

# CHAPTER 11

## TRANSITIONING TO ADULTHOOD: PROMOTING INDEPENDENCE AND SELF-DETERMINATION

### In this chapter, you will learn about:

- ASD and adulthood.
- Self-determination and human rights.
- Transitioning from high school: the transition plan.
- Adults with ASD and residential choices.
- Employment.
- Postsecondary education.
- Leisure, recreation, and integration into the community.

### ASD AND ADULTHOOD

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ASD is a lifelong developmental disorder with core deficits in language, socialization, and behaviors existing across the life span (Eaves & Ho, 2008; Hendricks & Wehman, 2009; Interagency Autism Coordinating Committee, 2011). Prevalence studies estimate that approximately 1% of children in the United States have ASD, which translates to approximately 730,000 individuals 21 years of age or younger (Centers for Disease Control and Prevention, 2009; Kogan et al., 2009). Although there are no current prevalence studies for adults with ASD (Autism Society of America, 2007), undoubtedly, there will be a very large number of adults with ASD leaving the public schools and accessing community supports. For instance, it is estimated that more than 380,000 people will need adult services by the year 2023 (Davis, 2009). Gerhardt and Lainer (2011) describe the upcoming needs of adolescents and adults with ASD as a “looming crisis of unprecedented magnitude” (p. 37).



Transition planning needs to occur as early as possible.

There is a growing body of research addressing early intervention and the needs of children with ASD. Unfortunately, far less research addresses the life course and best practice for supporting individuals with ASD during adulthood (Eaves & Ho, 2008; Inter-agency Autism Coordinating Committee, 2011). ASD is a lifelong disorder and needs are likely to change throughout the life span. The goals of least restrictive environment and inclusion are integral to a high quality of life throughout the life span. Given that ASD is a heterogeneous disorder, individuals with ASD have unique needs and may require a wide range of supports throughout their lives (Hendricks & Wehman, 2009).

Intentional and well-coordinated planning and implementation of plans is critical for effective transitioning from educational to community supports. In addition, support for realizing self-determination and the ability to express choice should be part of educational planning. Successful transitioning to adulthood depends upon identifying goals and providing foundational skills to realize those goals for individuals at all ability levels.

## SELF-DETERMINATION

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### *Self-Determination Recognized as a Fundamental Human Right*

The ability to make choices about one's life is considered a fundamental human right and is formally recognized on a federal and international level. Rights of **self-determination** for citizens of the United States are documented within the United States Constitution. Furthermore, Public Law 94-142 (IDEA), **Section 504 of the Rehabilitation Act**, and the Americans with Disabilities Act are examples of federal laws that specifically protect such rights of people with disabilities in the United States (Baker & Tabor, 2006). In 1971, the United Nations adopted the "Declaration of the Rights of Mentally Retarded Persons," affirming that people with intellectual

disabilities have the same rights as other people (United Nations General Assembly, 1971).

Self-determination is more than deciding what food to eat or clothes to wear. Rather, it refers to making *meaningful* decisions about your life based on an understanding of yourself and real-world experiences (Wehmeyer & Kelcher, 1996), and without undue influences or interferences (Wehmeyer, 1996). Examples of expressions of self-determination are presented in Table 11.1.

**Table 11.1** Examples of Expressing Self-Determination

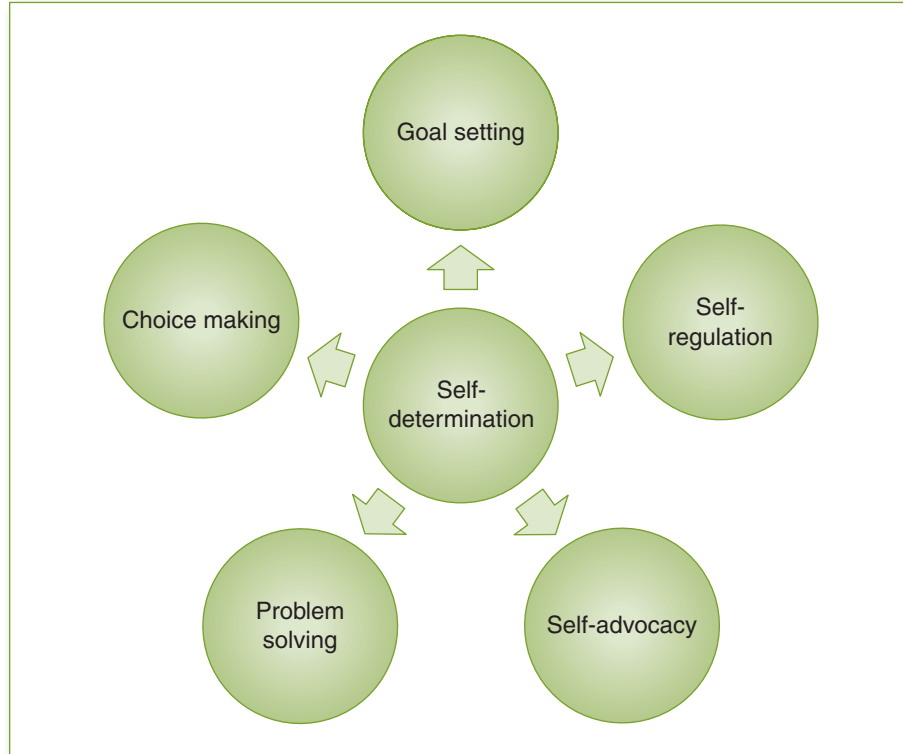
- Choosing where you would like to live as an adult.
- Choosing with whom you would like to spend your time.
- Choosing what type of job and/or postsecondary education you would like to pursue.
- Choosing recreation and leisure activities you would like to spend time doing.

