Life Journey Through Autism: A Guide for Transition to Adulthood







LORI LAPIN JONES PLLC

Life Journey Through Autism:

A Guide for Transition to Adulthood

by

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Dear Readers,

September 2021



Twenty-four years ago, I began my journey in the autism world when my son received his autism diagnosis. I became educated and trained. I learned to navigate and advocate. During my son's early intervention, elementary education, and secondary education years, I saw an exponential increase in autism awareness and services. I experienced tremendous successes and milestones with my son in school and at home. And just when I thought I could breathe, along came adulthood on the horizon. Once again, a path for my son had to be forged and, like fifteen years before, navigating the path was

daunting. If you are experiencing just that, thinking no one understands what you are facing, and not sure where to begin – you can breathe, because OAR gets it.

Life Journey Through Autism: A Guide for Transition to Adulthood is a resource that takes you through the adult transition journey. The guide provides information on laws and policies, transition planning, postsecondary education, vocation and employment, and life skills, including living arrangements, and health and safety goals. It does so methodically and comprehensively. To enhance the transition to adulthood, education and planning are key components, and in developing this guide, OAR recognizes the importance of these factors.

OAR remains committed to enhancing the quality of life for individuals with autism by providing competent information and useful resources. OAR also remains committed to being one step ahead in the autism education world – in fact, OAR's foray into the adult transition journey is not of recent vintage for this guide is an update of its original publication in 2006.

Transitioning into adulthood is one of the most significant steps in the life of an individual with autism. This guide will help you to navigate and embrace that journey. In my view, this adult transition guide is one of OAR's most useful and impactful resources.

Sincerely,

Lori Lapin Jones Lori Lapin Jones PLLC

Vice Chairwoman, Board of Directors

Dear Readers, September 2021



In an ideal world, a student's first day after graduating from high school would not look much different from their last day of school. That is, the transition planning and other preparation would have been so well developed that the student's progress did not come to a sudden stop when school ended but simply continued uninterrupted.

Transitioning from one phase of life to the next should be seamless. But accomplishing that requires a comprehensive approach to education that gradually helps children move from the sandbox on the

playground in kindergarten to changing classes through middle school, and then on to work and higher education after high school. For educators and parents, seeing and understanding what goes into this kind of long-range planning and preparation within the larger system of education and community supports can difficult.

Typically, parents and educators cannot rely on their own experience maturing into adulthood when planning for the needs of their child or student with autism. That is where this guide comes in for additional input and support. This guide helps draw attention to key areas of consideration with regard to the transition to life after high school, not only for teaching and instruction but also in terms of legal protections and the overall planning process. Much of the dignity and success of adulthood comes from being able to do things for oneself, and every child is entitled to grow into that place.

Contemplating transition planning from an ecological perspective, different readers will benefit from different sections of this guide and at different points in the process. However, a fundamental focus throughout all the planning is the overwhelming importance of keeping the goals and objectives of the person with autism at the center of the process. Ideally, the young adult transitioning into adulthood drives the process themselves. Encourage them to engage with this guide alongside with you and know which areas will be of greatest importance and relevance to them. However, if they need support in interpreting and understanding the areas where they need help, those providing such support – whether parents, family members, or educators – must be mindful of the young adult's goals and dreams.

We only have a limited time frame in which to leverage public school services. Schools can be a rich resource, but they often vary in quality based on a myriad factors, including state and

local policy as well as funding. Regardless of such differences, a fairly universal constant is the reality that once access to schooling ends, support opportunities dwindle, making it essential to get as much out of the school years as possible. This guide provides a roadmap for individuals with autism, their parents, and their teachers as they together advocate for the supports and instruction that will help maximize post-school outcomes.

As a society, we lose a tremendous amount of human capital when we fail to help all students reach their full potential – a loss that, in turn, diminishes what our communities can become. When we optimize opportunities for everyone and provide the support, structure, and instruction to everyone as they need it, the entire community benefits. Hopefully, this transition guide will serve as a resource in pursuit of these ends.

Sincerely,

Kerinfilm

Kevin M. Ayres, Ph.D., BCBA-D The University of Georgia Dear Readers, September 2021



The Embassy of the State of Qatar in the United States is a proud sponsor of the Organization for Autism Research. OAR provides a vital service that helps students build friendships with their autistic peers to help create inclusive and supportive educational environments. Their work does not just foster the developmental needs of people on the Autism Spectrum, it also ensures they find acceptance and understanding in their communities.

I have personally experienced the work OAR is doing, having had the honor of meeting with OAR's Executive Director, Michael Maloney,

during a visit by autism leadership to Doha in 2020. OAR's passion and dedication to the work they do is life changing for so many young people, and we look forward to partnering together to further enhance the programs they offer to students and educators across the United States.

The State of Qatar has a long history of supporting Autism initiatives at home and around the world. In 2007, Her Highness Sheikha Moza bint Nasser first proposed World Autism Awareness Day to the United Nations General Assembly. The Embassy of the State of Qatar in the United States has followed her example and is dedicated to supporting the US autism community nationwide. We are committed to facilitating organizations that teach essential skills, provide career opportunities, and build independence for individuals on the spectrum. We subscribe to a holistic viewpoint that true progress comes from providing resources to people with autism, their caregivers, and the community at large, and OAR is a prime example of an organization that is doing just that.

Thank you OAR for your commitment to the autism community, and thank you reader for enriching your knowledge on inclusivity and engagement. Together we can build a society accepting of all abilities.

With renewed appreciation,

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About the Embassy of the State of Qatar in the United States

The Embassy of the State of Qatar in Washington, D.C. houses Qatar's diplomatic mission to the United States. The primary purposes of the Embassy of Qatar are to highlight Qatar's policies on regional issues, strengthen Qatar-U.S. bilateral relations, and to assist Qatari citizens who travel or live in the U.S. The current Ambassador of the State of Qatar to the United States of America is His Excellency Sheikh Meshal Bin Hamad Al-Thani.

Over the past 20 years, the State of Qatar has been a leader in advancing autism research and awareness campaigns in the Middle East and around the world. As one of the original countries that proposed Autism Awareness Day, the State of Qatar is committed to improving autism awareness and support services for individuals on the spectrum and their families. In the United States, the Embassy of the State of Qatar hosts an annual gala that supports autism initiatives, while working year-round with grassroots community organizations that build inclusive environments for all people. Scan this QR code to learn more about Qatar's efforts in autism advocacy and research in the United States and in Qatar.

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INTRODUCTION

The transition from school to adulthood is a pivotal time in the lives of all students. For a student with Autism Spectrum Disorder (ASD), change of any kind can be challenging, and a transition as momentous as this can seem especially daunting.

As a parent of an autistic young adult, you have already accomplished a lot, from coping with the diagnosis to addressing all the challenges you may have faced over your child's school years. And you will continue to play a large role in the transition-related self-discovery and planning process for your autistic young adult. Thoughtful planning, sound information, and open communication will help you support your young adult and their transition team to create a solid transition plan that leads to success. It is the goal of this guide to support your family with this process.

Federal law requires that a transition plan be developed for autistic learners beginning at age 16. In practical terms, however, transition planning should begin sooner; generally, it should begin no later than age 14. But regardless of when the plan is developed, it becomes an integral part of the Individualized Education Program (IEP) and carries the same legal authority. The goal of the transition plan is to facilitate the movement from school to the world of adult work, living, and community participation.

Transition planning, therefore, refers to a process that uncovers, develops, and documents the skills, challenges, goals, and tasks that will be important as a student moves from school to adulthood. This is both an official process and one of personal discovery, which you and your young adult will undertake with the help of their school and other concerned professionals. Approaching transition planning with a positive goal orientation will help create a successful and rewarding process for both you and your autistic young adult.

The 2004 revision of the Individuals with Disabilities Education Act (IDEA) defines "transition services" as a coordinated set of activities for a child with a disability that is:

- Results-oriented focused on improving the academic and functional achievement of the young adult with a disability
- ► **Supportive** designed to facilitate the young adult's movement from school to postschool activities, including postsecondary education, vocational education, integrated or supported employment, continuing and adult education, adult services, independent living, or community participation

2 Using the Guide

► **Student-centered** – based on the individual young adult's needs, taking into account strengths, preferences, and interests

► Comprehensive – including instruction and related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation

Effective transition is central to more independent, involved, and enjoyable adult lives for autistic learners. As such, it always starts with vision: Where will this individual be at the end of this process? What skills will this individual have? What contexts will be the best for them to apply these skills?

Lewis Carroll, author of the children's classic *Alice in Wonderland*, wrote, "If you don't know where you are going, any path will take you there." By following the suggestions in this guide, you and your autistic young adult **will** know where you are going, and a sound transition plan will be your path to getting there – a successful adulthood for your autistic young adult.

USING THE GUIDE

Think of this as a user's manual for the transition to adulthood. With that in mind, every young adult's interests and needs are different. What works for one young adult may not be as important or useful for your child. Use this guide in whatever way works best for you. You may read about one issue at a time while completing the associated activities, or you may glance at what to expect in the years to come. Learn from and customize the guide's contents so that it may work for you and your family when you need it.

Language and Terminology

This guide is written for parents and guardians of autistic individuals who are preparing to transition into adulthood. With that in mind, the guide will refer to "your child," "your teen," and "your young adult" interchangeably throughout.

Autism is also a spectrum disorder, characterized by a continuum of abilities and challenges. Throughout the guide, we will use the word *autism* to represent this disorder and spectrum.

Using the Guide 3

Icons

Throughout the text, you will find icons that highlight specific types of resources. Look for the following icons:



The computer icon denotes a reference to an online resource.



The pen icon denotes a reference to a handout or activity for parents at the end of that chapter.



The pencil icon denotes a reference to a handout or activity for students at the end of that chapter.

Key Points

Throughout the text, you will see concepts that are **bolded** for emphasis.



At the end of each chapter, you will also see a summary of important points to consider.

References

Throughout the text, you will see citations such as the following: (author, year). The full reference for that citation can be found at the end of the chapter in the Resources section. It may be helpful to use these sections if you are interested in reading more details from the primary source.

Handouts and Activities

Each chapter of the guide includes handouts and activities related to the content of the chapter. Handouts include supplementary information such as tip sheets or detailed informational charts. Activities include worksheets and other templates that you or your child can fill out to work on the skills discussed in that specific chapter.



Your young adult is protected by certain laws and policies that will help during the transition process and throughout life. This chapter provides a brief overview of the key laws you should be aware of, while also introducing you to agencies that can help you sort out this information and its implications for you and your young adult's specific situation.

LAWS AND POLICIES

Three laws overlap to benefit and safeguard you and your autistic young adult as you begin the transition process: IDEA, Section 504 of the Vocational Rehabilitation Act, and the Americans with Disabilities Act (ADA). These laws help you and your young adult to access the most appropriate services to prepare for the transition to post-high school life. In addition, the federal Every Student Succeeds Act (ESSA) of 2015 addresses the educational needs of autistic individuals and will also be briefly discussed.

Individuals with Disabilities Education Improvement Act (IDEA 2004)

The evaluation, planning process, and subsequent services that your young adult receives at school are all provided because of IDEA requirements. That is, the IDEA provides federal funding to state and local school systems to provide special education services to eligible students with disabilities and guides how states and school systems provide services to these children. Specifically, the IDEA goals are to:

- ► Ensure that all children with disabilities receive **free appropriate public education**
- with special education and related services designed to meet their specific needs
- Prepare them for postsecondary experiences, employment, and independent living
- ► **Protect the rights** of children with disabilities and their parents

6 Laws and Policies

Assist states, federal agencies, and schools in providing an education to all children with disabilities in the **least restrictive environment**

Evaluate the effectiveness of educating children with disabilities

IDEA protects your young adult starting at age of 3 and continuing to 21 years old. It ensures that children with disabilities receive the services they need in relation to their strengths, challenges, and interests. IDEA requirements are facilitated through the IEP process. By age 16 (at the latest), the IEP process must include transition planning services that are:

- Outcome-oriented
- Based on the child's strengths and areas of need
- Focused on instruction and services for education, employment, and other postsecondary living skills

The amended IDEA (2004) also contains a requirement that says schools must provide a summary of performance to students once they transition from high school. This summary should include information about academic achievement and performance, as well as recommendations for individualized strategies useful for meeting transition goals. By adding to the requirements for transition planning, this provision strengthens the planning process.

It is important to note, however, that the IDEA protections you and your young adult are entitled to receive no longer apply once your child leaves high school or turns 21. This means that after that, it is up to you and your child to actively seek out the appropriate services and supports offered by the other laws that take its place, including Section 504 of the Vocational Rehabilitation Act and ADA.

Section 504 of the Vocational Rehabilitation Act and ADA

While you are most likely already familiar with the requirements of IDEA, you may be less familiar with Section 504 of the Vocational Rehabilitation Act and ADA. Whereas the IDEA mandates education and services for students, Section 504 and ADA are civil rights laws designed to protect people with disabilities from disability-related discrimination concerning services (such as school), employment, and public accommodations (e.g., equal access to a preferred restaurant). Section 504 applies to any institution (e.g., school systems) that receives federal funds; the more expansive protections under ADA apply to state and local government services as well as a number of public services, whether or not they receive federal funds. Both Section 504 and ADA require that students with disabilities not be denied access to services or supports that may be necessary to meet their needs or would be available to students without disabilities. Please note, however, that Section 504 and ADA are intended to promote equal access to activities and services and not to serve as guarantees of the appropriateness of the services accessed.

To be eligible for these protections, a child has to have (a) a physical or mental impairment that limits at least one major life activity (e.g., functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working) and (b) a history of this impairment in a major life area. An individual with a diagnosis of ASD qualifies for both Section 504 and ADA, which take on greater significance in adulthood when the entitlement protections offered under IDEA cease to be in effect.

IDEA, SECTION 504, ADA, AND THE TRANSITION PROCESS

The following lists summarize how these laws specifically impact your young adult during the transition process. **Handout 1-1:** *Comparison of ADA, IDEA, and Section 504 Legislation (on page 11)* provides more detailed information.

- ► IDEA requires a transition plan once your child reaches age 16 (certain states require it at age 14). This plan must have the following characteristics:
 - An outcome-oriented system based on your child's strengths, areas of interest, and accommodations
 - ▶ A transition plan that is monitored and revised as your child gets older
 - ▶ A team approach based on the specific services your child needs
 - A process that cannot be changed or modified without your knowledge and consent (that is, until your child reaches the age of 18 and can independently make changes for themselves)
 - ▶ Involvement of the autistic learner to ensure their goals and needs are addressed
 - Services that help address the skills and accommodations needed to prepare for transitioning post-high school
 - ▷ A summary of services acquired during the transition process to assist post-high school
- ► Section 504 and ADA work together to ensure that an autistic learner cannot be discriminated against in school and beyond by providing:
 - Equal opportunities to students with disabilities
 - ▶ Access to supportive services (such as an in-classroom aid)
 - ▶ Protections for the young adult post-high school (in college or at work)
 - ► Accessibility to all programs, including extracurricular activities
 - ▶ Protections for autistic learners in education and employment

Every Student Succeeds Act (ESSA 2015)

The Every Student Succeeds Act (ESSA) of 2015 replaced the No Child Left Behind Act of 2001. ESSA requires that all students be taught to high academic standards and be prepared to succeed in college and careers. Each state is required to work with parents to develop their state plan, determine accountability indicators of success, and release public report cards regarding school performance. In addition, ESSA may complement IDEA by funding college and career planning, career and technical education, and dual-enrollment classes in postsecondary institutions, all of which can play a role in transition planning. Refer to your state's Department of Education website for specific information on your state's ESSA plan.

STATE AND FEDERAL AGENCIES THAT CAN ASSIST IN THE TRANSITION PROCESS

The transition process can be confusing, but there are people and organizations outside of your school that can help you make sense of all the available information (Handout 1-2: State and Federal Agencies for Transition Assistance (on page 13)). This section highlights various agencies and services that may be useful to you and your young adult as you begin the transition process. Eligibility standards vary widely from state to state, so you may find that some of the resources listed here are unavailable to you, at least initially. If your young adult is denied services, a good rule of thumb is to always seek an appeal.

State Special Education Agencies

Each state's Department of Education has a Special Education Agency. These agencies offer state-specific information about transition requirements and planning, and provide additional information on the application of IDEA and ESSA. State contacts can be found at https://www2.ed.gov/about/contacts/state/index.html.

Division of Vocational Rehabilitation

Vocational rehabilitation is a nationwide federal program that helps people with disabilities find employment. Each state has a Division of Vocational Rehabilitation (DVR) agency or department, and many states also have local DVR offices. These agencies are designed to help people with disabilities prepare for, find, and keep a job, and can evaluate the individual's strengths and provide training and assistance, as needed. Some state DVR agencies have yearslong waitlists, depending on the individual state and the individual's identified disability category.

CHAPTER 1: AGENCY HELP/LEGAL INFORMATION

STATE DVR AGENCIES MAY PROVIDE:

- Diagnostic services
- Vocational evaluation
- Counseling
- Training

- Medical services and equipment
- Placement assistance
- Assistive technology
- Support services

During the transition planning process, a DVR representative may participate in one or more transition planning meetings (these meetings are discussed further in Chapter 2). These representatives specialize in the services and accommodations that may be useful as your young adult prepares for the transition post-high school. If a DVR representative has not attended a transition meeting for your child, ask your transition planning team to arrange for such a meeting. Generally, the majority of services offered by state DVRs are time-limited and of a less intensive nature than many autistic individuals require. Still, particularly if your young adult child demonstrates fairly significant levels of independence, coordinating with your state DVR is a critical step. To find your state agency, search the internet for "Vocational Rehabilitation" and your state, or go to https://askearn.org/state-vocational-rehabilitation-agencies/.

Administration on Intellectual and Developmental Disabilities

Under the Developmental Disabilities Act, the Administration on Intellectual and Developmental Disabilities (AIDD) is charged with ensuring that individuals with developmental disabilities and their families receive the services and support for which they are eligible (although funding may sometimes be unavailable). The ultimate goal of AIDD is to support the independence, growth, and productivity of people with developmental disabilities. (As previously noted, the availability of services through state AIDD agencies varies widely from state to state.)

STATE AIDD AGENCIES SHOULD HAVE INFORMATION ON ACCESSING THE FOLLOWING SERVICES:

- Respite care
- Family support
- Residential assistance
- Individual support

- Transition planning
- Behavioral support
- Community living
- Employment

Known variously from state to state as "Division of Developmental Disabilities" (New Jersey), "Office for People With Developmental Disabilities" (New York), or "Department of Developmental Services" (California), to name a few, each state has an AIDD charged with providing post-graduation training, education, and support. As such, a representative from your state's developmental disabilities agency should be involved in the transition planning process. AIDD agencies are listed by state at https://www.nasddds.org/state-agencies/.

