

D: The Parent/Guardian's Role

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

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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 ([link](#)), 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!

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