These examples of self-determination have implications for identifying skills needed to be successful in the community, providing opportunity for learning those skills, and determining other supports necessary to realize these goals. Self-determination goes hand-in-hand with the autism rights movement, which advocates for helping people with autism learn to be successful in community, but embracing choice and individuality (Solomon, 2008).

### ***Facilitating the Development of Self-Determination***

In addition to the philosophical and ethical reasons for promoting and supporting self-determination, individuals with ASD demonstrating strong self-determination have better outcomes as adults (Wehmeyer & Schwartz, 1998; Wehmeyer et al., 2010). In fact, self-determination contributes to an overall higher quality of life (Schalock, 1996). However, the development of self-determination does not occur in a vacuum but is facilitated by individuals and policies that provide supports and reduce barriers (Abery & Stancliffe, 1996). Furthermore, research indicates that instruction can be effective in promoting self-determination behaviors (Cobb, Lehmann, Newman-Gonchar, & Morgan, 2009).

Wehmeyer and colleagues (2010) describe areas to target for instruction to promote self-determination in individuals with ASD. Depending on the student's ability level instruction may target goal setting and attainment, choice making, problem solving, self-advocacy, and self-regulation. These components of self-determination are depicted in Figure 11.1 and described further below.

**Figure 11.1** Components of Self-Determination

- **Goal setting and attainment**—Learning to break complex goals into smaller component parts.
- **Choice making**—Providing opportunities for students to make choices throughout their day using visual prompts when needed.
- **Problem solving**—Learning how to identify that a problem exists and define what that problem entails, listing potential solutions, and considering what the outcomes may be for proposed solution. Predicting possible outcomes, particularly those involving the reaction of others, is often difficult for individuals with ASD. Social-emotional interventions addressing these skills (discussed in Chapter 10) may be an important component of this instruction. For instance, students can be taught to use **social autopsies** to analyze social problems, determine who was impacted and

how to correct the error, and develop a plan to prevent the error from occurring again (Simpson, 2005).

- **Self-regulation**—Learning how to manage one’s own behavior involves observing and evaluating oneself, setting target goals, and providing self-reinforcement for achieving those goals. Self-regulation is a type of cognitive behavior modification.
- **Self-advocacy**—Teaching students to advocate for themselves. Provide examples and models for how they can address situations that they feel are unfair. Provide feedback and reinforcement for successful attempts. Help students to establish their own class schedule, asserting their preferences, and meeting with teachers to address questions or concerns helps develop self-advocacy skills. Self-advocacy skills are dependent upon communication skills. Students with limited expressive language can be taught to self-advocate using augmentative communication systems (Kleinert, Harrison, Fisher, & Kleinert, 2010). Speech/language pathologists can create individualized education plan (IEP) goals that specifically address self-advocacy skills (Kleinert et al., 2010).

### **Person-Centered Planning**

**Person-centered planning (PCP)** is an approach to determining and setting goals that focuses on the hopes, dreams, and desires of the individual and his or her family (Klim & Turnbull, 2004). PCP is a strategy that can be used to support self-determination during the transition from secondary school to the community. A PCP team consists of the person with a disability, family members, educators, professionals involved in providing current or future supports, and others that are part of the student’s life (e.g., friends, community workers, and neighbors).

An example of PCP is Making Action Plans, or MAPs (Forest & Lusthaus, 1990; University of Kansas, 2002). A facilitator works with the individual with a disability to tell his or her “life story.” Next, the individual with a disability identifies short-term and long-term goals and dreams, assisted by a supportive team outlining time lines, resources, and supports available to reach the goals and the steps required to get there. MAPS may be an especially useful PCP tool for individuals with ASD, because each step is visually presented. Thus, the end result is a graphic representation of a plan of action, steps needed for achieving goals, and supports available.

### ***Cultural Issues Related to Self-Determination***

Although behaviors associated with self-determination (such as asserting preferences, setting goals, and self-advocacy) are linked to positive outcomes in adulthood, one's understanding of self-determination reflects cultural values. For instance, asserting one's independence, expressing individuality, being future oriented, and fulfilling desires of self versus the needs of a group are culturally laden values (Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005; Zhang, Landmark, Grenwelge, & Montoya, 2010). Thus, families from non-Western and collective cultural orientations may be less familiar, and possibly less comfortable, with the concept of self-determination embraced by public institutions (Smith & Routel, 2010; Zhang et al., 2010).

