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Managing the Transition Process from High School to College and Beyond: Challenges for Individuals, Families and Society

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Abstract. Transition to adulthood represents a significant challenge for individuals on the autism spectrum and their families. With the increase in diagnosis and appropriate treatment at younger ages, more adolescents on the spectrum have the potential for independent adult lives, including work and college. Yet our support systems have been slow to respond to the needs of individuals with typical dreams and aspirations but atypical development. This article addresses the challenges of the transition to adulthood from multiple perspectives and provides a framework for individuals, families, and supporting professionals to anticipate challenges and develop positive solutions.

Introduction

Adolescence and young adulthood have long been recognized as significant periods of transition for young people and their families. When conceptualized as a stage of individual development, this phase of life has generally been thought of as a period during which a young person moves toward increasing affiliation with his or her peer group, develops a growing sense of self that may differ from his or her parents, and ultimately establishes a work and personal life outside of his or her family of origin and its household. This period of transition is also considered a phase of the family's life cycle involving the culmination of many years of preparation for greater independence, along with the family's hopes and worries related to the young person "launching" successfully. The hoped for goal in this context is the emerging adult achieving an independent personal and professional life that is viewed as successful by his or her family while, at least broadly, adhering to cultural and societal standards. This success, or the failure to achieve it, is typically not only viewed as a reflection of the young person's functioning; it is

frequently viewed by many as the key measure of whether or not his or her parents were effective in raising their child.

These developmental goals are pertinent to individuals with Autism Spectrum Disorders (ASDs) as well as their families; however the impact of ASDs on individuals and their family dynamics poses specific challenges. The transition to adulthood for individuals with Asperger Syndrome (AS), High Functioning Autism (HFA) and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) is particularly challenging because of their unique characteristics -- the lack of services that address the special needs of such individuals in adulthood, and the expectations of society for a typical path to adulthood in the face of atypical problems.

Common impediments include specific diagnostic features such as difficulty with social interaction and relationship development, problems with maintaining conversation in social settings, patterns of thinking that may be perseverative or obsessive, and difficulty interpreting nonverbal cues or others' perspectives; common associated characteristics include over- or under-sensitivity in visual, auditory, tactile, or other sensory modalities, having unusual movements or clumsiness, difficulty with understanding or remembering oral directions, fine motor awkwardness, and emotional dysregulation. Comorbid conditions such as attention deficit disorder, anxiety and depression may present additional issues to be contended with. In addition to the obvious interpersonal struggles these individuals face, the seemingly simple organizational tasks of keeping food in the house, paying bills on time, and maintaining adequate personal hygiene are often at least as challenging.

Yet, despite having some or all of these difficulties, these individuals may be intellectually advanced, passionate about studying or doing work, focused on academic or work goals, loyal and hard-working, and they may have highly marketable skills. It is these contrasts, this uneven profile of strengths and impairments that make the transition to adult life so difficult. As others encounter these emerging young adults, they often struggle with reconciling how someone so bright and capable in certain domains of functioning can be so lacking in common sense, organizational skills, and/or social skills.

Society sees an individual who appears to be intellectually able to accomplish much, but is socially immature for his or her years and frequently has some unusual and/or peculiar characteristics that others may not understand. They may simply react with bewilderment; however in other cases, given the individual's strengths in certain aspects of functioning, his/her shortcomings may be misinterpreted as willful acts or character flaws instead of being reflections of the typically uneven neurobiological profiles of individuals with AS or HFA.

Support agencies often do not identify these individuals as needy or even eligible compared to their other clients. Parents may be frustrated when their son or daughter with so much potential seems unable to advance in life and they may be ashamed of how this appears to others who may think these difficulties are a result of inadequate parenting. Individuals on the spectrum themselves are often confused and/or ashamed when they fail to attain or maintain employment despite having the skills or credentials their job requires. Unlike conditions involving the visible challenges of impaired mobility, coordination, vision, etc., the autism spectrum conditions are relatively invisible. As a result, the potential for success can be overestimated for these individuals, leading to a lack of preparation and support for a realistic transition to adulthood.

Understanding the problems that are unique to this population and to this time of life will help individuals, families, schools, and support agencies develop the types of plans and services that can truly support the transition to adulthood. This article will provide an overview of some of the problems this

group of individuals faces as they encounter the “real world,” the role of families in helping them achieve their goals, some potential solutions to transitioning to the world of work, and ways in which the college experience can be utilized as a step toward greater independence for these young people.

The Transition to Adulthood

The transition of a neurotypical adolescent to independent young adulthood is usually challenging for the young person and his/her family, but for families who have a child with Asperger Syndrome, Autism, or Pervasive Developmental Disorder Not Otherwise Specified, the transition period to adulthood may be the most difficult period for them since the young person’s initial diagnosis. It is one of the most profound chapters in the ongoing process of accepting that they have a young person with special needs. The family has typically gone through many years of challenges, often including some degree of missed or misdiagnosis, and, to a greater or lesser extent, has usually grappled with the educational system, coped with lack of understanding from family and friends, experienced significant shifts in their social support system, dealt with a host of intrafamilial stressors, and experienced many additional trying experiences over the course of the young person’s life. **(Seligman & Darling, 2007)**

Launching young adults who have the potential for independence can be a complex and challenging experience for all. Typical tasks in healthy adolescent development include developing a more defined sense of self, values, preferences and goals that may, in some ways, be different than one’s family’s, establishing a peer support system, and preparing for the future with the ultimate goal of a functional and independent work and personal life. Exploration, and even risk-taking, are common aspects of this stage of development as well. It is undeniable that these tasks are affected by having an autism spectrum condition. Establishing an individualized sense of self is clearly a socially based task. It and most, if not all, aspects of healthy adult functioning are significantly impacted by impaired social skills, including the essential goals of establishing meaningful interpersonal relationships and an adequate social support system.

