

Roger Pugh, M.A.
Carbondale
Developmental Skills Training Specialist
Achieve Program

Southern Illinois University
870 Lincoln Drive
Mailcode 6832
Carbondale, IL 62901

(618) 453-2369
rpugh@siu.edu

www.siu.edu/~achieve
achieve@siu.edu/~achieve

**Students on the Spectrum and their Families: 10 Key Questions to Ask Your
Post-secondary Institution Service Providers**

Briefly, about me: My name is Roger Pugh. I completed my degrees from SIUC. In this field, I worked first as an undergraduate tutor, then as a graduate assistant for the Achieve Program. Achieve is a comprehensive academic support program for students with diagnosed learning disabilities, attention deficits, and other learning differences for university students at SIUC. After I completed graduate studies, I came back to Achieve when a full time position was available. I have worked at Achieve for 16 years. What is important to know: For me, on this side of the podium, this is the same information I always discuss, and for many of you, you may have some, or maybe even all, of this information. But it may be useful to you to know the common questions students and parents need to know how to ask and how to answer.

We are talking about an amorphous group---non-homogeneous students on a spectrum of autism disorders. This umbrella includes autistic disorder, also called "classic" autism; Asperger's Syndrome; Pervasive Developmental Disorder NOS, also referred to as atypical autism; and more generally PDD, which can

also include Childhood Disintegrative Disorder, and Rett Syndrome. Along this spectrum, one also might include Non-verbal Learning Disability, and severe ADD. They are difficult to categorize---but there are general characteristics which are associated with people with ASD:

The main signs and symptoms of autism involve language, social behavior, and behaviors concerning objects and routines:

- Communication—both verbal (spoken) and nonverbal (unspoken, such as pointing, eye contact, or smiling)
- Social interactions—such as sharing emotions, understanding how others think and feel (sometimes called empathy), and holding a conversation, as well as the amount of time a person spends interacting with others
- Routines or repetitive behaviors—often called **stereotyped behaviors**, such as repeating words or actions, obsessively following routines or schedules, playing with toys or objects in repetitive and sometimes inappropriate ways,

or having very specific and inflexible ways of arranging items

People with autism might have problems talking with you, or they might not look you in the eye when you talk to them. They may have to line up their pencils before they can pay attention, or they may say the same sentence again and again to calm themselves down. They may flap their arms to tell you they are happy, or they

might hurt themselves to tell you they are not. Some people with autism never learn how to talk. These behaviors not only make life challenging for people who have autism, but also take a toll on their families, their health care providers, their teachers, and anyone who comes in contact with them.

Because different people with autism can have very different features or symptoms, health care providers think of autism as a “*spectrum*” disorder—a group of disorders with a range of similar features. Based on their specific strengths and weaknesses, people with autism spectrum disorders (ASDs) may have mild symptoms or more serious symptoms, but they all have an ASD (NICHD, 2005).

Students diagnosed with Asperger's Syndrome and autism spectrum disorders (ASD) comprise a growing segment of the population of students with disabilities (Centers For Disease Control and Prevention, 2007). The prevalence of ASD has been rising annually 10 to 17 percent over the past decade (Hart, Grigal, & Weir, 2010). Current estimates consider the prevalence of ASD to be close to 1 in 100 individuals (Kogan et al., 2009; Williams & Williams, 2011). As the numbers of students with ASD has increased, the number of students with ASD pursuing post-secondary education has increased as well (Wenzel & Rowley, 2010).

Traditionally, post-secondary education has not been considered an option for students with ASD (Causton-Theoharis, Ashby, & DeClouette, 2009),

but this expectation has changed over the last decade. Though many students with significant disabilities stay in high school until age 21, a growing population of students with ASD are continuing their education in post-secondary settings (Causton-Theoharis, Ashby, & DeClouette, 2009; Eastman, 2010). Approximately half of youth with ASD but without intellectual disabilities pursue post-secondary education (Taylor & Seltzer, 2010). Though they participate, often their participation is not a typical, fully integrated college experience (Weir, 2004). Because ASD represents a wide spectrum of abilities and deficits, creating and implementing interventions for the population is difficult (Allen & Heaton, 2010). Few colleges and universities are confronting the realities of a student body with a growing number of students with ASD (Camarena & Sarigiani, 2009; Eastman, 2010; Hart, Mele-McCarthy, Pasternack, Zimbrich, & Parker, 2004).