Furthermore, families from diverse cultural perspectives may have different understandings of what it means to have a disability and the family's role of caring for a family member with a disability (Garcia et al., 2000; Rueda et al., 2005). Language barriers may provide additional barriers to addressing issues of self-determination (Rueda et al.). For instance, Blue-Banning, Turnbull, and Pereira (2002) conducted focus group interviews with Hispanic parents of youth and young adults with developmental disabilities. Focus group results reflected a diversity of goals for their children. Focus group themes included a desire for acceptance by family and community and expectations of their adult child living at home with them until marriage. PCP and other planning strategies that consider the cultural context of the family are likely to support positive outcomes when transitioning from public school (Smith & Routel, 2010). **Cultural reciprocity**, which involves developing collaborative relationships by respecting and striving to understand differences in perspectives and values, contributes to culturally sensitive services (National Center on Secondary Education and Transition, 2005).

## **TRANSITIONING FROM HIGH SCHOOL**

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### ***Research on Evidence-Based Practice***

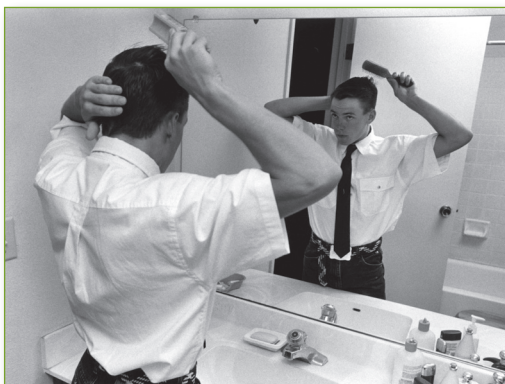
There is limited research on the transition from school to community living and employment for youth with ASD (Hart, Grigal, & Weir, 2010; Hendricks & Wehman, 2009; Seltzer et al., 2004). Furthermore, although evidence-based practices are required in the public school system, there is limited empirical research about interventions that promote successful transitions to community living (Wehman, Smith, & Schall, 2009). Based on a review of available

research on transition planning, Hetherington and colleagues (2010) suggest five components including: (1) student involvement, (2) parent and family involvement, (3) personalized relationships between students, educators, and families, (4) a meaningful curriculum driven by individual goals rather than standardized academic goals, and (5) student-oriented outcome-based goals. Overall, Hetherington and colleagues (2010) stress that transition planning needs to occur much earlier, include significantly more involvement of families and the student, and include implementation activities and outcome measures to support reaching transition goals.

Poor transition planning and implementation can result in less support and a reduced quality of life after high school. In fact, support characteristics provided in adulthood are a better predictor quality of life than severity and type of disability (Renty & Roeyers, 2006). To investigate these concerns, Shattuck and colleagues (2011) examined rates of service use as young adults with ASD transitioned from high school. Data collected from a nationally representative sample of parents of young adults with ASD revealed sharp decreases in services following high school. The study found that nearly 40% of young adults with ASD were no longer receiving any services, although they received them in high school through special education. The study also found differences in services by race and socioeconomic status. Adults with ASD who were African American and those living in families earning \$25,000 or less were far less likely to receive services.

### **The Individualized Transition Plan**

The Individuals with Disabilities Education Act (IDEA) is an example of federal legislation encouraging the development of self-determination in people with disabilities. IDEA mandates that, to the extent possible, students be encouraged to participate in the planning and decision-making process of the IEP alongside parents and educators. Thus, even in the elementary school years, teachers and parents must show students that they value their choices and preferences. At age 18, a student is said to have reached the “age of majority” and is allowed to make his own decisions, unless appointed a guardian or



It is important that the transition plan considers goals that promote independence.

chosen to share decision making. Students and parents must be informed of this transfer of parental rights to student at least 1 year before the student turns 18. Regardless of the child's age, communication skills, or ability level, her input in making choices about her life should be encouraged and valued.

In 1990, the reauthorization of IDEA included a mandate for providing transition services to students receiving special education services. A *statement of transition service needs* should be included in the student's IEP by age 14. The 2004 reauthorization of IDEA requires that an **individualized transition plan (ITP)** be written for a student receiving special education services by age 16. However, transition planning, can (and should) occur much earlier.

Integral to the transition plan is identifying the student's preferences for their lives after public school, including employment or further education, leisure and recreation, social/interpersonal, and residential. Based on transition goals established by the student, family, and educators, specific skill sets can be targeted within the IEP to support the successful transition from high school to the community. IDEA requires that, to the extent possible, students be involved in the IEP process, and particularly in the transition planning. In a study of 276 students with disabilities, Williams-Diehm and colleagues (2008) found that active involvement in transition planning was associated with higher levels of self-determination.

Preparing the ITP requires active student involvement, alongside a multidisciplinary team (National Council on Disability, 2000). Optimally, the multidisciplinary team includes the student and his family, educators and professionals associated with the school, and community supports associated with transition goals. However, a study commissioned by the Office for Special Education Programs of the U.S. Department of Education revealed that the majority of ITP meetings lack a representative from external support agencies in the community (Cameto, Levine, & Wagner, 2004). The lack of representation of community supports during transition planning is problematic given the variety of supports often needed for successful transitioning of individuals with ASD into the community (Wolfe, 2005). Table 11.2 describes key features of an ITP.

