swelling face, hands, feet, extremities
- Other anxiety or confusion, headaches, seizures

Airway restriction and cardiovascular symptoms are the gravest concerns out of these symptoms.

#### ANAPHYLAXIS

Anaphylaxis is a severe and potentially deadly allergic reaction. In anaphylaxis, the reaction can come on very fast (within minutes of exposure) and can affect multiple systems of the body. In addition to the extreme versions of the typical allergic symptoms mentioned above, anaphylaxis can mimic cardiac distress with a rapid heartbeat, drop in blood pressure, shock, fainting, or unconsciousness. **Anaphylaxis should always be treated as a medical emergency**, and the person needs to be moved to a medical facility as quickly as possible, even if emergency epinephrine is administered. Food Allergy Research and Education (FARE) also offers a free training module on recognizing and responding to anaphylaxis<sup>3</sup>.

Like other types of allergic reactions, anaphylaxis is unlikely to happen the first time a person is exposed to a particular allergen, but the person may not notice the first reaction. However, when people have already had an anaphylactic reaction to an allergen, they often have severe symptoms the next time, and they should **be prepared for an anaphylactic reaction to happen again someday**.

### ALLERGY & ANAPHYLAXIS EMERGENCY CARE PLANS

An allergy/anaphylaxis emergency care plan is a detailed and personalized first aid plan for a person at risk for an anaphylactic reaction. The plan includes details about what allergens to be concerned about, what symptoms require medications, what medications to use, and how much medication to administer. It is personalized to the patient and is prepared in consultation with a physician. A copy of the care plan needs to be with the adult leaders on any Scout outing, and if age-appropriate, a copy of the plan should be carried by the Scout with the allergy. While the BSA Annual Health and Medical Record (AHMR) includes questions about allergies, the AHMR is not necessarily on the person of the leader or Scout at all times. The care plan needs to be on their persons at all times when an anaphylactic reaction is possible. When a Scout with a care plan is attending camp, a copy of the care plan should be attached to the AHMR so camp medical staff know what the action plan is.

While there are several care plan forms available on the internet, you may want to look at the plan forms produced by the American Academy of Pediatrics (AAP/healthychildren.org) and Food Allergy Research & Education (FARE/foodallergy.org)

<sup>&</sup>lt;sup>3</sup> <u>https://www.foodallergy.org/life-with-food-allergies/anaphylaxis/recognizing-responding-to-anaphylaxis</u>

#### **EMERGENCY MEDICATIONS**

There is a general discussion about medication in Module F that you should read first. BSA 680-036 *Medication Use in Scouting* offers additional guidance for planning and preparation. Prescription and over-the-counter antihistamines may be emergency medications for an allergy even though we don't routinely think of them this way. Rescue inhalers, more commonly used for asthma, may also be an emergency medication for keeping the airway open. The emergency medication we are most familiar with is the epinephrine auto-injector, which you may know as an EpiPen<sup>®4</sup>. EpiPen<sup>®</sup> is just one model of auto-injector and there are other brand-name and generic models on the market. All models of auto-injectors use the same medication, but they do not all work the same, so it is important to know the differences. It is a good idea for the Scout or the Scout's family to explain to adult leaders how to operate their model of autoinjector and inhaler, ideally with a training simulator. All the manufacturers have training videos. During an emergency you are more confident when you have practiced.

Note that epinephrine is only available by prescription. It also has a limited life, whether used or not. Before an outing, leaders and families need to check the expiration date on the epinephrine auto-injectors to ensure the medication will not expire before the end of the outing.

With allergy and anaphylactic risks, some thought and planning are needed to assure that emergency medications are close by at all times. Leaving them with the camp health lodge or secured at the campsite may not be sufficient. Preferably, the Scout will carry the emergency medication on his or her person. However, there may be situations where the Scout is too young to be responsible for the medication, or where the Scout is not able to administer his or her own medication. In these situations, another responsible person will need to hold the emergency medication and stay close to the Scout at all times.

The Scout needs to notify the adult leader immediately if he or she self-administers the emergency medication. In ALL cases, the Scout needs further evaluation, observation, or treatment from a health-care provider when emergency medication (such as epinephrine) is used, even if the Scout feels okay. An allergic reaction can repeat itself up to four hours after the first reaction. Once the Scout has been cleared by doctors, the emergency medication needs to be replenished before resuming activities.

### MANAGING ENVIRONMENTAL EXPOSURES

Under the category of environmental allergies, we need to consider seasonal airborne pollen/mold allergies, direct contact with plants or animals, biting and stinging insects, and

<sup>&</sup>lt;sup>4</sup> EpiPen<sup>®</sup> is the registered trademark of Mylan Specialty LP.

contact with latex. Many people with mild to moderate allergies can manage the discomfort with over the counter medications, such as antihistamines and nasal steroids.

A challenge with Scouts is that young people may not know yet what triggers their allergies. Even if they do, they may not have figured out what times of year to avoid being outdoors or which medications are effective for them. For a skin contact allergy, they may not know how to recognize and avoid a plant that causes them trouble. For insect bites, they may not know how to identify the type of insect they need to protect themselves from. As a practical matter, a leader may not be able to do much to prevent such accidental and unexpected exposures. A leader can consider allowing the Scout to stay indoors for part of the day or possibly go home early from an event rather than be miserable.

Latex is made from the sap of the rubber tree, so it has plant proteins that are an allergen for some people. There are two common sources of latex in the Scouting program. The first source is first aid supplies. Latex is used in some gloves, tapes, bandages, adhesives, and more. We use these supplies for first aid teaching and training as well as to actually tend to minor injuries. There are non-latex substitutes for all of these first aid items, though it might take some effort to find them. If you have a Scout or adult in your unit with a latex allergy, it would be a good idea to convert the entire first-aid kit over to non-latex supplies. The other major source of latex is balloons and art supplies. Water balloon fights and party balloons could be a problem. One challenge is that non-latex balloons are not stretchy, so when latex balloons are necessary for science experiments you may have to figure out how to prevent direct contact for the Scout with a latex allergy.

A Scout that has had a serious environmental allergy reaction will usually have been evaluated by an allergist to identify which allergens present a health risk over and above general discomfort. In these situations, the leader, the Scout, and the family need to develop a plan to take into account what allergens might be present at any particular camping location at that particular time of year. Preparing an allergy/anaphylaxis emergency care plan is part of this process.

As a practical matter, there may be some events that a particular Scout cannot safely attend. However, the unit leadership should make an effort to find ways to adapt outings to allow all their Scouts to take part on an equal footing. It may take a change of venue or going at a different time of year, but that is a worthwhile tradeoff for allowing all youth the opportunity of Scouting.

# FOOD SELECTION

The obvious step with food allergies is to be careful with ingredient lists of the food you purchase. Usually less processed foods are safer. The most common food allergens are milk, eggs, peanuts, tree nuts, wheat, soy, fish, and crustacean shellfish. The Federal Allergen Labeling and Consumer Protection Act of 2004 requires these eight food allergens to be listed

on the label if they are present in any amount in a packaged food in the U.S. With that said, any food is a potential allergen, not just these eight types.

It is important to plan ahead for food allergies with the Scout and the family. Planning includes choosing the menu and reading labels before purchasing food. It is important to constantly check labels as the ingredients tend to change names. The entire list is important, even including flavorings and preservatives that are only trace ingredients. As if it were not hard enough, some ingredients have more than one name or abbreviation. For example baking soda, sodium bicarbonate, and bicarbonate of soda are all the same thing. Furthermore, some ingredients that are listed as one item in the ingredient list are actually mixtures. For instance, baking powder is a mixture of ingredients and may not have the exact same ingredients from one brand to another. FARE has resources to help make reading labels easier<sup>5</sup>.

There are three approaches to accommodating food allergies and other food restrictions when purchasing food for unit events. For social reasons, it is preferable to have the Scout with the allergy or restriction eating the same foods as everyone else. This means trusting others, beside the Scout and the Scout's family, to purchase food. This approach is only viable when the problem food ingredients are well identified and are all primary ingredients that will appear clearly in ingredient lists. In simpler terms, this is when the person buying the food can be given a short, clear list of ingredients to avoid.

The second option is for the Scout with the allergy or restriction to purchase and bring his or her own food for the outing and to make plans to cook in parallel with the rest of the group. This may be the only realistic option if the list of food restrictions is long or complicated. With this approach, the Scout should be given the group menu plan in advance and an opportunity to mimic the menu to stand out less from the group.

A hybrid approach is for the Scout with food restrictions or his family to plan and purchase the food for the entire group. Many will do so willingly just to be certain that there will not be a problem. While this solution is straightforward, it may become an unfair burden on the Scout and family to do this all of the time. Another difficulty is that in the Scouts BSA advancement system, there are rank requirements that require menu planning, food budgeting, and food purchasing for an outing, so other Scouts will need their turns to do the selection and purchasing.

A different type of complexity is involved when there is a meal or snack stop at a restaurant or convenience store while traveling. Depending on the maturity level of the Scout, a parent or guardian may need to come on a Scout outing to help watch out for problem foods.

The institutional cooking facilities used at Scout camp dining halls may not be able to provide or prepare special foods for someone with a food allergy. It is a good idea to contact the camp in

<sup>&</sup>lt;sup>5</sup> <u>https://www.foodallergy.org/life-with-food-allergies/living-well-everyday/how-to-read-food-labels</u>. FARE advised us in 2019 that this link may change but the content should still be available on their website.

advance to see what they can and cannot accommodate. In many instances, a Scout will need to bring food from home to have the specialty foods he or she needs.

No matter what the plan is for accommodating special food needs, **it is always a good idea for the Scout to have a personal stash of non-cook, shelf-stable food to substitute for one or two meals** when someone makes a mistake purchasing food or mixes a problem ingredient into otherwise acceptable food.

## FOOD PREPARATION

Preparation methods are just as important as selecting the right food products. Most food allergies are triggered by specific proteins that are found in that type of food. Even small particles of protein can trigger an allergic reaction, so it's important to avoid cross-contact of safe foods with allergens. When you are dealing with food allergies, you need to mentally disconnect the two steps of cleaning and sanitation. Cleaning is removing all the food particles (thus proteins) from the utensil and sanitizing is killing all the germs. For example, if you kill the germs by drying a dish with heat but leave behind a dried out particle of food on the surface, there is still a hazard for the person with the food allergy.

There is no substitute for soap and water when washing your hands, dishes, and surfaces. Hand sanitizer and water-rinsing are more likely to move allergens around than clean them. Dry your hands and dishes with fresh disposable towels. Porous things like sponges, scrubbers, cloth towels, and wooden utensils can never be trusted to be clean enough after the first time they are used. Either treat them as disposable or carefully segregate the ones used on allergenfree foods and utensils from the rest. You will find yourself using a lot of disposable paper towels to wipe up as you cook. Sanitizing wipes can be used, but only after the food has been cleaned from the surface.

In the extreme, the people preparing special food need to be isolated from allergen foods while they are cooking, and they need to have their own separate equipment (including deep fryers<sup>6</sup>), utensils, cleaning supplies, and storage containers to work with. This may not be achievable for a camp dining hall, so it may be necessary to cook in your campsite even though the camp serves cooked meals. With this said you may not need such total isolation unless a person is extremely sensitive to the smallest amount of the allergen or tends to have an extreme reaction to the allergen.

Outdoor cooking is an integral skill to Scouting programs. However, experience shows that Scouts are not the most diligent dishwashers and cleaners, so extra planning and supervision is needed to protect a Scout with a food allergy. Here are some practical points that avoid most of the problems:

<sup>&</sup>lt;sup>6</sup> Particles and oils from an allergen food can come out into the oil in a deep fryer and then be infused into everything that is cooked in the oil afterward.

- Cover wooden picnic tables with a plastic tablecloth before using them. You have no control over what foods were laid on them in the past and no practical way to clean them yourself.
- Don't store foods, ingredients, or seasonings in the same storage bins with cooking equipment.
- Use plastic totes with smooth surfaces instead of a traditional wooden chuck box. A wood surface chuck box can absorb allergens and is not easy to clean inside.
- Keep cooking containers and cooking tools clean between outings by storing them in new zip-type plastic storage bags or small trash bags that can be securely closed. Don't reuse these bags.
- Wash hands frequently with soap and water while cooking and make copious use of food-handling gloves.
- Teach Scouts to strip off and replace gloves before moving to a new task, handling a new food item, or handling a new cooking tool. The point is to not spread allergens from surface to surface.
- Have a generous supply of cooking bowls, pots, and utensils so you don't have to wash dishes while you cook. If there is a need, keep allergen-exposed and allergenunexposed cookware separated on an outing even after it has been washed, and keep the pieces dedicated to their purposes.
- No wooden utensils or cutting boards.
- Avoid sharing a camp stove between allergen-free foods and other foods due to the risk of spatters from one getting in the other.
- Teach and enforce a policy of "a spoon only gets used in one pot", "a knife is only used on one ingredient", and "each container only gets used once" before it is washed. The tools and containers are washed thoroughly with soap and water between each use and each ingredient.
- Wash dishes that have only been exposed to allergen-free foods first, before you wash the other dishes.
- If you use sponges, dish rags, and scrubbers to wipe surfaces and clean dishes, treat them like disposable single-use items. They cannot be cleaned well enough in a camping environment to be reused on the same outing.

- Washed dishes need to be inspected by an adult before they are used again. They need to be completely clean.
- Be prepared to modify any part of the cooking procedures and systems your unit uses based on the information and advice you get from the parents/guardians of the Scout with a food allergy.

### **SWALLOWING DISORDERS**

Swallowing disorders are physical disabilities that are often cared for by a speech and language pathologist. Other speech and language difficulties are covered in Module S. The process of swallowing involves many different muscles to move food and liquids from the mouth to the stomach without it going into the lungs. The muscles have to work in an exact sequence and with the right amount of effort as well.

Swallowing disorders are covered in this module because they create another type of special food that a Scout could need. A Scout with a swallowing disorder will typically have a plan (set of instructions) from a health provider. The instructions often include eating foods/liquids with a narrow range of consistency. Typically this means a soft or liquid diet, with careful control of water content and thickness (viscosity). Regular foods can be processed in a blender, and/or liquid diet supplement "shakes" can be used. There are also additives that can be mixed into liquid food to thicken or thin the mixture to the right consistency. Though not very common, some swallowing disorders require a feeding tube to bypass the regular swallowing mechanism.

A person with a swallowing disorder is always at some risk of aspirating food or fluids, which means that the solids or liquids go into the lungs rather than the stomach. It is possible for aspiration to happen without an obvious sign like choking, coughing, or wheezing. If you work with a Scout with a swallowing disorder, **pay extra attention to any sign of breathing difficulty** and promptly get the Scout evaluated by a health provider if that happens. Aspiration presents potentially serious health complications that are worth avoiding.

As Scout leaders we need to work with family and the care plan for swallowing that has been provided for the Scout. However, being realistic, it would be very difficult to provide the right kinds of foods and food preparation within the resources of a typical Scout unit, Scout camp, or restaurant. In most cases, the family will need to provide the food for the Scout on an outing. It may also be necessary for a family member to attend outings to help the Scout with food preparation or with use of a feeding tube. A more mature Scout may be able to care for himself on an outing, but that needs to be discussed with the Scout and his family before taking that option.

#### FOOD AVERSIONS

Scout leaders have all encountered picky eaters, because the menu is different from home and the food is cooked in unfamiliar ways. Food aversions typically work themselves out because most kids will not willingly starve themselves. When a Scout has a sensory disorder some sensations can be unpleasantly intense. Some Scouts with autism fall into this group. Eating is a complex sensory experience because food has taste, smell, texture, and appearance and **some Scouts refuse to eat many types of foods** no matter how much they are encouraged or reasoned with. Parents in these situations tend to be shy about asking for accommodations for their child or may not recognize it as a special need because they adapted gradually over the years at home.

Food aversions become a health and safety issue when there are not enough calories in the food that the Scout eats to sustain the Scout through the activity. At the same time, we need to preserve the dignity of the Scout and minimize the attention that a food aversion draws. Like an allergy, there are some foods that are in effect "no-go" and ultimately, you must find enough compatible food for the outing. Have a discreet and candid conversation with the family to learn what foods work well at home and what foods are simply no-go. For short-term outings and summer camp, it may be enough to allow the Scout to bring some familiar snacks from home to supplement the regular menu items.

High adventure trips with lightweight trail foods are another matter. One alternative is to seek out lightweight versions of foods that are well received at home, such as instant mashed potatoes, packaged meats, or dehydrated fruits and vegetables. Then, ask the Scout's family to test drive the lightweight foods at home. For freeze-dried foods, you can have a tasting event in advance of the trip for everyone in the group and use the results to accommodate the special needs. A strategy for non-cook meals is to issue out a variety of pre-packaged foods that the Scouts can trade between them as needed to accommodate food aversions. It is OK to sacrifice some long-term nutritional balance for energy content during a limited term outing.

# MEDICALLY RESTRICTED DIETS

There are a variety of diets that are prescribed for medical reasons. This is more common for adults than for youth, but there are a number of youth that need gluten-free diets. Some medical diets will require abstaining from particular foods or emphasizing particular foods, but most of them try to achieve a particular balance between major categories like sugars, starches, fats, protein, etc.

As with any other special food need, a person on a medically restricted diet may have to address the same kinds of food selection issues that were discussed earlier in this module.

### **RELIGIOUS DIETS**

As Scout leaders, we should not obstruct or discourage our Scouts from fulfilling their religious duties as they understand them. There are a number of faith groups that have dietary restrictions as part of their religious duties. The more familiar ones are kosher, halal, and variations on vegetarian diets. These diets create special needs for food selection similar to what is needed to address food allergies. Less obvious is that some religious diets place restrictions on food preparation as well, where certain food types are not allowed to touch each other or be mixed together. In some instances a particular cooking container or utensil is dedicated to a particular class of food. This may require extra cooking equipment. Some of the suggestions for preventing cross-contamination given in the earlier section on Food Preparation may be helpful here as well. The Scout and his or her family will need to explain what restrictions are imposed and may be able to offer ideas for alternative foods that would be pleasing to the whole group.

Another feature of religious diets is that some have prescribed times of fasting and others encourage fasting periodically at self-directed times. In consultation with the Scout's family, provisions might need to be made for food to be accessible at times other than customary meal times.

Author: Roger B. Tate Reviewers: Britt Flather and Midge Savage

# **MODULE J**

# UNDERSTANDING ANXIETY, DEPRESSION AND OTHER MENTAL HEALTH CONCERNS<sup>1</sup>

IN THIS MODULE

OVERVIEW COMMUNICATION WITH FAMILIES ANXIETY DEPRESSION OBSESSIVE COMPULSIVE DISORDER OTHER MENTAL HEALTH DISORDERS-Bipolar Disorder (Manic Depression) Eating Disorders Substance Abuse Breaks from Reality (Psychosis)

# IF YOU OR SOMEONE YOU CARE ABOUT IS PRESENTLY EXPERIENCING THOUGHTS OF SUICIDE, SELF-HARM, OR HARM TO OTHERS

# **STOP NOW AND CALL**

# LOCAL EMERGENCY SERVICES (911)

OR IF MORE APPROPRIATE,

## SUICIDE & CRISIS LIFELINE (988), or

NATIONAL SUICIDE PREVENTION LIFELINE

800-273-8255

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank the Child Mind Institute (childmind.org) for collaborating with us and reviewing the contents of this module for accuracy and usefulness.

## OVERVIEW

Anxiety, depression, and other mental health<sup>2</sup> disorders affect both youth and adults. At the outset, we need to recognize that Scouting volunteers generally lack the expertise to diagnose or treat youth with these conditions. The primary purpose of this module is to help you recognize when a Scout may be struggling, how you can support the Scout, and when these struggles are a cause for concern. That way you know when to turn to family members and professionals to assist the Scout with his or her immediate needs.

It may not seem like mental health concerns share much with other kinds of special needs and disabilities, but many techniques for supporting a Scout with a mental health concern are also useful in other situations. The broadly applicable methods are in Module F – Methods That Apply to Many Types of Special Needs and Disabilities. That material will only be repeated here if needs to be emphasized for a particular reason.

A Scout leader needs to be careful not to make assumptions about a Scout. Mental health symptoms can look different from one individual to another. Some behaviors that look like a mental health symptom may also be age-appropriate or developmentally "typical" behaviors at different ages. Children and adolescents are maturing as they grow, and are learning and developing new skills for regulating their emotions and motivating themselves. For example, a behavior such as a tantrum or emotional meltdown may be age-appropriate behavior rather than a sign of a mental health concern.

We need to be understanding if a Scout needs to take a break from participation in Scouting. Scouts experiencing severe mental health symptoms may need to step away for a while due to high level needs such as in-patient treatment. Scout leaders should be prepared to support the Scout and family when they re-integrate into the Scout unit and understand that advancement may not be the top priority. Participation in Scouting in general may be an important way for them to get back to their day to day activities and social skill building.

If you want to obtain more training, the National Council for Behavioral Health (thenationalcouncil.org or mentalhealthfirstaid.org) sponsors 8-hour training courses in Mental Health First Aid, for non-professionals that could encounter a person experiencing distress. You may also want to familiarize yourself with typical developmental milestones<sup>3</sup>, to better understand developmentally appropriate behavior.

<sup>&</sup>lt;sup>2</sup> The editors understand that the language used for these issues is constantly evolving and the term behavioral health is commonly used in professional circles. In order to accommodate non-professional readers, an editorial decision was made to use somewhat older terminology to make the information more accessible.

<sup>&</sup>lt;sup>3</sup> <u>https://www.stanfordchildrens.org/en/topic/default?id=the-growing-child-school-age-6-to-12-years-90-P02278</u>

## COMMUNICATION WITH FAMILIES

In Module F, there are sections that discuss *Joining Conferences* and *Communication* with the Scout with a special need, the family, and other Scouts in the unit. Rather than repeat that information here, we encourage you to stop and read those sections before continuing.

The Joining Conference will set a foundation of trust for ongoing communication with the family of a Scout. If you see behaviors as you go along that make you concerned for a Scout, or see signs of excessive fears or worries, share your concerns privately with parents and guardians. It is possible that these concerns are related to mental health conditions.

If you believe you need to talk to a family about behaviors that concern you, it is vital that you do not come across as telling the family what to do. You must not give the impression that you want them to seek therapy or that their child can't continue to be a Scout unless they do something. When you describe a behavior, stick to the facts and do not provide your own interpretation of what you see. It is actually better to give the impression that you are seeking information more than giving it. By asking if there is anything you need to do differently to support their child, it will be clear that you are on their side.

These discussions can continue with parents and guardians throughout the years that the Scout is part of your unit. You don't need to know a diagnosis in order to gain an understanding of the situation. Like with any special need, it helps to ask parents and guardians what trigger situations to manage or avoid and which behaviors signal that their child is getting into distress. It is also helpful to ask parents and guardians about any skills or methods of coping that help a Scout manage a behavioral or emotional hurdle.

As is discussed in *Joining Conferences*, the parents or guardians control how much information that they will share with you about a Scout's condition, or allow you to share with others. With mental health concerns, expect the family of the Scout to be careful about sharing, as they want to protect their child's self-image and prevent mistreatment by other children. If an unexpected but serious incident is witnessed by others, parents and guardians may feel pressured to either share unpleasant information or to remove their child from the Scout unit. Quick and compassionate response from the unit leaders may allow a youth to remain in Scouting who would otherwise miss out.

As with other types of special needs, parents of Scouts with mental health concerns may need to attend a Scout activity with their children at times, if the activity is more stressful to them than most or has a specific risk of triggering difficulty. Communicating the nature of the activity to families in advance will help everyone make good decisions about how to accommodate the Scout. It is fine for a Scout to receive extra guidance or monitoring during an event, opt out of part of an event, or leave an event early.

## ANXIETY

Anxiety is a combination of nervousness, fear, apprehension, and worry. Fear itself is not a medical condition. It is a natural emotion that is vital for responding to danger. Many fears are normal and appear at different ages. Young children can be fearful of separation and monsters. As children get older, they may worry about how their peers see them.

Everyone experiences different levels of anxiety from time to time. When a person's worries or fears are irrational or excessive for the situation, then it is cause for concern. When a child has an anxiety disorder, the fear and worry are persistent enough to cause problems in everyday life.

Some people experience excessive anxiety on a thinking, intellectual level, with self-talk, worrying, and brooding on a topic that triggers the anxiety. Sometimes, a child is very aware of the situations that cause anxiety. At other times, the anxiety acts at a more subconscious level, where the child may not feel OK, but not be able to identify what is triggering the feeling. Reactions could include avoidance of triggers or excessive seeking of reassurance from adults. Sleep disturbances are also common with anxiety. Anxiety can result in difficulty focusing and being distracted, which can be confused with attention deficit hyperactivity disorder (ADHD), which is discussed in Module K.

Anxiety can cause a wide variety of physical symptoms that resemble the adrenaline rush of a fight-or-flight moment. Racing heartbeat, shortness of breath, tense muscles, nausea, lightheadedness, and headaches have all been reported. Unfortunately, these same sudden symptoms can be caused by a serious medical emergency. The anxiety is amplified by the fear brought on by the physical symptoms. As a Scout leader, you need to err on the side of caution and **treat these symptoms as a medical emergency** regardless of whether or not you suspect anxiety. At the same time, there is no harm in doing what you can to try to help the Scout be calm. You want to do your best to keep your cool and speak calmly and confidently to the Scout. Use your other leaders to manage onlookers and help them not be swept up in the moment.

In a Scouting environment, excess anxiety could manifest itself with the Scout "getting stuck" and appearing fearful of trying an activity. It could also manifest itself as a panic attack with some of the physical symptoms listed above. One important clue is when the uncomfortable feelings do not ease when you try to coax or reason with the youth. It is OK to try to explain how perceived danger and risk have been managed and why the activity is safe, but if that reasoning makes no difference, it may be time to involve the family and or a health professional. Another "first-aid" method is to find or create a quiet space where the Scout can get away from the trigger and the larger group and try to self-regulate his or her emotions. (See Self Removal in Module F). Realistically, if quiet time is not helping fairly quickly, it is time to reach out to the family and allow the Scout to leave the event to take a longer break or receive care.

### DEPRESSION

Depression can affect life in multiple ways including your mood, physical symptoms, and how you feel about yourself (self-image) or your world. While most would think people with depression feel sad or down in the dumps, this is only one associated feature. Another distinctive feature of depression is the inability or reduced ability to experience pleasurable emotions such as joy. This may be seen as inability to have fun or no longer having fun during activities that used to be enjoyable.

Everyone feels sad or down at times, which is completely normal when there is an unfortunate life experience. For many youth with depression, they seem more irritable or cranky than sad or tearful. If you are concerned about a Scout's mood, compare the behavior you see to what you know about the Scout's recent life experience. Is there a rational connection between the mood and actual experience? One way a Scout leader may notice depression is by socially isolating behaviors. For youth with depression, it may become difficult to maintain friendships, make friends, and have positive interactions with others. When a teen disengages from social groups it may be a sign of depression or other mental health disorders.

Likewise, the physical symptoms of depression can be compared to past behavior. Appetite can change in either direction, with weight loss or weight gain outside of normal growth patterns. This may be difficult to notice, especially for Scouts in early adolescence where growth spurts and puberty make weight gain or loss developmentally appropriate. Sleep patterns can shift in either direction as well, either sleeping more than usual or insomnia. A general lack of energy, despite getting plenty of sleep, is another sign. A Scout leader will rarely spend enough time with a Scout to detect these kinds of changes. What you may notice is the Scout is failing to complete tasks or acting sluggish on outings.

Depression can also cause difficulty with distraction, concentration, motivation, and focus. This aspect can be confused with attention deficit hyperactivity disorder (ADHD), which is discussed in Module K.

Negative thinking patterns associated with depression can also significantly impact a Scout, particularly in how they view themselves or their environment. Youth can lose confidence in themselves and see themselves as having low value to others. A person who is depressed may also show signs of anxiety. More serious feelings would be continuing guilt or seeing himself or herself as a burden to the family. The most serious version is suicidal thinking, where the youth begins to believe the family or world would be better off without him or her.

The main thing to remember is that if a youth is depressed enough for you to notice it as a Scout leader, the youth needs help and likely needs treatment. A starting point is a frank and private conversation with the parents or guardians to share your concern. It is up to them to obtain treatment for their child but as a Scout leader, providing support can be seen as very helpful.

## **OBSESSIVE COMPULSIVE DISORDER**

Obsessive compulsive disorder (OCD) is another mental health disorder that has anxiety as a feature. The distinction is that the trigger of the anxiety is a recurring thought or image (the obsession) and the youth performs some kind of repetitive ritual activity (the compulsion) to manage the negative anxious feelings. Rituals and routines are not harmful in and of themselves. For example, having routines for sleep times, meal times and bath times are important for young children to have a sense of security and belonging in the family. Older children have routines for school, and rules and routines for playing games. Adolescents develop persistent interests in hobbies or activities that give them a sense of belonging in the social world.

What makes OCD different is a matter of degree, where the rituals become so frequent or involved that they take away too much time from the regular activities of daily life. They are time consuming and must be performed in order to decrease the obsessions. Rituals may be easily observed physical actions, like handwashing, or more mental activities, like silently counting things. The rituals involved in OCD run a wide gamut<sup>4</sup>, but there does appear to be a theme to the more common rituals in that they tend to be tasks that make things organized, clean, or "right". Individuals with OCD are searching for certainty, knowing something is clean, perfect or right.

In a Scouting context, we want to be sensitive to the social implications for a Scout with OCD. The ritual behaviors may make him or her stand out from the group and there is a risk of being socially isolated or bullied as a result. As a leader, you may need to emphasize and model empathy with your Scouts more than usual. If the family and professionals have a plan to help the Scout manage the disorder, you can help by being part of the redirection process. In many situations, the symptoms are not overtly problematic. For example, a youth may use the bathroom more frequently, but the ritual itself (e.g. handwashing or checking) may be less obvious.

### OTHER MENTAL HEALTH DISORDERS

**Bipolar disorder,** historically called manic depression, is characterized by mood swings that are extreme compared to the ordinary ups and downs of daily life. It is much less common than either anxiety or depression, and does not usually emerge until late adolescence or early adulthood. It is unlikely that a Scout leader will spend enough time with a youth to notice the patterns of symptoms that go with bipolar disorder. Like the other disorders discussed in this module, the basic behavior is not a disorder, it is a matter of degree. Adolescents typically have mood swings, but if you become concerned about the degree, it is good to discuss the matter privately with the family.

<sup>&</sup>lt;sup>4</sup> Examples include repeated: handwashing, counting, checking conditions, cleaning, stacking, organizing, repeating prayers, and recopying work.

In bipolar disorder, there is a swing between symptoms of depression, which were described in the previous section, and "manic" episodes. The manic phase can include feelings of elation, happiness, extreme confidence, and/or euphoria. The manic phase can also include sleep disturbance (usually needing less sleep than normal), irritable mood, anger, aggressive behavior, or racing thoughts. All of the dangers of depression are still present with bipolar disorder. In the manic phase, there are some additional concerns such as impulsivity and thrill-seeking or sensation-seeking, like reckless driving or increased substance use or sexual activity.

**Eating disorders** are another group of disorders that you might encounter as a Scout leader. They don't always have symptoms that a leader would notice and even then it is unwise to make any assumptions because the normal growth "spurts" of children and adolescents can vary widely in their rate and timing. Even atypical eating behavior could be the result of a food allergy or food aversion, topics which are addressed in Module H. Eating disorders are discussed here to prepare you if a Scout or family discloses this as a special need.

<u>Anorexia</u> is the restriction of calories to the point of starvation. Those with anorexia often have a distorted body image where they see themselves as fat when they are actually perilously thin. Any concerns you have about a Scout's low weight or eating behaviors should be discussed privately with the family because there are many other mental and medical conditions that can impact weight and eating, such as hypothyroidism or social anxiety. Anorexia has serious implications for overall health because the lack of nutrients can cause organ damage.

<u>Bulimia</u> is characterized by cycles of binge eating of large amounts of food followed by compulsive efforts to purge the food by vomiting, laxatives, or extreme exercise. Bulimia is typically less visible than anorexia and harder to identify. The individual may be of normal weight for their height. They are usually aware that their binge and purge behaviors are outside of social norms, so they will hide these activities from others. There is a risk of long-term damage to the gastro-intestinal tract from frequent vomiting and/or laxative use.

<u>Binge-eating disorder</u>, also called compulsive overeating, differs from bulimia in that the bingeing is not followed by an immediate forced purge. The binge may be followed by a cycle of extreme dieting. Those with binge-eating disorder may be normal weight for their age, overweight, or obese.

**Substance abuse** can take place without any underlying mental health issue. However, it bears mention in this module for several reasons. Often, substance abuse co-occurs with a mental health disorder, especially when the substance use is an attempt to manage emotions or feelings. In many instances, the use of alcohol or non-prescribed medication actually does the opposite and makes the mental health issue less manageable.

We hope that Scouts have a desire to be "mentally awake and morally straight" and "Clean" in accordance with the Scout Oath and Law. While a Scout may need to take a break from the Scouting program if he or she experiences substance abuse, this need not be a permanent disqualification.

**Breaks from reality** or psychosis are rare, but can occur in the context of substance abuse or a mental health disorder. A break from reality is when a Scout is no longer able to recognize the environment or the people around them. It can also be characterized by a Scout seeing or hearing things that others cannot see or hear. If a Scout leader suspects that this is happening, it should be treated as an urgent situation that requires professional help. Scout leaders are not equipped to handle this on their own.

A person who is experiencing a break from reality is not necessarily a danger to anyone. However, simply to make the situation easier to manage, you want to move other youth and uninvolved adults away from the immediate area while you are waiting for a professional to respond. If you feel in danger yourself, back away. If the person who needs help is moving around, do your best to keep track of where he or she is at so the professionals can be guided to the right location.

Authors: Mary Wangerin and Roger B. Tate Editor: Roger B. Tate Reviewers: Child Mind Institute, Britt Flather, and Midge Savage

# **MODULE K**

# UNDERSTANDING ATTENTION-DEFICIT HYPERACTIVITY DISORDER<sup>1</sup>

IN THIS MODULE:

OVERVIEW COMMUNICATION TYPICAL STRUGGLES & BEHAVIORS EXECUTIVE FUNCTIONING BEST PRACTICES FOR SCOUT LEADERS IMPULSIVENESS AND ATTITUDE ADJUSTMENT ABOUT MEDICATION

#### OVERVIEW

It is normal for children to sometimes have a hard time sitting still, paying attention, or controlling impulses. As children mature, they typically get better at maintaining their attention. What makes children with attention-deficit/hyperactivity disorder (ADHD) different from others is a matter of degree, where these abilities are behind their age peers. Just as other children get better at managing impulses, attention, and physical movement as they grow up, kids with ADHD also get better over time, but they may lag behind their age peers. There isn't a "cure" for ADHD, only treatments. Scouting can be a part of a youth's life that supports appropriate development and helps the Scout become more effective at what he or she wishes to do.

What we think of as ADHD has three major attributes: inattentiveness, impulsiveness, and hyperactivity. Each person's challenge is different because these attributes have a different severity for each person and come in different combinations from one person to the next. The total impact on someone's life can vary a great deal from one person to another because the combined effects of different symptoms can be greater than the effect of each one alone. For youth with ADHD, the problems are frequent and pervasive enough that they impact many aspects of daily life - school, home, Scouts, faith congregation, and community.

It is not our place as adults in Scouting to try to diagnose a Scout as having ADHD. It is better to focus on behaviors and recognize when the behavior patterns point us to ways we can help the

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank the CHADD (Children and Adults with Attention-

Deficit/Hyperactivity Disorder), chadd.org for reviewing the contents of this module for accuracy and usefulness.

Scout and his family. Since about 10% of the school population is affected by ADHD, it is a near certainty that there are some of these kids in every traditional Scouting unit.

Remember, Scouting does not have to be an all or nothing proposition. Depending upon the needs of the Scout and the intensity of symptoms, it may be appropriate for the Scout participate part-time, in just some of the unit's activities, or to participate for only part of an event. Allowing this flexibility gives a Scout a chance to benefit from Scouting in the short run, while in the long run growing into a successful, continuing, and expanding involvement in the Scouting program. The approach works best when the family and unit leadership function as partners and communicate well.

Working with Scouts who have ADHD can be frustrating at times, but the rewards for both the Scout and the leader can be great. It is often a trial and error process. Thank you for taking the steps that will allow more youth to participate in Scouting and benefit from the best the program has to offer.

## COMMUNICATION

If you have not already done so, we strongly encourage you to stop and read Module F before continuing on with this module. Module F tells you how to use a Joining Conference to begin the relationship with a Scout and his family. It also explains the importance of ongoing communication with the family as the Scout moves through the program. We do want to emphasize that in regard to ADHD it is important for all of us; adults in Scouting, family members, teachers, medical professionals, and therapists to think of ourselves as part of a team that supports this Scout.

# **TYPICAL STRUGGLES & BEHAVIORS**

A person with ADHD (inattentive presentation) has many, but not all of these struggles:

- Forgetful in daily activities
- Easily distracted
- Misplaces things
- Avoids or dislikes tasks requiring sustained mental effort
- Has difficulty with organization
- Struggles to follow multi-step instructions
- Has difficulty sustaining attention
- Misses details makes careless mistakes
- Does not appear to be listening

A person with ADHD (hyperactive-impulsive presentation) has many, but not all of these behaviors:

- Interrupts and/or intrudes often
- Gets up from seat at inappropriate times
- Fidgets and squirms frequently
- Excessive running and climbing in young children; restlessness in older youth and adults
- Moves and acts continuously, without pauses or breaks
- Has difficulty engaging in activities quietly
- Talks excessively
- Blurts out answers before questions are finished
- Has difficulty waiting and taking turns

## **EXECUTIVE FUNCTIONING**

While most people know that the effects of ADHD can interfere with learning and self-control, they don't know that people with ADHD often struggle with analyzing, planning, organizing, scheduling, keeping track of time and progress, and completing tasks. These kinds of skills are called "executive functioning" and are skills one needs to be productive<sup>2</sup>. While all children develop these skills gradually over time, this is another area where Scouts with ADHD are probably behind their age peers.

In the context of ADHD, the key elements of executive function are:

- Self-awareness knowing your feelings, thoughts, and actions; also recognizing how others see you
- Self-restraint controlling one's self-directed attention and impulsivity
- Holding thoughts to guide memory
- Retaining directions and sequences
- Awareness and regulation of emotions
- Self-motivation
- Planning and problem solving

While these executive functions are important for everyone, in Scouting they align with our "Be Prepared" motto, and our goal of building future leaders. Executive function skills are necessary for work and play. They allow us to reach out, coordinate, and complete projects both jointly and independently.

 $<sup>^2</sup>$  As a side note, executive functioning struggles are also a common feature of anxiety disorders, psychosis, some learning disorders, and autism spectrum disorders. Some people have these struggles without having ADHD.

You can support executive function skills in those with ADHD by:

- <u>Using Flexible Accountability</u> ADHD is not about the capacity to understand, it is about timing, sequence, and focus. Use teachable moments, not punishment
- <u>Writing it Down</u> Use and encourage the Scout to use signs, lists, note cards, journals, charts and checklists anything that makes information visual helps to build memory skills.
- <u>Making Time External</u> "Time blindness" adversely impacts planning, organizing, and selfregulation – use of clocks, timers, counters, verbal notice of time remaining or time elapsed supports independence and accountability
- <u>Making Motivation External</u> External forms of motivation tokens, charts, and rewards can be useful to establish a sense of self-motivation by reinforcing long-term goals with short term-rewards
- <u>Making Learning Hands-On</u> Doing is better than listening to instructions physical activity helps to get knowledge into memory
- <u>Stopping to Refuel</u> Self-regulation and other executive skills can be depleted quickly. Frequent short breaks of 3-5 minutes, involving physical activity, hydration, and redirection can help internalize executive function skills
- <u>Model /Teach Pep Talks</u> Positive self -talk can help build self-regulatory skills internalized "you can do this" statements aid in visualizing future rewards, as well as reviewing steps needed to achieve goals
- <u>Being Adaptable and Supportive</u> Making changes that will allow Scouts to show what they know then help them understand what went right, what went wrong, and why

### BEST PRACTICES FOR SCOUT LEADERS

Many ideas that work well for Scouts with ADHD will benefit your other Scouts too.

Take time to **learn what triggers difficult behavior** in them and what the Scout's warning signs are. If there is already a system that the family home or school use to help the Scout manage behavior, be consistent, and use the same system within the Scouting program.

**Monitor the tone of the group** and the interactions of individual Scouts. Make adjustments to the activity as needed. In particular, be willing to take breaks.

Give **advance explanation** for activities. Explain the overall goals, sequence of events, timetables, and give clear expectations whenever possible. Teach youth leaders to do likewise.

**Review directions with the Scout** one-on-one or better yet, one on two. Have the Scout's buddy listen to the directions also. This way the buddy can repeat instructions to keep everyone on track.

Use **chunking** to break tasks down into achievable smaller segments.

Encourage the **Scout to repeat or restate the directions back to you**. Encourage the Scout to ask questions. Mark off on a list or chart to visually show personal progress, even on small-scale multi-step tasks.

Stick to **plans and routines** as much as possible. Model and encourage youth leadership to do the same.

**Prepare for transitions** between tasks and activities. Give early warnings of change. A ten, five, and two-minute sequence is usually sufficient. Stick to the timetable and be clear as to what is to follow. If you have to change the plan, give advance notice as soon as practical.

**Consider using a buffer activity** like a water break, bathroom break, washing hands, or a quick game to divide larger activities at a transition.

Scouts with ADHD often have difficulty with **unstructured time**. It may be helpful if they can be given specific meaningful tasks during those times. Plan in advance to have some things available to do.

Be on the lookout to **give genuine compliments**, even for small things. Ignore minor inappropriate behaviors that are not disruptive or dangerous.

Make a plan with the Scout, so you can **discreetly communicate that you are getting concerned** about a behavior before it becomes a problem. This gives the Scout a way to self-regulate and develop self-control without being called out in front of the group or embarrassed. The agreed upon signal might be moving closer to the Scout, a gesture like tugging on your ear, or a noise like a pretend cough. Part of the plan can be an understanding that the Scout is allowed to break off from the activity for a while to regroup (self-removal) or is allowed to do a subtle physical activity, like pace in the back of the room.

Some Scouts may benefit from the use of a discreet **fidget tool**<sup>3</sup>. Directing them to use the tool in their pocket for a few moments, may be enough of a pause to enable them to return to the task at hand. It should be noted that these items are not toys and should only be used to relieve

<sup>&</sup>lt;sup>3</sup> Examples of fidget tools are a soft squeeze ball filled with sand or a couple of loose marbles contained in netting or small cloth sack.

tension or anxiety often occurring in activities or long projects requiring sustained concentration.

Technology can be a useful<sup>4</sup>. **Consider letting the Scout use a smartphone** or other devices to make notes of step by step directions, set timers, receive reminders, and receive redirections (the vibrate setting can serve as an inconspicuous method to help a Scout get back on track). Noise canceling earphones or background music may be helpful to focus some Scouts. Scouts can be encouraged or redirected by a text message from the Scout leader.

Allow for **frequent breaks** and opportunities for **purposeful movement**. Be cautious of prolonged unstructured physical activity, this can easily lead to deteriorating behaviors and exhaustion. Scouts who have ADHD have as much difficulty regulating play as they do work.

### IMPULSIVENESS AND ATTITUDE ADJUSTMENT

OK, this section title is a bit misleading, because the attitude that needs adjusting is probably yours and not the Scout's. Do not take challenges personally – keep cool! It is vital that the adults keep calm and carry on. Some Scout leaders and Scout units place a strong emphasis on getting their Scouts to be respectful of adults and well-behaved. With this viewpoint, it is easy to see the behaviors of ADHD through a lens of morality and judge the Scouts as disrespectful and disobedient. This regrettably can lead to "disciplinary" actions that do not serve the aims of Scouting. The *Corrective Action and Addressing Conflict* and *Self Removal* sections of Module F have great advice on handling poor behavior. If you have not read them, then do so before reading more here.

Scouts and Scouters with ADHD often possess great attributes, which when harnessed can be invaluable. Their energetic, clever, excited, happy-go-lucky, creative, enthusiastic, inquisitive, and spontaneous nature **can be fun** and make significant contributions to the success of your unit. The key to success in dealing with ADHD behaviors, as with many others, is to turn challenges into opportunities. Planning, observation, intervention, and redirection are important tools to support behavioral changes.

