The University of Maine DigitalCommons@UMaine

General University of Maine Publications

University of Maine Publications

6-1-2018

Maine Parent Guide to Autism Spectrum Disorders Booklet 3 : Living with autim—high school and adult life on the spectrum

Maine Autism Institute for Education and Research

Follow this and additional works at: https://digitalcommons.library.umaine.edu/univ_publications

Part of the Developmental Neuroscience Commons, Early Childhood Education Commons, and the Special Education and Teaching Commons

Repository Citation

Maine Autism Institute for Education and Research, "Maine Parent Guide to Autism Spectrum Disorders Booklet 3 : Living with autim—high school and adult life on the spectrum" (2018). *General University of Maine Publications*. 3442.

https://digitalcommons.library.umaine.edu/univ_publications/3442

This Book is brought to you for free and open access by DigitalCommons@UMaine. It has been accepted for inclusion in General University of Maine Publications by an authorized administrator of DigitalCommons@UMaine. For more information, please contact um.library.technical.services@maine.edu.

Maine Parent Guide to Autism Spectrum Disorders

Booklet 3: Living with autism — high school and adult life on the spectrum





Developed by Maine parents for Maine families umaine.edu/autisminstitute

Maine Parent Guide to Autism Spectrum Disorders

Booklet 3: Living with autism — high school and adult life on the spectrum

Maine Autism Institute for Education and Research 5766 Shibles Hall, Room 303, Orono, ME 04469-5766 Phone: 207.581.2352 Fax: 207.581.2428 maineautisminstitute@maine.edu umaine.edu/autisminstitute

©2018 Maine Autism Institute for Education and Research (MAIER)

MAIER is a partnership between the College of Education and Human Development at the University of Maine and the Maine Department of Education. Our mission is to build statewide capacity to improve outcomes for individuals with autism spectrum disorder (ASD) through leadership, training, professional development, collaboration, and research. All websites listed are current as of the date of publication, June 2018.

The University of Maine is an EEO/AA employer, and does not discriminate on the grounds of race, color, religion, sex, sexual orientation, transgender status, gender expression, national origin, citizenship status, age, disability, genetic information or veteran's status in employment, education, and all other programs and activities. The following person has been designated to handle inquiries regarding non-discrimination policies: Director of Equal Opportunity, 101 North Stevens Hall, University of Maine, Orono, ME 04469-5754, 207.581.1226, TTY 711 (Maine Relay System).

Our Second Edition of the *Maine Parent Guide to Autism Spectrum Disorders* introduces this new booklet, "Living with Autism: High School and Adult Life on the Spectrum." This volume is our effort to address the issues faced by families and individuals on the spectrum as they grow into adulthood.

While no one resource can fulfill the information needs across the lifespan, we had three goals for this new volume. First, we sought to provide an overview of issues related to life during and after high school, second, we strove to direct readers to the best resources for more in-depth information, support, and services, and lastly, we hoped to offer some content and personal reflections not readily found elsewhere.

Just as our earlier edition was enriched with photos and narratives from our MAIER family partners, we again reached out to listen and then pass along the wisdom and experiences through the voices and photos of Maine families. We are privileged to include several young adults on the spectrum who graciously and selflessly shared their stories in this volume and provided insight into their lives. We are grateful to these individuals and their parents, and to the professionals who willingly shared their expertise to make this new volume a reality.

There is always room for new voices, so please let us know if you have ideas, suggestions, or comments to help build our Family Partnership community at the Maine Autism Institute for Education and Research.

We are indebted to those whose time and efforts have made this series possible:

Susan Abbiati	
Jessica Archer	
Nikki Becker	
Karen Grotton-Pelletier	
Kathleen Leopold	
Laurie Robichaud	
Cheryl Stalilonis	

Tony Abbiati Connor Archer Cathy Dionne Felicia Kasprzak April Poulsen Niki Sheafe Roy Ulrickson III

MAIER Staff and Other Contributors

Deborah Rooks-Ellis, MAIER Director and Editor Donna Doherty, MFP Director, Project Coordinator and Editor Autism Society of Maine Matthew and Nancy Brown, Autism Safety Education and Training (ASET) Jennifer Beckett Jamie Michaud, CDS Amy Miller, CDS Anica Miller Rushing Courtney Pacholski Jennifer Seale, Ph.D., CCC-SLP Valerie Smith, Ph.D. Libby Stone-Sterling Jamie Treworgy Carrie Woodcock, Maine Parent Federation

Special thanks to Jan Breton, Director of the Maine Department of Education's Office of Special Services, for her ongoing support for this project.