10 Resources

Finding the appropriate agency – and the best person to help you find the right information at that agency – can be challenging and time-consuming. To make the process more manageable, we recommend documenting your phone calls and other means of contact for later reference. In **Activity 1-1:** *Contact Log Sheet (on page 15)*, we have provided a sample log sheet that you can use for this record keeping.

RESOURCES

- Organization for Autism Research. (2012). Life journey through autism: Navigating the special education system. https://www.researchautism.org/resources/navigating-the-special-education-system/
- ► U.S. Department of Education. (2017). A transition guide to postsecondary education and employment for students and youth with disabilities. https://www.sites.ed.gov/idea/files/postsecondary-transition-guide-may-2017.pdf
- ► U.S. Department of Education. (2010, August). Free appropriate public education for students with disabilities. https://www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html
- ► U.S. Department of Education. (n.d.). Office for Civil Rights. https://www.ed.gov/about/offices/list/ocr
- ► U.S. Department of Education. (n.d.). Protecting students with disabilities. https://www.ed.gov/about/offices/list/ocr/504faq.html
- Wright, P., & Wright, P. (2017, January 31). Key differences between Section 504, the ADA, and the IDEA. Wrightslaw. https://www.wrightslaw.com/info/sec504.summ.rights.htm

KEY POINTS – CHAPTER 1



Three federal laws – IDEA, Section 504, and ADA – benefit and safeguard you and your autistic young adult through the transition process.



IDEA protections end for young adults at age 21 or whenever they leave the public school system.



Other laws, such as Section 504 and ADA, become more important when entering adulthood; yet, you and your young adult must seek out these protections.



State and federal agencies may assist in the transition planning process; however, coverage and availability vary by state.

Chapter 1: Handouts/Activities ▷

HANDOUT 1-1: Comparison of ADA, IDEA, Section 504 Legislation



AMERICANS WITH DISABILITIES ACT (ADA), 1990	INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA), 1997/2004	SECTION 504 OF THE REHABILITATION ACT, 1973			
TYPE/PURPOSE					
 Civil rights law to prohibit discrimination Applies to public and private schools 	 An education act that guarantees free and appropriate public edu- cation Does not apply to priva- te schools 	 Civil rights law to prohibit discrimination Applies to public schools and private schools that receive federal funds 			
	ELIGIBILITY REQUIREMENTS				
 Documented diagnosis of ASD Qualified for the pro- gram, service, or job 	Documented diagnosis of ASDAge 3 to 21	 Documented diagnosis of ASD Qualified for the pro- gram, service, or job 			
RESPONSIBILITY TO PRO	VIDE A FREE, APPROPRIATE PL	JBLIC EDUCATION (FAPE)			
 Not directly Provides additional protection in combination with Section 504 and IDEA Reasonable accommodations to perform essential functions of the job Also applies to nonsectarian private schools 	• Yes	• Yes			
PROTECTIONS PROVIDED					
 Details the administrative requirements, complaint procedures, and consequences for noncompliance related to both services and employment Individuals discriminated against may file a complaint with the relevant federal agency or sue in federal court 	 Provides for procedural safeguards and due process rights to parents in the identification, evaluation, and educational placement of their child Disputes may be resolved through mediation, impartial due process hearings, appeal of hearing decisions, and/or civil action 	 Requires notice to parents regarding identification, evaluation, and placement before a "significant change" in placement Local education agencies are required to provide impartial hearings for parents who disagree with the identification, evaluation, or placement of their child 			



HANDOUT 1-1: Comparison of ADA, IDEA, Section 504 Legislation

AMERICANS WITH DISABILITIES ACT (ADA), 1990

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA), 1997/2004

SECTION 504 OF THE REHABILITATION ACT, 1973

STEPS/ACTIONS

- Specifies provision of reasonable accommodations for eligible students across educational activities and settings
- Reasonable accommodations may include, but are not limited to, redesigning equipment, assigning aides, providing written communication in alternative formats, modifying tests, reassigning services to accessible locations, altering existing facilities, and building new facilities
- With parental consent, an individualized evaluation must be conducted using a variety of technically sound, unbiased assessment tools
- Reevaluations are conducted at least every three years
- Results are used to develop an IEP that specifies the special education, related services, and supplemental aids and services to be provided to address the child's goals
- Provides for a placement evaluation that must involve multiple assessment tools tailored to assess specific areas of educational need
- Placement decisions must be made by a team of persons familiar with the student on the basis of their evaluation information and placement options
- Provides for periodic reevaluation
- Parental consent is not required for evaluation or placement

From ERIC Clearinghouse on Disability and Gifted Education. (2001). Overview of ADA, IDEA, and Section 504: Update 2001. https://www.ericdigests.org/2002-1/ada.html

HANDOUT 1-2: State/Federal Agencies for Transition Assistance



CTATE	CDECIAL	EDUCATION	ACENICIEC
	VPFI IAI		AL-ENILIES
		LUUCAIIUN	AULIVOLES

STATE SPECIAL EDUCATION AGENCIES		
Description	Services Offered	
Designed to ensure a free and appropriate public education for students protected under IDEA	 State-specific transition information State-specific ESSA information Dispute resolution 	

DIVISION OF VOCATIONAL REHABILITATION (DVR)

Description	Services Offered
Designed to help people with disabilities obtain, maintain, and/or improve employment A federally funded program administered by individual states	 Participation in transition planning meetings (when planning for work post-high school) Assessment of an individual's strengths, skills, and interests in relation to employment Career counseling and goal setting Training for job skills and maintaining employment Help with independent living skills that will aid in obtaining a job Job search and placement assistance Help with obtaining assistive technology (e.g., special computer software, visual aids) to use in the workplace

ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (AIDD)

ADMINISTRATION ON INTELLECTORE AND DEVELOT MENTINE DISABILITIES (AIDD)		
Description	Services Offered	
Provides services to individuals with developmental disabilities to help them achieve independence, productivity, inclusion, and community involvement Federal agency responsible for administering the Developmental Disabilities Act; each state has its own developmental disability agency or council	 Respite care Programs for families Residential living services and support Transportation Behavioral support Legal advice and services Advocacy Transition planning services Employment support 	



Organization for Autism Research's Scholarship Program



OAR is proud to support the postsecondary, undergraduate education or vocational-technical training of qualified individuals with an autism spectrum diagnosis through its \$3,000 scholarships. Since 2008, OAR has awarded scholarships to over 400 students across the United States! OAR offers two scholarships – see which one is right for you.

Who can apply?

Anyone with an established autism diagnosis and who will be enrolled full time at an accredited postsecondary institution of higher education in the United States during the school year following the application process may apply. There is no age limit!

When can I apply?

Applications are open annually from early December to early May.

Where can I apply?

Applications are only accepted online – learn more at bit.ly/OARScholarships.

Which scholarship should I apply for?

- The Schwallie Family Scholarship is for students attending two- or four-year undergraduate colleges or universities.
- The Lisa Higgins Hussman Scholarship is for students attending two-year universities, life skills or postsecondary programs, or vocational, technical, or trade schools.









ACTIVITY 1-1: Contact Log Sheet



CONTACT INFORMATION*

^{*} Name of individual you spoke with, address, phone number, and e-mail.

DATE	NOTES	FOLLOWUP INFORMATION



ACTIVITY 1-1: Contact Log Sheet

DATE	NOTES	FOLLOWUP INFORMATION



Transition planning allows you, your autistic child, and their school system to begin planning for the road to graduation and beyond. The planning process introduces you and your young adult to services, activities, instruction, and support designed to provide them with the skills necessary to succeed post-high school. An effective transition plan includes both short- and long-term goals as identified by the student, identifies the necessary supports, and is specific to the interests, abilities, and desires of your child.

While this process may seem overwhelming and even scary, starting early will allow you to take smaller, more manageable steps and help you and your child reach your goals successfully and, ideally, with less stress. This chapter outlines the key steps of the process, the overarching goals of transition planning, and how to create a successful transition plan that takes into consideration all of your young adult's strengths and plans for the future. (Remember, individual states may have slightly different processes and rules for transition planning, so be sure to refer to your state's requirements.)

The information from the transition plan will become part of your child's IEP, although it may be developed as a separate document called an Individualized Transition Plan (ITP). In either case, it may include information on such areas as:

- Vocational training and job sampling (similar to on-the-job training)
- ► Employment goals and a timeline for achieving them
- ► Goals in support of residential opportunities, including independent living
- Community participation goals, including social and leisure skills, travel training, purchasing skills, and personal care, to name a few
- ► Goals relevant to postsecondary education (college), when appropriate
- ► Coordination with state and private adult services agencies and providers

Long-term transition planning is an ongoing process that reflects the continuing development and changing needs of your child. You will work closely with your autistic child and the transition planning team at their school to create this guiding plan of action.

PLANNING TO PLAN - REFLECTING ON AND GATHERING INFORMATION TO BUILD YOUR CHILD'S TRANSITION PLAN

Start small, but think big! Before you begin the actual paperwork and planning with your young adult's school and IEP team to implement the transition plan, you can start planning on your own to lay a foundation for the entire process. This section outlines a three-step process to:

- 1. Facilitate thinking and brainstorming about your young adult's future (Assessment)
- 2. Begin planning future goals (Goal Writing)
- 3. Understand realistic challenges to these plans (Anticipating Obstacles)

Various activity worksheets, located at the end of this chapter and referenced throughout, will help you with this process.

Involve your autistic child in the planning process as much as possible. Person-centered planning not only empowers the individual, but also creates a more productive and effective transition plan in the long run.

Step One: Assessment

As you begin the transition planning process, think about the "big picture" of your young adult's future:

- ► What do you want your child's life to look like 5 years, 10 years, or 20 years from now?
- ► What do you NOT want your child's life to look like in 5 years, 10 years, or 20 years from now?
- What will your child need in order to achieve the desired goals and avoid the undesired outcomes?

As a parent of an autistic child, you may have struggled to adjust your expectations for the future you once dreamed of for your child. Realistic, concrete goals and expectations are the foundation of a successful transition plan. It is important not only to set progressive goals that your child can reach, but also to challenge your child to grow. Leave room to be pleasantly surprised by all that they can achieve through this process! Transition doesn't only apply to your loved one. It also applies to you – the parent. Parents have to be ready to allow their loved one to grow and learn through experiences, failures, and successes.

Throughout this discussion (often called "futures planning"), the concept of future quality of life is central. "Quality of life" basically refers to how satisfied your child feels about their education, work, recreation, spiritual life, social connections, community living, health, and emotional well-being. You may not have specific ideas about all of these areas, but you can start imagining what you would like for your young adult and what they would like for themselves as they transition out of high school. At different times in this process, you will begin to find connections among all of these areas and start to identify realistic and attainable goals. Although quality of life is often as much about the process as it is about the product, neither process nor product should be compromised as part of transition planning. Once you have this broad vision in mind, start brainstorming about some of the specifics, such as personal interests, strengths and challenges, past learning history, and the supports that will be necessary for your child along the way. These elements constitute the starting point of the transition plan and will be discussed further below.

Two popular planning protocols include Making Action Plans (MAPS) and Planning Alternative Tomorrows with Hope (PATH). MAPS is a five-step process designed to help students, parents, and education teams plan for the future. The process results in discovering who the student is, their strengths and needs, where they want to go in life, and the steps they need to take to get there. See **Activity 2-1:** *Making Action Plans (MAPs) (on page 29)* to start this process.

For more information about MAPs, see https://www.transitioncoalition.org/wp-content/originalSiteAssets/files/docs/makingdreamshappen1258858219.pdf.

PATH is another creative planning tool for the future that allows students, parents, and educators to explore their vision for the future and make an action plan to get there. The six steps to PATH are:

- 1. Create a clear picture or vision of where you want to be.
- 2. Identify your goals focus for the next year.
- 3. Ground yourself in the now.
- 4. Identify people to enroll on the journey.
- 5. Recognize ways to build strength.
- 6. Chart action steps needed to achieve your goal.

For more information, see https://pcp.sonoranucedd.fcm.arizona.edu/resources/person-centered-planning-tools/path.

Personal Interests

As with any adolescent, your autistic young adult may have strong – very strong in some cases – personal interests and hobbies. These preferences may be discovered by observing what makes your child happy, what they do during downtime, or what items or activities motivate them.

In addition, asking yourself or your young adult (as the central figure in this process) questions can form another jumping off point for considering future educational and vocational options. **Activity 3-1:** *Questions About Personal Interests* in Chapter 3 *(on page 47)* provides a good starting point.

Systematically answering these questions will allow you to begin to see the connections between what your teen is good at and interested in *now*, and what they can do in the *future*. Everyone, including you, is more able and willing to work and excel at something that they like to do, and your autistic young adult is no exception. Tailoring transition planning to your child's personal interests in a realistic, albeit ambitious, manner while suggesting clear and meaningful steps toward achieving their goals will help keep your child focused and engaged.

You, your young adult, and the rest of the transition team can work together to complete the worksheet in **Activity 2-2:** *My Dreams for the Future (on page 30)* to document your child's personal interests and explore their connections to the transition goals.

Strengths (Capabilities) and Weaknesses (Challenges)

You are well aware by now that there are areas of your child's life that they do better in and other areas that are more challenging. It is important to list all of their strengths and challenges, and then to look at them with a new eye. Consider these strengths and challenges in **Activity 2-3:** Examining Strengths and Challenges (on page 31).

Patterns of behavior previously considered to be potential challenges may actually help in the workplace – attention to detail may be especially valued in a quality assurance position, and punctuality is valued in any workplace. If your young adult is overly interested in sci-fi movies, is there a way in which this interest can be translated into a strength? If so, how?

Take a look at how your autistic young adult's specific capabilities and challenges can be turned into assets in the workplace or school, as illustrated in the following.

MARKETING CHARACTERISTICS AS EMPLOYMENT STRENGTHS		
Characteristics	Employment Strength	
Nonverbal	May be less likely to verbally disrupt coworkers	
Limited social interest	May stay more focused on work and not waste time	
Strong sensory preferences	May enjoy working in a quiet office	
ls very schedule- or rule- bound	Comes to work on time, takes breaks at the right time, and returns from break on time	
Appears ritualistic or compul- sive	May offer excellent attention to detail and quality control	

From Holmes, A., & Douglas, J. (2005). Meeting the needs of adults with autism. Paper presented at the ASA National Conference, Nashville, TN.

Past Learning History

Building from your child's strengths and challenges, it is useful to think about areas in which they have succeeded or been challenged in the past. The topics in **Activity 2-4:** *Building on Experience (on page 32)* may help in discovering those areas.

Previous experiences, whether good or bad, are sources of valuable information relevant to the transition planning process as they can illuminate areas where your young adult is more likely to succeed or areas that are more challenging and, therefore, should be avoided if possible.

Aside from the learning value, previous work experience, coupled with comprehensive, community-based instruction, makes it more likely that it will be easier for your young adult to access and maintain employment in the future. If your child has not had any work experience, consider looking for opportunities *now*, early on in the transition process. If actual work experiences are not a possibility, you may want to consider finding volunteer opportunities for your young adult in an area of interest to them, as this too can provide information on challenges, strengths, and weaknesses across a variety of tasks and environments. At first glance, finding such opportunities may not appear easy. However, by networking with friends, other parents, your employer, the businesses you frequent (e.g., local shops), and community services (e.g., houses of worship), and searching online, you will probably find a variety of opportunities just waiting to be discovered. (Chapter 4 includes additional information on employment.)

■ Support Structure

Throughout the life of your autistic child, an important support network of teachers, counselors, friends, family, and others has evolved. This support structure will continue to be important to both you and your young adult through the transition period and across new environments. However, because social relationships can be challenging for many autistic individuals, this area requires some closer consideration and attention. Use **Activity 2-5:** *Your Support Network (on page 33)* to brainstorm.

Step Two: Writing Overarching Goals

Later in the transition process, you will be asked to help determine – and write down – specific objectives you want your young adult to achieve. But now is the time to think of the broad, overarching goals that reflect the future you want for your young adult. You can think of this as a **mission statement** for the transition you envision.

EXAMPLES OF OVERARCHING GOALS

- My child will be able to live independently.
- My child will be comfortable and safe in a supported living situation.
- My child will have two or three close relationships.
- My child will contribute to the community.
- My child will find satisfaction in several of their daily activities.

These overarching goals should build from the information you gathered in the previous assessment regarding quality of life, personal interests, strengths and challenges, and past experience.

"My goals for my daughter are for her to be happy in whatever she does and to find some personal fulfillment and satisfaction. I believe her goals are the same. She needs to be and wants to be productive, wants to have a sense of independence."

- Mother of a 21-year-old autistic daughter

Activity 2-6: Documenting Overarching Goals for Transition (on page 37) is a worksheet that you can complete together with your young adult to prioritize and articulate broad goals for career, education, living, relationships, recreation, health, and community. These goals will become more structured – with specific tasks and objectives – as you work together to create the transition plan.

Step Three: Anticipating Obstacles

Most goals are not meant to be easy to accomplish and meet in a short amount of time. But goals can be broken into smaller steps that can gradually be achieved, one at a time.

As you think of the skills, lessons, materials, and information you and your young adult need in order to move through the transition process successfully, obstacles may present themselves. For instance, as you created the list of goals for your young adult, did you think of any skills that they may need to be successful? Or resources that will help them accomplish these skills? Lack of any key "ingredient" may delay, if not stall, the transition process. So, if certain skills need development, such as effective communication, toileting, table manners, cell phone use, or personal hygiene, now is the time to create a strategy to develop them.

"He loves work. He is very dependable. He will show up on time, finish work ahead of time, and his work ethic is great. But when he wakes up in the morning, he may not take a shower or brush his teeth. These are the things that we must work on with him."

Mother of a 24-year-old autistic son

Other obstacles may appear along the way, but you are building a solid plan that can be revised and modified to accommodate the changing needs, desires, and skills of your young adult.