While we want to embrace the positive behaviors, there will be some impulsive behaviors that are safety hazards and will have to be addressed. Realistically, the leaders on an outdoor activity may need to keep a closer watch on things with a Scout with ADHD than would otherwise be needed. It's a little late to interrupt climbing to the top of a tree or running headlong through rough terrain after it has already happened. There are things you can watch for proactively, before trouble starts. Sometimes our Scouts with ADHD can unknowingly serve as the early warning system that it is time to change the pace of an activity for the whole group of Scouts.

<sup>&</sup>lt;sup>4</sup> Youth protection rules for technology use would still apply. No inappropriate photo taking or recording. Text and email communications with the Scout must copy a parent or guardian as well.

Watch for these things for either an individual or the group as a whole:

- <u>Concentration</u> lost interest or hyper-focused
- <u>Distracted</u> focused on things other than the given task
- Being Distracting increased interrupting, walking about
- <u>Procrastination or Difficulty Getting Started</u> may indicate directions were not understood or remembered
- <u>Frustration</u> whining or destroying work may indicate the need for a break, review of the task, or breaking it into smaller segments
- <u>Fidgety Behaviors</u>- may need a short break with physical activity or redirection. There is some evidence that physical exercise helps people with ADHD settle down.
- <u>Increased Impulsive/Aggressive Behaviors</u> poking, prodding, and invasion of others' personal space most likely requires intervention or change of activity.

If a situation calls for immediate action and consequences are necessary, they should be prompt, proportional, and not reactive on the part of leadership. It is important to minimize the theatrics of the situation. Use a calm voice, limit verbal interactions, avoid yelling and public humiliation. Cooling off time and spaces (self-removal) can be useful options. The aim is to address the behavior and have the Scout rejoin the activity as soon as possible. This might happen during the current activity or may have to wait till the next event, depending upon the seriousness of the behavior and how long the Scout needs to regain control.

### ABOUT MEDICATION

BSA Risk Management has a guidance document on *Medication Use in Scouting* (BSA 680-036), which is a general document for all medications. While medications are often part of an ADHD treatment plan, medication use can be complicated and we need to explain some details in this module. If you have not experienced ADHD yourself or with a family member you may assume that medication will "fix" ADHD by itself, which is not true, and unfairly judge a parent if medications are not provided. It is not a Scout leader's role to suggest or require specific treatment options, medications, and or diets. With children, doctors may advise families to give the ADHD medications at some times of day and not at others, or to recommend periodic breaks from medication. The benefits of using the medication are balanced against the overall health of the child.

Per BSA 680-036, "Parents are cautioned against using a BSA event as a "drug holiday" by suspending administration of medications taken regularly by their youth member unless there are specific instructions from a health-care provider." Unit leaders, families, and Scouts with ADHD need to communicate in advance about medication needs, including a need for a break. Families should not surprise leaders by sending a usually-medicated Scout on an event without medication without prior notice. Scout leaders need a chance to consider the length of the

event and the activities that are planned in order to assess the risk to the Scout with ADHD and to others on an outing. Leaders should look for accommodations like providing some extra supervision or the Scout participating for only part of the event. If there is a situation where a Scout cannot be safely accommodated at an event unless medicated, the leaders need to explain it to the family in advance so they understand why and can consult their doctor. Leaders also need to be sure that they make such decisions in the best interests of their Scouts and not primarily for convenience.

Author: Tony Mei Editor: Roger B. Tate Reviewers: Britt Flather, Midge Savage, CHADD

# **MODULE L**

# UNDERSTANDING AUTISM<sup>1</sup>

IN THIS MODULE:

OVERVIEW SOCIAL BEHAVIORS AND CHALLENGES OF AUTISM LANGUAGE ASPECTS OF AUTISM SENSORY DIFFICULTIES OF AUTISM EXECUTIVE FUNCTIONING (SELF-ORGANIZATION) LIMITATIONS PHYSICAL BEHAVIORS LOSS OF CONTROL INCIDENTS & TRIGGERS COMMUNICATING WITH PARENTS OF SCOUTS ON THE SPECTRUM COMMUNICATING WITH THE SCOUT ON THE SPECTRUM STRATEGIES TO HELP A SCOUT WITH AUTISM SPECTRUM DISORDER

### OVERVIEW

The formal name for Autism is Autism Spectrum Disorder (ASD). It is a neurological condition that affects how the brain operates and impacts many aspects of life. In general terms, autism affects communication and social skills, the perception of risk, the ability to self-organize, and how sensory input is managed. The differences begin showing themselves gradually in early childhood, but it may take years before being properly identified as autism.

The word "spectrum" in the name signifies how Autism manifests itself in different ways in different people. Each of the major symptom categories has variations in both severity from one person to the next and in the way the symptom in expressed (e.g. impacting primarily vision or hearing). A person's overall level of functioning will vary depending on his or her individual combination of symptoms. Most children described as "on the spectrum" are able to participate in and benefit from Scouting programs.

Overall, in the United States 1 in 42 boys and 1 in 189 girls (CDC 2014) are diagnosed on the autism spectrum. Based on limited research and anecdotal experience, it appears that people with autism spectrum disorders are more concentrated in Scouting programs and somewhere between 1 in 15 and 1 in 20 Scouts are on the spectrum. This means most Scout units have one or more Scouts on the spectrum and all Scout leaders need some familiarity with the characteristics of autism and the strategies for making the Scouting program work for these youth.

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank the Autism Society of America (autism-society.org) for reviewing the contents of this module for accuracy and usefulness.

At the time of this writing (2020), popular drama shows are depicting more characters on the autism spectrum than ever. News shows are also featuring more people with autism. However, there has been a bias to show people with ASD who are either very high functioning or have savant intellectual skills. The reality is that people with ASD vary in intelligence like everyone else. Most of them would test at average or above average IQ. But that is only part of the story. Scouts on the spectrum tend to excel in memorization tasks, but they often struggle with abstract thinking and tend to have a one-track mind. While Scouts on the spectrum can quickly solve problems like they have seen before, they struggle to solve a new problem for the first time. This impacts how you teach skills to a Scout on the spectrum.

Even though Scouts on the spectrum are different from others, in many ways they mature at a normal pace, including physical growth, sexual maturation, and many aspects of cognitive development. Scouts on the spectrum will change as they grow up. A teen on the spectrum will have many of the attributes of his or her age peers but will interact with the world in a different way.

While a Scout on the spectrum will exhibit several of the characteristics below, few will exhibit all of them, and some of the characteristics will manifest themselves in different ways depending on the context and what other characteristics are present. There is an adage that "If you've met one person with autism, you've met one person with autism." You have not met them all.

As a Scout leader, you should not attempt to diagnose a youth as having autism. Leave that for health care and educational professionals. However, if you recognize a behavior pattern that resembles autism, feel free to try out any or all of the strategies described in this section. Keep using what works. So much about helping a Scout on the spectrum succeed is trial and error. Rest assured that there is little harm to trying out a strategy and learning that does not work. Just keep trying.

### SOCIAL BEHAVIORS AND CHALLENGES OF AUTISM

Inappropriate social behavior is one of the most obvious symptoms of autism spectrum disorders. Most of the inappropriate behavior occurs because children on the spectrum decode the social context incorrectly. They do not learn how to behave socially from context or by watching others as most children do. Instead, they have to learn how to interact with others from direct instruction. This struggle has several facets.

<u>Special Interests</u> – Children, and some adults on the spectrum, develop topics in which they are deeply interested, to the exclusion of others. These topics may be conventional for a child, such as cars, Pokémon, or Legos; or they can be very eccentric, such as a fascination with prime numbers. The topics can persist for anywhere from a few hours to several years. There may be one such topic or several that are active at any one time. When you engage a person on the

spectrum in conversation, the conversation often turns to their special interest, and it can be a challenge to get them to talk about anything else.

<u>Facial Expressions</u> – Most Scouts on the spectrum have a hard time understanding what a facial expression means until someone teaches them how to decode what they are seeing. You can imagine how hard it would be to cope if you couldn't tell if someone is angry with you or is amused by you. This aspect is sometimes called "face blindness".

<u>Tone of Voice</u> – Scouts on the spectrum are at constant risk of misunderstanding others because they do not catch the meaning beyond the actual words themselves. They do not catch on when something is said as a joke, or in sarcasm, or in irony. They also do not read the emotional state of the speaker that is conveyed in the tone of voice. For example, "Please sit down" takes on a whole new meaning when it is said in a short staccato burst through clenched teeth. This makes it especially hard as they hit the teen years where sarcasm and jokes abound.

<u>Familiar People</u> – Scouts on the spectrum, especially younger ones, do not easily distinguish between family, friends, acquaintances, and strangers. As a result, they may touch inappropriate people, invade another person's personal space, try to start a conversation with a stranger, or make physical contact in inappropriate ways.

<u>Rationality and Rules</u> – People on the spectrum learn to survive in a social world by building a mental rule book to capture all of the quirks of human behavior that others take for granted. For example, think about the unwritten rules about where to stand in an elevator car depending on how many people there are. They also assume that any rules that they are given are concrete and will be rigidly enforced on everyone. When there are deviations, people on the spectrum tend to appoint themselves to police the rules and can be rigid with others.

<u>Bullying and Other Abuse</u> - Scouts on the spectrum are vulnerable to being abused by practical jokes and bullying. They can also get taken advantage of by others during group games. Their inability to read the unspoken intent of others leaves them gullible and nearly defenseless. Once they understand who took advantage of them, they are long to remember and slow to forgive.

# LANGUAGE ASPECTS OF AUTISM<sup>2</sup>

Aside from missing the non-verbal cues in what others say, Scouts on the spectrum may have a harder time using language than others. The difficulties go in both directions (expressive and receptive).

<u>Nonliteral Language</u> – The English language is full of metaphors, similes, and idioms. All of these are times where the words that are spoken don't mean what they say because of the context or because of our cultural history. Consider the expressions "got off on the wrong

<sup>&</sup>lt;sup>2</sup> Module S is devoted to Speech and Language Disorders and has more complete coverage of this topic.

foot", "not even in the ballpark", and "raining cats and dogs". Such nonliteral expressions are lost on people on the spectrum unless they have made an effort to memorize the translations.

<u>Social Language</u> - While idioms are an obvious example, regular people also use indirect speech for emotional or social reasons. They "beat around the bush" to spare the feelings of others, let people down gently, give advice, make suggestions, or give hints. A person on the spectrum will rarely catch the intended meaning, but instead will focus on the actual words that are said.

<u>Unfiltered Speech</u> – Scouts on the spectrum tend to speak their mind without a social filter and have no idea when they are being verbally offensive.

<u>Age-Inappropriate Language</u> – Scouts on the spectrum tend to build a very grown-up vocabulary and syntax. They tend to use complex sentences with big words. While this makes them charming to adults, and they get along well with adults as a result, it also socially isolates them from their age peers. It is not unusual for them to speak and mispronounce words that they have only seen in print. For example, "façade" becomes "fa-kaid".

# SENSORY DIFFICULTIES OF AUTISM

With autism, stronger and weaker neural connections can form between the sensory organs and the brain. It is rare to have all of the senses affected equally and usually one sensory challenge will stand out. The struggles come in three forms and sometimes they are combined. One is that the youth on the spectrum perceives a sensation more strongly than most and it is uncomfortable. For others, the sensation is not painful, but it is so distracting that they just can't tune it out and do other things. A few of them are very insensitive to a sensation, which can be dangerous if they do not perceive pain when they should. On the plus side, a Scout on the spectrum may notice things that other Scouts do not, such as plants, animals, and insects in nature.

<u>Visual (Seeing)</u> - Visual difficulties come in several forms. One is simple brightness of lights being too intense for comfort. Another form is visual clutter in the field of vision, which makes it hard to concentrate. A small number of people on the spectrum can perceive the flickering of light fixtures or have a hard time reading text against a white background.

<u>Eve Contact</u> – A common trait of people on the spectrum is that they avoid eye contact. When asked about this, they usually explain that they just can't think when they are looking someone else in the eyes, so it is uncomfortable for them.

<u>Auditory (Hearing)</u> – Some people of the spectrum overreact to moderately loud noises. Others are driven to distraction by small repetitive noises, such as the sound of someone chewing gum, shoes shuffling across the ground, or the clicking of a ball-point pen. If a Scout on the spectrum has this difficulty and no way to get away from it, it can lead to an outburst. (See Module F for advice on "self-removal".)

<u>Tactile (Touch)</u> – Insensitivity to heat, cold, or touch does not draw much attention as a difficulty, but presents a safety hazard. Some on the spectrum have problems when certain fabrics touch their skin, with the way garments rub against them, or from being touched by others in some particular way. Some find that having firm pressure applied to them has a calming and centering effect for them. The tactile sensation of being in the water can make a Scout averse to swimming beyond all reason.

<u>Olfactory & Gustatory (Smell & Taste)</u> – Smells, flavors, and textures of food that ordinarily are tolerable in the mouth can be repulsive to some people on the spectrum. Surprisingly, **this presents one of the more serious risks to a Scout on the spectrum**. Scouts on the spectrum cannot be compelled to eat something repulsive to them and will not eat such foods no matter how hungry they become. Though often written off as "picky eaters" such Scouts can become seriously malnourished on longer Scout outings if their needs are not accounted for in food planning.

# **EXECUTIVE FUNCTIONING (SELF-ORGANIZATION) LIMITATIONS**

At all ages, people on the spectrum tend to struggle with a cluster of life skills that are known collectively as "executive functioning". They have a hard time organizing themselves. The struggle to create and maintain plans of action, schedules, budgets, or to-do lists. They have a hard time reacting to unexpected problems and difficulties, and fail to keep on top of paperwork. To a degree all young people struggle with these things, but a person on the spectrum does not learn from "life experience" in the same way and doesn't have the same motivational structure to overcome obstacles. "Natural consequences" or "learning the hard way" are not enough to get them to learn these skills on their own.

### PHYSICAL BEHAVIORS

<u>Motor Skills</u> – Scouts on the spectrum may have poor gross and/or fine motor skills. Gross motor skills are things like walking, running, jumping, and swimming. Fine motor skills are things like handwriting, using scissors, tying knots, and whittling. They may also have poor awareness of where their body and body parts are positioned in space and how much force they are exerting (proprioception). This means that a Scout on the spectrum may simply be clumsier than other children, and may trip over or bump into things or people. Since the Scouting program includes many motor tasks, motor skill limitations impact our teaching methods significantly and in some instances make it necessary to get alternative advancement requirements approved.

<u>Endurance</u> – Scouts on the spectrum may give the appearance of lacking endurance or physical stamina because they tend to stop, or they ask to stop an activity. There might be a physical disability along with the autism that needs to be considered. (See Module R for more information.) However, in many cases this limitation is more about mind than body. For example, Scouts on the spectrum may not understand the logic or value of a long hike, so it

seems pointless to them to keep going once after they have seen everything they can see. This can be overcome if an adult explains the purpose of the activity in terms the Scout can understand.

<u>Self-stimulation (Stimming)</u> – Scouts on the spectrum, and especially younger ones, sometimes have some form of repetitive motion or sounds (words, phrases, or noises) that they will make. Some examples are hand flapping, rocking the body, spinning the body or spinning objects, singing, echoing others, and noise making. While "stimming" is not well understood, it appears to be a response to stress and seems to be a way to control the sensory experience. Although it appears odd to others, it is a way to re-establish a degree of control.

## LOSS OF CONTROL INCIDENTS & TRIGGERS

Autism creates a complex and unique set of behaviors and struggles for each person with the disorder. This makes it impractical to create a list of specific triggers, because few of them would apply to any one person. It is more useful to explain what is going on inside a person with autism.

<u>Stress and Anxiety –</u> People on the spectrum process very little on a subconscious or intuitive level. That means they have to use their conscious intellect to process all of the rules of social behavior on top of all the regular thinking that is expected of them. The result is that a Scout on the spectrum is under a constant level of mental fatigue or stress that others don't experience. If you want to understand this condition, imagine how it would be if you had to move to a new job in a different community once a month and relearn all the subtle differences and new people each time. A person on the spectrum is mentally tired most of the time and has less of an emotional reserve than most people.

<u>The Triggering Process</u> – The triggering process begins when people on the spectrum are pushed against one of their unique challenges, with no good way to control or manage their situation. It may be that they cannot escape a distressing sensory environment. It could be that they are stuck dealing with a person who makes no sense to them or is being argumentative or demanding. It could be a situation where they are being pressured to perform when they do not believe they have the skills, or don't understand the instructions, or have to overcome an aversion. It could also be a situation where they are being prevented from finishing a task that is already started. A thoughtful observer can usually sense when a person on the spectrum is becoming distressed before he or she acts out and can intervene in the situation to defuse it before it gets out of control.

<u>Meltdown</u> – A meltdown is one of three common reactions to being overstressed. It is characterized by sadness and crying. Especially in the social world of boys, such behavior tends to get one labeled as weak, so the social consequences last long after the meltdown is over.

<u>Outburst</u> – An outburst is a verbal (loud) or physical reaction, such as yelling, swinging arms, throwing objects, or hitting others. It is intended to create some space to escape the situation. Outbursts are often misinterpreted for true anger, meanness, or aggression and get treated as disciplinary infractions when they should not be.

<u>Shutdown</u> – A shutdown is the opposite of an outburst. The Scout just stops interacting with the world or communicating and will usually sit down somewhere. If the Scout can physically leave the area he or she usually will. Until the Scout can recover, he or she will not respond to anyone trying to talk. This behavior looks a lot like sulking or "zoning out", but the goal is not to get his or her way or to punish others for refusing something.

<u>Recovering</u> – It is always better to intervene and create space for the Scout to calm down before a meltdown, outburst, or shutdown occurs. If it is already too late, help the scout get to a quiet space and give him or her some time to process the feelings and regain composure without talking right then. After that, it is worthwhile to talk to the Scout and help develop better strategies for the future. At a minimum, try to learn his or her advance warning signs or work out a code between you to allow you to help without embarrassing the Scout.

# COMMUNICATING WITH PARENTS OF SCOUTS ON THE SPECTRUM

The single best thing you can do to create a path to success for the Scout and the rest of your unit is to build a strong partnership with the parents of a Scout on the spectrum. Remember that all parents have similar dreams for their children as they grow up, such as for their children to live on their own, to form loving relationships with a spouse and children, and hold a good job.

<u>Joining Conferences</u> – Joining conferences are a good thing for every Scout whether they have a known disability or do not. You should read Module F as well, which has much more information on this topic. In short, a Joining Conference is a private and candid conversation between the parents of a Scout and one or two unit leaders and takes place within the first few weeks of joining the unit. During the joining conference you want to learn: (1) What are the Scout's unique strengths and struggles? (2) What tricks (accommodations and adaptations) are working for the Scout at home and at school? (3) What seems to trigger emotional or behavioral struggles? (4) How does he or she act when things are about to be overwhelming (warning signs)? (5) What concerns do the parents have about putting their child in Scouting?

<u>Openness about the Disability</u> – Parents of Scouts on the spectrum will have varying degrees of openness about the disability. You and your unit leadership will have to respect their confidentiality. Some parents will be very forthcoming with you about their child. Others know that their child has a disability but consider it to be a private family matter or do not want their child to be "labeled". Others function in a state of denial. Some do not even recognize a problem since they or other family members have similar issues.

<u>Ongoing Check-In</u> – Much as the Scoutmaster Conference serves as a regular check-in time with a Scout, you need to plan to check in every few months with the parents. This needs to be an open and candid conversation. Begin by asking what changes (hopefully positive) they are seeing in their Scout, and share the successful moments you have seen when the parents were not there. If you are seeing a behavior from the Scout that you don't understand or is getting in the way of his or her success, ask the parents what they know and how they manage that behavior at home and in school. During this kind of meeting, spend more time praising the Scout's accomplishments than addressing the difficulties. Parents need encouragement too.

<u>Appropriate Parent Alerts</u> – Once you have a sense of how the Scout handles the environment and what the individual trigger situations are, you need to use that knowledge to give parents advance notice when activities are coming up that might be overwhelming for the Scout on the spectrum. Parents may want to opt-out from a particular campout or event if the Scout just isn't mature enough or experienced enough to navigate the situation or if the sensory environment is unmanageable. While we want Scouts to experience challenges, we don't want to knowingly put them into situations where they cannot succeed.

<u>Learn the Scout's Early Warning Signs</u> - A parent has an advantage over any other adult in that they have a sense for when their child is getting overwhelmed and can intervene discreetly to keep their child from getting to the point of acting out. This means you need to invest time and attention to learn from the parents what the Scout's warning sign behaviors are, and when to be careful. The Scout program is based on surmountable challenges, so encouraging and pressing youth is a necessary part. However, you want to back off before the Scout on the spectrum is pushed over the emotional edge. It is always easier to take a break than recover from a meltdown or outburst. Rarely is a goal so urgent that it can't be put off until circumstances improve.

<u>Requiring Parents to Attend</u> – We should encourage all parents to participate with their children in the Scouting program, but there is only one good reason to require a parent to attend in order for a Scout on the spectrum to participate. That is when the health and safety of a unit member (including leaders and the Scout on the spectrum) is put at risk without the extra level of supervision only a parent can provide. Resist the urge to require parents to attend simply to make life easier for the leaders, other Scouts, and their parents. Remember, every Scout needs to chance to learn to function without mom or dad always being there. With that said, feel free to recruit parents of Scouts on the spectrum as leaders as they are often very committed to the success of all youth, including their own child. Such a parent should be used to work will all of the Scouts in the unit and only be considered "on call" to address specific issues with their own child.

### COMMUNICATING WITH THE SCOUT ON THE SPECTRUM

You will need to develop a different way of talking to communicate with a Scout on the Spectrum. First of all, you have to stop using idioms, analogies, and metaphors. Speak directly,

explicitly, and in plain language. Second, you need to be completely transparent and up front about what you want the youth to know and why. You don't have to be harsh in your tone, but don't flower anything up to try to spare his or her feelings. If you can't say what you need to say because others are listening, move the conversation to where you can speak more privately (in sight of others but out of earshot, per youth protection rules). Sometimes it is hard to tell if a Scout on the spectrum has heard and understood because he or she refrains from eye contact or doesn't give off body language. If you need to be sure you were heard, ask to have it repeated back to you.

<u>Giving Instructions in General</u> – Remember from the Executive Function section earlier, that a Scout on the spectrum typically cannot turn a general instruction, such as "pack your gear," or "clean up the patrol kitchen" into a series of steps or an action plan on his or her own. You and your youth leaders need to give very specific sequential instructions to Scouts on the spectrum for nearly everything. With practice, the Scout can remember the subtasks and improve in this regard. Break down tasks into smaller steps than you would for other Scouts. Again, do not assume he or she will learn by watching others.

<u>Direct Instruction about Social Rules</u> – In addition to the regular social world, Scouting has its own distinct culture and expectations for behavior. A Scout on the spectrum is not able to pick up on the social rules by watching others (modeling). When you see Scouts on the spectrum in situations where they are not conforming to regular expectations and it is being a problem, you need to step in and explain the situation to them. This is a three step process. First, tell him or her which behavior is "not working", such as talking too loud, standing too close, or not making eye contact. Second, tell the Scout how others react to that behavior. Using the same examples, others might see the Scout as angry, creepy, or as lying. Third, give a concrete rule that simulates culturally expected behavior, such as "leave at least two feet between you and the other person when you are talking", or "try to make eye contact for two seconds at a time and twice a minute". People on the spectrum navigate the social world with a mental rulebook and pick up rules and exceptions to rules a little at a time.

# STRATEGIES TO HELP A SCOUT WITH AUTISM SPECTRUM DISORDER

Scouting has much to offer a youth on the spectrum. In Scouting, we place youth in a wide variety of social contexts, with a wide variety of subjects, and with a wide variety of tasks. This variety is good for the Scout on the spectrum because it provides social experiences they can learn from and broadens their knowledge beyond their special interests. Scouting also allows them to participate and socialize with other Scouts of different skill levels. The human brain is a powerful thing and most of the strategies that follow take advantage of the fact that Scouts on the spectrum are able to learn most of what they need to become functional and successful adults. They will always be different, but they can be taught how to compensate and fit effectively into the social world. The role of a Scout leader is to facilitate that learning.

<u>Medications</u> – Since autism is fundamentally a brain "wiring" disorder, there are no medications for autism itself. However, a person on the spectrum might benefit from medication for anxiety or depression. Usually medications are provided for other conditions a person has and not for the autism itself. A Scout leader should not give families advice about medications. Medication use is a matter to be decided by the family in consultation with a health care provider.

<u>Mainstreaming</u> – The vast majority of Scouts on the spectrum can function in the traditional mainstream Scouting program for their age. The exception is for youth that have a significant intellectual delay or a profound communication limitation as part of their autism. Such youth may also need physical assistance with basic functions, such as eating and toileting, as well. (Other modules in the Inclusion Toolbox provide more information on these needs.) In such circumstances a special purpose unit may be the only way to serve these youth. In a nontraditional unit, the program can be adapted to a workable and enjoyable pace and a higher ratio of adults and caregivers can be provided. (See Module W for more on nontraditional units.)

<u>Healthy Unit Culture</u> – Your unit should create an accepting and tolerant environment for all your Scouts. It is hard for youth to empathize with others when they know nothing of the challenges a disability presents. It is often helpful for other Scouts in your unit to be told a little about the autism spectrum, without necessarily singling out the Scout on the spectrum. This is especially true for your youth leaders. Rather than focusing on getting the Scout on the spectrum to follow a youth leader, focus on training the youth leader how to encourage and lead a Scout on the spectrum. Any training of this kind should be done out of the presence of the Scout on the spectrum. Another tool is telling "social stories" in one-on-one, small-group, and large-group settings. Such stories are similar to a Scoutmaster's Minute. They are simple, step-by-step descriptions of social situations (teasing or bullying, for example) and are told from the perspective how a youth feels at the time. You can use these stories to help all of your Scouts see things from the perspective of another person, including the unique viewpoint of a Scout on the spectrum.

<u>Managing Special Interests</u> – Special interests need to be approached in a balanced way. To a certain extent you can exploit a special interest to get the Scout to work on related advancement tasks, but obviously that will not work for most of what the Scout needs to know. What you need to keep in mind is that the special interest serves as an intellectual "safe space" for the Scout, where he or she feels confident and in control. The Scout needs to be able to spend some time in the safe space. If you struggle to get the Scout to engage in another activity, you may have to resort to some form of bargaining, where he or she commits to spend some time on something else that you would like done and you commit to spending some time with the Scout talking about his or her topic of interest.

<u>Managing Sensory Issues</u> – The first thing you should understand is that you are not going to be able to get the Scout to a build up a tolerance to a problem sensory environment. In time, the Scout on the spectrum will develop coping mechanisms for sensory overload triggers. Until that happens, you can make adaptations to keep the stress from becoming unmanageable. For example, if visual overload is the issue, you could take down some of the decorations on the walls of your meeting space or concentrate them on one wall and turn the Scouts away from it when the meeting is in progress. If noise is an issue, consider moving the activity outside where sound dissipates better, or subdivide the group so fewer voices can be heard at one time. If the uniform shirt is irritating, encourage the Scout to wear a comfortable shirt underneath. If food tastes and textures are an issue, creative menu planning may help. When possible, get everyone in the group to eat foods that the Scout on the spectrum can tolerate. Be creative.

Making Transitions between Activities or Topics – Scouts on the spectrum need more structure and order than their peers. They function best when they have a "program" to follow for the meeting or outing. They do not like to stop in the middle of a sequence, which becomes a problem when you have not managed your time well. If your leadership style is free-spirited and you like to "let nature take its course" in your Scout meetings and outings, you and the Scout on the spectrum will be frustrated. Plan the sequence of activities, and foreshadow this sequence with your Scouts. Foreshadowing means giving everyone a preview of what activities are coming up and in what sequence. Repeat the upcoming list as you make each transition. This allows the Scout on the spectrum to anticipate transitions before they occur. One caveat however: Unless you know exactly what time you will change from one activity to the next, don't give an exact time to a Scout on the spectrum because he or she will hold you to it. It is better to say "later" or "very soon" than to say "a half hour" or "five minutes." Similarly, if you have planned some extra activities to do if time permits, don't include them in the preview until you are sure you will get to them. When you are sure, add the new information to your foreshadowing. If you work with a troop or crew, you need to train your youth leaders how to structure a meeting and provide foreshadowing.

<u>Self-Removal</u> – A powerful tool for helping Scouts on the spectrum cope with stress is to create ways for them to separate from a group, area, or activity at their own discretion. For safety sake, the Scout cannot be left totally unsupervised, but the Scout can be monitored from a distance by a responsible adult. What works best is to create and agree to a protocol with the Scout. In the protocol, the Scout needs to let a particular adult know that he or she is stepping away. Hand signals are OK as long as they have to be acknowledged. There needs to be an agreed upon place that that the Scout will go, perhaps a hallway or side room, or his or her tent if on a campout. The responsible adult needs to be able to look in on the Scout from time to time while he or she is "removed". The Scout needs to check back in with the adult before returning to the activities of the unit. A major point of the protocol is to keep the adults from thinking the Scout is missing, malingering, or being disobedient. Self-removal is not the same as a "time out" and while there are times when you may want to encourage the Scout to self-remove, it should never be used as a disciplinary tool.

Handling Inappropriate Behavior - There will be times when a Scout on the spectrum behaves badly, and you have to be careful not to overreact. The key thing to remember is that most inappropriate behavior results from social ignorance or misunderstanding the actions of others. There will also be times when a Scout on the spectrum pushes boundaries, tests limits, seeks attention, or tries to get out of work—just like any other Scout. Recognize that as a Scout on the spectrum matures and mainstreams, he or she will behave more and more like your other Scouts. If inappropriate behavior does occur, it is critical to get all the facts about an incident and understand the perspective of all the players before you choose how to respond. Be sure to get the perspective of the Scout on the spectrum. In general, an instance of inappropriate behavior is a teachable moment: You can help the Scout on the spectrum understand a rule of social behavior he or she didn't already know, or you can help the Scout see things from another's perspective. Remember that Scouts on the spectrum have to be taught these things in an overt manner. One advantage of working with these Scouts is that you can be very straightforward because their feelings are not easily hurt. Remember, Scouts on the spectrum may not understand subtext, so speak plainly so they understand your message clearly. You can be as direct with them as they are with you, but remember that direct is not the same as rude or harsh. You need to explain what was done, how it made others feel, and what should have been done, without belittling the Scout on the spectrum. If the behavior was truly meanspirited and some disciplinary action is appropriate, make sure the Scout understands what the consequences are and why they are being invoked.

<u>Personal Safety and the Buddy System</u> - Scouts on the spectrum, especially younger ones, are more likely than others to put themselves in danger without even realizing it. For example, since they are more comfortable with adults than others their age, they may wander off with a stranger and not realize they are separated from the group. They may get distracted by things around them and not notice that they are off the regular trail or that the group is moving away from them. They may jeopardize their safety by inattention to things around them, such as moving cars and crossing signals. Even though all Scouts should use the buddy system on outings, adhering to this system is especially important for Scouts on the spectrum. You cannot let your guard down when you are camping at a BSA camp or on private property. You also need to be thoughtful about who you assign to be the buddy for a Scout on the spectrum and choose a Scout with a good temperament for the job. The buddy may also need a little extra support, guidance, and encouragement from you. Do not rely on another Scout with special needs to be the buddy for a Scout on the spectrum.

<u>Hazards of Games</u> – Scouts on the spectrum perform poorly in team sports and other competitive environments. Since games and competitions are a common feature of Scouting, you need to keep an extra watch on things when a Scout on the spectrum is involved to assure that everyone is being a good sport and not taking unfair advantage of the weaknesses of a Scout on the spectrum. You need to be similarly watchful about youth-initiated games like "Truth or Dare" and practical jokes to keep them from getting out of hand and becoming bullying.

Pitching or Striking Camp - Sharing the work of pitching or striking camp is an important part of "esprit de corps" for a Scout unit, but the process is especially confusing and stressful for a Scout on the spectrum. In Scouting, youth lead this process, and they are still learning how to lead. If the Scout on the spectrum is being directed by a single leader, the stress level can be managed, but if several youth are giving directions at once (too many chiefs), the confusion and noise can trigger a meltdown. A boy leader can be taught to pay attention to the environment and manage it, but it may also be necessary for an adult to monitor the social interactions of the patrol and provide coaching before frustration becomes unmanageable. A second challenge is that a Scout on the spectrum often cannot break down a general instruction into its component parts and will do nothing as a result. For example, the Scout cannot turn "pack your personal gear" into a sequence of rolling up the sleeping bag, deflating and rolling an air mattress, putting everything into a duffel bag, and carrying the bag to the designated staging area. "Set up the patrol kitchen" and "Load the trailer" are just as cryptic. The Scout on the spectrum then acquires a reputation for being lazy or useless. The best solution is to have another Scout work side by side with the Scout on the spectrum throughout the process of pitching or striking camp. The "buddy" needs to be able to break instructions down for the Scout on the spectrum so he or she can help.

<u>Handling Multiple Scouts on the Spectrum in One Unit</u> - Given the statistics about autism, you may have more than one Scout on the spectrum in your unit, and even more if your unit becomes known as special-needs friendly. Whatever your number, remember that even though Scouts on the spectrum have similar disabilities, they are as different from each other as they are from the other Scouts. The adaptations you need to make will be somewhat different for each of these Scouts. It is a good idea to spread Scouts on the spectrum out among the dens or patrols of your unit if possible. This will give you the maximum flexibility to treat each Scout as an individual. Do not pair a Scout on the spectrum with another Scout with special needs as tent mates or camp buddies because they cannot effectively watch out for each other, and their differing needs will almost certainly cause clashes between them.

<u>Advancement Adaptations</u> – The majority of Scouts on the spectrum can complete the regular BSA advancement requirements if they are given enough time to master the skill and the opportunity to demonstrate the skill when they are in a productive frame of mind. Swimming challenges, discussed below, are an exception for some of these Scouts. Some forms of autism have related physical or intellectual disabilities. The advancement considerations for those situations are discussed in Module R for mobility impairments and Module P for intellectual disabilities.

<u>Instruction Style</u> – The EDGE teaching model (explain, demonstrate, guide, enable) works with Scouts on the spectrum, but you may need to go more slowly and break tasks into smaller steps than usual. You may also need to slow down to allow for limitations in motor skills. This additional time isn't difficult to devote at a unit activity, but it may be a problem in a larger setting, such as at summer camp. At camp, instruction tends to be compressed to a rapid-fire sequence, and the teachers at camp are often older Scouts rather than adults. This increased tempo of instruction can overwhelm a Scout on the spectrum, and since the camp counselors have limited teaching experience, they may not know how to compensate. As a unit leader there are a few things you can do to help with summer camp. (1) You can pair the Scout on the spectrum with a more mature Scout as a buddy to help stay on task during instruction time. (2) You can have an adult leader shadow the Scout to his or her classes and then continue working during free time. (3) Your ultimate fallback is to work with the Scout after camp and offer the additional instruction time needed for him or her to complete the badges.

<u>Organization of Advancement Work</u>– In advancement, we must not do the work for the Scout, but we can set the stage to give the Scout a realistic chance of success. For Scouts on the spectrum, you may need to supplement their self-organization. The Scout may have to be talked through the process of breaking down subtasks, finding opportune moments to complete work, identifying ways to combine tasks into one event, etc. In providing this assistance though, you must be on guard for advancement tasks where planning or analyzing is the point of the advancement task. Be especially careful with Personal Management merit badge and the Eagle Scout Service Project.

<u>Swimming Requirements</u> – Many non-swimmers are anxious about getting into the water and learning to swim. A meaningful fraction of Scouts on the spectrum have such a strong tactile aversion to getting into the water that the standard BSA swimming requirements are not achievable for them. They don't look any different from other Scouts, so it is hard for others to understand this. While you should certainly attempt all of the encouraging and coaxing you would do with any other Scout to try to get them over the hump, there may come a point where everyone must accept that the Scout's disability prevents him or her from completing the standard requirements as much as being quadriplegic would. This may be challenging to document to the satisfaction of an Advancement committee, but it is necessary to get alternative requirements approved if the Scout is to advance at all.

Author: Roger B. Tate Reviewers: Autism Society of America, Britt Flather, and Midge Savage

# **MODULE M**

# UNDERSTANDING BLINDNESS AND LOW VISION<sup>1</sup>

IN THIS MODULE:

**TYPES OF VISION DIFFERENCES** THE BIG PICTURE WHOLE UNIT ACCOMMODATION **TEACHING SKILLS BUILDING EMPATHY WITH ACTIVITIES** LEADING AND BEING LED **EMBRACING TECHNOLOGY CAMPING TIPS OUTDOOR SKILLS AND ADVANCEMENT TASKS** Writing Draw/Sketch/Diagram **Identify Animals and Plants Nature Observations** Orienteering **Target Sports** Swimming/Water Rescue Boating **Knife and Woods Tool Use** Fishing Fire Building/Stove Use/Cooking **Rope Work Climbing/Rappelling/Challenge Courses** Cycling

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank the National Federation of the Blind (nfb.org) for collaborating with us and reviewing the contents of this module for accuracy and usefulness.

#### **TYPES OF VISION DIFFERENCES**

In this module, we discuss three groups; those that are blind, low vision, or colorblind. Low vision is the accepted term for what was called previously called vision impairment. Adaptations for colorblindness are straightforward and are addressed in this opening section. Most of this module discusses how to accommodate blindness because the same adaptations and ideas can be applied, as needed, for someone with low vision. **Unless otherwise stated in this module, the words "blind" and "blindness" are intended to include all kinds of vision differences.** This aligns with the reality that service organizations for the blind also support those with low vision.

In this community, there are some people and organizations that prefer to use the term "blind" or "blind person" and others that prefer "person with blindness". The same distinctions apply to those with low vision. Some are comfortable being called blind and others prefer being called low vision or visually impaired. "Impaired" is a term that has mostly fallen out of use in this community. When you are speaking to or about an individual, we encourage you to ask how that person prefers to be described and then honor that preference. When interacting with a support organization, we encourage you to adopt the mode of address that they use amongst themselves. In this module, you will find both forms of address used.

**LOW VISION** is a broad category to describe many different ways of seeing, short of total blindness. For some, it is far vision that is blurred. Others cannot see close objects sharply, even with corrective glasses. Others may have poor depth perception. Others may have narrow fields of view, and others are unable to see in the center of their visual field. How their vision difficulty affects their life can be very different from one person to the next.

The primary difference between a low vision and total blindness is the ability to directly interact with written text and graphics. People with low vision may have a limited ability to read or write printed materials and might need to be aided with magnification, large print, contrast enhancement, or assistive technology. They may or may not use a white cane to walk around their environment. With this said, a Scout with low vision will likely need some, but not all, of the accommodations that a blind person might use. To support such a Scout, you will need to take time to understand that Scout's type of low vision and then review the rest of this module for the tools that you will need to help him or her. However, your goal is not to treat such Scouts as if they are different or totally blind, but rather to encourage them to use all of their abilities and their adaptive techniques to accomplish the same goals as any other Scout.

**COLORBLINDNESS** is an often overlooked struggle. Most people who are colorblind don't tell others about it, so it is easy to ignore. The practical concern in Scouting is to pay attention to situations where instruction materials have been color-coded to help those with regular color vision and then make sure colorblind people can distinguish them as well. For example, at a major Scouting event, colors were used to distinguish between the different bus routes. The buses were marked with colored signs with no writing. This could have been adapted for colorblindness by using a shape (square, circle, triangle, star, etc.) as well as a color for the signs

or by using a sign where the color is spelled out and the same color is used for the text color (the word "PURPLE" written in purple paint).

# THE BIG PICTURE

Blindness impacts four major aspects of the Scouting program: interfacing with text and graphics for learning (both reading and writing), moving around safely in an outdoor environment, completing manual tasks that require spatial awareness, and making observations. There are no Scout tasks that someone who is blind categorically cannot do. Let the Scout decide if he or she needs accommodations or assistance to do the task. Don't assume they will always need help. So in practical terms, a Scout leader and a blind Scout will have to work together and experiment to identify where the true limits for that Scout lie. This can be described as "collaborative trailblazing". As is discussed more fully in Module F, good communication with the Scout and family allows solutions from other parts of life to be carried over into Scouting as well.

The biggest obstacles for Scouting with blindness are two sides of the same coin. On one side is the well-meaning concern of adult leaders, guardians, or parents who try to shield these Scouts from danger by barring them from trying something. On the other side of the coin is the fear of the Scout, who lets inexperience and unfamiliarity stop him or her from trying something new. Encourage these Scouts to do everything they can possibly do for themselves, with the understanding that they may need a sighted person to give them information about the world that is beyond their physical reach.

A blind Scout should be able to participate in a mainstream traditional Scout unit, and most of the information in this module presumes this is the case. There are some Scout units made up of all blind/low vision Scouts. Like most special-purpose units, these units may have a higher ratio of support volunteers to participants, approaching one support volunteer for every participant. A vision-oriented special purpose unit can benefit from going camping with a buddy traditional unit to get a more mainstream experience. Special purpose units with sufficient funding may want to recruit and scholarship sighted Scouts to go to summer camp with them to help out

#### WHOLE UNIT ACCOMMODATION

Whole unit accommodation is promoting an attitude among all the Scouts where they all take a role in being helpful. A blind Scout relies on others for some information about what is around. Each time the Scout moves to a new location it takes time to build a mental map of where things are, and he or she will need some assistance this figuring out. The paradox is that in order to feel capable and confident you must first be informed by others. The Scout's companions serve as the eyes for the Scout, describing what is around in detail so the blind Scout can get oriented. This allows the blind Scout to participate and be proactive. The buddy system applies here like everywhere else in Scouting. A Scout who cannot see should not be left alone with no one to assist if desired. In rougher terrain, the Scout may want assistance from another Scout as a "sighted guide"<sup>2</sup> to move around. It is up to the Scout to decide whether to rely on a white cane or to ask for help from a sighted guide. Don't assume Scouts will need a sighted guide simply because they are blind.

Even when you are not moving around, the sighted people in the conversation circle need to be intentional about verbally describing the things they are seeing. This includes not just objects but other activities going on around the area that might be fun. It also extends to dining hall lines and buffets where companions need to describe what foods are available and to restaurants where the menu needs to be read aloud to assist the blind Scout. The Scout can order for himself when food orders are being taken.

It is good for everyone in the unit to be ready to offer help to the blind Scout. Ask "Would you like me to help?" and let the Scout have the power to decide whether the help is wanted or not. Helpful companions will need to learn not have their feelings hurt if help is refused. As everyone gets to know one another and relationships grow between the youth, the process of offering, asking, receiving, and refusing help gets easier and more intuitive.

# TEACHING SKILLS

Teaching new skills is different because the Scout cannot learn simply by watching others. Some things will need to be taught with hand-over-hand technique. Others will need to be taught using a three dimensional model of some sort. For example, you can create models of knots using thick rope that can be felt and used as a reference for the correct shape of the knot. Other skills will need to be taught by talking the Scout through the motions in fine detail.

No matter what method is used to teach, the person doing the teaching will need to plan farther ahead and arrange for more aids than would be needed for other Scouts. The basic questions will always be similar:

How can we make it possible for the Scout to have this experience or learn this skill? How do we let the Scout be in control of the process as much as possible? How can we do this safely? Is this realistic? What can we do if this method or strategy doesn't work for this Scout?

<sup>&</sup>lt;sup>2</sup> Sighted guiding is a method of walking with people who are blind while they hold on to you and you tell them about the obstacles and changes in elevation. This information is easy to find on YouTube and Google under the search term "sighted guide technique", so it is not being repeated in this module. You can ask the Scout who does not see and the family whether or not to encourage the whole unit to be trained in sighted guiding.

#### **BUILDING EMPATHY WITH ACTIVITIES**

The best way to help the sighted members of the Scout unit understand what life is like for the blind is to talk with blind people in the community and watch while they do ordinary tasks. Local blindness support agencies can help you with this. The Scouts will probably be amazed at what those with blindness can do, not what they can't do.

A leader may think that any blindfolded game or activity would promote empathy and understanding, but it takes a careful and nuanced approach to succeed at this. Asking a sighted person to perform a task while blindfolded does not give the same experience as not being able to see. A blind person has had plenty of time to become comfortable working without vision and to find ways to adapt. A blindfolded exercise will make being blind seem more difficult than it actually is. Another risk is that the exercise will unintentionally make light of the disability or make it seem worse than it is. This can encourage ableist attitudes. If you are thinking of including a blindfolded activity at an event to build empathy for a blind Scout in the unit, discuss this first with the Scout and the family to get their perspective on whether to proceed and, if so, how to present the activity so that it is not offensive. At a minimum, plan on an age-appropriate interpretation talk before the exercise to **focus the Scouts' attention on what they CAN do while blindfolded**, and then plan on completing the activity with an introspective reflection discussion about how their beliefs and attitudes have changed. While we want Scouts to be caring and relate to one another's life experience, we don't want them to "feel sorry" for others and treat them as anything less because of a disability.

