



Supporting Students on the Autism Spectrum in Higher Education

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The continuing rise in prevalence of autism, now at 1 in 88 (Center for Disease Control, 2012), has engendered greater awareness of the condition, followed by increased research, and improved interventions and strategies for individuals with Asperger Syndrome (AS) and High Functioning Autism (HFA). A part of the autism spectrum, persons diagnosed with AS and HFA experience significant challenges in communication, social interaction, repetitive motions, and restricted interests (APA, 2000). Yet, as suggested by the number of resources written on the subject, these individuals have the cognitive ability to process college level academics, and to attend institutions of higher education (Brown, Wolf, King, & Bork, 2012; Palmer, 2005; Freedman, 2010; Wolf, Brown, & Bork, 2009; Martin, 2010; Zager, Alpern, McKeon, & Mulvey, 2012; Shore & Rastelli, 2006).

These conditions have set the stage for increasing numbers of individuals with AS and HFA to enroll in institutions of higher education. However, challenges in social interaction, executive functioning and sensory issues create barriers to their success in academics, relationships, employment, and involvement in the community.

Different Strokes for Different Folks: External and Internal Models

In response to these challenges a growing number of programs have been created specifically geared towards supporting individuals on the autism spectrum. These programs can roughly be divided into two categories; external to, and internal to, an institute of higher education.

The External Model - External programs are not associated with universities; and have minimal

contact with administration, faculty, and staff. They provide varying degrees of support and education in interdependent living for individuals on the autism spectrum who are already enrolled in, or planning to enroll in, higher education. Examples include the College Internship Program (CIP) and the College Living Experience (CLE); both which have a number of branches around the United States.

The external model often involves individuals with autism sharing a house or apartment off campus with one or more roommates who also are on the autism spectrum. These programs provide support by educating these individuals on strategies to successfully navigate the challenges of living “on one’s own” in conjunction with attending a college or university. Some areas of focus include schedule and financial management, maintaining proper nutrition, addressing use of leisure time, and involvement in the community. Another important area of focus is promoting a deeper understanding of what having autism means in terms of the students’ success in education, and life in general.

Because these programs are external to colleges and universities, there is a substantial fee beyond what is paid for college tuition. This fee can reach upwards of \$60,000 a year, whereas costs for the internal model are significantly less.

The Internal Model - In contrast, internal models are housed within institutions of higher education with services being provided on campus, save for off-campus excursions organized by the program. Examples of internal programs include the Bridges to Adelphi Program, at Adelphi University in New York (www.students.adelphi.edu/sa/bridges), and the College Program for Students with Asperger’s Syndrome at Marshall University in West Virginia (www.marshall.edu/atc/content/college-program.php).

Generally, internal programs offer their students services in the areas of academics, social interaction, executive functioning, and vocational support services, as well as providing training for university faculty and staff. Another interesting aspect of the internal program model is the use of peer mentors to provide social role modeling. Some of the peer mentors are individuals on the autism spectrum who are at various stages of the program themselves.

The Bridges to Adelphi Program

The Bridges to Adelphi Program is an internal program that offers multifaceted, comprehensive, academic, social, independent living, and vocational support services to students who self-disclose with nonverbal and neurosocial disorders such as AS and HFA. Each Bridges student is assigned to a support team that includes an academic coach, a learning strategist, and a peer mentor.

There are many challenges that must be surmounted in order to achieve success in higher education for individuals on the autism spectrum. The Bridges Program, which is fee-based, is based on social learning theory (Bandura, 1977) and cognitive behavioral principles (Beck, Rush, Shaw, & Emery, 1979) as theoretical foundations.

Using a problem solving approach, Bridges services include *Academic Coaching* to help with executive functioning dysfunction, *Learning Assistance* to help with research, writing, and test preparation; and *Peer Mentoring* to help with social skills development.

