

Life Journey Through Autism: A Guide for Transition to Adulthood

by



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ORGANIZATION FOR AUTISM RESEARCH

Research and resources that help families today!

October 2006

Dear Readers,

In the beginning of 2003, OAR published its first guidebook titled *Life Journey Through Autism: A Parent's Guide to Research*. This Guide serves as an introduction to the world of autism research for parents of children newly diagnosed with an autism spectrum disorder. Subsequently, OAR published two additional volumes in the *Life Journey Through Autism* series, *An Educator's Guide to Autism* and *An Educator's Guide to Asperger Syndrome*. What you now hold in your hands is the next logical progression in this series, *A Guide for Transition to Adulthood*.

This new Guide, *Life Journey Through Autism: A Guide for Transition to Adulthood*, is designed to give parents, teachers, and other education professionals an introduction to the transition to adulthood process. Each of these topics contained herein could merit an entire volume of its own; therefore, this Guide is intended to serve as a starting point for parents and educators as they seek to learn more. Further, given the diversity of expression that constitutes the autism spectrum, it is likely that none of the information presented here will be relevant to all young adults on the spectrum (with the possible exception of the overview of laws in support of transition planning); but hopefully, most of it will be relevant to your son, daughter, student, or client. In that way, *A Guide for Transition to Adulthood* might best be understood as an overview of the myriad questions you will need to answer as part of the transition planning process, while recognizing the answers to those questions will be diverse and individualized, as the spectrum itself.

A few notes on the language used in this Guide: First, you will note that much of the Guide is written for the parent reader (e.g., "*your young adult with ASD*"), but the information contained therein is intended to be useful to a much more expansive readership. It is our hope that educators, transition specialists, administrators, and even employers and other community members will find this Guide accessible, informative, and useful. Second, whenever possible, the individual who is the focus of transition is referred to as the "young adult with ASD." However, there are times when this individual is referred to, from the parent's point of view, as "your child." In these cases "your child" refers only to the status of the individual relevant to his or her parents and is not a reference to age or ability. Also, while the terms "he" and "him" will be used primarily to make reading easier, we are using the pronouns to represent both genders equally.

I would like to take this opportunity to thank all those who have worked to put this book together. As with our other guides, we at OAR have relied on the knowledge and skills of the team at Danya International to make our vision of *A Guide for Transition to Adulthood* a reality, and I thank them for their outstanding efforts. I would also like to thank the members of OAR's staff and Scientific Council who worked with the Danya team to ensure this Guide would be as complete and informative as possible. A very special thank you also goes out to all the parents, professionals and adults on the spectrum who provided comments and feedback that helped us shape the content of this Guide. Your insights proved invaluable as we sought to identify those topics of greatest concern to the community. Thank you.

As you read through *A Guide for Transition to Adulthood*, it is my hope that this resource will help you as you strive to provide a life of happiness, competence, caring and joy for the individuals with ASD in your life.

Sincerely,

Peter F. Gerhardt, Ed.D.
President



SARRC

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Dear Readers,

It is a privilege to be able to collaborate with the Organization for Autism Research (OAR) on this new Guide, *Life Journey Through Autism: A Guide for Transition to Adulthood*. Historically, our overarching public goal at the Southwest Autism Research & Resource Center (SARRC) has been to create a broad range of services in a supportive environment for children with autism throughout their lifetimes—from early screening, interventions, and therapies, to enhancing the school-age academic environment and the related behavioral and developmental challenges that require ongoing attention. This new Guide is one way of continuing to advance this goal.

For the past several years, SARRC has been developing plans to bridge the gap between services for individuals and families impacted by autism and the need for training and education. As children enter their teen years, parents need continued assistance with resources that teach life skills and help them discover their child's unique interests and abilities. Fostering such self-identity will prepare young adults with autism for lifelong inclusion in the community and will maximize their independence, productivity, and enjoyment.

Although many affected individuals can pursue higher education and competitive employment opportunities, others are more limited. Beyond their varied abilities and interests, limited social skills for nearly all individuals with autism make it difficult for them to adjust to the workplace. With proper supports and services, coworkers and job coaches who understand autism, and tools like the *Guide for Transition to Adulthood*, we believe all individuals can be supported to lead happier, more productive and independent lives.

Thank you for caring and for taking the time to read and utilize the *Guide*. Working together, we can improve the quality of life today for all individuals with autism, and build a better and healthier future for them, their families, and our communities.

Warmest regards,

Denise D. Resnik
Co-Founder and Board Chairman

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This publication is the product of a collaborative effort between the Organization for Autism Research (OAR), the Southwest Autism Research & Resource Center (SARCC), and Danya International, Inc. (Danya). OAR and SARCC are dedicated to providing practical information to those living with the challenges of autism—individuals, families, educators, and other professionals. Danya is a health communications company committed to shaping healthier futures for children, families, and communities around the world through the creative use of technology and research.

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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. A transition as momentous as this can seem daunting indeed.

As a parent of a young adult with ASD, however, you have already accomplished so much, from coping with the diagnosis to addressing all the challenges you may have faced over your child's school years. And you will play a much larger role in the transition-related self-discovery and planning process for your young adult with ASD than you would for a neurotypical child. Thoughtful planning, good information, and open communication will help you work with your young adult and his 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.

Beginning at age 16, Federal law requires the development of a transition plan for learners with ASD. However, in practical terms, transition planning should begin sooner and, generally, no later than age 14. Whenever the transition plan is first developed, it is an integral part of the Individualized Education Plan (IEP) and carries the same legal authority. The goal of the transition plan is to facilitate an individual's movement from school to the world of adult work, living, and community participation.

Transition planning, therefore, refers to the 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 his 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 young adult with ASD.

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 post-school activities, including postsecondary education, vocational education, integrated or supported employment, continuing and adult education, adult services, independent living, or community participation
- ◆ **Student-centered**—based on the individual young adult's needs, taking into account strengths, preferences, and interests
- ◆ **Comprehensive**—includes 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 learners with ASDs. Effective transition planning, however, 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 him to apply these skills?*

As Lewis Carroll wrote, “If you don’t know where you are going, any path will take you there.” A good transition plan will be your path to a successful adulthood for your young adult with ASD.

CHAPTER 1: AGENCY HELP/LEGAL INFORMATION

Your young adult is protected by certain laws and policies that will help during the transition process and throughout his life. During your child's school years, the protections offered by IDEA and the IEP, which documented the accommodations and goals, were automatically provided. **The IDEA protections, however, end when your young adult turns 21. Other laws take their place; but, as these are not entitlement laws, it will now be up to you and your child to seek out their protections.** 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 child with ASD 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. The Federal "No Child Left Behind (NCLB)" Act of 2001 also addresses the educational needs of individuals with ASD; however, in the area of transition planning and support, the impact of NCLB remains to be determined and therefore is not discussed here.

Individuals with Disabilities Education Improvement Act (IDEA 2004)

The evaluation, planning process, and subsequent services that your child receives at school are all provided because of IDEA requirements. IDEA provides Federal funding to state and local school systems to provide special education services to eligible students with disabilities. It guides how states and school systems provide services to children with disabilities. 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 employment and independent living
- ◆ **Protect the rights** of children with disabilities and their parents
- ◆ 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 child from the age of 3 to 21. It ensures that your child receives the services he needs in relation to his strengths, challenges, and interests. IDEA requirements are facilitated through the IEP process. By age 16 (at the latest), the IEP process has to include transition planning services that are:

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

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

Section 504 of the Vocational Rehabilitation Act and ADA

While the IDEA requirements may be familiar to you, Section 504 of the Vocational Rehabilitation Act and ADA may be less so. 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, while 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 appropriate services or supports that may be necessary to meet their needs or would be available to students without disabilities. To be eligible for these protections, a child has to have (1) a physical or mental impairment that limits at least one major life activity (e.g., functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working) and (2) a history of this impairment in a major life area. An individual with a diagnosis of an ASD qualifies for Section 504 and ADA. Both Section 504 and ADA take on greater significance in adulthood when the entitlement protections offered under IDEA cease to be in effect. It should be noted that Section 504 and ADA are intended to promote equal access to activities and services and not intended as guarantees of the appropriateness of the services accessed.

IDEA, Section 504, ADA, and the Transition Process

The following lists in this section summarize how these laws specifically impact your young adult during the transition process. Appendix A provides more detailed information.

- ◆ IDEA specifically requires a transition plan once your child reaches age 16. 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 (**Note:** In states that transfer rights to the student at age 18, unless the parent has documentation showing that the individual is unable to offer consent [e.g., parent has applied for, and obtained, guardianship], the adult child, and not the parent, has the right to provide consent to any changes.)
 - Involvement of the child with ASD to ensure his 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 a child with ASD cannot be discriminated against in school and beyond:
- Equal opportunities available to students with disabilities
 - Access provided to supportive services (such as an in-classroom aid)
 - Protections provided for the child post-high school (in college or at work)
 - All programs accessible, including extracurricular activities
 - Protections provided for children with ASD in education and employment

Remember: After high school, IDEA requirements no longer apply, but Section 504 and ADA will continue to provide protections for your child. IDEA accommodations were provided automatically by your school. After high school, it is your child's (or your) responsibility to make sure the appropriate accommodations are requested in college or at a place of employment.

For more information on IDEA, Section 504, or ADA, please see the following resources:

- ◆ www.wrightslaw.com/info/sec504.summ.rights.htm
- ◆ www.ed.gov/about/offices/list/ocr
- ◆ www.ed.gov/about/offices/list/ocr/qa-disability.html
- ◆ www.ed.gov/about/offices/list/ocr/504faq.html
- ◆ www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

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 child's school that are also available to help you make sense of all the available information (see Appendix B). This section highlights various agencies and services that may be useful to you and your young adult as you begin the transition process. **You should be aware that eligibility standards vary widely from state to**

state, and you may find some of the resources listed here unavailable to you, at least initially. If your son is denied services, a good rule of thumb is to always seek an appeal.

Division of Vocational Rehabilitation

Vocational rehabilitation is a nationwide, Federal program for helping people with disabilities to find employment. Each state has a Division of Vocational Rehabilitation (DVR) agency or department, and many have local offices. These agencies can evaluate the individual's strengths and provide training and assistance. They are designed to help people with disabilities to prepare for, find, and keep a job.

During the transition planning process, a DVR representative may participate at one or more transition planning meetings (these meetings are discussed further in the next chapter). These representatives specialize in the services and accommodations that may be useful to your young adult to prepare for the transition post-high school. You can coordinate with the transition planning team to get a DVR representative, or search the Internet for "Vocational Rehabilitation" and your state. You should be aware that, generally, the majority of services offered by state DVRs are time limited and of a less intensive nature than many individuals with ASD may require. Still, particularly for those individuals with Asperger Syndrome or those who demonstrate fairly significant levels of independence, coordinating with your state DVR is a critical first step.