#### LEADING AND BEING LED

Blind Scouts can serve effectively as youth leaders. Take pitching a patrol campsite as an example. The youth leader functions without sight by communicating continuously with the followers and using their descriptions of conditions to make decisions. The youth leader gives verbal guidance to the group, and checks in on the status of each of the followers verbally. With practice, the followers get in the habit of reporting back verbally with their own status and the status of the task they are working on. If needed, the leader can have one sighted person stay close by to assist him while he directs the rest of the group. There is no reason a Scout who does not see cannot lead a hike and set the pace using either a white cane or sighted guide to navigate obstacles, and using a braille compass for navigation.

#### EMBRACING TECHNOLOGY

Traditional adaptive technology includes writing and reading Braille, using Braille devices like compasses and clocks, and using mobility aids like white canes<sup>3</sup> and guide dogs. Mechanical Braille writers, which look like a cross between a typewriter and a court reporting machine, are still in use. However, electronics and smart phone technology are rapidly changing the world for the blind. Speech recognition apps and text-to-voice readers continue to get better and they allow the blind to use computers and to communicate in written form with those that do not read or write Braille. It is not hard to imagine a future where cameras mounted in glasses frames have facial recognition software and object recognition software to audibly identify who is approaching to talk and what objects are nearby. The same electronic sensors that are being developed for self-driving cars could soon augment or replace the traditional cane and give audio cues to allow more independent movement.

Each form of adaptive technology takes time and training to learn to use. In the Scouting program, it is easiest to embrace whatever adaptive technology the Scout already knows how to use. Many smartphones have accessibility features in the operating system and it would be worthwhile for you to learn how to turn these on when needed. If your unit has a "no electronics" policy for outings, exceptions may need to be made to allow a Scout to use the adaptive technology that is built into a smartphone.

# CAMPING TIPS

Scouts who don't see need to be part of the camp set-up and breakdown experience. They may want a companion to work with while the campsite is being pitched and the positions of things are in a swirl. Once the dust settles, the Scout should be given a tour of where things are so he or she can begin moving independently. It is important that everyone knows that if you move something from place to place, you need to announce what you are doing, so the Scout knows what has changed.

As part of the initial tour of the campsite, you will want to identify hazards like holes in the ground, trip hazards, cactus, thorny plants, low hanging branches and drop-offs. Ask the Scout if he or she wants any areas marked off to make things easier. As always, the axe yard needs to be roped off. Depending on where you camp, you may need to bring some long stakes to tie rope or caution tape to, so rope fences are high enough off the ground to not be a trip hazard. If the Scout sees it as a benefit, consider running a guide rope from the open area of the campsite to the latrine. This helps the Scout take care of him or herself better and may be appreciated by everyone else to find the path to the latrine in the night.

<sup>&</sup>lt;sup>3</sup> There are special disc-shaped tips for canes for use in rougher terrain. Telescoping hiking poles or ski poles may also be practical substitutes for a cane.

If your unit camps at the same parks or Scout camps on a recurring basis, it will help the Scout if you can try to reserve the same campsite at the camp each time you go. This reduces the amount of effort for him or her to get oriented when you go camping.

A blind Scout keeps up with his things by keeping track of where they are in space. While blind people may try to be more organized and neat than other people, kids are still kids. Even if it looks messy, that is OK because everything is right where it was last left. The Scout's tentmate will need to understand that picking up after someone else is doing more harm than good and that you shouldn't move the Scout's things around in the tent if you can help it.

## OUTDOOR SKILLS AND ADVANCEMENT TASKS

Module E discusses how disabilities can be accommodated in most cases by an open-minded reading of the requirement, keeping in mind the intent and learning objective of the requirement. In the specific situation with blindness, what we need to point out here is that **it is reasonable to allow a sighted person to serve as the interface with the visual world**<sup>4</sup>, while the Scout him or herself does the advancement task. For example, a Scout could identify a type of flower by asking a sighted person to describe its features without giving the name of the flower. The sighted person tells the color, the size and shape of the petals and leaves, number of petals, how tall the flower stands, and whatever details are asked for. In the reverse, a sighted person could convert the pattern of the stars in a constellation into something tactile by poking holes through a paper plate, so the Scout can feel the pattern of the constellation.

With enough effort any advancement task can be completed, but not everything will be worthwhile for every person. Using the flower identification example again, the Scout will have to be taught to identify flowers by their features in the first place, and that will be harder and take more time than it would for others to learn by using photographs. If Scouting becomes more work than fun, advancement may need to take a back seat to other aspects of Scouting.

**Writing** – In a low-tech environment, the practical solution for writing requirements is to allow a scribe to take the verbal information the Scout gives and write it on the page. However, if you look closely, many requirements that we assume require a written product don't actually say that. Report, describe, discuss, and explain can all be done verbally. In a high-tech environment, it may be possible for the Scout to type directly or to use voice recognition software to create a document.

**Draw/Sketch/Diagram** – There are a variety of ways to produce a graphical product without the traditional pen and paper. Ask first if a verbal description would suffice or if it is OK for a scribe to draw on paper what the Scout tells him or her to. The next alternative is for the Scout to work with pen on paper with someone to help get the pen into starting position and to give audible feedback as the Scout draws. At the other extreme, the Scout could use modeling clay

<sup>&</sup>lt;sup>4</sup> On a practical basis this is not different than allowing a deaf Scout to have a sign language interpreter.

to sculpt something truly three dimensional. In between are 2-1/2 dimensional approaches that are flat but have features you can touch and feel. It is possible to draw using a ball stylus, heavy paper and a rubber mat to make creased lines in the paper that can be followed with the finger. Puffy paint or glue can be used to trace a drawing. Fingerpaint can be used to draw on a larger scale. A map can be created using "playdough" or modeling clay. Drawings can also be made with school glue and sand or glitter. If the shape can be shown by a dot pattern, holes can be punched in heavy paper to form the pattern. Support agencies may have specialized equipment that the Scout can use. Be aware that **if you need a drawing to teach something to the Scout, you will have to use one of these techniques yourself to make something the Scout can understand.** 

**Identify Animals and Plants** – While odors can be used to identify some plants and the sounds of calls can be used to identify some wild animals, most of this work will have to done by feel with something other than a live animal or plant. For animals, there are several options, which include pelts, hides, horns, antlers, and plaster casts of tracks. You could also reach out to a taxidermist or natural history museum to see if they would allow a Scout to examine mounted animals by touch. For plants, the options include touching leaves, flowers, and bark (insert your own poison ivy or cactus joke here).

**Nature Observations** – The Scout should make as many observations as possible using other senses, but in most cases, a Scout will need a helper to serve as his or her eyes and then as a scribe to record notes. The helper needs to be instructed to answer the Scout's questions and describe what is seen in such a way that the Scout draws his or her own conclusions. Helpers should write only the notes they are told to by the Scout. That way a helper is just an extension of the Scout rather than doing the work for the Scout.

**Orienteering** – The basics of orienteering are not an extraordinary challenge for a blind Scout. There are electronic talking compasses and mechanical braille compasses for the Scout to use to take a bearing. The electronic ones are much more precise. Likewise, pacing off distances is not particularly hard either. For many tasks the Scout may want a buddy to serve as a spotter. However, giving the Scout the experience of working with a map is a significant challenge. There are both high-tech and low-tech options for you to consider.

The high-tech option is to get maps printed in a tactile format. School systems and support agencies for the blind often have access to specialized large-format "Braille" or tactile graphics printers that put patterns of dents on paper or plastic sheets to create shapes and shading. The printers are relatively expensive, so the most practical solution for a Scout leader is to coordinate with the Scout's family, school, and service agencies to see if they can produce a functional tactile map for your orienteering training efforts.

For low tech solutions you can use the ideas previously discussed above for drawing and diagramming requirements. You can also create models on the ground using rocks, sticks, rope, or other materials at hand to build a small scale replica of the terrain shown on a paper map.

Another method to consider is using a shallow sandbox<sup>5</sup> to sculpt features from the topographic map into the sand. This instructional method allows the Scout to feel the lay of the land and it is also a great instructional aid for everyone else in the group. There is a high tech version of this called an augmented reality sandbox that earth science departments in colleges are using to teach topography effects. If you call around to local colleges, it would be worth the field trip to see one of these in action.

**Target Sports** – Even without vision, a Scout can master the underlying skills of marksmanship. Vision impaired shooting is a recognized Paralympic sport<sup>6</sup>. All people have an internal sense called proprioception, which allows us to intuitively know where every part of our body is at all times. It is how you can touch your nose or your opposite elbow with your eyes closed. A Scout that doesn't see can use this proprioception sense to maintain a consistent body position from shot to shot, or to swing a consistent arc with shotgun or tomahawk. Breath control, trigger squeeze, and arrow release techniques can all be mastered as well. All that a Scout needs is a spotter to assist with aiming (laser sights help) and to give feedback on where the last shot went. In working with the Scout, you need to emphasize consistent technique.

**Swimming/Water Rescue** – There are no obstacles to recreational swimming for a person without vision, provided the standard BSA Safe Swim Defense safety rules area followed; more specifically having a defined swim area, ability groups, swim buddies, and buddy checks. Obviously, for free swimming the buddy will need to be sighted. For the purposes of swim checks, it helps to give the Scout a swimming lane along the side of the pool or next to the dock so the Scout can touch off and maintain a straight course. All of the rescue methods required for Scouts BSA ranks can be performed using sound to locate the target subject. Surface rescue techniques for Swimming and Lifesaving merit badges can also be performed by ear. These merit badges have requirements to bring an object up from the bottom, which might be more difficult for a blind Scout, but the requirement does not state that the Scout must find the object on his or her own or that an aid to locating it cannot be used.

**Boating** – Again, with canoeing, rowing, kayaking, sailing and motorboating, the standard BSA Safety Afloat rules are generally sufficient, provided a blind Scout is paired with a sighted buddy. The sighted buddy will need to provide verbal guidance for the direction to go, but does not have to be steering the boat. For boating merit badges that require solo boat handling, a buddy needs to be aboard to provide directions (left/right) while the Scout performs the requirement.

**Knife and Woods Tool Use** – Standard BSA safety rules for handling knives, axes, and saws are generally sufficient to allow a Scout who is blind to work with these tools, although an extra emphasis on everyone following the rules is wise. When a Scout is learning to use these tools, a

<sup>&</sup>lt;sup>5</sup> It would be easy to build a sandbox from a piece of plywood with 2x4 boards around the edges. Fill it with a sack or two of playground sand from a home improvement store.

<sup>&</sup>lt;sup>6</sup> Paralympic vision impaired shooting uses an audio feedback system to give feedback on how close a competitor is to the center of the target.

sighted leader (youth or adult) needs to be present, to verbally coach the Scout until he or she is competent with that tool. During the learning phase, it is a good idea for the Scout to use a knife he or she is already familiar with or to start learning with a knife that will he or she will get to keep from then on. It is usually easy to identify which side of a knife blade is sharp from the shape of the grip<sup>7</sup>. The same is true with an axe handle. Special attention needs to be paid to giving the Scout safe space to work with a knife or in an "axe yard". Even without sight, it is not hard for a Scout to know where his body parts are in space so he can avoid swinging an axe at himself. Everyone in the unit needs to know to call out to the Scout before approaching and to speak up if the Scout asks "Am I clear?"

**Fishing** – Fishing is an activity where vision does not offer much advantage when the action is below the surface. From a safety point of view it is not that different from using woods tools. Take time to teach good casting technique with a practice plug or sinker weights to simulate the weight of the lure or hook. The Scout should have a buddy/spotter to help him aim his cast. Give the Scout plenty of space when casting and don't go close without announcing yourself. A flopping fish can cause injury by biting or sticking you with a fin spine, and the Scout probably won't have enough feel through the line and pole to judge when and where to safely grab the fish. A few suggestions for successfully removing the fish from the hook include either the Scout using gloves when grabbing the fish and removing the hook, or using a foot to hold the fish down until the hook is safely removed.

**Fire Building/Stove Use/Cooking** – Those who are blind can generally protect themselves from burn injuries by sensing the heat from a fire or hot object radiating onto their exposed skin and by moving in a deliberate manner when close to a heat source. However, it can be difficult to tell if a pan handle is too hot to touch when working near an open fire because heat is coming from too many directions. The Scout can use another object, like a stick to locate the pan handle. Once located, the scout can do a quick touch of the handle to note how hot it is<sup>8</sup>. Building a fire lay is not particularly difficult. Lighting a fire is still doable, but the Scout might want assistance from a helper to know if the match is lit and which way to move it to get to the tinder. You can still know if it helps to blow on the fire from the sounds the fire makes.

"Is it done?" Remember that cooking is a life skill that the Scout is also working on at home and learning how to manage. With practice and experience, the Scout can recognize whether food is done from how it smells and how it feels when it is stirred or when you push on it with a spatula. Many foods can be tested by allowing a spoonful to cool off and then taking a bite. Talking timers are very useful for preparing pasta and other foods. A talking meat thermometer can be used to check solid cuts of meat for doneness.

**Rope Work** – Knots and Lashings are not much harder to teach to a blind Scout than to any other Scout. You do need tactile rather than visual aids as examples. This means you have

<sup>&</sup>lt;sup>7</sup> This is not true for all knives, and double-edge knives are not recommended for novice users.

<sup>&</sup>lt;sup>8</sup> The "quick touch" is a good skill to teach any Scout working around a cooking area. Hot objects may get set down and it isn't obvious whether they are still hot.

models of the properly tied knots or lashings for a reference that he or she can feel. You don't have to use smooth rope for practice. Three-strand traditional rope is fine as long as the rope is not too thin. ¼ to ½ inch thick rope is fine. Aside from that, the learning process is one step at a time, with lots of practice, like for any other Scout.

**Climbing/Rappelling/Challenge Courses** – If there is ever a situation where not seeing is an advantage, it is not being able to see how far down the ground is. Rock climbing by feel is not much harder than climbing by sight. The same holds true for rappelling and high-element challenge course activities. In each of these activities, BSA safety rules and facilitator training are sufficient to assure that the Scout is tied into anchors and tethered by belay systems to protect from a fall. Scouts are secured before approaching the edge of any drop off. Like with any other Scout, it is important to have only one person giving voice commands and directions to the Scout. Too many voices become confusing.

The only situation that deserves special attention is rappelling down a natural rock face that has an overhang, because if you step off the overhang unexpectedly your upper body, hands, or head can hit the rock face. The climbing towers in use at many BSA facilities do not have these features.

A paradox is that **low-element challenge course activities may require more attention than high elements**. For instance, a balance beam style element may be low enough that other Scouts are not secured to belay systems, but present a hazard to a Scout who cannot aim his or her direction of fall. Work with the course facilitator to find ways to allow the Scout to participate. It may require rigging a temporary belay system or using other Scouts to act as "spotters" like we do for bouldering. Then the Scout will be able to do the same task as everyone else.

**Cycling** – The process of pedaling and balancing on a bicycle is not beyond the capability of a blind Scout. However, riding a single bicycle in a limited space is difficult. Tandem bicycles can be used to give a Scout the experience of cycling and to allow the Scout to participate in bike hikes. A sighted rider would do the steering in most cases, but that does not preclude a pair of riders developing enough teamwork to allow the Scout who does not see to steer. There are tandem bikes that are built for off-road mountain biking.

Authors: William D. Nutt and Dave Nutt Editor: Roger B. Tate Reviewers: National Federation of the Blind, Douglas Martin O.D., Midge Savage, and Britt Flather

# **MODULE N**

# UNDERSTANDING DEAF AND HARD OF HEARING<sup>1,2</sup>

IN THIS MODULE:

INTRODUCTION HOW DO I KNOW WHEN SOMEONE NEEDS ASSISTANCE? SOCIAL EFFECTS OF HEARING REDUCTION **BUILDING EMPATHY BY SIMULATION AND GAMES** HOW DEAF PEOPLE<sup>3</sup> COMMUNICATE **HEARING AIDS** COCHLEAR IMPLANTS SMARTPHONES AND OTHER HEARING TECH **CAUTIONS ABOUT TECHNOLOGY** SAFETY MATTERS TIPS FOR BETTER COMMUNICATION Individual and Small Group Gatherings Large Audience Events and Campfire Ceremonies SPECIAL SCOUTING SITUATIONS Swimming and Boating **Climbing and Rappelling Music and Dance Races and Derbies** SPECIALTY UNITS FOR DEAF SCOUTS TRAINING FOR DEAF SCOUT VOLUNTEERS

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank the American Society for Deaf Children (deafchildren.org) for reviewing the contents of this module for accuracy and usefulness.

<sup>&</sup>lt;sup>2</sup> The editors are aware that in professional circles, speech, hearing, and language disorders are usually grouped together. In the Inclusion Toolbox, we created a separate module for hearing because the adaptive approaches are meaningfully different than with the other two categories.

<sup>&</sup>lt;sup>3</sup> In the vast majority of the Inclusion Toolbox, we used conventional person-first language to avoid identifying someone by their disability. Deaf culture is different. Many who are deaf think of deafness as a difference and not a disability. In this module, the editors made exceptions to conventional person-first language in order to honor this difference. By no means do the editors wish harm or disrespect to any of these persons or groups.

#### INTRODUCTION

You likely know or live with someone who is deaf or hard of hearing. About 20% of the US population deals with this issue <sup>4</sup>. While many are older, there are a number of youth who are deaf or hard of hearing. This module will help you understand how hearing reductions can affect Scouts and give you tips and ideas on how to help them be successful and engaged in the Scouting program.

A hearing reduction can come from any of the three parts of the hearing system. The first part is mechanical transformation of sound into a nerve signal as it is funneled in from the outer ear, across the eardrum, through the internal bones, and in the cochlea. Differences in these parts can result in not hearing sounds loudly or reduced hearing at some pitches (frequencies).

The second part is getting the nerve signal from the mechanical part of the ear to the brain. Even if the mechanics are OK, problems with the auditory nerve can keep the signal from reaching its destination.

The third part of the hearing system is the brain itself, which decodes what is heard into words and language. An example of this type of hearing problem is called auditory processing disorder or central auditory processing disorder. This disorder is the auditory counterpart to dyslexia. The person hears all the sounds at normal volume but struggles to make sense of the sounds and words and interpret the spoken language. Central auditory processing disorder is discussed at length in Module Q with other learning disorders. A different struggle for the "brain" part of hearing is being able to filter out or ignore some sounds while listening to others. One example is the "party" effect where you can shift your attention and listen to a conversation across the room while tuning out the one right beside you. Another version is when you ignore background noise to focus on someone speaking to you.

The extent of a hearing reduction can vary all along the scale. It can range from difficulty hearing whispers, to having sound muted or garbled, to no understanding of speech at all, to total deafness. Hearing tests measure both the ability to hear a tone at varying levels of loudness and the ability to discriminate speech. In professional circles, there are many different classifications of hearing reductions, but in this discussion, we will simplify this to just a few to help you understand the differences.

Those with **mild hearing loss** struggle to hear soft sounds or high pitch sounds, like birds chirping or the melody of a song. Other sounds that may be missed are the sound of wind blowing through the leaves of trees or water running in a stream or faucet. People in this group may not even know that they are missing anything.

As hearing reduction moves into the **moderate hearing loss** range, the person hears sounds, but has trouble distinguishing between words. Human speech has very subtle differences

<sup>&</sup>lt;sup>4</sup> National Institute on Deafness and other Communication Disorders, 2018

between sounds. For example, think about how little difference there is between the words "great" and "crate", or between "gate" and cake". These kinds of subtleties represent sounds made in the back of one's mouth and are almost impossible to distinguish by speechreading (lip reading). In order to follow a conversation, you have to already know what the subject is. While your brain might be able to distinguish between "great" and "crate" in context, if you miss too many words, the whole message becomes gibberish.

In the **profound hearing loss** range, the person understands very little of what is said, or has very poor sound discrimination. Speech sounds are garbled, as if someone is talking with marbles in their mouth or are talking through a bad public address (PA) system. With profound hearing loss, one may be able to hear a very loud clap of thunder, a truck rumbling by, or an airplane overhead, but not be able to identify what the sound is. If people are having much trouble following a conversation in a noisy environment, they may shut down, not participate, or remain quiet and inattentive throughout. If you ask them if they hear you, they might say "yes" because they heard sounds, even though they did not understand what you said.

Medically speaking, **deaf** means hearing no sound at all.

## HOW DO I KNOW WHEN SOMEONE NEEDS ASSISTANCE?

The ideal answer is to have a **joining conference**, which is explained in detail in Module F. A joining conference is a private conversation with the guardians or parents of a Scout to find out the needs and strengths of the Scout. **Joining conferences should be part of welcoming every new Scout to a unit.** With a joining conference, you should not have to guess if a Scout has issues that may need to be supported. At the joining conference, you may notice the Scout uses hearing aids or wears a cochlear implant processor. Hopefully additional information will be disclosed. Keep in mind, some Scouts may choose to not share the fact they do not hear well.

"What if no one tells me about a hearing loss at the joining conference?" This does happen. At home, families may not have recognized a hearing reduction. When public schools conduct hearing and vision screenings, the parents may be told about a hearing loss and then choose to keep the information to themselves. Some youth don't want anyone to know that they struggle with hearing because they don't want their peers to see them as "different". (We will discuss other social effects a little later.)

In the end, you may not know for certain who needs assistance, but remember a hearing issue doesn't necessarily mean a cognitive issue. Here are a few tips to get you started, which benefit all Scouts. We will list more later on in this module.

- Speak clearly and directly to all Scouts. This minimizes misunderstanding for everyone.
- In addition to audible starting signals, use visual starters such as lights, flags, or hand signals simultaneously.

• Maximize what the Scout can learn from the visual environment. Utilize signage, scripts, manual hand signals, good lighting, expressive speaking, video captioning, sticky notes, or cue cards.

#### SOCIAL EFFECTS OF HEARING REDUCTION

Some youth will be open about having a hearing reduction while others will not. For that matter, some adults conceal their hearing struggles too. This is a common theme for "invisible" special needs where youth know they have a difficulty, but it isn't obvious to others. Youth have a profound need to belong and be accepted as they are, but at the same time they tend to downplay or hide the ways that they are different. We see this not only with hearing reduction but also with learning differences and other speech and language disabilities.

Even with the best efforts to hide a hearing reduction, when you don't understand everything that is expected from you, you are going to make mistakes. When peers don't understand, mistakes can make you look less capable and reliable than you really are. Such Scouts may avoid becoming leaders, be left at the edges of social circles, or lose motivation to advance in rank. Others may see them as close-minded, stubborn, or forgetful when that isn't true. The false impressions can have a deep impact on self-esteem. Isolation and lack of assertiveness are risks for many with hearing reduction. They also may be afraid to trust their own judgment.

On the other hand, some Scouts may try to compensate for the hearing reduction by taking the lead, feeling that if they are in the lead, they will know what is happening around them and what everyone should be doing. While this is an interesting approach, there is a social hazard of alienating the other Scouts. Scouts that are compensating this way may be seen as stubborn, bossy, and unwilling to listen, when in fact they are trying to save face and be more like everyone else. Social skills may suffer.

Bluffing is another way of trying to save face. Everyone wants to fit in, so those with hearing reduction may go along with the crowd, laughing and pretending they get all of the jokes. This only works until they caught in a bind when they do not really know what the joke is about, or can't discuss things that were just mentioned. It is common to have someone say "yes" to something they don't actually want to do. They may imitate the behavior of others because they think they are imitating someone who is following directions.

This is an area where a Scout leader can make a positive impact. The single best thing to do is pay attention to the values of the Scout Law and focus on creating a healthy unit culture. Every person has both strengths and weaknesses, and if you focus on encouraging all of your Scouts to be helpful, kind, courteous, friendly, and loyal to one another, everyone benefits. There is much more on this topic in Module C. In addition to creating a good unit culture, you can engage Scouts with a hearing reduction more directly, demonstrating that you care and making sure that their needs are accommodated, without making too much fuss. You can seek opportunities for these Scouts to play to their strengths and have successful outcomes to balance out the struggles. Like with any other Scout, if you see signs that a Scout is avoiding experiences that he or she used to like, it's time to plan a follow-up conference with the Scout and/or the family to compare notes and seek out ideas about how to achieve rather than stagnate.

You want to pay attention to the larger context of what is going on at a Scout event. A Scout who only "hears" the bare essentials is missing out on the community life of your unit. How would your life be if no one told you jokes, no one shared stories with you, or no one took time to tell you how and why they care about you? Everyone in your unit needs to be sensitized to share the mundane with the Scout and not just the important things.

## **BUILDING EMPATHY BY SIMULATION AND GAMES**

There is general information about building empathy in Modules C and F. A good way to replicate a hearing reduction experience for Scouters and Scouts is to have them put cotton or ear plugs in their ears, and for a more "profound" experience, add ear protectors on top. To do justice to the experience, try doing this for several hours at one time to capture the emotions, frustrations, and isolation you may feel.

Any number of Scout games and activities can be turned into "no talking allowed" versions. The challenge of playing touch football or pitching camp with only signs and gestures can be a fun challenge for everyone and help everyone understand what it is like to have your ability to communicate slowed down. Team building challenges can take on a whole new meaning. These activities work best when they become a routine part of the unit activities.

# HOW DEAF PEOPLE COMMUNICATE

There is more variety in how people who are deaf and have profound hearing reduction communicate than most people would imagine. The most significant difference is whether the person was always deaf or became deaf after learning to talk. People who are deaf before they learn to talk have to learn to express themselves in some form of manual sign language or with fingerspelling, which becomes their first language. You are probably aware of **American Sign Language (ASL)**<sup>5</sup>. ASL is composed of positions and gestures made with the hands, body and facial expressions, to convey abstract concepts as with any spoken language. Being its own language, ASL has a distinct grammatical structure that is not like English.

Being limited to manual sign language limits the pool of people that deaf people can talk to directly, and forces them to use interpreters or technology to interact outside their close

<sup>&</sup>lt;sup>5</sup> While American Sign Language (ASL) is the dominant sign language in the United States, there are many different sign languages used around the world. Furthermore, sign languages have local slang and dialects just like oral languages have.

community of friends and family. They have a harder time integrating themselves into peer groups when others do not know how to sign. Most deaf people have to interact with the wider community using written language. But understand that a person who reads, writes, and also signs is actually bilingual.

Things are different when a person learns to talk before losing hearing. The road to adequate communication is not as complex. The **Oral Method** of communication focuses on speechreading (lip reading) and making the most of a person's remaining hearing to understand speech. The idea behind this method is that this allows a person who is deaf or hard of hearing to communicate more effectively with hearing individuals.

These people typically use spoken language from muscle memory as the primary way of expressing themselves. It may be hard to build new vocabulary in spoken language because so many English words are pronounced in ways that violate phonetic rules (like using "ph" for the /f/ sound). Another thing that can happen over the years is that the person's speech can become less precise, contain less inflection, or become monotone. Without the constant feedback of hearing what you sound like, you may not enunciate all the sounds you don't hear anymore.

Over 90% of deaf and hard of hearing children have hearing parents. Some families who use spoken language may want to teach their children how to speak even though the children cannot hear. Children with profound hearing loss can be enrolled in programs that teach them to speak rather than rely on sign language. Since they cannot hear their own voices, they may practice by feeling the vibrations and watching the mouth formations of their teachers and others. This is a slow and steady process and it takes time to develop the skill well enough that others can understand the child.

Some families prefer **Total Communication** (TC) methods. The idea behind TC is for a person who is deaf or hard of hearing to use any and all communication methods that facilitate language acquisition. This system can include any combination of speech, fingerspelling, manual signs, gestures, speechreading, and amplifying sounds to use residual hearing. One distinction of this approach is that hand signs typically use English word order rather than ASL grammar.

There are different approaches to living and learning when you have no or nearly no hearing. Just like in bilingual families, some families may converse in one language (for example, sign language) at home and use the other (spoken language) elsewhere. Others will use the adopted language (spoken language) at home, and some will use a combination where some members express themselves in one language while receiving in the other. Imagine a conversation where the hard of hearing person speaks out loud and a family member responds in sign language.

Don't assume that people who cannot hear are able to lip read (speechread) or sign. Many individuals never learn to speechread. It is not easy, takes time to develop, and not everyone who tries can master it. Even so, it is not an accurate way to hear. Speechreading can be

compared to water skiing. Some people have a knack for it and get up on the water and go, while others just never get the hang of it. The same can be said of signing. Fortunately, many high schools now offer ASL as a foreign language course. Encourage your older Scouts to pursue this if it is available to them.

#### **HEARING AIDS**

Hearing aids are a tool for those with hearing reduction but who are not deaf. The basic idea of a hearing aid is to detect sound with a microphone, amplify the sound, and then send sound through a speaker into the ear canal. While this seems simple enough, hearing aid users are often frustrated with them. If you are hard of hearing at certain frequencies, amplifying all the sound doesn't help much because the sounds you need are still soft compared to the sounds that get in the way of understanding. Audiologists can Bluetooth newer hearing aids to personal smartphones to help the user adjust the sound and volume to their needs in any given situation. Hearing aids may not be practical, considering the wear and tear a child can create, and the replacement cost if they are lost. Many younger children do not have smartphones and in this case, the audiologist will need to adjust the hearing aids from time to time.

This matters in the Scouting program because a Scout that has hearing aids may not want to wear them all the time because they become uncomfortable. The Scout may also need to take the hearing aids out to protect them from water during swimming, showering, or extra sweaty activities. The Scout may also take them out to sleep.

#### COCHLEAR IMPLANTS

A cochlear implant is a small, complex electronic device that can help to provide a sense of sound to a person who is deaf or severely hard of hearing. Cochlear implants bypass damaged portions of the ear and directly stimulate the auditory nerve. An implant does not restore normal hearing. Instead, it gives a deaf person a useful representation of sounds in the environment and helps with understanding speech. A cochlear implant is very different from a hearing aid.

Current devices have two parts. One part is implanted under the skin and sends electrical signals to the cochlea to replace the signals that the small internal hairs normally create. The other part is the processor that sits outside the body. It may look like a hearing aid, with a short wire leading to a flat circular transmitter, or it may look like a small square box. Regardless of type, the outside transmitter is held in contact with magnets on top of the skin over the receiver of the implant. The signals from the outside processor to the implant are passed across the skin magnetically.

Like with hearing aids, the outside processor is not waterproof and needs to come off for aquatic activities and showering. It may also be uncomfortable to sleep on the side where the

implant is positioned. There will be times when a Scout needs to take off the outside processor of the cochlear implant. Be aware that when the outside processor is disconnected, the person with an implant is functionally deaf.

#### SMARTPHONES AND OTHER HEARING TECH

Smartphone technology is dramatically changing life for deaf and hard of hearing people and is allowing more open communication between non-hearing and hearing people than ever before. As a Scout leader, you may have to reconsider what restrictions you place on "tech" at Scout events when you serve Scouts with a hearing reduction. Everyone may need to be able to send and receive texts on an outing in order to include such a Scout.

The **simple texting function** has reduced the dependence on sign language as a means of communication. A Scout with a hearing reduction can communicate with both hearing and non-hearing friends by text. This is helpful because a Scout can have a bigger circle of friends, not just those that know how to sign.

**Voice-to-text** features on smartphones are rapidly displacing the need for telecommunications relay services. A person can speak into the phone, and the phone can translate the speech into readable text in real time. **Text-to-voice** capability allows non-verbal deaf people to express themselves in a hearing world. Older, less portable, special purpose voice synthesizers and voice recognition devices are falling out of use.

A smartphone with a set of earbuds has all the parts of a basic hearing aid. There are apps available to take advantage of this capability. While the apps lack the frequency sophistication of good quality hearing aids, they can be a practical substitute for milder hearing loss or as a backup if someone loses or forgets their hearing aids.

Many hearing aids and cochlear implants have Bluetooth technology, which allows them to connect directly and wirelessly as headsets to smartphones, televisions, music players and other devices. By eliminating the need to acoustically couple the sound, the user can get a clearer sound to the brain.

An **FM system** is a wireless hearing assistance device that can be used with or without hearing aids or cochlear implants. This system consists of a transmitter and a receiver, similar to microphone headsets you have seen used by performers or religious worship leaders. There can be several receivers at one time. This system works well in large group settings, meetings, or in noisy environments. The microphone transmitter is placed on the speaker and the user wears a receiver. The system can be equated to a personal "PA" system, where sound is heard directly by the user. During large group events in an auditorium, for example, the transmitter can be hooked up directly to a sound system and transmitted to the individual providing greater clarity of speech/sound and a reduction in background noise. During hikes, tours, and outdoor events, the leader wears the transmitter and the users wear receivers. Even if the leader is at a distance

(up to 200 feet) the users will be able to hear directions, explanations, and warnings. The leader does not have to shout to be heard. The downside of an FM system is that it is one-way communication, so it doesn't allow a user to get the leader's attention or ask questions over the system.

#### **CAUTIONS ABOUT TECHNOLOGY**

Any device a Scout uses to hear or communicate will also need to be recharged. This is not a huge problem, but it needs to be accounted for on every outing. Many people carry smartphones into the backcountry to use as cameras and GPS receivers, so they are used to thinking about extra batteries, power banks, or solar chargers. However, voice-to-text and text-to-voice applications can be dependent on a cell phone signal and therefore may demand more power than expected.

You do need to consider what would happen if all the devices became unusable on a backcountry outing. If your Scout depends on sign language to communicate you will want to make sure you have a hearing person in the group that can translate for her. At a minimum, a pad of waterproof paper and a pencil need to be in your gear.

## SAFETY MATTERS

We want Scouts with hearing reductions to be able to be part of every experience that their units can offer. At the same time, we need to manage risk to allow Scouts to do things that seem scary to them, without it actually being dangerous. For example, we want to give them a chance to rock climb, but we make sure that they have all the right rigging and harnesses to do that safely. We also rely on appropriate training of youth and adults in order to manage risk.

We need to make sure that each Scout is properly trained for the adventure activity that is being planned. For a Scout that does not hear well, this can mean some extra effort to make sure everything important is clearly understood. Plan to have visual aids for the safety information. It is a good idea to physically act out emergency procedures at the same time you are explaining them. Also, take time for the Scouts to practice the actions they may need to take to recover from a problem. For example, practice getting back into a whitewater raft, but in calm water. Another example would be simulating rappelling by walking backward across the ground. It may take someone with hearing difficulties longer to learn what they need to, so be sure to allocate enough time for training and practice before starting a high-adventure activity.

Even with good training, the outdoor adventure environment is not tame or controlled. This is especially true with boating activities. Even when sleeping, weather can change and create a situation where action must be taken. Aquatics and sleeping are also times when hearing aids, cochlear implants, and other electronic devices are not usable. Plan ahead to find a reliable way to give warnings or alert people to danger, that doesn't rely on speech or technology.

#### TIPS FOR BETTER COMMUNICATION

**Individual and Small Group Activities** - There are several basic things you can do to make communication easier for a Scout with hearing loss. These tips are for smaller gatherings where you are not using microphones and the room is lit.

- When you speak to the Scout, face the Scout directly to reduce sound distortion and let him or her watch your lips while you are speaking. Keep your chin up rather than looking down at the page when you talk.
- Be sure you have the Scout's attention before speaking. First, call out the Scout's name. If the Scout does not respond to the spoken name, use a visual signal next. It helps to have visual signals understood in advance. Next, use a gentle touch on the shoulder. Remember any signal will become annoying if it is overused.
- If the Scout Sign isn't working, try getting everyone's attention by flashing the lights on and off.
- Reduce background noise by moving learning activities outdoors, or away from other activities.
- When possible, get people to take turns when speaking and not talk over each other. Ask participants raise their hand before speaking and wait until they are called upon. A "talking feather" or "talking stick" can be a good strategy because it visually alerts everyone to who they should be watching and listening to.
- Make sure the room is well lit for Scouts that use speechreading or signing.
- Find a non-verbal way to tell the Scout the topic of discussion and to signal changes in topic. This is especially helpful for someone who relies on speechreading.
- Use visual aids and written instructions when you can. Don't forget you can draw in the dirt.
- Encourage the Scout to sit where he or she needs to be to best understand the speaker. This location will be different for every Scout and may not be where you think it is. If the Scout doesn't seem to be understanding the speaker, you can make suggestions about repositioning. Remember, many young people want to sit where their friends are, so get all of them to move as a group to where they need to.
- Repeat any questions or comments that are made by someone that the Scout doesn't see. This is a good habit to get into and it benefits everyone.

- If you are using videos, be sure they are captioned. If the videos or clips are not captioned provide a script for the Scout or find another way to teach. Consider using videos or clips from the Described and Captioned Media Program, (www.dcmp.org).
- Ask the Scout to repeat back information so that you can make sure he or she understood. This is better than being asked "Can you hear me?" or "Do you understand?" over and over.
- Teach in a smaller group.
- Try changing how you speak consider speaking at a slower pace, pausing a bit between phrases and sentences, using a higher or lower pitch, emphasizing key words, or using visual cues.
- Clear crisp speech works better than exaggerating your speech by talking loudly, spacing out words, or exaggerating the pronunciation of words.
- Try rephrasing when a Scout does not seem to understand you. Some words are easier to recognize when speechreading than others. For example, you could use "correct" instead of "right" or "yes". Use visuals, point, demonstrate.
- Trim facial hair around your mouth so your lips can be more easily seen.
- Use hand signals during games and sporting events.
- Encourage the Scout to speak (present) in front of others. Ask for his or her ideas.
- Use handouts for important information/instruction.
- Make an extra paper copy of your lesson plan or program and give it to the Scout so he can follow along.
- Have the Scouts sit in a "U" or circle formation, so no one's back is to the Scout who has hearing issues

**Large Audience Events and Campfire Ceremonies** – For campfires and large events, where sound systems are being used, or the lighting may be lowered, some more tips are in order:

• The Scout with a hearing reduction needs to sit near the "stage", so he or she can see the performers' faces and catch all of the body language, especially at nighttime or in low light.

- Ask performers to avoid using sunglasses, fuzzy beards, masks, or hats that hide the face or lips.
- Give the Scout a written copy of the program, or even better the whole script. At night or with low lighting, allow him or her to use a small red-light flashlight to look at the program/script during the performance.
- Make sure the performers are lit from the front and not back-lit. You can't watch a face when the face is in shadow.
- For campfires where there are no stage lights, keep the performers on the far side of the fire from the audience. Assign responsible people to shine flashlights on the performers to light up the action.
- Limit background music and noise as much as possible.
- Lanterns with aluminum foil reflectors can be used as stage lights for campfires. They are particularly helpful when a real fire cannot be used due to burn bans.
- When the Scout participates in skits and plays, make sure he can see visual cues and has a buddy who will help him keep his place with script lines and stage action.
- If you are using microphones, pay special attention to how you hold hand microphones. If you hold it directly in front of your face, the Scout cannot watch your mouth movements. While many hand microphones are built to brush against the lips, this is a problem for Scouts with hearing difficulties. Clip-on and over-the-ear hands free microphones are a better solution and not especially expensive.
- See if the facility has FM-broadcast listening devices for the hard of hearing. These allow a Scout to hear the sound from the microphones without it passing through the auditorium speakers and acoustics (refer to "Smartphones and Other Hearing Tech" section).

#### SPECIAL SCOUTING SITUATIONS

**Swimming and Boating** – The phones, hearing aids, or cochlear implants that the Scout uses most of the time are not practical when swimming, or when in a small boat that can easily overturn. The Scouts need to have some nonverbal signals worked out between them in advance of the activity. There are several ways to get one's attention by touching or splashing. In small boats it may be practical to communicate by tapping on the hull and feeling the tap through the seat. Tap codes could be used for "go right", "go left", "faster", "slower", and "stop". The hand signals used for cycling could be adapted to boating as well. **Climbing and Rappelling** – With these activities, the challenge is that the activity requires both hands most of the time. Each has a set of verbal commands that are part of the ordinary process. While a Scout with a hearing reduction can participate as a climber, rappeller, or belayer, an alternative way of signaling will have to be worked out. It may be possible to create alternative signals using rope tugs or head motions. A Scout that does not speak may still be able to make a noise to get the attention of another person.

**Music and Dance** – Even those who do not hear or hear well may enjoy music and dance in their own way, by feeling vibrations through the floor or low frequency sound in their chest on with their hands touching a surface. If dancing, drumming, or singing is something the Scout is interested in, try to provide those opportunities. Encourage the Scout to sit on the floor or stand near a speaker if that works. A particular arena where Scouts like this can shine is Order of the Arrow dance and ceremony teams where drums are used.

**Races and Derbies** - There are a wide variety of track options for Pinewood Derby, Rain Gutter Regatta, Space Derby, and other Scout events. Some have built-in timers and others do not. Furthermore, there are many camporee events where time is used as part of the contest. We just need to make sure when we plan these events that everyone can get a fair start, whether they can hear (or see) or not. The simplest substitutes are a starting flag to wave or using a light as a starting signal.

# SPECIALTY UNITS FOR DEAF SCOUTS

Before closing this module, we need to say a few words about units who serve Scouts who are all deaf. There are some Scouts who prefer to be with other Scouts who are deaf and use sign language. Hanging around with true peers provides the encouragement for them to thrive and grow. The leadership of a unit of Scouts who are deaf must consider the needs of the group in order to guide them to success. Ideally, the adult leaders and the Scouts themselves will utilize the same forms of communication. For these Scouts, certain ways of learning and participating lead to achievement just as Scouts who have hearing. One just needs to be aware of those needs and work within the Scouting structure. Scouts in these units can achieve the same level of accomplishments as their hearing Scouting peers.

#### TRAINING FOR DEAF SCOUT VOLUNTEERS

We do not want to leave adults who have hearing limitations out of Scouting leadership. A significant challenge is providing appropriate training opportunities. The Great Salt Lake Area Council (now part of the Crossroads of the West Council) has been a leader in running Wood Badge courses with hearing adaptations.

For more routine training, please be aware that PowerPoint and Google Slides have features that allow real-time captioning of live presentations. This is something that can be easily added to leader training events with a little advance planning. Be aware that sometimes it does take a little practice to operate these features, including having a headset microphone, which is recommended.

Author: Janet Kelly Editor: Roger B. Tate Reviewers: American Society for Deaf Children, Britt Flather, and Midge Savage

# **MODULE P**

# UNDERSTANDING INTELLECTUAL DISABILITY<sup>1</sup>

IN THIS MODULE:

OVERVIEW CHARACTERISTICS SAFETY CONCERNS CAREGIVER FATIGUE GENERAL SUPPORTS TYPES OF ADAPTATIONS Accommodations Modifications APPROACHES TO ADAPTATION INSTRUCTIONAL STRATEGIES ADVANCEMENT INCLUDING ADULT SCOUTS

#### **OVERVIEW**

Intellectual disability (ID)<sup>2</sup> can affect the ability to process information quickly, learn new material, remember what was learned before, interact socially, and make decisions for everyday life. A Scout leader does not need to know the cause to support a Scout with an intellectual disability. Scouts and leaders with intellectual disability sometimes have other disabilities as well. For multiple disabilities, you should look at other *Inclusion Toolbox* modules to find what you need to address the other needs of an individual Scout.

For many Scouts with intellectual disability, Scouting can be a profoundly effective program environment that supports their social and emotional growth, self-confidence, life skills, physical health, school-based individualized education plan (IEP), and medical or therapeutic treatment goals. In addition to youth, Scouting programs serve people with ID that are well beyond the age we usually think of as a youth. When you see the term youth or Scout in this module, remember that this can also mean an adult participant with ID. Some adult Scouts may be better served in a special-purpose unit with others with similar disabilities. They can

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank Special Olympics North America and The Arc for reviewing the contents of this module for accuracy and usefulness.

<sup>&</sup>lt;sup>2</sup> Historically ID was also called cognitive disability. Though there are a variety of underlying causes for intellectual disability, the preferred language is to use "intellectual disability" as an inclusive singular term.

continue to earn ranks and awards at their own pace and ultimately earn the Eagle Scout rank, regardless of age.