Students with ASD encounter transition, accommodations, and coordinated service problems as they advance to and complete post-secondary education. A lack of coordination of care exists among educational institutions and service providers as students with ASD prepare for transition to post-secondary education, once they enter post-secondary education, and as they matriculate through post-secondary education (Eastman, 2010; Geller & Greenberg, 2010; Hart, Mele-McCarthy, Pasternack, Zimbrich, & Parker, 2004; Stodden & Whelley, 2004). Students with ASD complete high school to find that there are few post-secondary institutions that provide specific services or programs (Kravets, Wax, & the Princeton Review, 2005; Raymaker, 2009; Wenzel

& Rowley, 2010), or that the services or accommodations are not comprehensive or integrated enough for their needs (Littlefield, 2010; Stodden & Whelley, 2004). Of the models for accommodations and services or programs that do exist, information on the effectiveness of the approaches is limited due to insufficient research on recommended practices (Briel & Getzel, 2009; Littlefield, 2010).

There are three main areas of support in which service gaps, or a lack of integration and coordination of services, creates or exacerbates problems for students with ASD who wish to access higher education. First, there is a lack of appropriate transition planning and transition services in high school (Eastman, 2010; Griffin, McMillan, & Hodapp, 2010; Hetherington, et al., 2010; Hurewitz & Borger, 2008). Transition to post-secondary education is a more complicated process for students with ASD because of the manifest expression of ASD across all components of campus life; this problem is by multiplied by transition teams who do not know how students with ASD present (Griffin, McMillan, & Hodapp, 2010; Leventhal, 2005). Secondary and post-secondary institutions have an opportunity to form policy together to reduce the likelihood of conflict, but rarely develop joint policies (Madaus & Shaw, 2006). Barriers in communication exist among schools, families and non-educational agencies, often resulting in conflict (Leventhal, 2005). Because information is not disseminated, parents, schools and agencies do not know how to perform results-driven planning or provide effective transition (Leventhal, 2005).

Second, there is a lack of appropriate services, accommodations, and transition planning at the post-secondary level (Littlefield, 2010). The comprehensive social, mental health, academic, and life skills support that students with ASD need typically fall outside the boundaries of required accommodations (Hart, Grigal, & Weir, 2010). Students with ASD might experience executive functioning difficulties, communication issues, socialization issues, and poor coping mechanisms in overstimulated environments, accommodations for which would be outside of standard accommodations (Hart, Grigal, & Weir, 2010; Zager & Alpern, 2010). Once students are in the post-secondary institution, programs to provide transition planning for navigating campus life and culture are not geared towards the needs of students with ASD (VanBergejk, Klin, & Volkmar, 2008).

Third, there is a lack of integration and coordination of care among the stakeholders and service providers who are available to participate in appropriate services. A small but growing number of institutions offer specialized services for students with ASD (Camarena & Sarigiani, 2009). However, it is still incumbent upon students or families of students with ASD to coordinate the options, accommodations, and different service providers. This requires interpersonal skills, and an understanding of the social contracts required to navigate different systems effectively, a skill set which is typically a deficit area for students with ASD (Hurewitz & Berger, 2008). More specifically for the State of Illinois, Leventhal (2005), in the *Autism Task Force Report*, outlines additional

challenges, including insufficient statewide technical support and training, underutilized transition planning technology, insufficient qualified personnel, limited professional development, teacher-education programs which lack training in best practices, a lack of coordinated, integrated services, no ownership of responsibilities and interagency cooperation, and no one in the highest levels who champions the cause of students with ASD.

Though the official title of the presentation today is “10 questions,” we really can distill this into one big question: What next? The answer to that question has changed dramatically over the last few years, and will likely continue to change. Fundamental questions about the purpose of college are being challenged, that speak to the heart of issues students with ASD present. As important as these philosophical challenges are, the campus climates towards people with ASD, the invisible attitude which permeates institutional culture, is also changing in response to increasing numbers of students with ASD on campus. You can apply the five stages of grief to this attitudinal shift!

Denial: These kids won't make it into college; we won't have to worry about them *here*.

Anger: These kids shouldn't make it into college! They are not college material! I'm a teacher, not a psychiatrist! They will ruin the reputation of our school!

Bargaining: Well, I don't mind if they are on campus, as long as I don't

have to alter what I do.

Depression: What a world, in which I have to teach students like that in my class. I'm no longer in control of my own teaching destiny. This is not what I signed up for.