The Transition Plan

THE TRANSITION PLAN

Characteristics of a Sound Transition Plan

IDEA specifies that transition planning is a coordinated set of activities for a student with a disability that is:

- ► Outcome-oriented a process with clear goals and measurable outcomes
- ► **Student-centered** based on the specific skills that the student needs and reflective of the student's interests and preferences
- ► **Broad-based** including instruction and related services, community experiences, development of employment and post-school living objectives, and acquisition of daily living skills and vocational evaluation
- ► **A working document** outlining current and future goals, along with the specific strategies for achieving these goals, and changes over time

What the Plan Should Include

Your child's transition plan will be customized based on their needs. In particular, a solid transition plan will include many of the following elements:

- ► Assessment of your child's needs, interests, and abilities
- ► Statement of preferences for education, employment, and adult living
- Steps to be taken to support achievement of these goals
- Specific methods and resources to meet these goals, including accommodations, services, and/or skills related to the transition goals
- ► Instruction on academic, vocational, and living skills
- ► Identification of community experiences and skills related to future goals
- Exploration of service organizations or agencies that provide services and support
- ► Methods for evaluating success of transition activities (e.g., a video portfolio)

Additional Logistical Information in the Plan

In addition to stating the goals for your young adult, the transition plan should include logistical information on how the plan will be implemented and monitored, such as:

- ► A timeline for achieving goals
- ► Identification of people or agencies to help reach these goals
- Clarification of how roles will be coordinated
- ► A plan for identifying post-graduation services and supports and obtaining the necessary funding

24 The Transition Plan

Handout 2-1: Sample IEP Transition Plan (on page 34) offers an example.

Measurable Goals Allow You to Evaluate Success

Ideally, all of the above goals should be measurable to ensure you have a precise way to determine when the goals have been reached.

EXAMPLE OF A MEASURABLE TRANSITION GOAL

Overarching goal: The student will have an appropriate work environment post-high school. **Measurable goal:** Together with the school guidance counselor, transition coordinator, or vocational rehabilitation counselor, the student will explore options for employment post-high school. The student will complete a vocational assessment and participate in a minimum of one unpaid internship, volunteer experience, or after-school job in an area of interest over the next 6 months. This participation is defined as a minimum of 5 hours/week for no less than 12 weeks. This will help the student determine further needs for vocational training.

Another way of describing strong IEP goals is using the acronym SMART. SMART goals are:

- **S Specific** the goal is specific in naming the skill that will be targeted and the desired result.
- M Measurable the goal is stated in such a way that progress can be measured.
- A Attainable the goal represents reasonable progress for your child.
- R Results-Oriented the goal clearly lays out what will be done to accomplish it.
- T Time-Bound the goal includes a timeline by which the child will achieve it.

See examples of SMART goals in Handout 2-2: Example SMART Goals (on page 36).

Who Is Involved

THE TRANSITION PLANNING TEAM Key Members You and your autistic child and interested family members Your young adult's transition coordinator Your young adult's general education teachers, when applicable Your young adult's special education teachers

The Transition Plan 25

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Optional and Helpful Team Members

- Advocacy organization representative
- Business education partnership representative
- Guidance counselor, when appropriate
- Residential services representative, when appropriate
- Mental health agency representative
- Postsecondary education representative, when applicable

Transition planning should help you and your young adult connect with the adult service system. Representatives from adult services organizations that may provide or pay for post-transition services must be invited to participate in the development of the IEP transition plan. If they are unable to attend, the school must find alternative ways of involving them in planning any transition services they might pay for or provide. It is important that each transition activity include someone who consents to monitor the provision of that service as outlined in the IEP.

Guidance counselors, related service providers, vocational rehabilitation counselors, and administrators all have a potential voice in designing transition plans for students. The specific roles of participants may vary, depending on the goals and needs of your young adult.

There is one major difference between transition planning and the IEP meetings you may be used to – **your autistic young adult must be actively involved!** The next chapter, Student-Centered Transition Planning, will assist you in preparing your young adult for the process so that it is as fruitful and stress-free as possible.

Your Role as a Parent

As a parent, you play a critical role in the development of the transition plan. Specifically, you will need to:

- ► Be your child's primary advocate in the absence of their ability to do so, with an emphasis on fading their dependency to allow ongoing growth to the best of their ability
- Provide unique and personal information about your child that is not otherwise reflected in the school's or agency's records
- Ensure the transition plan is meaningful, practical, and useful for your child
- Monitor transition planning in the IEP to ensure agreed-upon activities are implemented; frequent communication with your child and other IEP team members will help keep the plan a working document
- ► Promote your young adult's independence, self-advocacy, and decision-making
- ▶ Plan for future financial and support needs, such as guardianship, estate planning, Supplemental Security Income (SSI), and related work incentives, along with other sources of financial support (Center for Autism Research (CAR, 2014)).

The IEP team relies on your knowledge of your young adult. Effective transition planning adopts an approach that is sensitive to the culture and context of the family, thus empowering your family's role in guiding your autistic learner.

For more on advocacy, see OAR's *Life Journey Through Autism: Navigating the Special Education System* at https://www.researchautism.org/resources.

Families must be notified ahead of time when an IEP meeting includes development of a transition plan. Special education case managers often identify the purpose of the meeting and can provide draft goals ahead of the meeting, if requested.

IMPLEMENTING AND MONITORING THE TRANSITION PLAN

You will work with the transition team during a series of meetings to develop a comprehensive transition plan for your young adult. During the process, it is important to record important details at all planning meetings. Once the actual plan is completed by the team, it is a living, evolving document that should be reviewed and updated several times a year to ensure it continues to reflect and meet all of your young adult's needs and that adequate progress is being made to that end. Each team member is responsible for implementing the specific transition tasks, together with your autistic young adult.

By creating a document with outcome-oriented goals that can be measured, you can more efficiently and effectively monitor your young adult's progress. It is important to work with the transition planning team to periodically update this plan as your child continues through school to ensure a successful transition to adulthood.

What to Do If You Don't Agree With the Transition Services Provided by the School

Hopefully, the transition process will be a smooth, collaborative effort among all team members supporting your young adult. Nonetheless, it is important to know your rights as a parent if you cannot come to an agreement with the school regarding your child's education:

- ➤ You have the right to ask for an impartial due process hearing. A hearing may be held on any matter related to the identification, evaluation, or placement of your child or the provision of a "free appropriate public education" (FAPE). Hearings are to be held by either the State Department of Education or the school personnel directly responsible for your child's education. To obtain a hearing, make a written request to the person who is responsible for the education program your young adult attends.
- ► If you believe your child's educational rights are being violated by non-implementation of the IEP, make a written request to the person who is responsible for the education program your child attends or your state's Department of Education. IDEA affords parents procedural safeguards if agreement cannot be reached regarding

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the identification, evaluation, educational placement, or FAPE for their child. If you do not feel appropriate transition services are being provided, you may exercise your rights as explained in the *Procedural Safeguards for Children and Parents*, which can be obtained from your state or local districts. Professionals and volunteer advocates who know how to navigate the special education system can help you ensure your child's rights are being enforced.

For more information, see OAR's *Life Journey Through Autism: Navigating the Special Education System* at https://www.researchautism.org/resources.

Early Planning Leads to Success

Planning for your autistic young adult's future and exploring the world of postsecondary education or employment can seem daunting or even a distant prospect. However, starting to plan early and building goals related to particular life skills, postsecondary education, or employment into your young adult's transition plan/IEP breaks the process into manageable steps and helps engage an accessible, ongoing support system of transition team members.

The chapters that follow review important information related to the transition process and will help you maximize your planning:

- ► Student-Centered Transition Planning
- ► Postsecondary Education
- ► Vocation and Employment
- ► Life Skills

As you read this information, remember that you are your young adult's best advocate for their future. Tailoring the approach to your young adult's specific needs will lead to success.

RESOURCES

- Autism Self Advocacy Network & Family Network on Disabilities. (n.d.). Roadmap to transition: A handbook for autistic youth transitioning to adulthood. http://autisticadvocacy.org/wp-content/uploads/2016/11/Roadmap-to-Transition-A-Handbook-for-Autistic-Youth-Transitioning-to-Adulthood.pdf
- Center for Autism Research (CAR) at the Children's Hospital of Philadelphia. (2014). Turning 18: Options for when your child needs decision-making help. https://www.carautismroadmap.org/turning-18-options-for-when-your-child-needs-decision-making-help/?print=pdf

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► OCALI. (n.d.). Evolving postsecondary goals. https://www.ocali.org/project/transition-planning-and-the-iep/page/examples-of-evolving-postsecondary-goals

- ► OCALI. (n.d.). Transition to adulthood guidelines. https://www.ocali.org/project/transition_to_adulthood_guidelines
- ► The UNC Center on Secondary Education for Students with Autism Spectrum Disorder: https://csesa.fpg.unc.edu/families/supporting-transition
- ► The VCU Autism Center of Excellence: https://vcuautismcenter.org/resources/adolescence.cfm

KEY POINTS – CHAPTER 2



Starting the transition planning early helps to create more manageable steps to achieve goals.



Your autistic child's Individualized Transition Plan will become part of their IEP.



Work together with your autistic young adult to brainstorm future dreams and goals.



A transition plan is outcome-oriented, measurable, student-centered, and adaptable.



History

- How would you describe your life up to now?
- > What people have been important in your life?
- > What has happened to you so far that is important to you?

Dreams

- > What are your hopes and dreams for the future?
- > What would you like to do this year?
- > What would you like to do after high school?

Fears

- What do you not want to have happen in your life?
- > What worries you most about your future?
- What do you think will stand in the way of you getting what you want?

Who Is

- > Who are you?
- > What are your: strengths, gifts, talents, likes, dislikes, and skills?
- ➤ What do you like to do?
- ➤ Who are your friends?

Needs

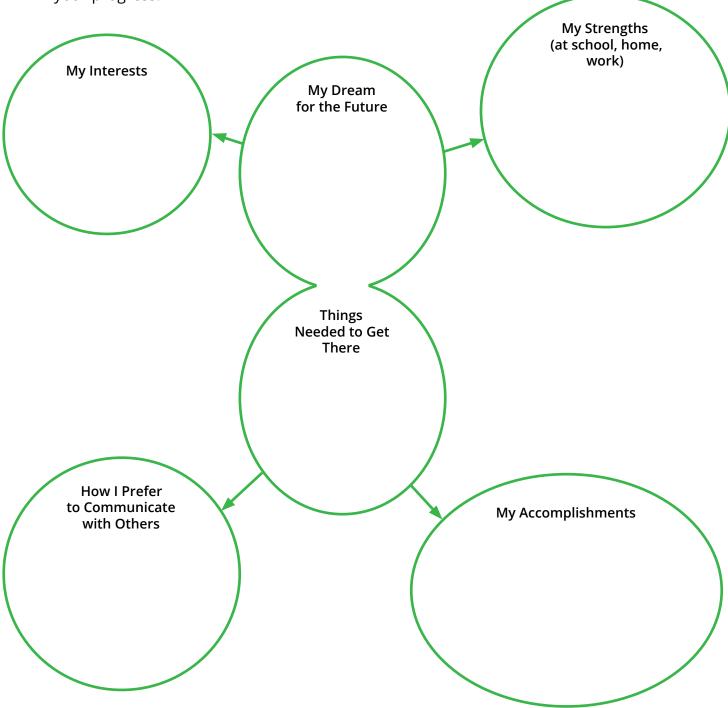
- > What is needed for the dreams that you listed to come true?
- > What would make your life better?
- > Who could help you with your plans for the future?
- > What can other people do to help you meet your needs?

Adapted from Furney, K. S., Carlson, N., Salembier, G., Cravedi-Cheng, L., & Blow, S. (n.d.). Making dreams happen: How to facilitate the MAPS process. Transition Coalition. https://www.transitioncoalition.org/wp-content/originalSiteAssets/files/docs/makingdreamshappen1258858219.pdf



ACTIVITY 2-2: My Dreams for the Future

First, write your dream for the future in the center circle labeled "My Dream for the Future" (do this independently or with a parent). Then, fill in the information in the outer circles. List as many ideas as you can come up with. Then, in each outer circle, put a box around what you think are the most important ideas. Draw a line into the center "Dream" circle, making a web of things that will help you achieve your goal. As a final step, write anything else you think you need in the outer circle around your "Dream" circle. Revisit this web of strengths in the future so you can keep track of your progress.



ACTIVITY 2-3: Examining Strengths and Challenges



What are the ways in which my child's strengths and challenges may benefit them as they transition beyond high school?	How can my child's challenge actually be strengths in the workplace?
To what extent do my child's challenges impact their ability to reach their goals beyond high school?	How can I help my child capitalize on their strengths to reach their goals beyond high school?

challenges impact their ability to reach their goals beyond high school?

capitalize on their strengths to reach their goals beyond high school?

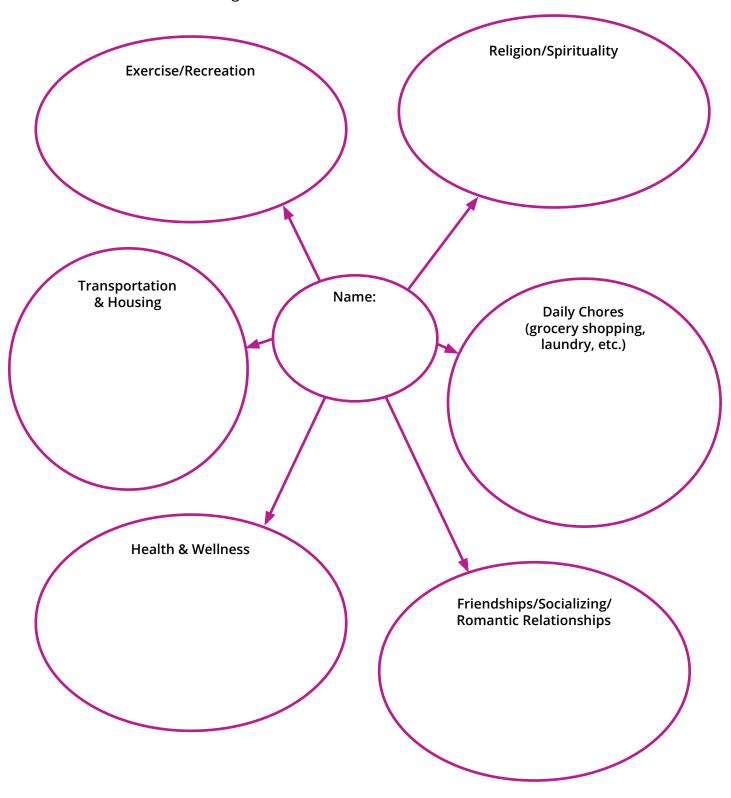


ACTIVITY 2-4: Building on Experience

	What was successful for my child?	What was unsuccessful for my child?
Areas of instruction (school subjects, extracurriculars)		
Teacher-student interactions		
Environmental conditions		
Accommodations in school		
Accommodations in the community		
Structured vs. unstructured situations		
Previous work experiences		



Consider who or what groups in your community can support your young adult in the following areas. Remember that the school supports your child is receiving now will not be available after graduation.





HANDOUT 2-1: Sample IEP Transition Plan

Student Name: Ophelia DOB: 1/11/05 School Name: Epitome HS

Grade: 10 IEP Meeting Date: 3/21/21

IEP Meeting Participants & Roles

Participants involved in the development of the IEP Transition Plan and the placement decision:

Participant Name Role

Ms. Smith
Ophelia
Student
Ms. Parker
GE teacher
Mr. Miller
District representative/LEA

Student's Measurable Postsecondary Goals

1. Education/Vocational Training:

After graduation, Ophelia will attend a two-year community college course and gain qualifications in culinary arts.

Special education teacher

2. Employment:

Ms. Ryan

After high school, Ophelia will continue her part-time job at a local restaurant and receive an increase in hourly pay as she completes restaurant courses.

3. Independent Living/Community Participation:

Ophelia will join a horseback riding group for young adults and participate at least twice a month.

4. Adult Services:

- a. Ophelia will work with her job coach once per month on communicating her restaurant performance and goals with her boss.
- b. Ophelia will take the city bus to her job.

5. Other:

Student's Present Levels of Academic Achievement and Functional Performance (PLAAFP)

Description: This is a summary of assessments that identify the student's current strengths, preferences, interests, and areas of need. It describes how the student's disability impacts their academic progress and participation in school activities. The summary includes the student's performance

HANDOUT 2-1: Sample IEP Transition Plan



and academic achievement levels (in reading, writing, math, science, social studies, etc.), as well as the student's functional performance levels (self-determination, social skills, communication, behavior, etc.). The student's desired postsecondary goals should be reflected in this section and throughout the other components of the IEP Transition Plan.

Measurable Annual Goals, Short-Term Objectives/Benchmarks, and Progress Report

Annual Measurable Goal #1:

Ophelia will practice taking the bus at least three times per month. Does this goal align with a measurable post-secondary goal? *Yes.* If so, which one? *4b.*

Measurable Benchmarks/Short-Term Objectives	Beginning Date
Obtain bus pass, bus schedule, and map	1/15
Review bus schedule and map	1/15
Take a bus trip to work with job coach with verbal prompting	1/31
Take a bus trip to work with job coach with no verbal prompting	2/28

Progress: How will progress toward this annual goal be measured? *Documentation of student progress tracker.*

Report: How and when will progress toward this annual goal be reported to the student's parent? How frequently? *Email summary of progress at the end of each session.*

Summary of Transition Services

Supporting IEP Goal	Transition Services/ Activities	Amount/ Begin/ Frequency End Date		Responsible Person/ Location	

List of Accommodations and Modifications

Accommodations/modifications:

Additional supports for school personnel to meet the unique needs of the student (training, equipment, etc.):



HANDOUT 2-2: Example SMART Goals

SMART GOALS	WHAT THAT MEANS	NON-EXAMPLE	EXAMPLE
Be clear and specific about the area targeted for improvement, such as by including specific skills or subject areas.		Michael will be able to comprehend reading materials .	Michael will demonstrate reading comprehension of grade-level text by creating story maps, graphic organizers, or retelling passages with 80% accuracy during 4 out of 5 tries.
Measurable	The goal is stated in a way that the student's progress can be observed and concretely tracked over time.	Jackson will be able to read faster.	Jackson will be able to orally read a third-grade passage at 90-110 words read correctly per minute by the end of the academic year.
The goal sets a higher bar that is realistic and achie- vable compared to the student's pre- sent level of perfor- mance.		Using her portable communication device, Tatyana will select a preferred activity from an array of 2-4 symbols 100% of the time.	Using her portable communication device, Tatyana will select a preferred toy, activity, or snack from an array of 2-4 symbols 80% of the time.
The goal sta- tes clearly laid outcomes, levels of performance, or deliverables.		Theo will work on employment activities.	Theo will create a personal resume, have it reviewed by Mrs. Garcia, and send the polished resume to 3 potential job prospects.
The goal includes a timeframe for when the student will achieve it, such as shorter-term benchmarks or annual goals.		Alex will read fourth grade material at 80-100 wpm with 1-3 errors.	By March 30, Alex will read fourth grade material at 80-100 wpm with 1-3 errors.