Achieving independence implies establishing a career and managing the stresses of life with relatively little support from one’s family of origin, yet individuals with AS or HFA may be likely to continue to need assistance in some domains of their functioning. It is common for the families of these youngsters, in contrast to families of neurotypical young people, to take a more active role in helping the young person pursue a fulfilling and independent adulthood. Although it may seem ironic that the young person’s ability to establish independence may require such active support from his or her family, but, in the long run, it is the judicious use of that dependence and its gradual transfer to other support systems that results in the greatest success in independent functioning.

The norms of Western industrialized societies place judgments upon those who cannot maintain independent employment. After all, it is the inability to work that is the defining criterion of “disability.” We know from surveys of adults with autism spectrum disorders, that finding meaningful employment is often an elusive goal. Adjusting to the world of work is one of the most difficult tasks individuals on the spectrum and their families face. And, although there has been a proliferation of services for children on the autism spectrum, the needs of adults, particularly those with independence potential, remain vastly underserved. Under- and unemployment are chronic problems for these individuals. Unemployment figures of 80% to 90% are not uncommon (Barnard et al., 2001) and income levels even among the college educated, lag substantially behind population means (Geller & Cavanagh, 2005). Given these unpleasant realities, it is critical for families, educational teams, and individuals on the autism spectrum to plan and cooperate for the best possible outcome.

Starting Where the Client Is

A cornerstone of all effective practice is to “start where the client is.” This deceptively simple adage is in reality quite complex. It involves awareness of one’s biases and requires taking the time to carefully listen to the client to verify that one truly understands that person/system within a multisystemic context including cultural, familial, spiritual, psychosocial strengths, concurrent stressors, and other dimensions. The partnership between the professional and client is most likely to be successful when there is agreement about where this journey is beginning (“starting where the client is”) as well as the intended destination, or at least direction in which the journey will head.

First, it is necessary to clarify whether the client is the individual with the ASD, his/her family members, the entire family system, the disability system, the educational system, etc. There may be multiple systems involved and they may not agree on what the agenda for change is going to be. Frequently there are differences between the vision, hopes, and worries of the individual’s family and what a young person with an ASD envisions for him/herself, given that individual’s difficulties in social functioning, tendency toward naïveté, and possibly unrealistic assessments of his/her capabilities. Professionals, as well as family members, may believe they know what is best for the young person and may be tempted to overtly or covertly try to push their agenda on the young person, but generally this is counterproductive to promoting independence. It is more advisable to do some joint “reality testing” of the young person’s goals, to try to help him/her discover potential problems with his or her plan. This is an important process for these individuals, as rigid thinking and a lack of realistic planning are often among their difficulties. It is important to keep in mind, as frustrating as it may sometimes be, that the goal is to assist the young person in creating an increasingly realistic “game plan,” not for him or her to accept the professional’s or family members’ notions of what the plan should be.

If the individual is not open to accepting suggestions from others, his or her plan may not be very realistic and families may need assistance “letting go” and allowing for the individual to learn by trial and error. Family members often need support in coping with the struggle between protecting and doing for a young person on the spectrum and the challenge of not interfering as that young person takes risks and experiences difficulty or failure in the process of becoming a more independently functioning young adult.

Blos (1967) conceived of mid-to-late adolescence as a period of “second individuation,” the first period being toddlerhood when the young child begins to develop a sense of self that is separate from his or her parent. At this age the child has the motor skills to explore his or her environment, but is capable of next to no judgment about safety issues. The parallel to later adolescence and young adulthood is that the young person has an increasing ability to explore, but again may not have a realistic sense of his/her capabilities and vulnerabilities. Both periods of development involve parents needing to decide between when to intervene and when to let “experience be the best teacher.” The stakes in late adolescence, however, are typically much higher than the days when they needed to let their toddler fall while learning to walk.

In situations where parents have decided their active involvement is indicated, others in the young person’s life -- teachers, grandparents, or others -- may intensify the challenge by accusing parents of “spoiling” the young person, not demanding enough, or being manipulated by him/her. These criticisms might be accurate in equivalent situations involving a neurotypical child, but there are no good roadmaps for parents regarding how to best raise a child on the spectrum as each is so unique in his/her presentations and needs. A professional familiar with these challenges for individuals with AS or HFA

and their families may be able to support and assist them in developing realistic plans to promote independence and self-advocacy abilities while still providing a shield from potentially damaging social and, at times, legal difficulties.

Although much attention is paid to the young person's expectations, the family's expectations may go all the way back to the time of diagnosis, when one of the first questions parents typically ask professionals is whether or not their child will have an independent life. There are as many answers to this question as there are individuals and ways of living. However, establishing realistic expectations is an important step toward developing goals. Although expectations may change over time, the tension between expecting too much and too little continues throughout childhood and early adulthood. Too high an expectancy produces anxiety from never being adequate in a parent's or one's own eyes, and too low an expectancy contributes to accomplishing much less than might have been achieved. The expectancy continuum is a special challenge for families with a member who has a spectrum condition because finding the best approach is a moving target of alternating highs and lows in independent function.