Most state DVR agencies may provide:

- ◆ Diagnostic services
- ◆ Vocational evaluation
- ◆ Counseling
- ◆ Training
- ◆ Medical services and equipment
- ◆ Placement assistance
- ◆ Assistive technology
- ◆ Support services

Administration on Developmental Disabilities

The Administration on Developmental Disabilities (ADD) is charged, under the Developmental Disabilities Act, to ensure people with developmental disabilities and their families receive the services and support for which they may be eligible (and, unfortunately, for which funding may be unavailable). The ultimate goal of ADD is to support the independence, growth, and productivity of people with developmental disabilities. (However, as previously noted, the availability of services through state ADD agencies varies widely from state to state.) Known variously from state to state as "Division of Developmental Disabilities" (New Jersey), "Office of Mental Retardation and Developmental Disabilities" (New York), or "Department of Developmental Services" (CA), to name a few, each state has an ADD charged with providing post-graduation training, education, and support. As such, a representative from your state's developmental disabilities

State ADD agencies should have information on accessing the following services:

- ◆ Respite care
- ◆ Family support
- ◆ Residential assistance
- ◆ Individual support
- ◆ Transition planning
- ◆ Behavioral support
- ◆ Community living
- ◆ Employment

agency should be involved in the transition planning process. The appropriate ADD agencies are listed by state on the following site: www.ddrcco.com/states.htm.

National Dissemination Center for Children with Disabilities

The National Dissemination Center for Children with Disabilities (NICHCY) is a national source of information on disabilities in children of all ages. It includes research-based information, law and policy information (such as on IDEA), and resources. NICHCY has information on disability-related resources by state to facilitate finding local organizations and agencies. Agencies serving individuals with disabilities, chapters of organizations, parent groups, parent training, and more are provided on the site. The Web site also includes research-based information on effective educational practices and services for children with disabilities. Not only is their information available online, but they also have trained information specialists to help you if you prefer to call.

The information and resources that NICHCY offers may be useful to learn more about transition-related resources for your young adult. You can access NICHCY here: www.nichcy.org.

Finding the appropriate agency—and the best person to help you find the right information at that agency—can be challenging and time consuming. We recommend documenting your phone calls for later reference. In Appendix C, we have provided a sample agency Contact Log Sheet that you can use for this record keeping.

CHAPTER 2: TRANSITION PLAN

Transition planning allows you, your young adult with ASD, and his 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 him with the skills necessary to succeed post-high school. A good transition plan will include both long- and short-term goals, identify the necessary supports, and be very 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 son reach your goals successfully and, ideally, with less stress. Therefore, 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.

This information will become part of your young adult'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 young adult. You will work closely with your young adult and the transition planning team at his school to create this guiding plan of action.

Planning to Plan—Reflecting and Gathering Information to Build Your Young Adult'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 will outline 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 worksheets, located at the back of this guide and referenced throughout, will help you with this process.

Involve your child with ASD in the planning process as much as possible. Person-centered planning not only empowers the individual, but it 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 he require to get to one and avoid the other?

As a parent of a young adult with ASD, you may have struggled to adjust your expectations for the future you once dreamed of for your child. But realistic, concrete goals and expectations are the foundation of a successful transition plan. It is important not only to set goals that can be reached by your child, building one on the next, but also to be sure to challenge your child’s growth and leave room to be pleasantly surprised by all that your child can accomplish through this process.

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 son feels about his 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 should start imagining and thinking about what you would like for your young adult and what your child would like for himself as he transitions 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 for your child. Although the concept of quality of life is often as much about the process as it is about the product, neither process nor product should be readily 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 young adult along the way. These constitute the starting point of the transition plan. For overviews of two popular planning protocols, PATH (Planning Alternative Tomorrows with Hope) and MAPs (Making Action Plans), please see:

Falvey, M. A., Forest, M., Pearpoint, J., & Rosenberg, R. (2000). *All my life's a circle: Using the Tools: Circles, MAPs, and PATH*. Toronto, Canada: Inclusion Press.

Pearpoint, J., O'Brien, J., & Forest, M. (1998). *PATH: A workbook for planning alternative tomorrows with hope for schools, organizations, businesses and families*. Toronto, Canada: Inclusion Press.

Personal Interests

As with any adolescent, your child with ASD may have strong, very strong in some cases, personal interests and hobbies. These preferences may be discovered by observing your young adult to see what makes him happy, what he does during downtime, or what items or activities motivate him. In addition, asking yourself or your son (as the central figure in this process) questions like the following can form another jumping off point for considering future educational and vocational options:

- ◆ Are there certain topics or activities of particular interest to your young adult?
- ◆ Are there certain topics, activities, or environmental conditions that your young adult does not like or has difficulty tolerating?
- ◆ What are your young adult's current academic or related strengths or talents?
- ◆ To what extent does your young adult's current skill set match the demands of desirable activities or environments?
- ◆ What are your young adult's dreams?
- ◆ What kind of support will your young adult require to achieve his goals after graduation?
- ◆ What are your hopes regarding this process?
- ◆ What are your fears regarding this process?

Systematically answering these questions will allow you to begin to see the connections between what your child is good at and interested in *now*, and what your child can do in the *future*. Everyone, including you, is more able and willing to work and excel at something that he likes to do, and your child with ASD is no exception. Tailoring transition planning to your child's personal interests will help keep him focused and engaged, while suggesting clear and meaningful next steps toward achieving his goals.

You, your young adult, and the rest of the transition team can work together to complete the worksheet provided in Appendix D to document your child's personal interests and explore his connections to the transition goals.

Strengths (Capabilities) and Weaknesses (Challenges)

You are obviously well aware that there are certain areas in your child's life that he does better in and other areas that are more challenging to him. It is important to list all of your young adult's strengths and challenges, and then to look at them with a new eye. Consider the following:

- ◆ How can these areas be of benefit to your young adult as he transitions beyond high school?
- ◆ What are some areas in which a certain challenge may actually become a strength?
- ◆ How can you help your young adult best capitalize on a specific strength?
- ◆ To what extent do the identified challenges directly impact your son's potential in the workplace or other areas of adult life?

In real life, patterns of behavior previously considered to be potential challenges may actually help in the workplace—things like attention to detail may be especially valued at a quality assurance position, and punctuality is always valued in any workplace. If your young adult is overly interested in sci-fi movies, is there a way in which this can be translated into a strength? If so, how? Take a look at how specific capabilities and challenges that your young adult faces can be turned into assets in the workplace or school. For example:

Marketing Characteristics as Employment Strengths¹

Characteristics	Employment Strength
Nonverbal	May be less likely to verbally disrupt fellow coworkers
Limited social interest	May stay more focused on work and not waste time
Strong sensory preferences	May enjoy working in a quiet office
Is 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 compulsive	May offer excellent attention to detail and quality control

Building on Experience

Building from your child's strengths and challenges, it is useful to think about areas in which he has succeeded or been challenged in the past. The following questions may help in discovering those areas:

- ◆ What areas of instruction have engaged your young adult and been areas of success? What areas were challenging?

¹ Holmes, A., & Douglas, J. (2005). *Meeting the needs of adults with autism*. Paper presented at the ASA National Conference, Nashville, TN.

- ◆ What specific challenges did your young adult face in school and what was done to minimize them?
- ◆ What types of teacher-student interactions were most helpful to your young adult?
- ◆ What environmental conditions were most conducive to learning? What environmental conditions were most disruptive to learning?
- ◆ If there were challenging situations in the past, particularly in the community, how were they most beneficially resolved? What did you or others do that worked well, somewhat well, or not at all?
- ◆ Does your young adult do well in settings with minimal structure? What does he like about these less structured environments?
- ◆ If job experiences have already been provided, how did they go? What could have been done better?

Previous experiences, whether good or bad, are excellent sources of valuable information relevant to the transition planning process. These experiences can illuminate areas where your young adult is more likely to succeed or areas that may not work the best for him. This kind of knowledge is also extremely valuable to the transition planning process.

Aside from the learning value, previous work experience, coupled with comprehensive, community-based instruction, makes it more likely that your young adult will have an easier time accessing 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 having your son volunteer in an area of interest as this, too, can provide information on your child's interests, challenges, strengths, and weaknesses across a variety of tasks and environments. Finding such opportunities may not, at first glance, 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), you will probably find a number of opportunities just waiting to be discovered.

Support Structure

Throughout the life of your child with ASD, a support network of teachers, counselors, friends, family, and others has been important and helpful. 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 someone with ASD, this area requires some closer consideration and attention:

- ◆ What supports will be needed to encourage social interaction and relationships?
- ◆ Can you explore avenues for socializing, such as religious affiliation or other community activity?

Friendships and Relationships

It is important for your child to be taught the **difference between a stranger, friend, acquaintance, boy/girlfriend or family member**, and what types of interactions are appropriate with all of these different types of people.

Strategies:

- ◆ Have a discussion with your young adult about the people they encounter on a daily basis.
- ◆ Create flash cards with pictures on them and label them friend, stranger, acquaintance, etc., along with the roles and interactions associated with each.
- ◆ Develop an activity in which your child will sort and match various work cards/pictures to the appropriate social heading. For example: "Activities I Do With My Friends" versus "Activities I Do With My Family," or "Ways to Greet People I Know" versus "Ways to Greet People I Don't Know."
- ◆ Talk about the different types of people they know and the appropriate way to act around each type.
- ◆ Teach your young adult that he has the right to say "no," and ensure that the means to do so (Augmentative Communication System, Picture Exchange Communication System - PECS™, etc.) is available.
- ◆ Give your young adult different scenarios and ask him to role-play how he would interact with the other person. Consider videotaping these role-plays and using them later for video modeling.
- ◆ Develop a list of rules (a social story might work here), which may be useful to govern these interactions with different types of people.
- ◆ Provide the opportunity to use these new discrimination skills in the environments where they would be of most use (e.g., the mall).

Where possible, it is also important for your young adult to know how to **make and keep friends**.

Strategies:

- ◆ Discuss with your young adult what makes a good friend and what qualities they would like in a friendship.
- ◆ Discuss what qualities they bring to a friendship.
- ◆ Use examples of friendships from books or movies to help facilitate the discussion.
- ◆ Scripts of conversation starters or appropriate topics of discussion could be used.
- ◆ Brainstorm possible places to meet people who could be friends.
- ◆ Discuss different types of friends, such as acquaintances, coworkers, or closer friends.
- ◆ Stress that friendships take time to develop.

- ◆ How well do people in the community (where he is most likely to work, shop, recreate, etc.) know your son? What do they know about him?
- ◆ What supports, if any, are needed to structure time for recreation?
- ◆ Does your young adult have any special interests that others may share? Can these serve as the basis for a social relationship or friendship?
- ◆ Are there service organizations at a local high school or college that coordinate a buddy or mentor program in which same-age peers are paired with individuals with disabilities for social outings and activities?
- ◆ Keep in mind that many of the people involved in your young adult's support network leading up to graduation will not be there after graduation. Developing comprehensive and effective support networks is, almost by definition, an ongoing process.

Step Two: Writing Overarching Goals

Later in the transition process, you will be asked to help determine—and write down—many specific objectives you want your young adult to achieve. But now is the time to think of the broad, overarching goals that qualitatively 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 his 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.