Disclaimer: The Maine Autism Institute for Education and Research is a partnership of the College of Education and Human Development at the University of Maine and the Maine Department of Education. The content of these handbooks does not necessarily reflect the position or policy of MDOE or MAIER, nor should the content of this handbook be considered an endorsement for the use of any particular intervention. All listed websites are current as of June 2018.

You Bring Out the Best in Me

You bring out the best in me The stand up and cheer in me

The stay up all night the need to figure it out in me The "I know I can find the answer" and sheer willpower in me

You bring out the patience in me The need to understand in me The never give up in me and having to take risks in me

You bring out..... The compassion in me and need to take care of you

The wonder in me and learning to live each moment in me

You bring out the "try one more time" in me Never give up in me

You bring out the creative thinking in me The must "think outside the box" teacher in me

You bring out the hope in me The perseverance and dedication in me The belief "we can overcome anything" and keep going in me

> You energize me Teach me Motivate me Guide me with..... A love so strong it sometimes aches in me

> > You bring out the calm in me laughter and joy in me the fighter in me

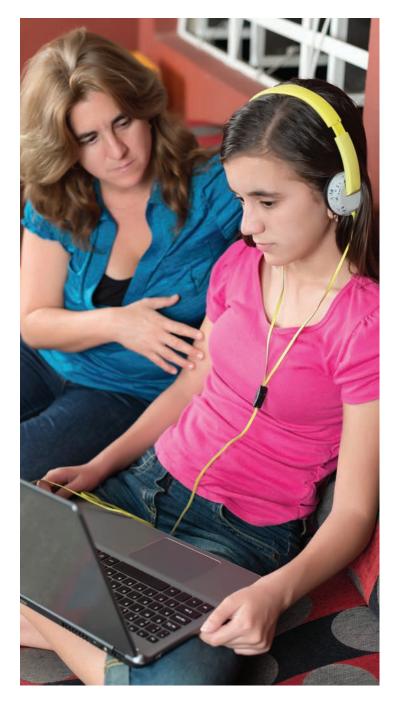
You bring out the best in me The person, inside, I was always meant to be

For all of the many, many times you have shown gratitude and thanked me It was you, Connor, who inspired me.

- Jessica Archer

Table of Contents

.2
.2
.3
.4
.5
.6
.8
.9
10
12
12
15
16
17



tarting high school is a major milestone for all teens, including your child with autism. As your teen adjusts to new changes and challenges, it is important to begin planning and preparing for adult life. This includes assessment of your teen's preferences, interests, needs and strengths (PINS) in order to guide goal planning for further education, work, recreation, transportation, health care, selfdetermination, legal issues and community living. Transition planning that begins early can provide your adolescent with the time to explore options and plan for chosen alternatives with family and his education team. It often takes many attempts to find a good post-school "fit" for your teen. Starting post-school transition planning early will also provide important guidance for making the transition to adult life in the community a success.

High school and transition planning



n Maine, schools are required to begin transition planning for all children with an IEP no later than ninth grade or at age 16, whichever happens first. The student, parents and IEP team, and adult services representatives (i.e., vocational rehabilitation, adult service coordinators) must work together to create a plan to investigate options and opportunities based on your adolescent's needs, interests and plans for the future.

Keep in mind that once your child graduates or "ages out" of public education (at age 21), all entitled educational services end. While access to a public school education is every child's right under IDEA, access to adult services are determined by a young adult meeting specific qualifications for services and by the availability of funding and resources. This is why it is important to start this process early so that you, as a family, can learn as much about your options for post-school adult services as possible to determine a good fit for your young adult.