Maintaining hope in the face of difficulty is another tightrope walk. Families always hope for continued development and an eventually happy, well-adjusted life for their child. However, the transition to adulthood may provide particular stressors as hope and reality begin to interface. Some individuals on the spectrum have developed academic, cognitive, and social skills to a point that proceeding to an independent life seems assured. For others, the picture may be less predictable. This is why it is so important to plan early and well for this stage of life. Baron-Cohen et al (2005), Gillberg et al (2001), and Wing et al (2002) have specifically examined the differential expression of the autism disorders across ages. Individuals on the autism spectrum often make progress unevenly in the transition periods of life as new stresses are brought to bear on their underlying characteristics. Someone who may have done very well in elementary school may find the stresses of middle or high school to be overwhelming, or someone who has had difficulty in the teenage years may find a niche in adult life that is more fulfilling.

In light of this, in addition to "starting where the client is," it is necessary for professionals and family members to periodically verify that they continue to have an accurate appreciation of the young person's situation and objectives as they change. The key to helping an individual achieve goals is to match the level and types of support to the person's current need. Unfortunately, for those on the autism spectrum who are capable of independent lives, community-based supports are unevenly developed and require widely divergent eligibility requirements depending on locale. Trying to find appropriate supports where none may exist or working to promote natural supports in the community can place further demands on families. This is one reason why cooperative planning to create a viable transition plan that involves everyone who plays a key role in a student's life is so critical.

The Transition Plan – Beginning the Process

Under IDEA (Individuals with Disabilities Education Act), every student who has a special education classification has the legal right to a plan for transition from the educational system to adulthood. This plan must be developed collaboratively, involving the full participation of the student, his/her family, and the appropriate school personnel. Other members in the student's life, such as therapists, coaches, agency service representatives, and medical professionals, may also contribute their knowledge to the development of this plan. By age fourteen, the planning must begin, and by sixteen, the elements of the plan must be in place. It is critical for individuals and their families to work together with schools and professionals to develop specific interventions that can prepare these young adults, in a realistic and

practical way, for the world of work and adulthood. (Korpi, 2008) True transition planning is specific to the strengths and needs of the individual and should include:

- Opportunities to continuously develop necessary social skills
- Specific instruction in the development of social thinking skills and other so-called “hidden curriculum” aspects of life (Myles)
- Steady cumulative development of life skills including money management, hygiene, housekeeping, maintenance of health, personal organization, and traveling or driving
- Sex education and instruction about managing related personal behavior in adult settings
- Supportive pre-vocational activities including learning about appropriate workplace behavior and understanding the work search process
- Supportive volunteer or internship experiences as initial work experiences
- Intensely supported first-job experiences in organizations that ensure the young person on the spectrum continues to develop an appropriate understanding of the world of work and its social elements
- Well-planned, appropriate support for post-high school education, be it college, technical education, an apprenticeship, or other training
- Developing leisure interests and planning leisure activities

Currently, transition planning is often the weakest link in a student’s education plan. School districts often do not have sufficient contacts in the world of work and vocational training and the special education departments that often lead the planning may have little experience with the concept of individuals on the autism spectrum attending college and the supports they may need. While there are certainly pockets of excellence in developing effective transition plans in some school systems, it behooves individuals and their families to learn to be leaders in the process.

Through the transition plan, school personnel, families, and community providers should be helping the individual on the spectrum develop the wide array of skills identified in that learner’s unique transition program. The following is a description of some of the highly varying characteristics that may need to be addressed in anticipation of a young person moving from the school-based system of supports to the more individually based and self-managed life he or she will lead after high school.

Social Skills

Social skill deficits are a hallmark of the autism spectrum disorders. People who have adequate social skills are often unaware of how handicapping problems in this area can be. Virtually every work environment requires some element of social skill. Therefore it is important that social skills are directly taught and practiced throughout the school years and well into adulthood. In anticipation of adult work settings, the transition team should especially consider helping the individual develop basic conversation skills including recognizing when others are uncomfortable, when he or she is being too talkative, and in what situations casual conversation is appropriate on the job. Parents worry as they observe their son or daughter lagging behind peers in these areas, yet teaching specific social skills is not a traditional parental role and most parents do not know where to start. However, while research in this area is just beginning to emerge, current review papers (White et al., 2007; Rao et al., 2008; Matson et al., 2008; Bellini et al., 2007) suggest that parents can play a critical role by:

- Learning how to reinforce social skills by encouraging and supporting get-togethers
- Helping their child maximize strengths and special interests in social settings by finding opportunities (e.g. chess club) for him or her to interact with interested others
- Negotiating with the committee on special education to implement a true social skills program that is individually designed and data-driven
- Seeking out social skills training groups in the community that are evidence-based and include opportunities for generalization
- Reinforcing and generalizing what is learned in social skills instruction in daily life

Students who have been exposed to social training and who have practiced these skills with peers throughout childhood and adolescence are likely to have an easier time managing the social aspects of college and/or work. However, more complex social relations like adult bullying on the job or becoming unknowingly embroiled in office politics may sometimes be problematic. Mentors within one's job setting can be helpful in better understanding the social context of the work environment. Learning to identify someone within a job setting who is willing to play a mentorship role is a support that many neurotypical people employ in new job settings. It is part of self advocacy to learn how to request such support as an adult. Agencies that support individuals with ASDs on the job may also identify a helpful mentor. While family members or therapists can never truly know what is happening on the job and what the young person is, or is not, understanding from a social perspective, a mentor has a view of the social dynamics that can be invaluable in helping manage those issues before they result in job loss. Finally, it is critical to understand the social demands of any job so that the best possible match can be made between the student's actual skills and the job he or she would like to have. More work experiences during the transition period are likely to result in a better understanding of the varying demands across job settings.