Appendix E is a worksheet that you can complete, together with your child, 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 IEP.

"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 daughter with Asperger Syndrome

Step Three: Anticipating Obstacles

A goal is not meant to be easy to accomplish, and it is not something that will only take a short amount of time to achieve. But each goal can be broken into smaller steps for achievement. As you think of the skills, lessons, materials, and information you and your young adult need to move through the transition process successfully, obstacles may present themselves. For instance, as you created the list of goals for your child, did you think of any skills that he may need to be successful? Or resources that will help him accomplish them? Lack of any key "ingredient" may delay, if not stall, the transition process. So, if certain skills need development, such as effective communication techniques, toileting, table manners, cell phone use, or personal hygiene skills, 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 son with Asperger Syndrome

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 with ASD.

The Transition Plan

Characteristics of a Good 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 young adult’s interests and preferences
- ◆ **Broad-based**—includes 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**—outlines current and future goals, along with the specific strategies for achieving these goals, and changes over time

What the Plan Should Include

Your young adult’s transition plan will be customized based on his needs. In particular, a solid transition plan will include many of the following elements:

- ◆ Assessment of your young adult’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 to 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
- ◆ Identified responsible people or agencies to help with these goals

- ◆ Clarification of how roles will be coordinated
- ◆ A plan for identifying post-graduation services and supports, and obtaining the necessary funding

Writing Measurable Goals Allows Evaluation of Success

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

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 his 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.

Who is Involved

The Transition Planning Team

Key Members

- You and your child with ASD and interested family members
- Your young adult's transition coordinator
- Your young adult's general education teachers, when applicable
- Your child's special education teachers
- DVR or ADD representative
- Administrators
- Psychologists
- Speech and language pathologists
- Other related service providers

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. Adult service organizations (including those listed above) that may provide or pay for post-transition services need to be invited to participate in the development of the IEP transition plan. If they are unable to attend, then the school must find alternative

ways of involving them in planning any transition services they might pay for or provide. Each transition activity should 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. These 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—it is required that your young adult with ASD be involved! The next chapter on “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 very important role in the development of the transition plan. You will need to:

- ◆ Be your son’s primary advocate in the absence of his ability to do so
- ◆ Provide unique and personal information about your child that is not reflected in the school’s or agency’s records
- ◆ Ensure the transition plan is meaningful, practical, and useful for your individual 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 support²

The IEP team relies on your knowledge of your child. 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 adult child with ASD.

Families must be notified ahead of time when an IEP meeting includes development of a transition plan. While many schools will send materials prior to the meeting to help you think about your vision for your child’s future, other schools may not. You will have to initiate the process yourself. The worksheet you completed earlier in Chapter 2 will also help you prepare for this meeting independent of who initiates the meeting.

² Center for Innovations in Education (CISE) at the University of Missouri, Columbia. (1999). *Fundamentals of transition*. Columbia, MO: Author. Available online at www.cise.missouri.edu/publications/funtra_ns/

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. You should record important details during any 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 reflects and meets all of your young adult's needs, and adequate progress is being made to that end. Each team member will be responsible for implementing the specific transition tasks, together with your child with ASD.

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 young adult continues through school to ensure a successful transition to adulthood.

What to Do If You Do Not Agree With Transition Services Provided by the School

Hopefully, the transition process will be a smooth, collaborative effort among all team members supporting your child with ASD. 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 hearing.** A hearing may be held on any matter relating 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, you should make a written request to the person who is responsible for the education program your child attends.
- ◆ **If you believe the educational rights of your child are being violated by nonimplementation of the IEP,** you should make a written request to the person who is responsible for the education program your child attends or your state's Department of Education.

For more information on your rights as a parent, please see the following Web site:
www.fapeonline.org/Parental%20Rights.htm

The IDEA affords parents procedural safeguards if agreement cannot be reached regarding the identification, evaluation, educational placement, or FAPE for your 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.

Early Planning Leads to Success

Planning for your young adult's future and exploring the world of postsecondary education or employment may seem daunting or even a distant prospect. However, starting to plan early and building particular life skills, postsecondary education, or employment goals into your young adult's transition plan/IEP will break the process into manageable steps and help 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 his future. Tailoring the approach to your young adult's specific needs will lead to success.

CHAPTER 3: STUDENT-CENTERED TRANSITION PLANNING

Effective transition planning will impact your young adult's future. **Not only will your young adult's involvement, to whatever extent possible, help guide the team to create purposeful and specific plans for his life after graduation, but, ideally, it will also provide your young adult with an important opportunity to advocate for himself.**

Your young adult may need to learn new skills or further develop existing ones to participate meaningfully in the transition planning process. Your child may require help in determining how to choose goals and in identifying his interests and skills across specific areas. Your child may also need some direction on the social rules about participating in these meetings. Some students with ASD want to lead the meetings directly, and others may just want to be in the room. However, specific communication and advocacy skills will help your young adult be a full participant in this process.

If your 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 his preferences are taken into account.

Prior to the initial and subsequent ITP meetings, you and your child's IEP team can help prepare him as follows (see Appendix F for preparation activities and materials):

- ◆ **Foster self-determination skills**—Speak up for what he wants, what he is interested in, and how he would like to accomplish it. How would he best communicate his desires?
 - For a person to be able to advocate for his needs independently, he must develop an understanding of his strengths and weaknesses, as well as the necessary supports or accommodations he will require. The worksheet in Appendix G will help your child learn important ways to advocate for himself.
- ◆ **Prepare in advance and be sensitive**—If this is the first time your young adult has been involved in this planning process, he may never have seen the IEP document. Therefore, your young adult may not understand what it does or how it makes him different from peers:
 - Explain the general purpose of the planning process and its impact
 - Make sure your young adult 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
 - Involve your young adult in the brainstorming and planning stages; the “Transition Plan” chapter will begin to familiarize your young adult with the areas to be discussed in the ITP meetings

Self-Determination Skills Tips

For visual learners:

- ◆ Draw a map and pictorial representations of where your child is now, what his goals are, and what is needed to reach those goals. This could 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 him participating in his favorite activities.

For verbal learners:

- ◆ Brainstorm to identify your child's strengths and make a list of these 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 interest or observe individual reactions.
- ◆ Provide actual opportunities 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 above assessments are based on a reasonable sample of experience.

- ◆ **Educate your young adult about ASD**—Helping your young adult understand how having ASD may impact him will help him educate others, advocate for himself, and build a realistic transition plan:
 - Discuss in concrete terms the impact of your young adult's ASD symptoms on his education, job choices, and independent living status.
 - Discuss in concrete terms what strengths he brings to the table independent of being a person with ASD.
 - 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.
- ◆ **Educate yourself**—If you are familiar with the process and your rights, then you will create a more comfortable environment for your young adult:
 - You know your child best. You will need to present the transition team with what you think is possible for your young adult, instead of being limited by the options they offer to you.
 - School transition teams may not be aware of all of the opportunities or even the current laws that are applicable to individuals with ASD.
 - You should use the information on activities you compiled in Chapter 2 as a basis.

- ◆ **Communicate, communicate, communicate!**—Keep the communication process open between you, your child, and the ITP team. This will create a positive, goal-oriented transition environment for everyone involved.³

To be an active participant in the transition planning process, your young adult with ASD, **to the best of his ability**, should be able to:

- ◆ Communicate preferences
- ◆ Make choices based on individual preferences
- ◆ Set goals or help choose relevant goals
- ◆ Identify and solve problems that may arise
- ◆ Advocate for himself

These skills can be built into the transition plan as behavioral goals, since it may take time for your young adult to be able to accomplish them. Every one of these skills that your child develops will help make him 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 son's current IEP (e.g., adaptive, social, and behavior).

Resources

Web Sites

Inclusion Press – www.inclusion.com

The Beach Center on Disability – www.beachcenter.org

³ Adapted from ERIC/OSEP Special Project. (2000).

CHAPTER 4: VOCATION AND EMPLOYMENT

Whether a job provides financial support, personal fulfillment, social opportunities, or some combination of these, it is a very important component of adult life. In fact, what one does for a living is often regarded as a defining feature of that person and his role in society. Finding the right employment match for a student with ASD may be challenging, but the rewards can also be great in terms of personal satisfaction in a job well done and as an active, participating, well-regarded member of society.

IDEA Federal special education law requires that school districts help students with disabilities make the transition from school to work and life as an adult. **Although IDEA mandates services and programs while your young adult is in school, there are no federally mandated programs or services for individuals once they leave the school system.** This means that your adolescent will need to make the most of this transition period to develop his life skills and prepare for entering the work force. A broad timeline is presented below.⁴

Early in high school or middle school, with support from both you and the transition team, your child with ASD should:

- ◆ Learn more about the wide variety of careers that exist.
- ◆ Take part in vocational assessment activities in the community through “job sampling” at the actual places of employment.
- ◆ Have the opportunity to learn, by practice and exposure, what his work preferences might be.
- ◆ Identify training needs and effective strategies to address deficits.
- ◆ Be provided with sufficient opportunity to develop basic competencies in independence, self-monitoring, travel training, and life outside the classroom.

While in high school, your young adult, you, and the transition team should:

- ◆ Develop effective disclosure strategies relative to your son’s abilities and needs.
- ◆ Identify critical skill deficits that may impede the transition to post-21 life and provide individualized instruction to minimize the deficits.
- ◆ If applicable, learn the basics of the interview process and practice being interviewed.
- ◆ Learn more about school-to-work programs in the community, which offer opportunities for training and employment through job sampling, youth apprenticeships, cooperative education, tech-prep, mentorships, independent study, and internships.

⁴ NICHCY. (1999). Technical Assistance Guide.

- ◆ Become involved in early work experiences, particularly those emphasizing work-based or on-the-job learning experiences, including volunteering, job sampling (i.e., trying out a job for several hours or days), internship programs, and summer jobs.
- ◆ Identify transportation options for getting to and from work, as well as other community-based options; determine to what extent your young adult will need to develop the skills related to using public transportation.
- ◆ Reassess interests and capabilities based on real-world experiences and redefine goals as necessary.
- ◆ Identify gaps in knowledge or skills that need to be addressed.
- ◆ Contact the DVR or ADD agency and/or the Social Security Administration before age 16 to determine eligibility for services or benefits post-graduation.

Finding a Job

As you are considering a work environment for your young adult with ASD, it will be important to consider both his likes and interests, and also what impact his disability will have on employment. You can use the information you gathered during the earlier assessment part of Chapter 2 to help pinpoint where your young adult's interests and a career might intersect. This section of the guide will discuss other things to consider when finding a job for your young adult.

Vocational Education is One Option

- ◆ Be aware that vocational training may be included as part of the transition services.
- ◆ Vocational education is an organized program that prepares individuals for paid or unpaid employment.
- ◆ Vocational training is a long-term project that begins by developing student awareness of possible career choices and positive work attitudes very early in the transition process.
- ◆ Vocational training is provided by your state's DVR or by school-based vocational programs. Speak to your child's guidance counselor to find out who to call to arrange these services for your child with ASD.