ACTIVITY 2-6: Documenting Overarching Goals for Transition



As you plan for your child's transition to adulthood, this worksheet may be useful as you brainstorm together on goals for their future. Have your child circle the boldfaced goals that seem realistic and are of interest to both of you, and then complete

the statements that follow the goals you have circled. In 5 years, I see myself in or completing college. To attend college, I need to ...

In 5 years, I see myself working as a ...

To obtain this position, I need to ...

In 5 years, I see myself enjoying ...

To do these things, I need to ...

In 5 years, I see myself practicing my faith/spirituality by ...

To practice my faith/spirituality, I need to ...



ACTIVITY 2-6: Documenting Overarching Goals for Transition

In 5 years, I see myself in the following relationships:

To make or keep these relationships, I need to
In 5 years, I see myself (in my community)
To be a part of my community, I need to
In 5 years, I see myself (to stay healthy)
To be able to do these things, I need to
In 5 years, I see myself living
To live there, I need to
To live there, Theed to



Student-centered planning, also called "person-centered planning," is an approach to transition planning that prioritizes the interests and aspirations of the individual student. Specifically, the focus is on helping students develop the tools and skills necessary to design their own goals for their career, education, living situation, and other aspects of adult life. The team builds the transition plan around the student's goals by equipping the student with the tools and resources needed to reach those goals.

Student-centered planning involves students meaningfully in all aspects of the transition process and helps them develop the skills they need to live an independent life once they no longer have an IEP and transition team to support and guide them. In addition to helping the team create purposeful and specific plans for their life after graduation, your young adult's involvement in the transition planning process also provides them with an excellent opportunity to advocate for themselves.

SELF-DETERMINATION SKILLS

In order to be an active participant in the transition planning process, your autistic teen needs to develop **self-determination skills** – the skills that enable individuals to speak up for what they want, what they're interested in, and how they would like to accomplish it. Self-determination skills also allow individuals to have a strong understanding of their strengths and weaknesses, feel in control of their own lives, make important decisions, and figure out creative solutions to problems.

To be an active participant in the transition planning process, your autistic young adult, to the best of their ability, should be able to:

- ► Communicate their preferences
- Make choices based on individual preferences

- ► Set goals or help choose relevant goals
- ► Identify and solve problems that may arise
- Advocate for themselves

These skills can be built into the transition plan as behavioral goals, since it may take time to be able to accomplish them. Every one of these skills that your child develops will help make them become a more active participant in the transition planning process. If your school is reluctant to include these goals as early as you have suggested, consider embedding the same goals in other categories in your child's current IEP (e.g., adaptive, social, and behavior). See **Handout 3-1:** *Preparing for the Transition Planning Meeting (on page 45)*.

School transition teams may not be aware of the benefits of student-centered planning or even the current laws that mandate student participation in the transition planning process, so it is important to discuss this approach with the IEP team. Your child has a right to participate in this process; under IDEA, students with disabilities must be invited to transition planning meetings. Additionally, research shows that developing the self-determination skills that are emphasized in student-centered planning results in better outcomes in academics, independent living, and employment for students with disabilities (Shogren et al., 2015). Finally, students become more motivated to meet their IEP goals if they have a say in defining them and understand why they are important.

CENTERING THE STUDENT IN TRANSITION PLANNING

Below are some ways that you and your transition team can foster self-determination skills and student-centered planning:

- ► Educate your autistic young adult Helping your young adult understand how having autism may impact them will help them educate others, advocate for themselves, and build a realistic transition plan:
 - ▶ Discuss in concrete terms the impact of your young adult's autism symptoms on their education, job choices, and independent living status.
 - ▶ Explore in concrete ways what strengths they bring to the table.
 - ▶ Start these discussions early, and be sure to focus on your young adult's strengths, as well as challenges and ways in which these challenges might be minimized.
 - Encourage your child to connect with the larger autism community. Participation in both online and in-person social groups for autistic people can help show your young adult that they are not alone and give them an opportunity to get advice from people who have already been through what they're going through now.

- ► Help your autistic young adult to understand the results of their assessments Reviewing the results of your young adult's assessments with them will help them get a better sense of their strengths, weaknesses, and interests:
 - Discuss the results of your young adult's transition assessments with them and encourage them to make suggestions for further assessments or supports needed.
 - Ask your young adult about their own evaluation of their qualities and encourage the transition team to use interview-style assessments that focus on your child's goals.
 - Ask for formal assessments, known as interest inventories or strengths assessments, that not only identify skill sets but also connect them to potential job considerations.
 - ► Collaborate on possible IEP goals with your young adult what supports are they interested in having and how would they address their areas for improvement?
 - ▶ Follow up with your young adult as new assessments are conducted, explaining the progress that they have made towards their goals.
- ► Allow your autistic young adult to define their own goals to the extent possible Guiding your child through this process ensures that they are in control of their future and helps them develop a sense of agency and control feeling empowered to act on their own behalf.
 - ➤ Your child may require help in determining how to choose goals and in identifying their interests and strengths across specific areas. Use Activity 3-1: Questions About Personal Interests (on page 47), Activity 3-2: Developing Self-Advocacy Skills (on page 48), and Activity 3-3: Goal Plan (on page 50) to brainstorm about their interests and their goals for the future.
 - ► Allow your young adult's interests, not just their strengths, to guide the transition plan. Although it is tempting to orient towards the things they're best at, those might not be the areas that they're the most interested in. Work with your young adult and the transition team to design realistic goals around their interests and help them build the skills necessary to reach them. See Activity 3-1: Questions About Personal Interests (on page 47) for sample questions to help your young adult identify their interests.
 - ▶ Help your child develop their goals further by exposing them to new experiences. If possible, find opportunities for them to shadow or intern with individuals in their desired careers.
 - ➤ The Department of Vocational Rehabilitation is required to fund Pre-Employment Transition Services (Pre-ETS) for students with disabilities. These services include training, job and college counseling, work-based learning experiences, and selfadvocacy instruction. All of these can be valuable tools in narrowing down your

child's career interests and equipping them with necessary skills and experience. Reach out to your local DVR to see what kinds of services are available in your area. More information may be found at https://workopportunities.net/employment-services/vr-preets/.

► Encourage your young adult to advocate for themselves and their needs in social and educational situations.

- ▶ Instead of being limited by options that the transition team offers, you and your child can present the team with what you think is possible.
- ► The worksheet in **Activity 3-2:** Developing Self-Advocacy Skills (on page 48), as well as many of the resources at the end of this chapter, can be a useful tool to get your young adult thinking about self-advocacy. Whenever possible, encourage them to speak for themselves and complete tasks independently.
- ► Involve your autistic young adult in IEP/ITP meetings Meaningfully including them in these meetings is an essential aspect of student-centered planning:
 - Some autistic students want to lead the meetings directly; others just want to be in the room. Tailor your young adult's level of participation to whatever suits their skills and comfort. For example, some students may want to present a PowerPoint or play a pre-recorded video message where they discuss their goals. Encourage your child to participate in meetings as early as possible.
 - ▶ Request that the other members of the IEP team speak directly to your young adult when they are present, rather than speaking about them as though they aren't in the room.
 - Explain the general purpose of the planning process and its impact. If this is the first time your young adult has been involved in this planning process, they may never have seen the IEP document. Walk them through the documentation that will be referenced during the meeting and help them get acquainted with their rights as a student.
 - ▶ Make sure your child has plenty of time to prepare and ask questions, and to provide the necessary accommodations to do so.
 - ▶ Discuss what will happen at the meeting in advance to minimize surprise and anxiety.

If your autistic young adult cannot or does not want to participate in transition planning meetings, IDEA regulations expect schools to take other steps to make sure that the student's preferences are taken into account.

➤ Your young adult may also need some direction with regard to the social rules for participating in these meetings. Review the agenda for the meeting and make sure your young adult knows who will be present and their respective roles. Encourage them to listen carefully to the other members of the transition team and to speak up with their opinions to the extent that they are comfortable.

SELF-DETERMINATION TIPS BY LEARNING STYLE

For young learners:

- ► Include your child in IEP meetings as early as possible, even if only for a brief introduction. Providing your child with a favorite snack at the meeting can help them become interested in attending.
- ► Prompt your child by giving them simple choices, such as asking them which homework assignment they would prefer to work on first, to help them become familiar with the process of decision-making.
- Encourage your child to keep track of their time and tasks using a planner or calendar.

For visual learners:

- ▶ Draw a map and pictorial representations of where your young adult is now, what their goals are, and what is needed to reach those goals. This may be done as a spider web of connected ideas or a timeline with connecting boxes.
- Have your child assist you in drawing pictures or cutting and pasting photos on the computer of them participating in their favorite activities.

For verbal learners:

- Brainstorm together to identify and make a list of strengths.
- ► Create a list of activities or skills your child generally needs assistance with and the accommodations most likely to be effective and available.

For nonverbal learners:

- Consider using photographs or videos of different activities to assess their interest or observe individual reactions.
- ► Provide actual opportunities for your child to experience different community/vocational options to assess interest or observe individual reactions.
- ► Provide a sufficient level of exposure to these activities so that the assessments are based on a reasonable sample of experience.

44 Resources

Activity 3-4: Self-Determination Checklist Student Self-Assessment (on page 51) may be a use-ful starting point. Also, your young adult may like to complete Activity 3-5: Your Person-Cen-tered Planning Meeting (on page 52) prior to any meeting.

RESOURCES

- Autism Self Advocacy Network. (2016). Roadmap to transition: A handbook for autistic youth transitioning to adulthood. https://www.autisticadvocacy.org/bbook/roadmap/
- ► Beach Center on Disability https://www.beachcenter.lsi.ku.edu
- ► Cornell Person-Centered Planning Education Site https://www.personcenteredplanning.org
- ► I'm Determined https://www.imdetermined.org
- ► Institute for Community Inclusion https://www.communityinclusion.org
- ► Iris Center online training module on Secondary Transition: Student-Centered Transition Planning https://www.iris.peabody.vanderbilt.edu/module/tran-scp
- National Gateway to Self Determination https://www.ngsd.org
- ► O'Brien, J., Pearpoint, J., & Kahn, L. (2015). *The PATH & MAPS handbook: Person-centered ways to build community.* Inclusion Press.
- ► Paradiz, V. (2009). The integrated self-advocacy ISA curriculum. Autism Asperger Publishing Co.
- ► Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A. J., Little, T. J., & Lopez, S. (2015). Causal agency theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities*, 50(3), 251–263.

KEY POINTS - CHAPTER 3



There are many ways you, your transition team, and your autistic young adult can prepare for transition planning together.



Student-centered planning, or person-centered planning, is an approach to transition planning that prioritizes the interests and aspirations of the autistic individual.



Encourage your child to develop self-determination skills and participate in the transition planning process early on, such as by setting goals or advocating for themselves.

Chapter 3: Handouts/Activities ▷



You can prepare for your young adult's transition planning meeting in many ways. The lists below highlight some activities to complete ahead of time and materials to bring with you to the meeting.

DO AHEAD OF TIME

Prepare documentation:

Prepare questions for the team; list in order of priority.

Complete **Activity 3-3:** *Goal Plan* or create a document with the goals you and your child have for their future.

Prepare a preliminary list of services you think may be appropriate.

Review background information:

Review your child's previous IEPs.

Review the results of any assessments done since the last IEP meeting.

Review your rights and the laws related to transition planning.

Determine logistics – attendees and location:

Find out who will be attending the meeting.

Invite additional participants (any individuals you think may be helpful, including advocates or representatives from service agencies).

Confirm meeting time and location.

Prepare with your young adult:

Discuss the meeting with your child, addressing their questions and how they can be involved at the meeting.

Review the background information with your child.

Practice any skills your child may need help with.

Prepare a PowerPoint presentation/video message (optional) that your child can share about their interests and goals.

Set goals and have a strategy:

List what you want to have accomplished by the end of the meeting.



HANDOUT 3-1: Preparing for the Transition Planning Meeting

BRING TO THE MEETING

List of questions.

Activity 3-3: Goal Plan or goals for your child.

Notebook and pen.

Recording device (find out if you need permission from the school to record the meeting).

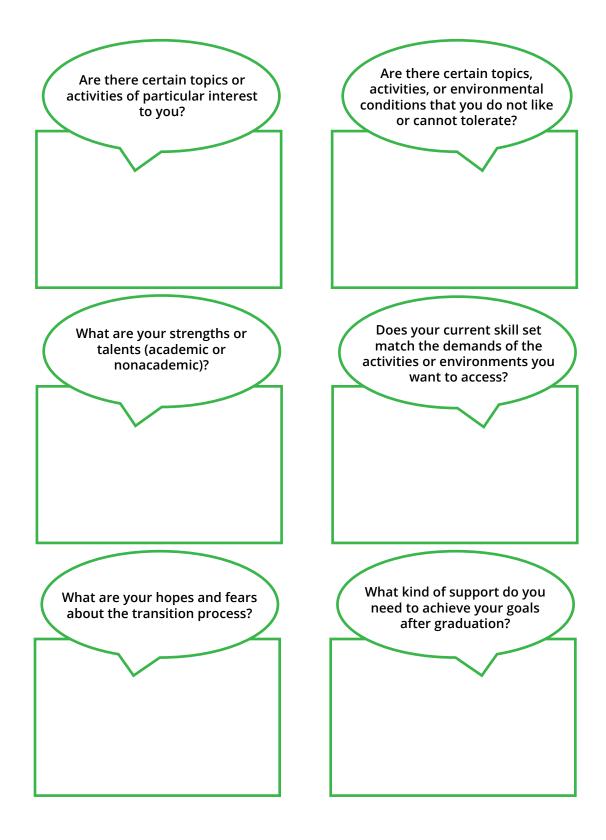
Any recent assessments or reports on your child that may be useful.

Any articles or other research that may help the team understand your child's needs better.

Copy of the latest IEP document.

PowerPoint presentation and/or other prepared materials.







ACTIVITY 3-2: Developing Self-Advocacy Skills

Self-Advocacy – Help yourself to get the resources **you** need to succeed.

Tip #1: Have a support system. You may have a trusted teacher, a friend, or a parent who can help you. Brainstorm ideas with them, practice your advocacy skills, and ask them to accompany you to provide support during the process.

Practice: List two people who can help you with this process. Write down why they are good choices for help.

Tip #2: Know yourself and what you need. Think about the things you have used in the past to be successful. Then you can explain not only WHAT you need, but WHY you need it!

Practice: Make a list of the services you have received in the past that have been especially helpful.

Tip #3: Know your rights under ADA, IDEA, and Section 504. Review **Handout 1-1:** *Comparison of ADA, IDEA, and Section 504 Legislation* if you need a refresher.

Practice: Write down one of the most important protections YOU think ADA or Section 504 offers you.

Tip #4: Be relaxed. In most situations where you must advocate for yourself, there is nothing to be nervous about; you are entitled to certain services under the law. Stay calm and take your time.

Practice: To help feel more confident, complete this statement and say it to yourself if you need to feel more comfortable asking for certain services: "It is my right to receive

to succeed."

Tip #5: Be prepared. Make a list of things you want to say and ask for. This will help to keep you on track as you meet with the appropriate people. Also, be sure to write down any questions you may have.

Practice: Pretend you are calling a college admissions office. Write down three questions you would like to ask the admissions staff about the accommodations commonly offered at the school.

ACTIVITY 3-2: Developing Self-Advocacy Skills



Tip #6: Present specific and clear ideas, feelings, and thoughts. Be specific about what you want or need in the situation. It's okay to be direct and upfront.

Practice: Your professor has scheduled a test. You would like accommodations for taking the test in a different way. In three sentences or less, write what you would tell that professor.

Tip #7: Use "I" statements. You want to be clear that the opinions or needs you express are your own.

Practice: "I believe I need extra time to take tests in this class because ..." Write an "I" statement of your own here:

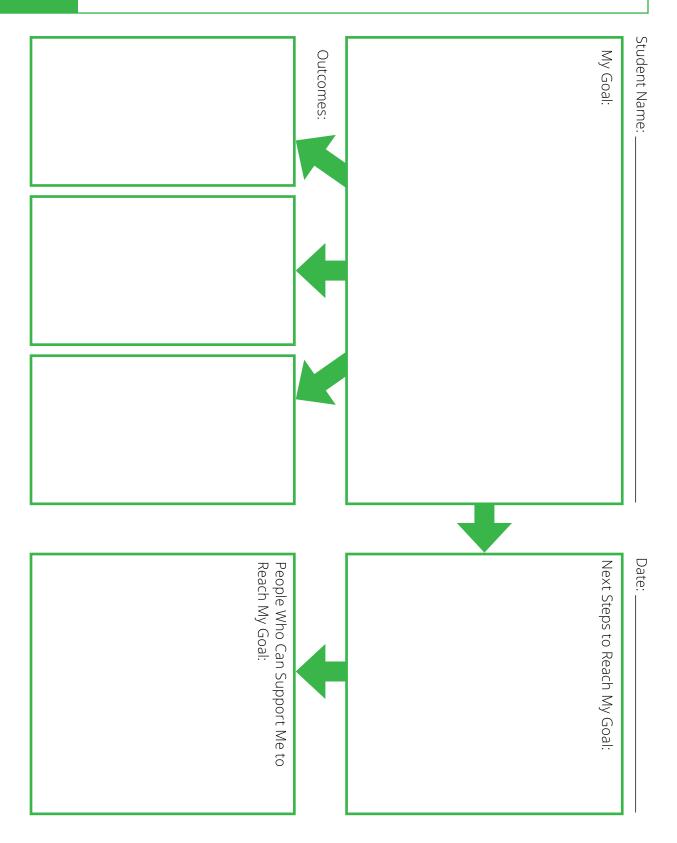
Tip #8: Ask for feedback from the person you are speaking to. It is important to make sure that they understand what you are saying and that you understand their point of view.

Practice: Think about the last time you had a miscommunication with a fellow student or instructor. What feedback from them could have prevented the miscommunication? Write your ideas here:

Tip #9: Educate others. You are an expert on how autism impacts your life. Use your knowledge and skills to educate others about you and what you need.

Practice: Pretend you just met someone for the first time. They ask you to explain what autism is and how it affects your life. Explain to them in three sentences:





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ACTIVITY 3-4: Self-Determination Checklist



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Student Name:	Date:

Self-determination skills help you to know ...