## HOUSING

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### ***Lack of Residential Supports***

Regardless of an individual's level of impairment, it is important that they have the opportunity to express their preference in future living arrangements. Although individuals with greater needs (e.g., communication, mobility, sensory



**Table 11.2** Key Features of an Individualized Transition Plan

- Individualized based on the student's skills, goals, interests, and preferences for life after secondary school.
- Consists of a multidisciplinary team, including the student with a disability, family members, educators, professionals working with the student, and representatives of community supports in areas such as housing, employment, leisure, and recreation. Thus, interagency collaboration (e.g., school personnel, social security administration, department of vocational rehabilitation, and supportive employment agencies) is essential.
- Has outcome-oriented goals oriented to life after high school, not just focused on what can be accomplished while in school. Goals consider planning for vocational training, integrated employment, postsecondary education, recreation and leisure, independent living, and community participation. A *functional vocational evaluation*, an assessment providing information about job or career interests, aptitudes, and skills may be requested to assist with the ITP.
- Transition goals must be reviewed and progress toward meeting goals considered during each IEP meeting after age 16.
- Schools must provide a *summary of performance* when a student transitions from public school, due to exceeding age for public school services (usually after age 22) or graduating, which documents academic achievements and functional performance.
- Other issues to address in ITP to support successful transition may include interpersonal skills needed for success in a job setting, self-advocacy, self-monitoring, and safety skills associated with privacy, communicating needs, and issues related to sexuality. Furthermore, many individuals with ASD have comorbid mental health disorders, particularly depression and anxiety. These difficulties may be exasperated by the stress of transitioning to a new routine. Supports to address mental health should be part of transition plan discussions.

impairments) may require more diverse and intensive supports, level of impairment should not be the determining factor as to where an individual with ASD should live.

The majority of individuals with ASD will require some degree of residential service or support during their lifetime (Gerhardt & Lanier, 2011). While the demand for services of adults with ASD is increasing, the available supports are in limited supply (Autism Society of America, 2007; Gerhardt & Lanier, 2011). Unlike educational services under IDEA, services to adults with ASD are not a federal mandate. For instance, states determine the criteria for eligibility for the Medicaid HCB Waiver program, one of the major funding sources for services

for adults with developmental disabilities. Depending on the population and financial resources of the state, there are often long waiting lists for Waiver slots (Autism Society of America, 2007).

The Autism Society of America reported in its position paper *The National Crisis in Adult Services for Individuals With Autism* (2007) that there are approximately 25 agencies in the United States having highly specialized programs for adults with ASD. Furthermore, the report describes poor-quality services overall due to high rates of staff turnover, poor staff training about ASD, and inadequate Medicaid reimbursement rates.

Theoretically, there are many options for individuals with ASD. However, the cost and availability of these options vary widely. Available supports, opportunities for community integration, and number of individuals residing in the residence are the main differences among the choices. However, the types of care available and the quality of that care are not tied to the residential model (Gerhardt, 2009). Issues that may prevent individuals with ASD from living independently include affordability (difficulty finding paid employment, high costs of living as compared with government support or other means of financial support), accessibility (particularly for individuals who use wheelchairs or other mobility devices), and availability of supportive housing due to limited governmental funding (The ARC, 2011).

## **Residential Options**

### **Living at home with family**

Recent studies of adults with ASD living in the United States indicate that as many as 79% (Shattuck, 2011) are currently living with their parents. For some families and individuals with ASD, living in the family home is the preferred residential setting. Individuals with ASD living at home with their parents may be eligible for government funds such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and Medicaid waivers. However, families need to be proactive in securing these financial supports (National Institute of Mental Health, 2010). Funding may also be available to provide supports for transportation, job training, respite care, and other services. It is essential that future residential preferences be discussed during transition planning, and the transition planning team invite community agencies to facilitate interagency collaboration. Although family living has potential benefits (e.g., living in a familiar environment with loved ones who understand ASD and the individual), caregiver burnout and limited opportunities for socialization and community integration may become problematic. Many caregivers desire to

continue having their adult child with ASD live at home, but need more in-home support. Parents are often concerned about the lack of future residential opportunities, and who would care for their adult children with ASD when they are no longer able to do so. Adults with ASD living at home with aging caregivers face an uncertain future without careful planning for transition services.

### Supportive group living

Underlying the concept of **supportive living** is the belief that severity of disability should not prevent individuals from life experiences typical of their nondisabled peers. Thus, with appropriate supports, individuals with ASD (and other disabilities) can choose to live outside their family's home and within the community. People with ASD may benefit from exercising self-determination to choose a residence that allows them to live in a particular setting and follow routines they find most comfortable (Gerhardt & Lanier, 2011). Some parents are surprised at the increased independence of their adult child with ASD after moving into a partially supported living environment; yet, parents may be unsure if the support staff can provide the same level of care that they provided their child (Hitzing, Saverino, Leary, & Sousa, 1995).

Transitioning to a supportive living environment presents many opportunities for increasing skills in socialization, problem solving, and negotiation through experiences. For instance, successful living in a shared household may require planning for and negotiating issues such as furniture arrangements, paying bills, addressing undesirable behaviors, rules about visitors, groceries purchased and meal preparation, household duties like cleaning, and access to television (Muller, 2009).