Acceptance: I recognize that these students are students first, and offer a unique challenge and perspective for me and my class. I am glad I improved my teaching skill set to be a better teacher for all of my students. In the process, I became better at expressing my own concerns and expectations for appropriate behaviors in my class.

Following those stages, I would suggest that as individual professors, departments, and institutions gain more experience with this group, they will move to a sixth stage, recruitment! We are beginning to see this occur, though different people and institutions are at different stages.

Question 1

To prepare for what is happening next, you should consider what is happening right now in your family, and in your student's life. So, your first question might be: "What are we doing right now to prepare for the transition to post-secondary education?" Whenever "now" is for you, if you are parents of a freshman or a senior, you need to assess what you know will be difficult, specifically, the transition from secondary education to post-secondary education. Are you meeting with your transition IEP team? Have you begun to develop a list of realistic and attainable goals for your student? Have you

worked to remediate executive skills, develop cognitive strategies, follow behavioral plans, and to implement technology for accommodations? Is your student building self-regulation, efficacy, and advocacy skills? Are those skills reinforced across settings? Are you researching all of the options that are available to you? Have you worked to coordinate your students' aspirations and goals with your school counselor, IEP team, community service providers, and potential college matches? These activities are all things that need to happen now. This process will take longer for you than for the next family. Plan now.

Question 2

Coordinating resources for a smooth transition is hard, but you should depend on your family, school, and others for help in reaching your goals. However, you might ask yourself, as the student getting ready, "What can I do, myself, personally, now, to ready myself for this transition?" You can work to improve your abilities in five key areas: Self-regulation, self-efficacy, self-advocacy, independence, and involvement.

Self-regulation and self-efficacy are essentially cognitive skills you can develop. Self-regulation involves a person carefully observing and considering his or her own behaviors, and acting upon those behaviors to decrease negative behaviors and increase positive behaviors. Students who self-regulate are continually asking themselves, "Does this strategy work for me in this situation?" In order to self-regulate, students must shift their focus

from comparing their performance to peers to self-comparisons, and from being reactive to being proactive learners. Goals direct activities, and students must learn that there are different ways to attain goals, and how to select the best way to complete a specific task (Garcia & Pintrich, 1994; Pintrich, Smith, Garcia, & McKeachie, 1993).

Self-efficacy describes a person's beliefs in one's own ability to manage the situation at hand. According to Bandura, people with a strong sense of self-efficacy:

- View challenging problems as tasks to be mastered.

- Develop deeper interest in the activities in which they participate.

- Form a stronger sense of commitment to their interests and activities.

- Recover quickly from setbacks and disappointments.

People with a weak sense of self-efficacy:

- Avoid challenging tasks.

- Believe that difficult tasks and situations are beyond their capabilities.

- Focus on personal failings and negative outcomes.

- Quickly lose confidence in personal abilities (1997).

In order to improve self-efficacy skills, you should engage in a conscious cognitive strategy to assess responsibility and attempt tasks at which you can succeed, but also challenge you. Your parents and instructors can facilitate this by assessing tasks themselves and evaluating your progress on tasks. These are difficult requests to make of any person, but in so doing, you can gain the

confidence to approach a task as something to do which will improve your skill and confidence.

You should build self-advocacy skills. You'll hear that term a hundred times before you're through high school. What does it mean? Primarily, and this can be hard, that you understand and accept that you have a disability, but that you're not defined by a disability, and that a teacher, or school has an obligation to provide accommodations to you. Our job is not to measure your disability, but your ability. Accommodations help us do that accurately. You must be confident in your ability to explain your needs to others. That's what being a self-advocate means. It takes courage, determination, and the necessity, sometimes, to educate those who don't understand your needs.

Be as prepared as you can to be independent. You will have more time, more responsibilities, more decision making power, and far fewer controls over your life. College can be a difficult transition. What you learn now, about how to manage your time, plan and prioritize the things you have to do, and function without the Mom and Dad alarm clock may determine your success.

And, be involved. Studies show that students decide to stay or leave a campus within six weeks of starting school, primarily because they either feel connected to their school community or they do not. Take the time now to engage in other activities at school besides school.