- ▶ yourself
- ▶ your goals
- ▶ the supports you need to reach your goals

Use the following scale to rate the statements below:

3 = almost always/most of the time 2 = sometimes 1 = rarely or never

	Rating		
3	3 2 1		
			I set goals to get what I want or need.
			I make plans for reaching my goals.
			I check my progress on how I am doing toward my goals.
			I attend my IEP meetings.
			I participate in my IEP meetings.
			I know the goals listed in my IEP.
			At school, educators listen to me when I talk about what I want or need.
			At home, my parents listen to me when I talk about what I want or need.
			I have others in my life who help me to accomplish my goals.
			I ask for help when I need it.
			I know what I need, what I like, and what I enjoy doing.
			I tell others what I need, what I like, and what I enjoy doing.
			I help to make choices about the supports (educational services) and accommodations that I need in school.
			I can describe my learning difficulties to others.
			I believe I have control to direct my life.
			I take care of my personal needs (clothes, chores, meals, grooming).
			I make friends with others my age.
			I make good choices.
			I believe that working hard in school will help me to get a good job.

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ACTIVITY 3-5: Your Person-Centered Planning Meeting

Review the steps to leading your meeting in the table below. Check which steps you want to do and which steps you want others to perform for you at your meeting.

	l will	Write the name of the person
Action:	do this:	you will ask to help you with this step:
A. Introduce yourself.		
B. Ask everyone to introduce themselves.		
C. Review past goals by sharing what goal(s) you worked on during the last year.		
D. Ask for feedback. Ask what others think about your goals.		
E. Listen to what your team members say.		
F. Tell the team what jobs you like.		
G. Tell the team what goals you have.		
H. Ask the team for how they can help you with your goals.		
I. Ask questions when you don't understand.		
J. Thank everyone for coming to your meeting.		
K. Work on your goals every day.		

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Finding and maintaining a job requires a variety of key life skills – communication, social, presentation, technology – to name a few. Right now, a career is down the line for your young adult, but they are already preparing for success on the job, including practicing these skills at home (often the first workplace!).

The Individualized Transition Plan (ITP) discussed in Chapter 2 may include goals for employment, preparing now for a potential job, and for a future one. IDEA requires that schools support students with disabilities to make the transition from school to work. To that end, goals, clear steps, and attainable outcomes can be built into the transition plan. The transition period will help autistic learners develop skills for entering the workforce, and will be guided by their interests, goals, and desires for the future. Building skills and preparing for first jobs and experiences are the first steps to long-term employment.

TRANSITION PLANNING

Your Young Adult's Role

Like any good student-centered transition plan, this process involves your child leading the way, to the best of their ability, regarding their interests, preferences, and goals for employment.

They will:

- ► Identify interests and skills needed for employment
- ► Develop and enhance life skills to reach employment goals
- Participate in the transition planning process
- Take the lead in searching for and finding employment

Your Role as a Parent

- Advocate for your student to gain employment skills in the transition planning process
- Monitor transition planning for employment-related skills
- ► Promote and encourage your young adult's self-determination and independence
- Find opportunities for your child to practice employment-related skills at home, such as time management, technology skills, teamwork

PLANNING SEQUENCE - STARTING EARLY

Starting in middle school or early in high school, you and your child should:

- Start having conversations about work and jobs. These conversations will tie in well with your discussions from Chapter 2 about interests, goals, future ideas.
- Explore job sampling, job shadowing, informational interviews, and experience through volunteering. Through such experiences, your child can learn about the wide variety of jobs and careers that exist, and perhaps gain skills through similar tasks at home, at school, or in the community. Completing chores or other activities around the home can build responsibility and work-related skills.
- Participate in vocational assessment activities at school or in the community, such as DVR or a related agency.
- Seek opportunities for your child to develop competency in independence, self-monitoring, and life skills outside the classroom.
- ► Identify training and skills that will support their needs.

In high school, you, your autistic child, and the transition team should:

- ► Reaffirm and reassess life and work goals related to interests and capabilities.
- Break down employment goals into realistic pieces and identify the steps and skills needed.
- Identify strengths and weaknesses relative to work interests and focus on skill development for work tasks.
- ► Identify and find tools and resources to support self-regulation, stress management, and time management. These skills are important in the workplace and can be enhanced in high school, with the help of occupational therapists and other service providers.

Take advantage of programs that offer opportunities for training and employment through job sampling, school-to-work, apprenticeships, cooperative education, tech-prep, mentorships, independent study, and internships.

- Assess transportation needs and capacity to get to work.
- Discuss effective disclosure strategies for work environments.
- Contact DVR, ADD agency, and/or SSA before your child turns 16 to determine eligibility for services or benefits post-graduation.

THE EVOLVING NATURE OF WORK

The career and employment opportunities available to an autistic individual reflect the breadth of the entire job market. In addition, the flexibility of some workplaces and the evolving nature of work can provide additional options that are especially suitable for an autistic young adult. Where and how people work is ever changing, which opens up different types of opportunities for autistic individuals, depending on their needs, interests, and job match.

Traditional

A traditional work environment includes jobs that may be part-time or full-time, based on a 40-hour work week. Some jobs are temporary or seasonal, where the length of employment is based on a specific time period.

Vocational

Vocational work refers to more hands-on or technical jobs, which may include car repair, culinary arts, graphic design, and many others. Vocational training – a type of organized program that prepares individuals for paid or unpaid employment – may be a part of transition services. Check out your state's VR website to gain more information about core services offered and services like trial work experience/apprenticeship, assistive technology, benefits analyses, and other job search costs covered by VR.

Self-Employment

Through self-employment, an individual owns their own business and earns income for themselves; income may come through contracts and/or freelance work as part of this business.

Remote - Telework

Remote work (telework, telecommuting, working from home, flexible workplace, etc.), where employees can work from anywhere and don't have to commute or travel to a central place, office, store, or building, has become much more common in recent years. Different types of employers and jobs offer unique schedules or opportunities for remote work certain days of the work week or full-time.

CATEGORIES OF EMPLOYMENT

Competitive

A full-time or part-time job with market wages and responsibilities is considered competitive employment. Most jobs are considered competitive employment, such as waiting tables, cutting grass, fixing cars, teaching, computer programming, and even writing guidebooks on transitions!

Supported

In supported employment, autistic individuals work in competitive jobs alongside neurotypical individuals and receive support services while on the job. Supported employment may also include career assessments, job training, job development skills, and job coaching. Support services vary by state and may be short-term in nature. Supported employment is often found at universities, hotels, restaurants, office buildings, or small businesses.

Supported employment may be funded through state developmental disabilities or vocational rehabilitation agencies, but families need to ensure that: (a) supported employment, by definition and statute, is intended for people with severe disabilities; and (b) autistic individuals can, in fact, work if given the proper support, training, and attention to job-match characteristics. If ineligible for state-funded services, some supported employment may be paid for privately.

Secured or Segregated

In secured or segregated employment, individuals with disabilities (not necessarily autism-specific) work in a self-contained unit and are not integrated with non-disabled workers. This type of employment is generally supported by a combination of federal and/or state funds. While competitive and supported employment are ideal vocational options for many autistic individuals, secured or segregated employment may be the only viable option for those with higher support needs, and is preferable to no employment.

Categories of Employment 57

Competitive	Supported	Secured/Segregated
 Fully integrated into general workforce Requires special skills Natural supports and consequences Employment supports offered as needed 	 Community integration Ongoing job support Wages and benefits Place first, then train Personalized, flexible supports in place Built-in safety net 	 Group learning Basic skills building Minimal compensation or unpaid Behavioral supports

Preparing to Work

Like many young people, some autistic individuals are excited to get a job. Perhaps they want to earn some extra money to buy items they want, or to learn more about a particular area that they really like. Others may feel more comfortable just staying home and not want to become part of the workforce. Getting to the "why," or the intention behind working, can be an important part of the process for your young adult and also a helpful personal motivator. Do they:

- Want to learn more about a particular topic?
- ► Enjoy working on a particular job or task?
- Want opportunities to contribute to a group effort?
- ► Want to enhance social opportunities?
- Want to begin a component of adult life?

You may find that your young adult's intention may be a combination of these factors or none of these (they may not want to work!). Working together on future goals and wishes, and discussing how work may fit in could be a starting point. Chapter 2 offers some activities to brainstorm and work on together.

Beyond intention are the necessary skills – life, social, communication, and job skills – that will help your young adult thrive in the workforce. The section "Ensuring Success on the Job" below dives into more detail on specific skills that autistic individuals may build as they prepare for employment.

Finding a Job

The first job may not be "the job" for life. First jobs are great for gaining experience and learning new skills. This is the place to start – finding a first or even a second job – with your autistic young adult, where they can practice skills, get experience, and keep growing in the workforce.

When starting to look for a job, it is helpful to facilitate a conversation with your loved one and their support team on questions such as the following.

- How many hours can your child work at any given time?
- ► When are they available? Evenings, weekends, weekdays?
- ► What type of work environments should they try to avoid?
- ► What type of support is needed for your child to succeed in the workplace? (Job coach, written instructions, etc.)*
- ► What types of work or industry appeal to your learner?
- ► How will they get to and from the work site?

As your autistic young adult searches for jobs, they need to consider the match between themselves and a particular job. The "job match" refers to the extent a particular job meets an individual's needs in terms of challenge, skills, interest, comfort, camaraderie, status, hours, pay, and benefits. Generally, as people move through the job market over time, they develop more skills and get closer and closer to their ideal job match.

Autistic individuals are motivated to work with a correlation to the extent they enjoy the work and are treated with the same respect as neurotypical coworkers. While money may not be a motivation, they do still appreciate receiving a paycheck for their efforts. A good job match is of critical importance in these cases. When considering things that contribute to job match, they can be classified into physical and social components.

PHYSICAL AND SOCIAL JOB MATCH COMPONENTS		
Physical Job Match Components	Social Job Match Components	
 Hours of employment Acceptable noise levels at job Pay, leave, other benefits Acceptable activity levels Physical requirements of the job Acceptable margin of error (quality control) Production requirements 	 Acceptable level of interaction with coworkers and supervisors Clear job expectations Grooming and hygiene requirements Demands on communication skills Personal space available Opportunities for food/snacks Coworker training and support Community status 	

Another possibility when looking for work is to explore neurodiversity initiatives. Some employers have specific autism at work programs, although these tend to fit individuals with high skills in technology or specific college degrees. While jobs, availability, and companies may change over time and availability differs throughout the country, for some autistic young adults, exploring neurodiversity recruitment programs may be an option.

^{*} Work and school accommodations may be different. Parents may consider conversations with the school team and/or DVR representative to elaborate on accommodations that may be successful in the workplace.

Job Search **59**

JOB SEARCH

The job search can seem like a job itself! Remember, there are a wealth of resources to support the job search, many aimed at helping autistic individuals. Inquiring among agencies that address supported employment, agencies that support people with special needs, friends, family, colleagues, and acquaintances may be the best first job search strategy.

Online job search strategies may include job boards advertising job openings, virtual job fairs, company websites, and social media (like LinkedIn). Other methods include in-person visits to stores/locations, in-person career fairs, or employment/staffing agencies. Allow your young adult to explore and practice different ways of searching for a job.

The job search and application process includes many parts, which can be practiced and prepared for before and during the process. These parts include:

- Finding appropriate jobs
- Applying to jobs
- Crafting resumes and cover letters
- ► Preparing for interviews and interviewing (developing scripts for practice can help)
- ► Following up with companies after submitting applications and interviews

The job search takes effort, persistence, and patience. Most likely, there will be rejections and setbacks. There are a lot of skills involved, and building these skills can be worked into a transition plan for greater success. **Handout 4-1:** *Job Possibilities (on page 65)* includes some job ideas.

ENSURING SUCCESS ON THE JOB

Personal Disclosure

When considering a possible job or employment in general, it is important to consider when and if your autistic young adult will disclose their diagnosis. If they have had assistance securing the job and are receiving job coaching, the primary question is not whether or not to disclose, but rather what information is relevant for disclosure and to whom. Remember, in all cases, disclosure is a personal choice, and there is no law obligating anyone to disclose that they have a disability. However, to be eligible for accommodations under ADA, some level of disclosure is necessary. **Handout 4-2:** When (and If!) to Disclose (on page 67) provides information on timing options for disclosure, helping you and your young adult to think through the positives and negatives about disclosing at various stages in the job search process. There is no one correct answer for when to disclose; however, once disclosed, that information legally must be kept confidential by the employer.

Some questions for your young adult to consider when thinking about disclosure include:

- ► What is the intention behind disclosing? For informational purposes, to create awareness, or to ask for accommodations?
- What supports and accommodations would you benefit from in the workplace?
- ► Do you feel comfortable telling your boss or coworkers?
- For which aspects of the job might you benefit from your supervisor's help in developing strategies? Do you need to disclose in order to ask for this?

Accommodations on the Job

According to ADA, a qualified employee or applicant with a disability is someone who can perform, with or without reasonable accommodation, the essential functions of the job in question. Reasonable accommodation may include, but is not limited to:

- Making existing facilities used by employees readily accessible to and usable by persons with disabilities
- Restructuring or modifying work schedules
- Acquiring or modifying equipment or devices; adjusting/modifying examinations, training materials, or policies; and providing qualified readers or interpreters

An employer is required to make an accommodation to the known disability of a qualified applicant or employee if it would not impose an undue hardship on the operation of the employer's business. "Undue hardship" is defined in ADA as "an action requiring significant difficulty or expense when considered in light of factors such as an employer's size, financial resources, and the nature and structure of its operation."

Reasonable accommodations under ADA can include longer training periods, written lists of tasks to complete and the time of day they are to be completed, and making sure there are no seriously distracting sights and sounds in the work area. For a more complete list of reasonable accommodations specific to autism, see **Handout 4-3:** Reasonable and Common Job Accommodations (on page 70).

Educating Employers and Coworkers

If your autistic adult decides to disclose their autism, they should be prepared to help the employer, supervisors, and possibly coworkers better understand autism and how it affects them relative to the workplace (i.e., training, performance, and assimilation/social interaction). It may be helpful for employers and coworkers to receive formal training about autism so that they can better understand and offer support when necessary. Ideally, the autistic employee

and the employer should cooperatively brainstorm and develop such training. The autistic employee could participate in a staff-wide discussion, for example, to help dispel myths about autism and share the strengths, experiences, and areas of support that are specific to them.

Workplace-Specific Social Skills

Although social skills may not be necessary for your young adult to perform the actual job, they may be needed to help them *keep* the job or be more socially included at work. The social skills demanded vary from place to place, but there are basic skills that every employee should know. The following sections provide an overview of the areas where your autistic young adult may need assistance or training to perform the job.

Personal Presentation

As an employee, your young adult will represent the company they work for. People make judgments about an individual based on appearance. Therefore, it is important to present oneself appropriately and professionally. Aspects of personal presentation include:

- ► Age- and job-appropriate clothing and footwear
- ► General cleanliness and good hygiene
- Grooming of hair, teeth, and nails
- ► Interpersonal greetings ranging from someone saying "hello" to high fives, fist or elbow bumps, and initiating an introduction

Communication Skills

Some autistic individuals have trouble effectively communicating their wants, needs, likes, or dislikes to others. Scripts can be developed to practice typical work social situations. As such, instruction in the following communication skill sets may help:

- Expressing preferences or likes
- Ordering one's lunch
- Excusing oneself to use the restroom
- ► When, and with whom, it might be appropriate to start a conversation
- ► Listening skills
- Obtaining help when necessary
- Level of response to others
- Eye contact during regular interaction
- ► Voice volume, tone, and tempo

Social Behaviors

Social behaviors, by definition, are particularly challenging for autistic individuals. Complicating this issue is the belief among many employers that social competence on the job (e.g., being a team player) is as important as production competence. Therefore, some areas of social competence that should be covered in your transition plan include:

- General manners, including responding to greetings, not interrupting others, etc.
- Table manners, particularly if one wants to be socially included with colleagues during lunch
- Awareness of others' personal space across all work environments
- Understanding private behavior as being different from public behavior
- Recognizing when assistance is needed and obtaining it
- Tolerance of unusual sounds, actions, behavior of others, and changes in schedule of activities
- Social rules regarding the appropriate touching of others
- ► What to do during breaks
- ► What to talk about and what not to talk about at work (confidentiality)

REINFORCING SUCCESS - SUPPORTING THE NEW EMPLOYEE

Considering, searching, applying, and getting a job requires a tremendous amount of effort, but the process can lend itself to incredible skill-building and independence. As with all parts of the transition planning process, your young adult should take center stage as the main advocate, decision-maker, and planner, according to their needs, skills, and desires. They can and should take great pride, as will you, in each step along the way to becoming an employee!

RESOURCES

- Disability: IN (neurodiversity initiatives): https://www.disabilityin.org/what-we-do/committees/autism-at-work-roundtable/
- Grandin, T., & Duffy, K. (2008). Developing talents: Careers for individuals with Asperger syndrome and high-functioning autism. Autism Asperger Publishing Co.
- ► Hire Autism: https://www.hireautism.org/
- ► Job Accommodation Network: https://www.askjan.org/
- ► National Collaborative on Workforce and Disability: http://www.ncwd-youth.info/

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► OCALI. (n.d.). The employee with autism spectrum disorder. https://www.ocali.org/project/employee_with_asd

- Office of Disability Employment Policy: https://www.dol.gov/agencies/odep
- ► Virginia Commonwealth University. (n.d.). Workplace readiness toolkit. https://www.centeron-transition.org/transition/employment/workplacereadinessskills.html

KEY POINTS – CHAPTER 4



Employment skills can start being developed as early as middle school, and can be built into the transition planning process.



Your autistic young adult should lead the way in searching for and finding employment.



Many job search options and resources are available to support an autistic individual in finding a job.



A wide range of employment options, settings, and formats are suitable for autistic individuals.



Workplace-specific social skills can be practiced, and employers can also be educated about creating and maintaining workplace environments that contribute to an autistic individual's success.

HANDOUT 4-1: Job Possibilities



JOB IDEAS FOR AUTISTIC INDIVIDUALS WHO NEED MORE SUPPORT

Reshelving library books – Memorizing numbering system and shelf locations

Factory assembly work – Especially if the environment is quiet

Copy shop – Running photocopiers; printing jobs could be lined up by somebody else

Janitor jobs – Cleaning floors, toilets, windows, and offices

Restocking shelves – Available in many types of stores

Recycling plant – Sorting jobs

Warehouse – Loading trucks, stacking boxes

Lawn and garden work – Mowing lawns and landscaping work

Data entry – Office work or research assistance

Fast-food restaurant – Cleaning and cooking jobs with lower demands on short-term memory

Plant care - Watering plants in a large office building

JOB IDEAS FOR AUTISTIC INDIVIDUALS WHO REQUIRE LESS SUPPORT

Autistic individuals tend to be specialized in how they think. There are three common types of thinking styles: (a) visual thinking or thinking in pictures; (b) music and higher math; and (c) nonvisual, verbal thinkers.