Navigating high school

This section provides guidelines for parents as your child progresses through high school and includes suggestions for working with your child's IEP team on transition planning. It is important to keep in mind that your child is central to the transition process, and with your support, and the guidance of the transition team, he or she can explore their goals and make plans for adult living.

The following information was compiled from several transition resources, including *High School and Beyond: A Guide to Transition Services in Maine* (DHHS/CFS), *The Parent's Guide to College for Students on the Autism Spectrum* (Brown, 2012),

Transitions can be challenging for both you and your child. Think positive." – Maine Parent and *Pathways to Transition* (Woodfords Family Services). However, this is just a beginning; parents are encouraged to seek out these resources for more information and guidance through this process. (See Reference list at the end of this volume.)

Grades 9 and 10

- Federal law requires transition planning begin at age 16, focusing on the student's course of study as it relates to his or her long-term plans.
- Individualized transition planning should focus on developing a vision for adult life.
- Transition services must include instruction and related services, community experiences, development of employment or other postschool adult living objectives, acquisition of daily living skills and provision of a functional vocational evaluation.
- Your child should participate in IEP meetings to articulate his or her interests and goals for life after high school.
- Help your adolescent create and use a time management system for class assignments and out-of-class activities.
- Work toward increasing independence at home, and encourage your adolescent to be responsible and accountable for managing his or her free time and academic demands.
- If your child is not eligible for special education services, investigate eligibility for 504 accommodations.
- Discuss possible career options together
- Encourage your child to consider the different routes to employment (higher

education, technical training or supported employment).

- Explore community vocational opportunities and services, even if further education is planned.
- Begin discussions of the importance of work experiences and job-related skills, such as resume preparation and interviewing.
- Explore and learn to manage disability technology and request assistive technology accommodations to be considered in vocational planning.

Research studies suggest one of the best predictors of employment after high school is work experience before graduation. The Maine Department of Labor/Division of Vocational Rehabilitation (VR) offers Pre-employment Transition Services to students with disabilities starting at age 14. Taking advantage of the opportunity to explore pre-employment services before mandatory educational transition planning

Living with the challenges of autism as a teenager, and into the early years of adulthood, can be daunting. There are so many changes that already come during your teenage years. Adding the challenges of autism, can complicate your daily routine, and lead to stress that you already have just by growing up as a teenager and young adult." – Young adult living with ASD begining at age 16 gives you and your teenager a better idea of what goal to set.

Group sessions typically take place in a school or a community setting, and include sessions on job exploration, work-based learning experiences, post-secondary education exploration, and other life-skill building activities. For more information on applying for Pre-employment Transition Services offered by Maine's VR services, talk with your school or visit maine.gov/rehab/dvr/ youth_transition.shtml.

Grades 11 and 12

In addition to continuing with and building on the activities outlined for grades 9 and 10.

- Finalize the transition IEP. Your teen should increase participation and initiation of all things related to their educational services and transition planning.
- Participate in summer jobs or volunteer activities to gain valuable work experiences and test goal appropriateness through experiences and activities.
- Practice interviewing skills with your child.
- Secure various options for postsecondary education and/or employment.
- Develop residential and community participation supports and contacts.
- Include transition services in the student's IEP by age 16.
- Develop linkages with adult services.

Remember, entitlement to special education services ends when your adolescent graduates,

withdraws from high school, or reaches age 21. Under IDEA, school districts are required to provide students with a Summary of Performance (SOP) at this time. This document includes a summary of your teen's academic achievement and performance of daily functions (e.g., communicating, time management), and includes recommendations for assisting him in reaching his post-secondary goals.

If your child is considering continuing education:

- Support your child in working with her guidance counselor to develop a list of possible colleges and post-secondary schools.
- Help your child research schools online.
- Visit potential schools with your child.
- Try to schedule a day for your teenager to shadow a current student at a potential school.
- Support your child in applying to his selected post-secondary schools.

For a more in-depth discussion of higher education for your child, see "Exploring and planning for post-secondary education" later in this volume.