Question 3

Perhaps the next question you might ask would be “What are my options for post-secondary education?” Education can take many forms---life skills training programs, college living experience programs, trade or technical schools, apprenticeships or internships, open enrollment schools or exclusive schools, junior college or four-year colleges or universities. Some colleges might be specialized schools providing comprehensive services for unique populations, others might be more traditional schools which offer specialized or comprehensive services, while others might be standard schools with mandated or required services for students with disabilities. Your choices are greater now than ever before, and will continue to expand. For many of you, the “traditional” college will present unique challenges which many disability support service providers are not required to accommodate, so specialized services or settings might matter. Even within specialized services providers or settings, there are a variety of options, which can be described along four axes:

1. exclusive-to-inclusive models;
2. center-based-to-campus-based models;
3. independent service-to-integrated service models; and
4. public funded-to-private funded models.

What might be best for you is not the same as what might be best for another person, but below, I have presented how our model fits along these axes.

Following recommendations for best practices described in the emergent research on programs for students with ASD at post-secondary institutions (Causton-Theoharis, Ashby, & DeClouette, 2009; Zafft, Hart, & Zimbrich, 2004), the inclusive model provides students with individualized services and supports while students are taking classes with peers in the traditional college setting (Scott, Clark, & Brady, 2000; Briel & Getzel, 2009). Inclusion is our core philosophy guiding the success of students with ASD in the college setting.

If the inclusive model supports best practice, it follows that campus-wide service delivery is a best practice goal as well. Even if a college has a specific program or center for students with ASD, services should not stop at the door of the center. Students with ASD will need services which might extend into dormitory living, campus buildings, and off-campus activities. A campus-based approach is a more flexible than a center or off-campus based approach for an inclusive program.

The program should be integrated. One of the principle activities of a comprehensive campus-wide program is to coordinate services among and between a variety of service providers who might work with students with ASD, to collaborate with other on campus offices and off-campus agencies to provide better services, and to create and integrate new services into the supports that each student receives.

Our model is a fee-for-service program, but grant-funding, internal funding, and other sources can fund specialized services or programs. How programs are funded determine their flexibility and longevity.

Question 4

Once you understand the options, you must visit the schools that fit your goals. You might ask “Why, how, when, and with whom should I schedule a visit?” There is no substitute for a visit to a college. You can listen to other people, look at it online, or read about it, but until you actually go and get a firsthand opportunity to see it and talk to the people that you will have to negotiate with as you complete school, you won't have a good sense of the fit. Usually, a school has a new student admissions office, or a campus visit office, or someone to coordinate and help you plan your visit. Make sure that a part of your visit includes an opportunity to speak with a representative of the disability office or specialized support program. See if you can arrange to speak with somebody there about how he or she has used services or adapted to the campus. Speak with people from housing, from financial aid, and from departments in which you are interested. Do not be afraid to ask them direct questions about what they do, and how they will work with you. If you can coordinate your visit with other things that are happening on campus, then attend or participate in those events while you are there. Really soak it in. That may be the place you invest a couple hundred thousand dollars in!

Question 5

Once you have identified some schools that might be a good fit, you will need to apply. You might ask, "What is the application process like for most colleges? Is it any different for students with ASD? What information is typically needed in order to process an application for admission? What information is typically needed to process an application for the office of disability support services or for a specialized program?"

Application processes differ for each institution. Some schools may have open admissions, which means that students do not have to meet a minimum ACT requirement, for example, to register for classes. Some schools have specific requirements. Others might depend more on personal statements and recommendations for admission than strict academic requirements. I can speak for SIU, and generalize, that the admissions process for students with disabilities is no different than the admissions process for other students. For schools that have specialized programs, those programs will make recommendations to admissions to admit those students. However, even for specialized programs, students still have to submit all required material. A typical university admission will require the submission of high school transcripts, an ACT or SAT score, contact information, social security number, possibly a recommendation letter, and usually some application fee. An office of disability support typically needs current diagnosis of disability, current records of accommodations with support for those accommodations. I hesitate to say simply submit the current IEP,

because IEP's are put together in very different ways in different school systems. Sometimes IEP's contain everything you need to submit to a disability office. Sometimes they do not. The best first step is to contact the disability office of the school you are interested in and ask for exactly what they need. Specialized programs often need more information, will have separate applications, and might require interviews, or that you complete a battery of tests with them before you are accepted into their programs. You should check with those programs to see exactly what they need.

Question 6

A related question is "What are the admission criteria? Are there any circumstances in which students with ASD may still be eligible even if they do not meet the admission criteria?"