Receptive Language

Understanding directions and requesting help is an area of weakness for individuals on the autism spectrum that must be overcome or supported for successful work. Learning how to advocate for one's needs in this area may circumvent later problems. Employers may lack an understanding of this aspect of communication deficit and naturally expect employees to speak up if they do not know what to do. Developing this ability can start at a young age if parents and teachers work together to help children find ways to express themselves, rather than self-isolate in the face of frustration. Practicing patterns of task planning, setup, and completion from the simple to the complex can help children and teens with ASDs develop the cognitive patterns and personal responsibility for understanding academic and later, job demands. The more an individual practices a positive, structured pattern of behavior, such as starting and finishing laundry or an English composition, the more likely it will be utilized in other settings.

Executive Functions

Many individuals on the autism spectrum share difficulty with executive function skills. These are the skills most associated with one's ability to organize. Many people develop ways to manage including calendars, lists, and electronic organizers. Because individuals on the spectrum sometimes have difficulty generating alternatives when problems arise, they may need some assistance in developing structures and routines within which they can then successfully function. For example, having difficulty with time management may manifest itself as not getting to work late, taking too long for lunch or

breaks, or over-focusing on an insignificant part of a job task while not leaving enough time to finish the more important aspects. Making a plan in the morning to overcome procrastination, making visual lists of things to accomplish before work, or having the assistance of a life coach or job coach to help smoothly develop new routines can help with time management. For school-aged students, such behavioral work may be included in the individualized educational plan as part of the transition to adulthood. After graduation, developmental disability agencies may be able to provide habilitation specialists if it is part of an individual's treatment plan. Coaching may be part of a college support program or may be available for families who would like to step back from too much involvement in a student's daily living tasks.

A related area is personal appearance. How one looks on the job requires a certain amount of social judgment and the organizational ability to have clothes ready to wear. Hygiene also contributes to personal appearance. These are areas where a young person on the spectrum may need some assistance. Developing an effective organizational structure (visual, lists, computer reminders, etc.) may help someone who finds this area of functioning challenging. This kind of support may be found through a personal management course for individuals on the spectrum, the services of a life or job coach, or the support of a family member.

Transportation

Managing transportation is affected by a number of factors including where one lives, the ability to drive or be able to afford a car, and the ability to utilize public transportation, including its related pressures. **(Zaks, 2006)** These issues should all be important parts of the transition plan and should be worked on from various perspectives by the individual, the school, the family and other pertinent agencies that may be offering this type of support. It is not an uncommon problem for young people on the spectrum to be trapped at home and unable to work because of transportation issues. Because there are so many other employment barriers, planning ahead in active ways is critical. Some do not drive because of spatial perception issues, difficulty processing information quickly, or poor social problem solving abilities. Driving lessons that are more supportive, and perhaps occur over a longer time than is typical for most young people, may be helpful in ameliorating some of these difficulties. However, if safe driving is not a realistic goal, specific plans need to be developed that take into account the reality of getting to work independently. This may include planning housing that is well located near transportation systems and practice at utilizing such systems.

Financial Management

Developing independent financial management skills is a process that begins in childhood and extends well into adulthood as one learns to navigate the financial challenges encountered in handling the details of daily life as well as those necessary in achieving long-term financial independence. Because individuals on the spectrum are so often uneven in achieving aspects of maturity that occur more predictably for others, parents sometimes avoid exposing their children to some of the small opportunities for managing money on a day-to-day basis. Managing small amounts of money, engaging in banking activities, or having an after-school job in high school can all be steps toward having a more mature concept of financial management. Such activities can be important ingredients in a transition plan for a student on the autism spectrum.

Self-Presentation

Self-presentation is a critical element of obtaining and keeping a job for which individuals on the autism spectrum often need special support. Their difficulty with theory of mind (seeing others' perspectives) makes it problematic for them to understand how others perceive them through their resumé, personal appearance, or performance on a job interview. If these elements are part of a well-integrated transition plan and have been practiced and rehearsed during the adolescent school years, it is more likely that obtaining a job will be successful. **(Cohen, in press)** However, for students who are integrated into mainstream settings, there is frequently little preparation for anything but academic pursuits. For mainstreamed students on the autism spectrum, it is necessary for individuals and their families to strongly advocate for specific training in preparing for the workplace and not being content with "will go to college "as a transition plan. Students need support in the following areas:

- Developing an effective resume or portfolio of work **(Fast, 2004)**
- Understanding important personal appearance standards
- Presenting oneself from the beginning as an organized, effective person
- Performing well in job interviews, including anxiety management