In the spirit of meaningful inclusion, equity, and diversity, every Scout should have the opportunity to be part of a traditional Scout unit, while honoring the choice of any Scout to participate in a special-purpose unit if that works better for the Scout. There are many reasons why a person with ID might want to participate in a traditional, i.e. mainstream, Scout unit rather than a special purpose unit. For example, a person may be more comfortable being a Scout alongside siblings or cousins, familiar people from school, or friends from their faith group. Another reason for choosing a traditional Scout unit is because the person is already familiar with the meeting location from other activities, or it is just a convenient or accessible place to go for regular meetings.

# CHARACTERISTICS

Like all Scouts, Scouts with intellectual disability have a wide range of strengths, challenges, interests, behaviors, and communication skills. They can have gaps in basic life skills<sup>3</sup> relative to their age. They can be literal learners and frequently struggle with making inferences, and picking up on the social context. They may or may not behave impulsively. Many Scouts with ID will meet the BSA criteria for Registration Beyond the Age of Eligibility (RBAE), which is participating in Scouting at an older age than is allowed for other youth. RBAE is explained in more detail in Module E.

The individual abilities and challenges of a Scout need to be considered when developing a plan for success. **It is important to remember that Scouts with ID can and do learn** even if their learning takes place at a slower rate and complexity throughout their lifetime. They experience the same hopes and emotions as people without intellectual limitations. They often express the same age-related interests as age peers. They want to be respected, included, and experience activities. They need to do all that they can, in order to be all they can be.

While this module discusses intellectual disability in general terms, please understand that there is a wide range of ability within this class and each individual's needs need to be addressed in an individual way. For example, individuals with milder intellectual disability can live independently as adults and master basic academic and social skills. With appropriate training they can hold competitive jobs, own businesses, begin and maintain adult relationships/marriages, be parents, and actively participate in community life. Those with moderate disability can learn to take care of their personal needs, perform simple tasks, and engage in supportive living and employment arrangements. Individuals with more substantial delays can require the on-going support of caregivers. Educational efforts are often directed at

<sup>&</sup>lt;sup>3</sup> These are more formally called adaptive behaviors. They are part of every facet of daily living. Examples include picking out appropriate clothes to wear, making a purchase, working a vending machine, following school rules, taking turns, waiting in a line, etc.

providing communication opportunities and experiential activities that develop functional life skills; for example, washing hands, dressing, brushing teeth, and toileting.

# SAFETY CONCERNS

Some Scouts with intellectual disability may need close supervision if they are at increased risk for accidents and injuries. This may include getting lost, wandering off, or not recognizing dangerous situations for what they are. Some examples include oncoming traffic, agitated or defensive wildlife, hazardous weather, fire, and thin ice. Delayed reactions can turn something seemingly safe, like having a ball thrown to the Scout in a game, into a hazard. This is a topic to discuss with a Scout's family or caregiver when the unit leaders are getting to know the Scout.

In addition, some Scouts may struggle to communicate when they are injured or in pain, even with a broken bone, deep cut, or burn; so pay close attention and be sure to further inspect and ask clarifying questions if there may have been an injury.

## CAREGIVER FATIGUE

Some Scouts with intellectual disability have needs that require extra support, sometimes significantly extra support, in their everyday lives and at Scouting activities. Scout leaders need to recognize that families of these Scouts are under unusually heavy demands to care for their children while earning a living and meeting the other obligations of regular life.

Another difficulty for these families is the constant struggle with schools, agencies, and insurers to get the resources their child and family need to get by, much less flourish. These families may also struggle economically to pay for therapies, care, and resources needed to properly support their family member with ID.

This reality is hard to accommodate with a volunteer-driven organization like BSA. To the extent we can, we want to support these families by allowing them to be in Scouting without obligating them to serve as Scout leaders or requiring them to provide the adapted program for their own children. As discussed in Building a Unit Leadership Team in Module C, the unit leadership may need to recruit some additional non-parent adults to support Scouts with ID.

#### **GENERAL SUPPORTS**

As explained in Module F, it is important to involve the Scout, family, and Scout leaders in developing the best path to meaningful Scouting engagement. For Scouts with intellectual disability, the perspectives of health and education professionals that are familiar with the individual are helpful as well. The first step is for leadership to get to know the Scout and become familiar with the general nature of the disability with a Joining Conference. The best

path for the Scout might not include traditional Scout advancement like you are used to. If you have not already done so, you will also want to look at the sections on Individual Scout Advancement Plans, and Registration Beyond the age of Eligibility in Module E.

Your attitude is important to success. Be patient, caring, empathetic, supportive, and understanding. Scouts with ID are often aware of their limitations, but they have the same desires and fears related to success and achievement as other people their age. They also may have a harder time understanding how well they must do to meet the performance expectations for a certain goal.

Scouts with intellectual disability are at greater risk of bullying, harassment, manipulation, practical jokes, and being made fun of. More subtle, but equally harmful, is to treat Scouts with ID as servants or "mascots" because they are compliant. Do not ask a Scout with a disability to do something for you when you would not ask that of anyone else. Pay attention to how your Scouts interact with each other and don't let anyone take advantage of anyone else.

The best practices when dealing with Scouts with intellectual disability can be summarized as follows:

- Be clear and concise.
- Use simple language and short sentences.
- Demonstrate tasks whenever possible.
- Break down directions into small steps and repeat as necessary.
- Use flip cards, posted signs, checklists, and other visual cues for safety items (like in axe yards), schedules, and routine processes (like dishwashing)
- Make things easy to read with pictograms and simpler text for signage and written instructions
- Provide multiple opportunities for practice.
- Don't talk down to the Scout or use a louder voice. They are not hard of hearing and baby talk is not clearer.
- Respect their chronological age and interact like you would with anyone else their age.
- Celebrate small gains and progress towards intermediate goals.

# TYPES OF ADAPTATIONS

The term **adaptation**<sup>4</sup> is used here to include anything that is done to allow a Scout to participate fully in the program. It applies to any intervention (change from the typical way of doing things) that levels the playing field. In reality, adaptation is an umbrella term for two different kinds of interventions: **accommodations** and **modifications**.

<sup>&</sup>lt;sup>4</sup> "Adaptation" is a different concept from "adaptive behavior" even though they sound similar. See footnote 3.

Adaptations are typically tailored to the individual. The factors include:

- Age
- Individual strengths and weaknesses
- Desired outcomes
- Reasons for participation
- Resources available<sup>5</sup>

There are many ways to ensure that an individual benefits from participating in Scouting. Working together; adult leaders, youth leaders, and families can provide consistent and sustainable ways to maximize the involvement of all Scouts.

**Accommodations** do not change what is learned. However, the way the learning takes place is changed. Accommodations usually change the learning environment in some way. For example:

- the task may be broken down into smaller parts
- the task may completed over an extended period of time
- methods of response may be changed
- the physical environment may be changed
- frequent repetition, prompting, or clarification may be needed
- individualized instruction
- extended practice
- special seating arrangements
- enhanced buddy system
- schedule cards and reviews
- establishing a process for asking questions
- extra time for practicing games or demonstrations

Begin by assuming the Scout *can* accomplish the task and give him or her a chance to do so, even if it takes multiple attempts. Once an inclusive attitude is adopted, it may be readily apparent what accommodations are or are not needed. You can and should talk to the family about strategies used at school and at home that you can adapt to Scouting activities. You may also find good ideas in some of the other modules of the *Inclusion Toolbox* that deal with related disabilities. If you need personal assistance in developing a success plan, contact your Unit Commissioner and/or Council or District Special Needs Committee. If you cannot find the answer or resources you need, you can contact the BSA National Special Needs and Disabilities Committee (SpecialNeedsChair@scouting.org).

<sup>&</sup>lt;sup>5</sup> Providing an individualized program will usually take more resources in terms of people and time than group programming. One of the advantages of a special-purpose Scout unit, where the members have similar functional abilities, is being able to leverage resources more efficiently by providing an adapted program to more than one Scout at a time.

**Modifications** on the other hand, change the task or activity to bring the opportunity within the reach of a Scout with significant limitations related to a disability. There is a place for program modifications in Scouting. Scouts with more significant disability can benefit from being encouraged to participate in some manner in as many activities as safely possible, even if it is unlikely that they will master a skill. For example, a Scout could have the opportunity to go along in a canoe on a float trip even if paddling or steering the canoe is too difficult. Another example would give the Scout the opportunity to create the wraps to form a lashing even if someone else has to tie the starting or ending knots.

Scouting can benefit those who do not place much emphasis on advancement, regardless of ability level. They will still grow socially, emotionally, and cognitively from the varied experiences and community and peer interactions that are inherent in a strong Scouting program. Unit leadership needs to be open to working with parents and youth to explore ways to be inclusive and provide benefit to the Scout.

# **APPROACHES TO ADAPTATION**

For discussion, we are breaking adaptations for intellectual disability into nine categories. An adaptation can be used by itself or in combinations, as best meets the needs of the Scout and the situation. They can be used for a specific task or as part of a regular ongoing program. These adaptations could be either accommodations or modifications depending upon the extent of the changes.

- **Quantity** Reduce the number of items or activities the Scout is working on at any given time. Allow for additional practice before moving on. *For example:* Work on only one phrase of the Scout Oath at a time.
- **Time** Increase time allotted for a task. *For example:* Break task down and allow additional time. Use time reminders to help the Scout stay on task or help prepare for change of activity.
- Level of Support Increase personal assistance to maintain focus and prompt use of a specific skill. For example: Assign "peer buddies"<sup>6</sup>. Help youth establish self-organizing skills by asking "what should you do next?" Develop a checklist for the Scout to mark off as tasks/steps are completed.
- Input Adapt the way instruction is delivered. *For example:* Use visual aids, hands-on activities, small group practice, or pre-teach key concepts or terms.

<sup>&</sup>lt;sup>6</sup> A peer buddy is different from the ordinary buddy system used throughout Scouting for safety purposes. A peer buddy is a fellow Scout that stays with the Scout with a need to help him or her manage. See Module E for a fuller explanation.

- **Output** Adapt how the Scout responds. For example: Allow scribes and verbal responses rather than writing out answers. Use multiple choice or yes/no questions. Have Scout demonstrate a skill or use a drawing to explain an activity.
- **Participation** Adapt the extent to which a Scout is actively involved in a task or activity. *For example:* Reduce the time a Scout is required to pay attention, letting him or her attend to another activity. Involve the Scout in setup, or distribution of materials, or another meaningful task.
- **Difficulty** Adapt the skill level, or type of task. *For example:* Allow use of cue cards and memory aids. Have a Scout work on simpler First Aid skills or knots. Break tasks down into extremely small steps.
- Alternate Goals (usually utilized for those with moderate to severe intellectual disability) Adapt the goals or outcomes while using the same materials. For example: While studying maps, the expectation is that most Scouts will be able to locate all the features listed in the legend. An alternate goal for a Scout with a disability could be able to identify one prominent feature, such as water or a road.
- Substitute Curriculum (usually utilized for those with moderate to severe intellectual disability and those who participate in Scouting primarily for social and communication interaction) Provide substantially different materials and instruction. For example: A Scout with very limited communication and adaptive skills enjoys the ceremonies involved in the unit's programs. This Scout then attends unit activities and meetings and participates in opening and closing ceremonies, but may spend much of the time at these events engaged in an individual activity, not impacting over-all programing.

# **INSTRUCTIONAL STRATEGIES**

Leaders should remember that Scouts with ID may have delayed functional life skills, such as time and money management, organizational skills, social skills, and self-care and hygiene. When these skills come into play in group settings and form the foundation blocks for many skills that will be taught, leaders may need to support the Scout with ID to work through these basic skills and the starting part of a task.

Strategies usually refer to methods or techniques used by instructors, while adaptations refer more to actions on the part of the learner. A list of instructional strategies is just that - a list. Think of it as a menu of options. Some options will work with one Scout, but not another. Even with the same Scout, a strategy may work at some times but not others. You want to use what you know about the Scout, what you learn from the family, and what works at school to guide your choices, but it is more important that you keep trying to find effective strategies than it is to succeed in your first efforts. Just as you strive to be patient with the Scout, be patient and forgiving with yourself also. All of these strategies flow from a foundation of trust between the teacher, the learner, the family, and the medical or educational professionals that support the Scout.

Strategies to consider when working with Scouts with intellectual disability include:

- Establish consistent routines and expectations for each meeting.
- Establish a clearly defined and posted system of behavior rules and consequences. These can be referenced as a cue to the Scout to redirect attention to on-task behavior. A card or picture can serve as a visual reminder to use appropriate behaviors, like raising a hand, or lowering a voice.
- Tell Scouts in advance what they will learn.
- Use a combination of oral, visual, and written instruction. Repeat often.
- Allow frequent breaks
- Break tasks down into component steps. Focus on one at a time.
- Encourage self-monitoring techniques such as checklists, timers, and visual calendars.
- Teach one concept at a time.
- Encourage the Scout to quietly talk to himself or herself while learning or practicing a skill, and to use other metacognitive<sup>7</sup> techniques.
- Allowing for extra practice time. Plan to reteach the skill component frequently in order to maintain and extend knowledge.
- Use interactive small group learning situations
- Involve peers, buddies, parents, leaders, and others to provide review and practice opportunities.
- Provide opportunities for problem solving, reasoning and real-life application of skills. This helps maintain and transfer information.

<sup>&</sup>lt;sup>7</sup> Metacognition is thinking about how you are thinking and learning. Practical examples are asking yourself questions as you are thinking, reciting back instructions while you are doing something, reciting back rhymes or memory aids for steps, writing down notes, or repeating back prior knowledge.

- Provide Scouts an opportunity to calm down when they become frustrated or overstimulated and regain control of their environment. See Self Removal in Module F for more on this topic.
- Offer praise for good effort. Do not make comparisons to others or to past efforts.

#### ADVANCEMENT

To reemphasize a point from the explanations in Module B and Module E, advancement is just one method of Scouting and not a mission of Scouting. It should serve the needs and healthy development of the Scout, not the other way around. Even without disabilities, there are some Scouts that are highly motivated by earning awards and recognitions and others that are not motivated by this at all. The others participate in Scouting for fun, adventures, friends, etc.

We shouldn't exclude Scouts with intellectual disability from pursuing ranks and awards if the traditional advancement system is attainable or can be made to work for them. At the same time, we have to recognize that for Scouts with more significant disability, many of the traditional advancement tasks may not be possible no matter how much adaptation is provided and how much time is allowed. For these Scouts, the Scouting program emphasis needs to shift to providing life experiences and developing functional living skills. We do not want to lose sight of the fact that **adaptations allow Scouts to be part of the entire life of the unit**. We also need to recognize that **a Scout may benefit from simply "being part"** of a Scout activity, even when he or she isn't able to do everything for the activity. In situations like this, a unit may want to emphasize the presentation of event patches at ceremonies alongside the usual ranks and badges

For Scouts with ID that want to pursue ranks and awards, but have unusual challenges achieving them, there are a variety of adaptations available within the BSA advancement system. While the rules are more relaxed at the Cub Scout level, the procedures for approving alternatives at the higher program levels are complicated<sup>8</sup>. Those procedures are covered in Module E and are not being repeated here.

Scout advancement is supposed to be both a means of "certifying" an accomplishment and a motivation to keep making progress. The challenge for a Scout with ID is that it takes more time to master skills than for others and the work needs to be done in smaller pieces. The usual recognitions may come so far apart that they lose their value as a motivator. A possible solution is **micro-recognition**. Unofficial recognition items and events are created to celebrate

<sup>&</sup>lt;sup>8</sup> In Cub Scouting advancement, Scouts do not have to do something correctly or completely in order to receive credit for doing their best. To receive advancement credit in the other programs, a Scout must complete a requirement as it is written, or complete an alternative requirement that has been approved in advance, usually by the council advancement committee.

steps along the way that would not ordinarily receive special attention. For example, a hanger can be made for the uniform that is used to attach beads or ribbons that signify completion of individual advancement requirements or portions of multi-part requirements. This strategy is the same as what we do with Cub Scout adventure belt loops and with Scouts BSA merit badge sashes, it is just more finely grained.

Before embarking on this path, the idea needs to be discussed with the Scout's family to make sure it is respectful and actually beneficial to the Scout's healthy development. The motivational benefit of more frequent recognition needs to be balanced against the preference of the Scout or family to be treated like everyone else.

#### INCLUDING ADULT SCOUTS

Scouting can and has been used effectively by supportive living-focused organizations as part of their programs to serve adults with intellectual disability. It is worth noting that these adults may behave in ways that seem immature or child-like, but they are not children and rarely see themselves as children. Since they have a blend of adult and youthful interests, in many cases these Scouts function best in a special-purpose Scout unit with others of comparable age and ability.

With appropriate support from the other Scout leaders, there are also situations where an adult with a disability can function as an adult volunteer with a Scout unit. The youth in the unit benefit from the experience of an adult who is different from most and they learn to appreciate people despite their differences. BSA youth protection policies provide appropriate training for adults with ID to be part of a Scout unit. This approach can be an effective way to allow an individual adult to share in the Scouting experience when there are not enough similar people to form a special-purpose unit.

Authors: Midge Savage, Nathan A. Schaumleffel, Ph.D., Anthony Mei Editor: Roger B. Tate Reviewers: Shawn Ullman of The Arc, Amie Dugan and Jeremie Ballinger of Special Olympics North America

# **MODULE Q**

# UNDERSTANDING LEARNING DISORDERS<sup>1</sup>

**IN THIS MODULE:** 

OVERVIEW DYSLEXIA DYSGRAPHIA DYSCALCULIA (CENTRAL) AUDITORY PROCESSING DISORDER EXECUTIVE FUNCTIONING ISSUES

#### **OVERVIEW**

The National Institutes of Health defines learning disorders as "disorders that affect the ability to understand or use spoken or written language, do mathematical calculations, coordinate movements, or direct attention." As a practical matter, a person with a learning disorder does not have an intellectual disability or difficulty understanding or retaining ideas once they have been received. Unless you interact with a child in a school or learning setting, you rarely notice the disorder. The struggles show up in Scouting settings when we teach information. Learning disorders can vary widely in how they present themselves and how severe they are. A person can have a learning disorder that is significant enough to present difficulty but not severe enough to qualify for special education services at school. Learning disorders can appear by themselves, but it not unusual for them to overlap with other conditions. These disorders are lifelong conditions.

People who have learning disabilities are often very bright. Their overall level of day to day functioning is not affected. What is affected is receiving, sending, and organizing information. This mismatch has a social impact and **such Scouts may** 

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank the Learning Disability Association of America (Idaamerica.org) for reviewing the contents of this module for accuracy and usefulness.

go to extremes to hide their struggles from others and avoid embarrassing themselves. When forced into situations where they feel weak due to their disability, they may be stressed and may misbehave to distract others and escape the task. Being bright, these Scouts will invent workarounds to accomplish what they need to without relying on their weaker skills, such as a Scout with writing difficulties who will use voice-to-text on the phone. Sometimes, you never notice these difficulties because the scout has become so adept at avoiding the area of weakness without adult intervention.

### DYSLEXIA

Dyslexia is the most common learning disability. It affects somebody's ability to take in information from the written word. More specifically, it is difficulty in decoding words for what they are and seeing letters in the original sequences or orientations. Several letters in English are mirror images of one another (b-d, p-q, w-m, u-n, z-s) or near misses (c-o, y-w, i-l, h-b, r-v). Some people with dyslexia also describe letters as flipping or jumping around on the page as they look at it so that the "picture" is not static.<sup>2</sup> When reading a passage, sometimes there are enough decoding problems while trying to read that the overall meaning gets lost. Since you have to be able to see what you are doing while you write, people with dyslexia often struggle to write as well. Words and letters can come out of order. This is not exactly the same as dysgraphia, but it has the same effect of being hard to understand in written communication.

As a practical matter, it is not so important that a Scout leader identify that a Scout is struggling with dyslexia as it is to recognize when a Scout has an exceptionally hard time with reading and writing tasks. Dyslexia is a life-long condition. While special training can allow a person to cope when they must, and using alternative ways to teach can keep a youth from being left behind intellectually, the struggle itself never goes away.

So, what does it look like?

<sup>&</sup>lt;sup>2</sup> While this is reported, there is not research to support this as a characteristic of dyslexia. Dyslexia is not a visual disorder as many believe. It is a disorder related to phonological (sounds in a language) and orthographic (sound to symbol mapping) processes.

- Scouts with dyslexia will often avoid tasks that involve reading, especially reading out loud.
- You may see them mouthing words when they read silently to themselves.
- Expect the Scout to show stress when asked to read aloud in a group, and don't be surprised if he or she tries to escape the room rather than attempt to read aloud when asked.

Helping Scouts with dyslexia is as simple as supplying all your Scouts with multiple ways the access the information needed to reach advancement.

- The Scout handbook can be found in audio format through the Bookshare program (bookshare.org).
- There are accessibility features in smartphones that will read aloud the text on the screen.
- Consider using other kinds of visual aids besides text when you are teaching.
- If a Scout has to make a presentation, using a poster or a role play may allow him to be more effective.
- Text from a computer can be printed in larger dyslexia-friendly fonts<sup>3</sup> that have been shown to make reading easier.
- A buddy can help when reading tasks are unavoidable and can function as a scribe when the Scout in question has a hard time writing.
- Given the growing abundance of voice-to-text and text-to-voice technology, it may be appropriate to let a Scout bring electronics on outings rather than having a strict "no electronics" policy.

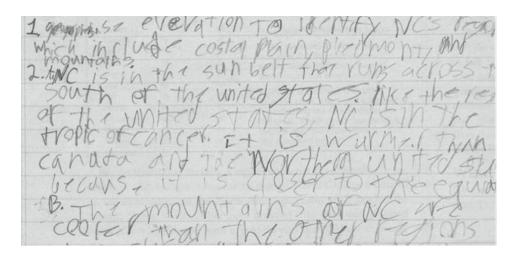
## DYSGRAPHIA

Dysgraphia is a difficulty in writing, that is, putting information in written form. Often a person with dysgraphia is smart and can speak articulately, but avoids tasks involving writing or drawing. The effects are more obvious with handwritten documents. The writing will look like it came from a much younger person, with reversed letters, and uneven letter sizes. Typewritten text will have

<sup>&</sup>lt;sup>3</sup> In this module, the editors have attempted to format the text in dyslexic-friendly ways. The color of the text is not pure black. A san-serif font was used. The text is left justified. A single space is used after periods. Bold text is used for emphasis rather than italics. The font size was increased to 14 point.

many misspellings, missing punctuation and capitalization. If they use autocorrect for spelling in the word processor, incorrect words get substituted.

Also, a person with dysgraphia will be able to frame thoughts and ideas when speaking but will have a much more difficult time constructing coherent ideas in written form. Also, the act of writing is physically exhausting. The struggles with writing by hand may also show up with other tasks that need fine motor control like tying knots and doing craft projects.



An example of handwriting from a dysgraphic student<sup>4</sup>

To help scouts with this disability:

- Be as flexible as possible with what you accept as written information.
- When possible allow groups to work to together on writing tasks
- Use a scribe to assist with writing.
- Allow extra time for a writing task by allowing the scout to start the task before the meeting.
- Allow extra time for fine motor activities
- Change the scale (size) of the task to turn a fine motor activity into a gross motor activity.
- Review important paperwork before it is turned in for rank advancement and allow the scout to make corrections as necessary.

<sup>&</sup>lt;sup>4</sup> https://www.dyslexicadvantage.org/wp-content/uploads/2016/08/Screen-Shot-2016-08-23-at-11.06.58-AM.jpg#prettyPhoto

### DYSCALCULIA

Dyscalculia<sup>5</sup> affects a Scout's ability to complete any tasks that involve numbers and calculations. This can include:

- Telling time
- Converting word problems into math
- Dividing up expenses and food buying for outings
- Expanding recipes and figuring out how much of each ingredient is needed
- Totaling up mileage for segments of a trip
- Using scale and proportion with maps
- Personal budgeting and money management

It is not unusual for someone with dyscalculia to also struggle with short-term memory tasks like remembering a list or a sequence of instructions. Like with dyslexia, a youth may try to manipulate the situation to avoid having to do math tasks, like avoiding games that rely on counting.

As with the other "dys" learning difficulties, you can use more than one approach to providing information. For example:

- Use written words or spoken directions to substitute for manipulating numbers
- Use objects or tally marks to count with
- Use diagrams and charts to express math ideas
- Use physical or "pretend" money to discuss ideas
- Allow and encourage the Scout to use calculator and mapping apps to augment his or her abilities and do tasks independently

<sup>&</sup>lt;sup>5</sup> If you have never heard it spoken out loud, the pronunciation is dis-kal-kyul-ya.

## (CENTRAL) AUDITORY PROCESSING DISORDER

The "dys" learning struggles just discussed related to decoding written symbols. There is a counterpart for spoken language called central auditory processing disorder or just auditory processing disorder. It is far more common than most people know and many of those who struggle with it may not know it. In this disorder, a person struggles to distinguish between similar sounds in speech and in connecting the sounds to the words being said. While the effect on a person's life is similar to being hard of hearing, the difference is that the ears work fine, but the brain struggles to decode the signal. Background noise makes it harder. Simply speaking louder or amplifying sound is not a solution.

Scouts with this struggle may not appear to be "getting it" like others are when you are giving a verbal lesson. Watch for Scouts that asks "What?" a lot, or seem to ignore others who are speaking to them. Another sign is hesitation when a group task begins, as though the Scout is unsure what he or she should be doing. As a social effect, don't be surprised if these Scouts do things to avoid being put on the spot. They may spend time by themselves off to the side, whittling or reading a book. When work is being divided up, they may volunteer for tasks that don't take much talking (listening) to others.

So how can you help?

- When you speak to the Scout, face the Scout directly to reduce sound distortion and let the Scout watch your lips while you are speaking.
- Move learning activities outdoors, or away from other activities, to reduce background noise.
- Use visual aids and written instructions when you can. Don't forget you can draw in the dirt.
- Encourage the Scout to sit close to the speaker.
- Ask the Scout to repeat back what was said, if you aren't sure he or she understood
- Teach in a smaller group
- Try changing how you speak go slower?, pause a bit between phrases and sentences?, use a higher or lower pitch?, emphasize key words?
- Give instructions to the Scout and the Scout's "buddy" at the same time, so the buddy can help repeat instructions if needed.

• Encourage the Scout to speak in front of others. Ask for the Scout's ideas.

## **EXECUTIVE FUNCTIONING ISSUES**

Executive functioning is a term that describes all of the skills needed to organize and complete tasks. As a practical matter, younger kids in general are gradually learning "executive functioning" and are not especially good at it. It may not become clear that a person is truly challenged in this regard until they are out-ofstep with their age peers.

While executive functioning issues do not fit some definitions of a learning disorder, these struggles do impact the process of learning, completing school work, and completing Scout advancement tasks. People with attention deficit/hyperactivity (Module K) and autism (Module L) typically struggle with executive functioning, but they are not alone.

The particular challenges of executive functioning include:

- Following long sequences of instructions
- Setting goals
- Breaking down a larger task into the steps needed to complete it
- Putting steps into the right sequence to be productive
- Understanding where decision points will be (flowcharting)
- Budgeting time and money
- Staying focused and on task till a step is completed
- Keeping up with details

Those who struggle with executive functioning tend to have some other behaviors as well. These include:

- Rigid attitude about routines, irritability regarding changes in routine
- Routines and habits that appear compulsive
- Difficulty shifting from one task to another when appropriate
- Messy living and work spaces

So how can you help?

- Take time to talk the Scout through planning tasks
- Allow a Scout time to finish the step he or she is working on before changing tasks or activities
- Give advance notice when you expect a change from routine
- Maintain the routines that do not get in the way
- Keep sequences of instructions short and be willing to check in frequently
- Break general instructions into smaller steps when giving instructions
- Avoid throwing off sleep/wake times
- Watch for when a Scout is idle while others are at work. Then redirect or re-instruct.

Author: Britt Johnson-Dunlop Editor: Roger B. Tate Reviewers: Learning Disability Asso. of America, Britt Flather, and Midge Savage

## **MODULE R**

# UNDERSTANDING PHYSICAL DISABILITIES<sup>1</sup>

IN THIS MODULE:

INTRODUCTION **BEING PREPARED** MOBILITY CHALLENGES **Bumps, Steps, and Thresholds Uphill and Downhill Slope** Left-Right Cross-Slope Surface Texture Doorways Pathfinding Power Chairs and Scooters Are Not Always the Answer **USING HELPERS** USING TRANSPORTATION **UPPER BODY CHALLENGES** Pinching Gripping **Arm Strength** Feeling Positioning Shaking FUNCTIONAL PRIVATE SPACE Tents **Bathrooms & Latrines** Showers **Clothes Changing Incontinence Needs Cleaning Up Accidents** ADAPTATIONS FOR SCOUTING ACTIVITIES Hiking Cycling Orienteering Shooting Archery Swimming/Water Rescue

<sup>&</sup>lt;sup>1</sup> The Boy Scouts of America would like to thank United Cerebral Palsy (UCP.org) for reviewing the contents of this module for accuracy and usefulness.

Boating Knife and Woods Tool Use Fishing Fire Building/Stove Use/Cooking Rope Work Climbing/Rappelling/Challenge (COPE) Courses/Zipline ADVANCEMENT CONSIDERATIONS Demonstrate/Show Write/Draw/Sketch/Diagram Physical Fitness Requirements

#### INTRODUCTION

Physical disabilities are conditions where people cannot move or control their bodies well. They encompass a broad variety of limitations and underlying causes. Some conditions that cause physical disabilities also impact intellectual ability, vision, hearing, or speech. Those topics are addressed in other modules of the *Inclusion Toolbox* and you may need to review that information to help a specific individual.

The first goal of this module is to help you relate to what it is like to live with a physical disability, so you will take action to help. The second goal is to give you specific methods and strategies for solving the more common challenges.

Typical humans are among the best adapted creatures on earth in terms of going where we want to. We can't fly, but we can crawl, walk, run, climb, swim, jump, vault, reach, pull up, tumble, wriggle, and roll on the ground. We can even move sideways when it suits us. With all these abilities, **we have a hard time noticing all the little obstacles we encounter as we move**. Most of us don't realize how losing a little bit of this capability makes it much harder to do something. Honestly, the best way to "get real" is to try making it through a day without an ability. Try one of these challenges for a whole day:

- Wear a pair of mittens (loss of pinching ability)
- Keep your dominant arm in a sling and don't use that hand for anything
- Keep one foot off the ground and use crutches
- Take a loaded baby stroller everywhere you go, without ever stepping away from it (route-finding with a wheelchair)
- Wear a cervical collar and do not turn your head
- Stop for two minutes for every 100 steps you take (loss of speed with crutches or wheelchair)
- Limit yourself to 1000 steps for the day (endurance/stamina limitations)
- Go grocery shopping, but you can't buy anything more than 4 feet above the floor (height & reach limits)

For some people, like those that are missing limbs or are paralyzed, it is easy to understand what accommodations they might need. However, there are many other people where the challenges are less obvious, like people with weak grip, nerve damage, or malformed joints. Physical disabilities can be caused by injury or damage to brain, nerve, muscle, bone, joint, or connective tissues. Some physical disabilities are present from birth but many others are from illness, injury, chronic pain, or progressive disease. Almost everyone will experience a short-term physical disability during their lifetime due to an injury, like breaking a bone or spraining an ankle.

People with physical disabilities use assistive devices to access their environment, and some people use several devices. This could be anything from a simple knee brace up to a customized van with hand controls and built-in chair lift. To communicate and control devices they may use anything from a simple joystick up to eye-tracking devices and voice synthesizers.

To address the diversity of needs within the general category of physical disabilities, we will focus the discussion on three major themes: lower body disabilities and mobility, upper body limitations and doing fine work with hands, and accommodating daily living tasks, like grooming, dressing, and toileting. An individual can have disabilities from any or all of these aspects.

A great deal could be said about how to make spaces and buildings accessible. This module discusses how to cope with situations that you must work with as they are, where you are not in a position to change the terrain or building features. Module AA<sup>2</sup> provides information about practical ways to improve accessibility at BSA camps and facilities.

#### **BEING PREPARED**

Advance preparation is especially important for physical disabilities. While Scouts are resourceful, you cannot count on being able to improvise on short notice. Every kind of mobility equipment has limitations and even with mobility equipment, there are places a Scout cannot go unless some access provisions are made in advance. There are many activities that a Scout with a physical disability can participate in, but only if special equipment is already available and in place.

Preparation is important for regular meetings at the unit's usual meeting place. This is easier than at other locations because you get "do overs". That is, you can take advantage of the learning curve and you can put permanent access solutions into place. You can also focus on the specific needs of your Scout to make adaptations. One-time outings at other locations are a greater challenge, but since "outing" is essential to "Sc-outing", preparing for outdoor activities and new locations is important as well.

<sup>&</sup>lt;sup>2</sup> At the time of this release, Module AA has not been started. In the meantime, reach out to Outdoor Programs and Properties at the BSA National Office.

Communication with the Scout is a key part of the preparation. The Scout and family need to know as much as possible about an upcoming event. This includes details about both the activities and the venue where the event is being held. While you may be confident as a leader and organizer, it is very hard to spot all the potential trouble spots when you don't live with that disability. **Think of the family members of the Scout as your teammates** in spotting the needed adaptations and keeping you from wasting time and energy on unnecessary ones.

The staff of an event need to hear from the Scout and family as well. Unlike the regular leaders of the Scout's unit, **camp staff members have no history or experience with the Scout** and are responsible for many more Scouts than just the one with a disability. Someone needs to reach out to the camp director long before the camp season opens to explain what the Scout's needs are likely to be and what activities and merit badges the Scout wants to attempt. This allows a chance to be inventive and create solutions that are easy and effective.

Advance previews are a great tool. Five minutes of looking at something is better than five hours of talking about it. See if there is any way for the Scout and family to go out to the location ahead of an event to spot the problem areas. In some instances, a simple item brought from home will address a lot of challenges. For summer camp or day camp, see if you can go out during the staff training/set-up days for the camp. Not only can you address the physical obstacles of the camp, the Scout can get acquainted with some staff members and you can talk to staff about how to include the Scout in the camp's activities. These conversations go so much better when the staff is not in the mad swirl of holding camp with large numbers of Scouts.

#### **MOBILITY CHALLENGES**

There is a wide range of mobility devices that a Scout or adult may need. These include:

- Braces for legs, knees, ankles, wrists
- Prosthetic limbs<sup>3</sup>
- Cane
- Underarm crutches
- Forearm crutches
- Walkers
- Manual Wheelchairs
- Powered Chairs/Scooters
- Golf Carts
- Utility Off-road Vehicles (UTV)
- Wheelchair Accessible Conversion Vans/SUVs

<sup>&</sup>lt;sup>3</sup> Prosthetic limbs can be configured for general purpose movement or specially configured for a particular sport or work task.

Even if you use a mobility device, every movement is still harder and slower than for other people. Even customized accessible road vehicles take more time and effort to load and unload than other vehicles.

The ideal surface for moving around is like a basketball court, which is hard, smooth, flat<sup>4</sup>, level<sup>5</sup>, and open. Any deviation from this ideal surface makes movement harder. Stairs defeat everything except prosthetic legs, canes, and crutches, but even with those devices you can have a hard time managing stairs. Less than ideal terrain impacts manual (self-propelled) wheelchair users more than anyone else, so for the rest of this section we will use that example to explain the problems that terrain creates.

**Bumps, Steps, and Thresholds** – The diameter of the wheels limits how tall a vertical step a wheelchair can cross. The front wheels, called caster wheels, are smaller. Unless the user is able to "pop a wheelie" it is hard to force the front wheels over any step taller than one inch. A little taller step can be jumped while going backward, using the drive wheels. A user with good upper body strength might be able to climb a 3-inch step, but the effort is like weightlifting and the chair tilts face down during the maneuver. Anything more will require help from another person.

**Uphill and Downhill Slope** – A downhill slope is an obstacle because a manual wheelchair only has "parking brakes", not running (friction) brakes. **The user has to drag his hands along the drive wheels to control the speed going downhill**. A long downhill run exhausts your grip pretty quickly, not to mention tolerating the heat from the friction. Very few outdoor rolling surfaces are dead level. Even those lovely sidewalks across college campuses run up and down to line up with the natural slope that the buildings were placed on. Building codes in the United States set limits on how steep a ramp can be (1 inch of vertical rise for each foot of horizontal run, or 5 degrees on a protractor), and how high it can go between landings (30 inches of vertical height). **Pushing yourself up a slope that steep feels like running a short sprint**. Even with shallower slopes, it helps to have a level spot to rest for every foot of vertical change in elevation.

**Left-Right Cross-Slope** – Most outdoor paved surfaces have a slight slope to drain off rainwater. On sidewalks a cross-slope of one inch in four feet is common and is treated as "flat enough" in building codes. For a wheelchair user, cross-slope makes pushing much harder because the chair wants to turn downhill. To compensate, the user has to push harder with the downhill arm. **One arm can end up doing the work of two**. Don't be surprised if a person with a wheelchair takes over the middle of the road, where the crown is, just to reduce the effort.

**Surface Texture** – Like any other wheel, wheelchair wheels roll easiest on a hard smooth surface. Scout camps have a lot of unpaved walkways, so you need to be aware of the effects of other types of surfaces. There are air-filled tires available for wheelchairs, similar to bicycle

<sup>&</sup>lt;sup>4</sup> Flat is all in one plane.

<sup>&</sup>lt;sup>5</sup> Level is perpendicular to gravity.

tires. These help with rough surfaces but do nothing to help with slopes. The size of the gravel on a path makes a difference (smaller is better), and so does how hard the surface is packed. **Trying to roll through loose dirt, sand, or gravel feels more like plowing than rolling**. Imagine walking through a swimming pool, across sand dunes, or through deep powder snow. A muddy path is not only a mess because the mud gets all over your hands and clothes, but it is hard pushing and you can get stuck. Hard packed dirt and packed small gravel are not too bad unless there are other obstacles like roots and rocks in the pathway. A wheelchair user may want to be in the part of a roadway where vehicles have already packed down the surface rather than off to the side.

**Doorways** – A person using a wheelchair, walker, crutches, or other mobility devices needs more space to navigate a doorway than a standing person does. Unless there is enough space for the wheelchair to move around when doors are being opened, an otherwise accessible doorway may be impassable. Aside from this, any door that has a spring-loaded closer is going to be hard for someone in a wheelchair because you need both hands to drive the wheelchair and don't have an extra one to pull on the door and hold it open.

**Route Finding** – Even when a building has an accessible entrance, the location may not be obvious. A person with a wheelchair may have to try several different paths to find the door that is accessible. With Murphy's Law, it seems like it is always on the farthest side of the building and is at the farthest point from the place inside the building where you are going. This often means that wheelchair users have to exert more effort than others to get where they are going.

**Power Chairs and Scooters Are Not Always the Answer** - The common types of power wheelchairs and scooters can drive up and downhill with little effort on the part of the user. This extends the distance you can go and how fast you can move, but at the expense of overall fitness and cardiovascular health. Power chairs have lower ground clearance and smaller drive wheels than manual wheelchairs, and are heavier. This makes them more vulnerable to bogging down on soft surfaces and getting stuck going over humps. Power scooters are narrower than manual wheelchairs, which makes them more prone to tip over on cross-slopes. Another thing to recognize is that **being able to propel yourself is empowering** and has benefits for your mental state and self-image.

#### USING HELPERS

The preceding section makes it clear that most terrain outdoors is hard for those with physical disabilities to cross and they need others to extend their capabilities. **Ideally, everyone in the Scout unit works together to provide the extra help the Scout needs.** At its most basic, this is just an extension of the Buddy System we use with all Scouts. In a Scout unit, the leaders may have to coach the Scouts on the kinds of help that are needed. Here are some common needs:

- Opening and holding doors
- Carrying things from place to place
- Lending a hand or an arm to steady someone
- Helping a wheelchair get over a small obstacle
- Carrying a food tray in a dining hall or restaurant
- Reaching for things that are too high or too low for the Scout to reach
- Stowing and getting out mobility aids when using vehicles
- Doing small tasks for people whose hands don't work well, like packing and unpacking
- Exploring ahead to locate an accessible entrance for the Scout

It is good for everyone in the unit to be ready to offer this level of help to the Scout with a physical disability. Ask "Is there anything you would like me to help with?" and "What would you like me to do?" and let the Scout have the power to decide how much help is wanted. Helpful companions will need to learn not have their feelings hurt if help is refused. As everyone gets to know one another and relationships grow between the youth, the process of offering, asking, receiving, and refusing help gets easier and more intuitive.

Allowing a helper to push you in a wheelchair or unpack for you requires trust. With a wheelchair, the Scout must trust you to not crash into something or mishandle an obstacle. You need to pay attention to your own footing because if you fall while you are pushing a chair, you can pull it down with you. In the case of unpacking, the Scout has to trust you to see and handle his or her personal things without making fun of anything, like the color or style of underwear, and without talking about this with others.

Some Scouts with physical disabilities need help with more personal needs like getting dressed, bathing, or using the bathroom. Some may also need help with special medical equipment. This kind of help is the realm of family members and professional caregivers. Generally, professional caregivers have the legal permission of the Scout's parents and guardians to provide care to their child and to make certain decisions as if they were the parent or guardian. They also generally have a close relationship with the Scout and can be a great resource in making the program a success for that Scout. We should recognize that these paid caregivers have been legally given these permissions and responsibilities.

The current (2020) BSA youth protection training (YPT) does not directly address professional caregivers, presumably because it is not a common situation. Not knowing better, unit leaders sometimes stop a Scout from going on an outing, or require a parent to attend an outing even though the parents or guardians have a professional caregiver who can stand in their place. Though acting in good faith as they understand the youth protection rules, this can create unnecessary hardship and conflict.

If we treat a professional caregiver like a parent, there are still things a caregiver must do: (1) The caregiver needs to complete BSA YPT training like any other adult on an outing. (2) The caregiver needs to be registered as an adult with BSA, primarily to obtain BSA background

checks. (3) The caregiver must complete the appropriate BSA annual health and medical record (medical form) for the outing, long-term or short-term. (4) The caregiver should have appropriate power-of-attorney documents for decision making. (5) For long-term camps and schools, the camp/course director should be given advance notice that a non-parent caregiver is coming to camp, to make sure that any special documentation the camp needs is brought to camp. This is important because laws and regulations vary from state to state and the camp needs to be in compliance with local law.

#### USING TRANSPORTATION

Even with personal helpers, a Scout with a physical disability needs to budget energy and time to be able to participate in the activities that are most meaningful. **To get the most out of a large-venue outing** like summer camp, a camporee, or jamboree, **the most practical solution is to use some kind of vehicle transportation to get around the venue**. The first question is who is going to provide the vehicle and driver. The second question is how to honor the other safety concerns of the venue where a vehicle is moving in and amongst pedestrians.

For a major event, it is worth asking in advance whether any on-site transportation will be available. It is not uncommon to have power scooters available for rent at public venues. Scout camps are notorious for having rough roads and that will dictate what kinds of vehicles might work. The Scout will need to be able to get back and forth to every activity area at the camp from his campsite. Hardcore off-road power chairs that use "tank tracks" do exist, but they are still too expensive for most families. More practical vehicles are golf carts and utility work vehicles called UTVs. They have limited top speeds that fit a camp environment better than a road vehicle. They are also available for short-term rentals from farm and construction equipment rental companies. Using a regular road vehicle is always an option as long as it has sufficient ground clearance for camp roads.

In most situations you will want a vehicle with at least four seats and a place to load and secure the mobility equipment the Scout needs while at the activity area. That provides room for a driver, the Scout with the disability, a buddy Scout, and a caregiver. The Scout should be allowed to have a buddy come along in the vehicle for social reasons if nothing else. It is no different than allowing two Scouts to talk while they walk together to a location. The other reason for a buddy to come along is to comply with "no one-on-one" contact rules for youth protection.

If you have special transportation needs and need to use a vehicle at a Scout camp or other venue where most people are on foot, do not surprise the camp administration and staff with this need. You need to work things out with the camp administration to set reasonable allowances and restrictions for the use of the vehicle. You will likely need to be able to keep the vehicle at your campsite even if others are not allowed to do so. You can expect to have some restrictions, like speed limits, not using certain roads with high foot traffic, or avoiding driving in the busiest areas.

#### UPPER BODY CHALLENGES

The type and effect of upper body limitations will vary widely from one person to another. As a general philosophy when working with Scouts, we seek to empower and enable the Scout's efforts. That means taking some time to understand what the Scout can do physically and allowing the Scout to do as much as he or she can. Sometimes an adaptive device can fill in the capability gap. Sometimes a helper needs to amplify the force the Scout can exert. Sometimes you need to help stabilize a shaking hand. And yes, there are times when the helper needs to physically do a task while the Scout directs the helper through the task.