If your teen is planning to enter the workforce:

- Contact local and state agencies involved in employment services. A good place to begin is the State of Maine Department of Labor, Bureau of Rehabilitation Services. Visit maine. gov/rehab or call 207.623.6799.
- Apply for Vocational Rehabilitation (VR) Services. VR counselors can help your child



develop employment goals and establish a plan based on their interests and abilities. Activities include job tours, job shadowing and coaching, and paid work experiences. For more information about VR, visit maine.gov/rehab/dvr/youth_transition.shtml, call 207.623.6799 or talk with your school counselor.

• Explore employmentforme.org, developed by the Maine DHHS Department of Labor and the Muskie School of Public Health to provide information about employment resources and initiatives in Maine. Check out the section for youths in transition.

Family support for transition planning

There are several organizations and agencies in Maine dedicated to helping adolescents and young adults with disabilities and their families prepare for the transition to adulthood. The Autism Society of Maine (asmonline.org) and the Maine Parent Federation (mpf.org) both have excellent resources for transition, including workshops, online videos, and a lending library with books and DVDs you and your teen can borrow. Full contact information can be found in *Volume 4: Resource Guide*.

Access Maine (accessmaine.org) is a website dedicated to providing a variety of information and resources for Maine citizens with disabilities. In addition to a section devoted to transition planning, there are many other sections with helpful information, resources and links on independent living, including housing, transportation, employment and advocacy.

The Think College website (thinkcollege.net) has a plethora of resources on college options for people with disabilities including technical assistance, training, resources for families, and a college search feature.

This is not a complete listing. Talk with your education and health care providers for information about other resources in your area.

Final thoughts on transitioning to adulthood

The Pacer Center, a parent training and information center for families of children and youth with disabilities, offers the following suggestions for teens and young adults facing the transition to adulthood. Read "Ten Tips that May Help Your Child's Transition to Adulthood," online at pacer.org/parent/php/PHP-c107.pdf.

• Develop self-determination and selfadvocacy skills. All young people need a strong sense of their strengths, abilities, interests and values.



When my child turned 18, it was both exciting and a bit nerve-wracking. After graduating from high school, all of the build-in supports disappear and we as parents feel a bit on our own to make the best possible life for our child."

– Maine Parent

- Expand social and community support networks. Social and community networks are more than fun, they are important tools that help tie people into the community and provide a wider network of support.
- **Build a work resume.** Many young people struggle to find work experiences that help them compete in the job market. Summer jobs, helping neighbors and volunteering are great solutions. Video resumes are a great way of showcasing what an individual can do rather than what challenges they have for a future employer. Starting this process early, helps make the task less daunting. Enlist the assistance of school and adult service professionals.
- Learn soft-employment skills. These include things such as being able to accept direction, returning from breaks on time, deal with conflict, have the confidence to make decisions, and engage in appropriate communication. Work on manners and social skills that will assist in employment success.
- **Practice money management skills.** Financial education is an important part of transition.

Children need the self-determination skills developed through saving, spending, gift giving and budgeting.

- Connect with adult service providers. The IEP team will no longer be available to coordinate disability-related services young adults with ASD may need, such as accommodations, transportation, physical or speech therapy, and job development services. Begin to develop relationships with adult service providers early. If you do not reach out to them, they may not know what your family's needs are.
- Explore housing options. While some young adults may stay in the family home for a short while, others may live in residential housing with services, cooperative housing, educational institution dormitory, an apartment with or without roommates, or they may own a home. Starting this process early helps make the task less daunting. Enlist the assistance of school and adult service professionals.
- Plan for health care needs. Like most people, young adults with disabilities need to begin managing their health care, prescription drug use and insurance issues.
- Visit post-secondary training and education programs. Visiting a college or employment training program will help young adults with ASD visualize the future.
- **Prepare for change.** Helping your child plan for the future can lead to success, as long as you stay flexible. Plans will change no matter how carefully they are developed,

and life includes challenges and stumbling points. Allowing your son or daughter to be flexible with future plans will help him or her to develop the self-determination and selfadvocacy skills important for adult life. In Maine, families can contact the State of Maine Department of Health and Human Services for information on disability services, housing, health (including MaineCare), Social Security, guardianship, employment and vocational rehabilitation in the state. Visit maine.gov/dhhs or

Legal considerations

call 207.287.3707.