Jobs That Match the Talents of Visual Thinkers

Architectural and engineering drafter	Theater lighting director
Auto mechanic	Jewelry maker and other crafts
Photographer	Industrial automation programmer
Machine maintenance technician	Web designer
Animal trainer	Landscape designer
Computer troubleshooter	Veterinary technician
Graphic artist	Biology teacher



HANDOUT 4-1: Job Possibilities

Jobs That Match the Talents of Nonvisual Thinkers and Verbal Thinkers		
Journalist	Stocks and bonds analyst	
Budget analyst	Book indexer	
Translator	Copyeditor	
Bookkeeper and record keeper	Speech therapist	
Librarian	Accountant	
Special education teacher	Inventory control specialist	
Jobs That Match the Talents of Music and Math Thinkers		
Computer programmer	Electronics technician	
Math teacher	Musician/composer	
Engineer	Music teacher	
Chemist	Statistician	
Physicist	Scientific researcher	

Adapted from Grandin, T., & Duffy, K. (2008). Developing talents: Careers for individuals with Asperger Syndrome and high-functioning autism. Autism Asperger Publishing Co.



WHEN TO DISCLOSE

On-the-Job Application/Cover Letter

Pros	Cons	Other Considerations
 Allows applicant to relax about employer possibly finding out. Enables the employer to decide if autism is a concern. 	 May exclude your child before having a chan- ce to present themsel- ves and demonstrate strengths and capabi- lities. No way of knowing if hiring was based on diagnosis. 	 Immediate disclosure may make finding a job more difficult; however, when your child does find employment, they are less likely to have autism-related prob- lems on the job.

At the Interview

Pros	Cons	Other Considerations
 Offers the opportunity to answer any questions about autism and its impact on the job. Allows applicant to request accommodations for the interview. Discrimination is less likely in person. Can help the employer make sense of any observed autistic characteristics, potentially reducing fear, confusion, or misinterpretation of these characteristics. 	 Too much emphasis on diagnosis may distract from discussion of your child's strengths and abilities. 	 Your child will need to be comfortable answe- ring questions and leading a discussion about autism and how it affects them specifi- cally.



HANDOUT 4-2: When (and If!) to Disclose

WHEN TO DISCLOSE

After Hired But Before Beginning Work

Pros	Cons	Other Considerations
 If the hiring decision is changed and you are sure your child's autism will not interfere with their ability to perform the job, legal action is warranted. 	 Employer and person- nel department may distrust your child and feel they should have been told beforehand. 	 Will need to evaluate your child's autism to determine its impact on the specific job duties and then be able to explain specifically that it will not interfere with their performance.

After Beginning Work

Pros	Cons	Other Considerations
 Your child will have the chance to prove themselves before disclosing. They will be able to discuss and educate their peers and supervisors about autism. Your child may be protected by law if disclosure affects employment status but ASD does not keep them from performing job safely. Can help the supervisor and coworkers make sense of any observed autistic characteristics, potentially reducing fear, confusion, or misinterpretation of these characteristics. 	 Your child may be anxious at work. Employer may be upset that they were not told sooner. Could lead to disability-related stereotypes, discrimination, or bullying from supervisors or coworkers. 	 It may be harder for your child to disclose the longer they wait. Your child needs to decide to whom to disclose their diagnosis (e.g., no one, supervisors only, supervisors and close coworkers, or everyone).



WHEN TO DISCLOSE

After a Problem

Pros	Cons	Other Considerations
 Your child will have the chance to prove themselves before disclosing. 	 Employer may be upset that they were not told sooner. Could perpetuate myths and misunderstandings about autism. 	 May be difficult to re-establish trust with coworkers.

Never

Pros	Cons	Other Considerations
 Your child's employer cannot provide accom- modations or respond to difficulties due to autism unless they are aware of the diagnosis. 	 Risk of being fired for reasons that employer may have been more understanding about if they were aware. Could lead to myths and misunderstandings about autism. Coworkers may have been more understanding if they were aware of your child's diagnosis. It may be emotionally stressful for your child to "mask" part of their identity at work. 	As you and your child become more confident that performance will not be hindered by having an autism, the issue of disclosure becomes less important.



HANDOUT 4-3: Reasonable and Common Job Accommodations

ADA guarantees that your young adult may request certain accommodations in the workplace. Other accommodations may be needed, depending on their needs and where they are working.

QUESTIONS TO CONSIDER:

- How do the employee's symptoms impact their performance on specific tasks?
- What reasonable accommodations can be provided to address them?
- Do the supervisors and coworkers require training?

ACCOMMODATIONS TO CONSIDER:

Presentation	Timing and Scheduling
Daily checklists for completing and prioritizing tasks Written or verbal reminders Written or picture instructions next to machines, such as postage machine, copier, printer Pictures or drawings of the assigned task Templates of forms or documents Performance feedback presented visually (charts, diagrams) Task flow chart	Consistent schedule Advanced notice of schedule or activity changes Timers and watches Wall calendars and planners Large tasks broken down into small steps Timer or alarm as a reminder Timelines for completion of task Assignment of one task at a time Multiple breaks

Training	Response	Setting
Mentor or job coach Training on appropriate workplace behaviors (e.g., interacting with customers) Consistent supervision by one person Regular and immediate feedback on perfor- mance (positive and constructive)	Provision of qualified readers or interpreters Voice recorder Written instructions Headset for telephone or a speaker phone Acquisition of new or modification of existing equipment	Minimal clutter in the work environment Minimal noise in the work environment (e.g., no radios or music) or permission to use noise-canceling earplugs Information for coworkers about autism Designated desk or workspace Alternative lighting for photosensitivity Desk organizers Fidget devices



Working together, you and your autistic young adult will decide the most appropriate post-secondary goals. Achieving them will always involve the same planning elements: measurable goals, interim steps, clear desired outcomes, and appropriate supports. With proper preparation and transition planning, the process can be customized for your young adult, thereby increasing the potential for success. This chapter discusses how to find the right match for your autistic young adult and how to make sure the process is beneficial for everyone involved.

PREPARING FOR POSTSECONDARY EDUCATION – WHERE TO GO AND WHAT TO STUDY

If postsecondary education is a goal for your young adult and the schools they are considering require proficiency tests, such as the SAT or ACT, their transition plan should include preparatory work for these assessments. They can work with their special education case manager or guidance counselor to request accommodations when registering for standardized testing.

The transition planning process should help identify your child's academic strengths to better determine a match between their interests and a school. Begin exploring early. Help your young adult look into potential summer courses at a community college or explore other options, such as technical or trade schools in your area, to see what is a good fit. Meet and network with current students and attend an information meeting at a local college. The more you can prepare your young adult for the college environment and experience, the more effective their transition will be.

Choosing the Right School

Deciding on a postsecondary program is a milestone for all teens, and your autistic young adult is no exception. Finding the right match is the key to success, and many types of programs are

available that may accommodate their needs. Consider all the options, set your requirements, and then narrow the field of candidates. You can use the checklist in **Activity 5-1:** *Comparing Postsecondary Programs (on page 77)* for evaluating colleges as you begin your search. Here are some general suggestions and things to consider:

- Vocational school, community college, technical institute, state school, or a smaller liberal arts school may all be good options, depending on your young adult's skills and areas of interest.
- ► Certificate programs may provide good training in an area of interest. These programs are sometimes less expensive and time-consuming than vocational schools.
- Some autistic individuals prefer two-year community colleges to start out because they can live at home. However, at the end of these two years, they may wish to transfer to a four-year college. Such a move will require, minimally, some degree of transition planning to identify and address the potential challenges and stressors associated with the new educational environment.
- If your autistic young adult would benefit from a curriculum that focuses on developing independent living skills, job skills, and self-determination, consider starting with a life skills program or autism transition program. You may want to work with a guidance counselor during this process to explore all available options.
- You and your young adult may want to visit particular schools and programs and meet with admissions counselors to gain more detailed information.
- Orientation programs at schools or even on the internet provide a lot of detailed information to help determine the most appropriate choice for your young adult.

Once you and your child have determined a specific program or university, it is important to determine what support services they offer. Most, if not all, colleges and universities have a department that specializes in ensuring compliance with both ADA and Section 504 of the Rehabilitation Act of 1973. Some colleges offer general disability services, some have autism-specific services or college support programs, and in some areas, independent agencies provide support to college students.

Find out what types of disability-related resources colleges offer their students and how to access these accommodations. By becoming familiar with the system and the services provided, your young adult will be better prepared to advocate for themselves, thereby increasing their chances for success.

SELF-ADVOCACY: A KEY SKILL IN A COLLEGE ENVIRONMENT

Once your young adult is accepted into college, the role of advocate needs to fall less on you and far more, if not fully, on them. In fact, self-advocacy skills are considered so critical to suc-

cess in college that many institutions don't even have a mechanism by which you, as the parent, can advocate on their behalf. In college, the student is the main advocate. Therefore, it is essential that your young adult is prepared with self-advocacy skills to help them communicate their needs to the appropriate person in the appropriate manner. (Public universities generally have an office of Disability Support Services, which is the best place to begin.)

OAR's Finding Your Way: A College Guide for Students on the Spectrum is a great resource for autistic college-bound students: https://www.researchautism.org/how-we-help/self-advocates/college.

The process of promoting effective self-advocacy starts by reviewing the types and intensities of services and supports that were useful to your child in high school and explaining how they might be beneficial in college. Aside from knowing what supports they need, your autistic young adult must be able to effectively communicate these needs. Certain skills or, more accurately, skill sets, are critical to the process, including:

- ► How, when, and to whom to disclose:
 - Much like disclosing one's autism in the job search and subsequently the workplace, your college-bound young adult will face similar decisions in the college environment. Your young adult is an expert on their experience of being autistic and has a unique opportunity to let others know, to the extent possible and appropriate, what it is like. This may be especially important when working with professors. In addition, it is important to understand that disclosure is not an all-or-nothing proposition. Each individual will need to learn both how and when (or if) to disclose, and how much information they need to disclose, in what format, and to what end. In short, disclosure is a much more complex and personal process than simply saying, "I am autistic."
 - Disclosing to a professor and receiving appropriate accommodations can make the difference between academic success and failure. Disclosure to peers and classmates, on the other hand, may be much more selective and have a range of positive and social ramifications.
 - Even autistic young adults with fewer skills and more complex learning or behavioral challenges can effectively and appropriately disclose by (as one example) handing out preprinted information cards.
- A broad understanding of their rights:
 - Discuss with your young adult what rights and protections are afforded to them under IDEA, ADA, and Section 504. Work with them to better define what, in their particular case, may constitute a "reasonable accommodation" in the college classroom.
 - Discuss the rights of others in their classes, dorms, and related social activities. How might your young adult best balance out these often competing agendas?

- Learning to be an effective advocate requires practice. Role-plays, social scripts, and video modeling may be useful here.
- ► If you don't ask, you won't know (Shore, 2004):
 - ▶ The social world of college is sometimes confusing, even for neurotypicals. A good advocacy strategy for your young adult, therefore, is to ask a trusted person if they are confused or if they don't understand why something is happening or has happened.
 - Finding out as much as possible about "new" situations (e.g., attending a first concert) by asking questions beforehand can effectively reduce later problems.

SKILLS ESSENTIAL TO COLLEGE SUCCESS

In addition to self-advocacy skills, your young adult needs to rely on many key skills to succeed in the college environment, such as organization, time management, and independent living skills.

- Organization and time management: Identify these skills (generally referred to as "executive function skills") as goals in your child's transition plan so there is time to develop them before college. Knowing how to organize assignments, manage time, set priorities, and break larger projects down into steps is critical for success in a post-secondary setting.
- ► Independent living skills: If your young adult is living on their own at college, tasks such as laundry, money management, cleaning, problem solving, health and wellness, transportation, stress management, etc., will take on a greater relevance than they had in high school. These skills can be developed before the first day of college with the help of occupational therapists or other service providers.

Finally, your young adult may encounter social challenges that are magnified in the college environment. Talk to them about topics such as peer pressure, alcohol and drug use, sexual safety, social media/cyber safety, and conflict resolution with roommates. For detailed tips on how to address these issues, refer to the list of books and websites at the end of this chapter.

SETTING UP - AND USING - SUPPORT SERVICES

It is important to keep in mind that the protections once offered by the IEP and the transition plan will no longer be available as entitlements in a postsecondary setting. Universities do not have a responsibility to identify students with disabilities or determine what supports they need. You and your young adult are responsible for seeking out the protections, provided

by Section 504 and ADA, from disability-based discrimination (see Chapter 1). Your young adult must disclose their disability and prepare the necessary documents in order to request certain accommodations and services to help them fully participate in classes and other activities (e.g., extra test-taking time, ability to audio record lectures). Failure to do so blocks your young adult from receiving accommodations that could make the difference in their college experience. (Note: While some colleges or universities allow the student to complete a form designating a parent as the primary advocate, this is not the norm and, in some cases, is not even appropriate.)

Here are some suggestions for getting the support your young adult needs from their college (Sicile-Kira, 2006):

- Locate an experienced guidance counselor or student services staff member who can advocate for your young adult throughout their college career. Such support may come in the form of information about services on campus, introductions to groups on campus with shared interests, recommendations of professors who may be more willing than others to provide accommodations, and so on.
- Provide the college (professors, counselors, resident assistants, etc.) with information about autism and how it affects your young adult, specifically challenges they face and strategies that can be used to assist them. Developing a one-page "fact sheet" about autism and characteristics specific to your young adult may be helpful.
- Be sure your young adult discusses the options for taking exams with their professor at the start of the semester. Exams may be modified based on your young adult's particular needs; for example, professors may provide extended time or make exams untimed.
- Suggest that your young adult continue to use the strategies that worked in high school, such as written schedules, visual aids, recording lectures, and other accommodations.
- Explore student organizations on campus that may be of interest to your young adult (gaming club, recreational sport, etc.). This may be a place where they can make friends and talk to trusted peers about navigating college life. Some campuses have clubs led by and run by autistic students. If such a club doesn't exist, your young adult may consider starting one.

Further education will open up a whole new realm of possibilities for your young adult's future. While it will be tough for you to let them go – probably tougher than for the parent of a neurotypical child – it is important for you to avoid being a hovering parent and let your young adult have some freedom to explore their new environment. If postsecondary education is a realistic goal for your autistic young adult, preparation and planning can make this process go smoothly, and it will help to relieve some of *your* worries.

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RESOURCES

► Autism Self Advocacy Network. (2013). Navigating college: A handbook on self-advocacy written for autistic students from autistic adults. The Autistic Press.

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KEY POINTS - CHAPTER 5



Transition plans can include preparatory work towards postsecondary education goals.



Unlike high school, students are responsible for actively advocating for themselves in college.



It is essential to practice self-advocacy skills prior to and during postsecondary education; these skills may include, but are not limited to, determining when, how, and to whom to disclose and advocating for one's educational rights.



Other key skills for success in postsecondary education include organization, time management, and independent living.



Many programs and schools offer autism-specific services or college support programs that will match your child's needs.

ACTIVITY 5-1: Comparing Postsecondary Programs



This worksheet provides a comparison checklist to use when exploring postsecondary education options. Picture your child's ideal college environment and what would be needed to meet their specific needs. Then use the checklist when you are researching the different education options.

INSTITUTION NAME AND LOCATION					
Four-Year College					
Two-Year College					
Vocational/Technical College					
Life Skills/Transition Program					
Small Student Population					
Dorm Living Option					
Living at Home Option					
Transportation Options					
Part-Time Option for Taking Classes					
Variety of Course Modes (online, in-class, hands-on)					



ACTIVITY 5-1: Comparing Postsecondary Programs

INSTITUTION NAME AND LOCATION					
Student Advisor to Assist Student in Planning Course Selection					
Major of Interest to Student					
Career Counseling					
Clear Admissions Requirements					
Financial Aid Options					
Extra Fee for Special Education Services					
Clear Policies for Requesting Disability Services and Accommodations					
Technology Provided to Assist Students					
Experience with Autistic Students					
Tutoring Available					
Interesting Extracurricular Activities and Organizations					



Growing up may mean moving away from home, exploring independent living, attending a postsecondary program, or getting a job. Many skills built during transition planning will expand and facilitate successful transitions to adulthood. Hand in hand with maintaining a job and finding a great place to live, technology skills permeate every aspect of daily life. This chapter reviews multiple living arrangement options that may be available for your autistic young adult, provides guidance on how to create transition plans to establish new routines and structures, and highlights skills to build on in the transition planning process for fulfilling transitions post-high school.

LIVING ARRANGEMENTS

As awareness of autism has grown over the years, communities have welcomed the need to support various living arrangements for autistic young adults. Supports now expand from handson assistance to completely independent housing. These housing opportunities continue to be competitive, often resulting in long waiting lists. Young adults need time to practice and prepare for their transition while they are at home, so it is recommended that all families begin planning and preparing early.

This section highlights common living arrangements and how they are typically structured, ordered from the most independent to the most supportive. Note that this list is not exhaustive and the details for each arrangement can vary widely in your own community. In this regard, the Centers for Independent Living are valuable resources that provide additional information about living arrangements and how to find them in your state (https://acl.gov/programs/centers-independent-living/list-cils-and-spils).

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► Independent Living – This type of arrangement is best suited for young adults who have learned the critical safety and life skills needed to live on their own without daily support or supervision. In this arrangement, residents live in a home, apartment, studio, or other residential space where they have exposure to peers and are responsible for their own care and residential upkeep. Often, young adults do not transition immediately to independent living, but gradually move through different levels of support as they work toward complete, independent housing.