Supportive living may involve only limited supports with supportive staff visiting periodically to address concerns, offer training, help pay bills, etc. On the other hand, some individuals with ASD may require greater support, sometimes called **community living arrangements (CLA)**, in which support staff provide 24/7 assistance with home and community supports (Autism Society, Greater Philadelphia Chapter, 2009). Both supervised living situations with limited supports and those with more intensive supports differ from traditional group homes, with a greater focus on consumer choice, self-determination, and smaller number of individuals living in the residence.

### Other options

Across the country, long-term institutional care is being phased out. Today only the most disabled and medically fragile individuals live their lives in institutions. The goal is for integration of individuals with disabilities into the community

to the greatest extent possible. However, there are some interesting larger residential models, such as farmstead programs, that offer unique living experiences with opportunities for personal development, vocational training, independence, and socialization (Gerhardt & Lanier, 2011).

Another option for high-functioning individuals with ASD is fully independent living without supervision. Only a small percentage of adults with ASD live independently. However, with social support, strong transition planning and implementation, and vocational/job preparation, fully independent living is possible for some individuals with ASD.

In addition to the residential models discussed in this chapter, sometimes parents and community leaders collaborate to create unique residential and community supports for adults with developmental disabilities. Consider the following interview (see the Chapter Reflection box “Meeting the Needs of Adults With Developmental Disabilities”) with Barbara Monday, one of the founding parent members of DIGS (Develop Independence, Growth, and Security for adults with developmental disabilities in our community).

### CHAPTER REFLECTION: Meeting the Needs of Adults With Developmental Disabilities: Develop Independence, Growth, and Security (DIGS) for Adults With Developmental Disabilities in Our Community

Author.



*Barbara Monday is a founding parent of DIGS and shares her experiences creating this organization.*

DIGS was developed by a group of parents, caregivers, and concerned citizens to address the lack of social, recreational, work opportunities, and residential options for adults with developmental disabilities in our community.

When we first got together, we each wrote a mission statement about what we hoped to accomplish. It was interesting how similar our mission statements were. They *all* involved securing safe long-term housing, recreation, and leisure activities for the adults with developmental disabilities in our community. Our long-term goal was to create a residential option for adults with developmental disabilities

that was safe, offered choice and independence, and could be permanent. We didn't want our children in a community-based home that could close and for our children to be transferred from home to home throughout their lives.

Over the years, DIGS has provided adults with developmental disabilities a core group of friends, opportunities to learn new skills and develop leisure skills and interests. Also, the parents have found a support group of friends with whom they can share concerns and ideas. For instance, after a birthday party for her adult son, a mother came over to me crying. She hugged me and thanked me for the opportunity to have a birthday party for her son. She said that she never gave him a party with his peers before, because she didn't think anybody would come. But everyone in DIGS came to this party and had a great time! Children with developmental disabilities are often bussed to schools far from their homes. So parents rarely get to know the parents of their child's classmates.

DIGS has become a bridge to the community. We currently have an adult choir that has weekly rehearsals and performs all over the county. We also have a camera club, dance club, and an art club. Being

in the DIGS choir teaches many skills that may serve as a bridge to joining a church choir. For instance, you learn how to behave in a rehearsal, how to stand on the stage and look out toward the audience, and how to sing in public. Our camera club members can learn skills serving as a bridge to joining the local camera club in town. Furthermore, leisure activities can lead to future work opportunities. For instance, we make and sell garden art as a fund-raiser, and learn many useful skills in the process.

One of the best things about DIGS is that these adults have a peer group of friends. They learn how to be a friend and how to engage with friends during community events.

*Tom is Barbara's son. He is an adult with a developmental disability and an active member of DIGS.*

When asked what he liked most about DIGS, Tom named six to ten friends. Despite expressive language deficits, Tom enthusiastically described where his closest friends worked and other things about them. He mentioned a girlfriend as well. Tom is looking forward to living on his own someday, especially living with his friends!

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Visit the DIGS website at <http://www.orgsites.com/ga/digs>. For additional information about residential options for individuals with ASD, refer to the National Association of Residential Providers for Adults with Autism (NARPAA) at <http://www.narpaa.org>. In addition, *Autism Advocate* published by the Autism Society, Greater Philadelphia Chapter (2009) devotes an entire issue to residential options for individuals with ASD.

## PLANNING FOR EMPLOYMENT

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### *Transition Planning*

Adults with ASD across the spectrum have low rates of employment compared with their peers (Eaves & Ho, 2008; Taylor & Seltzer, 2011). In a review of the literature on ASD and employment, Hendricks (2010) reported 50% to 75% of individuals with ASD are unemployed. Furthermore, employed individuals with ASD tend to work fewer hours and earn less in weekly wages than individuals with other types of disabilities (Cimera & Cowan, 2009). There is a need for better transitional planning, including vocational evaluations, internships/shadowing, and teaching skills needed for success such as communication and social skills used in a job setting. Educators with knowledge about state and community vocational supports are better able to assist with planning and implementing the transition plan for young adults with ASD (McDonough & Revell, 2010). Employment has many benefits for all individuals. For instance, in addition to providing financial benefits, employment offers social opportunities, promotes personal dignity that is associated with a high quality of life, and may enhance cognitive skills (Hendricks, 2010).