Workplace Behavior

Although obtaining employment presents a problem for young adults on the autism spectrum, maintaining a job can be equally challenging. Here a weakness in social problem-solving can sabotage an employee with otherwise excellent job skills. This is another area that should be well delineated on the transition plan and is particularly important for those students who are following an academic pathway toward college. No matter what degrees are obtained, being able to socially interact on the job is always an important part of maintaining employment, yet one that academically talented youth are seldom taught in high school. Even students on the spectrum who are in more self-contained special education settings may not receive training sufficiently specific to their particular disability. Some job support agencies try to prepare young adults for problems they may encounter on the job but, again, to help someone whose primary disability revolves around social interaction requires true expertise in the autism spectrum conditions. The best way to acquire workplace management skills is through an active transition plan mandated by IDEA. Under special education mandates, a student classified as being in the autism spectrum should be eligible for appropriate services provided by educational staff, who have expertise in the autism conditions. Of particular importance is developing workplace skills in the following areas:

- Being a good self advocate by understanding when it is appropriate to seek help or make a complaint about work conditions
- Controlling emotional expression in the workplace
- Understanding how to resolve conflict in workplace settings
- Identifying a supportive person in the workplace who can act as a mentor for confusing situations and day-to-day questions
- Recognizing typical social conflicts that occur in any work setting and having a plan of action for resolving them

For example, workplace aggression or bullying is not easy for anyone to manage, and current data tell us that it is becoming an increasingly common occurrence **(Neumann, 1998)**. For individuals on the autism spectrum who may have endured bullying as children and teens, having such experiences impinge on their adult life may bring back a flood of old negative emotions. Someone who has prepared for and

practiced social problem-solving and conflict management has developed a strategy that can help when these types of experiences occur.

Given the broad range of issues that need to be addressed and the relative lack of awareness in some school settings regarding the special transition planning needs of these individuals, one way to promote the development of the many competencies required for adult independent life is to create an ongoing course designed for college-bound and high-functioning work-bound individuals on the spectrum who have the potential for leading an autonomous life. Such a course can provide information and direct experience in a number of crucial areas that students on the spectrum in mainstream high school classes typically do not get, yet need to understand if they are going to function on their own. Although a given high school may not have a sufficient number of such adolescents to create the necessary enrollment for such a program, if offered on a district-wide or regional basis, this can be a cost-effective way to more adequately address the educational mandate of transition planning.

Schools have been offering similar courses for self-contained special education students for years, but seldom do mainstreamed students have such exposure. For students on the autism spectrum who are being mainstreamed, there is a real need to learn some of these life skills specifically and directly. Such a course needs to encompass the following characteristics:

- It should be delivered by someone knowledgeable and experienced about autism spectrum conditions and their adult manifestations
- Professionals with specialized and practical knowledge about the world of work at all levels should play an important role in instruction
- Manualized, evidence-based approaches should be utilized
- The material should be delivered with sufficient intensity to address the needs
- A primary goal of the intervention should be to help the individual become a competent self-advocate
- Some of the instruction should occur in natural work environments
- Explicit plans for generalization should be a core dimension
- While the goal is to help support individuals becoming independent at work, it is important to help them realize when they have a need for support and the appropriate mechanisms that may be available, including job coaching, mentorship, and adult developmental services

Further Education

For the families of a student with an autism spectrum disorder, the typical rite of passage to adulthood through a college experience raises an issue that has recurred throughout the young person's life: identifying and addressing the needs of a child with a widely uneven profile of strengths and shortcomings. Like the transition from elementary to middle school, transitioning to college brings with it a host of new challenges. The family must again realistically assess the strengths and weaknesses of their son or daughter, as well as have frank conversations with their child as part of the planning. Many families are so concerned about this transition that they fail to allow for any individuation to occur. Others naïvely assume that the transition will proceed smoothly because their child is finally entering a system where their intelligence will be appreciated.

One of the many changes for the young person and family is the recognition that students over 18 are considered to be adults; therefore, parents will not receive communication about their son or daughter

unless a waiver has been signed by the student and specific agreements have been made with college staff. It is important to realistically assess how communication works between parents and student. Is it likely that the student will confide problems that occur, or is the student's style of communication less forthcoming? As poor communication skills are a hallmark of autism spectrum conditions, keeping important communication lines open is significant and can greatly affect adjustment at college.

Going to college or other post-graduate training should always be a means to an end and not the sole end point of transition planning. Unfortunately for many students with high functioning autism and Asperger Syndrome, their sole transition planning goal has been reduced to "going to college," rather than recognizing this transition as an important component of overall preparation for adult life. For these students, this planning should begin in early adolescence and focus on life and career goals, rather than solely on academic achievement. It should also emphasize attaining independence in as many areas as possible. Families need to remember that the services the student received during high school should be part of the equation in considering what supports may be needed in college. Also, during these planning years, it is important to consider what supports can be phased out successfully before college with the goal of independent adulthood in mind. Families and students need to know what can be realistically expected at college and aim to create independence with those possible supports in mind.

Students, their families, and their educational team need to consider the following aspects of the young person's functioning during the planning period before college:

- Academic: what modifications have been in place and how does the student perform in various types of the classroom settings?
- Psychological well-being: what therapies and medications are currently being utilized?
- Physical well-being: how independent is the student in managing his own exercise, medications, diet, and sleep cycle?
- Social: how are the student's basic social skills and relationship development skills? Does the student have a social network upon which he or she can depend?
- Life coaching: is it realistic to expect the student to be able to function independently in basic life skills or is it necessary for that student to receive coaching support services in order to live successfully at college?
- Family life: how much support has the family been giving the student and is it realistic to assume that that student can be successful living away from home?

All of these factors must be realistically discussed among the family, student, and educational staff who have been supporting that student, long before the application process to college begins. Then potential colleges can be chosen that have a good chance of meeting the student's needs.