- Supervised Living In a supervised living arrangement, the young adult is expected to complete their daily life skills and live independently, but have available an adult family member, caregiver, or paid worker to provide a general level of supervision and limited hands-on support. Commonly, the young adult may live with their parents, relatives, or a family friend as a "roommate." This arrangement helps reduce concerns of social isolation and provides a safety support in the event of an emergency or other unexpected event.
- Supported Living Under this arrangement, the young adult lives in a home, apartment, or group home and receives daily, ongoing support from a caregiver or independent service provider for check-ins and assistance with daily tasks. For example, an aide is hired to assist the young adult by helping them wake up on time and get dressed for work, preparing meals for the day, and cleaning the home. Different types of supported living include:
 - Cooperative Living This living arrangement is commonly known as a "co-op." Similar in the level of support available at a group home, the co-op enables several families of dependent adults to form a cooperative agreement whereby they share ownership of the home and support of the adults living there. In addition, families commonly hire an agency or independent caregiver to provide a variety of support and independent living skills training to the residents.
 - Supervised Apartment Living This arrangement is similar to a college dorm or campus. Young adults of various levels of independence and skills live in an apartment complex that is monitored and supported by a housing agency. The agency provides resident assistants who are responsible for creating social activities, monitoring resident cleanliness, and providing support with resident self-care such as therapy or training on how to become more independent.
 - Supervised Group Home Living In communities where supervised apartments are not available, group homes are often more common. In a typical group home, three to six adults with various living skills support needs live together in a house that is owned and facilitated by an agency. These homes are often staffed by trained personal care workers who assist the residents with various aspects of living. Group homes often provide behavioral health and medical care assistance as well.

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► Adult Foster Care — In this arrangement, the young adult lives in the home of another family who is responsible for assisting them with their daily living needs. This type of arrangement is most commonly used for adults with disabilities who were previously placed in juvenile foster care and are transitioning into adulthood.

▶ Institutional Care — Institutional care, also known as residential care, includes large care facilities that provide comprehensive medical and daily living care. Such facilities are able to support young adults who need complete hands-on assistance with their daily living skills and commonly also need behavioral health and/or medical skilled care. Residents of these facilities are typically assigned an interdisciplinary team of physicians, psychiatrists, therapists, nurses, vocational educators, and daily care staff to support their needs through a treatment plan.

PREPARING EARLY

While the physical transition to a new living environment will not occur until your child has at least finished high school, preparation for that transition can start much earlier. As autistic individuals generally require more time to learn life skills, it is recommended that key personal care and daily living skills be introduced no later than the early teenage years. Regardless of when your child begins the preparation process, a range of key skills will help foster independence and success. The following provides a general list of recommended skills to teach. These should be individualized and tailored to your youth's abilities and needs.

Life Skills

Life skills, also known as "daily living skills" or "activities of daily living," include a range of tasks people use on a daily basis, such as maintaining proper hygiene or cooking a meal. How well your young adult develops these critical life skills by the time they are ready to transition to adulthood will help determine the type of living arrangement they will thrive best in. For example, individuals who need hands-on support to use the toilet, bathe, or dress themselves on a daily basis will likely start with a group home as opposed to living in a less supportive environment such as supervised living.

Because we are all unique, there is not a specific list of life skills all individuals should learn. **Handout 6-1:** *Life Skills (on page 87)* provides a suggested list of life skills organized by category. Consider early on the potential living arrangement your young adult may transition into, then build a list of skills they will need to succeed in that environment. Remember that to perform an entire skill independently, your young adult may require the aid of useful tools such as visual schedules or reminders.

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Functional Skills

So-called functional skills refer to skills we all need to navigate the daily mechanics of living independently, regardless of living arrangement. The nature of these skills varies even more widely than daily living skills, and may include household maintenance, money management, shopping, or other tasks that your child may not need to learn yet.

Harnessing the power of technology, including responsible use and engagement, is another functional skill. Technology skills infuse modern-day life and benefit individuals in many areas, such as household tasks (like ordering groceries), job searches, social connections, and paying bills.

It is important to teach skills that are meaningful for both your young adult and your family as you support your child in becoming as independent as possible. In that regard, it is helpful to keep in mind that some functional skills, like driving, may take more time, resources, and support than others. **Handout 6-2:** Functional Skills (on page 88) includes a list of functional skills as well as tips for teaching them.

■ Time Management

While many autistic youth thrive on structure, they often have difficulty staying organized and managing their time effectively. From picture-based visual schedules to smart systems on handheld devices, many tools are available to help organize time more effectively and efficiently. Here are some recommendations to support your young adult's success:

- ▶ Break each day up into smaller schedules: To make the day appear less overwhelming, organize the day's events into blocks of time, and break those out into smaller tasks. For example, the first block in the day, "Morning Routine," would include smaller tasks such as "Wake Up," "Get Dressed," "Brush Teeth," "Apply Deodorant," and so on. This strategy can help make the day's events feel achievable, reduce anxiety, and lead to success.
- ► Create an individualized activity schedule: When living independently, there are many tasks that do not have to be done on an assigned day but should be completed weekly, such as household chores. This ambiguity in a schedule can be confusing. To address this, first create a weekly to-do list of tasks to be accomplished by the end of the week. Then, on the daily schedule, allocate enough time to complete two tasks from the to-do list. Your young adult then has the autonomy to select what tasks to complete each day from the list of weekly chores while ensuring that everything gets done by the end of the week.
- ▶ **Use an organizer:** Electric or paper planners are an excellent way to organize ongoing responsibilities. Organizers can be divided into tabs or sections so that the individual tasks are grouped according to categories. Using a planner also provides the consistency and predictability of having not only a place for organizing and keeping together a list of tasks to be completed but also a place for retaining important information such as your youth's address or emergency contacts for a quick reference.

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Health and Safety Skills

In addition to daily and functional living skills, it is important to prepare your young adult with the skills necessary to maintain their health and safety. Certain skills, such as responding appropriately to a fire alarm, may need ongoing practice to ensure they are retained over time. **Handout 6-3:** *Health and Safety Skills (on page 90)* provides a basic list of health and safety skills.

Despite its enormous benefits, technology presents additional safety issues, including cyber-bullying, access to inappropriate content, and identity theft. Technology education is therefore important, including education on planning and prevention skills for online safety.

It is critical that your young adult acquires the necessary skills with the ultimate goal of being able to perform them consistently independently. The AASPIRE Healthcare Toolkit for Adults on the Autism Spectrum (https://www.autismandhealth.org/) offers worksheets and strategies to help your young adult begin to manage their own doctor appointments. In addition, Handout 6-5: Medical Health Form (on page 93) helps young adults prepare for medical appointments.

OAR's *Life Journey Through Autism: A Guide to Safety* outlines the Safety Planning Cycle and offers tips to help you and your young adult prepare for household, school, and community safety risks (https://www.researchautism.org/resources).

Sexuality and Relationships

Autistic individuals are very often left out of the conversation about sexuality, almost as if they are incapable of having sexual thoughts, feelings, and needs. In reality, many autistic people are sexual beings, and all autistic people need the information and skills necessary to make healthy decisions about sexuality. In discussions of this nature, it is important to address your young adult based on their actual age, instead of their cognitive age, to ensure they are receiving accurate and age-appropriate information.

As your child matures, it is necessary to educate them about the changes in their body and feelings. Puberty can be a difficult time for adolescents, and especially confusing and challenging for autistic individuals. You and your family should decide on the best way to address these physical and emotional changes, while keeping open and positive methods of communication.

This is also a critical time to address relationships with members of the opposite sex or of the same sex, appropriate social skills related to friendship and dating, and the differences between the various types of relationships we encounter throughout life. As parents, it is important to know what, if any, sexuality education is being provided by the school or any other support organization.

Safety is a critical topic in general and as it pertains to sexuality and relationships. Your child may lack certain skills (e.g., distinguishing between appropriate and inappropriate

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behaviors) that would help them determine if a situation is safe. Discuss how to recognize and avoid potentially dangerous situations that may occur as your child matures, including advances from strangers, keeping in mind that many cases of abuse are perpetrated by a known person. From an early age, it is crucial to teach the difference between appropriate and inappropriate touching and behaviors. For learners with limited verbal comprehension, discrimination training in the form of stranger/friend and good-touch/bad-touch[®] (https://www.childhelp.org/subs/childhelp-speak-up-be-safe) remains important and can often be taught with a combination of pictures and actual role-play instruction.

For more information on sexuality and relationship topics to discuss with your young adult, visit https://www.researchautism.org/sex-ed-guide for OAR's Sex Ed. for Self-Advocates guide.

Hobbies and Recreation

Many autistic learners have certain areas of interest or specific topics that they really like, for instance, math, Lego[®], animals, computers, transportation, video games, or a specific movie or TV series. As part of the transition planning process, consider how your young adult's special interests can be used to help them make friends outside of the classroom. For some interests, there are related organizations that meet socially – anime clubs, science fiction clubs, computer/technology clubs, chess clubs, robotics clubs, and so on. Introduce your young adult to these groups and encourage them to participate. Meeting new people based upon a similar interest, making a friend, and expanding potential support systems can be extremely helpful as your child gets older. **Handout 6-4:** *Exercise and Personal Health (on page 92)* offers some helpful tips for creating healthy routines, motivating your child, and de-stressing.

RESOURCES

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- ► Partington, J. W., & Mueller, M. M. (2012). The assessment of functional living skills guide Essential skills for independence at home, school, and in the community. Behaviour Analysts, Inc.
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KEY POINTS – CHAPTER 6



Support in living arrangements includes many options, ranging from hands-on assistance to complete, independent housing.



Consider the living arrangement that may fit your young adult and build the necessary living skill goals into their ITP.



It is important to teach skills that are meaningful for your young adult and support them to be as independent as possible.



Adulthood and independence pose new risks and threats to your young adult. Safety skills, from technology to relationships, remain important and coincide with many life skills.

HANDOUT 6-1: Life Skills



TOPIC	RECOMMENDED SKILLS TO TEACH	TIPS ON TEACHING SKILLS
Hygiene	 ✓ Bathe or shower ✓ Toilet, including menstrual care ✓ Brush teeth ✓ Wash face ✓ Apply deodorant and/or body spray 	 Break down the skill into individual steps. Laminate a sign with the steps and place it in the shower or bathroom for easy reference. Use pictures for quick reference. Use numbers on the steps and number the specific items in the bathroom. For example, if Step 3 is brushing teeth, put the number 3 on the toothbrush.
Grooming	✓ Shave✓ Style hair✓ Take care of nails✓ Take care of contacts or glasses	 Consider alternatives to traditional razors, including clippers or liquid hair remover. Explore different types of nail clippers that vary in sharpness and the noise they make when they clip, or teach your youth to use a nail file if needed. Assign specific days for the youth to clean their glasses, making it a scheduled routine.
Dressing	 ✓ Get dressed and undressed ✓ Identify clean and dirty clothing ✓ Identify when to change self when soiled ✓ Match clothing ✓ Select clothing for the weather ✓ Identify appropriate and inappropriate clothing 	 Break down the skill into individual steps, using visual aids with pictures as helpful reminders. Include in the routine a step to automatically put dirty clothing in the clothes hamper, in the washing machine, etc. Keep matching simple. Buy sets of clothing that always are worn together. Set temperature thresholds for wearing types of clothing. For example, always wear a coat if below 60 degrees, always wear gloves if under 30 degrees, etc.
Routines	 ✓ Follow a morning routine ✓ Follow an evening routine ✓ Wake up on time ✓ Leave home on time and secure the home upon leaving 	 Break down the skill into individual steps, using visual aids with pictures as helpful reminders. Use electronic reminders such as alarm clocks or virtual assistants (e.g., Alexa, Siri, Google Assistant). Provide a visual reminder by the front door to lock all doors, windows, etc.



HANDOUT 6-2: Functional Skills

TOPIC	RECOMMENDED SKILLS TO TEACH	TIPS ON TEACHING SKILLS
Meals	 ✓ Prepare cold meals ✓ Use the microwave or stove ✓ Understand food types for balanced meals ✓ Identify spoiled and undercooked food ✓ Package leftovers properly 	 Assign a day for menu planning and cleaning for the week. This day the youth will identify meals for the week and clean out any spoiled foods from the home. Use visuals of food groups to help in planning well-balanced meals. Explore different types of containers and utensils for proper storage. Teach how to date leftovers and make a routine for throwing out foods after an assigned date.
Phone Use	✓ Make a call✓ Answer a call✓ Write down details from a call✓ Maintain a phone book	 Practice what to say, how to ask who is calling, and writing down the information for a message. Memorize or program important phone numbers into the phone to assist with contacting people. Learn how to identify spam or fraudulent calls and how to respond appropriately to them.
Household Use	 ✓ Use various light switches (bedrooms, kitchen, under cabinets, etc.) ✓ Use a thermostat ✓ Open and close door and window locks ✓ Use garage or electric doors 	 Post visual reminders next to doors to turn off lights or consider use of motion detection lights. Explore the use of smart systems for the home. Keep a simplified list of instructions or tasks for how to troubleshoot common remote control issues such as changing the source, low battery, etc.
Household Care	 ✓ Wash dishes ✓ Do laundry ✓ Organize and pick up belongings ✓ Vacuum or sweep ✓ Use disinfectant wipes and sprays 	 Break down the skill into individual steps, using visual aids with pictures as helpful reminders. Create a list of home maintenance instructions such as changing an air filter or replacing smoke detector batteries. Practice using basic tools, such as hammers and screw drivers, at home before the transition to other living arrangements.

HANDOUT 6-2: Functional Skills



TOPIC	RECOMMENDED SKILLS TO TEACH	TIPS ON TEACHING SKILLS
Transportation	 ✓ Use a map or GPS device for common routes ✓ Understand distance to locations and when to walk vs. use transportation ✓ Understand when and how to use bus routes, subway or train ✓ Understand how to use a taxi 	 Determine whether a paper or an electronic map is preferable. When using electronic maps, teach how to navigate when the GPS fails or does not have signal. Encourage flexibility by teaching alternative modes of transportation or routes when the normal one cannot be accessed. Identify common signs and visual signals for public transportation.
Money	✓ Identify currency✓ Use a credit card✓ Understand bank services✓ Make and maintain a budget	 Create a "cheat sheet" or list of reminders of money services commonly used. Set limits and clear rules for what can and cannot be purchased with their credit card Practice safe money storage and credit card transaction skills.
Shopping	 ✓ Purchase clothing ✓ Purchase food ✓ Purchase household supplies ✓ Identify the price with discount tags ✓ Make a choice or selection 	 Create a list of items to purchase at the store, including details such as size (for clothing) or shapes and colors for novel items. Remember that each store has different ways to display a discount price; practice asking store clerks for help. When given a list or a menu of items, practice reviewing all of the items and selecting their choice.
Technology	✓ Conduct a job search✓ Use social media✓ Understand online shopping	 Create a list of job search engines and key words for particular interests. Keep passwords safe and protected. Use all privacy settings when accessing social networks. Identify signs of online scams and phishing attacks.



HANDOUT 6-3: Health and Safety Skills

TOPIC	RECOMMENDED SKILLS TO TEACH	TIPS ON TEACHING SKILLS
Medication	 ✓ Follow a schedule for routine medications ✓ Take the correct dose ✓ Schedule refills ✓ Use of over the counter medications 	 Consider use of medicine bottle timers that lock the medication closed until the next dosage time. Consider using visual reminders, timers, pill dispensers, or other tools to ensure that routine medications are taken correctly. Specify what to do if they take the incorrect type or number of pills.
First Aid	 ✓ Maintain a first-aid kit ✓ Use bandages and basic supplies ✓ Apply sunscreen ✓ Apply bug spray 	 To practice these skills, use training videos or pretend scenarios with dolls/figurines. For sunscreens or insect repellants, use lotions or color-changing supplies that show when areas have been missed. Teach how to remove lotion or sprays from the eyes or other surfaces.
Emergencies	 ✓ Know personal information (e.g., name, phone number, address) ✓ Know how to react during a house fire ✓ Know who and how to call for medical or personal emergency 	 Keep an identification card in wallet or purse. Teach how to request help when not home, including how to accurately describe their surroundings. Practice escaping different houses or buildings in the event of an emergency. Teach avoiding elevators in case of fire.
Community Safety	 ✓ Understand stranger danger ✓ Travel in safe areas ✓ Know how to ask for help ✓ Know how to identify "safe" staff in a public setting ✓ Understand the meanings of emergency signs 	 Provide examples and discussion of appropriate vs. inappropriate touching, being mindful of cultural norms. When teaching "safe" community helpers, use common individuals such as police officers, store staff (e.g., are they wearing a name tag), etc. Use walks and outings in the community to learn emergency signs. Find common signs about electricity, heat, flooding.

ACTIVITY 6-3: Health and Safety Skills



TOPIC	RECOMMENDED SKILLS TO TEACH	TIPS ON TEACHING SKILLS
Health	 ✓ Understand symptoms of common illnesses (e.g., cold, flu, allergies) and how to treat them ✓ Understand how to care for a skin rash ✓ Know when to call family support or physician for help 	 Create a health care binder with common symptoms, how to treat them, and when to call for help. Use visual aids in the bathrooms as reminders of handwashing and other hygiene tasks to prevent illnesses. Create a medical health form with medical history and prescription details to bring to and update at each physician visit (see Handout 6-5: Medical Health Form (on page 93)).
Exercise	 ✓ Maintain a routine ✓ Complete specific activities such as running, weightlifting, walking, etc. ✓ Travel to and use a local gym 	 Establish a set schedule to complete exercise activities each week. Teach the importance of staying hydrated and how to identify if they are straining themselves while exercising. A list of exercises, tips, and tricks is located in Handout 6-4: Exercise and Personal Health (on page 92).
Cybersafety	 ✓ Understand internet social safety ✓ Understand financial safety ✓ Understand cyberbullying 	 Warn that if meeting someone from the internet in person, always bring a trusted person along. Clarify when it is safe to share personally identifying information (e.g., real name, address, financial/credit card information, or Social Security number). If feeling uncomfortable online, for any reason, exit the website and tell a trusted person. Teach never to send pictures to unknown people.



HANDOUT 6-4: Exercise and Personal Health

Exercise is an important way to maintain healthy habits and also aids in reducing stress. Below is a list of exercises, tips, and tricks to motivate your young adult to maintain an exercise routine.

Ways to Create Interest in Exercise Routines

- ▶ Biking find a map of local trails and make a goal to bike through each one
- Boxing explore a local gym to find a mentor to box with
- Dance and fitness classes use the class to learn about various cultures and music
- Jogging set a goal to jog for the entirety of a favorite song
- ► Jumping rope practice counting skills while jumping
- Karate encourage your youth's peers to join a class and work collaboratively to earn belts
- Skating start with a birthday party or social event with peers to create interest
- Swimming don't focus on swimming laps, but encourage any type of swimming as exercise
- ► Team sports create a backyard sports team to play soccer, football, etc.
- Walking make a bingo sheet of local items to find in the neighborhood during walks
- Weightlifting ask the local gym for mentors or coaches to teach skills and provide encouragement
- Yoga try new yoga classes such as yoga with goats to create interest

Tips and Motivators

- ► Join a gym with family or friends and set a dedicated schedule to attend each week
- Set up community sports teams to play soccer or kickball
- Reward your young adult for exercising a specific number of times by given them something related to their favorite hobby
- Buy your youth new workout clothes
- Create a game or competition; for example, whoever can make the most baskets at the gym gets to pick where to go out to dinner
- Suggest reading a favorite book while on a stationary bike
- ► Take a fitness class together
- ► Dedicate time to create a favorite, healthy snack after the activity (trail mix, apples with peanut butter, etc.)