**Vocational rehabilitation** is available to some individuals with ASD. However, adults with ASD are often denied services, especially those on the severe end of the spectrum (Lawer et al., 2009). Overall, individuals with ASD are underserved by state and federal vocational rehabilitation programs (Dew & Alan, 2007). It is important that families understand that after age 22, support services are no longer entitlement based (such as IDEA mandates for free and appropriate education). Instead, different laws translate to a new array of eligibility criteria for obtaining services. There is no agency that is charged with serving adults with ASD. Rather, factors such as presence of an intellectual disability, physical or sensory impairments, comorbid mental health conditions, and the economic resources of the community impact the types of services available.

Students with ASD and their families benefit from transition planning guiding by educators who identify key resources that can clarify these processes for families (McDonough & Revell, 2010). Early vocational training is critical for obtaining meaningful employment as an adult (Carter, Austin, & Trainor, 2011). Using data from the National Longitudinal Transition Study-2, Carter and colleagues (2011) found that students with an intellectual disability were almost four times as likely to be employed than individuals with ASD without an intellectual impairment. Furthermore, good communication, independent

self-care skills, and parent expectations of employment were predictive of early employment. Parent expectations played a role in early job experiences.

## EMPLOYMENT MODELS

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Despite similar core deficits, individuals with ASD have a wide range of interests and skills. The level of independence and need for supports varies significantly across the spectrum. Different models for employment and meaningful work experiences should be considered. Work experiences are selected based upon the individual's needs, skills, job availability, and available supports. Other issues such as transportation and mental health concerns are also important considerations.

### **Competitive employment**

**Competitive employment** refers to engagement in meaningful paid employment with limited supports (Holmes, 2007). Success on the job is greatly enhanced by employers and employees who provide a supportive environment (Hendricks, 2010). This may include tolerance for unusual behaviors (such as stereotypic or repetitive behaviors under stress), a need for routine, and difficulty with pragmatic and abstract language. Thus, it is often important that colleagues of individuals with ASD understand the disorder. To this end, adults with ASD must learn how and when to self-disclose information about ASD.

Workplace modifications may also promote job success. Hillier and colleagues (2007) suggest an environmental assessment addressing noise level, interruptions, crowding, lighting, and space navigation. Flexible employers willing to make environmental accommodations can provide an environment for the individual with ASD to be a productive asset to the organization.

### **Supportive employment**

Many individuals with ASD will require some degree of support while employed. As an alternative to the traditional sheltered group workshops, that generally provided a rote-working task in an environment segregated from the community, **supportive employment** helps individuals with ASD work within their community. Many individuals with ASD benefit from on-the-job supports, which allow them to participate in meaningful and sometimes paid

employment (Lawer et al., 2009). Callahan (1986) identified four characteristics of supported employment:

- Integration—Work with nondisabled coworkers and integrated at work.
- Paid work—Pay commensurate with work performed.
- Individualized services—Job selection, training, and supports individualized based on the needs of the individual.
- Wide variety of ongoing supports—These include transportation, time management, and advocacy.

Sometimes, supports are needed only at the beginning of the job, involving training and helping the individual advocate for accommodations. Other times, more intensive support is needed on a daily basis. A **job coach** (sometimes referred to as employment specialist or consultant) helps identify a job that fits the individual's interests and skills, provides supports for initial employment, and gradually reduces the coaching role as the individual adjusts to the job setting. A job coach systematically analyzes the tasks needed to perform the job and teaches elements of the task needed for success. Often, applied behavior analysis is used to teach tasks, collect data on performance, and gradually fade prompts and reinforcers (Rusch & Hughes, 1989). Another role of the job coach is to identify and implement natural supports to facilitate integration of the individual with a disability into the work setting (Hagner, Rogan, & Murphy, 1992). For instance, the job coach may work with the supervisor to create a visual and frequent feedback system, identify and train a peer mentor, and help the individual with ASD socialize with colleagues (Gerhardt, 2009). A job coach may slowly scale back in daily contact and check in weekly or monthly. The type and extent of these supports depend on the needs of the individual with ASD.

### **Other Opportunities for Meaningful Work Experiences**

Some individuals with ASD who have more significant impairments may require greater support than what is offered through supported employment. However, despite the level of impairment, all individuals have the right to meaningful work experiences. Access to these experiences may be provided through adult day service programs, which may include sheltered workshops or day activity centers. From their study of post-high school educational and occupational activities of young adults, Taylor and Seltzer (2010) found that over half of the study participants (56%) attended either sheltered workshops



or day activity centers. Generally, these work opportunities provide work for groups of individuals with disabilities until the job is complete. In addition, volunteer activities provide individuals with ASD opportunities to contribute to society, to socialize and be included in their community, and to learn new skills.

## POSTSECONDARY EDUCATION

Postsecondary education increases the chances that people with ASD will develop skills resulting in meaningful employment and increased opportunities for inclusion in the community (Holmes, 2007; Stodden & Mruzek, 2010). College provides a transition to adulthood marked by enhanced experiences with socialization and independence, fundamental to being a successful adult (Hart, Grigal, & Weir, 2010). Students with all types of disabilities, including intellectual disabilities, may benefit from participating in postsecondary education experiences (Hart et al.).