What Kinds of Jobs are Available for Individuals with ASD?

The employment available for an individual with ASD reflects the breadth of the entire job market. Generally, a job may belong to any of three categories that vary in the amount of support they offer the worker with a disability. Ranging from least to most supportive, these categories are competitive employment, supported employment, and secured or segregated employment—although neither is mutually exclusive, and an individual may find employment in more than one category.

Competitive Employment

A full-time or part-time job with market wages and responsibilities is considered competitive. Usually, no long-term support is provided to the employee to help him learn the job or continue to perform the job. The majority of jobs are considered competitive employment, such as waiting on tables, cutting grass, fixing cars, teaching, computer programming, or *writing guidebooks on transitions!* Competitive employment is most often associated with individuals who are already fairly highly skilled, such as an adult with Asperger Syndrome, but may be suitable for other individuals with greater challenges as a function of the task and the environment in which they are to work.

Supported Employment

In supported employment, individuals with autism work in competitive jobs alongside neurotypical individuals. One of the characteristics of this type of employment is that the person receives ongoing support services while on the job. The support is provided as long as the person holds the job, although the amount of supervision may be reduced over time as the person becomes able to do the job more independently. Examples of work environments allowing this type of support often include universities, hotels, restaurants, office buildings, or small businesses.

“Entrepreneurial supports” is a term for a new and particularly innovative type of supported employment. In this situation, a new business is created around the skills and interests of a very limited number of individuals. For example, a young adult who likes to destroy things he does not see as “perfect” could have entrepreneurial support developed for him where he would go to different offices and be their document shredder. For documents they want shredded, they could tear the corner (making it imperfect), and he could gladly feed it into the shredder. Through this program, he could be contracted with a number of offices; going to one or two offices a day to shred documents would be his job. Often, a Board is formed for this new organization that consists of family members, support personnel, community members, and, ideally, at least one member with experience running a for-profit business. This Board helps ensure the organization’s success.

Supported employment, in whatever form it takes, can be funded through state developmental disabilities or vocational rehabilitation agencies, but **families will have to advocate strongly that: (1) supported employment, by definition and statute, is intended for people with severe disabilities; and (2) individuals with ASD can, in fact, work if given the proper support, training, and attention to job match characteristics.**

Secured or Segregated Employment

In secured or segregated employment, individuals with disabilities (not necessarily autism specific) work in a self-contained unit and are not integrated with workers without disabilities. This type of employment is generally supported by a combination of Federal and/or state funds. Some typical tasks include collating, assembling, or packaging. While such programs remain available, critics argue that the sheltered workshop system is more often geared toward the fostering of dependence within a tightly supervised,

nontherapeutic environment than toward encouraging independence in the community at large.

Types of Employment⁵

Secured/Segregated	Supported	Competitive
<ul style="list-style-type: none"> ◆ Segregated ◆ Focus on group learning ◆ Basic skills building ◆ Minimal compensation or unpaid ◆ Behavioral supports in place through job tenure 	<ul style="list-style-type: none"> ◆ Community integration ◆ Ongoing job support ◆ Wages and benefits ◆ Place first, then train ◆ Flexible, wide-ranging supports in place that are personalized ◆ Built-in “safety net” 	<ul style="list-style-type: none"> ◆ Fully integrated into general work force ◆ Requires special skills ◆ Natural supports and natural consequences ◆ Employment supports offered as needed

Job Match

When searching for jobs for your young adult with ASD, it is important to consider the match between your son and a particular job’s social, navigation, and production requirements. This “job match” is the extent to which a particular job meets an individual’s needs in terms of challenge, interest, comfort, camaraderie, status, hours, pay, and benefits. Generally, as people move through the job market over time, they get closer and closer to an ideal job match.

Individuals on the spectrum may not be as motivated by money as their neurotypical coworkers are. So, for the majority of individuals with autism, their motivation to work will be directly related to the extent to which they enjoy the work they are being asked to do. **A good 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, as shown below.

Physical and Social Job Match Components

Components of the Physical Job Match	Components of the Social Job Match
<ul style="list-style-type: none"> ◆ Hours of employment ◆ Acceptable noise levels at the job site ◆ Pay, leave, and other benefits ◆ Acceptable activity levels ◆ Physical requirements of the job (e.g., lifting) ◆ Acceptable margin of error (quality control) ◆ Production requirements 	<ul style="list-style-type: none"> ◆ Acceptable level of interaction with coworkers and supervisors ◆ Clear job expectations ◆ Grooming and hygiene requirements ◆ Demands on communication skills ◆ Personal space available ◆ Phone/vending machine/cafeteria ◆ Coworker training and support ◆ Community status

⁵ NICHCY. (1999). Technical Assistance Guide.

Job Search

Look to see what employment options are currently available in your area. Networking among friends, colleagues, and acquaintances will often be your best job search strategy. Once opportunities are identified, find out what kinds of skills your young adult will need to be successful in those environments. Then, identify what supports your young adult might require to do this job. This exercise can be done in advance of an actual job search to start your thinking about these topics.

Think “job carving.” Remember, the U.S. job market is both highly technical and generally complex, with most employees being required to handle multiple components of a given job. This complexity, however, can play to the advantage of adult learners with ASD through a process referred to as job carving⁶. Job carving is a specialized job development process that recognizes and takes advantage of this complexity by “carving” separate tasks from more complex jobs and, subsequently, combining these tasks into a new job that meets both the needs of the adult learner and the potential employer. Please note that if the needs of both parties are not met, no job can be carved. Effective job carving requires direct knowledge of a potential employee’s abilities, interests, and limitations, along with observational and negotiating skills.

The charts in Appendix I offer more lists and details of possible jobs that both low-functioning and higher functioning individuals on the spectrum may enjoy based on their interests and thinking styles.

The Range of Possible Jobs for Individuals with Autism

- ◆ Reshelving library books
- ◆ Copy shop
- ◆ Restocking shelves
- ◆ Math teacher
- ◆ Stocks and bonds analyst
- ◆ Copyeditor
- ◆ Veterinary technician
- ◆ Factory assembly work
- ◆ Janitor jobs
- ◆ Computer programmer
- ◆ Engineer
- ◆ Book indexer
- ◆ Landscape designer
- ◆ Biology teacher

If you are unable to find anything that seems appropriate for your young adult, you may have to craft something specific to match his interests and skills. You can engage the transition team at school to help with this effort.

⁶ Nietupski, J. A., & Hamre-Nietupski, S. (2000). A systematic process for carving supported employment positions for people with severe disabilities, *Journal of Developmental and Physical Disabilities*, 12, 103–119.

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 young adult will disclose that he has ASD. If he has had assistance securing the job and is being provided with job coaching, the primary question becomes not should one 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 will be necessary. Appendix J provides more information on timing options for disclosure, helping you 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.

Accommodations on the Job

According to ADA, a qualified employee or applicant with a disability is an individual 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
- ◆ Job 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 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 should 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 Appendix K.

Educating Employers and Coworkers

Should your young adult decide to disclose, both employers and coworkers need to be educated about ASDs so that they can offer support when necessary. They will need to be trained on how to best work with your young adult. As part of the transition process, the

transition team can establish what information will be necessary to teach future employers and coworkers about autism, and your young adult in particular. Be sure to emphasize areas where he will need help, along with his particular strengths.

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 him or her 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 young adult with ASD may need assistance or training to perform the job.

Personal Presentation

As an employee, your young adult will represent the company he works for. People also make judgments about an individual based on his appearance. Therefore, it is important that your young adult present himself 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 shaking hands and initiating an introduction
- ◆ Issues related to sexual orientation

Communication Skills

Individuals on the spectrum typically experience great difficulty effectively communicating their wants, needs, likes, or dislikes. As such, instruction in the following communicative skill sets may be appropriate as a function of individual interest and/or ability:

- ◆ Expressing preferences or likes
- ◆ Ordering their own 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 individuals on the spectrum. Complicating this issue for learners with ASD 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 (Hawkins, 2004) that should be covered in your transition plan are:

- ◆ 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 same
- ◆ 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 on your break
- ◆ What to talk about and what not to talk about at work

Resources

For more information on transition as it relates to vocation and other employment options, please consult these resources.

Print Resources

- Grandin, T., & Duffy, K. (2004). *Developing talents: Careers for individuals with Asperger syndrome and high-functioning autism*. Shawnee Mission, KS: Autism Asperger Publishing Co.
- Hawkins, G. (2004). *How to find work that works for people with Asperger syndrome: The ultimate guide for getting people with Asperger syndrome into the workplace (and keeping them there!)*. London: Jessica Kingsley Publishers.
- Newport, J. (2001). *Your life is not a label*. Arlington, TX: Future Horizons.
- Nietupski, J. A., & Hamre-Nietupski, S. (2000). A systematic process for carving supported employment positions for people with severe disabilities. *Journal of Developmental and Physical Disabilities, 12*(2), 103–119.
- Wehman, P. (2006). *Life beyond the classroom: Transition strategies for young people with disabilities*. Baltimore: P. H. Brookes Publishing.

Web Sites

Perner, L., Ph.D. *Marketing a person on the autistic spectrum: Some business school lessons*. Available at www.larsperner.com/ASA2004.ppt

Shore, S. *Survival in the workplace* and *A day in the life*. Available at www.udel.edu/bkirby/asperger/survival_shore.html

Multimedia

Coulter, D. "Asperger Syndrome: Transition to College and Work" [Video]. Available at www.coultervideo.com

CHAPTER 5: POSTSECONDARY EDUCATION

The ITP may include goals for further education, depending on the abilities and interests of your young adult. Working together, you and your child will decide the most appropriate goal, but the inputs for getting there successfully will always be the same: measurable goal, interim steps, clear desired outcome, and proper support. This chapter discusses how to find the right match for your young adult with ASD and how to make sure the process is beneficial for everyone involved.

The transition to a college environment can be difficult for many individuals with ASD. However, with preparation and transition planning, the process can be customized for your young adult, thereby increasing the potential for success.

Preparing for Postsecondary Education—Where to Go and What to Study

If postsecondary education is a goal for your young adult, then your young adult's transition plan should include preparatory work for proficiency tests and assessments, such as the SATs. Also, the transition planning process should help you and your young adult identify his academic strengths to better determine a match between his 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. 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 his transition will be.

Choosing the Right School

Deciding on a college is a milestone for all teens—and your young adult with ASD is no exception. Finding the right match for your young adult with ASD will be key to his success, and many types of programs are available that may accommodate his needs. Consider all the options, set your requirements, and then narrow the field of candidates. You can use the checklist in Appendix H for evaluating colleges as you begin your search:

- ◆ 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 area of interest.
- ◆ Certificate programs may provide good training in an area of interest.
- ◆ Some individuals with ASD may prefer 2-year community colleges to start out because they can live at home yet begin the postsecondary process. However, at the end of these 2 years, he may want to transfer to a 4-year college, which would

require, minimally, some degree of transition planning to identify and address the potential challenges and stressors associated with the new educational environment.