Some of the primary challenges that internal model programs face, and how the Bridges to Adelphi Program addresses them are listed below:

Gaining the Trust of the Students so That They Will Disclose When They Have a Problem, and Ask for Help - The first goals for any support program for individuals with nonverbal and neurosocial disorders such as AS and HFA should be to get the students to come in and access service, disclose their worries and problems, and accept advice. Often, illogical thinking as well as prior stigmatization and social and academic traumas (which can lead to denial, hierarchical thinking, and in extreme cases, result in Post-Traumatic Stress Disorder) can lead to reluctance or refusal to access services and/or ask for help.

“I’m not like that anymore,” “I don’t want to be in Special Education anymore,” and “They are more disabled than me” are comments that are often heard from students. In these and similar cases, the Bridges to Adelphi Program attempts to build trust through creating non-judgmental and cooperative partnerships with students, and by creating an unconditionally positive environment which focuses on areas of strength.

Besides trying to de-stigmatize diagnoses and challenge illogical thinking, students are told that they can be helped with almost any problem that they report or disclose, but that no one can read their minds. Unlike high school, self-report is the primary source of information, so that if they report everything is alright and that they have been doing their work and going to classes, that is what the support staff will believe.

Cognitive Dysfunctions That Often Result in Avoidance and Procrastination - Individuals with AS and HFA often struggle with negative thoughts about themselves, their world, and their future (Beck, Rush, Shaw, & Emery, 1979). These thoughts often result in false beliefs that they cannot, or will not, be successful, so why should they bother trying? If they become organized around these beliefs, they may stop doing homework and readings, working on research papers, taking exams, or even going to classes. If they do not disclose to support staff, the long term academic consequences can be quite negative.

Individuals with AS or HFA can also struggle with concrete, yet illogical, thinking styles that can result in negative consequences. As a result, these students allow themselves restricted reactions and decision options that, although illogical, limit the ways that they deal with the anxieties stemming from conflicts or confusion. Because this thinking style is designed to create order in a chaotic world, even with regular challenges from the staff, this thinking is quite difficult for the students to change, and often contributes to their inability to solve problems.

Executive functioning dysfunction (EFD) also causes problems for individuals with AS or HFA. In addition to more obvious difficulties like keeping track of assignments and due dates, which a good support program should be focusing on, EFD can also present with more difficult problems to help with such as sleep and waking management, medication management, self-care, and diet. Since freshman year may be the first time students with AS or HFA have been responsible for these issues, the academic and social consequences from EFD resulting poor self-care can be extremely negative in the first year of college.

The Bridges to Adelphi Program attempts to address these cognitive issues through challenging and monitoring negative thinking, and offering positive reinforcement for any cognitive changes, no matter how small.

Mandated Services in K-12 vs. Offered Services in College - Many students with AS and HFA currently entering college have benefitted from early identification. They have likely had Individual Education Plans (IEP’s), and received mandated services in K-12. Additionally, their parents have been instrumental in the acquisition and management of those services. In college,

services are no longer mandated, they are offered, and parents are no longer part of the equation. Students must access their own services and have the ability to self-advocate. This can often be a struggle for students, especially freshmen.

The Bridges to Adelphi Program addresses this issue by asking parents to encourage their children with AS and HFA to come to all scheduled meetings and access all available services. Additionally, Bridges staff monitors syllabi, create weekly assignment schedules, and encourages students to access their academic accommodations.

Communication with Faculty - Maintaining university academic standards, while advocating for students with disabilities such as AS or HFA is a balancing act. All college students are entitled to academic accommodations if they document their disabilities. But because of cognitive disabilities, negative and illogical thinking styles, and EFD, college students with AS and HFA often need more help than the standard academic accommodations such as extra test taking time or note takers. These students benefit from having understanding faculty members who can be flexible with the different ways that they think, work, learn, and process information.

The Bridges to Adelphi Program addresses these issues by getting written consent to communicate with faculty members and then working closely with the faculty through regular contact, and by providing training and awareness sessions for faculty and staff. Faculty members are also asked for regular updates on student progress in their classes. If informed, most faculty members will provide extra time for students to complete assignments, be willing to understand time management struggles, and have regularly scheduled one on one meetings with students.

