



Training Parents to be Advocates for Their Adult Sons and Daughters with Autism

A Research Report for Families and Community Partners

Julie Lounds Taylor, Ph.D., Vanderbilt University Medical Center
Meghan Burke, Ph.D., BCBA-D, University of Illinois at Urbana-Champaign
Leann Smith DaWalt Ph.D., University of Wisconsin at Madison

Introduction:

It can be difficult for youth on the autism spectrum to get the services they need after they leave high school.

The Individuals with Disabilities Education Act (IDEA) ensures that youth with disabilities (including autism) are eligible for mandated services through the school system until the age of 22 years or until they exit high school. However, after high school exit, these youth encounter an adult service system that is often inadequately funded and difficult to navigate. Families must contact separate departments and agencies for services related to employment, home and community, and postsecondary education, among others. Along with locating these supports and speaking with representatives of their respective organizations, families must understand specific eligibility requirements, funding mechanisms, and programming for each.

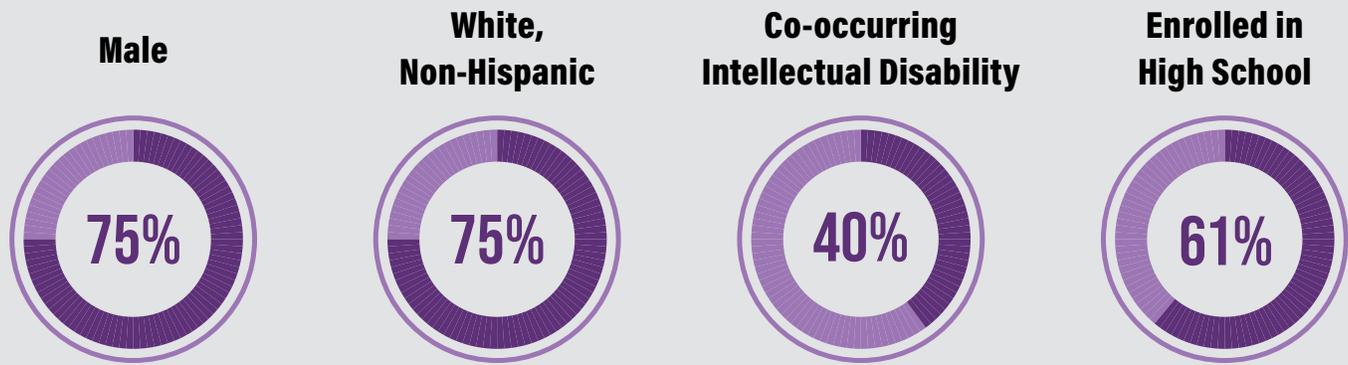
Often, the time and labor required to seek out services and to advocate for the unique needs of their child is a weighty addition to parents' preexisting responsibilities at home and at work.



Past research has demonstrated that inability to access these needed services can lead to additional challenges for autistic youth, including higher rates of emotional and health problems, declines in levels of independence, and reduced participation in work and postsecondary education. To make matters worse, studies have shown that youth on the autism spectrum who belong to an underrepresented racial or ethnic group, or whose families have lower incomes, are less likely to receive the services that they need.

Because of this, many caregivers have expressed feelings of being overwhelmed and ill-equipped to advocate for services for their youth with autism after high school.

Participant Demographics for Youth with Autism:



Taking this feedback from parents into consideration, researchers within the Vanderbilt Kennedy Center, in partnership with the University of Illinois Urbana-Champaign and the Waisman Center, University of Wisconsin-Madison, developed a 12-week advocacy training program named **Advocating for SupportS to Improve Service Transition (ASSIST)** to help parents learn how to best advocate for services for their young adult on the autism spectrum.

The purpose of the training program, and the subsequent research that came from it, was to improve the transition to adulthood for youth with autism.

Researchers created programming with parents in mind, but they also wanted to include the perspective of young adults with autism in the data collection to measure how the ASSIST program might influence youth outcomes.

Study Questions:

- Is taking in the training program with families in a group setting more advantageous than being provided the print materials only without the in-person element of the training?
- How do families feel about the ASSIST program? Are busy families able to participate, and is there a way of participating (in-person versus online) that works better than other ways?
- What barriers, if any, might make it more challenging for families to participate?