You do not have to have a mobility or lower body disability in order to have an upper body limitation. Many Scouts with upper body limitations will try to hide this from others to avoid being embarrassed or ridiculed. A Scout that has a lower body disability but no upper body limitation will still need some adaptations to allow tasks to be done from a sitting position or from a wheelchair. A wheelchair will often obstruct upper body motion in some way that will need to be accounted for.

**Pinching** – Many detailed tasks require an ability to pinch something between the thumb and one or two fingers. In terms of basic living, if you cannot pinch and hold a button, you cannot button your clothes. If you can't pinch a zipper pull you can't zip up clothes, tents, backpacks, or anything else. If you cannot pinch something for a long time, you can't write with a pen or pencil, use a paintbrush, or work with small tools for crafts. With clever adaptations, many pinching tasks can be eliminated, for example by replacing buttons with Velcro<sup>®6</sup> squares or magnets. Other tasks can be converted from a pinching task to a gripping task. For example, knotted cords can be tied to zipper pulls to extend them. A tool, like pliers, can be used to pinch with. The handles of tools can be lengthened or thickened so they can be gripped with the whole hand. Foam tape and epoxy putty work well for enlarging a handle.

**Gripping** - Gripping or squeezing an object uses different muscles from those used to pinch and do small controlled motion. Grip is more important than you might think because you cannot lift or pull anything with force if you cannot grip it. Anyone who has moved furniture can understand that even if you have the strength to lift a heavy object in every other respect, you can't lift something heavier than your grip can handle. If you've moved furniture you also understand that how long you can maintain a grip matters. There are devices to enhance grip strength for specific tasks. For example, in adapted archery, there are devices that attach to the hand, arm, or wheelchair to hold the bowstring while the bow is pushed away from the archer. There are special gloves with a strap that wraps over the outside of the fingers and back to the glove to keep the hand in a curled position to hold a handle or lift a dumbbell. Other modified gloves have a hook-shaped metal shank that can be used to catch a handle while leaving the fingers free.

<sup>&</sup>lt;sup>6</sup> Velcro<sup>®</sup> is a registered trademark Velcro BVBA.

**Arm Strength** – No matter how strong we are, all of us have limits to how much force we can exert. Short of a high-tech powered exoskeleton, there is little that one can do to enhance the basic strength that a person has. Instead of adaptive devices, we turn our focus to accommodations to limit the amount of force a Scout has to generate to what he or she can physically do.

**Feeling** – Upper body limitations are not all about strength. Anything we do that requires delicate handling or precision relies on our nerves and touch sensations too. A good example is holding a drink in a paper cup. You need to hold the cup firmly enough to not slip out of your hand, but not too tightly or you will crush the cup and it will fall out of your hand that way.

**Positioning** – The human body has a "sixth sense" that most people have never heard of. Proprioception is the sense of where all of your body parts are positioned and how fast they are moving<sup>7</sup>. To demonstrate this to yourself, hold your arm out to your side, close your eyes and then touch the tip of your nose with your index finger. Most people can do this without looking because there are nerves all over your body to tell your brain what position all of your joints are in and your brain remembers how long your bones are. There are some people that have difficulty with coordinated movement. To adjust for this, they may move more slowly and carefully and use their eyes to closely follow their body motions.

**Shaking** – Some types of physical disabilities affect how nerve signals go to muscles, and result in shaking, tremors, or muscle spasms that make it hard to manipulate objects in a useful way. For example, using utensils to feed yourself can be very frustrating with shaking hands. There are some adaptive technologies that can help with this. Sometimes a hand or wrist brace can resist the shaking physically and can allow a person to use a pen despite tremors. Extra heavy eating utensils and cooking implements can reduce the shaking at the end of the tool. More advanced technology uses a vibrator inside the tool that shakes to counteract a muscle tremor and keep the end of the tool from shaking. For computers, there are accessibility settings that can be adjusted to reduce duplicated keystrokes. A larger format keyboard may be helpful too.

#### FUNCTIONAL PRIVATE SPACE

Many of the activities of ordinary life take longer when you have a physical disability. This includes toileting, bathing, grooming, getting dressed, and changing in and out of swimwear. A person with a disability needs patience from others and has to plan ahead to allow time to get things done.

The physical space you live in makes a difference when you have a physical disability. You travel with a lot more stuff (equipment and supplies) to support your disability and have to bring enough supplies to carry you through the entire outing. You can't just run to the store if you run out.

<sup>&</sup>lt;sup>7</sup> This sense also extends to memorizing where fixed objects are in a familiar space like your home. If someone moves a piece of furniture you find yourself running into it until your mind map compensates.

**Tents** – To deal with time issues, you want to place tents housing those with physical disabilities as close as possible to latrines, cooking/eating areas, and group activity areas. Some types of tents don't work well with physical impairments. Those with upper body limitations need to have cords or handles attached to the zipper pulls in order to work the zippers. Metal tooth zippers are preferred because they tolerate rougher use than plastic ones and are less prone to jam.

For Scouts using wheelchairs, walkers, and crutches; the tent will usually need to be tall enough to get into while standing upright. The doorway needs to be wide enough for a wheelchair. Special attention needs to be paid to the threshold. Some tents have "bathtub" floors, where the threshold is several inches high. Unless a wheelchair can push down the fabric as the chair rolls over, this will not work.

Another factor is that you cannot put as many people into a tent together. When you need to sleep on a cot rather than the ground and park a wheelchair or walker beside your bed, there isn't as much room for other people in a tent. Realistically a 6-person cabin style tent may only hold two people; the Scout with the disability and a buddy or caregiver.

Sometimes it makes sense to have an extra tent that serve as a "garage" for the Scout's extra equipment and supplies. The garage can also be used for some of the group gear. This is a good use for an older tent that has too much age or wear to use for sleeping anymore.

**Toilets and Latrines** – Toilet and bathing facilities at Scout camps are rapidly improving, but it will take time to make things better for everyone everywhere. This section does not talk about how facilities can be built or permanently modified to make them accessible. That is addressed in Module AA<sup>8</sup>. Instead we will focus on ways to make the most out of existing imperfect facilities and create workable temporary spaces at a campground.

At most Scout camps there are facilities tucked away in buildings that the campers and unit leaders are unaware of because they are reserved for staff or adults. Dining halls usually have a restroom for the kitchen workers and may have a clothes washer and dryer for washing dish rags. Staff quarters often have bathrooms with fixtures similar to home. The camp headquarters or business office usually has a restroom. The health lodge/medical facility usually has restroom and shower, and these may be wheelchair accessible. The important thing is to take the time to ask about these facilities when you get to camp because they are out of sight and out of mind even for the staff. It should be possible to allow Scouts with physical disabilities to use these restricted facilities while they are in camp. This will solve a lot of problems while the Scout is in the central core area of the camp.

<sup>&</sup>lt;sup>8</sup> At the time of this release, Module AA has not been started. In the meantime, reach out to Outdoor Programs and Properties at the BSA National Office.

At the campsite, the Scout may be too far from an accessible latrine to be workable. There are ways to improve upon older style latrines. If the latrine has a single-person stall, like an outhouse, you can enlarge the private space by screening it with a tarp to create a vestibule. This allows the door to the stall to remain open while a wheelchair or walker sits in the doorway. If the pathway inside the latrine is an impassable maze, or the latrine is on a raised platform, you may have to create a complete temporary facility. This is easier than it sounds. If your unit travels with a gear truck or trailer, bring a couple of sheets of exterior grade plywood to lay on the ground as the floor. This gives you an 8 foot by 8 foot square area to work in that is out of the dirt and wheelable. Sightscreen the temporary platform with tarps and four poles (lashings and knots anyone?), or pitch a pop-up shelter over it and attach tarps to the shelter legs. A folding toilet chair and a 5-gallon bucket create a temporary toilet. For washing, bring a garden hose to extend water from the faucet at the campsite to the temporary latrine. Be sure to put a valve or spray handle at the end of the hose that the user can control. A smaller bucket on a small folding table can serve as the sink. While Scouts tend to avoid bathing, this kind of improvised facility is good enough for sponge bathing and cleaning up as well.

One last topic about bathroom facilities is signage. It is worthwhile for a unit to have some premade signs to use with latrines and bathrooms to address privacy between youth and adults, males and females, and disabled and typical people. Some flippable signs could say open/closed, occupied/open, female/male, or adult/youth.

**Clothes Changing** – Some activities at camp, like swimming and boating, require special clothing to participate, but there may not be an adequate changing area at the venue. A good example would be a Scout with upper body limitations that require him or her to have help getting into or out of clothes. You can pitch a large tent or tarps at the venue to create a space where the Scout and caregiver can work, out of sight of others (see the Using Helpers section above regarding youth protection). Even if the Scout can get dressed without assistance, you may still need a large tent to provide enough room to maneuver if the permanent changing space is cramped.

**Incontinence Needs** – There are some physical disabilities that cause a loss of sensation or control of the bladder, the bowels, or both. A person who cannot feel when the bladder is getting full may use a catheter to empty the bladder on a regular schedule. Young people are usually trained how to do this for themselves, but if not, a family member or caregiver may need to help a Scout with this. Others may use "adult diapers" to manage their needs. Even when a Scout is used to taking care of waste needs on a schedule, things can be different at camp. He or she may be eating and drinking on a different routine from home, with different foods than normal. In hot weather we try to increase fluid intake, which can also change the normal routine.

As a related matter, we need to think about discreet disposal of the waste diapers and catheters to spare Scouts from unwanted attention and embarrassment. Catheter users prefer single-use disposable catheters, which can be up to 20 inches long. While diapers and catheters

can be disposed of with regular trash, you want to provide opaque trash bags and tall trash cans, so nothing is left in view.

**Cleaning Up Accidents** – There are some disabilities that result in occasional unexpected bowel or bladder control issues. While the family of the Scout needs to make provisions for extra clothes and may need to send a caregiver, it is wise for the Scout unit to have a few supplies to handle an unexpected accident. This includes a spare sleeping bag if one gets wet, disposable gloves, antiseptic hand wipes, and a few large zip-lock bags for containing soiled clothing until it can be cleaned. This is a good idea whether you have Scouts with special needs or not because any youth could slip and fall into mud or water and then need a little help.

#### ADAPTATIONS FOR SCOUTING ACTIVITIES

**Hiking** – A mobility disability does not mean "no hiking". There have been Scouts who completed long distance treks on crutches, with the support of the other Scouts in their crew. A Scout who uses a wheelchair can still go on hikes with a reasonable choice of location. An internet search can usually find accessible trails in your area. One site worth special mention is the Rails-to-Trails Conservancy<sup>9</sup> (railstotrails.org). The experience of a hike is much more than just walking from one place to another.

**Cycling** – There are a variety of adaptive cycles available to suit different physical abilities. This includes variations on tricycles that are powered by either feet (natural or prosthetic) or by hands. The hand powered cycles can use either a cranking motion or a rowing motion. Tandem bicycles are another way a person with a disability can participate in a bike trip.

Like with hiking, the terrain needs to be taken into account when planning a bike trip for a Scout with a disability. You want to have better paved and flatter terrain to make up for the extra effort it would take to propel yourself with your hands or to pedal with a prosthetic foot or leg. Many of the accessible trails that are available for hiking will also permit cycling.

**Orienteering** – Orienteering instruction is no different for a Scout with a physical disability, unless the Scout lacks the dexterity to manipulate a compass. Inexpensive oversized teaching compasses are on the market and can be easily modified to work like map compasses. The next step is to find reasonable terrain for a compass course. Although traditional competitive orienteering includes cross-country running, competitive courses can be designed where each station can be accessed by a road or wheelable trail. Arguably, requiring all the competitors to find and stay on accessible routes would make the orienteering more challenging.

<sup>&</sup>lt;sup>9</sup> The Rails-to-Trails Conservancy focuses on converting abandoned railroad right-of-ways into recreational trails. Since railroads have tight restrictions on slope and flatness, these trails are especially well-suited to wheelchair and bicycle traffic. They are also longer routes than you can easily find with most accessible trails.

**Shooting** – Shooting ranges need to be prepared to be accessible in advance of an activity. You want to create a shooting station where the bench rest or railing height can be adjusted to match the height of a shooter sitting in a wheelchair or a regular chair. This will accommodate Scouts with lower body disabilities for the most part. You need to prepare for a shooter who lacks the strength to lift and hold the weight of the gun for a reasonable length of time. Large beanbags can be used to create an arm/gun support that will conform to the shooter. A third type of shooter to prepare for is one who cannot absorb the force of recoil, but can aim and pull the trigger. A pivoting gun rest, where the gun is mounted to the rest and the rest is anchored to the bench or the ground is a workable solution. The fourth type of shooter is one who has an uncontrollable shake or tremor. In some cases, having a vertical pole to lean or rest the gun against will work. A pivoting gun rest that has friction built into it could allow a shooter to get the gun into position without having to hold it throughout the shot. Shooters may need a trigger extension or a pushbutton trigger release. For time management reasons, many shooters with upper body limitations will need a helper to reload and do other things to speed up the range operation so the shooter can shoot in rounds with everyone else.

**Archery** – Seated archery is a simple adaption to allow on the range and will accommodate most lower body disabilities. The other two challenges for archery are finding a way to draw the bow and finding a way to grip and release the bowstring. A grip problem requires special equipment that will need to be obtained in advance. A mechanical release allows the bowstring to be held by a "claw" that you release with a pushbutton or squeezing action. There are versions for one-armed archers that can be operated with your teeth. When a mechanical release is used, the bow is drawn by pushing the bow away from the body, which is the reverse of conventional archery.

One of the simplest adaptations for limited upper body strength is to have a bow available that has a light draw weight and then combine that bow with a target that is closer to the shooting line than the rest of the targets and therefore within the "throw distance" of the light bow. Both left-handed and right-handed bows will be needed. A Scout can learn the form and technique of archery without shooting at a long distance. This also serves the needs of smaller and younger Scouts. A different adaptation is to allow the Scout to use a compound bow that is adjusted for a low draw weight at full draw. An archery assistant helps the archer draw the bow to a full draw, and then hands control of the bow to the Scout to aim the shot and release the bowstring.

**Swimming** – Every willing Scout should have opportunity to get into the water and have fun. The most difficult challenges don't have anything to do with swimming itself. They are creating accessibility so wheelchairs can navigate through the gates and dressing spaces to get to the water and providing private space where a caregiver can help the Scout out of street clothes and into a swimsuit.

Most safety concerns can be solved by using flotation aids for the Scout with a physical disability. In addition to lifejackets/PFDs; pool floats, kickboards, small surfboards, and

paddleboards are options to allow Scouts to move about in the water. The other safety concerns can be resolved by having a responsible buddy stay with the Scout and help position and move him or her through the water. An important thing about the buddy is that **the Scout needs to be able to trust the buddy completely**. If another Scout is going to be a helper, the helper needs to be taught that he or she can never play a trick in the water on the Scout that needs help.

Special lifting equipment is available for pools that will allow a person in a wheelchair to transition onto a movable chair, swivel out over the pool, and then be lowered slowly and smoothly into the water.

**Boating** – It is difficult to give specific guidance for boating with physical disabilities because of the wide variety of watercraft, water conditions, and limitations a Scout could have. If a wheelchair is going onboard a larger craft, there need to be **provisions to tie down the wheelchair** so it does not move around on deck. For smaller craft, you may need to build a seat back for the seat to support the Scout's upper body. Tying a Scout down is not advised.

If the Scout is unable to maintain a safe, face-up floating position on his or her own, the buddy will need to be able to function as a lifeguard. Safety Afloat requires the buddy to be an adult who has passed the BSA swimmer-level test. However, that may not be enough skill level by itself to manage the risks. The adult buddy needs to be familiar and comfortable enough with the watercraft that he or she can give due attention to the Scout, and also needs to have in-the-water rescue skills to assist the Scout in the event of an overturn.

Scouts with a physical disability, even moderate ones where they could be rated as a swimmer, **should not be alone in a boat.** That does not mean that a capable Scout cannot do the solo boat handling required for merit badges (e.g. paddle a canoe or kayak, steer a sailboat, or drive a motorboat), but it does mean there should be a second person on board to assist in an emergency. A good example of this need would be a Scout that experiences seizures.

**Knife and Woods Tool Use** – In a general sense, these tools are no different from the other tool modifications that were discussed in the upper body challenges sections above. As a practical matter, the need to use a knife for anything other than cooking has always been limited. Furthermore, as the Scouting movement embraces "leave no trace" conservation principles, we are building fewer fires. Land managers are limiting the use of open fires and restricting the gathering of firewood in many locations. Our focus then falls on teaching knife and wood tools safety. These skills can be taught using hand-over-hand techniques so Scouts can have the experience of using a tool while limiting the risk of a tool getting out-of-control to the point it becomes a hazard.

With this said, since Scouts are generally allowed to keep personal knives if used responsibly, a Scout with a physical disability needs to be allowed to have a type of knife that he or she can use safely. In some cases that means a Scout will not be able to open or close a folding knife

and will need a fixed-blade sheath knife. While a personal knife does not need to have a large blade, it may need to have a large grip.

**Fishing** – Like swimming, most of the challenges of fishing have little to do with fishing itself. Often the biggest adaptation that is needed is to **make a level place for a chair or wheelchair to sit near the water** so you don't have to sit tilted forward or be at risk of rolling off into the water. Obviously, there needs to be an accessible path to the fishing spot. Fishing from a dock is more straightforward, but the gangplank from the shore onto a floating dock may be too steep to manage without help from others.

The other challenges of fishing come from upper body limitations. The first thing is to **provide a tether for the fishing rod so it does not fall into the water if it is dropped**. (Frankly, this is a good idea for fishing with younger Scouts too, since they sometimes get excited when they hook a fish and drop the pole.) Sometimes, the fishing pole handle will need to be longer or to be lengthened to allow it to be used two-handed or to be strapped to the forearm. When the Scout has difficulty using her or his hands, a helper will be needed to bait hooks and get fish off the hook, for the safety of the fish and those fishing.

**Fire Building/Stove Use/Cooking** – The most obvious accommodation needed for these activities is to get the height of the "working surface" at the right level for a Scout who uses a wheelchair. A Scout with a physical disability can usually build and tend a campfire. It may mean that the campfire is in an elevated fire pit rather than on the ground. You can also use a fire pit bowl on top of a stone platform built in the field by other Scouts. Many units will also have round metal "oil change" pans for their Dutch ovens and one of these pans can be used as a fire platform for a smaller campfire. A couple of adjustable height plastic folding tables may be needed for the Scout to be able to have the stove at a lower or higher level than usual. If a Scout has grip limitations, you may need to create a set of cooking tools with extra thick or long handles. You may also want to have a rocker knife in the cook kit.

**Rope Work** – All Scouts who are learning how to tie knots and make lashings can benefit from the adaptations for a Scout with a gripping or pinching limitation. The secret is to use large diameter, solid color, braided (boating-style) rope. The braided rope bends easily and the large diameter makes it easier to see what you are doing. Thicknesses up to 5/8 inch are readily available<sup>10</sup>. Another good adaptation is to use ropes of two different colors to teach joining knots. This makes the shape of the knot easier to see and the paths of the different ropes through the knot clear. While good lashings require natural fiber three-strand rope to be secure, you can teach lashing with the softer thicker rope.

**Rock Climbing/Rappelling/Challenge (COPE) Courses/Zipline** – High element challenges are more about the mental challenge of working a puzzle or controlling fear than the physical

<sup>&</sup>lt;sup>10</sup> Another good source for rope is used climbing rope. Camps regularly have to decommission rope by cutting it into short lengths. The short lengths are still good for knot-tying instruction.

challenge. These activities are not beyond the capabilities of a Scout with a physical disability, though the process and equipment setup will be very individualized. The details of what to do are too complex to do justice to in this module. In most set-ups, the climber needs to be equipped with both a chest harness and a waist harness. This allows the climber to remain upright after a slip and eliminates the risk of slipping out of a waist harness because the shape of your hips or legs is different from most people. Those climbers who cannot use leg force to lift themselves will need some kind of counterbalance device to support part of their weight so they can enjoy the challenge without it being impossible for them.

#### ADVANCEMENT CONSIDERATIONS

As explained in Module E, in most cases disabilities can be accommodated by an open-minded reading of the requirement, keeping in mind the intent and learning objective of the requirement.

**Demonstrate/Show** – There are many requirements that use the word "demonstrate" or "show". While for many Scouts that will mean "do the task by yourself, while I watch you", this is not a viable option for some physical disabilities. What we need to point out is **that it is reasonable to allow an able person to amplify the force a Scout can exert or to steady a shaking hand**<sup>11</sup>, while the Scout does the advancement task. For a Scout who cannot use hands, **it is reasonable for another person to "be the hands" of the Scout** while the Scout directs the task. The person serving as the "robot" needs to carefully follow the instructions of the Scout and not think on behalf of the Scout.

**Write/Draw/Sketch/Diagram** – Here we address a Scout who is unable to wield a writing implement at all. Otherwise, we should be willing to accept a document that communicates what it needs to even if it is not elegant. In a low-tech environment, the practical solution for writing requirements is to allow a scribe to take down the information the Scout gives verbally and write it on the page. However, if you look closely, many requirements that we assume require a written product don't actually say that. Report, describe, discuss, and explain can all be done verbally. In a high-tech environment, it may be possible for the Scout to type directly or to use voice recognition software to create a document.

There are a variety of ways to adapt to produce a graphical product without the traditional pen and paper. First decide if a verbal "word picture" would suffice, or if it is OK for a scribe to draw what the Scout tells them to. The next alternative is for the Scout to work with pen on paper with someone to help move the hand to a starting position and steady the hand while the Scout draws. Fingerpaint can be used to draw on a larger scale.

**Physical Fitness Requirements** – In some cases, a Scout with a physical disability will not be able to perform certain kinds of exercises that are identified in advancement requirements. You will need to get alternative requirements approved, but we still prefer to have them be a

<sup>&</sup>lt;sup>11</sup> On a practical basis, this is no different than allowing a deaf scout to be assisted by a sign language interpreter.

physical activity. If the Scout works with an occupational or physical therapist, ask questions and try to use exercises that the Scout already needs to do for therapeutic purposes. Even with a disability, a Scout benefits from the discipline and activity of exercise, and the Scout can certainly show improvement as the physical fitness requirements ask.

Author: Scott Hellen Editor: Roger B. Tate Reviewers: Diane Wilush, National President, United Cerebral Palsy; Midge Savage; Sandy Payne

# MODULE S

## UNDERSTANDING SPEECH AND LANGUAGE DISORDERS

IN THIS MODULE:

WHAT IS SPEECH? ARTICULATION STUTTERING OR DYSFLUENCY VOICE DISORDERS WHAT IS LANGUAGE? EXPRESSIVE LANGUAGE RECEPTIVE LANGUAGE SOCIAL COMMUNICATION SCOUTS THAT DO NOT SPEAK

In Module C and Module F of the Inclusion Toolbox, we explained that effective communication with the family and the Scout is essential for accommodating any special need or disability. For those with speech and language challenges, the family of the Scout is likely your best guide for information to help their child. If you have not read the section on Joining Conferences in Module F, be sure to do that.

Speech and language challenges are invisible disabilities. As with many other disabilities, Scouts with speech or language challenges may behave differently from others. They may avoid situations that requiring speaking, to avoid drawing attention to their disabilities. They may also pretend to understand conversations and instructions they did not fully understand. A leader may have to make an extra effort to maintain a positive unit culture to encourage Scouts to communicate using their preferred method. A leader will also need to monitor the reactions of other Scouts to prevent bullying and teasing. This is discussed more fully in the Addressing Safety section in Module F. Additionally, adults working with scouts with social communication issues need to be aware that when a Scout communicates in a way that appears disrespectful, lazy, or disinterested, this may be a feature of the disability rather than his or her personality.

The overarching goal of supporting a Scout with a speech or language disability is to help the Scout understand and be understood rather than try to reduce the differences in how the Scout sounds compared to others.

### WHAT IS SPEECH?<sup>1</sup>

"Speech" and "language" are different, and a person can struggle with either or both of them. Speech is how we say sounds and words. Speech includes three aspects:

- Articulation, which is how we make sounds by moving the mouth, lips, and tongue. For example, we need to be able to say the "r" sound to say "rabbit" instead of "wabbit."
- Voice, which is how we use breath and our vocal folds (commonly called vocal cords) to make sounds. Our voice can be loud or soft, pitched high or low, or hoarse or smooth. We can hurt our voice by talking too much, yelling, or coughing a lot.
- Fluency, which is the rhythm of our speech. We sometimes repeat sounds or pause while talking. People who do this a lot may be described as stuttering.

#### ARTICULATION

Articulation is how we produce speech sounds. Scouts with articulation delays or disorders will have speech that sounds different than other youth their same age. They may have difficulty producing one or many sounds correctly. Some of the differences could even resemble a foreign accent.

A Scout with an articulation disorder may be very difficult to understand. They may also use hands or body language to make themselves understood. They may get frustrated because they can't be understood, and misbehave as a means of communicating. This is more common when they are very young.

When communicating with a Scout who has trouble producing the speech sounds correctly, remember:

- The Scout may have typical cognitive skills and hearing and no difficulty understanding you.
- You do not need to change how fast or loud you talk.
- The Scout may (or may not be) embarrassed about how he or she speaks.

<sup>&</sup>lt;sup>1</sup> <u>https://www.asha.org/public/speech/development/speech-and-language/</u>

#### Tips for working with Scouts with articulation disorders:

- Ask Scouts to repeat/rephrase/write or act out what they are trying to say. Do not act like you understand if you don't. It's very important that you respect and honor the Scouts' attempts to communicate, as well as their wishes and needs.
- Ask the family of the Scout for tips about how to communicate with and understand their child. Many people can be more easily understood if you know which sounds they substitute for others.
- Don't correct the child's speech.
- Allow Scouts with articulation disorders to choose how they want to communicate, perhaps by writing down answers instead of presenting information orally.

#### STUTTERING OR DYSFLUENCY

Fluency is the rhythm or smoothness of our speech. Scouts with dysfluent speech, or who stutter, struggle to get words out. They often repeat sounds or words, and appear to physically struggle to move to the next sound or word. They often substitute other words for words that they tend to stutter on. As a result, their word choice or vocabulary may seem different from others their age. Dysfluencies tend to get more severe when the person is under stress or pressure. People who stutter may be as smart as anyone else, but may be embarrassed by their stuttering. It is important to realize that they do not usually have other language or developmental issues.

#### Tips for working with Scouts with dysfluency or stuttering:

- If such a Scout volunteers to speak in front of a group, encourage him or her, but do not put anyone on the spot.
- When possible and if needed, allow Scouts to present material in alternative ways like written work, posters, pictures, photos, or videos.
- If a verbal presentation is necessary, allow time for preparation and practice beforehand.
- Do not finish words for the Scout. Patiently wait for him or her to finish expressing the thought.
- Do not tell the Scout to slow down or "relax". It is better to set a relaxed mood in the first place.

#### **VOICE DISORDERS**

Voice is the way we produce sounds. Most Scouts with voice disorders will have hoarse or whispery voices. Some Scouts may have other voice disorders that cause their voices to be very quiet and difficult to hear. Since voice disorders can be caused by underlying medical conditions or by overuse/misuse of the voice, it is good to ask the family of the Scout what accommodations are made at home or school to assist the Scout, and do likewise.

**Tips for working with a Scout with a voice disorder**, in addition to tips recommended by the family:

- Allow the Scout to present information in other forms written, drawing, pictures, photos or posters.
- Conduct conversations in quiet places, so you can hear the Scout.
- Provide a microphone and sound system if the Scout wants to present to a larger group.

#### WHAT IS LANGUAGE?

Language refers to the words we use and how we use them to share ideas and get what we want. Language includes:

- Word meanings Some words have more than one meaning. For example, a "star" can be a bright object in the sky or someone famous.
- Modifying words to make new words For example, we can say "friend", "friendly", or "unfriendly" and mean something different each time.
- Putting words together to express ideas For example, in English we say, "Peg walked to the new store" instead of "Peg walk store new."
- Adapting messages to the situation For example, if someone is standing on your foot, you might be more polite at first and say, "Would you mind moving your foot?" But, if the person does not move soon, you may shout, "Get off my foot!"

#### EXPRESSIVE LANGUAGE

Expressive Language is the way we use words and sentences to express ourselves. Scouts with expressive language delays or disorders have difficulty using the intended words and building sentences to express themselves. Their vocabulary is sometimes less varied than other Scouts their age. They may struggle to get their point across. Some children with expressive language

delays or disorders also struggle with written expression as well<sup>2</sup>. Scouts with expressive language disorders may or may not also have receptive language disorders (discussed next).

#### Tips for working with Scouts with expressive language delays or disorders:

- Accept shorter answers (both written and spoken) than you would otherwise expect.
- Allow Scouts to report or present information in a variety of ways3. Allow them to use posters, pictures, drama, oral or written presentations. Allow them to use a variety of presentation methods in the way that allows them to express themselves the best.
- Allow extra time to prepare and practice before presentations.
- A Scout with an expressive language delay or disorder may shut down and stop talking when they get frustrated. Allow the Scout time to regroup and then ask how you can help. See Module F for a discussion on self-removal to manage stressful situations.

#### **RECEPTIVE LANGUAGE**

Receptive language is how we understand the language we hear. When the brain connects the sound of a word to the wrong word or concept, you get confused. Scouts with receptive language delays or disorders may have difficulty following oral presentations, conversations and directions. The effect is similar to a hearing reduction, but the underlying struggle is different. Scouts with receptive language delays or disorders may appear to be listening but do not understand what is said. Others may act out because they are frustrated that they cannot understand what is asked of them or what is being said in a conversation.

#### Tips for working with Scouts with receptive language delays or disorders:

- Check for understanding. After giving the Scout instructions or discussing important information, check for understanding by asking him or her to repeat back the instructions or the information. If he or she needs clarification, explain again in a different way but don't talk down to the Scout.
- Break down instructions into small bites of information. Give the Scout one step at a time. Once they finish one direction, give them the next step.
- Pair the Scout with a buddy who can also hear the same instructions and repeat them back.

<sup>&</sup>lt;sup>2</sup> Though this effect is a little different, there is a discussion of Dysgraphia in Module Q with learning disorders.

<sup>&</sup>lt;sup>3</sup> Module E discusses how to make accommodations for advancement requirements that are typically done in written or verbal form.

• Teach with a variety of methods. Show illustrations (pictures or photos), use video, draw things out, write things out, or physically demonstrate in addition to verbal instruction.

#### SOCIAL COMMUNICATION<sup>4</sup>

The ability to use speech and language for social interaction is very important. This adds another layer to language beyond words and sentences. There are many subtle "rules" in every culture about what you can say in different situations and to different people. In speech and language circles, this is often called "pragmatic language". These rules vary from one culture to another. Here are some of the major skills for social communication:

- Using language for different functions/reasons: these include greetings, sharing information, requesting, demanding information or action, thanking, or acknowledging other people
- Adapting your communication to the listener. For example,
  - talking to someone older than you differently than you would to someone younger
  - treating someone you don't know well more formally than a friend
  - respecting the position or authority of another person
  - distinguishing between formal and informal situations
- Following sequences for conversation and storytelling. For example:
  - Beginning with a greeting
  - Signaling the topic at the beginning
  - Taking turns while talking
  - Letting others talk
  - Staying on topic
  - Ending with a farewell
- Using gestures and body language. For example:
  - Standing at the right distance from other people
  - Showing interest/disinterest through posture and eye contact
  - Using facial expressions to add meaning and context to the words

All children need time and experience to learn unstated social rules. Social communication issues vary from day to day and will change over the years as a Scout matures. A scout with a social communication struggle may have a hard time being accepted socially into the group. Adult leaders may misunderstand Scouts with social communication issues. The Scout may

<sup>&</sup>lt;sup>4</sup> Atypical social communication is a relatively common feature of autism spectrum disorders but not the only feature. Autism is discussed in Module L. However, don't assume that a child with a social language challenge is on the autism spectrum.

come across as disrespectful, disinterested in others, bossy, demanding, or odd; when that is not his or her intent.

#### Tips for working with Scouts with social communication delays or disorders:

- Understand that they may appear "rude" or disinterested when in one on one or group situations when they are not intending to look that way.
- Include these Scouts in discussions with a personal, targeted invitation to contribute. Do not assume that they will chime in like other Scouts do.
- Facilitate communication between the Scout and the other Scouts in the group. The Scout with social communication differences may not immediately or spontaneously communicate with peers and will often be left out of groups.
- Check for understanding with the Scout since they may not understand the gestures or nonverbal communication that accompanied the instructions.
- Be very careful in your use of sarcasm, similes, metaphors and idioms when speaking with the Scout. Discourage sarcasm by other Scouts. These types of communication are very often misunderstood by someone with social communication differences.

#### SCOUTS THAT DO NOT SPEAK

Some Scouts are not able to use verbal speech and language to communicate<sup>5</sup>. Some others find themselves unable to speak in certain situations<sup>6</sup>. A Scout that does not speak may or may not have a hearing problem. The Scout may or may not have difficulty understanding what you are saying. These Scouts may be able to say some words but they do not use enough spoken words or sentences to express themselves fully. They may use other means of communication. These include gestures, sign language, facial expressions and specialized tablets or computers with special software that allow them to speak through the device. These specialized devices are called AAC (Augmentative and Alternative Communication) devices<sup>7</sup>. Some families call them talkers, speech devices, communication devices, or VODs (voice output devices). The Scout unit does not need to provide this equipment but should make use of the technology the Scout already has available. Using AAC, these Scouts are communicating using words but not with their natural voice. It is good to ask the family of the Scout what accommodations are made at home or school to assist the Scout and do likewise.

<sup>&</sup>lt;sup>5</sup> Speech and language professionals usually refer to these youth as "nonverbal" or "nonoral".

<sup>&</sup>lt;sup>6</sup> The formal name for this condition is "selective mutism".

<sup>&</sup>lt;sup>7</sup> There is additional information above alternative communication technology in Module N which addresses hearing difficulties.

**Tips for working with a Scout who does not speak**, in addition to tips recommended by the family:

- Allow the Scout to present information in other forms written, drawing, pictures, photos or posters.
- Use a small whiteboard to communicate in the outdoors or other locations where electronics are not practical.
- Be very patient with the Scout when he or she is communicating. It takes much longer to communicate via gestures or a communication device than with spoken words.
- If a Scout is using a communication device, talk with the family about the need to add any Scouting vocabulary to the device. For example: Scoutmaster, merit badge, camporee, names of knots, or types of camping equipment.

Author: Betsy Furler, CCC-SLP Editor: Roger B. Tate Reviewers: Daniel C. Tullos Ph.D, CCC-SLP, ASHA Fellow; Midge Savage; Britt Flather **MODULE T** 

# **RESERVED FOR FUTURE USE**

MEMBERSHIP

## MODULE U

## **SPECIAL NEEDS & DISABILITIES COMMITTEES**

IN THIS MODULE:

OVERVIEW PURPOSES AND OBJECTIVES FOR A COMMITTEE HOW TO CREATE A COUNCIL SPECIAL NEEDS & DISABILITIES COMMITTEE RECRUITING ADVOCATES FOR A COMMITTEE ALTERNATIVE ORGANIZATION STRUCTURES NATIONAL SPECIAL NEEDS & DISABILITIES NETWORK

#### **OVERVIEW**

All BSA councils can benefit from cultivating knowledgeable local resources (volunteers, professionals, and consultants) to help districts, units, leaders, and families; providing special needs information and strategies. Approximately 15% of BSA youth<sup>1</sup> are known to have special needs/disabilities and there are more that have not been formally diagnosed or who keep that information private. This module discusses how to provide this support with a Council Committee or an individual champion. **One size does not fit all**, but however you decide to organize your committee, the overall goal remains the same: Provide support to Scouts with special needs and their leaders, to ensure the fullest possible participation in the Scouting program. **Most special needs & disabilities committees will start with a limited number of goals that address the Council's most pressing needs.** Over time, the work of the committee typically broadens as new opportunities are identified and volunteers recruited. A successful committee is one that is responsive to the needs of its Scouting Community.

This usually begins with an individual, a "special needs/disabilities inclusion specialist" or "champion", who advises leaders and fields questions for youth who have special needs/disabilities. Over time, as the council sees new opportunities and better understands its special needs population, this often leads to forming a committee to better serve this population. Depending on the needs of the council, this group is often organized first as a subcommittee of advancement or membership, but it can be much more than this. While it may start out with a particular focus, in time we recognize that such a committee will touch on every key element<sup>2</sup> of the council.

<sup>&</sup>lt;sup>1</sup> In this Inclusion Toolbox, the words "youth" and "Scout" includes chronological adults who are registered beyond the age of eligibility (RBAE) and are functioning as youth in Scouting units.

<sup>&</sup>lt;sup>2</sup> e.g., membership growth, advancement, outdoor program, training, properties, finance, and development

#### PURPOSES AND OBJECTIVES FOR A COMMITTEE

Each council knows its own needs and priorities best, and the charter of a special needs & disabilities committee<sup>3</sup> needs to reflect those priorities. The following lists of possible purposes and objectives are more comprehensive than most councils have resources for. Do not let this overwhelm you. Instead, **think of these as a menu of possibilities for your council to choose from**. There is no single way to run such a committee and no one expects a special needs & disabilities committee to do everything that is listed here.

**Membership**<sup>4</sup> – grow the number of youth participating in Scouting by encouraging recruitment and retention of youth with special needs<sup>5</sup>

- Identify special needs service organizations and schools that could charter a Scout unit
- Identify special needs organizations and schools that could host a parent talk, youth talk, or recruiting rally
- Have special needs and disability specialists on-call to help individuals and units during recruiting drives
- Develop relationships with other organizations that Scouts could serve, enhancing goodwill and building the reputation of Scouting in the community
- Promote inclusion of youth with special needs into traditional Scouting units
- Consult with people who want to found a special-purpose Scout unit for a specific disability
- Encourage units to make use of adults with special needs as leaders
- Organize membership surveys to identify what kinds of special needs are represented and in what numbers
- Facilitate the registration of Lone Scouts where that is the best program option for the Scout.

**Training/Leader Development** – develop volunteer leaders that are prepared to serve Scouts with special needs or disabilities

- Provide one-on-one consulting for leaders, Scouts, or families that are having struggles in the Scouting program
- Organize and teach training sessions at the district or council levels (Roundtables, University of Scouting, College of Commissioner Science, etc.)
- Support youth and adults with disabilities in participating fully in other training, such as Wood Badge or NYLT

<sup>&</sup>lt;sup>3</sup> There are a number of different names that councils are using for these committees. There is no specific recommended name for this group.

<sup>&</sup>lt;sup>4</sup> See Footnote 5

<sup>&</sup>lt;sup>5</sup> Ability diversity is another dimension of inclusion/diversity to keep in mind when growing membership, alongside gender, ethnicity, economic status, and religious affiliation.

- Help recruit leaders/adults with special needs or disabilities to serve on training course staff
- Disseminate newsletters and training materials developed by the national special needs & disabilities committee
- Support camp staff training
- Promote and complete nomination procedures for BSA and non-BSA awards and recognitions for volunteers and youth in the council's special needs programs
- Encourage volunteers and professionals to attend national special needs conferences at the Philmont Training Center (summer) and Sea Base (January)

#### Advancement

- Consult with Scouts, parents, guardians, and unit leaders that need to come up with alternative advancement requirements and merit badges
- Help people use the required forms for requests for advancement alternatives and registration beyond the age of eligibility
- Advise the council advancement committee as they review applications for alternative requirements and merit badges
- Advise the committee designated by the council executive board<sup>6</sup> as they review applications for registration beyond the age of eligibility
- Consult with units and districts that are performing boards of review for Scouts with special needs

#### Commissioners

- Serve as a resource for commissioners when a unit has a struggle related to special needs or disabilities
- Maintain a library of reference literature that commissioners can use with units
- Provide commissioner service to Lone Scout Friends/Counselors

#### Liaison/Communication

- Advocate for Scouts, Scouters, and participating family members with disabilities as they interact with the Scouting organization
- Recruit/maintain a special needs/disabilities inclusion specialist for each district
- Assist with council websites and media communication to maintain awareness of special needs
- Seek out and share stories of accomplishments by Scouts in your council who have overcome difficulties or have served the special needs community
- Identify people with specific skills or knowledge in special needs to serve as consultants or committee members

<sup>&</sup>lt;sup>6</sup> In this module, functions related to registration beyond the age of eligibility (RBAE) have been listed under Advancement because the procedures are described in the Guide to Advancement (BSA 33088). To be precise, review of RBAE applications is a responsibility of the council executive board, but the board can delegate this responsibility to another committee or group. While most often this is the council advancement committee, it could be the membership committee or some other group of council volunteers.

- Maintain lines of communication with the national special needs & disabilities committee as well as area and region special needs champions
- Ensure that the needs of youth with special needs and disabilities are included in the local council strategic plan, integrating the key issues from the National Strategic Plan

**Camping/Program/Facilities** - Provide guidance and resources to the council, districts, and units for reducing barriers at facilities and using technologies for overcoming remaining barriers.

- Consult with camp activity directors to create accommodations that allow Scouts with special needs and disabilities to participate and enjoy as many activities as they wish to
- Recommend special equipment needed for persons with disabilities
- Develop and staff a council-wide disabilities challenge (experience) event, using traditional Scouts and leaders as staff. Such events will be underwritten as much as possible by community resources. Maximizing public exposure should be considered.
- Assist with planning of district and council events to assure all can participate
- Assist the Order of the Arrow chapter in identifying projects that will benefit campers with special needs

#### Finance/Development

- Identify and prioritize facility improvements and equipment purchases to increase access and opportunities for youth to participate fully in Scouting
- Solicit individuals and groups willing to fund improvements to support those with special needs
- Solicit funds for camperships for Scouts with special needs and to cover extra expenses for caregivers to attend camp
- Seek grants to support the council's special needs programs
- Seek in-kind donations or loans of equipment and supplies
- Provide tours of existing council facilities for potential donors to show what is needed and how it will be implemented
- Provide reports to supporters to show how their resources benefited youth

#### HOW TO CREATE A COUNCIL SPECIAL NEEDS & DISABILITIES COMMITTEE

This discussion assumes that your council already has an individual special needs/disabilities inclusion specialist in place. This person is likely to be the seed for building a committee, and may serve as its first chair. Here is a recommended process for growing to the next level. Remember the Area and Region special needs and disabilities champions stand ready to offer advice and support during this process.

- Council President in consultation with the Scout Executive recruits a committee chair
- Scout Executive appoints a staff adviser for the committee.

- The committee chair and staff adviser determine the potential for the council to serve youth with disabilities. They make a preliminary survey to:
  - assess how many Scouts in the council have special needs or disabilities, what needs are present, and which districts/units they are located in<sup>7</sup>
  - estimate the Total Available Youth (TAY) with disabilities or special needs in the council or district territory<sup>8</sup>
  - develop a list of local agencies and organizations that serve persons with disabilities or are interested in serving them, who could partner with BSA for events
  - survey commissioners and unit leaders to identify the most important needs for the council
  - o develop a list of potential chartered organizations and recruiting partners<sup>9</sup>
  - develop a list of interested persons and organizations that could be funding sources for special needs Scouting programs
- The Council President, Scout Executive, committee chair, and staff advisor identify the priorities for the committee and establish its initial charter (scope of work)
- The committee chair and staff adviser recruit people with interest and knowledge to serve Scouting for youth with disabilities or special needs to serve on the committee. The committee composition includes the skill set to support the current objectives.
- The committee holds launch events/meetings at the district level to explain what the committee will do and how it will help local Scouting
- The committee hosts a disabilities awareness training opportunity
- Once the committee is established and functioning, make plans to periodically reassess council needs and update the committee charter to prioritize those needs. A survey to identify numbers of Scouts being served can be done alongside the recharter process each year<sup>10</sup>. The composition of the committee may need to be realigned to support updated objectives.

#### **RECRUITING ADVOCATES FOR A COMMITTEE**

People who know how to serve youth with special needs/disabilities come from a variety of backgrounds. The best recruits for this committee will have a passion for working with these youth, and may have experiential or professional backgrounds with specific disabilities. If you ask around, you may find that there are Scout volunteers who are already doing this kind of work on their own. You may also find volunteers that are already serving in health and safety, shooting sports, outdoor program, and other elements of the council organization. In addition,

<sup>&</sup>lt;sup>7</sup> A Council Special Needs & Disabilities Membership Tool (survey form) is available from the National Special Needs & Disabilities committee for you to tailor to this purpose.