Although it may be hard to imagine your adolescent as a legally independent adult, there are important legal issues to consider as your child approaches late adolescence. One important thing to keep in mind is that by law, once your child turns 18, he or



Making a decision about guardianship is a tough one. Not all adults on the spectrum need a guardian, but for my son, it was the logical and right thing to do."

– Maine Parent

she will have reached the age of majority in Maine. This means your child will have all the rights and responsibilities of an adult. This includes consent for educational evaluations and the IEP while in school, as well as the right to vote, marry, get a credit card and obtain medical treatment.

As a parent, you may want to consider the degree to which your adolescent is able to make these decisions. For some individuals with autism, considering some form of legal oversight for decision-making may be appropriate. However, there are alternatives to petitioning the court for full guardianship (the most restrictive option). Options include becoming her payee to help manage her financial resources, limited or partial guardianship (e.g., medical decisions), power of attorney, and supported decision-making.

To learn more about guardianship and its alternatives, visit the Maine DHHS Office of Aging and Disability Services (OADS) guardianship information webpage (maine.gov/dhhs/oads/ aps-guardianship/guardianship.html) or call 207.287.9200.

To learn more about supportive decision-making, see these resources:

- Supported Decision-Making: A project of Disability Rights Maine: supportmydecision.org
- Supportive Decision-Making: A project of the Autistic Advocacy Network: autisticadvocacy. org/2016/02/the-right-to-make-choices-newresource-on-supported-decision-making
- National Resource Center for Supported
 Decision-Making: supporteddecisionmaking.org

As a family, you will want to explore and determine the right amount and types of support for your young adult with ASD to help him or her achieve the highest degree of independence possible. We encourage you to gather information, and consider your options well before your child's 18th birthday.

Adult life on the spectrum: Accessing adult services and supports



nce your child leaves secondary school and enters the adult world, he or she may need continued support and services to be successful in adult life. When your child turns 18, you can apply for MaineCare, which provides benefits to individuals who meet income guidelines and have a documented disability. Once approved, MaineCare can open up opportunities for adult support services in addition to medical care. This includes Section 21 (home and community benefits) and Section 29 (support services) waivers to access services to support persons with intellectual disabilities or autism spectrum disorders to live as independently as possible at home, in the community, or at a job.

MaineCare waivers are a means to access support services, but your young adult must apply and be approved through the Maine Department of Health and Human Services (DHHS). Learn more about the application process at maine.gov/dhhs/oads/ home-support/disability-with-autism/index.html.



After graduating from high school, I have been involved with the WABAN program. I get rides from my various job coaches back and forth from the Animal Welfare Society in my local area on Tuesdays, Thursdays and Fridays. While we are there, my job coach will give me assistance if I ever need it. Since I don't normally need any, they tend to just leave me to my work and I can find them nearby if I have any questions or if I need help.

My various duties include cleaning kennels, walking dogs and filling treats. Cleaning kennels may not seem like the most exciting job, but the animals can't do it for themselves, which is why I'm there. The thing I enjoy the most about my job is that it makes me feel like I'm needed, which in this case is exactly what's going on since the people working there are very busy and my work really helps them out a lot." – Young adult living with ASD

Once approved for a waiver, your child will use a case manager to help him or her determine the services needed and how to access those services. The Maine Developmental Disabilities Council offers a toolkit for selecting adult community service providers, available to download from their website: maineddc.org/index.php/resourcespublications/community-support-toolkit.

The Center for Community Inclusion and Disability Studies at the University of Maine also offers resources to learn more about important services and supports for adults living on the autism spectrum, including advocacy, employment, housing, recreation, and transition. For more information, visit ccids.umaine.edu/resources/ for-individuals-and-families.

Employment

Many teens and adults on the spectrum desire to and are capable of being employed. While the necessary skills, interests, training and supports will vary widely among persons on the autism spectrum, there is support to help your teen or adult child through this process. A good place to start is with the State of Maine Department of Labor, Vocational Rehabilitation Services.