Who Took Part:

The ASSIST project recruited as research participants 183 parents and two grandparents of transition-aged youth with autism across three research sites in three separate states in the U.S. (Tennessee, Illinois, and Wisconsin). On average, parents were 51.7 years of age (range=37.0-71.4). Most (89.7%) identified as female and mothers. Approximately 84.3% of the sample were White, non-Hispanic, and just under 80% had obtained a bachelor's degree.

The youth with autism averaged 20.1 years of age (range=16.2-26.8). Three-fourths (75.1%) were male, and 74.6% were White, non-Hispanic. About 40.0% of the youth had co-occurring intellectual disability (ID), and 60.5% were enrolled in high school.

Enrolled research participants agreed to a three-year commitment to measure the training program's effectiveness.

Study Design:

The study was meant to assess whether ASSIST could be delivered in similar ways across study sites; whether families were able to participate in ASSIST and felt the program was useful; and whether the program improves parent advocacy ability and leads to better service outcomes for transition-age youth with autism.

Previous research had found that families who participated in more advocacy activities were receiving more services. The time and effort families put into advocating for their young adult with disabilities makes a difference in their child's outcome, which is why researchers thought a training program like ASSIST might prove helpful.

What Was Involved:

Before the training began, researchers conducted interviews with the parent participants, during which they collected information about the youth with autism, including age and gender; confirmation of autism and/or intellectual disability diagnosis; whether the youth had exited high school; and number of services the youth with autism was already receiving. Services included speech/language services, psychological/mental health services or counseling, and transportation, among others. Researchers also collected information on several factors that might influence how families experience ASSIST, including the family's race/ethnicity, income, parental stress and mental health, and youth's independence and self-determination.

One half of the enrolled families (the treatment group) took part in the 12-week facilitator-led program alongside other families, while the remaining half of the families (the control group) received the learning materials without the live training. (This group would have the opportunity to take part in the live training a year later.) This division was made to determine if participation in facilitator-led training with other families had more impact on the youth's outcomes than if participation was done alone, without facilitator-led training.

During the live ASSIST training, each two-hour session was led by a program facilitator with experience in adult services and in leading groups. Each session focused on a different aspect of adult services and supports, including person-centered planning, models of decision making, supplemental security income, social security disability insurance, health insurance, Medicaid waiver, employment, post-secondary education, housing, special needs trusts, and advocacy.

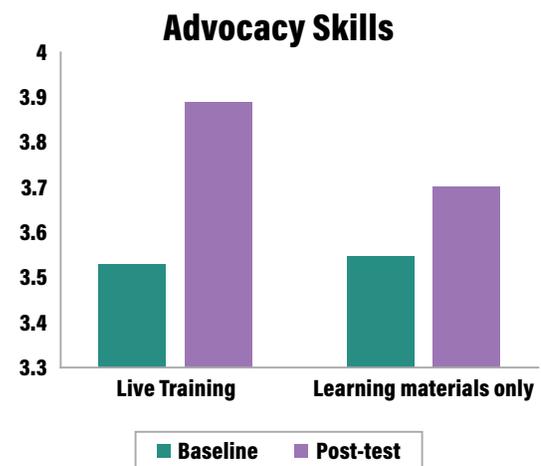
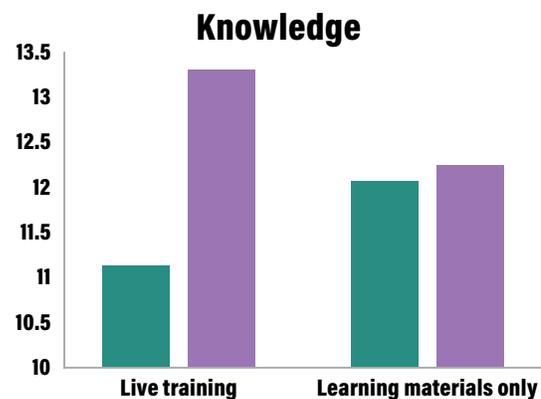
At each session, an introductory video was presented that contained general information about the session's topic. After the video, a guest speaker with expertise in the topic gave a presentation about its local aspects in the respective state where the training was offered. Participants were given "tip sheets" with key points for each session with national and local resources, which they assembled in a binder provided by the research team.