<sup>&</sup>lt;sup>8</sup> In general, we expect to see a higher percentage of special needs and disabilities in Scouting than in the general population due to the flexibility built into our program. You will need to be thoughtful about using estimates from educational organizations, advocacy groups, and government agencies; and adjust for the limitations in their primary data and the purposes for which they developed their estimates.

<sup>&</sup>lt;sup>9</sup> A recruiting partner in this context is an organization that does not or cannot charter a unit but will give an audience to a recruiting presentation. Many schools and service organizations fall into this category.

<sup>&</sup>lt;sup>10</sup> See footnote 7

you can look for parents of Scouts with disabilities, special educators, medical professionals, caregivers, adults who have disabilities, and volunteers for affinity organizations that serve a specific disability or special need. These are all excellent sources for committee members. The search team should try to identify the skills needed to support the assigned committee objectives. For example, if advancement support is a key objective, the team will want some members who understand the prevalent disabilities in the council, know advancement requirements, and are able to understand how a given disability will pose a significant challenge for a Scout (and therefore what alternatives make unique sense for that Scout.) The search should also consider Scout volunteers and members of the community who have expertise in accessibility issues and adaptive technology and devices.

#### ALTERNATIVE ORGANIZATION STRUCTURES

The objectives chosen for your council's special needs & disabilities committee will determine where the committee would best fit into the council organizationally. Here are a few suggested alternative structures:

- The council committee can be a stand-alone committee answering to the Council Executive Board and providing support to all other council committees.
- Where program functions comprise the key objectives (activities, advancement, camping, training), the committee can be a subcommittee within Program, providing input and support to the other Program subcommittees.
- Where advancement is the key objective, the committee can be a subcommittee to the council advancement committee.
- Where membership is the key objective, the committee reports to the council membership committee.
- The committee could be a "matrix" committee made up of representatives/liaisons from each of the other council operating committees
- The committee could function as a separate district, with its own district structure and serving Scouts, leaders and units who have special needs/disabilities throughout the council

Aside from the organizational position, the council executive board will want to consider whether to make the lead volunteer a member of the council executive board and what title to assign the lead volunteer.

#### NATIONAL SPECIAL NEEDS & DISABILITIES NETWORK

At the time of this writing (2020) a national network is in its infancy. The representative element at the National Council is the National Special Needs & Disabilities Committee, which is currently part of the Program Development Support Committee. The near-term effort is to have an identified special needs and disabilities awareness champion for each Council and Territory. A private Facebook group "BSA Special Needs Champion Network" has been created for these champions to communicate with one another and with the national committee<sup>11</sup>. It is envisioned that these champions will be an integral part of the Program Committees will be formed at the Territory level as well.

The intent of this network is to transfer information on best practices throughout the BSA organization and thereby support the successful delivery of the Scouting program to all youth. The network is expected to be a path for good ideas and unforeseen challenges to come in from the grassroots as well as for special needs/disabilities-related information to go out from the national committee. A second intent is to place knowledgeable specialists as close to their clients as practical within the BSA organizational structure.

The Territory champions are expected to support councils in forming their own special needs and disabilities committees and in identifying their goals. The champions would have deep knowledge of official BSA information on special needs/disabilities and the processes for providing a quality program for all youth. They would also acquire an understanding of the laws and regulations for the states in their Territory that relate to special needs and disabilities.

Author: Anthony Mei Editor: Roger B. Tate Reviewers: Midge Savage and Britt Flather

<sup>&</sup>lt;sup>11</sup> Other resources you may be interested in are the "Abilities Digest" and "No Scout Left Behind: A Guide to Working with Scouts with Disabilities" Facebook groups and AbleScouts.org. The national committee can also be reached at SpecialNeedsChair@scouting.org

## **MODULE V**

## **EVALUATING ADVANCEMENT ALTERNATIVES**

IN THIS MODULE:

**OVERVIEW KEEPING THINGS IN PERSPECTIVE Every Scout is Unique Scouts Grow Over Time** What is Expected of Scouts without Disabilities What is Important about a Requirement Some Requirements May Only Require an Accommodation **Comparable Challenge** Life is Harder for a Scout with a Special Need or Disability A Person with a Disability Has a Support Team **PROCESSING REQUESTS FOR EXCEPTIONS Document Limitations Subject Matter Expertise** Face to Face Meetings **REGISTRATION BEYOND THE AGE OF ELIGIBILITY** HANDLING APPEALS

#### OVERVIEW

This module is for Scouting volunteers and professionals who are entrusted with evaluating whether Scouts with special needs or disabilities qualify for exceptions from the regular requirements of the advancement system. It does not replace the rules for advancement found in the *Guide to Advancement (2021)* (BSA 33088), which is the authoritative document. Rather this module provides insight and perspective to assist you in applying the *Guide to Advancement*. The decision-making is left to the authorized volunteers and professionals.

For the remainder of this module, we assume you have already read the *Guide to Advancement* and are familiar with the portions that apply to Scouts with special needs and disabilities (Section 10). You may also want to review Module E, which discusses advancement from the perspective of the Scout, the family, and the unit leadership.

The topic of registration beyond the age of eligibility (RBAE) is discussed in this module as it is often, but not always, handled by the council advancement committee.

#### **KEEPING THINGS IN PERSPECTIVE**

Before commenting on the mechanics of reviewing applications for exceptions, a few philosophical points are in order.

**Every Scout is Unique** – Every Scout is unique, whether the Scout has a special need/disability or not. This means that each time you evaluate a Scout's request for an exception, the details of the disabilities will be different and the process you use to evaluate the request may need to reflect the situation. Fundamentally, this is why the BSA leaves it up to trusted and trained volunteers and professionals to make these judgements. It is impossible to write a rulebook or scoring system that could assess every situation fairly.

**Scouts Grow Over Time** – Most youth with special needs or disabilities are going to mature in many ways during the years they are in Scouting. While Cub Scout advancement is designed to reset the clock with each school year, in other Scouting programs advancement challenges are expected to be met over a period of years. Not everything is within the capability of a new 11 year old Scout, nor should it be. Time is a factor to keep in mind when you evaluate the need for exceptions. If you, in your role as evaluator, believe that the Scout will likely be able to complete the regular requirement in a year or two without delaying things too much, the committee may want to defer making a decision rather than approving or rejecting a request right away. A delay will need to be balanced with the overall time available for the Scout to earn the rank he or she is striving toward. The decision to defer a decision will need to be explained to the people closest to the Scout, and ideally, the committee will set a time in the future to reconsider the application.

What is Expected of Scouts without Disabilities - A Scout rank is a multi-faceted array of challenges, and a typical youth will find some tasks easier than others. If a Scout with a special need finds that a few requirements are really hard to complete, many requirements are doable but take an effort, and a few requirements are really easy; he or she is effectively "typical". At the other extreme, if there is a requirement or required badge that a Scout could not possibly complete, a reasonable alternative is needed. We want it to be challenging for a Scout with a disability to earn a rank, like it is for everyone, but not unfairly difficult. There are no guarantees that any individual will be able to become an Eagle Scout.<sup>1</sup>

What is Important about a Requirement? – Scout requirements usually have a purpose, but the purpose is rarely explained in the requirement itself. When we look at creating an alternative requirement or badge we need to start by trying to understand what the intent of the original requirement was to begin with and how it relates to other requirements. Then we can look for something else that could meet that intent. For ideas, think about this (admittedly incomplete) list of possible intent:

<sup>&</sup>lt;sup>1</sup> Guide to Advancement Section10.2.2.0

- Show knowledge was attained
- Have an experience or a variety of experiences
- Learn or try a skill
- Think something through on a higher level
- Consider your future
- Face and overcome fear or adversity
- Show compassion or serve others
- Learn to teach or lead

**Some Requirements May Only Require an Accommodation** – An accommodation does not change the requirement, only the circumstances of how it is completed. Sometimes, changing the circumstances may allow a merit badge to be completed "as written" without having to apply for an alternative merit badge. Accommodations are best explained with a few examples:

- Allowing a buddy or lifeguard to be nearby in the water for a swimming/water rescue requirement.
- Having a quiet space or special lighting to work by.
- Allowing the Scout to complete the requirement at a different time of day than usual.
- Allowing a requirement that is usually done on an overnight campout to be done indoors or at another type of event.
- Allowing a second person to serve as the eyes, ears, or hands of the Scout.
- Allowing the Scout to use notes or memory aids.
- Allowing the task to be broken into smaller steps that are done at different times.
- Allowing unconventional tools or materials to be used for the task.

**Comparable Challenge** - The honor that goes with the rank needs to be deserved, and it needs to mean the same thing over time. We want all Scouts that earn a rank to have been challenged in a way that is fair to everyone who earns that rank; past, present, and future. The challenge of advancement for Scouts with special needs is to be fair. As all parents know "fair" is not always "the same as for everyone else". Even "challenge" is difficult to measure because it could mean different things in different circumstances, such as required strength/skill, level of effort, amount of time needed, or the quality of the product made. So if we assume the objective of alternative requirements is to make a rank about as hard for a Scout with a disability to earn as it is for a typical Scout, there will always be a devil in the details.

**Life is Harder for a Scout with a Special Need or Disability** – The defining attribute of a special need or disability is that the condition makes ordinary life more difficult. What will vary is which life functions are harder and by how much. It is good for an evaluator to remember that such a Scout may have had a much harder time than other Scouts just doing the regular requirements that he or she could complete. While there is no provision in the *Guide to Advancement* for "life-learning credit" or to simply waive requirements, it might not be fair to make an alternative requirement take as much effort as the original requirement would for a typical

Scout. An evaluator is encouraged to look at the entire body of work of the Scout relative to his or her specific disabilities when considering alternative requirements and badges.

A Person with a Disability Has a Support Team – With rare exceptions, a team of people have rallied around a Scout with a special need or disability. In addition to parents, guardians, grandparents, and siblings, you will find teachers, health professionals, fellow Scouts, and Scout leaders. These people have also made sacrifices to support the Scout and have a vested interest in the outcome of the decisions about exceptions to regular advancement requirements. If the advancement committee decides to deny a request for an exception, the "team" needs to come away understanding the decision and feeling that the situation was evaluated completely and fairly. Since you won't know in advance what you will decide, you need to handle the process of the evaluation in a transparent and supportable manner from the beginning.

#### PROCESSING REQUESTS FOR EXCEPTIONS

The *Guide to Advancement* does not dictate specific procedures for reviewing requests for alternative requirements or remaining a Scout beyond the typical age limit<sup>2</sup>, nor does this *Inclusion Toolbox*. While that allows for flexibility for councils to create processes that work best for them, the processes your council uses need to be thought out in advance and codified. It is important for the users of your evaluation system (members of your council) to be able to know what the steps are, what documentation and forms they will need, who their points of contact are, how long to expect to wait for answers, and how they can appeal a decision if it comes to that. Having an organized and consistent process makes it easier for applicants to accept the decisions that are made. It is also important for the council professional staff to have access to and understanding of these processes so they can respond to questions quickly and accurately.

**Document Limitations** – While certain documents are mentioned in the *Guide to Advancement* to be submitted to request an exception to regular advancement or age; these documents have limitations and may not be enough by themselves for a proper evaluation. The BSA annual health and medical record (AHMR or "medical form") was designed for different purposes than documenting a disability and does not have much space for explanations. Statements from health professionals will likely use specialized terminology that may be unfamiliar to you. Some of the supporting documents will be written by people that are unfamiliar with the Scouting program and therefore may misunderstand what the Scout would be asked to do.

<sup>&</sup>lt;sup>2</sup> The process for a time extension for the Eagle rank is codified in some detail in the *Guide to Advancement*, in recognition that this process needs to be completed both quickly and responsibly. The length of an extension that can be approved at the council level is six months maximum.

**Subject Matter Expertise** – The *Guide to Advancement* recommends getting help from subject matter experts when evaluating individual requests for exceptions<sup>3</sup>. It is preferable to have an advisor that has good knowledge of the effects of the disabilities and good knowledge of the Scouting program.

Councils are encouraged to form Special Needs & Disabilities Committees (see Module U for more details) to support Scouts with special needs and disabilities in various ways. Some of these committees are organized under the council advancement committee and others are placed in other parts of the organizational structure. Ideally, a Special Needs & Disabilities Committee has members with subject matter knowledge on different kinds of disabilities or has a network of knowledgeable people who do. This is the first resource for technical assistance.

However, they are also councils that have yet to form a Special Needs & Disabilities Committee. The evaluators still need subject matter knowledge to put the requests into proper context, even if they do not have ready access to experts. This is one reason why Modules H through S of the *Inclusion Toolbox* were created. These modules describe different special needs and disabilities in the Scouting context and can give more insight.

**Face to Face Meetings** - The most straightforward way to get to know the Scout and the effects of the disabilities is to have a face-to-face meeting(s) with the Scout, his or her family, and the unit leader. This is allowed or encouraged by the *Guide to Advancement* in sections 9.0.4.1(3), 10.2.2.2, and 10.2.2.3, but is not required. The style of such a meeting would typically be similar to a Board of Review (BOR), with a parent or advocate present to help the Scout and the evaluators communicate. Like a BOR, we do not want to test or retest the Scout, but to get to know the Scout. Unlike a BOR, the evaluators may also want to ask questions of the caregivers for the Scout.

#### **REGISTRATION BEYOND THE AGE OF ELIGIBILITY**

The registration beyond the age of eligibility (RBAE) process often falls to the council advancement committee and is addressed in the *Guide to Advancement*. The council executive board is officially responsible for reviewing RBAE applications, but they can delegate that responsibility to another council committee<sup>4</sup>. Most often that is the council advancement committee, but not always. That is why the instructions are to send the application to the council Scout executive.

The criteria for RBAE are explained in detail in the *Guide to Advancement* Section 10.1.0.2 and do not bear repeating here. RBAE is not appropriate for most special needs or disabilities. RBAE is used when a Scout or potential Scout's intellectual capability is much different from his

<sup>&</sup>lt;sup>3</sup> This also applies to Scouts in smaller specialized programs like Venturing and Sea Scouting, where the members of the council advancement committee may not be fully familiar with the differences from Scouts BSA advancement.

<sup>&</sup>lt;sup>4</sup> It should not be delegated to an individual or a district committee.

or her physical age. RBAE by itself is not sufficient to ensure that the Scout, or the other Scouts in the unit, can be well served by the Scouting program. The challenge is that a Scout with these disabilities is usually living life on two levels at once. The Scout is living as an adult in many ways and is being supported and trained to be as independent in his or her living as possible. In this sense, a Venturing program may be the best match for the Scout. On the other hand, the Scout is functioning in a more child-like way in terms of intellectual pursuits and having fun. In that sense, the activities associated with Cub Scouting or Scouts BSA may be more appropriate. This combination of needs is difficult to meet in a traditional unit. Though not a formal part of the RBAE approval process, the committee that considers the request for RBAE status is in a good position to counsel the Scout and family and help put them in touch with a unit that will fit their needs well.

#### HANDLING APPEALS

The BSA can be proud of the training we make available to our volunteer leaders and professionals. However, there are rare times when Scout units or individual leaders create their own rules and processes for advancement that deviate from national policy. There are also rare situations when the local or individual interpretation of national policy results in an error of judgment or an injustice. There are also times when Scouts and families misunderstand what is being asked of the Scout and believe a requirement was completed in a satisfactory manner when it was not. When these situations happen, the council advancement committee often ends up being responsible for dealing with those who suffered as a result.

An event may or may not result in a formal appeal, depending on whether or not the misfortune was the result of a formal decision. Either way, an appeal needs to be given deeper investigation than the original decision, so that there is additional information to consider. The aggrieved party needs the opportunity to be heard directly on the issue. The original decision makers should have an opportunity to explain themselves and their reasoning. While reaching a consensus between the stakeholders is desirable, it is not always possible.

It is important to recognize that how an appeal is handled and how the outcome is delivered are important in and of themselves. By the time someone has made an appeal, that person no longer has a purely intellectual interest in the outcome. There is an emotional dimension as well as they protect the interests of others. That isn't surprising considering that several Scout Laws have emotional dimensions. Furthermore, BSA members hold themselves and others in the organization to higher standards for honesty and integrity than they would another person. Those whose decisions are being challenged also have an emotional investment because strong feelings are triggered when it seems that your skill or reasonableness is being challenged.

#### Author: Roger B. Tate

Reviewers: Mark Chilutti, Alyssa Hightower, Sandy Payne, and Midge Savage

### **MODULE W**

# COMMISSIONER SERVICE FOR UNITS WITH SPECIAL NEEDS SCOUTS

IN THIS MODULE:

OVERVIEW PROMOTING INCLUSION JOINING CONFERENCES PRACTICAL COMMISSIONER CHALLENGES Starting up Joining Conferences Units that steer Scouts with challenges away A Scout that could be better served by a special-purpose unit Exhausted or frustrated leaders Parents that don't understand how their child is being treated Advancement expectation disconnects Acceptance of others and bullying Overwhelmed disability-friendly units Resistance to non-parent caregivers Including special-purpose units in larger events USING LONE SCOUTING FOR SPECIAL NEEDS

#### OVERVIEW

This module is addressed to commissioners, who are called in when units are struggling. One of the key unit service functions is **"Linking unit needs to the district operating committee and other resources"**. The *Inclusion Toolbox* is one of those resources to help you help others. The editors of the *Inclusion Toolbox* encourage you to review the table of contents to get familiar with what you can find here. In addition to this module, we ask you to skim Modules C, D, and E, to set a foundation for your commissioner work.

In this module we draw a distinction between **special-purpose Scout units**, where all of the members share a common special need or disability, and **traditional Scout units** that have a diverse group of members. Most of the attention of this module is focused on traditional units. While special-purpose units have their place, we hope to mainstream most Scouts with a

special need into a traditional unit. Our best data<sup>1</sup> indicate that about 15% of youth already in Scouting have an identified special need or disability and there are more who have milder forms or haven't received a diagnosis. This means that **the vast majority of traditional Scout units are serving Scouts with special needs**, whether the leadership realizes it or not. There is also room to grow Scouting membership by being more inclusive of Scouts with differing abilities

#### **PROMOTING INCLUSION**

From its founding, Scouting has been a world-wide movement that celebrates what we all share as human beings and the common ground we all have as Scouts. That means respecting each other's differences and finding ways to include everyone in our programs if at all possible. When you consider these ideals at your local level, there are two aspects. The first is respecting the differences between one unit and the next in your district and council. The make-up and personalities of the leadership of each unit give the unit a distinctive culture. The second aspect is respecting the differences between the families and Scouts that are part of an individual Scout unit.

As a commissioner, you seek to have healthy units in order to fulfill the promise of Scouting to the most number of youth possible. This is not always easy for every unit. On one hand, people have a natural affinity for others that are like them, but on the other hand, people benefit from sharing life experiences with those who are not like them. There is also a habit in Scout units to keep doing things in the same way they did in the past (traditions). It often takes extra work to be inclusive, but it is worth the effort. A commissioner can gently encourage units to be more accepting and inclusive by helping them broaden their horizons beyond their unit traditions. Maybe the unit can plan a joint outing with another group where their Scouts interact with others who are different from them. Maybe the unit can play games where Scouts get to simulate a disability. Maybe the unit can recruit at a special needs parents group in addition to their usual schools, faith groups, etc.

#### JOINING CONFERENCES

Joining conferences are one of the most powerful tools for getting a Scout with a special need, the family, and the unit leadership working as a team. Module F has complete information on how to conduct a joining conference. A joining conference is similar to a parent-teacher conference at the beginning of a school year. Ideally, the adult leader that will have the most interaction with the Scout meets with the parents or guardians to get to know the Scout better. In Cub Scouting, where new leaders and youth often arrive at the same time, experienced

<sup>&</sup>lt;sup>1</sup> Our best data sources as of 2019 are council-wide surveys taken in four BSA councils. This is supported by data on the general population of school-age children. There is good reason to believe youth with special needs are over-represented in Scouting. We also need to remember that there is a general bias in parents to underreport special needs, especially less severe ones.

leaders in the Pack help provide "quick start" mentoring for new leaders to do joining conferences.

Ideally, joining conferences are held for every Scout in the unit. This keeps Scouts with more obvious special needs from being singled out, and it keeps Scouts with less obvious special needs from being left out. A good argument can be made that every Scout is an individual and has unique strengths and struggles and is worth getting to know better through a joining conference, diagnosis or not. This is also a time to respond to concerns that parents and guardians may have but are not comfortable bringing up in a larger group.

#### PRACTICAL COMMISSIONER CHALLENGES

We are not going to repeat your basic commissioner training in this module. Many detailed questions you might have are covered in other modules of the Inclusion Toolbox, so we are going to trust you to seek out what you need. For the remainder of this module, we are going to give practical advice for situations you may encounter as a commissioner. These situations focus on Scouts with special needs and disabilities, but you will probably come to appreciate how things we do to support these Scouts will often benefit all Scouts.

# **Starting up Joining Conferences** - *How do I help a unit start using joining conferences when they have never done so in the past?*

Here the answer is probably different for a Cub Scout unit than for other types of Scout units. In Cub Scouts units, the program has a natural annual cycle that usually aligns with the school year and the new Scouts are often concentrated in the lowest grade level dens. The best solution is to plan on joining conferences with the new Scouts' families in the first month of the program year, but try to have a similar follow-up conference with all of the Scouts' families towards the end of the program year. The follow-up conference can also be used as a chance to learn likes and dislikes and get ideas for the Pack's annual planning conferences, but there is a good reason. There are a lot of kids that do not get identified as having special needs until they have been in school for a few years. They may have been struggling before, but with more knowledge comes more opportunity to serve their needs.

For Scouts BSA, it is fairly easy to organize joining conferences with new Scouts after your recruiting events or the cross-over of Webelos into your troop. For existing Scouts in the troop, a joining/follow-up conference can be planned to happen near the same time as a Scoutmaster Conference. To clarify, the two conferences serve different purposes and cannot be combined into one event, but a Scoutmaster Conference represents a time for reflection on how a Scout's journey has gone and where it is going next. This reflective moment is a good time for a joining/follow-up conference. Wise Scoutmasters plan Scoutmaster Conferences with Scouts that have not advanced in rank in more than a year as well as those who have completed ranks.

For older age programs, the key difference is the role of the Scout in the process. With Venturing and Sea Scouts, the joining conference is primarily with the Scout, with a parent or guardian attending, rather than the other way around. It is still worthwhile to have a conference with each Scout in the unit. However, it is less likely that follow-up conferences will be needed. By the time a Scout is a teenager, the difficulties associated with a special need are pretty well understood by the family and the Scout and not likely to change as much over time.

When joining conferences start up in a unit, it needs to ultimately include all of the Scouts, so the purpose and the plan need to be communicated with all of the families in the unit. Obviously, a positive outlook in the communication helps rather than looking at it as a task to check off to be "good Scouts".

# **Units that steer Scouts with challenges away** - *How do I deal with a unit that is chasing Scouts with disabilities away rather than seeking to include them?*

First, let's understand that the unit leaders probably mean well, even if they are not handling the situation well. The most common reason for this diversion is that the unit leaders lack confidence that they can do well by a Scout with a special need. They honestly believe there are other Scout units that would serve the Scout better. That may in fact be true for any one individual, but it can form a disappointing pattern where rather than try, the unit leaders push difficulties off on someone else. Sadly, the other Scouts/families in the unit never get the benefit of knowing people with special needs and practicing the Scouting values of kindness, helpfulness, and loyalty. When a Scout is turned away from a unit, there is a risk that a youth that could have been a great Scout gets discouraged and never joins any unit.

Another reason we see for diversion is when unit leaders put the welfare of the Scouts of their unit as a whole above those of an individual Scout. They don't want to "hurt" the rest of their Scouts by slowing them down to accommodate a Scout with a disability. While we don't want to see opportunities withheld from any Scout, sometimes it is good for a "high-performer" to be challenged to slow down to make an activity possible for another Scout that is less capable. This is little different than having older Scouts mentor younger ones.

A third reason we see diversion is that the unit leaders have a "health and safety" rationale for not being comfortable accepting the Scout. There is a mistaken notion that people with disabilities are fragile. A few are fragile, but that is not the norm. As the rest of the *Inclusion Toolbox* makes clear, the limitations on a Scout with a special need are usually due to a lack of imagination about how to make an activity possible, rather than an inherent limitation of the Scout.

A commissioner can make a difference by letting the unit leaders know about training opportunities on the topic of inclusion of special needs. If you can identify specific concerns, there are portions of the *Inclusion Toolbox* you can use for handouts or training. There may be a way to get the unit to help at an event for a special needs/disabilities service organization, like Special Olympics, where the Scouts and leaders can have first-hand interaction. Another

suggestion would be to ask the District Committee to organize a "disabilities awareness camporee" or community event that involves several units. Changing hearts and minds is a slow process.

**A** Scout that could be better served by a special-purpose unit - When is it appropriate to redirect or transfer a Scout away from a traditional unit to a specialty unit?

A Scout should not be excluded from a traditional unit when the family is willing to provide the supportive care that the unit cannot directly provide, but there are times when even the best intentions are not sufficient for the Scouting program to serve that youth. If the Scout cannot help but be left out of a major part of the traditional unit program, a special-purpose unit that operates a more functional program may be needed. As a commissioner you will want to help link these families to units. Your council's special needs and disabilities committee or council special needs and disabilities champion can help you locate the special purpose units in your area.

The most common situation is with intellectual disabilities where the intellectual "age" and chronological age of the Scout are much different. A special-purpose unit can offer a Cub Scout program to an older youth or a Scouts BSA program to a chronological adult. Most other special-purpose units are chartered to special schools or group homes, where Scouting can be a part of their educational or developmental purpose<sup>2</sup>. If a youth attends such a school but the family approaches a traditional unit to join, a frank discussion to understand what goals the family and youth have for Scouting would guide the decision to join a traditional or special-purpose unit.

Scouting has options to serve people who are too old to register for a particular BSA program but intellectually function as a younger person. With appropriate documentation they can be "registered beyond the age of eligibility" (RBAE). This could include a teen registered as a Cub Scout or an adult registered in Scouts BSA, Venturing, or Sea Scouts. Since a Scout with a disability may be approved to participate in Scouting indefinitely, the chartered organization and unit leadership should carefully consider at what point the age difference between the Scouts in the unit and the Scout with special needs is no longer appropriate. For example, the age and size mismatch between a 9 year-old Bear Cub and a 14 year-old Bear Cub may be too much for safety. In this situation, helping the Scout with special needs find a unit that is made up of older Scouts more like him or herself will provide a better experience for the Scout and the Scout's family.

There may be a practical reason why a family wants a special-purpose unit for a non-intellectual disability. This makes sense when a disability requires substantial support infrastructure or accommodations and those resources could be shared between several Scouts. Maybe they can share modified transportation vehicles, tactile models (visually-impaired), a sign language

<sup>&</sup>lt;sup>2</sup> Adults with intellectual disabilities have both adult and child-like aspects to their self-images (identities) and their interests. It is difficult to reconcile these aspects in a traditional unit.

interpreter, or special instruction methods. In these situations, a family should not be forced into a special-purpose unit, but we should be willing to help them find or start one if that is their desire.

**Exhausted or frustrated leaders** - *How do you encourage a bedraggled leader who is exhausted or frustrated by a Scout (or Scout family) with a disability?* 

This is one of the most common difficulties in a unit that has Scouts with special needs. Often, the time and effort it takes to support a Scout with special needs is significantly higher. It is easy for a unit leader to become discouraged or to be overworked. It is important as a commissioner to recognize when this is occurring in a unit.

These difficulties typically take one of three forms: (1) The leader knows that Scout behaves differently from the other Scouts but doesn't know why and sees the Scout as a behavior problem. (2) The leader knows the Scout has a disability, but doesn't know how to accommodate it. (3) The leader knows what to do, but just doesn't have enough help with the Scout during activities.

This is where unit contacts can make all the difference. It is unlikely a commissioner will know what is going on before a serious conflict occurs unless the commissioner is visiting the unit and keeping an eye out. The things to watch for are grouchy/snappy behavior from leaders or chaotic behavior from the youth. Be careful not to label specific Scouts as troublemakers when they may be acting out to compensate for their special needs or are anxious because their needs are not being accommodated.

To deal with the first two types of situations, begin by talking to the frazzled leader when the youth are not around and find out what he or she knows about the Scout. If there was never a joining conference for the Scout, that would be the next step. It is amazing how much patience you can have once you know a Scout has a disability and that the "misbehavior" is an effort to cope with or compensate for his or her struggles. If the family does not disclose a special need or disability, that is not necessarily the end of the trail. The leader can take a guess about the special need and read the module of the *Inclusion Toolbox* that discusses it. Then the leader can start experimenting, trying out different types of accommodations until something works. If the accommodations work, the problem is solved even if the family never acknowledges or discloses a special need.

The third situation, where there just isn't enough help, comes up most often with Cub Scout dens, where there are typically only two or three adults available at meetings. A Cub Scout with a special need may need one adult dedicated to him or her to manage stress or to assist. Additional training, so the leader understands the disability and what accommodations may work, can reduce the burden by reducing overstimulation or other triggers for difficult behavior, but it may not be enough. However, the ultimate solution usually includes getting more adults to help.

The unit committee needs to be encouraged to take initiative to obtain more help for the overloaded leaders. Their options include (1) asking for greater involvement by the family of the Scout that is struggling, (2) getting another parent or committee member to step in as an additional assistant leader, (3) see if an older Scout can serve as a Den Guide or Troop Guide to provide an extra hand, and (4) reaching out to the charter organization for some additional volunteers.

**Parents that don't understand how their child is being treated** - *How do you help a unit avoid or deal with conflict with parents over how their child with a disability is treated?* 

Conflict will always be a part of what we do in Scouting. We constantly challenge everyone involved to do difficult things and by its nature the challenge will create conflict. A typical unit will also have a turnover of both youth and adult leaders which, by nature, will also cause "storming" within the unit.

Most conflict with families of Scouts with special needs can be avoided with good communication. Once more, joining conferences are the first step to come to common expectations. But even so, parents and guardians of Scouts with special needs may be accustomed to people catering to their needs or having schools and other institutions cater to their needs. These families may not understand the personal challenge and managed-risk environment of Scouting. Module B and Module D of the Inclusion Toolbox were written to be tools to help new parents understand how Scouting works for a youth with a disability.

When a unit has a Scout with special needs, it often forces a unit to make changes. They may change what activities are planned, the speed with which the unit moves, or many other aspects. With these variations, it is easy for conflict to arise if we don't communicate the purpose or desired result of the changes. A significant amount of conflict can be generated by the families of the other Scouts, who do not want their child "held back" to accommodate others. The best way to avoid conflict with the entire unit is to have a clear plan and to communicate it with the entire unit of Scouts and Scouting families. This plan would address not only potential changes to Scouting activities to accommodate different abilities, but more specifically how the program will still offer opportunities for more capable Scouts and how advancement will not be changed without substantial reasons.

Once conflict occurs, we should be aggressive at solving the issues. The longer misunderstandings exist, the greater the chance of hard feelings building or worse yet, broken relationships developing. The biggest risk is for the unit leadership to set itself up in opposition to the family, trying to dictate terms and conditions, when we should be trying to partner with the family as a unified team in the best interests of the Scouts.

A commissioner may serve as a mediator. Speak with each side to gather the information. Though you will know some people better than others, keep an open mind, don't take sides, and put aside preconceived notions. Assure the people you talk to that your goal is unity and great relationships in the unit. The more individuals trust you the more likely you will be to get the vital information. Once the problems have been identified, search for solutions. The search may mean talking to individuals one at a time or it may involve the whole unit. It may mean bringing in a special needs and disabilities specialist from your Council. A consensus solution gives you the best chance to bring peace back to the unit.

**Advancement expectation disconnects** - *How do you help units and families form appropriate advancement expectations for their Scouts with disabilities?* 

Many of the most serious conflicts we see in Scouting related to disabilities and special needs are related to advancement. Two modules have been provided in the Inclusion Toolbox on the topic of advancement to use for better understanding. Module E is for parents, guardians, and unit leaders and Module V is for district and council professionals and advancement volunteers.

It is rare for issues to come up in the Cub Scouting program because the standard for performance is "do your best"? When the standard changes to "as written, nothing more and nothing less" at the Scouts BSA level, problems emerge when the people involved in advancement (parents, Scoutmasters and Assistant Scoutmasters, merit badge counselors, and advancement committee members) are not reading from the same playbook.

As a commissioner, there are some things you can look for. If parents at the back of the room are asking you questions about advancement during a unit visit, the unit has not been communicating well with the families and the entire group may need a training session. If you hear rumors about a unit being unusually lax or rigid in their interpretation of requirements, that is something to investigate further. You can also look for patterns in advancement, where first year Scouts seem to advance unusually quickly or slowly.

There are two faulty beliefs that parents or guardians may have that you want to pay attention to. One is that their Scout should be given credit for a requirement when the Scout has made his or her best effort, regardless of quality, like in Cub Scouts. The other is that requirements should be interpreted or flexed to the point that every Scout with a disability can pass the requirement. While there is a lot of reasonable flexibility to be had in interpreting advancement requirements, this flexibility has its limits. There are advancement requirements that are out of reach for certain Scouts. That is why we have procedures to develop and approve alternate requirements<sup>3</sup>. A Scout can earn ranks but is not entitled to them.

For an individual Scout, the best approach is for the unit leader to start talking with the family about advancement early, when the Scout begins the Scouting adventure. **Advancement is a method of Scouting, but not an aim or mission.** The Scout may not benefit from pressure to advance in the ordinary way as much as from having the opportunity for experiences. The family would be well served if they understand that you don't have to earn ranks to be a good Scout or to benefit from the program.

<sup>&</sup>lt;sup>3</sup> These are detailed in the *Guide to Advancement* and there is supporting information in Module E and Module V of this *Inclusion Toolbox*.

The second part of the early discussion is to help the family understand what opportunities for advancement requirements are built into the unit's plans and what things the Scout needs to do "outside of class". The leaders and families need to decide how they are going to provide extra teaching and practice for a Scout with special needs, and who will take responsibility for what. In an ideal situation, there will be a person like an Assistant Scoutmaster to be a mentor and liaison between the Scout, the Scout's family, and the rest of the unit leadership.

The third part of the early discussion is pacing. Do they want to work extra hard to advance at the same speed as others? Do they want to maintain a slower effort that balances other personal and family needs, even if other Scouts advance in rank faster? If they have the Eagle rank as a goal, a Scout with a special need may have to work more efficiently than others and need more guidance in planning his or her work.

Once a Scout has been in the Scouts BSA program for a year or so, some thought needs to be given to whether the Scout will need alternative advancement requirements in order to reach First Class. In this review, remember that Scouts mature and become more capable as they grow, with or without a special need. A task that looks impossible today may not be impossible in a couple of years. But if there are requirements through First Class rank that look insurmountable within the next year or two, encourage the unit and family to begin applying for alternative requirements. When a Scout has been in the Scouts BSA program for three years, thought needs to be given to the remaining Eagle-required merit badges and whether alternative badges will be needed. If so, that approval process should be started.

**Acceptance of others and bullying -** *How do you coach a unit to improve the diversity acceptance of its members and/or reduce bullying?* 

A commissioner can help a unit understand how important the unit culture is to having a good program. A healthy unit pays conscious attention to the values of the Scout Law, and in the context of acceptance, especially the laws Loyal, Helpful, Friendly, Courteous, and Kind. While every instance is unique, bullying generally occurs when a lack of understanding or even fear exists between individuals. In a Scouting unit, Scouts may pick on individuals that are different from most of the group and the motivation may be varied. Scouts with special needs and disabilities are particularly attractive and vulnerable targets for bullying.

Remember, bullying has subtle forms, not just physical abuse, threats, and coercion. Taking advantage of weaker, more vulnerable, Scouts when playing games is also bullying. So is taking advantage of a Scout's naiveté. Making a Scout the regular butt of jokes is a problem. Defaming or telling lies about someone is bullying.

A good strategy for building empathy and preventing bullying is to employ activities and games that give Scouts the opportunity to experience life from the perspective of another. The *Special Needs & Disabilities Activities Guide* has information on some activities that could be used and there are more ideas in some of the modules on specific types of disabilities.

When bullying is already occurring in a Scout unit, it is best to try and understand the nature of the bullying and if possible, the motivation. A unit leader can try to identify what makes the victim different from those that are doing the bullying. If so, some individual discussions should occur to gain control of the bad situation.

In the long-term, group training is a better solution. This training should consist of general antibullying lessons. In the case where a Scout that is different is being picked on, it would be appropriate to build activities and training surrounding the special need in concern. Having the Scout or the Scouting family participate in the training may personalize the training and build some empathy in the unit. In the end, whole-unit training builds a shared investment in the message and allows the entire unit to be conscious of offending situations and then self-police. When the unit holds itself accountable for the behavior, you are more likely to stop bullying before it starts.

# **Overwhelmed disability-friendly units -** *How do you get extra resources for a unit that is disability-friendly but becoming "over-saturated" with kids with disabilities?*

Any unit that is highly successful at serving youth draws extra attention from prospective Scouts. This is also true of traditional Scout units that do a good job of serving those with special needs. An unintended consequence of these good efforts is that the units grow and end up with an unusually high fraction of Scouts with special needs. There are other unintended consequences that a commissioner, or more correctly a district commissioner corps, needs to prevent.

Before discussing how to help the overloaded unit, we should not forget that this is also a sign about how other Scout units in the area are handling Scouts and potential Scouts with disabilities. The leaders of other units are likely making referrals to send families away rather than invite these youth to join their own units. They may be well-intentioned in the short-run, but limiting the experience of their other Scouts and the diversity of their units. It is also possible that other Scout units are doing a poor job of accommodating and integrating Scouts with special needs so families are voting with their feet. However, for every poorly treated Scout who finds a new unit, many more will leave Scouting altogether, with a bad taste that they share with others. An overloaded disability-friendly unit may be a sign that leaders throughout the district need better training about disabilities. Roundtable is one vehicle for doing this training, but it may be necessary to have a special training event for leaders of all units.

When the ratio of Scouts with special needs in a unit goes up, so does the required ratio of adults to Scouts. Before the situation reaches a breaking point, a commissioner may need to step in. The initial focus is on the unit committee. The unit committee itself will need to grow in size and some of the committee members will need to take a more active role in the unit than is typical. In the short run, the committee may need to depend on the families of the

Scouts with special needs to bridge the gap until a more permanent solution is discovered. It may also be necessary to scale back activities until more help can be brought on board.

If the unit is struggling but not in a crisis, the committee will still need to grow, but can focus on longer term solutions. There are often untapped and underutilized resources to be found. One opportunity is to see if grandparents of Scouts are willing to become active volunteers. Another is to reach out to the charter organization to see if they have members who would get involved in Scouting, knowing that there is a need. A third opportunity is to reach out to affinity and parent's associations for youth who have the same special needs as Scouts in the unit. It may also be possible to use contacts within the district committee to find Scout volunteers that stopped participating actively with a unit when their children became adults, but would be willing to start a "second career" as unit leaders.

If a unit is having success serving Scouts with special needs and has a manageable amount of support, these unit leaders are a valuable resource for spreading those skills to other units in the area. A district commissioner corps can work strategically to spread these skills to other units by inviting a unit leader from the effective unit to visit the committee meeting of another unit, or better yet, to come along on a campout and give pointers.

# **Resistance to non-parent caregivers -** *How does a unit respond to having a paid, professional caregiver for a Scout on an outing in lieu of a parent or guardian?*

The general BSA youth protection training assumes that Scouts are capable of self-care in things that require privacy, such as toileting, bathing, changing clothes, and sleeping quarters. Parents and guardians are given special privileges to be alone with their child and help with these tasks. While not very common, there are some Scouts with disabilities that need full-time, round-the-clock assistance with basic life functions, including the previous list plus feeding and administering medications. While the families of these Scouts often provide the bulk of this care, the burden is more than many can handle alone. They often will have paid professional aides that care for the Scout for part or all of the day.

Generally, paid caregivers have the legal permission of the Scout's parents and guardians to render care to their child and to make certain decisions as if they were the parent or guardian. They also generally have a close relationship with the Scout and can be a great resource in making the program a success for that Scout. We should recognize that these paid caregivers have legally been given these permissions and responsibilities.

The current (2020) BSA youth protection training does not directly address this situation, presumably because it is not common. Not knowing better, unit leaders sometimes obstruct a Scout from going on an outing, or require a parent to attend an outing even though the parents have a professional caregiver who can stand in their place. Though acting in good faith as they understand the YPT rules, the leaders can create unnecessary hardship and conflict that could come to a commissioner's attention.

If we treat a professional caregiver like a parent, there are still things the caregiver must do: (1) Meet any state or local requirements for professional caregivers. (2) The caregiver needs to complete BSA YPT training like any other adult on an outing. (3) The caregiver needs to be registered as an adult with the Scout unit, primarily to obtain BSA background checks. (4) The caregiver must complete the BSA annual health and medical record (medical form) appropriate to the outing, long-term or short-term. (5) The caregiver should have appropriate power-of-attorney documents from the parents or guardians. (6) For long-term camps, the camp director should be given advance notice that a non-parent caregiver is coming to camp and make sure that any special documentation the camp needs is brought to camp.

# **Including special-purpose units in larger events** – How do I help a special-purpose unit engage with other Scout units and participate in larger or more challenging outings?

Special-purpose units are always at risk of becoming isolated from the larger fellowship of Scouting. While we can set up special sessions or programs of camp for Scouts with disabilities, and it may be necessary to set aside special areas for them to be located at camp, we need to work at including these units in the regular activities to the maximum extent possible. In addition to a long term camp or camporee situation, a special-purpose unit may struggle with just going on a regular camp-out, because they need help over and above what the usual leaders and caregivers can provide.

While Module AA and the BB Series go into the details of how to make camp disabilitiesfriendly, a commissioner for a special-purpose unit has a matchmaker role to play. A specialpurpose unit can accomplish much more when they go on outings or go to camp with a "buddy" traditional unit. The buddy unit can often offset the need for additional full-time adult leadership in a special-purpose unit. Pairing up with a buddy unit for a camporee allows for integrated patrols to participate more fully in the events and activities than a patrol made up of all special needs. A commissioner helps put leaders from different units in contact so that they can camp together. Let's not forget that the Scouts from the traditional unit will have an experience that will change their lives as well.

Another way a commissioner can help is with recruiting buddy Scouts to attend camp with a special-purpose unit. It may be possible for the special-purpose unit and its financial supporters to give ordinary Scouts a campership to a second week of camp to serve as assistants to Scouts with disabilities.

#### USING LONE SCOUTING FOR SPECIAL NEEDS

It is our preference for all Scouts with disabilities to participate in traditional Scouting units in an inclusive manner. When traditional units are not workable, we typically look at specialpurpose units as the next best option. For a few Scouts, being part of a traditional or specialpurpose unit just did not work. This might include Scouts with severe intellectual disabilities, emotional control/mental health struggles, lower-functioning autism, or other disabilities where a unit could not provide a safe and inclusive experience for that particular Scout. The last remaining option for such a youth to benefit from Scouting is the Lone Scout program (Fact Sheet BSA 210-515). Commissioners need to bring this option to the family so they can decide if it will work for their child and family situation. Sometimes Scouting program ideas and requirements can be integrated into the school-based individualized education plan (IEP) or into a therapeutic plan for applied behavioral analysis (ABA), recreation, music, aquatic, equine, physical, occupational, and/or speech therapy.

It needs to be highlighted that while a Lone Scout does not belong to a Scout unit, he or she can still participate in all of the district, council, and national events that other Scouts do. This includes pinewood derbies, fundraising sales, service projects, day camp, camporee, summer camp, and jamboree experiences. The Lone Scout Counselor (often a parent, but not always) will need commissioner support and need to receive district and council communications like any other Scout unit. The Lone Scout Counselor may be a special education teacher, teacher's assistant, ABA therapist, or even a direct support professional (see the Lone Scout Friend and Counselor Guidebook – BSA 511-420).

Author: Michael Burge Editor: Roger B. Tate Reviewers: John Cherry (Asst. Natl Commissioner for Education &Training), Midge Savage, Britt Flather

## MODULE BB-1

# CAMP PROGRAM FOR SCOUTS WITH SPECIAL NEEDS AND DISABILITIES

## **SWIM AREAS**

IN THIS MODULE:

**OVERVIEW** SWIM CHECK STRATEGIES Leader Communication **Parent/Caregiver Communication** Nonswimmers **Practice Jumps Reach Poles and Edge Lanes CLOTHES CHANGING SPACES OPERATING STRATEGIES Flotation Aids** Early Start and Departure Shade for Mobility Equipment Managing Waves & Splashing SPECIFIC SITUATIONS Deaf Scouts and Scouts that are Non-verbal Blind Scouts **Physical Disabilities Intellectual Disabilities** Autism

#### OVERVIEW

This module is for Swim Area Directors at BSA Scout Camps. It applies to all ages of Scouting. The goal is to provide a concise guide that focuses on the interaction between various types of disabilities and swim area programming. This module focuses on things that are within the control of the swim area staff rather than permanent improvements to the facilities.