Admission criteria vary from institution to institution. For example, at SIUC, for automatic admission, a student must submit an ACT of 23 or greater, or if the student's class rank is in the upper half, the student's ACT can be 18 or greater. Other schools have open admissions, which we talked about a moment ago. There are some circumstances in which students with ASD may still be eligible even if they do not meet admission criteria. Most schools have a conditional admissions program for students who do not meet the entrance criteria (regardless of disability), and some schools have specialized programs which can recommend students for admission.

Question 7

Given that options for services are changing, parents and students often want to know, "What kinds of services/programs are typically offered for students with ASD? Is there a fee for Student Support Services at most colleges?"

What is available to you will range from no specialized services to a variety of specialized services. Typically, you could expect a disability office to provide, depending on disability, Braille or enhanced print texts, electronic texts, books-on-tape, notetakers for classes, assistive technology, wheelchair accessibility, sign language interpreters, test proctoring, housing access, personal attendants for students with mobility impairments, and access to available on campus resources.

Specialized ASD programs generally offer significantly more than what is required by law, and often provide help in those areas specifically not covered by law, including many of the previously listed services, and also supervision, mentoring, social skills training, counseling, tutoring, advocacy, remediation, organizational assistance, and other services, such as recreational opportunities.

Any institution which receives federal funds must provide equal opportunity and access for students with disabilities at no additional cost for students. Exactly how those services are provided, and what is considered equal opportunity and access varies from institution to institution. Specialized programs of support often exist separately from a university's disability support office, and often there is a fee for support through those programs.

Question 8

Besides some of the very specific questions you might ask because you are a student with ASD, there are some other questions that a student with any disability should ask.

Good questions to ask include:

How many students total are served by your disability office?

How many students with (your specific disability) are served by the disability office?

How many full-time staff are employed at the disability office?

Does your school provide an additional or separate program of specialized services for me?

How do you provide or DO you provide (list the accommodation: test proctoring, tutoring, audiobooks, notetaking, remediation, supervision, computer resources, advocacy, organizational help, counseling, other services)?

What are your hours of operation?

What information specifically do I need to provide to receive services through this office?

Does the school allow for substitutions or waivers for certain academic requirements?

What is the average class size?

What is the student to staff ratio on this campus?

Question 9

For many students and families of students with ASD, as important as the choices for services, majors, and activities are, choices for housing are even more important. The question, “What are my choices for housing?” is one that I regularly get.

Again, you might expect, that different institutions have different housing options. Some colleges are commuter campuses, in which students do not live on campus. Most four-year colleges and universities are residential schools, in which a person lives at the school. However, there are on-campus and off-campus living situations. Again, my filter is SIUC, but at SIUC, for freshmen, there are four on campus living areas, and for sophomores, there are five, and then also off-campus living choices as well. On campus, a student will likely have a roommate, but can choose a single room. Some specialized programs might have unique housing environments for students in their programs. During your visit, take the opportunity to tour housing and speak with a housing representative to understand your options.

Question 10

Many times, students will have anxiety about the challenges they will face on campus. Parents are often concerned that their son or daughter will not be accepted, won't “fit in,” won't find healthy recreational activities, won't develop positive interpersonal relationships, won't manage their time, or won't meet the demands of their work, to name just a few of the issues at hand. I have

often been asked, "In your experience, what is the biggest challenge for students with ASD at the college level?"

I think that transition is the biggest issue. The biggest challenge from high school to college is understanding that you are now the person primarily responsible for any accommodations you receive. You are primarily responsible for communicating with your professors and making sure you understand the assignments. You are primarily responsible for managing your time, for going to class, for going out on the weekends, for doing your laundry, and so many other things. Some students feel like their new-found freedom and free time is truly "free," but of course it isn't. There is always a price to pay for your actions. All of the other issues I mentioned earlier are areas of concern as well, but transition is key.

However, you are not alone. The way to manage transition effectively is to use the resources available to you. Depending on the setting, there may be specialized counselors available to help coordinate your activities and time; there may be community resources to use; there may be peer mentors. Unfortunately, at some places, there may be scant resources. Parents may still need to be involved, whether students like it or not. The colleges which are preparing for students with ASD are incorporating parent participation into their operating plans.

I hope you found this overview useful. Good luck to you in your search for a college. The right one is out there for you. Feel free to contact me by phone

or email if you have any questions regarding this presentation, about other questions you might have, or specifically about the Achieve Program .

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