Assessing Readiness

For young people going away to school, college is often their first experience in living on their own. Many college students are not totally ready to manage all aspects of independent living, but it is important to learn how to do so. For students on the autism spectrum, these challenges may be

particularly acute. Important practical questions to consider regarding the young person's skill set include:

- Has the student been managing money during high school?
- Does the student drive and will driving be part of the college experience?
- Is the student experienced in doing laundry, caring for clothes, and shopping for necessities?
- Is the student responsible for physical health issues such as eating properly, getting enough sleep, and taking medications as needed?
- Does the student seek medical and mental health care when needed?

While many families have been providing support in these areas, it is unrealistic to expect that students without experience in managing these aspects for themselves can suddenly do so. Therefore it is highly advisable that these types of self-care activities be supported and practiced in the years preceding college. A student with significant deficits in self-management may well need the support of a coach or other designated adults to avoid becoming overwhelmed by such challenges while trying to adjust to the college experience.

Communication

Parents want their sons and daughters to be able to express their needs and wishes effectively and advocate for their own benefit. But how does a young person become an effective self-advocate? **(Reiff, 2007; Hane et al., 2004)** Before a student goes to college, parents might want to ask themselves the following questions:

- Does the student fully understand his or her diagnosis, its implications, and the issues that may arise at college?
- Is the student capable of communicating individual needs calmly and effectively?
- Does the student understand the complexity of disclosure in terms of to whom, how much, and when?
- Has the student been practicing self advocacy through participation in meetings regarding the individual educational plan?
- How does the student cope with frustrations when specific needs are not met?

The answers to these questions should help determine what assistance is needed to enable the student to navigate the various support systems within the college setting either independently or with some judicious help. To receive any accommodations on campus, it is necessary to disclose one's specific needs to the disabled student services office. To be eligible for services from this office, there must be specific documentation of the student's disability. Then professors are made aware of the specific accommodations required for an individual student, but the specific disability is never disclosed to them. In some cases, students may wish professors to have a better understanding of their needs, but it is up to them to disclose this information. This is why it is important to have a discussion with the young person beforehand about who needs to know what and why those people need to know it. This may help the student begin to better understand defining boundaries regarding self-disclosure, another frequent area of difficulty for individuals on the autism spectrum.

High School Versus College

Exactly what are the major differences between high school and college for students on the autism spectrum? **(Bedrossian & Pennamon, 2007)**

In high school their days are filled and structured, but in college their time is rather unstructured with, at times, few actual hours of instruction. Structure is generally very helpful for students on the autism spectrum and many find organizing their time and creating their own structure quite challenging. In high school, teachers often give many small assignments. They may collect them daily or structure long-term assignments by having deadlines for the component parts. In college, professors often give large, infrequent assignments that require even more extensive planning, but they do not provide students with a time line for each step of the assignment. For students with weaknesses in executive function, assignments with no organizational boundaries can be overwhelming. It is critical for students on the autism spectrum with this type of deficit that supports be put in place to help them learn this important skill.

In high school, much of students' time is planned by adults, be they parents, teachers, religious leaders, or coaches. In college, while there may be many similar demands on time, it is almost entirely up to the student to plan how time is spent. In high school, there is mandatory attendance of classes. This imposes an external structure that makes it very difficult for a student to skip class because an assignment is not completed or because he or she is feeling anxious about what may happen in class. In college, attendance is generally not mandatory. This lack of structure can work against the student who uses avoidance to handle stressful situations. For example, students on the autism spectrum who have poor communication skills may feel overwhelmed by being unable to ask a professor for clarification on an assignment or for extra time to complete it. This circumstance frequently leads students to continue to skip class until they are so far behind, the situation is almost irretrievable.

In high school, there is almost constant adult supervision of academic work, self-management, and social behavior. In college, there is little day-to-day supervision. Resident life is frequently managed by other students who have little sophistication about the significant issues that may confront a student with an autism spectrum disorder. Awkward social situations often get out of hand before notice is taken by college staff and many a student is asked to leave campus before he or she understands what has happened. Naïve social skills, for example, may be incorrectly interpreted as stalking behavior and lead to expulsion. Making a realistic assessment of a student's social coping skills and putting needed supports in place before such a crisis occurs is always indicated. A common strategy is to involve a therapist familiar with the autism spectrum at or near college who can help a student through some of the new social experiences that will inevitably occur. In addition to providing more traditional psychotherapeutic support, such a therapist can effectively serve, in essence, as a one-to-one social skills instructor.

Academic Level

For so many students with autism spectrum disorders, academic functioning has been their strongest area of achievement. Therefore these students and their families may tend to seek a college situation where the highest level of academic challenge is available. However, it is important to consider the academic level of the college in context with all other issues.

The academic level of the college needs to be such that students can concurrently achieve goals for independence and vocational exploration and not be totally overwhelmed with focusing on academic demands. Many young adults with autism spectrum disorders have all sorts of college and graduate degrees yet are unable to establish a fulfilling vocational life. Therefore, choosing a school where the

student is most likely to graduate with the ability to maintain employment and lead an independent life is sometimes more important than a school that solely excels in academic opportunities. Unlike neurotypical students who may be able to parlay a liberal arts education into a decent job with little specific training, students with autism spectrum disorders often lack the social skills, flexibility and ability to generalize that are necessary to “fit” into an unfamiliar job role.

