

# Introduction



# About the Autism-Friendly Youth Organization Guide

The purpose of this guide is to better prepare youth-serving organizations to serve youth and families with autism. In this document, autism refers to Autism Spectrum Disorder (ASD), which includes individuals diagnosed with Autistic Disorder, Pervasive Developmental Disorders, Not Otherwise Specified, and Asperger's Disorder.

Autism Speaks believes that recreation and leisure activities are particularly important for people with autism. We know that participating in such activities often produces opportunities to practice social skills, physical aptitude and increase motivation while also increasing self-confidence and fuller integration into the community.

The information that follows will be useful for helping integrate youth with autism into your existing programs, communicating with parents, and training your staff. With help from respected experts in the field of autism and special education, experienced parents and caregivers, we have included an introduction to autism and specific strategies that will allow you to lead the way for youth with autism to have the same formative experiences through community organizations that are available to their typical peers.

We have included a wealth of information, from a wide variety of sources. New tools and resources will be added as they become available. We encourage you to become familiar with the kit and share it with your youth organization colleagues.

The **blue text** are links you can click on for further information.

## About Autism Speaks

Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Suzanne and Bob Wright, the grandparents of a child with autism, founded Autism Speaks in February 2005. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed over \$180 million to research and developing innovative resources for families. Each year *Walk Now for Autism Speaks* events are held in more than 95 cities across North America. On the global front, Autism Speaks has established partnerships and related activities in over 40 countries on five continents to foster international research, services and awareness. To learn more about Autism Speaks, please visit [AutismSpeaks.org](http://AutismSpeaks.org).





***“One in every 88 youth in America is on the autism spectrum. That is at least one athlete in every six youth basketball teams, one youth in every two Scout troops and countless kids among summer camps and after-school programs.***

***My professional and personal worlds collided when a college student, earning his Wood Badge beads, approached me – a professor, a Scouter, the Executive Director of the Nonprofit Leadership Alliance and the parent of a child with autism. We worked together to develop a local Boy Scout leader training on autism-friendly scouting, which expanded my interest on working with youth organizations so that they can more effectively serve youth with autism.***

***Nearly every major national youth-serving organization in the United States focuses on specific areas of youth development. Boy Scouts of America focuses on character and moral development, personal fitness, and citizenship. Boys and Girls Clubs of America focus on developing youth into productive, caring, responsible citizens. Camp Fire builds caring, confident youth and future leaders.***

***Ultimately, serving youth with autism as part of these programs coincides with the missions of nearly all youth-serving organizations. I like to call including people struggling with autism in youth organizations a Mission Match. This makes the responsibility of youth-serving organizations to serve young people and families struggling with ASD not only a good idea, but also a mission-focused ethical responsibility.”***

***Dr. Nathan A. Schaumleffel, CPRP, CNP, CFRM, IYD***

***Parent of a Child with Autism***

***Associate Professor of Recreation and Nonprofit Leadership & Campus/Executive Director,  
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## Autism Speaks Autism-Friendly Youth Organization Survey Findings

In 2012 Autism Speaks conducted a national survey on community youth organizations. Through this effort, we've learned more about the barriers youth with autism face in fully participating in these programs and have a better understanding of what would help organizations successfully include young people with autism.

This survey assessed the needs and wants of parents /caregivers of youth with autism in the area of youth organizations. Of the 1,018 respondents, 83% parents of males, and 17% parents of females – youth with autism.

- When asked about the organized youth activities they would like made available to their youth, team sports and camping/outdoor adventure topped the list.
- The key unmet needs families experience in relation to youth organizations are:
  - Staff educated on autism and trained on effective interventions to help people with autism
  - Programs and/or summer camps offering adaptive services for people with autism
  - Affordable programs
  - Opportunities for socialization with neurotypical youth
- Of those respondents whose youth participate in youth organization programs:
  - 56% felt that their child was moderately or extremely safe, while 18% felt their child was not safe at all.
  - 57% were moderately or extremely satisfied with the program their child participated in while 19% were not at all satisfied with their current program.
- The top barriers that families experience to having their child participate in a youth organization are:
  - No programs specifically designed for youth with autism (55%)
  - Lack of behavior management services (50%)
  - Untrained staff (50%)
  - Expense of the program, lack of scholarships (48%)

Survey respondents felt the key training needs for youth organization staff that Autism Speaks should address were behavior management, tips for working with people with autism, communication strategies, and activity safety risks like wandering, hypothermia, drowning, etc.

This survey served as some of the impetus for the development of this guide and a web portal that will serve to better prepare staff and volunteer youth program leaders on appropriate ways to interact with, mentor, and manage youth on the autism spectrum. These resources will be updated regularly, as new information becomes available, so I encourage you to check back regularly at [www.autismspeaks.org/family-services](http://www.autismspeaks.org/family-services).

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Mother of an adult son with autism





## Credits and Acknowledgements

Autism Speaks would like to recognize the Autism-Friendly Youth Organization Guide Advisory Board for their support and guidance.

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