- ◆ You may want to work with a guidance counselor during this process to explore all available options.
- ◆ You may want to visit particular schools and meet with admissions counselors, as they will be the best able to provide you and your young adult with more detailed information.
- ◆ Orientation programs at schools or even the Internet provide a lot of detailed information to 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 services they may offer to help your young adult with ASD. 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. Find out what types of disability-related resources they offer their students, and the process to access these accommodations. By becoming familiar with the system and the services provided, your young adult will be more adequately prepared to advocate for himself, increasing the chances for success.

Self-Advocacy: A Key Skill in a College Environment

Once your son is accepted into college, the role of advocate needs to fall less on you and far more, if not fully, on him. In fact, self-advocacy skills are considered so critical to your child's success in college that many such institutions do not even have a mechanism by which you, as the parent, may advocate on their behalf. As such, it is of critical importance that you prepare your child with self-advocacy skills to help him communicate his needs to the appropriate person in the appropriate manner. (Public universities generally have an office of "Disability Support Services," which is the best place for him to begin.) You can begin the process of promoting effective self-advocacy by reviewing the types and intensities of services and supports that were useful in high school and explaining how they might be beneficial in college.

Additional Skills Your Child Will Rely on in College or Further Education

Organization and time management: Identify these skills (generally referred to as "executive function skills") as goals in your child's transition plan to develop them before college. Organizing assignments, managing time, setting priorities, and breaking projects down into steps are all key skills to assist your child in a postsecondary setting.

Independent living skills: Your child may be living on his own at college, and tasks such as laundry, money management, cleaning, problem solving, living with a roommate, sexual safety, etc., will take on a greater relevance than they had in high school. These skills should be developed before the first day of college with the help of occupational therapists or other service providers available to your child.

Aside from knowing what supports your young adult's needs, he must now effectively communicate these needs. Certain skills or, more accurately, skill sets are critical to the process:

- ◆ How and when to disclose:
 - Your young adult is an expert on his experience of being a person on the spectrum and has a unique opportunity to let others know, to the extent possible and appropriate, what it is like. In addition, it is important for him to understand that disclosure is not an “all or nothing” proposition. Each individual will need to learn both how and when to disclose, in addition to how much information he needs to disclose, in what format, and to what end. Disclosure is a much more complex and personal process than simply saying, “I have autism spectrum disorder.”
 - Even young adults with fewer skills and more complex learning or behavioral challenges can effectively and appropriately disclose by (as one example) using preprinted information cards that they may hand out.
- ◆ A broad understanding of his rights:
 - Discuss with your young adult what rights and protections are afforded to him under IDEA, ADA, and Section 504. Work with him to better define what, in his particular case, may constitute a “reasonable accommodation” in the college classroom.
 - Discuss the rights of others in his classes, dorms, and related social activities. How might your young adult best be able to balance out these often competing agendas?
 - Learning to be a good advocate requires practice. Role-plays, social scripts, and video modeling may be useful here.
- ◆ If you don't ask, you won't know⁷:
 - The social world of college is sometimes confusing, even for your young adult's neurotypical peers. A good advocacy strategy therefore is if you are confused, if you do not understand why something is happening or happened, ask a trusted person.
 - Finding out as much as possible about “new” situations (e.g., attending a first concert) by asking questions beforehand can effectively reduce later problems.

⁷ Shore, S. (Ed.). (2004). *Ask and tell: Self-advocacy and disclosure for people on the autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Setting Up—and Using—Support Services

It is important to keep in mind that the protections once offered by the IEP and transition plan will no longer be available as an entitlement in a postsecondary setting. Universities do not have a responsibility to identify students with disabilities or determine what supports are needed. As noted previously, **this responsibility falls on you and, primarily, your young adult.** As discussed in Chapter 2, ADA and Section 504 protect your child from discrimination based on his disability if disclosed. Your young adult can request accommodations to help him in the college setting to fully participate in classes and other activities. (**Note:** While some colleges or universities may allow the student to complete a form designating a parent as the primary advocate, this is not the norm and, in some cases, may not even be appropriate.)

Here are some suggestions for getting the support your young adult needs from his college⁸:

- ◆ Provide the college (professors, counselors, resident assistants, etc.) with information about ASD and how it affects your young adult specifically, including challenges he faces and strategies that can be used to assist him. Developing a one-page “fact sheet” about ASD and your young adult may be helpful to distribute.
- ◆ Locate an understanding guidance counselor or student services staff member who can advocate for your young adult throughout his college career. This support may come by providing information about services on campus, introductions to groups on campus with shared interests, recommendations of professors who may be more willing to provide accommodations, and others.
- ◆ Suggest that your young adult use the same strategies from high school for help in college, such as written schedules, visual aids, tape recording lectures, and other accommodations.
- ◆ Be sure your young adult discusses the possible options for taking exams with his professor at the start of the semester. Exams may be modified based on your young adult’s particular needs, specifically, by making them untimed or with an extended time.
- ◆ Investigate organizations on campus with which your son may have a shared interest (a gamers club, for example). This may be a place where he can meet a trusted peer to assist with navigating college life.

Further education—whether college or technical school—will open up a whole new realm of possibilities for your young adult’s future. While it will be tough for you to let him go—probably tougher than for the parent of a neurotypical child—it will be important for you to avoid being a hovering parent and to let your young adult have some freedom to explore his new environment. If postsecondary education is a realistic goal for your young

⁸ Sicile-Kira, C. (2006). *Adolescents on the autism spectrum: A parent’s guide to the cognitive, social, physical, and transition needs of teenagers with autism spectrum disorders*. New York: The Berkeley Publishing Group.

adult with ASD, preparation and planning can make this process go smoothly and successfully, and it will help to relieve some of *your* worries.

Resources

These Web-based and print resources provide more information on planning for postsecondary education with a child with ASD.

Books

- Harpur, J., Lawlor, M., & Fitzgerald, M. (2004). *Succeeding in college with Asperger syndrome*. London: Jessica Kingsley Publishers.
- Palmer, A. (2005). *Realizing the college dream with autism or Asperger syndrome: A parent's guide to student success*. London: Jessica Kingsley Publishers.
- Shore, S. (Ed.). (2004). *Ask and tell: Self-advocacy and disclosure for people on the autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Web Sites

- Association for Higher Education and Disability – www.ahead.org
- U.S. Department of Education. *Students with disabilities preparing for postsecondary education: Know your rights and responsibilities*. Available at www.ed.gov/about/offices/list/ocr/transition.html
- Williams, G., & Palmer, A. Chapel Hill TEACCH Center. *Preparing for college: Tips for students with high functioning autism and Asperger syndrome*. Available at www.teacch.com/college.html

CHAPTER 6: LIFE SKILLS

This section discusses various residential options for adults with ASD. In addition, we discuss many of the life skills that may be particularly important to your young adult as he moves toward adulthood. Many of these skills can be addressed in the context of your young adult's transition plan. Early and adequate instruction and preparation in life skills is critical to ensure your young adult is prepared for the transition to adulthood.

Living Arrangements

Adults with ASD can live in many different situations. Because there may be waiting lists, all require early planning and preparation. The following is a list of different types of common living situations, listed from most supportive to least supportive. You may have to create a specific opportunity that best fits your child's needs. For additional information on this topic, please go to the Centers for Independent Living Web site: www.ed.gov/programs/cil/

- ◆ **Supervised group home living**—Typically, three to six individuals live together in an agency-run home. These homes are often staffed by trained personnel who assist the residents with various aspects of living, depending on their needs. Daily organized activities are usually conducted outside the home.
- ◆ **Adult foster care**—Your young adult and possibly another individual could live with a family that has been recruited to assist them with daily living. An agency would oversee the recruitment of these foster caregivers, certify the home, and provide guidance and financial support to the foster family.
- ◆ **Supervised apartment living**—This may be a good choice if your young adult will need some assistance but would prefer to live in a larger apartment complex with neurotypical individuals. Usually, there is an agency staff person or service provider onsite to respond to emergencies and offer limited assistance based on your young adult's needs.
- ◆ **Supported living**—Your young adult would live with extra support in his own place or in your home. It can mean living with another person who has a disability or with a neurotypical individual. The level of care provided by the support person will vary, depending on the needs of your young adult. Needed services and supports are brought to the home instead of the person going out for them.
- ◆ **Independent living**—This is usually in an apartment that would be rented or owned by your young adult. Outside training and support will need to be provided to help your young adult learn to become independent, with an emphasis on the daily living skills mentioned in the next section.

Life Skills

Throughout the transition process, you can continue helping your young adult master many of the life skills associated with independence in the community. Your young adult may have mastered some of these skills, but others may be more difficult and/or quite complex (e.g., driving a car). As always, the best strategy is to prioritize the skills with the highest functional relevance (i.e., the ones he will actually use most often) as part of his transition plan.

Personal Care

Personal care includes a broad set of daily living skills ranging from personal grooming and hygiene to dressing, doing laundry, clothes shopping, and beyond. Help your young adult develop a daily routine inclusive of showering, shaving (if appropriate), applying deodorant, and so forth. Together with your young adult, you can develop and implement task-analyzed chains (steps) for each of these skills (such as, shampoo first, rinse, conditioner second, rinse, wash face with soap, etc.) For dressing, start by helping your young adult pick out appropriate clothes (e.g., by season or activity) for school the night before, and explain why certain types of clothing are more appropriate for certain environments. Then systematically fade yourself out of the process, thereby allowing your young adult to choose his own clothes and complete his grooming tasks without direct supervision. These are important steps toward independent living.

Time Management

Many children with ASD have difficulty staying organized and managing their time effectively. From Velcro-fastened activity schedules to electronic personal digital assistants (PDAs), the tools are available to help your young adult organize his time more effectively and efficiently. Here are some key skills and tips that can help along the way:

- ◆ **Break each day up into chunks:** Assign various tasks for each time period. For example, your child may be in school from 8 a.m.–3 p.m. From 3–4 p.m., he may work on homework; from 4–5 p.m., update his schedule for the next day; from 5–6 p.m., help with dinner, and so on. By *chunking* the tasks, it will help your child stay organized and not get overwhelmed.
- ◆ **Create an individualized activity schedule:** You can help your child put together a “To Do” list of items, including homework, chores, and appointments or leisure/recreation activities. Over time, allow your young adult to do this on his own and check his progress (self-monitoring).
- ◆ **Use an organizer:**
 - **Simple paper organizer:** These organizers can be divided by tabs and include sections for “To Do” lists, homework assignments, and a schedule of

activities. Again, help your young adult establish a routine to check and update the organizer.

- **Electronic organizer (PDA):** If your young adult likes technology, this could be a fun way to learn about organization. Most organizers have calendars and places to create “To Do” lists with pop-up reminders when a task should start. Help your child learn how to use these organizers. Create a routine to update the list and schedule every night.

The development of simple time management and organizational skills will help make your young adult’s transition to adulthood that much easier.