ACTIVITY 6-5: Medical Health Form



Medical appointments can be challenging for autistic young adults, even if routine with a familiar doctor and staff. If your young adult struggles with providing their medical information, this medical history form can be filled out by the family or caregiver and a copy provided for each visit.

Contact Infor	mation		
Name of Youth:			Date of Birth:
			City:
State:	Zip:	Home P	Phone:
Emergency Conta	act & Phone:		
Medical Infor	mation		
Height:	Weight:	Eye Color:	Hair Color:
Scars or Identifyi	ng Marks:		
Primary Diagnos	es (e.g., ASD):		
Other Medical Co	onditions:		
Recent Medical H	listory (surgeries	s, procedures, etc.):	
Current Prescrip	tions (name and	dosage):	
Additional Medic	al Care Provider	s (name, specialty, p	hone):
Personal Info	rmation		
Method of Comn	nunication (e.g.,	verbal, sign language	e, written, pictures):
Sensory, Medical	, or Dietary Issue	es and Restrictions, i	f any:
Notes for a Succe	essful Visit (includ	de actions to avoid a	nd any deescalation techniques):

CHAPTER 6: LIFE SKILLS



Planning for your child's future doesn't end after high school. While it may be difficult to think about a future when you are not around to care for your child, it is important to begin taking the necessary steps to secure the supports and services they will need after your death.

At the beginning of the transition planning process, you brainstormed your adulthood goals for your child, including goals related to quality of life, living, education, and employment. As you begin planning farther into the future, you will need to address and compose legal documents that articulate lifestyle, financial, legal, and other requirements for your young adult's continuing care.

PEOPLE INVOLVED

Begin by identifying key people who can assist you in the process. This should include, when possible, your family, your autistic young adult, an attorney, a financial advisor, caseworkers, medical practitioners, accountants, teachers, therapists, and anyone else involved in providing services to your young adult. In some cases, a professional known as a lifetime assistance planner can be contracted to act as a "team" advisor to make sure that all parts of the plan are coordinated and complete. Usually, however, this role falls to the parent, the transition coordinator, or the autistic individual. Make sure that the attorney, financial advisor, and other planning professionals all have specific knowledge and experience serving people with disabilities.

DEVELOPING A LIFESTYLE PLAN

Lifestyle planning is a way in which the family records what they want for the future of their loved one. This plan can be developed as a **letter of intent** written by you and can provide

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information about your autistic young adult. The letter can include medical and treatment history, current ability levels, and your hopes and goals for the future. The letter may cover:

- ► Interest in continuing education, forms of employment, and forms of residence
- Religious beliefs and practices
- ► Supports related to advocacy, behavior management, medication management, etc.
- ► Daily living instructions, such as for bathing, eating, and dressing
- Preferences and interests with regard to music, movies, games, and social and physical activities
- Dietary needs and preferences
- ► Environmental preferences (e.g., does not like fluorescent lighting)
- ► Personal or idiosyncratic preferences (e.g., prefers a specific coffee mug)
- ► Medication guidance
- Any and all lifestyle options that will ensure quality, dignity, and security throughout life

The letter of intent is not a legal document, but it provides important context to guide the future care of your child. Emotionally, it records your feelings about the future as well as your young adult's goals. Practically, it provides detailed information on medical and behavioral history, effective interventions and supports, your young adult's strengths and challenges, and specific care instructions. Some families even videotape daily tasks to illustrate key instructions. A detailed letter will help provide valuable insights for future caregivers and a smooth transition.

Start your letter of intent now, and then revise and update it, as needed, to ensure that it remains an appropriate resource for your young adult. You can find a template for a letter of intent in **Activity 7-1:** *Template for Letter of Intent (on page 101)*.

LEGAL PLANNING

Most of all, preparing for the future means establishing legal protections to ensure your wishes are carried out as intended, in the best interests of your autistic young adult. Find a lawyer who specializes in special needs and/or disabilities to help you create legal documents tailored to your family. They will use appropriate language and methods to provide for your young adult. The basic documents you should consider creating include a will, a Special Needs Trust (SNT), and an ABLE account.

Will

After your death, a will provides specific, detailed plans for your estate and the care of your young adult. If you do not have a will, the state usually divides your property and assets equally

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among your family members, including your young adult. Because certain government benefits have financial eligibility requirements, leaving your estate to your autistic young adult may make him ineligible to receive these resources. Therefore, it is essential to prepare your will and estate to maximize the benefits and protections, ensuring financial stability and continued care.

Supported Decision-Making

The ability to make our own choices helps determine our quality of life. Some people are more equipped to advocate for themselves and problem solve, while others may need more or less support in specific areas.

When your autistic young adult reaches the age of majority (i.e., becomes a legal adult), some or all of your parental rights transfer to them. As an adult, they will be legally responsible for making key decisions about their health, finances, education, living arrangements, and more. If your autistic adult has limited capacity to make and communicate choices, or if you believe they require protection from financial abusers, they may benefit from additional help to manage their affairs.

To help determine their ability to manage their own affairs and make decisions for themselves, consider the following questions:

- ► Do they understand the circumstances surrounding a decision why it needs to be made, and when?
- ► Do they understand the consequences of the options made available?
- Are they able to identify the appropriate resources or people to negotiate and finalize the decision?

Supported decision-making is a person-centered process of providing the least restrictive supports and services to help an individual make their own decisions and to increase structured supports only as needed.

For your young adult's safety and overall wellbeing, there are several support tools and resources to consider. Here are a few options, ranging from limited to full support:

- ► **Informal support** in the form of advice from family and friends can help them make informed decisions while maintaining decision-making power.
- Signed consent forms allow family members or friends to participate in the evaluation process by granting them access to certain documents.
- A **healthcare proxy** is a person who is granted access to medical records and empowered to make medical decisions on the autistic adult's behalf.
- A **power of attorney** grants somebody authority to make decisions on specific matters of life (e.g., finances) on behalf of an individual who is absent or becomes incapacitated. The power of attorney can access records and have decision-making power in specific areas such as financial management or education.

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Limited guardianship gives a court-appointed person (the guardian) the legal rights to make decisions for the wellbeing of the autistic adult in specific areas, such as health care or housing.

Full guardianship is the most restrictive form of support, as it is a court-ordered arrangement that transfers all decision-making power from the "incapacitated" adult ("ward") to the guardian. The guardian has full authority over all aspects of the ward's life, including health care, financial management, living arrangements, travel arrangements, right to marry, and personal care. Full guardianship should only be used when other options are not viable. However, for some individuals with greater support needs, full guardianship is the only viable possibility. Under these unique circumstances, full guardianship is designed to protect, not take away, the rights of the autistic individual.

For more information on decision-making support options, visit the National Resource Center for Supported Decision-Making at https://www.supporteddecisionmaking.org. Remember, laws around guardianship vary by state.

OAR's *Life Journey Through Autism: Navigating the Special Education System* contains more detailed information (https://www.researchautism.org/resources).

Special Needs Trust

A Special Needs Trust, or SNT, is a specific type of trust used for special needs planning. It is a legal way for you to provide financial supports for your child to maintain a good quality of life, while allowing them to remain eligible for certain government benefits, such as Medicaid, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and Medicare. Such funds cannot be used for basic needs and expenses such as housing, food, and medical treatments that would otherwise be covered by government benefits.

Many types of resources can be used to fund the trust, including your family's savings, investments in stocks and mutual funds, IRAs, 401(k)s, real estate, home equity, and life insurance. Because there are strict and constantly changing rules regarding trusts and government benefits, it is important to work with an experienced lawyer who is familiar with estate planning for special needs. In addition, a number of agencies may be able to help you establish an SNT. Do your own research, consider getting referrals from other families who have already gone through the process, and always consult with an attorney to ensure compliance with all relevant federal and state regulations.

FINANCIAL PLANNING

Consider the financial resources necessary to support your adult child after your death. You can begin by creating a detailed budget of expenses that includes everything from housing

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to personal needs, both currently and in the future. This will give you an idea of how much money will be needed to care for your young adult and help set a goal for building a trust fund. The worksheet on future expenses, provided as **Activity 7-2:** Calculating Future Expenses (on page 105), may help you with this process.

Next, consider how you will cover the costs and/or fund the trust. Don't forget to include the government benefits, such as Social Security, that your child may receive. Consider setting up an ABLE account, which is a tax-advantaged savings account to help you save money for eligible beneficiaries with disabilities that can go toward qualified disability expenses.

Here are some resources to help you determine what benefits and financial supports you and your child qualify for.

Social Security Administration: https://www.ssa.gov/benefits/disability/

USA.gov: Disability Services: https://www.usa.gov/disability-services

A complete estate and financial plan can help provide comfort, mitigate family conflict, and protect your child from predators when you are gone. A financial planner who specializes in special needs can be a very useful in guiding you through this process.

Stepwise Preparation Process

The following is a stepwise plan to consider as you work to protect the special needs of your young adult.

- 1. **Prepare a life plan.** Working together with your young adult, discuss residential needs, employment, education, social activities, medical and dental care, religion, and end-of-life arrangements. You can use many of the goals from transition planning as part of this plan.
- 2. Write a lifestyle plan and letter of intent. Write down the goals for your young adult's future. Include information regarding care providers and assistants, attending physicians, dentists, medicine, functioning abilities, types of activities enjoyed, daily living skills, bereavement counseling, end of life care, and rights and values. An accompanying videotape may help clarify your specific desires in any of these areas.
- 3. **Determine finances.** Use the worksheet in **Activity 7-2:** *Calculating Future Expenses (on page 105)* to determine your young adult's future expenses. Remember to include savings, life insurance, disability income, Social Security, and other government benefits.
- 4. **Prepare legal documents.** Choose a qualified attorney to assist in preparing wills, trusts, powers of attorney, guardianships, living wills, and other planning needs.
- 5. **Consider a Special Needs Trust (SNT).** An SNT holds assets for the benefit of your autistic young adult using the income to provide for their supplemental needs. If drafted properly, assets are not considered income, so government benefits are not jeopardized. Appoint a trustee to administer this trust.

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6. **Use a life plan binder.** Place all documents in a single binder and notify caregivers and family where they can find it.

- 7. **Hold a meeting.** Give copies of relevant documents and instructions to family members and caregivers. Review everyone's responsibilities.
- 8. **Review your plan.** At least once a year, review and update the plan. Modify legal documents as necessary.

These steps were developed by Barton Stevens, ChLAP, founder and Executive Director of Life Planning Services in Phoenix, AZ.

RESOURCES

- ► ABLE National Resource Center: https://www.ablenrc.org/
- Mass Mutual: https://www.massmutual.com/lp/specialcare
- Special Needs Alliance: https://www.specialneedsalliance.org/find-an-attorney/
- Special Needs Answers: https://www.specialneedsanswers.com/
- A Special Needs Plan: https://www.aspecialneedsplan.com

KEY POINTS – CHAPTER 7



Planning your estate can be a poignant, challenging, and daunting process.



Start early and take a step-by-step approach to create important documents for the future care of your autistic adult.

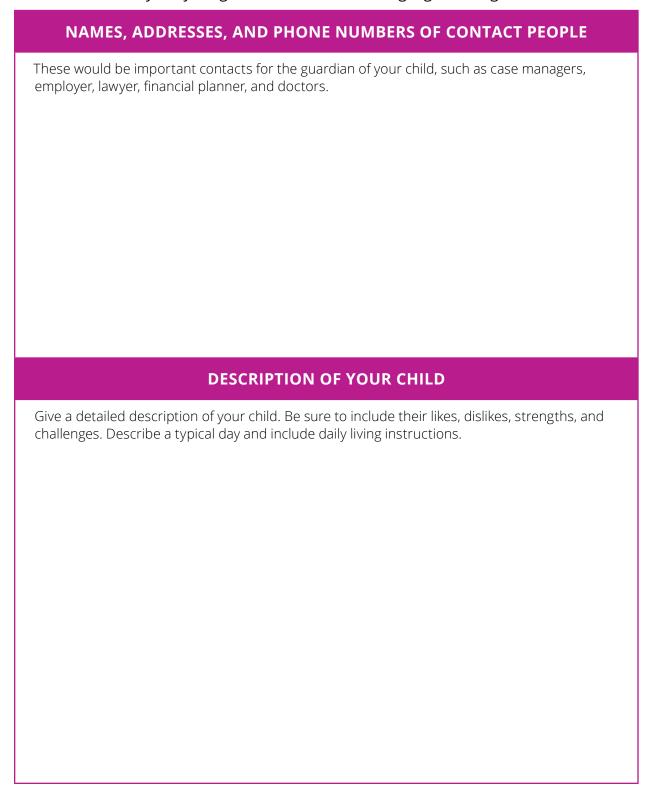


Future planning is a person-centered process; determine the appropriate level of supported decision-making with your autistic young adult throughout this process.

Chapter 7: Handouts/Activities ▷



A letter of intent allows you to state your goals and wishes for your young adult's future after your death. Use this template to brainstorm/outline the major areas in your letter of intent. Involve your young adult and be sure to highlight their goals for the future.



CHAPTER 7: LOOKING AHEAD



For each of the topics in the following sections, include as much information as possible. In each area, state past development, current functioning, and wishes and goals for the future.

HOUSING/RESIDENTIAL			
EDUCATION			
EMPLOYMENT			



HEALTH CARE AND MEDICAL HISTORY
BEHAVIOR MANAGEMENT
Be sure to include treatments that have been or are currently being used, behavior modification techniques that work, etc.
SOCIAL ENVIRONMENT



RELIGIOUS ENVIRONMENT		
OTHER		

ACTIVITY 7-2: Calculating Future Expenses



Start putting together a list of potential costs for the care of your autistic young adult. After you have completed the table below, you will need to give some thought as to how many years you think you will need to prepare for, and multiply the table total by that number. Remember, this is just an estimate. You can use this information as you establish a trust or investments, or investigate government benefits.

TYPE OF COST	AMOUNT PER YEAR
Rent	
Utilities (phone, electricity, water)	
Care assistance (live-in, respite, supervisory)	
Personal care (haircuts, toiletries)	
Entertainment (books, movies, magazines)	
Allowance	
Clothes	
Transportation	
Insurance	
Training (for employment)	
Education costs	
Special equipment	
Medical care	
Treatment	
Groceries/food	
Medicine	
Recreation (vacations, TV, sports, clubs)	

CHAPTER 7: LOOKING AHEAD



ACTIVITY 7-2: Calculating Future Expenses

TYPE OF COST	AMOUNT PER YEAR
TOTAL	
TOTAL	

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SOME FINAL COMMENTS

Successful transition to adulthood is commonly defined as a person having enhanced quality of life and playing a productive role in society, such as through employment or further education. Many autistic students struggle with this transition and continue to need coordinated services and supports.

As you look over the horizon and begin to think about your child's future, keep the following in mind:

- ► Start planning as early as possible, and no later than age 16.
- Set high but realistic goals. It is easy to be successful when you set the bar too low. Think big and have high expectations. Keep your eyes on the prize of your long-term transition goals for employment, living, and/or postsecondary education. Frame all your discussions with reference to those desired outcomes.
- ► To the maximum extent possible, work cooperatively with all involved in the process to the benefit of the autistic young adult.
- ► Remember that transition planning is a process, and first drafts of ITPs are rarely the final draft.
- ► Involve extended family and friends in the process, particularly in the area of employment, as they may have contacts and resources you do not.
- ► Reach out to families who have been through the transition process, as they are often a valuable resource for advice, tips, and knowledge of opportunities.
- ► With reference to community skills, remember to teach where the skills are most likely to be used. For example, it is more effective to teach grocery shopping at an actual supermarket than it is to teach it in the classroom.
- Identify the level of "risk" with which you are comfortable, and then work to maximize independence within that framework. (For example, while you may be uncomfortable with your young adult crossing the supermarket parking lot without close supervision, they may not need the same intensity of supervision inside the supermarket.) As the young adult gains greater independence across tasks and environments, reassess your acceptable level of risk.
- Remember, you are an essential part of this process.
- ► Good, effective transition planning is effortful and time consuming. Enhancing quality of life and independence, with effective transition supports throughout the process, are the ultimate objectives.

Transition planning is not about what is probable. It's about what is possible! Effective transition planning involves high expectations, a bit of risk, tremendous cooperation, and significant effort on the part of the young adult, their family and teachers, school administrators, community members, and adult service providers. The outcome of this concerted effort – enhanced quality of life and independence – is worth the effort.

Adulthood represents a time in one's life where there are increased levels of independence, choice, and personal control. These are all qualities that can and should be part of any autistic adult's life. For many young autistic people and their families, the transition to adulthood is a daunting one, marked by significant changes in available services. Proper planning can ease this difficult transition, however, and ensure that all autistic individuals build the skills and establish the supports that will allow them to take advantage of all that adulthood has to offer.

OAR's Life Journey Through Autism: A Guide for Transition to Adulthood (2nd ed.) provides an overview of the transition to adulthood process for parents who are traveling this path with their child for the first time. Packed with evidence-based tips, resource recommendations, informational handouts, and activities for parents and young adults, the guide includes information about how to:

- Initiate the transition planning process and engage your child, their family and friends, the school's professional staff, and representatives from adult service systems as members of your child's transition team.
- Prepare for the changes in available supports and legal protections that accompany the transition to adulthood.
- Center the transition plan around the interests and strengths of your child.
- Equip your child with the self-determination skills they need to advocate for themselves, problem-solve, set goals, and develop a plan for their own future.
- Prepare your child to navigate higher education, employment, independent living, and other relevant aspects of adulthood.

The Organization for Autism Research (OAR) is a national nonprofit organization dedicated to promoting research that can be applied to help families, educators, related professionals, and autistic individuals find the much-needed answers to their urgent questions.

Special recognition goes to Lori Lapin Jones PLLC for its continued interest in the needs of individuals with ASD. The development and distribution of this guide were made possible thanks to the generous support of Lori Lapin Jones PLLC.

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www.researchautism.org





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