Following each session, participants were asked to give evaluations on that evening's trainings, and their thoughts on the training program as a whole.

Findings:

❑ Does ASSIST improve parent advocacy ability?

Compared to families who received the learning materials only, **those who took the live training learned more about adult services and had greater gains in their advocacy skills.** This finding was similar across all three study sites, and for both families of youth who were still in high school and those whose youth had already exited high school. The greatest gains were made for those families who came into the live training with the least amount of information about adult services, which suggested that ASSIST might be especially helpful for those families who need the most support in advocating for their autistic youth.



❑ **Do families find ASSIST valuable?** Following the first group of participants completing the training program, researchers from the three training sites in Wisconsin, Illinois, and Tennessee compiled their findings. **Results across the three sites suggested that participants found ASSIST to be useful, with around 85% of participants giving favorable evaluations after each session.**

- ❑ **Are families able to attend the sessions?** On average across the three sites, 84.6% of the participants attended 75% or more of the sessions (either live or by watching the recording), with nearly 50% attending all 12 sessions. Ninety-two percent of participants found that the number of sessions (12) and length of each (two hours) “worked for them.”
- ❑ **Can virtual delivery be effective?** The ASSIST program was originally intended to be in-person, but when the move to online was necessary due to COVID-19, the ASSIST team decided to factor potential differences between the two modes of dissemination (in-person versus virtual) into their research. **Findings from that work showed that positive gains can be made in both forms of training**, with virtual training perhaps more beneficial for families who might not live in an area where in-person training is available, as well as families whose personal circumstances (e.g. work schedule, lack of caregiver in the home) may prevent them from being able to attend an in-person group.
- ❑ **What barriers make it difficult for families to participate in ASSIST?** Thirty-seven participants (59.7% of those who completed an end-of-series evaluation) indicated some barriers to participation. The most common challenges to participation were conflicts with work and family emergencies. About 15% of families identified “other” barriers, which included having family members visit from out of town, family and home life challenges, prior commitments, or forgetting the session.

Limitations:

Though the findings to date of this study are promising, there are also important limitations to this work. First, most of the research participants were White non-Hispanic, and there were more participants with higher levels of education (past high school) than initially anticipated. The lack of diversity is a limitation common to much of autism research and may have been made more apparent by the need to deliver ASSIST online once COVID-19 made in-person gatherings difficult. The ASSIST team worked with families to access the technology they needed to meet online. However, families without reliable access to technology may have decided not to participate.

Finally, through the happenstance of COVID-19-related restrictions on social gatherings, the ASSIST team had the unexpected opportunity to examine participant satisfaction and preference for ASSIST when delivered in-person

versus online. Further study about ASSIST being delivered in varied modes will be necessary to determine which one is more beneficial for families.

Next Steps:

Continued analysis about the benefits and limitations of ASSIST are ongoing and will be the subject of future research reports. Since the creation of this report, Meghan Burke, Ph.D. (Principal Investigator, University of Illinois Urbana-Champaign site) has received research funding to adapt ASSIST to be culturally responsive and relevant for Spanish-speaking and/or Latinx families. The team is excited to have the opportunity to revise ASSIST to make it as effective as possible for groups that might encounter additional challenges advocating for services for their autistic transition-aged youth.

Heartfelt Thanks:

The ASSIST team is grateful to the families who took part in this study. They are our partners in discovery. Without families taking part in research, we could not advance our society’s understanding of how children with and without disabilities grow and learn.

We are also grateful to the many community partners and agencies that worked with us to develop ASSIST and deliver it to families. These partners include The Arc Tennessee, The Autism Project of Illinois, Disability Rights Wisconsin, and the many local experts who lent their time and expertise to the program. We are inspired by our local disability communities and could not have done this research without their involvement.

Questions?

Contact a member of the ASSIST team at transitions@vumc.org.

ASSIST

Advocating for SupportS to Improve Service Transitions