Managing Parent Expectations - Since many parents of students with AS and HFA have been heavily involved in accessing services and managing their child's academic careers, it is often understandably difficult for them to back away when their child enters college; resulting in the "steel umbilical cord" (McManmon, 2012, p. 14). However, because of the Family Educational Rights and Privacy Act (FERPA), they can no longer have the access to faculty and staff that they used to have.

The Bridges to Adelphi Program attempts to deal with this issue by getting written consent from students to have contact with parents, and by offering group and individual parent meetings. The consent to contact is used only when all problem solving attempts by staff have not been successful, and the student is in danger of failing a class. Individual parent meetings are held only with the student present at the meeting. Group parent meetings are used to provide information and updates of services that are upcoming or newly available.

Managing Staff Expectations - Helping staff understand and manage the possible stresses of working with the AS and HFA population, and accepting the limits of the program and their own work is critical. Staff must remain alert to keeping their own needs and expectations separate from the student's abilities. A college semester can be a roller coaster of emotions for students and staff. It is important for staff to present to the students as reliably available and professional.

The Bridges to Adelphi Program addresses this issue through extensive staff trainings, and weekly one on one supervision meetings.

Addressing Vocational Challenges - With the incidence of under and unemployment for people with AS and HFA being much higher than that the general population, the Bridges to Adelphi Program recognizes the importance of providing support in this area as well. Students are offered

standardized vocational and personality tests. Group support meetings are available for students to address and resolve issues related to employment they may have while in school, or for questions related to employment after graduation.

Research Into the Bridges to Adelphi Program - While there is much anecdotal evidence that the Bridges to Adelphi Program and other internal programs are very helpful to individuals on the autism spectrum, we have taken it upon ourselves to objectively measure the efficacy of the work done at Adelphi University. Initially we plan to examine how student attendance to regularly scheduled group and individual support meetings correlate to academic success. Additionally we plan to look at changes in self-esteem upon entering the program, and at regular intervals, and how they correlate to academic success as well. It is our hope that results from this research will suggest areas of efficacy for the Bridges to Adelphi Program and point to areas that may be in need of improvement. Eventually we hope to expand this research to other programs servicing students with AS and HFA.

Summary and Conclusions

Individuals with AS and HFA present with widely diverse problems and challenges that are different from neurotypical college students. Therefore, there is not one approach; be it choosing an external or internal model, or even between programs within a model that will be effective with all students. For all programs it is important to engage in an individualized, problem solving approach, focusing on identifying individual areas of strength, while acknowledging and addressing areas of weakness or challenge.

By working to the strengths of individuals on the autism spectrum in higher education while recognizing and addressing the very real challenges faced by this population, programs such as the Bridges to Adelphi Program can make a significant positive difference for people with autism achieving success in college and university life, which hopefully generalizes to life after graduation.

When making the decision on which college to attend, or what program seems to suit the student best, there are many variables to examine beyond the standard considerations of area(s) of study, geographical location, and type and size of the campus. For those with AS and HFA, the decision of choosing an internal or external program of support, dorming or commuting, four year college or community college, an honest appraisal of student readiness, as well as the cost of participation in a specialized support program should all be considered.

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Stephen M. Shore, EdD was diagnosed with “Atypical Development and strong autistic tendencies” and deemed “too sick” for outpatient treatment. Dr. Shore was recommended for institutionalization. Nonverbal until four, and with much support from his parents, teachers, wife, and others, Stephen is now a professor at Adelphi University where his research focuses on matching best practice to the needs of people with autism.

In addition to working with children and talking about life on the autism spectrum, Stephen

presents and consults internationally on adult issues pertinent to education, relationships, employment, advocacy, and disclosure as discussed in his books *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, *Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum*, the critically acclaimed *Understanding Autism for Dummies*, and the newly released DVD *Living Along the Autism Spectrum: What it Means to Have Autism or Asperger Syndrome*.

President emeritus of the Asperger's Association of New England and former board member of the Autism Society, Dr. Shore serves on the boards of the Asperger Syndrome and High Functioning Autism Association, the Autism Services Association, and other autism related organizations.

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