Hobbies and Recreation

Many learners with ASD have certain areas of interest or specific topics that he or she really likes, for instance, math, LegosTM, animals, machines, or a specific videotape/DVD. As part of the transition planning process consider how individual interests might be used to help your son or daughter develop contacts outside of the classroom. Some interests (i.e., hobbies) have related organizations that meet socially—Yu Gi Oh!TM or Magic: the Gathering[®] clubs, science fiction clubs, computer/technology clubs, chess clubs, military history clubs, and so on. Introduce your young adult to these groups and encourage his participation. The ability to meet new people based upon a similar interest and expand his potential support system can be extremely helpful as your young adult gets older.

Sexuality and Relationships

As your child matures, it is necessary to educate him about the changes in his body and feelings. Puberty can be a difficult time for most adolescents, and especially confusing and challenging for an individual with ASD. You and your family should decide on the best way to address these physical and emotional changes with your young adult with ASD, while keeping open and positive methods of communication. This is also an important time to address relationships with members of the opposite sex, as well as appropriate social skills related to friendship, dating, and the difference. As the parent it is important to know what, if any, sexuality education is being provided by the school or any other support organization.

Safety is a very important topic. Interpersonally, your child may lack certain skills that would help him 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. For learners whose verbal comprehension may be limited, discrimination training in the form of stranger/friend differential, good-touch/bad-touch[®], or who can or cannot help you with your menstrual cycle remains important and can often be taught with a combination of picture discrimination and actual role-play instruction.

Daily Living Skills

A variety of daily living skills increases in importance during the transition period. Start early and practice these skills so your young adult will be better able to take care of himself throughout adulthood. Remember, some of these skills may be specifically listed in his transition plan at school. The chart below lists various skill areas that may be helpful for your young adult to focus on during this time period. In Appendices L and M, you will find two worksheets to complete with your young adult on the topic of budgeting and expenses.

Skill Area	Importance	Skill-Building Steps and Activities
GENERAL SKILLS		
Phone Skills	<ul style="list-style-type: none"> ◆ Aids in safety and seeking help ◆ Teaches basic social skills ◆ Increases independence ◆ May be necessary for his job 	<ul style="list-style-type: none"> ◆ 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 him with contacting people
Cleaning and Maintaining a Home	<ul style="list-style-type: none"> ◆ Increases independence ◆ Reduces caregiver's workload ◆ Develops possible job skills ◆ Helps promote social inclusion 	<ul style="list-style-type: none"> ◆ Demonstrate the different types of cleaning products for different areas, such as floors, bathroom, toilet, and other areas; emphasize safety; and show your child the appropriate tools to use with them, such as paper towels, sponges, and gloves ◆ If appropriate, read the directions together ◆ Start your child shadowing you and watching as you clean the house ◆ Next, assign a small job to your child that will be his responsibility
Laundry and Clothing Skills	<ul style="list-style-type: none"> ◆ Increases independence ◆ Teaches responsibility for his own appearance 	<ul style="list-style-type: none"> ◆ Provide instruction on sorting clothes into different types of loads ◆ Explain measuring detergent and using the washing machine and dryer ◆ Demonstrate how to iron and provide supervised practice
MONEY MANAGEMENT		
Bank Services	<ul style="list-style-type: none"> ◆ Allows your child to make more of his own decisions 	<ul style="list-style-type: none"> ◆ Set up a simple checking account and/or savings account for your child to really help with mastering the skills of paying bills, saving money, and budgeting resources

Skill Area	Importance	Skill-Building Steps and Activities
Bank Services (cont.)	<ul style="list-style-type: none"> ◆ Decreases others' ability to take advantage of them 	<ul style="list-style-type: none"> ◆ Arrange a visit to a local bank and meet with a customer service representative with your child to discuss the different banking options and how to access them ◆ Discuss what a checking account is and how it can be used to pay bills and keep track of transactions ◆ Show your child how to write a check and how to record checks in a ledger; a simple "cheat sheet" inserted into a checkbook can also be a useful reminder for your child about how to write checks
Budgeting	<ul style="list-style-type: none"> ◆ Increases independence ◆ Allows your child to make more of his own decisions 	<ul style="list-style-type: none"> ◆ Help your child understand the weekly expenses that he may incur, such as for food, clothes, school supplies, and maybe entertainment ◆ Help your child determine the appropriate amount to spend in each category and then monitor his spending accordingly ◆ Set up a monthly meeting with your child to review his accounts and budget, update them as needed, and monitor his spending and acquisition of these important skills
Credit Cards	<ul style="list-style-type: none"> ◆ Increases independence ◆ Provides financial security in an emergency ◆ Helps to build their credit rating and expands future financial options 	<ul style="list-style-type: none"> ◆ Explain how credit cards work, making sure to cover the finance charges and minimum monthly payments ◆ If you feel a credit card may be useful for your child, get one with a low limit, such as \$500, and help your child monitor his spending and bill paying
TRANSPORTATION		
Public Transport	<ul style="list-style-type: none"> ◆ Increases independence ◆ Provides increased opportunities for work and recreation 	<ul style="list-style-type: none"> ◆ Review the train or bus schedules to help your child determine the appropriate time and route to get him to the designated destination ◆ Review maps of the routes, as well as where your home is located, to orientate your child to the area

Skill Area	Importance	Skill-Building Steps and Activities
Public Transport (cont.)		<ul style="list-style-type: none"> ◆ Quiz your child to see if he has mastered how to determine the appropriate method of transportation to a location ◆ Discuss the cost for using public transportation, as well as how to plan enough time to get to a certain location on time ◆ Give your child a map and a tip sheet with directions, along with important phone numbers to call if needed
Driving	<ul style="list-style-type: none"> ◆ Increases independence ◆ Provides increased opportunities for work and recreation 	<ul style="list-style-type: none"> ◆ Get driving lessons from a driving school or a rehabilitation center that caters to the needs of individuals with disabilities ◆ Highlight other important safety rules, such as not talking on the phone when driving or changing the radio station ◆ Keep important directions in a file in the glove compartment

Health

Various health-related skills, such as fitness, nutrition, and managing doctor's appointments, will help your child as an adult. In Appendix N you will find a handout with tips and ideas for encouraging your child to exercise.

Skill Area	Importance	Skill-Building Steps and Activities
Exercise	Reduces stress, provides opportunities for social interaction, and increases fitness and health	<ul style="list-style-type: none"> ◆ Find an activity, such as running, weightlifting, rowing, or other fun outdoor activities, that may give your child a fitness outlet and also a way to meet people ◆ Try recreation centers in your area that may also have classes or activities of interest to your child ◆ Help your child access these services and appreciate them early so that he will more readily use them as an adult
Nutrition and Cooking Skills	Serve as key daily living skills	<ul style="list-style-type: none"> ◆ Start by asking your child to help out in the kitchen ◆ Assign small tasks, such as measuring or slicing, and work on recipes together as you prepare lunch or dinner

Skill Area	Importance	Skill-Building Steps and Activities
Nutrition and Cooking Skills (cont.)		<ul style="list-style-type: none"> ◆ Compile a list of your child's favorite meals, with detailed recipe guidelines ◆ Show your child basic cooking techniques and how to use appliances; allow him to practice and maybe take notes ◆ As cooking lessons progress, use cookbooks offering step-by-step, illustrated instructions ◆ Highlight positive nutrition habits, and provide your child with a list of appropriate types of food and amounts to eat each day (such as how many vegetable or fruit servings, meat servings, dairy servings) ◆ Create a weekly menu plan to help your child plan nutritious meals, along with a detailed shopping list ◆ Make meal preparation a family experience, sharing the techniques with everyone in your family and also sharing responsibilities
Appointment Keeping/ Time Management	Helps to manage doctor's appointments	<ul style="list-style-type: none"> ◆ Begin by explaining which doctors help with which services, such as the dentist, psychologist, occupational therapist, pediatrician, or other providers your child regularly visits ◆ Give your child a calendar, and begin helping him manage and keep track of appointments ◆ Have your child compile a list of relevant questions for the doctor before any appointment; help him make sure questions are answered once there ◆ Create a toolkit, including calendar, notebook, and list of phone numbers of providers

Conclusion

There are many life skills that will help your child with ASD as he becomes an adult. Preparation and practice are key to learning these skills. You may also have other topics that you want to ensure your young adult has mastered before graduating. Remember to work with your young adult's transition planning team to include the specific challenges or skills on his plan. By building these skills into the transition planning process, the team will help you assemble the appropriate resources to ensure these goals are met for a successful transition.

Resources

- Griffiths, D. M., Richards, D., Fedoroff, P., & Watson, S. L. (Eds.). (2002). *Ethical dilemmas: Sexuality and developmental disabilities*. Kingston, NY: NADD Press.
- Newport, J., & Newport, M. (2002). *Autism-Asperger's & sexuality: Puberty and beyond*. Arlington, TX: Future Horizons, Inc.
- Schwier, K. M., & Hingsburger, D. (2000). *Sexuality: Your sons and daughters with intellectual disabilities*. Baltimore: P. H. Brookes Publishing.
- Sicile-Kira, C. (2006). *Adolescents on the autism spectrum: A parent's guide to the cognitive, social, physical, and transition needs of teenagers with autism spectrum disorders*. New York: The Berkeley Publishing Group.
- Volkmar, F. R., & Wiesner, L. A. (2004). *Healthcare for children on the autism spectrum: A guide to medical, nutritional and behavioral issues*. Bethesda, MD: Woodbine House.
- Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.

CHAPTER 7: LOOKING AHEAD

Planning for your young adult's future doesn't end after transition. While it may be difficult to think about a future when you are not around to care for your young adult with ASD, it is important to begin taking the necessary steps to secure the accommodations and services he will need after your death.

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

People Involved

Begin by identifying key people who can assist in the process. This should include, when possible, your family, your young adult with autism, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, and anyone involved in providing services to your young adult. In some cases, a professional known as a "Lifetime Assistance Planner" can be contracted with 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 student. To locate a Lifetime Assistance Planner, search in your local yellow pages or on the Internet for a Chartered Lifetime Assistance Planner (ChLAP).

Developing a Lifestyle Plan

Lifestyle planning is a way that the family records what they want for the future of their loved ones. This plan can be developed as a letter of intent written by you, the parent or caregiver, and can provide information on your young adult with ASD. This letter can include medical and treatment history, current ability levels, and your hopes and goals for the future. Some topics this letter should cover are:

- ◆ Bathing and dressing preferences, including the type and level of assistance that may be provided and by whom
- ◆ Preferences with regard to music, movies, and related 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 his adult 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 excellent insights for future caregivers and a smooth transition.

Start your letter of intent now, and revise and update it, as needed, to ensure that it remains an appropriate resource for your young adult with ASD. You can find a template for a letter of intent in Appendix O.

Legal Planning

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

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, then the state will usually divide your property and assets equally among your family members, including your young adult with ASD. Because certain government benefits have financial eligibility requirements, leaving your estate to your young adult with ASD may make him ineligible to receive these resources. Therefore, it is essential to prepare your Will and estate to maximize the benefits and protections for your young adult with ASD, ensuring financial stability and continued care. A lawyer can help you put the necessary arrangements into place.