IDEA Versus ADA

As one begins to plan for college, it is critical to understand the difference between IDEA and Americans with Disabilities Act (ADA). Many students with autism spectrum disorders have been granted educational support services based upon their classification under special education law. Every year their programs have been reviewed and (at least in theory) appropriate support mechanisms have been put into place. All school-aged students have a legal right to a free and appropriate education, and special services must be put in place to ensure that this occurs.

The situation is quite different under ADA, where there are no specific rights except that a person cannot be excluded from participation based solely on his or her disability. In a college setting this means that reasonable accommodations may not fundamentally alter programs or academic standards. For example, if a student is a physics major, he or she probably cannot ask to be excused from mathematics. However, if a student is a visual learner, he or she may be able to request pre-class notes if the professor agrees. ADA is much more open to interpretation and negotiation and the student must be ready to help make those negotiations independently. Disability offices on college campuses are much more familiar with helping students with learning disabilities or physical disabilities develop needed supports and accommodations than they are with students with autism spectrum disorders. The combinations of supports needed for young people on the autism spectrum can be more variable and require more creativity than the supports needed for their neurotypical counterparts. Functioning in the areas of academics, social interaction, life support, and career planning may all need some measure of specialized accommodation to ensure a successful college experience. Therefore the college experience needs to be carefully planned and the availability of a major that has direct, practical applicability to a specific job should be a factor in college selection.

While supports cannot fundamentally alter programs or academic standards for students, typical issues for individuals on the autism spectrum that can receive support are time management, multiprocessing, understanding the larger picture, prioritizing responsibilities, and organization. Aspects of time management skills that may require support include waking up and getting to class on time, limiting time on the Internet, planning large assignments and anticipating accurately how long studying may take. Some students may have difficulty with multiprocessing -- for example, taking notes while listening to a professor or looking and listening at the same time in social situations. These students may need support from an autism expert in practicing quick shifting among incoming channels in social situations or identifying ways of obtaining information presented in class such as sharing notes or tape recording lectures. One style of learning, such as auditory or visual, may be more critical to students with autism spectrum disorders than it is to more typical students, necessitating the ability to self-advocate about just what they need to succeed.

The concept of central coherence is frequently a difficult one for students on the spectrum. Central coherence implies that one can abstract larger meaning from a series of details. Sometimes this is conceptually difficult for students with autism spectrum conditions, who tend to be better at learning information than abstractions, making certain kinds of courses more difficult for them than others. A

student with this difficulty and his or her family should pause before considering applying to a college requiring a heavy distribution of more philosophical or literary courses and instead seek out more information/content/fact-based programs such as computer science or engineering, which may present fewer impediments for the young person.

Specific Supports

Many college disability offices offer seminars for students with organizational problems in the summer or early in freshman year. Taking such a course may help the student develop strategies for college work and also provide an opportunity to interact with the staff who may become valuable supports throughout the college years. Setting up a plan with the disability office and developing a relationship with the school's disability officer before the student starts college is highly advisable. Averting potential problems with confidentiality by making sure the proper releases are in place will allow communication between the young person's parents and the disability office and pave the way for collaborative, and hopefully proactive, planning. It is important the disability office comes to view the student's family as a resource rather than as over-involved, and anxious parents who are having difficulty letting go.

Social Aspects of College

For many students on the autism spectrum, the social aspects of college are the most difficult. While they may look forward to attending college to establish a new identity, they will be taking with them the same often-limited set of skills that have restricted their social functioning up to that point. Issues that may be challenging for some students include eating in the cafeteria, approaching and joining organizations, finding potential friends with similar interests, and surviving dormitory living. Additional problems may include a tendency to dominate class discussions, having difficulty understanding how his or her behavior in classes is perceived by others, and finding classmates who can be counted on for notes and/or homework help or who may be potential study partners.

Many students on the spectrum rely on specific patterns of behavior they have developed to understand social expectancies in the new environment of college. But the spontaneous sociality and new experiences of college can particularly strain these resources by requiring entirely new ways of behaving the student is not anticipating. Issues such as getting along with roommates, making new friends, and interacting with potential romantic partners represent the typical challenges for all young adults in college. Such problems should be anticipated and worked on during the years preceding college with therapists trained in the development of social skills and social cognition. It is important to bear in mind that there could be serious ramifications for social impropriety, albeit unintentional, at college.

How can families help their students be ready for these kinds of social challenges? Different colleges have widely different social milieus. Together, students and parents should investigate the social culture of any college they are considering. Students on the spectrum are generally likely to do better in atmospheres where diversity is appreciated and unique individuals are valued, rather than campuses that appear to value a person based on his or her success at conforming and achieving within more narrowly defined norms. . Campuses that have specific programs or supports for students on the autism spectrum may tend to have an atmosphere of greater tolerance and understanding. Such programs may help avert the potentially serious consequences of inappropriate social behavior by helping students become more adept at social communication, appropriate social distance, and approaching the issues of dating, romance, and sexuality. Families need to realize that in the long term, these aspects of college

life may be more critical for their child's success than the criteria young people and their families more typically utilize during the college selection process.