Vocational Rehabilitation (VR) is a program to help persons with disabilities find and keep a job. Individuals must apply for services and provide documentation of their disability. VR counselors work with individuals to explore their interests, skills, and capabilities to develop employment goals and a plan to get there, including training, if necessary. To learn more about this program, download a copy of the *Consumer Handbook for Vocational Rehabilitation Services* from the State of Maine Department of Labor website: maine.gov/rehab/dvr/vr.shtml.

For persons on the autism spectrum, employment can be challenging due to communication, sensory, or social challenges associated with their diagnosis. However, these challenges affect individuals in different ways, thus accommodations and strategies to support success in the workplace must be individualized. Employment specialists If your child has a Trust Fund or a large sum of money set aside for their future needs, you should consider setting up a Special Needs Trust Fund. Funds from a Special Needs Trust can be used for living expenses, recreational activities, educational expenses, etc. while still qualifying for government programs, such as SSI and MaineCare. If this is an option for your family, find a lawyer who specializes in Special Needs Trust Funds to help you." – Maine Parent

working with your child should focus on finding a good match between your child's interests and skills, their learning style, and the environmental demands of the workplace (Kurtz & Jordan, 2008). To learn more about potential supports for persons with ASD in the workplace, download "Supporting

For people with disabilities, having Social Security Income (SSI) opens up many services to them, not just a monthly check. Once your child has SSI, he or she will qualify for MaineCare as well, but you will need to notify DHHS (Maine Department of Health and Human Services) that SSI has been approved. Applying for SSI is a long process and a bit frustrating, but worth it in the end." – Maine Parent



Individuals with Autism Spectrum Disorders: Quality Employment Practices" from the UMaine Center for Community Inclusion website (ccids. umaine.edu/resources/for-individuals-and-families).

Social Security Income

For adults living with autism, some form of financial support may be necessary for independent or supported living. Social Security Income (SSI) is a federal program that provides a monthly income to adults who are disabled and living on little or no income. Once your child turns 18, you can apply for SSI to determine if your child is eligible. Contact your local Social Security Office for guidance. You can find your closest Social Security office at socialsecurityoffices.info/state/maine. If your child has been receiving Social Security benefits as a minor, you will need to reapply after they turn 18 to determine eligibility as an adult.

Exploring and planning for post-secondary education

oday, individuals with autism are pursuing post-secondary education more frequently than in the past. This may be an option for your son or daughter to explore. Importantly, your child must be capable and interested in this option, and willing to lead the process. As a parent, your role will be to support their efforts and be available when necessary.

Many post-secondary options exist for youth on the autism spectrum, including vocational schools, two-year and four-year programs, and graduate and professional schools. Supports vary from institution to institution, with some offering specialized programs and housing for students on the spectrum and others providing varying levels of support and services through their disability or student accessibility services offices.



When researching options, consider what will be most important for your child's success. Not only will your child need to be prepared for the rigors of higher education, they will need to manage social situations and independent living skills in new ways. While your child is no longer entitled to an education as they were under IDEA, they are ensured equal access under the Americans with Disabilities Act (ADA). Students with disabilities must meet the same academic and behavioral requirements as all students, with "reasonable accommodations" when needed.

If your child is considering post-secondary education, we encourage you to view "College and Students on the Spectrum" (youtu.be/GZp459zssr0), on online video created by autism and education experts at the Yale University School of Medicine's Child Study Center. This hour-long presentation offers guidance to families with a child considering and preparing for college. Additionally, a MAIER Family Partnership parent suggests *The Parent's Guide to College for Students on the Autism Spectrum* by Jane Thierfeld (Brown & Colleagues, 2012) as a helpful guide.

To learn more about post-secondary institutions with special programs for students with ASD, visit collegeautismspectrum.com/collegeprograms. html#college or thinkcollege.net.

While each institution will have its own procedures for accessing services and requesting accommodations once accepted, most follow similar guidelines. A Maine parent who supported her son through this process offers the following guidance to families whose children have been accepted to a post-secondary institution:

"As with all students heading to college, preparation is key. For a student with ASD, visiting the campus and talking to the student center for special services is important to start the process. In order to carry accommodations forward to a college setting, it will be The first semester of college was challenging, especially as I had to meet new friends and balance a new job that took time to navigate. However, with time, I was able to adjust and challenge myself in new and exciting ways."