Guardianship

Your Will can establish a guardian for your child with ASD. This person, such as a family member or other trusted individual, can be named in your Will and can serve to help manage the affairs of your child as he gets older. If your child is an adult (age 18 or older) when you pass away, there are different types of guardianships that may be appropriate, depending on the needs of your child. For example, a guardian can be charged with managing the financial and medical affairs for your child, making decisions on his behalf.

Special Needs Trust

Another legal protection would be an SNT. An SNT is a way to provide financial support to your child with ASD to maintain a good quality of life, while allowing him to remain eligible for certain government benefits. An SNT is managed by a trustee, who you appoint on behalf of your child with ASD. Because there are strict rules regarding trusts and government benefits, it is important to work with an experienced lawyer who is familiar with estate planning for individuals with disabilities. There are a number of agencies that 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 now adult child after your death. You can begin by creating a detailed budget of expenses that includes everything from housing 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 a goal for building a trust fund. The worksheet on future expenses, provided as Appendix P, may help you with this process.

Next, you must begin thinking about how to cover the costs and/or fund the trust. There are a number of different resources to consider, including stocks, mutual funds, IRAs, 401(k)s, real estate, home equity, life insurance, and others. Don't forget to include the government benefits, such as social security, that your child may receive. A financial planner can be a very useful person to guide you through this process, especially one who specializes in special needs issues.

Stepwise Preparation Process⁹

The following is a stepwise plan to consider and protect the special needs of people with disabilities:

1. **Prepare a life plan.** Decide what you want for your young adult regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements. You can use many of your goals from transition planning as part of this plan. Development of this plan was discussed in detail in Chapter 2 of this guide.

⁹ The 10-step process was developed by Barton Stevens, ChLAP, founder and Executive Director of Life Planning Services in Phoenix, AZ.

2. **Write a lifestyle plan and letter of intent.** Write down the goals you have 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 located in Appendix P to determine your young adult's future expenses. Determine the resources you will need to cover the costs. Don't forget 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 an SNT.** An SNT holds assets for the benefit of your young adult with ASD and uses the income to provide for his supplemental needs. If drafted properly, assets are not considered income, so government benefits are not jeopardized. Appoint a trustee to administer this trust.
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 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.

Conclusion

Planning your estate can be a poignant, challenging, and sometimes daunting process. Start early and take a step-by-step approach to create important documents for the future care of your young adult with ASD. You will also empower yourself and your family by taking control of the process and making sure it takes into account the best interests of you and your young adult with ASD. Remember, a solid future plan should be detailed enough to provide:

- ◆ Lifetime supervision and care
- ◆ Supplementary funds to help ensure a comfortable lifestyle
- ◆ Ongoing access to government benefits
- ◆ Dignified final arrangements for your young adult
- ◆ A basis for avoiding family conflict!

Some Final Comments

Adults with ASD continue to exist outside the societal mainstream in numbers far greater than is appropriate. Among the many reasons for this “underinvolvement,” the continued failure to adequately and appropriately plan for the transition to adulthood is perhaps the most within our immediate ability to correct. Transition planning is not about what is probable, but 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, his family and teachers, school administrators, community members, and adult service providers. But the outcome, a job coupled with true quality of life, would appear to be worth the effort. As you begin to think about the future for your son, some things to keep in mind include:

- ◆ It is easy to be successful when you set the bar low, so think big and have high expectations.
- ◆ Start planning early, certainly no later than age 16 years.
- ◆ To the maximum extent possible, work cooperatively with all involved in the process to the benefit of the young adult with ASD.
- ◆ Remember that transition planning is a process, and first drafts of ITPs are rarely the final draft.
- ◆ 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.
- ◆ Involve extended family and friends in the process, particularly in the area of employment, as they may have contacts and resources you do not.
- ◆ With reference to community skills, remember to teach where the skills are most likely to be used. 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 him crossing the supermarket parking lot without close supervision, he may not need the same intensity of supervision in the supermarket.) As the young adult gains greater independence across tasks and environments, reassess your acceptable level of risk.
- ◆ Remember, you are a critical part of this process no matter what title you have (parent, speech pathologist, transition specialist, etc.).
- ◆ Good, effective transition planning is effortful and time consuming. Sadly, there are no known shortcuts; however, when it is done well, the outcomes are well worth the effort.

Resources

Web Sites

Bart Stevens Special Needs Planning, LLC

www.bssnp.com/AboutUs.asp

8687 E. Via De Ventura #308

Scottsdale, AZ 85258

480-991-0900

This Web site provides families and professionals with help in planning for the future care, supervision, security, and quality of life for a loved one with special needs.

Autism-PPD Resources Network

www.autism-pdd.net/estate.html

14271 Jeffrey #3

Irvine, CA 92620

This Web site includes detailed information on estate planning in relation to children with ASD.

Autism Society of America

www.autism-society.org/site/PageServer?pagename=MetDESK

7910 Woodmont Avenue, Suite 300

Bethesda, MD 20814-3067

301-657-0881 or 1-800-328-8476

ASA has partnered with MetDESK, a division of MetLife, to assist families of individuals with autism in life planning.

APPENDICES

Appendix A: Comparison of ADA, IDEA, and 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	An education act that guarantees free and appropriate public education	Civil rights law to prohibit discrimination
ELIGIBILITY REQUIREMENTS		
<ul style="list-style-type: none"> ◆ Documented diagnosis of ASD ◆ Qualified for the program, service, or job 	<ul style="list-style-type: none"> ◆ Documented diagnosis of ASD ◆ Aged 3 to 21 	<ul style="list-style-type: none"> ◆ Documented diagnosis of ASD ◆ Qualified for the program, service, or job
RESPONSIBILITY TO PROVIDE A FREE, APPROPRIATE PUBLIC EDUCATION (FAPE)		
<ul style="list-style-type: none"> ◆ 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 	<ul style="list-style-type: none"> ◆ Yes 	<ul style="list-style-type: none"> ◆ Yes
PROTECTIONS PROVIDED		
<ul style="list-style-type: none"> ◆ 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 	<ul style="list-style-type: none"> ◆ 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 	<ul style="list-style-type: none"> ◆ Requires notice to parents regarding identification, evaluation, placement, and 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 a student
STEPS/ACTIONS		
<ul style="list-style-type: none"> ◆ 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 	<ul style="list-style-type: none"> ◆ With parental consent, an individualized evaluation must be conducted using a variety of technically sound, unbiased assessment tools ◆ Reevaluations are conducted at least every 3 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 	<ul style="list-style-type: none"> ◆ 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 his evaluation information and placement options ◆ Provides for periodic reevaluation ◆ Parental consent is not required for evaluation or placement

Appendix B: State and Federal Agencies for Transition Assistance

Division of Vocational Rehabilitation (DVR)	
Description	Services Offered
<p>Designed to help people with disabilities obtain, maintain, and/or improve employment</p> <p>A federally funded program administered by individual states</p>	<ul style="list-style-type: none"> ◆ Participate in transition planning meetings (when planning for work post-high school) ◆ Assessment of 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 ◆ Obtaining assistive technology (e.g., special computer software, visual aids) to use in the workplace
Administration on Developmental Disabilities (ADD)	
Description	Services Offered
<p>Provides services to individuals with developmental disabilities to help them achieve independence, productivity, inclusion, and community involvement</p> <p>Federal agency responsible for administering the Developmental Disabilities Act; each state has its own developmental disability agency or council</p>	<ul style="list-style-type: none"> ◆ Respite care ◆ Programs for families ◆ Residential living services and support ◆ Transportation ◆ Behavioral support ◆ Legal advice and services ◆ Advocacy ◆ Transition planning services ◆ Employment support
National Dissemination Center for Children with Disabilities (NICHCY)	
Description	Types of Services
<p>Web-based information and toll-free number</p> <p>Provides detailed information and resources related to disabilities in children and youth</p>	<ul style="list-style-type: none"> ◆ Specific information on different types of disabilities ◆ Questions and answers about IDEA and other disability-related laws ◆ Database that provides easy-to-access information on effective interventions ◆ Information on IEPs and transition planning ◆ Educational rights and services for children with disabilities ◆ Organizations and resource contacts in each state ◆ A toll-free number (with bilingual services) to talk to an information specialist

Appendix C: Contact Log Sheet

Agency/Organization	Contact Information*
* Individual you spoke with, address, phone number, and e-mail	

Date	Notes	Follow-up Information

Appendix D: Dreams for the Future

Begin by writing your dream for the future in the biggest circle in the center. Then, fill in the information in the outer circles. List as many ideas as you can come up with! Then, in each smaller circle, put a box around what you think are the most important ones. Draw a line into the big center circle, making a web of those 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 “goal circle.” Revisit this web of strengths as you get closer to transition so you can keep track of your progress.

The diagram consists of a central circle and four surrounding circles, all connected by arrows pointing outwards from the center. Each circle contains horizontal lines for writing.

- Central Circle:** **My Dream for the Future**
- Top-Left Circle:** **My Interests**
- Top-Right Circle:** **My Strengths (at school, home, work)**
- Bottom-Left Circle:** **How I Prefer to Communicate with Others**
- Bottom-Right Circle:** **My Accomplishments**
- Bottom-Center Circle:** **Things Needed to Get There**

Appendix E: Documenting Overarching Goals for Transition

As you begin planning for your young adult's transition post-high school, this worksheet may be useful to brainstorm together on goals for his or her future. Have your young adult circle the bold-faced goals that seem realistic and are of interest to you both, 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 [for fun]

To do these things, I need to

In 5 years, I see myself practicing my faith by

To practice my faith, I need to

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

Appendix F: Preparing for the Transition Planning Meeting

You can prepare for your young adult's transition planning meeting in many ways. The lists below highlight some preparation activities and materials to bring.

Do Ahead of Time

Prepare documentation:

- ◆ Prepare questions for the team; list in order of priority
- ◆ Complete Appendix E or create a document with the goals you have for your child's future
- ◆ Prepare a preliminary list of services you think may be appropriate

Review background information:

- ◆ Review your child's previous Individualized Education Plans (IEPs)
- ◆ Review your rights and the laws related to transition planning

Logistics – attendees and location:

- ◆ Find out who will be attending the meeting
- ◆ Invite additional participants to attend the meeting (any agency or advocacy individuals who may be helpful)
- ◆ Confirm meeting time and location

Prepare with your child:

- ◆ Discuss the meeting with your child, addressing his questions and how he can be involved at the meeting
- ◆ Practice any skills your child may need help with

Set goals and have a strategy:

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

Bring to the Meeting

- ◆ List of questions
- ◆ Appendix E or goals for your child
- ◆ Notebook and pen
- ◆ Tape recorder (inquire 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 last IEP document

Appendix G: Developing Self-Advocacy Skills

Self-Advocacy—standing up for yourself to get the resources YOU need to succeed

This worksheet will help you practice some common situations where you may need to use your self-advocacy skills.