Establishing a Network of Support

Lists of what the typical college student needs to succeed on campus often read like a list of what our "atypical" college students find most difficult. Generally such lists include:

- Having self-directed study habits, including being able to study large amounts of information for tests and planning and executing long-term assignments
- Being able to advocate for themselves with professors, college administration, and other students
- Being prepared for class and organizing their studying and work assignments
- Being timely in both getting to class and completing work
- Keeping themselves and their room clean and organized
- Understanding appropriate classroom and campus behavior

Therefore families and their students should be realistic in assessing what supports are necessary, who needs to be part of a support network and the intensity of the supports that are indicated. It is easier to remove supports when they are no longer needed than to frantically put them in place to avoid failure. It is important for the team of individuals who have been supporting a student, including special education personnel, individual therapists, parents and other family members, tutors, or coaches to discuss with the student the supports that have been of help before college, and how they can be implemented in a college setting. The understanding that comes from this discussion should help guide not only college selection but the development of a specific plan for support at the chosen college. More and more colleges are developing specific supports for students on the spectrum, including specific housing, mentors, support groups, and coaches. In other college settings, students of the spectrum may take advantage of generic services from a counseling center, the disability office, or tutoring services, but there may be no specific expertise in autism spectrum disorders.

Once a college is selected, the process of negotiating services and finding local support resources that may meet student's specific needs should begin. The goal of creating a team is not to infantilize the young person, but to put in place a specific group of people who can assist the student in taking the next steps toward independent adulthood. Parents who had fulfilled all of these roles for years need to give careful consideration to how they can step safely away from this responsibility, while providing their son or daughter with opportunities for growth.

If there were mental health professionals involved in ongoing care, every effort should be made to locate similar individuals at or near the college and to interview to determine their expertise and compatibility with the student. College coaches can be particularly valuable during this period as their time may be more available and affordable. They should possess the requisite characteristics of knowing what is needed for students on the spectrum and being able to work cooperatively with the student and college staff to help actualize individual goals. Unfortunately, finding qualified coaches can be challenging and may require a large investment in networking or even supporting a likely candidate to receive training. But the more frequent presence of a coach and the more adult-to-adult relationship that coaching entails can be an extremely positive influence for the young person's emerging independence. Colleges may be able to suggest such individuals or may have such support available through more specialized programs for students on the spectrum.

There are colleges with more ornate support services designed for students with special needs and they should be investigated as viable alternatives for students who have such uneven patterns of development that they are truly not yet ready to be on their own. Community colleges may also be a very appropriate bridge to a four-year college, as many have excellent support mechanisms and allow the student to spend some more time at home while developing some maturity in managing adult life. It may be an appropriate plan to save living on a campus for later and to allow the student to adjust to studying, managing time, and functioning with professors and other students before tackling the idea of living away from home.

Whatever the particular needs are, the planning process should be a cooperative endeavor begun by the transition team and followed up on by the group of individuals who will become the new support network for the entering freshman. The development of a new team also supports the changes the parents will be making in the frightening process of allowing their son or daughter to find a place in the world.

During orientation, all college students are presented with a code of conduct. It is particularly critical that students on the spectrum read and understand this document. Having a social disability is never an excuse for infractions of this code; therefore, it behooves all families to consider carefully the explicit rules and the implicit social understanding that underlies them. Going over this document together and perhaps creating a short list of concrete social rules is a good strategy for helping students understand what is expected of them. Generally, college students on the spectrum appreciate the structure of having rules but may not always understand all the social subtleties they contain. For example, how much is too much contribution to class discussion versus showing interest and enthusiasm? Students on the spectrum may be dogmatic, tend to dominate discussions, attempt to participate too often in class and alienate their professors and fellow students.

Preparing for the World of Work

Many families do not encourage their children to seek out job experiences during high school because they feel their son or daughter need to concentrate on academics and other critical aspects of development. Even in college, families may feel that working is a distraction from the main reason for attending college. However, we know that under- and unemployment remain chronic problems for these individuals. Thus, it is very important for the family and student to jointly consider the importance of a vocational goal and the critical steps needed to achieve it. All jobs have social aspects and it is critical that students begin as early as possible to appreciate the social skills necessary for their own successful employment.

Because some students on the autism spectrum find it difficult to imagine situations outside of their own experience, concrete work experiences can best help them in establishing realistic expectancies for college majors and career directions. Volunteer work, internships, and part-time paid work can all be successful steps toward the ultimate vocational goal of full-time paid employment. In addition they can provide valuable experience in finding and obtaining work, writing resumes, and being interviewed. Establishing a realistic career path is critical to later employment because, unlike more neurotypical students, individuals on the spectrum need to have a more specific skill base and not rely on social skills and social connections to find initial jobs. In high school, learning about jobs and the world of work should be part of the student's individual transition plan. In college students need to be assertive in finding these kinds of opportunities as their value in helping young people achieve eventual independence cannot be overemphasized.

Conclusion

The transition from late adolescence to independent young adulthood is a long and gradual process that begins years before the young person is approaching high school graduation. As they have in earlier stages of the young person's development, parents need to be well-informed advocates and self-aware regarding the ways they may create obstacles or inadvertently promote unnecessary dependency in their son or daughter. And, while it also requires the supportive involvement of a motivated, cooperative, and skilled team of education, mental health, and vocational professionals, it is ultimately the young person approaching the transition who must be at the core of this process. It will come as no surprise to the family and professionals who work with this population that it is an imperfect world with less than optimal choices. There is a clear need for additional supports and programs for these individuals who tend to be perceived as "not disabled enough." But despite these realities, young people with AS and HFA and their families should remember that there are many individuals with AS and HFA who have crossed this seemingly great divide and have gone on to lead as independent, productive, and satisfying lives as their neurotypical counterparts.

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