Every willing Scout should have opportunity to get into the water and have fun. Many swimming area hours get dedicated to advancement-related activities like merit badges, Cub

adventures, and special award opportunities like snorkel, scuba, and mile swim. However, opportunities for recreational time in the water are especially important for Scouts with disabilities so they can enjoy camp, try new things, and cool off on hot days.

A pool area has a natural advantage over other camp program areas in that it already has hard surfaces and relatively good accessibility. (Shoreline access is discussed in Module BB-2.) The swim area staff has the advantage of getting to talk to leaders from every unit and evaluate almost every camper during swim check. Much of this module is centered on the swim check process and how to make the most of it.

You will encounter some Scouts whose disabilities are obvious, like physical disabilities<sup>1</sup>, blind, deaf, or Down syndrome. For every obvious disability you encounter, there will be several Scouts with less obvious special needs like learning disabilities, ADHD, autism, history of seizures, or anxiety disorders. Camp is exciting and challenging and over the course of a multi-day camp session, Scouts with disabilities may tire out or act out more as time goes on. Some Scouts with milder special needs may start camp without needing accommodations but begin to need them later on.

A last thing to remember is that young swimmers may need extra support and consideration even though they are not disabled and do not have an identified special need.

#### SWIM CHECK STRATEGIES

**Leader Communication** – The starting point for integration of Scouts with special needs is talking to the unit leaders that bring the Scouts to swim check. The leaders can identify Scouts with known disabilities or needs for you. Ask what types of accommodations they think are needed and how your staff can help.

**Parent/Caregiver Communication** – It is not unusual for a parent, family member, or caregiver to attend camp with their Scout with a disability and to be at swim check. This is a good time to ask what their individual goals are for their child when it comes to swimming. Even if the caregiver is used to physically supporting the Scout in the water, encourage the Scout to bring a similar age buddy to the swim area for the fun and social aspects of swimming. Three-person buddy groups with two Scouts and a caregiver are fine.

**Nonswimmers** – Be sure to pay attention to the Scouts that do not want to attempt the swim test and plan to be nonswimmers. Remind them that they don't have to be able to swim to come to the swim area and play in the water. Encourage them to come for instructional swim time and learn. Encourage them to dangle their feet in the water while the others are doing

<sup>&</sup>lt;sup>1</sup> Physical disabilities include people who need mobility equipment like wheelchairs and crutches, but also include people that have limited strength, endurance, or coordination.

swim tests. Not only does this let them cool off, it gives you a way to identify Scouts that have sensory issues and are unable to be in the water at all.

**Practice Jumps** – The first step of the swim test, jumping off and letting your head go underwater, is the often the most daunting part for novice swimmers. Many Scouts are short enough that you can give them an opportunity to take a practice jump in a part of the swim area that is deep enough for them to go underwater, but where an adult can stand in the water. Knowing that there will be someone in the water to help them if they need it can help Scouts get over the mental hump. Another way to practice is with a sliding/hopping entry from a seated position on the edge of the dock or pool. A lower entry gives the experience of going under the water with less splashing.

**Reach Poles and Edge Lanes** – Hearing and seeing in the water are a little difficult for everyone, and swim areas tend to be noisy. Scouts with poor vision benefit from having a swimming lane along the side of the pool, dock, or a buddy boat where they can touch off and maintain their position in the lane. With either vision or hearing limitations, the lifeguard supervising the test can communicate with the swimmer with touches from a reach pole. Before the swimmers enter the water, explain how and where you will touch them if the swimmer is drifting off course or getting close to the end of the swim area for a turn.

#### CLOTHES CHANGING SPACES

Some young Scouts and Scouts with special needs and disabilities have a hard time changing clothes by themselves. It is OK to encourage them and their caregivers to change clothes at their campsites, but depending on how tightly the camp program is scheduled, they may need to change at the swim area. We assume that your facility has divided spaces for youth male, youth female, adult male, and adult female changing spaces but you may not have individual privacy partitions. If your swim area does not have a private space where an adult family member can enter along with their Scout, or a private space large enough for both a wheelchair user and a caregiver to move around in, you may need to improvise in some way. One option is to allow the Scout/caregiver pair to take over the swim area office for a few minutes. Another option is to pitch a tent nearby that can be used as a changing space. The doorway of the tent needs to be wide enough for wheelchair access and tall enough to walk through while standing up, to support users of crutches and those pushing wheelchairs.

#### **OPERATING STRATEGIES**

**Flotation Aids** - Most safety concerns for people with physical disabilities can be solved by using flotation aids. PFDs, pool floats, kickboards, small surfboards, and paddleboards are options to allow Scouts to move about in the water on their own. PFDs are also helpful for Scouts who are anxious in the water or have experienced seizures. Knowing for certain they can remain on the surface can allow Scouts to relax and have fun while they improve their swimming skills. As a practical matter, there is no reason to restrict the use of flotation aids during recreational swimming periods.

**Early Start and Departure** - A person who uses a wheelchair or crutches will need some help to get in and out of the water because the equipment needs to be moved to the water's edge to enter and then be moved away to have a clear walkway around the swim area. This situation is easier to manage if these swim area users are allowed to get into the area before the general group is released to get in the water, similar to preboarding on an airline flight. Some Scouts with sensory noise challenges can benefit from this as well. As a counterpart, it is also a good idea to assist them by giving them a head start at the end of a swimming period so they can move away from the water, move their buddy tags, and get into the changing areas before the walkways get crowded with exiting swimmers.

**Shade for Mobility Equipment** – Wheelchairs and other mobility equipment need to be shaded or covered while the user is in the water. Direct sun can make the surfaces hot enough to burn. This is particularly important because some people with physical disabilities also have nerve conditions where they cannot feel heat and/or pain and will not know they are being injured.

**Managing Waves & Splashing** – There are some Scouts that will find the splashing and wave action in a crowded area at open swim time to be distressing, either because they have limited mobility to protect their faces or have sensory issues with noise or being surprised by water hitting their faces. If you take a look at the overall swim schedule, you may be able to accommodate these Scouts by allowing them to have recreational water time alongside the instructional swim class or a smaller merit badge/adventure/award class.

#### SPECIFIC SITUATIONS

**Deaf Scouts and Scouts that are Non-verbal** - Hearing aids or cochlear implants that a deaf Scout may use most of the time cannot get wet, so they are not worn when swimming. A Scout that uses a communication device<sup>2</sup> for speaking has the same problem. Having a swim buddy that can hear/speak and translate for the Scout is the easiest solution, but it is good to also have some hand signals worked out between the Scout and the swim area staff in advance. It is also possible for the staff to get someone's attention with a reach pole.

<sup>&</sup>lt;sup>2</sup> The formal name is augmentative and alternative communication (AAC) devices. These use keyboards or touch symbols to create speech.

**Blind Scouts** – For free swimming, the Scout will need a sighted buddy to help avoid obstacles. All of the rescue methods required for Scout ranks can be performed using sound to locate the target subject. Surface rescue techniques for Swimming and Lifesaving merit badges can also be performed by ear. These merit badges have requirements to bring an object up from the bottom, which might be more difficult for a blind Scout. However, the requirements do not say that the Scout must find the object on his or her own, or that an aid to locating it cannot be used.

**Physical Disabilities** – Swim area staffers may need to help get a Scout transferred from a chair into the water. Even though these Scouts might look frail, that does not necessarily mean they are fragile. When Scouts are unable to control their movement in the water, they need a responsible buddy to stay with them and move them through the water. An important thing about the buddy is that the Scout needs to be able to trust the buddy completely. If another Scout is going to be a helper, the helper needs to be taught that he or she can never play a trick in the water on the Scout that needs help.

**Intellectual Disabilities** – Some Scouts with intellectual disabilities may be hard to coax out of the water when you need them to come out, because they are having fun. When they come back for another swim session, take a minute to talk with them to reach an agreement about how they will behave when it is time to come out and how you will let them know it is time to come out.

**Autism** – Some Scouts on the autism spectrum have such a strong sensory aversion to getting into the water that the standard BSA swimming requirements are hard or impossible for them to achieve. They don't look any different from other Scouts, so it is hard for others to understand this. Leaders and family members may be strongly motivated to get them through the beginner and swimmer tests so they can advance in rank. Where this impacts the swim area operation is that the regular swim check environment is noisy and hurried enough that the Scout cannot do his or her best and then Scout can become a bottleneck in the process. If you sense this is going on, act promptly and quietly offer the Scout/Leader/family member the option of coming back to the swim area at a less busy time to attempt the swim test. This keeps a Scout that is already in an uncomfortable situation from becoming a spectacle and a target for teasing.

Author – Brent Worley Editor – Roger B. Tate Reviewed by – Program Support Subcommittee of the National Special Needs & Disabilities Committee

## MODULE BB-2

# CAMP PROGRAM FOR SCOUTS WITH SPECIAL NEEDS AND DISABILITIES

## WATERFRONT AND BOATING

IN THIS MODULE:

OVERVIEW COMMUNICATION MOBILITY ACCESS TO THE WATER'S EDGE INCLUDING NONSWIMMERS & BEGINNER SWIMMERS PFD RISK ASSESSMENT BUDDIES AND BUDDY BOATS SPECIFIC SITUATIONS Physical Disabilities Blind Scouts Deaf Scouts and Scouts that are Non-verbal Intellectual/Learning/Executive Function

#### OVERVIEW

This module is for Waterfront Directors at BSA Scout Camps and supplements the information in *Safety Afloat*, which is the authoritative document. It applies to all ages of Scouting. The goal is to provide a concise guide that focuses on the interaction between various types of disabilities and programming in natural bodies of water and with boats. This module focuses on things that are within the control of the waterfront staff rather than permanent improvements to the facilities. **Since aquatics safety information is presented at varying levels of detail across BSA documents and web resources, key information has been copied over into this module for easy reference.** If your camp conducts its swimming activities at a waterfront location, see Module BB-1 for information on swim area operations.

Every willing Scout should have opportunity to get in and onto the water and have fun. **Opportunities for recreational time on the water are especially important for Scouts with disabilities** so they can enjoy camp, try new things, and cool off on hot days. While techniques discussed here can be applied to watercraft instruction time like merit badge classes, this module focuses on the less structured recreational time.

The waterfront program area has a natural advantage over other camp program areas. The most widely effective accommodation for Scouts with disabilities in boats and in open water is wearing a personal flotation device (PFD). Since PFDs are required for every activity in a natural body of water besides swimming in a controlled area, no extra equipment or planning is required for many Scouts with special needs or disabilities.

The waterfront program area also has more complexity than some other program areas. There is a wide variety of watercraft that can be used and there may be aquatics play structures, swimming areas, and fishing areas located in or near boating areas. (Fishing activities are addressed in Module TBD and swimming areas are addressed in Module BB-1.) Non-powered craft include canoes, kayaks, rowboats, paddleboats, small sailboats, and standup paddleboards. Motor powered craft include "Jet Ski<sup>®</sup>"<sup>1</sup> personal watercraft (PWC), motorboats, and pontoon boats. Each type of watercraft has its own procedures and sequences for launching, propelling, steering, and landing that need to be taught and adhered to.

Since passing the BSA swim test is a prerequisite for the watercraft merit badges, we tend to assume that a Scout that can pass the swim test can do everything else it takes to operate a watercraft. The swim test is not a clean dividing line. Some people who could not complete the swim test, like a person with lower body paralysis, could successfully paddle, row, sail, or drive. There are also people who can physically complete the swim test and all the actions needed for boat handling, but need extra instruction or time to learn the skills of boating or need a mature person in the boat as a buddy to assist with decision making.

#### COMMUNICATION

Some Scouts have disabilities that are obvious, like physical disabilities<sup>2</sup>, blind, deaf, or Down syndrome. For every obvious disability you encounter, there will be several Scouts with less obvious special needs like learning disabilities, ADHD, autism, or anxiety disorders. Camp is exciting and challenging and over the course of a multi-day camp session, Scouts with disabilities may tire out or act out more as time goes on. Some Scouts with milder special needs may start camp without needing accommodations but begin to need them later on.

The Scouts that come to participate at the waterfront do not necessarily identify themselves to the staff as having a special need. The key thing to remember is if a Scout is making errors in following instructions or rules it could easily be due to features of a special need or disability rather than ignorance or disobedience. If you take a little time to interact with the Scout directly, you can get a sense of whether extra help will be needed.

<sup>&</sup>lt;sup>1</sup> Jet Ski<sup>®</sup> is a registered trademark of Kawasaki

<sup>&</sup>lt;sup>2</sup> Physical disabilities include people who need mobility equipment like wheelchairs and crutches, but also include people that have limited strength, endurance, or coordination.

If you have a question or concern about an individual Scout and want to know more about him or her, reach out to the adults from the unit. First, look around your program area. In some instances, a family member, caregiver, or unit leader is discreetly watching their Scout from a distance. Feel free to approach while someone else on your staff watches over the Scout. Otherwise you will have to track down an appropriate adult. If you won't be able to leave the waterfront during "business hours" you can try to catch the unit leaders at the next mealtime or use your camp commissioners to reach out to the leaders and ask them to come to see you at the waterfront.

#### MOBILITY ACCESS TO THE WATER'S EDGE

It is rare for a camp to have a wheelchair accessible path all the way to the water's edge. Users of wheelchairs and crutches often need vehicle transportation from the central area of the camp to the waterfront. Local conditions, like the steepness of the shoreline, vary too much to give specific advice, but it is worthwhile to think through in advance how the waterfront staff will generally transport such a Scout from the last accessible point to the water and into a boat. If the Scout must be physically carried, take guidance from the Scout, family member, or caregiver on the most comfortable and safe way to do so.

Wheelchairs and other mobility equipment need to be shaded or covered while the user is in the water. Direct sun can make the surfaces hot enough to burn. This is particularly important because some people with physical disabilities also have nerve conditions where they cannot feel heat and/or pain and will not know they are being injured.

#### **INCLUDING NONSWIMMERS & BEGINNER SWIMMERS**

From Safety Afloat - Point 3 – Swimming Ability

For activity afloat, those not classified as a swimmer are limited to multiperson craft during outings or float trips on calm water with little likelihood of capsizing or falling overboard. They may operate a fixed-seat rowboat or pedal boat accompanied by a buddy who is a swimmer. They may paddle or ride in a canoe or other paddle craft with an adult swimmer skilled in that craft as a buddy. They may ride as part of a group on a motorboat or sailboat operated by a skilled adult.

To restate this in the affirmative, Scouts of any ability level may go out in small boats. They do not have to pass the BSA swimmer-level test first. They may learn to paddle, row, and operate boats if they are willing and physically able to do so. With precautions, Scouts may go out in boats even if they cannot paddle, row, or pedal.

As we will discuss later, you may need to make individualized adjustments to allow a Scout or adult with a special need or disability on the water. Some examples are:

- Equipment modifications like adding backrests, securing the Scout into the seat on larger boats, increased flotation aids, etc.
- An increased level of skill for the Scout's buddy. This could be aquatics skill, demonstrated by merit badges or certifications, or it could be maturity and decisionmaking.
- A three-person buddy group where one of the buddies could focus attention on the Scout with the disability after an overturn.
- Improving the supervision ratio for the activity as a whole, using aquatics staff and other qualified adults and or support boats.

**Be creative.** These adjustments might require deviations from BSA Aquatics rules and procedures or deviations from the traditions of the camp. Remember that there is a decision framework (flowchart) in the BSA Aquatics Staff Guide for you to use to meet the objective of safety when not every rule can be followed. It is reasonable to compensate for one rule that needs to be relaxed by making another procedure more restrictive. **A copy of the decision framework is included at the end of this module.** 

#### PFD RISK ASSESSMENT

A Scout that completes the BSA swimmer-level test in a clear pool may not be ready for an open water experience where the bottom is not visible or is not smooth. The difficulties can be mental as well as physical. We expect that beginners and nonswimmers will be on calm water and wearing PFDs, but for a Scout with a disability you may want to assess the risk for the Scout if he or she goes into the water unexpectedly. Some PFDs are designed to help turn a person face-up in the water and others are not. It is good to know if the Scout with limited mobility is capable of turning face-up and floating while wearing a PFD.

With the Scout's consent, this can be evaluated in shallow water by turning the Scout face down in the water and seeing if the Scout will need assistance to turn face up. This also tells you whether the Scout is likely to panic if he or she ends up in the water. Understand that if a Scout is not able to turn face up without assistance, that does not disqualify the Scout, it just means you need to account for that in your planning.

A PFD assessment has other potential benefits and you may want to implement it with all of your Scouts. With or without a disability, some Scouts have little prior experience being in open/murky water or using a PFD. If a Scout has anxiety with being in murky water, a PFD assessment will reveal this. The assessment is also a chance for the Scout to learn to trust that the PFD works, and to become more confident about going on the water. Another thing to remember is your interest and professionalism in conducting a PFD assessment gives the supporting family members or caregivers confidence in you and your program.

#### **BUDDIES AND BUDDY BOATS**

While the general responsibilities of a swim buddy and buddy boat are well understood, namely to maintain a lookout for one another and assist if there is a problem, the priorities can change when one of the boaters has a special need or disability. This is partially addressed by requiring a beginner or nonswimmer to have an adult buddy when they are in a paddlecraft (e.g. canoe, SUP, kayak). Even if an adult is not required by *Safety Afloat*, the waterfront staff will want to make sure that a Scout with a disability has a more skilled and mature buddy than ordinary, that the buddy is aware of the disability, and is prepared to prioritize assisting the buddy over recovering the boat.

The role of the buddy boat may need to be emphasized as well. It needs to be clear which boat is the buddy boat for the Scout with a disability and the people in that boat understand that the boats need to stay closer together than they would otherwise.

#### SPECIFIC SITUATIONS

**Physical Disabilities** – Remember that physical disabilities can include a variety of conditions, not just difficulty walking. They include upper body limitations and limitations on muscle control, stability, grip, or coordination. It is difficult to give specific guidance for boating because of the wide variety of watercraft, water conditions, and limitations a Scout could have. If a wheelchair is going onboard a larger craft, there need to be provisions to tie down the wheelchair so it does not move around on deck. For smaller craft, you may need to build a seat back for the seat to support the Scout's upper body. Tying a Scout down is not advised.

If the Scout is unable to maintain a safe, face-up floating position on his or her own, the buddy will need to be able to function as a lifeguard. *Safety Afloat* requires the buddy to be an adult who has passed the BSA swimmer-level test. However, that may not be enough skill level by itself to manage the risks. The adult buddy needs to be familiar and comfortable enough with the watercraft that he or she can give due attention to the Scout, and also needs to have in-thewater rescue skills to assist the Scout in the event of an overturn.

Scouts with a physical disability, even moderate ones where they could be rated as a swimmer, should not be alone in a boat. That does not mean that a capable Scout cannot do the solo boat handling required for merit badges (e.g. paddle a canoe or kayak, steer a sailboat, or drive a motorboat), but it does mean there should be a second person on board to assist in an emergency. A good example of this need would be a Scout that experiences seizures.

**Blind Scouts** – The standard BSA *Safety Afloat* rules are generally sufficient, provided a blind Scout is paired with a sighted buddy. The sighted buddy provides verbal guidance for the direction to go, but does not have to be steering the boat. With one-person craft, like kayaks or

paddleboards on calm water, the buddy could in fact be in a buddy boat. For boating merit badges that require solo boat handling, a buddy needs to be aboard or close by to provide directions (left/right) while the Scout performs the requirement.

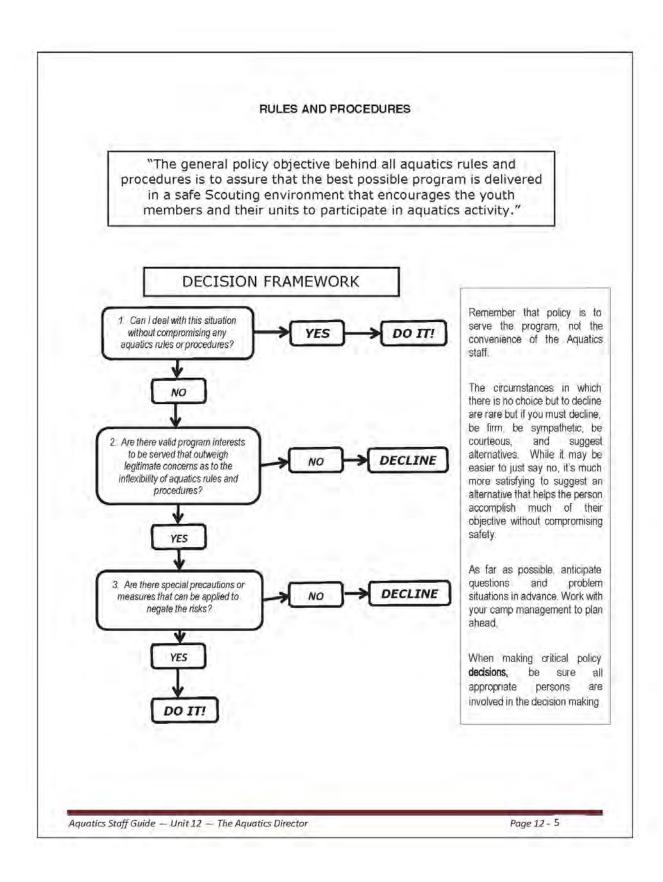
**Deaf Scouts and Scouts that are Non-verbal** – The hearing aids or cochlear implants that a deaf Scout may use most of the time cannot get wet, so they are not worn in boats that can overturn. A Scout that uses a communication device<sup>3</sup> for speaking has the same problem. The Scout needs a boat buddy who can hear/speak and translate for the Scout. This is particularly important in a waterfront area where the staff cannot reliably get someone's attention by touching or hand signals. Within the boat, the deaf Scout and buddy need to have some nonverbal signals worked out between them in advance of the activity. There are several ways they can get each other's attention by touching or splashing. In small boats it may be practical to communicate by tapping on the hull and feeling the tap through the seat. Tap codes could be used for "go right", "go left", "faster", "slower", and "stop". The hand signals used for cycling could be adapted to boating as well.

**Intellectual/Learning/Executive Function**<sup>4</sup> – Though distinct, these three classes of special needs relate to decision-making ability and learning/remembering sequences of operations. Such a Scout will need more instructional time than others and may need one-on-one instruction to learn necessary boating skills. In any event, the Scout needs to be paired with a mature buddy that he or she is willing to take directions from. In this situation, the buddy takes on the responsibility of managing risk and is ready to assume leadership if a boat overturns or runs into trouble. In a group instruction situation, you may want such a Scout to be in the same boat as the instructor.

Author – Brent Worley Editor – Roger B. Tate Reviewed by – Program Support Subcommittee of the National Special Needs & Disabilities Committee

<sup>&</sup>lt;sup>3</sup> The formal name is augmentative and alternative communication (AAC) devices. These use keyboards or touch symbols to create speech.

<sup>&</sup>lt;sup>4</sup> Executive Functioning is the collection of skills that go with the ability to organize work, such as breaking complex tasks down into simpler steps, prioritizing, placing work in sequential order, and dealing with the unexpected. This special need occurs on its own and in conjunction with ADHD and autism.



## MODULE BB-3

# CAMP PROGRAM FOR SCOUTS WITH SPECIAL NEEDS AND DISABILITIES

## **SHOOTING SPORTS - GUNS**

IN THIS MODULE:

OVERVIEW

THE TWO KINDS OF SCOUTS WITH DISABILITIES ASSISTANTS FOR SCOUTS WITH SPECIAL NEEDS **CAMP ORIENTATION STRATEGIES GENERAL OPERATING STRATEGIES** Time Management **Designated Lane Giving Range Commands Addressing Safety Issues** SPECIAL TRAINING FOR A SCOUT'S ASSISTANT Main Things Vigilance **Speed and Proximity** Strength Authority SPECIFIC SITUATIONS Wheelchairs Blind/Low Vision Deaf/Hard of Hearing/Non-Verbal Sound Sensitivity Lower Body Physical Disability **Arm/Upper Body Strength One-handed and Hand Strength Limitation** SUGGESTED EQUIPMENT LIST

#### **OVERVIEW**

This module is for Range Officers responsible for shooting activities involving gas and spring propelled projectiles; including BB gun, chalk ball, airsoft (plastic BB), rifle, black powder, shotgun, and pistol. (Activities with low velocity projectiles; such as arrows, sporting arrows, slingshots, tomahawks, and knives are addressed in Module BB-4.) The goal is to provide a concise guide that focuses on the including various types of disabilities in gun range programming. This module focuses on things that are within the control of the range staff rather than permanent improvements to the facilities. It also incorporates the coach-pupil model of range operation, with Scouts paired up at the firing line, with one shooting and one coaching at any given time.

In this module, the **range officer** is the person in charge of a particular shooting range while it is open and active. Additional staff members at a shooting range are called **range aides**. Range aides are under the supervision of the range officer. Participants may be used to using the term "Rangemaster" for one or the other of these roles, but avoid confusion in this module that title is not used. Range aides have shooting skills and might teach in the shooting activity. Later, we will introduce the term "**assistant**". An assistant is a person who supports a person with a disability on an individual basis, but has no special shooting knowledge or skill. There may be times when a range aide serves as an assistant for a person with a disability, but a typical assistant would not be qualified as a range aide.

Every willing Scout should have the opportunity to learn to shoot safely, have fun, and enjoy the sense of accomplishment that comes from making contact with the target. BSA shooting sports are subject to age restrictions that correspond to the BSA program levels. However, the underlying reasoning is not spelled out, and all **range officers need to pay attention and help Scouts that are having difficulty even though they meet the age requirements for the activity**.

You may be tempted to try to apply an arbitrary equivalent age to a Scout with a special need or disability to decide whether to allow a Scout to participate. This is problematic in many ways. The way an individual Scout's abilities interact with a specific activity is unique and there is no way to create a formula to score whether a Scout can or cannot be allowed. A typical range officer would not have the medical/behavioral health skills to make such an assessment. Fortunately, **in nearly every case, the special needs of an individual Scout can be accommodated safely with additional personal support and supervision.** 

You will encounter some Scouts whose disabilities are obvious, like physical disabilities, blind, deaf, or Down syndrome. Physical disabilities include people who need mobility equipment like wheelchairs and crutches, but also include people that have limited strength, endurance, or coordination. For every obvious disability you encounter, there will be several Scouts with less obvious special needs like learning disabilities, ADHD, autism, history of seizures, or anxiety disorders. Camp is exciting and challenging and over the course of a multi-day camp session, Scouts with disabilities may tire out or act out more as time goes on. Some Scouts with milder

special needs may start camp without needing accommodations but begin to need them later on.

A last thing to remember is that younger, Cub Scout age, shooters may need extra support and consideration even though they are not disabled and do not have an identified special need.

### THE TWO KINDS OF SCOUTS WITH DISABILITIES

There are a lot of different types of special needs and disabilities and any one person could have a combination of needs, and people can have different levels of disability from the same condition. However for the purposes of running a shooting program we can boil this down to two different groups, with just a little bit of overlap. **The dividing line is the maturity/intellectual ability of the Scout.** In the first group are Scouts that have a need, but they can understand range commands and operations and take the safety rules seriously. Their needs have to do with the mechanics of shooting. Most Scouts in this group will arrive at the range with someone to assist them and their needs fall into the general category of adaptive sports, with equipment modifications. We will get into adaptations later.

In the second group are Scouts who could have erratic behavior once they are on the range. There are a variety of disabilities that could result in erratic behavior, but the point is not to exclude them from the range but to find a way to prevent unsafe actions. Some of these Scouts will arrive at the range with someone to assist them and you can work with the assistant. The more challenging situation is when such a Scout arrives at the range with only an ordinary "buddy Scout" and no one identifies the Scout to the range staff before the Scout gets on the range. We will discuss how to manage this group of Scouts in more detail later.

## ASSISTANTS FOR SCOUTS WITH SPECIAL NEEDS

Additional personal support and supervision at the shooting range solves nearly all problems. In practical terms this means a person to provide one-on-one support for the Scout. A range aide can serve as the support person, but that is most appropriate for a Scout that only needs personal help at the shooting range and nowhere else at camp. Some Scouts with special needs or disabilities that come to the shooting range will have an assistant with them. An assistant can come in many forms. It could be a responsible mature Scout (peer buddy), parent/guardian, adult leader from the Scout's unit, professional caregiver, chaplain, etc. An important thing to recognize is that **the Scout and the assistant form a team**, and they need to be thought of as one unit at the range. The assistant is not a spectator or an extraneous person that needs to be kept away from the firing line. The assistant knows more about the Scout's abilities and limits than the range officer does, and knows how to best help the Scout. The other important thing to recognize is that **the range officer and the assistant also form a team** to assure the shooting experience is both safe and enjoyable. This second team will need some time to coordinate their efforts before shooting starts.

## CAMP ORIENTATION STRATEGIES

While all Scouts arriving at camp get seen by the camp medical department and for swim check, traditionally the range officers don't get to know a Scout until the Scout turns up at the range for a class or for an open shooting time. This is manageable if you have enough staff at the range to operate the range while freeing up the rangemaster to work out the details with the Scout with special needs and his or her assistant.

A better solution is to build a time into the schedule, either on camp arrival day or the first morning of camp, to meet with any leaders, parents, guardians, or caregivers that brought a Scout with special needs to camp or have an unusual concern. (This is actually a good idea for every camp program area.) This will allow you to focus attention on the actual accommodations you need to come up with, and give you and your staff time to think some things through. It also allows you to build a rapport with the assistants that will be coming to the range with Scouts and help them understand what your safety concerns are so they can accommodate you as well.

Another subject to discuss if time permits, is what the Scout's individual goals are. A Scout doesn't have to achieve a high level of marksmanship to have a good time and learn about the sport of shooting. On the other hand, if the Scout wants to shoot with accuracy, you can talk about ways to get enough practice time and instruction to meet that goal.

## **GENERAL OPERATING STRATEGIES**

**Time Management** – Shooting ranges are a popular camp feature and we often want to maximize the number of Scouts that can participate. We are used to operating ranges in shooting cycles where all the shooters are kept synchronized. When a Scout with a disability is on the range, that Scout may not be able to fire at the same rate as other shooters. This can create a situation where the other Scouts could resent being held up by the Scout with special needs and the Scout with the special needs may feel pressured and frustrated, unnecessarily. Rather than bog down the entire shooting activity, consider allowing the Scout with a need to remain on the firing line for two or three cycles while you rotate other shooters on and off the firing line. From a safety standpoint, the key thing is to have the range cold at the right times. The range officer will ensure that ammunition is removed from all positions while anyone is down range. If a person needs to remain at a firing position on the range for any reason, the firearm shall also be removed from that position. The unfired ammunition can be reissued as needed to complete the target round. Unfired rounds in the breech can be ejected to clear the gun.

**Designated Lane** – It is a good idea to take a look at your range before camp season starts and designate a shooting lane for those Scouts with a disability that require an assistant with the Scout at the range. Since every range is different, you will want to consider different features

to choose the lane that would work for you. (1) Can the Scout get in and out of the range without being obstructed by other shooters? (2) Can the Scout stay on the range more than one shooting cycle without obstructing the passage of other shooters that are leaving and entering? (3) Which lane has enough space for a table or bench to be set up to support a shooter in a chair? (4) Which lane has enough space for both the Scout and an assistant to be in the lane at once? (5) Understanding that the assistant is providing direct supervision of the Scout, which lane allows the range officer the best sightlines to supervise all of the shooters on the range?

**Giving Range Commands** –We are used to giving range commands verbally, and most command sequences expect a verbal response from the shooter. At a typical shooting range at a BSA camp, the people on the range are using passive hearing protection, so everyone is at a disadvantage. Verbal range commands obviously do not work for deaf Scouts, and there are others that are non-verbal and are not able to reply out loud. There is a section later in this module to address their needs. This leaves two practical options that would support everyone else. The first is to convert to electronic noise-cancelling hearing protection devices that allow ordinary speech to be clearly heard and the other is to implement a visual signaling system of flags or lights to communicate the most critical commands, like "cease fire". Although it may take some ingenuity to implement, a system that would turn or drop targets out of view would be another way to get the attention of a shooter.

Addressing Safety Issues – Safety is the number one priority on any range. How the instructor/range safety officer handles these issues is critical to supporting participants in their understanding and enjoyment of the activity. The action(s) of the instructor will depend on the nature of the safety issue.

While we want to maximize inclusion of Scouts with different abilities into the shooting program, it needs to be said that **the health and safety of Scouts must take a priority**. One of the jobs of the Scout's assistant is to recognize when the Scout is struggling and needs to leave the range for a while to regroup (self-regulate).

If the range officer needs to remove a participant from the range, take time to explain to the Scout and the assistant what the problem was (if it wasn't obvious to the participant), and why it is an issue. Ask the Scout how the problem can be resolved, and what the Scout can do differently to be allowed return to the range. It might be as simple as saying they understand and will try to do better. As options, you can offer additional training or shooting at times when you can provide better supervision or when there are fewer distractions.

A difficult situation that can occur is when a Scout arrives at the range without an assistant or a responsible adult from the Scout's unit and the range officer/instructor is unaware that the Scout has a special need. If the participant has to be removed from the range for not following safety procedures this can create hard feelings between the Scout's unit and the camp staff. The most important message to communicate to the Scout is that he/she is not being banned from the range but the range staff needs to get help from the unit leadership to resolve the

issues. We suggest using a "take home" note or card that you can send back to the campsite with the Scout. Here is a sample text that you can edit for your purposes:

RANGE RETURN INSTRUCTIONS
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\_\_\_\_\_\_\_of Unit \_\_\_\_\_\_\_likely needs an accommodation in order to shoot safely at the \_\_\_\_\_\_\_ range and the shooting staff needs input from those that know the camper best. He/she has been asked to leave the range for now and to return later with a unit leader, caregiver, parent, or guardian to discuss what we need to do differently to allow this youth to shoot on the range. The shooting staff wants every camper to have an enjoyable, educational, and safe experience at our range. The best way to achieve this is with clear communication between everyone involved.

Sincerely yours,

Range Officer

Outright banishment from a range is a last resort. Every effort must be made to resolve safety concerns with the Scout and the unit leaders before banishment. Any time a Scout is asked to leave the range for any reason, the program director should be notified. A conference between the range officer/instructor, program director, and Scout's unit leader should be requested.

## SPECIAL TRAINING FOR A SCOUT'S ASSISTANT

Range officers always provide an orientation for shooters arriving at the range for the first time to explain the type of guns being used, the features of that specific range, and to review the range commands. An assistant arriving with a Scout with special needs will need this same training and a little more. If you are using a range aide as a Scout's assistant while at the range, these supplemental instructions will still apply. The range officer cannot be the individual's assistant if there are any other participants on the range.

All assistants need to know that they are being relied on to be the hearing/speaking translator to communicate range commands back and forth. This needs to be fast and the method the assistant uses to communicate with the Scout through hand signals, signs, or touch needs to be worked out and practiced before firing any guns. Be sure to have a way for the Scout to acknowledge a command.

For a Scout in the first group that we mentioned earlier, where the Scout has sufficient maturity to comply with range rules without any concern, the discussion with the assistant and Scout will focus on what the Scout needs help with specifically, and how equipment on the range can be deployed to make shooting workable. That is the easier situation.

With Scouts in the second group where the Scout may not be relied on as an individual to follow range rules by himself or herself, the discussion with the assistant takes on another dimension. Not every caregiver will be willing and able to take on the role of a shooting assistant, but they won't be able to make that decision until the range officer has briefed them on the responsibilities.

**Main Things** – The assistant needs to understand the two things that must be accomplished are that (1) no shots are fired after a cease fire command; and (2) no one goes downrange to retrieve anything until a cease fire/stop command has been called and all ammunition is secured. The assistant must be able and willing to do what it takes to accomplish this, including taking hold of the shooter.

**Vigilance** – The assistant needs to understand that they are providing a focused set of eyes and ears to keep the range safe for everyone. They are not there to take pictures or videos of the Scout's experience to share with folks back home. The assistant needs to remain focused on where the firearm is pointed and on controlling that.

**Speed and Proximity** – The assistant needs to be able to act quickly to respond to unexpected movements of the gun. This means that the assistant needs to stay physically close to the Scout that is shooting on the range.

**Strength** – When a disability creates a realistic concern that the Scout might wave a gun around, the assistant has to be strong enough to physically control the direction of the gun and overpower the Scout's movements. A size mismatch between a stronger Scout and a weaker assistant could be a problem. The obvious example would be a Scout that has an intellectual disability and is physically an adult, but is participating in Scouting as a youth. In situations where an assistant must take control, this means taking hold of the gun, not the Scout. So, if there is a reasonable concern about gun waving, it would be prudent to exclude the Scout from shooting pistols or similar short arms, because they don't offer enough grip points for the assistant.

**Authority** – The assistant is operating under the authority of the rangemaster but also has authority over the Scout. If the assistant recognizes that the Scout is not in a "good head space" for safe shooting or is being distressed in some way, the assistant needs to remove the Scout from the range and has the authority to do so.

**Working with the Coach-Pupil** – The assistant should involve the coach-pupil partner of the Scout with a disability as a support person when it will help the situation. The partner benefits from being exposed to a different person and the Scout with a disability feels more included.

### SPECIFIC SITUATIONS

**Wheelchairs** – Shooting ranges have a natural advantage over most other camp program areas in that they are compact and often have some hard surfaces, which make accessibility easier to create. Permanent modifications to provide access to the shooting range for wheelchairs and mobility equipment is outside of the scope of this module. It bears mention in passing that it should be possible to bring a shooter up to the firing line and be able to transfer a shooter from a wheelchair to another chair for shooting. If the range staff needs to help a Scout transfer from and to a mobility chair, they need to take direction from the Scout and the caregiver to do so in the most comfortable way. A Scout that looks frail may not actually be fragile.

**Blind/Low Vision** - Even without vision, a Scout can master the underlying skills of marksmanship. All people have an internal sense called proprioception, which allows us to intuitively know where every part of our body is at all times. It is how you can touch your nose or your opposite elbow with your eyes closed. A Scout that doesn't see can use this proprioception sense to maintain a consistent arc with shotgun and can synchronize the motion to the sound of a target thrower. For other shooting, the Scout will need a gun with a laser sight and a spotter to guide the aiming. A steel "gong" target for the Scout to shoot at is recommended because it gives immediate positive feedback when the shot lands on target. All that a Scout needs is a spotter to assist with aiming. A Scout who doesn't see well may need extra instruction time, off of the firing line, to learn how to load and clear the gun by feel.

People with low vision may not get their best vision by looking straight ahead. It could be that they see best while their eyeballs are turned up, down, left, or right. They probably do this all the time and don't think about how it looks to others. It is OK to ask the person how much vision they have and if there is anything you can do to make the target more visible. If you need more information about vision, see Module M.

**Deaf/Hard of Hearing/Non-Verbal** – The challenge here is not the actual shooting, but communicating to keep the range safe. The Scout will need a second person with him or her to translate both ways, to give and acknowledge commands. If a hearing Scout is paired with a non-hearing Scout as coach-pupil, the hearing Scout can help make sure that cease-fire commands are communicated. If the Scout already has a tablet, sign language, signboard, or other means of communicating, you want to use that first. While it is not a good choice for range commands, for shooting instruction it is helpful to have a clipboard-size signboard with icons or words that the assistant and Scout can use to communicate by pointing. A small whiteboard and markers can help with communication as well.

We also need to discuss the use of hearing protection for deaf or hard of hearing Scouts. It is appropriate to require the use of hearing protection for all Scouts, even those with poor hearing. For the hard of hearing, we want to do what we can to protect their residual hearing. Totally deaf Scouts may not see a point in this and resist your request. But you can and should ask these Scouts to wear hearing protection as a good example to others even though they might not benefit from hearing protection themselves. Refusal should not be treated as grounds to ask them to leave the range.

A person that uses hearing aids or cochlear implants for hearing will need to wear over-the ear hearing protection if they are using their hearing aids or cochlear processors. (If you aren't familiar, the cochlear processor looks like a larger hearing aid, with a transmission coil that attaches to the head behind the ear.) If they choose to take off their hearing aids or processors for shooting, they will be temporarily deaf and the recommendations in the preceding paragraphs apply. While someday these devices may be able to block the sound of a gun report with their software, at present we cannot count on that, so hearing aids and processors need hearing protection just like normal hearing does. It is not necessary for a Scout to remove the devices to use over-the-ear hearing protection. They are small enough that they are not too uncomfortable to wear along with earmuffs.

If you need more information about hearing, see Module N. For more about non-verbal communication, see Module S.

**Sound Sensitivity** - There are some disabilities that make a Scout more sensitive to sound than most and it can be painful or distressing. This is fairly common with autism. This can be resolved in part by doubling up on hearing protection, with both earplugs and an over-the-ear hearing protector. Another option is electronic noise cancelling hearing protection muffs that have volume controls on them.

**Lower Body Physical Disability** - You want to create a shooting station where the bench rest/table or railing height can be adjusted to match the height of a shooter sitting in a wheelchair or a regular chair.

**Arm/Upper Body Strength Limitation** - You want to be prepared for a shooter who lacks the strength to lift and hold the weight of the gun for a reasonable length of time. When combined with an adjustable height bench rest, large beanbags can be used to create arm/gun supports that will conform to the shooter. Bean bags can also be positioned to absorb the recoil of the gun.

**One-handed and Hand Strength Limitation** - Whether the Scout has an injury or condition that requires shooting one-handed, or a fine motor control limitation like a tremor or limited hand strength, the solutions are similar. There are pivoting gun rests on the market that can be attached directly to a chair or to a bench that carry the weight of the gun and stabilize it for shooting with limited hand strength. It may be necessary to improvise an extension for the trigger assembly. There are commercially available add-on devices that allow the trigger to be operated by biting, blowing into a tube, or sucking on a tube (sanitize for each shooter). These are moderately expensive but worth considering.

### SUGGESTED EQUIPMENT LIST

For safety reasons, it is a good idea to purchase commercially available equipment when it is available rather than using something homemade. In shooting sports, there are many devices available for purchase as adaptive equipment even though some of it was marketed for other purposes. This list isn't intended to limit your creativity or prevent you from providing equipment with additional capability.

Most gun ranges should be able to afford the following basic equipment:

**Laser sight, binoculars, steel "gong" target, and target holder** - The thickness of a steel target needs to be matched to the caliber of the gun. The target holder tilts the steel target at an angle to the line of fire and gives better control of the deflected bullets.

**Chair, shooting bench (table), and bean bags** - This allows for shooting from a seated position and supporting the gun and the shooter's arms in different ways to allow people with strength and endurance limitations to shoot. The table can be something as simple as a couple of sawhorses with a piece of plywood across them or a small plastic folding table.

**Double hearing protection** – Have both earplugs and over-the-ear hearing protection available. If the standard issue is earmuffs, have some earplugs on the side and if standard issue is earplugs, have some earmuffs on the side.

Hand held signboards for communicating with Scouts by pointing at words and symbols.

If you can afford more equipment, additional suggestions are:

Chair-mountable pivoting gun rest

Mouth-operated trigger release

Electronic noise-canceling hearing protection

Authors – Chris Werhane and Tony Mei Editor – Roger B. Tate Reviewed by – Janet Kelly and Eric Falkman



## MODULE BB-4

# CAMP PROGRAM FOR SCOUTS WITH SPECIAL NEEDS AND DISABILITIES

## SHOOTING SPORTS – ARCHERY, TOMAHAWK, SLINGSHOT

IN THIS MODULE:

**OVERVIEW** THE TWO TYPES OF SCOUTS WITH DISABILITIES ASSISTANTS FOR SCOUTS WITH DISABILITIES **CAMP ORIENTATION STRATEGIES GENERAL OPERATING STRATEGIES Time Management Designated Lane Giving Range Commands Addressing Safety Issues** SPECIAL TRAINING FOR A SCOUT'S ASSISTANT **Main Things** Vigilance **Speed and Proximity** Strength Authority **SPECIFIC SITUATIONS Tomahawk and Knife Throwing Ranges** Wheelchairs Blind/Low Vision Deaf/Hard of Hearing/Non-Verbal Lower Body Physical Disability **Arm/Upper Body Strength Limitation Hand Strength Limitation One-Handed** No Hands SUGGESTED EQUIPMENT LIST

### OVERVIEW

This module is for Range Officers responsible for shooting activities such as archery, sporting arrows, slingshot shooting, tomahawk throwing, and knife throwing. Shooting sports with gas and spring propelled projectiles; including BB gun, chalk ball, airsoft (plastic BB), rifle, black powder, shotgun, and pistol are addressed in Module BB-3.) The goal is to provide a concise guide that focuses on the including various types of disabilities in shooting sport programming. This module focuses on things that are within the control of the range staff rather than permanent improvements to the facilities.