### **Legislation Supporting Postsecondary Education for People With Disabilities**

Over the years, societal changes have led to increased support for integrating individuals with disabilities into the community at all levels, including education, employment, residential, and other aspects of community life (Stodden & Mruzek, 2010). Legislation and policy changes reflect these views. For instance, current federal legislation, such as No Child Left Behind (NCLB) and IDEA, are more focused on academic preparedness requiring students with ASD and other disabilities to have increased access to the general academic curriculum and inclusion in statewide standardized testing. Furthermore, the American with Disabilities Act (ADA, amended in 2008) requires public institutions to provide reasonable accommodations ensuring equal access in both work and educational settings.



College provides a transition to adulthood marked by enhanced experiences with socialization and independence, fundamental to being a successful adult.

**The Higher Education Opportunity Act (HEOA) of 2008** provides further support for people with ASD and other developmental disabilities. In October 2009, a Government Accountability Office (GAO) report was published to address questions about HEOA (U.S. Governmental Accountability Office, 2009). The report cited that 11% of students attending colleges and universities were identified as having a disability and that these numbers were increasing. In the report, the GAO recommended a coordinated approach to supporting people with disabilities in postsecondary schools and providing technical assistance. The report noted that postsecondary schools face challenges in addressing needs of students with disabilities, such as ASD, because they may require specialized knowledge.

### ***Postsecondary Education and ASD***

Postsecondary education is associated with a greater likelihood of economic and social independence (Levy & Perry, 2011). Results from the National Longitudinal Transition Study 2 (NLTS2; Wagner, Newman, Cameto, Garza, & Levine, 2005) indicated that approximately 20% of individuals with ASD attend a vocational, business, or technical school; 35% attend a 2-year college; and 1% attend a 4-year college. However, other studies report smaller percentages of individuals with ASD pursuing postsecondary education (Levy & Perry). Parents and teachers are encouraged to discuss the possibility of attending a postsecondary education program early in transition planning.

The following topics are recommended to support transition planning for students considering postsecondary education:

- **Investigate community colleges, public 4-year, and private colleges and universities.** Invite a school guidance counselor to attend the ITP meeting to share information about local colleges and preparing applications for admission. Consider the pros and cons of different types of postsecondary programs. For instance, a 2-year program may offer more individualized support for students with disabilities. Likewise, though a small private school may not have the resources of a large university, some private schools offer a more personalized approach to supporting students with disabilities. Students with ASD may be eligible for testing accommodations for the ACT and SAT. Students who are not earning an academic diploma may consider taking continuing education courses or auditing college courses.

- **Consider vocational postsecondary programs.** Vocational programs offer the development of skill sets associated with specific career paths. According to the National Longitudinal Transition Study 2 (NLTS2), only 22% of students with ASD have postsecondary vocational training documented on their ITP (Wagner et al., 2005).

- **Teach students to self-disclose and self-advocate.** Unlike public high schools, students with disabilities *must* self-identify and advocate for themselves to receive support services. Although this may seem embarrassing to the student, the sooner they self-identify as having ASD the more quickly they will receive supports to help them succeed. One of the first steps is identifying the office of disability services at the postsecondary school. It may be helpful to contact the director and determine if there are other students with ASD and the types of accommodations typically provided. Each postsecondary institution determines if a student is eligible for accommodations. If they are found eligible, the postsecondary institution determines what they consider to be *reasonable* accommodations. This is likely to vary greatly from college to college.

- **Often students will need to contact their professor to share information about their learning needs.** The director of disability services will provide a letter of accommodations stipulating the accommodations a professor needs to make. These accommodations are not necessarily the same as those on the student's high school IEP. In fact, the college professors will have nothing like an IEP, only a list of basic accommodations. These accommodations will *not* reduce the course workload or change the nature of the assignments. For instance, the student may be given extra time on exams or the opportunity to take them in the office of disability services, have access to adaptive technology, be provided academic support such as a tutor, or be provided with a note taker during class. However, the student is unlikely to be given different tests, different assignments, or extended time for turning in written assignments like term papers or projects. Questions or concerns students have about the course need to be addressed to the professor teaching the class. Approaching a professor can be a daunting task for any student. Students need to be able to describe their preferred learning style. For instance, they may need to explain to the professor that they process auditory information (such as lecture) more slowly than visual information. Thus, they might request copies of the professor's PowerPoint slides if they are not already available, and/or permission to audio-tape the course lecture. Tips on how to contact and talk with professors (email letters, checking office hours, etc.) will be helpful.

- **Request a current psychological evaluation before graduating.** Generally, a current psychoeducational evaluation may be requested by the IEP team during the student's last year of high school. Most postsecondary institutions will require formal documentation of ASD (or another disability). For ASD this will be in the form of a psychological evaluation that has been conducted within the past 3 years (U.S. Governmental Accountability Office, 2009). Postsecondary institutions rarely implement or pay for these costly evaluations, and insurance companies are unlikely to reimburse students for a psychological evaluation for the purpose of documenting a disability. Thus, if the evaluation is not done before leaving public high school, the student would be responsible for the cost of the evaluation.