- Individual living with autism

essential to have documentation of his or her disability and the need for accommodations. For example, if your child needs extended time on a test, this need must be documented and supported by the school psychologist and/or special education director and teachers.

Once approved for accommodations, the collegebound student must meet with the special services office on their college campus to develop an accommodation plan. At the start of each semester, the student will need to request and acquire a letter of accommodation from the special services office to deliver to their professors. The college student should recognize that this is now his or her responsibility. However, the special services office continues to be their resource on campus for assistance.

As will all new settings and situations, it might be helpful to role-play or talk through the process your child will take to distribute his or her accommodation letters to each professor. There are many resources and people on college campuses who want to help, and it is important to seek those resources prior to the start of the first semester." A young adult living with ASD and attending college offers these words of advice to high school students considering post-secondary education:

Transitioning out of high school into college can seem daunting. These steps can help you get on the right track:

- Set a plan and meet with your current special education director at your high school to discuss the transition process.
- 2. If you already have an IEP or 504 Plan, you should be familiar with the accommodations that are in place before meeting with Student Accessibility Services at your post-secondary institution. Ask your high school special education office to review your current accommodations with you.
- Schedule a meeting with Student Accessibility Services on campus once you are accepted into a post-secondary institution.
- Make sure to review and ask about your current accommodations and other types of accommodations that may be available. It is better to have more accommodations in place and end up not needing them.
- Make sure that you have documentation of your disability. You will need this to access support services and will be used to inform your instructors/professors of your disability.



- 6. Make sure to advocate for yourself if any issues occur or if changes need to be made to your accommodations.
- 7. Most importantly, develop a positive relationship with your instructors and professors, allowing you to succeed in your college classes.

Closing

s your child grows and develops throughout adolescence and into adulthood, there will be many transitions, perhaps some disappointments and frustrations, but successes and triumphs as well. Learning, growth, and development of new skills and accomplishments continues throughout your son or daughter's adult life. As we close this volume, we would like to leave you with these final thoughts from the voices of individuals experiencing life on the autism spectrum.



I try to find time to relax with family and friends. While it is hard for me to relax, I feel that it is important to find time for laughter and happiness, even if you are as passionate or driven about things as I am."

- Individual living with autism

C Throughout my teenage years, I needed to gain self-confidence that would help me grow as an individual. I needed to try to do activities that would bring me out of my comfort zone. I fortunately had some amazing friends that encouraged me to try new things, even when I was not a big fan of doing so."

- Young adult living with ASD

I am a young adult with ASD. I started off working for my local fire department when I was 14. I absolutely loved being there, but I never thought I would become a firefighter because of my ASD. I am now a part-time firefighter for my home town, and I absolutely love what I do. I am now in school to become an EMT and become a full-time firefighter. Just because you have ASD, don't let it stop you from becoming the person you want to be. I myself have better days than others, but that happens to all of us. Don't let it stop you from achieving your dreams. We all have dreams, go for it!" – Young adult living with ASD

Key points from Booklet 3

- Transitions can be challenging. Be patient with yourself and your child.
- Start transition planning early; seek out resources and support that is available to help.
- Support your child in their chosen goals, but remember they must take increasing responsibility for transition and future planning.
- Take advantage of vocational rehabilitation services while still in high school. One of the best predictors of employment after high school is work experience before graduation.
- Consider guardianship issues early; it is better to have the necessary legal concerns addressed before your child reaches the age of majority (18 years old).
- Explore and apply for adult services and supports early, the process can be challenging, but worth the effort.
- Explore all possibilities for employment, post-secondary education, and life in the community with your child. Support their interests, skills and abilities in finding the right match for adult life.

References and resources

Access Maine. *Transition Planning (Ages 14–25)*. accessmaine.org/living_transition.htm

Access Maine. A Transition Guide for Families of Youth and Young Adults with Developmental Disabilities. accessmaine.org/Toolkits/GuideforFamilies/guide.htm

Autism Society of Maine: Resources and workshops. Call 800.273.5200, email: info@asmonline.org or visit asmonline.org.