Ranges for low velocity sports are typically placed on lightly improved land and don't typically have paved surfaces for access. Such ranges are also likely to be set up on a temporary basis and may be incorporated at public events where spectators may gather. Both factors mean that thought needs to be given about how to give participants with mobility impairments access to the range.

Low velocity sports have two inherent advantages over gun ranges. The first is that these sports are quieter, so hearing protection is not required and it is easier to use verbal communication. The second is that it is easy to see when the projectile has been drawn far enough back to become a hazard, unlike a gun where we assume it is loaded at all times and we can't watch the trigger closely. The disadvantage of low velocity sports is that it takes more physical strength and coordination to launch the projectile than with a gun.

In this module, the **range officer** is the person in charge of a particular shooting range while it is open and active. Additional staff members at a shooting range are called **range aides**. Range aides are under the supervision of the range officer. Participants may be used to using the term "Rangemaster" for one or the other of these roles, but avoid confusion in this module that title is not used. Range aides have shooting skills and might teach in the shooting activity. Later, we will introduce the term "**assistant**". An assistant is a person who supports a person with a disability on an individual basis, but has no special shooting knowledge or skill. There may be times when a range aide serves as an assistant for a person with a disability, but a typical assistant would not be qualified as a range aide.

Every willing Scout should have the opportunity to learn to shoot safely, have fun, and enjoy the sense of accomplishment that comes from making contact with the target. BSA shooting sports are subject to age restrictions that correspond to the BSA program levels. However, the underlying reasoning is not spelled out, and all **range officers need to pay attention and help Scouts that are having difficulty even though they meet the age requirements for the activity**.

Low velocity target sports are offered to younger Scouts than gun shooting is. (*In this module the term "Scout" applies to a participant in any of the BSA program levels. Where a distinction needs to be made between program levels, "Scouts BSA" is used.*) This actually makes it easier to adapt to Scouts with special needs and disabilities than in other program areas because many of the accommodations we need for disabilities are the same ones we need for young

Scouts. In most other cases, the special needs of an individual Scout can be accommodated safely with additional personal support and supervision. Some Cub Scout age participants also may need extra support and consideration even though they are not disabled and do not have an identified special need.

You will encounter some Scouts whose disabilities are obvious, like physical disabilities, blind, deaf, or Down syndrome. Physical disabilities include people who need mobility equipment like wheelchairs and crutches, but also include people that have limited strength, endurance, or coordination. For every obvious disability you encounter, there will be several Scouts with less obvious special needs like learning disabilities, ADHD, autism, history of seizures, or anxiety disorders. Camp is exciting and challenging and over the course of a multi-day camp session, Scouts with disabilities may tire out or act out more as time goes on. Some Scouts with milder special needs may start camp without needing accommodations but begin to need them later on.

## THE TWO KINDS OF SCOUTS WITH DISABILITIES

There are a lot of different types of special needs and disabilities. Any one person could have a combination of needs, and people can have different levels of disability from the same condition. So, every individual is different. However, for the purposes of running a target sport program we can boil this down to two different groups, with a little bit of overlap. **The dividing line is the maturity/intellectual ability of the Scout.** In the first group are Scouts that have a need, but they can understand range commands and operations and obey the safety rules. Their needs have to do with the mechanics of shooting. Most Scouts in this group will arrive at the range with someone to assist them and their needs fall into the general category of adaptive sports, with equipment modifications. We will get into adaptations later.

In the second group are Scouts who could have erratic behavior once they are on the range. There are a variety of disabilities that could result in erratic behavior, but the point is not to exclude them from the range but to find a way to prevent unsafe actions. Some of these Scouts will arrive at the range with someone to assist them and you can work with the assistant. The more challenging situation is when such a Scout arrives at the range with only an ordinary "buddy Scout" and no one identifies the Scout to the range staff as having a need before the Scout gets on the range. We will discuss how to manage this group of Scouts in more detail later.

## ASSISTANTS FOR SCOUTS WITH SPECIAL NEEDS

Additional personal support and supervision at the range solves nearly all problems. In practical terms this means a person to provide one-on-one support for the Scout. A range aide can serve as the support person, but this makes the most sense for a Scout that only needs personal help at the range and nowhere else at camp. Some Scouts with special needs or disabilities that come to the range will have an assistant with them. An assistant can come in many forms. It could be a responsible mature Scout (peer buddy), parent/guardian, adult leader from the

Scout's unit, professional caregiver, chaplain, etc. An important thing to recognize is that **the Scout and the assistant form a team**, and they need to be thought of as one unit at the range. The assistant is not a spectator or an extraneous person that needs to be kept away from the firing line. The assistant knows more about the Scout's abilities and limits than the range officer does, and knows how to best help the Scout. In many instances, the assistant will be doing things like retrieving arrows and tomahawks from down range. The other important thing to recognize is that **the range officer and the assistant also form a team** to assure the shooting experience is both safe and enjoyable. This second team will need some time to coordinate their efforts before shooting starts.

## CAMP ORIENTATION STRATEGIES

While all Scouts arriving at camp get seen by the camp medical department and for swim check, traditionally the range officers don't get to know a Scout until the Scout turns up at the range for a class or for an open shooting time. This is manageable if you have enough staff at the range to operate the range without the rangemaster, to free up the rangemaster to work out the details with the Scout with special needs and his or her assistant.

A better solution is to build a time into the schedule, either on camp arrival day or the first morning of camp, to meet with any leaders, parents, guardians, or caregivers that brought a Scout with special needs to camp or have an unusual concern. (This is actually a good idea for every camp program area.) This will allow you to focus attention on the actual accommodations you need to come up with, and give you and your staff time to think some things through. It also allows you to build a rapport with the assistants that will be coming to the range with Scouts and help them understand what your safety concerns are, so they can accommodate you as well.

Another subject to discuss if time permits, is what the Scout's individual goals are. A Scout doesn't have to achieve a high level of marksmanship to have a good time. On the other hand, if the Scout wants to shoot with accuracy and qualify for merit badges, you can talk about ways to get enough practice time and instruction to meet that goal.

## **GENERAL OPERATING STRATEGIES**

**Time Management** – Shooting ranges are a popular camp feature and we often want to maximize the number of Scouts that can participate. We are used to operating ranges in shooting cycles where all the participants are kept synchronized. When a Scout with a disability is on the range, that Scout may not be able to shoot as fast as other participants. This can create a situation where the other Scouts could resent being held up by the Scout with special needs and the Scout with the special needs may feel unnecessarily pressured and frustrated. Rather than bog down the entire activity, consider allowing the Scout with a need to remain on the firing line for two or three cycles while you rotate other participants on and off the firing

line. From a safety standpoint, the key thing is to have the range cold at the right times. The range officer will ensure that any type of ammunition (arrows, slingshot ammo, tomahawks, or knives) is removed from all positions while anyone is down range. If a person needs to remain at a firing position on the range for any reason, the bow or slingshot shall also be removed from that position.

**Designated Lane** – It is a good idea to take a look at your range before camp season starts and designate a shooting lane for those Scouts with a disability that require an assistant with the Scout at the range. Since every range is different, you will want to consider different features to choose the lane that would work for you. (1) Can the Scout get in and out of the range without being obstructed by other participants? (2) Can the Scout stay on the range more than one shooting cycle without being in the way of other participants that are leaving and entering? (3) Which lane has enough space for a participant in a chair? (4) Which lane has enough space for both the Scout and an assistant to be in the lane at once? (5) Understanding that the assistant is providing direct supervision of the Scout, which lane allows the range officer the best sightlines to supervise all of the participants on the range?

**Giving Range Commands** – We are used to giving range commands verbally, and most command sequences expect a verbal response from the participant. Verbal range commands obviously do not work for deaf Scouts, and there are others that are non-verbal and are not able to reply out loud. One solution is having an assistant with each Scout that can get the Scout's attention by touch or hand signals and confirm that signals are acknowledged by the Scout. Another solution is to implement a visual signaling system of flags or lights to communicate the most critical commands, like "cease fire".

Addressing Safety Issues – Safety is the number one priority on any range. How the instructor/range safety officer handles these issues is critical to supporting participants in their understanding and enjoyment of the activity. The action(s) of the instructor will depend on the nature of the safety issue.

While we want to maximize inclusion of Scouts with different abilities into the shooting program, it needs to be said that **the health and safety of Scouts must take a priority**. One of the jobs of the Scout's assistant is to recognize when the Scout is struggling and needs to leave the range for a while to regroup (self-regulate).

If the range officer needs to remove a participant from the range, take time to explain to the Scout and the assistant what the problem was (if it wasn't obvious to the participant), and why it is an issue. Ask the Scout how the problem can be resolved, and what the Scout can do differently to be allowed return to the range. It might be as simple as saying they understand and will try to do better. As options, you can offer additional training or shooting at times when you can provide better supervision or when there are fewer distractions.

A difficult situation that can occur is when a Scout arrives at the range without an assistant or a responsible adult from the Scout's unit and the range officer/instructor is unaware that the Scout has a special need. If the participant has to be removed from the range for not following safety procedures this can create hard feelings between the Scout's unit and the camp staff. The most important message to communicate to the Scout is that he/she is not being banned from the range but the range staff needs to get help from the unit leadership to resolve the issues. We suggest using a "take home" note or card that you can send back to the campsite with the Scout. Here is a sample text that you can edit for your purposes:

Content of the shoot of the sho
accommodation in order to shoot safely at the range and the shooting staff needs input from those that know the camper best. He/she has been asked to leave the range for now and to return later with a unit leader, caregiver, parent, or guardian to discuss what we need to do differently to allow this youth to shoot on the range. The shooting staff wants every camper to have an enjoyable, educational, and safe experience at our range. The best way to achieve this is with
5
Sincerely yours,
Range Officer

Outright banishment from a range is a last resort. Every effort must be made to resolve safety concerns with the Scout and the unit leaders before banishment. Any time a Scout is asked to leave the range for any reason, the program director should be notified. A conference between the range officer/instructor, program director, and Scout's unit leader should be requested.

## SPECIAL TRAINING FOR A SCOUT'S ASSISTANT

Range officers always give an orientation when participants arrive at the range for the first time to explain the equipment being used, the features of that specific range, and to review the range commands. An assistant arriving with a Scout with special needs will need the same training plus a little more. If you are using a range aide as a Scout's assistant while at the range, these supplemental instructions will still apply. The range officer cannot be the individual's assistant if there are any other participants on the range.

All assistants need to know that they are being relied on to be the hearing/speaking translator to communicate range commands to the Scout and acknowledgements from the Scout. This needs to be fast and the method the assistant uses to communicate with the Scout through hand signals, signs, or touch needs to be worked out and practiced with the Scout before coming up to the firing line. With archery ranges, the assistant can drop a hand into the field of vision of the shooter to get his or her attention while the assistant is still behind the projectile.

For a Scout in the first group that we mentioned earlier, **where the Scout can comply with range rules** without any concern, the discussion with the assistant and Scout will focus on what does the Scout need help with specifically, and how equipment on the range can be deployed to make shooting workable. This is the easier situation.

With Scouts in the second group where the Scout may not be relied on as an individual to follow range rules by himself or herself, the discussion with the assistant takes on another dimension. Not every caregiver will be willing and able to take on the role of a shooting assistant, but they won't be able to make that decision until the range officer has briefed them on the responsibilities.

**Main Things** – The assistant needs to understand the four things that must be accomplished are that (1) no shots are fired after a cease fire command; (2) no one goes downrange to retrieve anything until a cease fire/stop command has been called and all ammunition is secured; and (3) no one points the bow or slingshot high (sky draw) or to the side while drawing. The assistant must be able and willing to do what it takes to accomplish this, including taking hold of the shooter.

**Vigilance** – The assistant needs to understand that they are providing a focused set of eyes and ears to keep the range safe for everyone. They are not there to take pictures or videos of the Scout's experience to share with folks back home. The assistant needs to remain focused on where the projectile is pointed.

**Speed and Proximity** – The assistant needs to be able to act quickly to respond to unexpected movements of the bow, slingshot, or the Scout. This means that the assistant needs to stay physically close to the Scout that is shooting on the range. With tomahawk and knife throwing this is not always possible.

**Strength** – When a disability creates a realistic concern that the Scout might wave a projectile around or run downrange during shooting, the assistant has to be strong enough to physically control and overpower the Scout's movements. A size mismatch between a stronger Scout and a weaker assistant could be a problem. The obvious example would be a Scout that has an intellectual disability and is physically an adult, but is participating in Scouting as a youth.

**Authority** – The assistant needs the authority to call cease fire at any time if the Scout they are working with moves across the firing line. If the assistant recognizes that the Scout is not in a

"good head space" for safe shooting or is being distressed in some way, the assistant needs to remove the Scout from the range and has the authority to do so.

## SPECIFIC SITUATIONS

**Tomahawk and Knife Throwing Ranges** – It is more difficult to accommodate Scouts that could have erratic behavior on tomahawk ranges than on other types of ranges. An assistant cannot be as close to the thrower as in other sports because of the wind-up for the throw. There isn't a place to safely grab the tomahawk or knife once it is in motion. However, there is a big difference between a tomahawk or knife range with one lane, where participants go one at a time and a larger range with multiple throwers going in rounds. With a single-lane range, the thrower can move closer or farther from the target and have greater success. The range officer can work directly with the thrower and monitor both the throwing motion and whether the thrower is getting agitated and might have problem behavior. Thirdly, there are fewer people close by the thrower to be at risk from a wild swing. A practical accommodation for a multiple lane range is just to operate for just a few minutes with just one thrower.

**Wheelchairs** – Permanent modifications to provide access to the shooting range for wheelchairs and mobility equipment is outside of the scope of this module. It bears mention in passing that it should be possible to bring a participant up to the firing line and be able to transfer a participant from a wheelchair to another chair for shooting. If the range staff needs to help a Scout transfer from and to a mobility chair, they need to take direction from the Scout and the caregiver to do so in the most comfortable way. A Scout that looks frail may not actually be fragile.

**Blind/Low Vision** - Even without vision, a Scout can master the underlying skills of marksmanship. All people have an internal sense called proprioception, which allows us to intuitively know where every part of our body is at all times. That is how you can close your eyes and still touch your nose or your opposite elbow. A Scout that doesn't see can use this sense to maintain a consistent position from shot to shot with a bow, and can synchronize the aiming motion to the sound of a target thrower for sporting arrows. To get zeroed in on the target, the Scout will need a bow with a laser sight and a spotter to guide the aiming. For slingshots, the spotter gives verbal guidance after each shot to zero in on the target.

People with low vision may not get their best vision by looking straight ahead. It could be that they see best while their eyeballs are turned up, down, left, or right. They probably do this all the time and don't think about how it looks to others. It is OK to ask the person how much vision they have and if there is anything you can do to make the target more visible. If you need more information about vision, see Module M.

**Deaf/Hard of Hearing/Non-Verbal** - The challenge here is not the actual shooting, but communicating to keep the range safe. The Scout will need a second person with him or her to translate both ways, so the Scout can acknowledge commands. If the Scout already has a

tablet, sign language, signboard, or other means of communicating, you want to use that first. While it is not a good choice for range commands, for shooting instruction it is helpful to have a clipboard-size signboard with icons or words that the assistant and Scout can use to communicate by pointing. A small whiteboard and markers can help with communication as well. If you need more information about hearing, see Module N. For more about non-verbal communication, see Module S.

**Lower Body Physical Disability** – If the only disability is not being able to stand or walk, the shooter can usually shoot from a seated position in a chair. The chair faces to the side from the direction of shooting to allow the arms to be extended without hitting the backrest. If the wheelchair is narrow enough, the Scout may be able to use a bow while sitting in the regular wheelchair. If the Scout has to transfer to a regular chair to get a narrower profile, consider whether the Scout needs to have the torso supported. This can be done with a gait belt to allow the Scout to be supported by an assistant or to be secured to the back of the chair.

**Arm/Upper Body Strength Limitation** – Using a bow/slingshot with a light draw weight will compensate for most arm strength limitations. When you use a light draw bow/slingshot, the target needs to be moved close enough to the shooter to be in range with the lighter launcher. You want to be prepared for a participant who lacks the strength to lift and hold the weight of the bow for a reasonable length of time. A bow stand can be used to carry the weight.

**Hand Strength Limitation** - Whether the Scout has a fine motor control limitation like a tremor or limited hand strength, the solutions are similar. A caliper release aid allows the bow to be drawn with the wrist and then released by gentle pressure from a finger or cheek.

**One-handed** – In this scenario, an arm is missing but the other arm and hand are strong enough to draw and release. There are two ways to set up special equipment for this situation and different shooters will have different preferences. In one set-up, the bow/slingshot is held in place by a bow stand and the shooter draws and releases with the "good" hand and arm. In the other setup, the bowstring is held to a chair or the shooter's torso by a caliper release aid and the "good" hand and arm are used to push the bow away to draw the bow. The release is operated by a mouth trigger or pressure from a cheek.

**No Hands** – A person with this disability will be accustomed to doing things with their feet that others do with their hands. For archery, the usual arrangement is to attach a caliper release to the shooter's torso and then push the bow away and aim with one foot.

## For additional ideas see the Adaptive Archery Manual from USA Archery.

https://www.usarchery.org/participate/adaptive-archery/adaptive-archery-resources

## SUGGESTED EQUIPMENT LIST

For safety reasons, it is a good idea to purchase commercially available equipment when it is available rather than using something homemade. In shooting sports, there are many devices available for purchase as adaptive equipment even though some of it was marketed for other purposes. This list isn't intended to limit your creativity or prevent you from providing equipment with additional capability.

Most archery ranges should be able to afford the following basic equipment:

**Bows with light draw weights** – These can be recurve or compound bows. These are needed anyway for young scouts that do not have disabilities. Remember to get both left and right-handed versions.

#### Laser bowsight

**Caliper release aids** - These eliminate the pinching force needed to grip the bowstring and draw the bow. They can be strapped to the wrist, shoulder, or torso and operated with a single finger or pressure from the cheek. Some can be operated by a biting action (sanitize for each shooter).

**Chair and stool** – A chair allows the shooter to work from a seated position and provides an attachment point for a bow stand or caliper release. A stool may be sufficient to allow someone with lower body strength limitations to shoot from a near-standing position.

**Bow Stand** – Unlike bow stands that are simply places to rest the bow between shots, an adaptive bow stand has a way to anchor it to the ground or ballast it so it can withstand the force of drawing the bow. It can also be mounted to a chair.

Hand held signboards for communicating with Scouts by pointing at words and symbols.

## Small Whiteboard and Markers

Authors – Chris Werhane and Tony Mei Editor – Roger B. Tate Reviewed by – Eric Falkman





## MODULE BB-5

# CAMP PROGRAM FOR SCOUTS WITH SPECIAL NEEDS AND DISABILITIES

## HANDICRAFTS AND STEM HAND WORK

IN THIS MODULE:

OVERVIEW
THE BIG PICTURE
CAMP ORIENTATION STRATEGIES
GENERAL APPROACHES
Accessibility
Work Areas
Pacing for One-Session Projects
Multistep Models
Be Observant
UPPER BODY PHYSICAL CHALLENGES
Pinching
Gripping
Arm Strength
Shaking
One-handed Work
SPECIFIC SITUATIONS
Deaf/Hard of Hearing Scouts and Scouts that are Non-verbal
Blind/Low Vision Scouts
Sound/Noise Sensitivity
Autism
SUGGESTED EXTRA EQUIPMENT AND SUPPLIES LIST

## OVERVIEW

This module is for Handicrafts Directors at BSA Scout Camps and for instructors for STEM activities that have hand work requirements. This might seem to be an odd combination, but for example building a model rocket for Space Exploration merit badge requires the same set of skills and types of adaptations as traditional handicrafts. This module applies to all ages of Scouting and "Scout" as used here means any youth participant from Lion to Venturer.

This is a quick guide to the interaction between handicrafts/hand work and various types of disabilities. It supplements the handicrafts skills training you already have. It does not teach you how to do or teach handicrafts, but how to adapt materials, tools, and methods to better serve Scouts with special needs and disabilities. While we discuss some temporary improvements for accessibility, permanent improvements are beyond the scope of this module.

Handicrafts is about more than making a piece of art or a useful object. Like an African watering hole, the handicrafts area at a camp is a draw for Scouts that are different or have struggles with other kinds of activities. In some cases, their leaders or families steer them toward a handicrafts merit badge so that they can have a "win" at camp when other badges are hard for them to complete. For other Scouts, the handicrafts area is a substitute for "alone time", a place to unwind from other activities that force them to interact with others. For some, handicraft activities are a chance to have control over a small part of their world and compensate for the chaos and frequent demands from leaders that they experience at camp. You may also attract some Scouts that are recovering from injuries and don't have their usual options.

Every willing Scout should have opportunity to express his or her creative abilities, even if they have obstacles that make the process harder than for others. You will encounter some Scouts whose disabilities are obvious, like physical disabilities<sup>1</sup>, blind, deaf, or Down syndrome. For every obvious disability you encounter, there will be several Scouts with less obvious special needs like learning disabilities, ADHD, autism, history of seizures, or anxiety disorders. Camp is exciting and challenging and over the course of a multi-day camp session, Scouts with disabilities may tire out or act out more as time goes on. Some Scouts with milder special needs may start camp without needing accommodations but begin to need them later on.

A last thing to remember is that young Scouts may need extra support and consideration even though they are not disabled and do not have an identified special need.

<sup>&</sup>lt;sup>1</sup> Physical disabilities include people who need mobility equipment like wheelchairs and crutches, but also include people that have limited strength, endurance, or coordination.

## THE BIG PICTURE

There is a difference in how we use handicrafts in Scouts BSA and in the younger age programs. With younger age groups we aren't really trying to build skills so much as provide something that is fun and different. We usually take a whole den at a time and guide them through the project in parallel. This means we have only a fixed amount of time to complete the work. The kids in a den are going to have a wide range of ability and interest levels, even without any special needs to account for.

STEM hand work projects at the Scouts BSA and older levels, have the same onesession/parallel work model. The Scouts choosing these badges may have a similar strong interest in the STEM subject matter but have a wide variety of dexterity and past experience handling the tools and materials. Like in Cubs, we aren't trying to build crafting skill but to give a relevant one-time experience.

The handicrafts experience is different with handicraft merit badges in Scouts BSA. The interest level of the learners is more uniform and we expect work to get completed over multiple sessions, which gives everyone some flexibility. While we don't expect Scouts to master an art form, we do expect them to demonstrate specific skills and express themselves through their work product.

## CAMP ORIENTATION STRATEGIES

While all Scouts arriving at camp get seen by the camp medical department and for swim check, traditionally the handicrafts staff doesn't get to know a Scout until the Scout turns up for a class or for a free crafts time. This is manageable if you have enough staff to run the activity while freeing up the handicraft director to work out the details with the Scout with special needs and his or her assistant.

A better solution is to build a time into the schedule, either on camp arrival day or the first morning of camp, to meet with any leaders, parents, guardians, or caregivers that brought a Scout with special needs to camp or that have an unusual concern. (This is actually a good idea for every camp program area.) This will allow you to focus attention on the actual accommodations you need to come up with, and give you and your staff time to think some things through. It also allows you to build a rapport with the assistants that will be coming with Scouts and help them understand what your operating concerns are, so they can accommodate you as well.

Another subject to discuss if time permits, is what the Scout's individual goals are. A Scout doesn't have to achieve a high level of artistry/craftmanship to have a good time and learn about a craft. On the other hand, if the Scout wants to do high quality work, you can talk about ways to get in more practice time and instruction to meet that goal.

### **GENERAL APPROACHES**

**Accessibility** - In running a craft area you will always have limitations on how much space you have to work with. While you may not be able to build paved access or ramps, you will want to manage the layout of furniture to allow access for wheelchair and crutch users. A 32 inch aisle is enough to pass through, but more space is needed to turn around. It is a good idea to have a designated space for Scouts to set down daypacks rather than have them clutter the floors and aisles in your space.

**Work Areas** – If you had all the space in the world, you would probably have a separate space for each type of craft and leave the tools and materials for that craft out all the time. That is rarely realistic. However, if your space will allow it, it is a good idea to have at least two different work spaces, with one dedicated as an instructional space and the other as an independent craft (free play) area where Scouts and adults can come and go as they please. With some special needs, it is good for a caregiver to have an option for an outlet activity when the Scout is not faring well in a structured class or activity. There will also be some adults at camp that are at loose ends at times and would enjoy an independent craft activity. The independent area will still need to be supervised by one of your staff, if for no other reason than keeping it from turning into a lounge.

If your camp schedule requires two different classes to run at the same time, try to separate them into different areas or locations. This will reduce the distractions for everyone and make it easier to stay on task. It also helps the hard of hearing because they are only hearing instructions from one voice.

**Pacing for One-Session Projects** – When a project needs to get done in one session, it puts time pressure on slower workers. The practical solution to help a Scout work faster is some one-on-one assistance. In your mind's eye, imagine how a surgical nurse helps a surgeon by placing tools and supplies in the right easy-to-reach place, at the right time, in the right order; and holds objects still while the surgeon works on them. The helper could be a crafts staffer, an adult that is chaperoning the den, or a more experienced Scout. Make sure the helper understands that the role is to assist and not to do the work for the Scout.

An alternative approach to consider is to pair off the Scouts from the beginning and have each pair make two items. One is the "Doer" on the first pass while the other is the "Helper", and then they swap roles on the second pass.

Part of the challenge of one-session projects is handling the kids that are quick studies or gifted in that craft and finish earlier than others. Your first instinct may be to repurpose them to help the slower Scouts. This strategy has more problems than you may realize, especially with young Scouts. When a skill comes to you naturally, it is hard for you to explain how to do it to anyone else, and you don't empathize with why they are having a hard time with it. Just be aware of this social dynamic and understand that "the natural" has a special need in learning how to get along with others. An alternative to handle fast workers is to have something for them to do with left-over time. That could mean having some drawing supplies handy or a simple clean-up task they can do.

**Multistep Models** – We have some Scouts that struggle to break down a broad general instruction into a series of steps<sup>2</sup> and others that struggle to visualize an object from a verbal description. Having physical examples to go by will help these and many other Scouts as well. As an advance activity, build models of what the project will look like at each step in the process and organize them in sequence. For smaller/flatter objects, the models can be mounted on a "step board" which will make them easier to handle and use over and over again.

The models would also be supplemented by verbal and written instructions, and with demonstrations of how to use the tools. The goal is to teach with as many approaches as possible so each Scout can latch on to an approach that works for him or her.

**Be Observant** – It is normal for some Scouts to struggle more than others, whether they have an identified special need or not. Scouts with special needs are unlikely to identify their disability to the handicrafts staff because they don't want to draw attention to their limitations. To offset this, the staff will have to be proactive to engage with Scouts that are progressing slowly or look "stuck". The important thing is to take time to talk to these Scouts and ask what kind of help they want or need to be successful. Asking in this way allows you to help a Scout without forcing him or her to disclose a disability. Remember that when you live with a disability you figure out your own tricks for getting things done and you want others to work with you instead of imposing their own solutions on you.

## UPPER BODY PHYSICAL CHALLENGES

We are focusing more attention on upper body physical disabilities than other disabilities in this module because they require more advance planning for your handicrafts staff and possibly additional tools or materials.

**Pinching** – Many crafts require an ability to pinch something between the thumb and one or two fingers. If you cannot pinch something for a long time, you can't write with a pen or pencil, use a paintbrush, or work with small tools. With clever adaptations, many pinching tasks can converted from a pinching task to a gripping task. For example, pliers can be used to hold nails and tacks. The handles of tools can be lengthened and thickened so they can be gripped with the whole hand. Foam tape, rubber pipe insulation, and epoxy putty work well for enlarging a handle. A short handle can be extended by splinting a longer wood handle to it with duct tape or gaffer's tape.

<sup>&</sup>lt;sup>2</sup> This is one aspect of "executive functioning" and it occurs with several different invisible disabilities.

A different type of accommodation is to provide something to push against to pinch a small object. Sorting trays can be used to organize small supplies but also provide a side wall to make pinching easier.

**Gripping** - Grip is more important than you might think because you cannot lift or pull anything if you cannot grip it. Anyone who has moved furniture understands that even if your arms are strong enough to lift a heavy object, you can't lift anything heavier than your grip can handle. There are devices to enhance grip strength for specific tasks. There are special gloves with a strap that wraps over the outside of the fingers and back to the glove to keep the hand in a curled position to hold a handle. Other modified gloves have a hook-shaped metal shank that can be used to catch a handle while leaving the fingers free. If you had to improvise something like this, consider having the person hold the tool loosely and then mummify the hand in stretch wrap. If the difficulty is mostly dropping tools, you can use duct tape to create a strap on the tool that goes over the back of the hand.

**Arm Strength** – No matter how strong we are, all of us have limits to how much force we can exert. Simply allowing the elbows or forearms to rest on the table helps with this. With crafts we have a couple of other options to consider. One is to use substitute materials, for example carving a bar of soap, chunk of florist's foam, blob of spray foam insulation, or block of clay instead of wood, or using softer balsa wood in place of a harder wood. The second approach is to use hand-over-hand assistance where a helper provides the force while the Scout steers and points the helper's hand.

**Shaking** – Some types of physical disabilities affect how nerve signals go to muscles, and result in shaking, tremors, or muscle spasms that make it hard to manipulate objects in a useful way. Sometimes a hand or wrist brace can resist the shaking physically and can allow a person to use a pen despite tremors. Strapping some weight (1 to 3 pounds) to the hand or wrist or adding weight to a tool can reduce the shaking at the end of the tool. Another option is to just work at a larger scale when doing the craft so that the smaller imperfections don't matter as much.

**Reaching** – Range of motion can be a factor for some Scouts. A simple aid is to bring the work closer. Another is a work surface that is tilted toward the Scout, which can be accomplished with a slant board. In a pinch, a 3-inch binder can be used as a slant board.

**One-Handed Work** – Even something as simple as having a broken arm may make it necessary to work one-handed. You need a way to hold the workpiece still while working on it with the other hand. For painting, drawing, and similar tasks, painter's tape can be used to hold the paper down to the table and it can be removed afterward. For larger objects, you can clamp the piece to the edge of the table. Home improvement stores carry a variety of inexpensive clamps for woodworking that you can choose from. A rubber friction mat can be laid on the work surface to reduce slipping and sliding. For carving, there is a tool called a bench hook that give resistance from sliding and protects the main work surface. If you are working on a wood work surface like a picnic table and don't have to keep the surface perfect, you can drive a few

nails part-way into the wood to rest the workpiece against so it does not slide. If none of that will work, you can have a helper do the holding and turning of the workpiece for the Scout.

## SPECIFIC SITUATIONS

**Deaf/Hard of Hearing Scouts and Scouts that are Non-verbal** – The most important adaptation for these Scouts is to seat them close to and across from the instructor, so they can watch, and learn as much as possible without relying on verbal instructions. It is OK to use gestures to communicate even if you don't know sign language. Make sure to look at them when talking to them, so they can lip read to supplement their hearing. Take advantage of texting on a mobile phone to communicate with the Scout. If there is no cell coverage, a couple of small whiteboards can be used to communicate with each other.

**Blind and Low Vision Scouts** – These Scouts can do a wide variety of handicraft tasks. The most important adaptation is to let them have their own set of tools and supplies that they do not have to share with another Scout. People with low vision adapt by remembering exactly where they lay down a tool and they do not need anyone else moving objects around while they are working. This is another situation where sorting trays can be put to good use. Before you assume they need a sighted helper or guide, ask them if that is what they want and if so, what they want the helper to do.

Do not dismiss the idea of offering graphic arts to Scouts that are blind. They can use heavy stock paper and a metal embossing stylus to create drawings that can be traced out by feel. You will need a cushion layer under the paper, which could be something as simple as a flat piece of cardboard or foam core board. A rubber friction mat can be used for this as well. These Scouts might do better with finger paints than brush paints, but they can paint. They can create touchable art with gel paints or white glue and sand.

**Sound/Noise Sensitivity** – Some crafts, like leatherwork and wood carving can be inherently noisy because you have to pound or tap on tools, like chisels and leather embossers. The noise can be too much for Scouts with sensory sensitivity. There are two approaches to solve this. If you have the space and can keep watch, let the Scout to move to a table at a distance from others, or better yet, work outdoors to let the sound carry. The other approach is to give the Scout a pair of noise control earmuffs or earplugs to wear. He or she will be hard of hearing while wearing them, so adapt accordingly.

**Autism** – Some Scouts on the autism spectrum have a strong need to finish the task at hand before they will shift to another task without getting upset. This is especially true for younger Scouts. The best solution is called "foreshadowing". You begin telling everyone from the beginning of the session which steps you want to complete in that session. If you plan to shift from one craft project to another during the same session, tell the Scouts that the transition time is approaching with a five minute warning and a one minute warning. If you know that the project can't be completed in one session, like when glue or paint needs to dry, tell them in

advance and explain to them how they are going to get the opportunity to finish up or pick up their work later.

Sometimes Scouts on the autism spectrum will work slowly because they are trying to do a better quality job than is necessary. It is unlikely that you will persuade them to loosen up and lower their standards. If you see this happening, take a moment to tell these Scouts that while there won't be enough time to finish during that same session, they can have more time to work on their project during free crafts time, in the evening at their campsite, or after they get home from camp.

#### SUGGESTED EXTRA EQUIPMENT AND SUPPLIES LIST

Painter's tape Slant Board Rubber friction mat Heavyweight paper Embossing stylus Small variety of woodworking clamps Pliers Clothespins for manipulating small objects Rubber pipe insulation for enlarging handles Gaffer's or duct tape Extra clay for adding heft or weight to tools Florist's foam Small whiteboards and markers Noise control earmuffs and/or earplugs





SLANT BOARD

RUBBER PIPE INSULATION





RUBBER FRICTION MAT

SORTING TRAY



**BENCH HOOK** 

Author – Ann Bruner-Welch, PA Editor – Roger B. Tate Reviewed by – Sandy Payne, Chad Hayes - Program Executive – Longhorn Council, Susie A. Feshold, OTR

# **APPENDIX 1**

# DISABILITY AND SPECIAL NEEDS LANGUAGE MATTERS

A continuing challenge for the BSA National Special Needs and Disabilities Committee (NSNDC) is the many times we are approached by an advocate who thinks we are not using the best words to describe their disability/condition/interest group/community and wants us to change our messaging. This appendix is intended to help those advocates understand why we phrase things the way we do.

The goals for our committee can be summarized as:

- (1) promoting inclusion in the traditional Scouting program of youth with different abilities and adults with disabilities who may participate in the youth program (RBAE)
- (2) equipping Scouting volunteers and professionals to make sensible accommodations for differences in abilities as they execute their individual parts of the Scouting program
- (3) promoting inclusion of adults with different abilities into our corps of volunteers and professionals, and
- (4) advocating within the BSA organization to ensure people with different abilities are reflected in our literature and that their needs are taken into account when developing policies for implementing Scouting.

We do this by gathering information on best practices for adapting elements of the Scouting program and best practices for working with youth with various classes of ability differences. Then we turn around and distill that information into newsletters, resource documents, and training materials to distribute throughout the BSA family. It is important that we communicate in plain language so our volunteers don't have to be subject matter experts to do good things for their Scouts. At the same time, as best we can, we want to promote the use of language that is respectful and inoffensive.

We have learned that there is vast amount of diversity within the special needs and disabilities community. That makes it hard for us to find wording that laypeople understand and is also universally acceptable to the entire community of special needs and disabilities. Candidly, we do our best, but we haven't found a way to please everyone. As you read further, you will likely find that we used a word or phrase in a way that you would not. Just know we mean well and we are trying. Here are some of the challenges we face:

Language changes over time. At the 1977 National Jamboree, an event was offered called the "Handicapped Awareness Trail". At the time, the word handicapped was broadly acceptable and was commonly used to reference our community and to promote what we now call inclusion. As time passed, the next generation of advocates pushed for the use of what we now call "person first" language, and using the term "with disabilities" instead of handicapped. In 1990, the Americans with Disabilities Act (ADA) was passed and that usage was the commonly accepted language by then. As time passed into the 21<sup>st</sup> century, there was a growing recognition that there were a variety of "invisible disabilities" that were not included in the ADA definition of disability but did require supports and accommodations. Rather than label them disabilities, which had a legal meaning by then, the next generation of advocates pressed for calling them special needs. Recently, the term special needs started putting off some of the latest generation of advocates and some people that still identify with "disability" in the way it was used in the ADA. For no obvious reason, every time someone invents a new way of speaking to be respectful and inclusive, it becomes trite and offensive after it has been used for a while. We are still figuring out what comes next in terms of the best widely-accepted usage. For the purposes of our communications, the NSNDC shoots for language that is widely understood, even if it is not at the leading edge of what is used within the special needs/disabilities communities.

Language is used differently by different professional groups. For every type of special need/disability, there are several types of support people for that need. These usually include a medical/therapeutic component, an educational component, a social services component, an advocacy component, a family component, and then the general public. Aside from the general public, each one of these support components develops its own jargon, acronyms, slang, and preferred forms of address. The words the specialists use are wonderful because they have precise and rich meanings and they allow for quick communication within the group. But those same words are not well known to the other professional groups, much less the general public. *For the purposes of our communications the NSNDC translates technical words into everyday language that our volunteers (i.e. general public) understand and can act on.* 

Language is used differently in different parts of the country. It isn't surprising that when you have so many distinct communities with all of the different types of needs and all the different support professions involved, that sometimes new words and new ways of using words will crop up in one part of the country, but not others. Those that understand the regional vocabulary tend to assume that everyone uses words the same way while everyone else wonders what the new words mean and if they are worth adopting. For the purposes of our communications, the NSNDC uses the most widely understood version of terms so we can use the same messaging nationwide. When new jargon becomes broadly understood, we will start to use it ourselves.

**Language tells how we see ourselves.** In recent years, we are seeing a tension emerging between the person-first language that has been the accepted mode of writing for many years and identity-first language. The difference between the two is that person-first people have a self-image where their condition does not define who they are. They have "it" but want to be

defined by their other characteristics instead. Identity-first people see their condition as an essential attribute of who they are (their self-image) like they might think of their gender, race, height, religious/cultural identification, etc. While the NSNDC supports the right of each individual in the Scouting family to be referred to in the way he or she wants, we need ways to talk about people as a group and ways to identify specific needs or conditions. For the purposes of our communications the NSNDC continues to use person-first language in most situations when discussing groups, while recognizing and occasionally making exceptions for subgroups where identity-first language appears to be the dominant preference of members of that group.

## **APPENDIX 2**

## **CREDITS AND ACKNOWLEDGEMENTS**

The writers, editors, and reviewers of the *Inclusion Toolbox for Special Needs and Disabilities* stand on the shoulders of a great many advocates, educators, and care professionals, along with Scouting volunteers and professionals. Many served without individual credit and others built on the work of their predecessors. To this great congregation of forerunners – Thank You!

## MODULE A – INTRODUCTION

Author : Roger B. Tate Reviewers: Midge Savage & Sandy Payne

## **MODULE B - Basics of Scouting from a Special Need Perspective**

Author: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

## MODULE C - Unit Leader's Role Supporting a Scout with a Disability

Authors: Tony Zizak, Angela Zizak, and Julie Hadley Editor: Roger B. Tate Reviewers: Midge Savage and Sandy Payne

## MODULE D - Parent-Guardian's Role Supporting a Scout with a Disability

Author: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

## **MODULE E - Navigating Advancement Requirements**

Author: Roger B. Tate Reviewers: Mark Chilutti, Midge Savage, and Sandy Payne

## **MODULE F - Methods that Apply to Many Disabilities**

Author: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

## **MODULE G - Organizations that Support Those with Disabilities**

Author: Michael Bradle Editor: Roger B. Tate Reviewers: Sandy Payne and Midge Savage

## **MODULE H - Allergies and Food Issues**

Food Allergy Research and Education (FARE, foodallergy.org) Author: Roger B. Tate Reviewers: Food Allergy Research and Education, Britt Flather and Midge Savage

## MODULE J – Anxiety, Depression and Other Mental Health Concerns

Child Mind Institute (childmind.org) Authors: Mary Wangerin and Roger B. Tate Reviewers: Child Mind Institute, Britt Flather, and Midge Savage

## **MODULE K - Attention Deficit Hyperactivity Disorder**

CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder), chadd.org Author: Anthony Mei Editor: Roger B. Tate Reviewers: Britt Flather, Midge Savage, CHADD

## MODULE L – Autism

Autism Society of America (autism-society.org) Author: Roger B. Tate Reviewers: Autism Society of America, Britt Flather, and Midge Savage

## MODULE M – Blindness and Low Vision

National Federation of the Blind (nfb.org) Authors: William D. Nutt and Dave Nutt Editor: Roger B. Tate Reviewers: National Federation of the Blind, Douglas Martin O.D., Midge Savage, and Britt Flather

## MODULE N – Deaf and Hard of Hearing

American Society for Deaf Children (deafchildren.org) Author: Janet Kelly Editor: Roger B. Tate Reviewers: American Society for Deaf Children, Britt Flather, and Midge Savage

## **MODULE P – Intellectual Disabilities**

Authors: Midge Savage, Nathan A. Schaumleffel, Ph.D., Anthony Mei Editor: Roger B. Tate Reviewers: Shawn Ullman of The Arc, Amie Dugan and Jeremie Ballinger of Special Olympics North America

## **MODULE Q – Learning Disorders**

Learning Disability Association of America (Idaamerica.org) Author: Britt Johnson-Dunlop Editor: Roger B. Tate Reviewers: Learning Disability Asso. of America, Britt Flather, and Midge Savage

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## **MODULE R – Physical Disabilities**

United Cerebral Palsy (UCP.org) Author: Scott Hellen Editor: Roger B. Tate Reviewers: Diane Wilush, National President, United Cerebral Palsy; Midge Savage; Sandy Payne

## **MODULE S – Speech and Language Disorders**

Author: Betsy Furler, CCC-SLP Editor: Roger B. Tate Reviewers: Daniel C. Tullos Ph.D, CCC-SLP, ASHA Fellow; Midge Savage; Britt Flather

## **MODULE U – Special Needs & Disabilities Committees**

Author: Anthony Mei Editor: Roger B. Tate Reviewers: Midge Savage and Britt Flather

## **MODULE V – Evaluating Advancement Alternatives**

Author: Roger B. Tate Reviewers: Mark Chilutti, Alyssa Hightower, Sandy Payne, and Midge Savage

#### **MODULE W – Commissioner Service for Units with Special Needs Scouts**

Author: Michael Burge Editor: Roger B. Tate Reviewers: John Cherry (Asst. Natl Commissioner for Education & Training), Midge Savage, Britt Flather, Anthony Mei

## **MODULE BB-1 - Aquatics - Swim Areas**

Author – Brent Worley Editor – Roger B. Tate Reviewed by – Program Support Subcommittee of the National Special Needs & Disabilities Committee, National Aquatics Committee

## MODULE BB-2 - Aquatics – Waterfront and Boating

Author – Brent Worley Editor – Roger B. Tate Reviewed by – Program Support Subcommittee of the National Special Needs & Disabilities Committee, National Aquatics Committee

#### **MODULE BB-3 – Shooting Sports – Guns**

Authors – Chris Werhane and Tony Mei Editor – Roger B. Tate Reviewed by – Janet Kelly and Eric Falkman

### MODULE BB-4 – Shooting Sports – Archery, Slingshot, Tomahawk, Knife

Authors – Chris Werhane and Tony Mei Editor – Roger B. Tate Reviewed by – Eric Falkman

#### MODULE BB-4 – Handicrafts and STEM Hand Work

Author – Ann Bruner-Welch, PA Editor – Roger B. Tate Reviewed by – Sandy Payne, Chad Hayes, Susie A. Feshold, OTR

#### **APPENDIX 1 – Disability and Special Needs Language Matters**

Author – Roger B. Tate Reviewed by - National Special Needs & Disabilities Committee