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Additional information for teachers supporting students with the transition to postsecondary education can be found in the report *“Transition of Students With Disabilities to Postsecondary Education: A Guide for High School Educators”* available at <http://www2.ed.gov/print/about/offices/list/ocr/transitionguide.html>.

## TEACHING TIPS

- Collaborate with parents, teachers, and the student each year to identify goals after high school. Provide opportunities to visit different job sites, talk with and shadow employees, and build skills needed for employment. Skills that may be associated with a particular job, such as completing paperwork, stacking items on a shelf, or cleaning, can be broken down into discrete steps and written into the IEP. Include professionals that support vocational exploration and conduct vocational assessments to participate in IEP and transition planning meetings.
- Work with parents and the student with ASD to consider residential options after high school. Identify the skills needed to build independence to the fullest extent possible, particularly if living away from one's family home is the goal. Help families identify resources for investigating residential options. School social workers, state representatives from community agencies, or others may need to be invited to transition planning meetings to provide current information about resources and how to obtain them.
- Work with the school counselor to help students with ASD who are interested in pursuing postsecondary education identify and evaluate programs. Include self-advocacy skills into IEP goals to help students transition successfully to educational environments where a special education teacher will not be available to navigate accommodations.

## SUMMARY

Unprecedented numbers of young adults with ASD will be transitioning from high school in the near future. However, residential, housing, and community living support services for adults with ASD are limited. Furthermore, there is little research regarding best practices for effectively transitioning individuals from school to the adult life. Self-determination, the fundamental human right to make meaningful decisions about one's life, contributes significantly to overall quality of life. Teachers can teach skills that help students with ASD become actively involved in communicating their preferences, self-advocate, and participate in constructing their educational and transition plans.

The ITP is written by the IEP team in collaboration with relevant community agencies. IDEA requires an ITP by the time a student with an IEP turns 16, but earlier planning is encouraged. The transition plan is important for helping students plan for housing, employment and/or postsecondary education opportunities as they transition from high school.

Although most adults with ASD reside with their families, supportive group living is receiving increasing attention as a living option allowing for greater independence and community integration. However, availability and cost can make supportive living difficult to access. Transition plans are essential for preparing for competitive or supportive employment. Work experiences, such as day activity shelters and sheltered workshops, may be options for individuals with more severe impairments. Increasingly, postsecondary education is an option for individuals with ASD, enhancing vocational opportunities.

## DISCUSSION AND REFLECTION QUESTIONS

1. How can teachers help students with ASD develop self-determination? Consider how educators can collaborate with families to recognize cultural differences in the conceptualization of self-determination.
2. Describe components of an ITP and the types of issues that should be addressed. Make a list of agencies in your community that support adults with disabilities who might be invited to transition planning meetings.
3. What are the residential options for adults with ASD, and why do so many adults with ASD live with their families? Consider supports necessary to improve the overall quality of life for adults with ASD living with their families and their families.
4. Describe the models of employments available in the United States for people with ASD.
5. What types of activities are important for preparing a high school student with ASD for future employment or transitioning to postsecondary education?

## RECOMMENDED FURTHER READINGS AND INTERNET SOURCES

- Autism Society of America: Position Paper on *The National Crisis in Adult Services for Individuals With Autism*. [http://support](http://support.autism-society.org/site/DocServer/Adult_Services_vMay2007.pdf?docID=2601)

### Transition and Self-Determination

- Issue of *Focus on Autism and Other Developmental Disabilities*, 25 (2010, September) devoted to postsecondary transition.
- Leake, D., & Black, R. (2005). *Essential tools: Cultural and linguistic diversity: Implications for transition personnel*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, National Center on Secondary Education and Transition.
- Oregon Health and Science University, Center for Self-Determination National Center on Secondary Education and Transition. <http://www.ncset.org>
- Self-Advocacy Synthesis Project: reviews research on self-advocacy models for students with disabilities. <http://sdsp.uncc.edu/>
- Self-determination resource website for teachers. [http://www.selfdeterminationak.org/resources\\_for\\_teachers.html](http://www.selfdeterminationak.org/resources_for_teachers.html)
- Wehman, P., Datlow, S., & Schall, C. (2008). *Autism and the transition to adulthood. Success beyond the classroom*. Baltimore, MD: Paul H. Brookes.

### Employment

- Advancing Futures for Adults With Autism: National consortium seeking to create meaningful futures for adults with autism including homes, jobs, recreation, friends, and supportive communities. [www.afaau.org](http://www.afaau.org)

### Postsecondary Education

- Going to college website funded by a grant from the U.S. Department of Education, Office of Special Education and Rehabilitative Services to help students with disabilities prepare for college. <http://www.going-to-college.org/index.html>
- Civil Rights. <http://www.ed.gov/about/offices/list/ocr/transition.html>
- Students With Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities—guide from the Office for Transition of students with disabilities to postsecondary education: A guide for high school educators. <http://www2.ed.gov/print/about/offices/list/ocr/transitionguide.html>
- Think College: a web site about college options for people with intellectual disabilities. <http://www.thinkcollege.net/>

### Housing/Residential Issues

- National Association of Residential Providers for Adults with Autism. <http://www.narpaa.org>

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