Brown, Jane Thierfeld (Ed.D.), et al. (2012). *The Parent's Guide to College for Students on the Autism Spectrum.* Shawnee Mission, KS: AAPC Publishing.

Brown, Jane Thierfeld (Ed.D.). (Sept. 17, 2014). Personal communication. *College and Students on the Spectrum*: (youtu.be/ GZp459zssr0), on online video created by autism and education experts at the Yale University School of Medicine's Child Study Center. This hour-long presentation offers guidance to families when your child is considering and preparing for college.

Courageous Steps Project is a nonprofit founded by Connor Archer, a young adult with ASD. This project is dedicated to increasing awareness of persons living with developmental challenges and providing resources to local programs that help children and young adults with developmental challenges. You can learn more about Courageous Steps, and how to become involved with this project at thecourageousstepsproject.org.



High School & Beyond: A Guide to Transition Services in Maine: Produced by the Youth and Community Engagement Team at the University of Southern Maine, Muskie School of Public Service with funding from the Maine Department of Health and Human Services. Available at maine. gov/dhhs/ocfs/cbhs/documents/5-2-18Youth%20 Transition.pdf or by contacting Autism Society of Maine.

Loo, Stephanie. Asperger's Association of New England. (Aug. 7, 2014). Personal communication.

Lowell, Allyson and Martinez, Dina. *Pathways to Transition*. Portland, ME: Woodfords Family Services.

Maine Developmental Disabilities Council: maineddc.org. MDDC promotes and advocates for equal opportunities for persons with developmental disabilities to participate in every aspect of community life through advocacy, training, demonstration projects, and support. Call 207.287.4213/800.244.3990.

Maine Parent Federation. Information packet on transition, online videos. Call 800.870.7746 (Maine) or 207.588.1933, Email: parentconnect@ mpf.org or visit startingpointsforme.org.

Ohio Center for Autism and Low Incidence (OCALI). (2009). *Ohio's parent guide to autism spectrum disorders (2nd ed.)*. Columbus, Ohio: OCALI. Available online: ocali.org/project/ohio_ parent_guide_to_ASD. Ohio Center for Autism and Low Incidence (OCALI). Lifespan Transitions Center: ocali.org/ center/transitions.

Selecting A Community Service Provider: A Toolkit for Assessing Adult Developmental Services. (2015) Available from the Maine Disabilities Council. Phone: 207.287.4213 or 800.244.3990; maineddc.org/images/PDFs/Community-Supports-Tool-Kit-Feedback-Submission-form.pdf.

State of Maine/Department of Health and Human Services. Information on disability services, housing, health (including MaineCare), Social Security, guardianship, employment and vocational rehabilitation in the state of Maine. Website: maine.gov/dhhs. Phone: 207.287.3707.

Supporting Individuals with Autism Spectrum Disorders: Quality Employment Practices. The Institute Brief: Issue 25, December 2008. Institute for Community Inclusion, UMass, Boston. Available online at ccids.umaine.edu/wp-content/ uploads/sites/26/2010/01/ASDBrief.pdf.

Think College (thinkcollege.net) is a website of resources on college options for people with disabilities (including technical assistance, training, resources for families, and a college search feature).



Autism ribbon used with permission of the Autism Society of Maine

Maine Parent Guide to Autism Spectrum Disorders

Booklet 1: What to do when you suspect an Autism Spectrum Disorder

Booklet 2:

Accessing educational and social services and interventions

Booklet 3:

Living with Autism: High school and adult life on the spectrum

Booklet 4:

Resource guide for Maine families

The Maine Autism Institute for Education and Research works to build statewide capacity to improve outcomes through leadership, training, professional development, technical assistance, collaborative consultation, technology, and research for individuals with autism spectrum disorders (ASD) throughout the spectrum and life cycle.



5766 Shibles Hall, Room 306, Orono, ME 04469-5766 207.581.2352 • Fax: 207.581.2428 maineautisminstitute@maine.edu • umaine.edu/autisminstitute