Tip #1: 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'd like accommodations for taking the test in a different way. In three sentences or less, try writing what you would tell that professor.

Tip #2: Use "I" statements. You want to be clear that your opinion or needs are your own.

Example: "I believe I need extra time to take tests in this class because..."

Write an "I" statement of your own here:

Tip #3: Ask for feedback from the person you are speaking to. It is important to make sure he understands what you are saying and that you understand his 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 #4: Be relaxed. There is nothing to be nervous about; you are entitled to certain services under the law. Stay calm and take your time.

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: 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 #6: 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're calling a college admissions office. Write down three questions you would like to ask the admissions staff about the accommodations commonly offered.

Tip #7: Have a support system. You may have a trusted counselor at the university, a friend, or a parent who can help you. You can brainstorm ideas with them, practice your advocacy skills, and have them with you as a 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 #8: Know your ADA, IDEA, and Section 504 rights. Review Appendix A of this guide if you need a refresher.

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

Tip #9: Educate others. You are an expert on how ASD 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. He has asked you to explain what ASD is and how it affects your life. Explain this to him in three sentences:

Appendix H: Comparing Colleges

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

Name and Location of Institution										
										Four-Year College
										Two-Year College
										Vocational/Technical College
										Small Student Population
										Dorm Living Option
										Living at Home Option
										Offers a Major That Interests Student
										Clear Policies to Help Students with Disabilities Receive Services and Accommodations
										Financial Aid Options Available
										Accommodation Letters Provided to Professors Regarding Students and ASD
										Extra Fee for Special Education Services
										Written Materials Available on Their Special Education Services
										Detailed Orientation Process
										Advisors to Assist Student in Planning Course Selection
										Technology Provided to Assist Students
										Career Counseling Offered
										Clear Admissions Requirements Provided
										Has Experience with Students with ASD
										Clear Instructions Provided on Required Documentation to Receive Disability Services
										Part-Time Option for Taking Classes Offered
										Interesting Extracurricular Activities and Organizations Offered
										Courses Offered in a Variety of Modalities (in-class, Web-based, and hands-on)
										Tutoring Available

Appendix I: Job Ideas

Possible Jobs for Lower Skilled Individuals With Autism	
Reshelving library books —Can memorize numbering system and shelf locations	
Factory assembly work —Especially if the environment is quiet	
Copy shop —Running photocopies; 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 —Water plants in a large office building	
Possible Jobs for Higher Skilled Individuals with Autism and Asperger Syndrome	
Often, individuals with high-functioning autism/Asperger syndrome tend to be specialized in how they think. There are three common types of thinking styles: (1) visual thinking or thinking in pictures; (2) music and higher math; and (3) nonvisual, verbal thinkers (Grandin, 1999).	
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
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. (2004). *Developing talents: Careers for individuals with Asperger Syndrome and high-functioning autism*. Shawnee Mission, KS: Autism Asperger Publishing Co.

Appendix J: When (*and If!*) to Disclose

WHEN TO DISCLOSE		
On-the-Job Application/Cover Letter		
Pros	Cons	Other Considerations
<ul style="list-style-type: none"> ◆ Allows applicant to relax about employer possibly finding out. ◆ Enables the employer to decide if autism is a concern. 	<ul style="list-style-type: none"> ◆ May exclude your child before having a chance to present himself and demonstrate his strengths and capabilities. ◆ No way of knowing if the reason he was not hired had to do with his diagnosis. 	<ul style="list-style-type: none"> ◆ Immediate disclosure may make finding a job more difficult; however, when your child does find employment, he is less likely to have autism-related problems on the job.
At the Interview		
Pros	Cons	Other Considerations
<ul style="list-style-type: none"> ◆ Offers the opportunity to answer any questions about autism and its impact on the job. ◆ Discrimination is less likely in person. 	<ul style="list-style-type: none"> ◆ Too much emphasis on diagnosis may distract from discussion of your child's strengths and abilities. 	<ul style="list-style-type: none"> ◆ Your child will need to be comfortable answering questions and leading a discussion about autism and how it affects him specifically.
After Hired but Before Beginning Work		
Pros	Cons	Other Considerations
<ul style="list-style-type: none"> ◆ If the hiring decision is changed and you are sure your child's ASD will not interfere with his ability to perform the job, legal action is warranted. 	<ul style="list-style-type: none"> ◆ Employer and personnel department may distrust your child and feel as though they should have been told beforehand. 	<ul style="list-style-type: none"> ◆ Will need to evaluate your child's ASD to determine its impact on the specific job duties and then be able to explain specifically that it will not interfere with his performance.
After Beginning Work		
Pros	Cons	Other Considerations
<ul style="list-style-type: none"> ◆ Your child will have the chance to prove himself before disclosing. ◆ He will be able to discuss autism with his peers at work. ◆ Your child may be protected by law if disclosure affects employment status but ASD does not keep him from performing his job safely. 	<ul style="list-style-type: none"> ◆ Your child may be anxious at work. ◆ Employer may be upset that you did not tell them sooner. ◆ Could impact his interaction with peers. 	<ul style="list-style-type: none"> ◆ It may be harder for your child to disclose the longer he waits. ◆ It may be unclear who he should tell.

WHEN TO DISCLOSE		
After a Problem		
Pros	Cons	Other Considerations
<ul style="list-style-type: none"> ◆ Your child will have the chance to prove himself before disclosing. 	<ul style="list-style-type: none"> ◆ Employer may be upset that you did not tell them sooner. ◆ Could perpetuate myths and misunderstandings about autism. 	<ul style="list-style-type: none"> ◆ May be difficult to re-establish trust with coworkers.
Never		
Pros	Cons	Other Considerations
<ul style="list-style-type: none"> ◆ Your child's employer cannot provide accommodations or respond to difficulties due to autism unless they are aware of your child's diagnosis. 	<ul style="list-style-type: none"> ◆ Risk of being fired for reasons that his employer may have been more understanding about if they were aware. ◆ Could lead to myths and misunderstandings about autism. 	<ul style="list-style-type: none"> ◆ As you and your child become more confident that his performance will not be hindered by having an ASD, the issue of disclosure becomes less important.

Adapted from Aase, S., & Smith, C. (1989). *Career development course sequence*. University of Minnesota, Disability Services.

Appendix K: List of Reasonable and Common Job Accommodations

ADA guarantees that your young adult may request certain accommodations in the workplace. Your young adult may need others, depending on his needs and where he is working. These accommodations may include:

- ◆ Pictures or drawings of the task
- ◆ Templates of forms or documents
- ◆ A note taker
- ◆ A voice recorder
- ◆ Written instructions
- ◆ Daily checklists
- ◆ Written or verbal reminders
- ◆ Written or picture instructions next to machines, such as postage machine, copier, printer
- ◆ Minimal clutter in the work environment
- ◆ Minimal noise in the work environment (such as no radios or music)
- ◆ Large tasks broken down into small steps
- ◆ A “Where to” guide for resources or coworkers
- ◆ A timer or alarm as a reminder
- ◆ Additional hands-on training
- ◆ Headset for telephone or a speaker phone
- ◆ Multiple breaks
- ◆ Performance feedback presented visually (charts, diagrams)
- ◆ Mentor or job coach
- ◆ Information for coworkers about ASD
- ◆ His own desk or workspace
- ◆ Checklist for completing task
- ◆ Timelines for completion of task
- ◆ Assignment of one task at a time
- ◆ Training on appropriate workplace behaviors (e.g., interacting with customers)
- ◆ Notice before changes (such as rearranging supply closet or change in job-related work)
- ◆ Consistent supervision by one person
- ◆ Prioritization of tasks
- ◆ Regular feedback on performance (positive and constructive)

Appendix M: Sample Monthly Budget

In addition to keeping track of his monthly expenses (using Appendix L), your young adult will also benefit from maintaining a monthly budget. Sit down with him to brainstorm different categories to include in the budget (or use the ones provided) and determine a monthly amount for each category. At the end of the month, total all of the income and expenses for the various budget categories based on Appendix L. Did he go over the budgeted amount? Why? What can be done differently this coming month?

Category	Monthly Budget Amount	Monthly Actual Amount	Difference
INCOME			
Allowance			
Miscellaneous Income			
INCOME TOTAL			
EXPENSES			
School Supplies			
Lunch			
Snacks			
Entertainment (movies, arcade, etc.)			
Cell Phone			
Clothes			
Transportation Costs			
Savings			
Gifts			
CDs or Music			
Toiletries			
Games			
Hobbies			
Internet			
Magazines			
EXPENSES TOTAL			

Appendix N: Information About Exercise

Exercise can be an important stress management tool for your young adult, as well as a great way to stay healthy and relax! Use these tips and tricks to help motivate your young adult to get into an exercise routine.

Types of Exercise

- ◆ Jogging
- ◆ Swimming
- ◆ Team Sports (basketball, volleyball, hockey, soccer, etc.)
- ◆ Biking
- ◆ Aerobics
- ◆ Yoga
- ◆ Pilates
- ◆ Boxing
- ◆ Karate
- ◆ Tai Chi
- ◆ Walking
- ◆ Skating
- ◆ Weightlifting
- ◆ Jumping rope

Tips and Motivators

- ◆ Join a gym as a family, and make it a family activity
- ◆ Coordinate a block party, and play soccer or kickball
- ◆ Reward your young adult for taking the time to exercise with something that he really gets excited about
- ◆ Buy him new workout clothes
- ◆ Make it a game or competition; for example, whoever can make the most baskets wins a prize!
- ◆ Get your young adult a favorite book that he can read while on a stationary bike
- ◆ Use fun workout tapes/DVDs
- ◆ Take a yoga class together
- ◆ Teach your young adult about the benefits of exercise (physical, well-being, stress reliever)
- ◆ Provide a yummy, healthy snack after the activity (granola bar, apples with peanut butter, etc.)

Appendix O: Template for Letter of Intent

A letter of intent allows you to state your goals and wishes for your young adult's future after your death. This template highlights the major areas to cover in your letter of intent. You may want to work with your young adult to be sure to highlight his goals for the future.

Names, Addresses, and Phone Numbers of Contact People

These would be important contacts for the guardian of your child, such as case managers, employer, lawyer, financial planner, doctors.

Description of Your Child

Give a detailed description of your child. Be sure to include his likes, dislikes, strengths, and challenges. Describe a typical day.

For each of the topics in the following sections, include as much information as possible. In each area, state:

- ◆ Past development
- ◆ Current functioning
- ◆ Wishes and goals for his future

Housing/Residential

Education

Employment

Medical History and Care

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

Appendix P: Calculating Future Expenses for the Care of Your Young Adult with ASD

Use the worksheet provided to start putting together a list of potential costs for the care of your child with ASD. 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 the care of your young adult with ASD, and multiply the table total by that number. Remember, this is just an estimate. You can then use this as you establish a trust, investments, or investigate government benefits.

Type of Cost	Amount per Year
Rent	
Utilities (phone, electricity, water)	
Care assistance (live in, respite, supervisory)	
Personal care (hair cuts, 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)	
Other	
TOTAL	

