Autism Goes to College, 9/25/07
Sponsored by: Penn Autism Network, University of Pennsylvania

MEETING NOTES

Attendees:

- Julianne Albiero-Walton, Ed.D., LPC, East Stroudsburg University
- Lisa Burton-Grika, M.S.Ed., Community College of Philadelphia
- Andrea Coren, Arcadia University
- Neila Douglas, University of the Arts
- Christine Foley, Fairleigh Dickinson University
- Yvonne Foster, Lebanon Valley College
- Zoe Gingold, Holy Family University
- Renee Grammes, DeSales University
- Wendy Kohler, Temple University
- Shirley Mersky, Rider University
- Edith Miller, East Stroudsburg University
- Lisa Mimmo, University of Pennsylvania
- Nancy Mott, Villanova University
- Alice Nagle, University of Pennsylvania Student Disability Services
- Anne Osowski, Shippensburg University
- Maureen Reustle, M.Ed., L.D.T.C., Ocean County College
- Amy Ricedorf, M.S., Lebanon Valley College
- Scott Robertson, Penn State University and Autistic Self-Advocacy Network
- Tony Rostain, M.D., M.A., University of Pennsylvania
- Tracey Rush, Swarthmore College
- Lori Shery, ASPEN, Asperger Syndrome Education Network
- Annie Steinberg, M.D., University of Pennsylvania
- Marie Stevens Cooper, M.S., Bucks County Community College
- Jane Thierfled-Brown, University of Connecticut Law School
- Stefanie Ulrich, Fairleigh Dickinson University
- Vincent Varrassi, Fairleigh Dickinson University
- Ryan Walters, PA Department of Public Welfare, Bureau of Autism Services
- Jorja Waybrant, Dickinson College
- Lorraine Wolfe, Boston University
- Deirdre Wright, University of Pennsylvania and ASCEND Group, the Asperger Syndrome Alliance for Greater Philadelphia
- Vana Zervanos, St. Joseph's University
The “Autism Goes to College” forum convened at 1pm at Irvine Auditorium.

The forum opened with a presentation by Tony Rostain, M.D., M.A., on "Major Issues Facing College Students on the Autism Spectrum." Slides for this presentation are attached. Dr. Rostain invited participants to answer the following questions:

• What are the major challenges and opportunities faced in your efforts to facilitate successful adaptation to college for students on the spectrum?
• How do we define and identify students on the autism spectrum and others with social learning disorders?
• What are some of the helpful interventions used?
• What are specific areas of interest related to this topic?

The participants introduced themselves and addressed these identified issues.

**East Stroudsburg University**

**Julianne Albiero-Walton, Ed.D., LPC, Professor, Disability Specialist**  
**Edith Miller, Professor/Director, East Stroudsburg University**

Julie and Edith work with 450 students. East Stroudsburg offers a Delta Alpha Pi National Honor Society for students with disabilities. There are 12 chapters across the country and they have sponsorship from Read and Write Gold. “We have found that regardless of nature of disability, they own their disability, much more than support groups,” said Edith. In fact, support groups were not positively received by the students.

Notes about the Honor Society:
• The students become self-advocates and advocate for others.
• Participants receive faculty member recognition.
• They have two students with Asperger Syndrome.
• Must be an honor student to be in honor society
• Offers academic support but not social support.
• Had Jonathan Mooney on campus.

**ASPEN, Asperger Syndrome Education Network**

**Lori Shery, President**

Lori said that one issue is students not availing themselves of disability services. “They need to feel good about themselves so they can self advocate,” said Lori. Other points:
• Students are most successful if they learned self-advocacy from a young age.
• We need to educate parents to prepare children for the transition to higher ed.
University of Connecticut Law School
Jane Thierfeld-Brown, Director of Student Services
Jane has helped to develop an autism pilot program at the University of Minnesota. The program focuses on evaluating best practices in the following areas:
• Guiding career choices;
• Transition (the earlier the start, the better, ideally in middle school);
  Working with families on independence;
• What does the family want? How are they helping or hurting to meet the goals?
Other remarks from Jane:
• A lot of the services that are required are not typical services and many are going to fee-for-service
• Families may have to pay extra for these accommodations because the services are far above and beyond what colleges typically provide

Fairleigh Dickinson University
Vincent Varrassi, Campus Director, Regional Center for College Students with LDs
Stefanie Ulrich, Director, Center for Psychological Services/COMPASS
Christine Foley, Graduate Student
“We’ve created an unofficial ambassadorship, at the Regional Center to familiarize students with the campus and to have students learn to advocate,” said Vince. “The students may come in being bashful about their disability, but then they go out and speak about it to others and are strong advocates with a strong voice.”

The college recently launched COMPASS (Community Promoting Academic and Social Success), a comprehensive program for students with Asperger Syndrome, encouraged by Lori Shery from ASPEN and Vince. It emanates from the Center for Psychological Services, a training ground for School Psychologists and Doctoral Students.

Vince’s main question: “How do we do the outreach and help high schools prepare students with AS for the college environment?”

Notes about COMPASS:
• The ultimate goal is to educate the whole campus community about Asperger Syndrome, i.e., what are strengths and challenges?
• Have combined several services through counseling services: group therapy, academic support (e.g., organizational skills and time management), and individual sessions.
• Training school psychologists who are grad/doctoral students to understand AS.

Vince shared these links on the National Center for Learning Disabilities website:
• “Making the Leap to College: What Students with Learning Disabilities Need to Know” ( www.ncld.org/content/view/1113 )
• “Planning for College Success for Students with Learning Disabilities,” by Vince Varrassi ( www.ncld.org/content/view/1096 )
Ocean County College  
*Maureen Reustle, Dean of Academic Services*  
“We have a peer mentor group, but there are no students on the spectrum in the group yet,” said Maureen. Her department presents to parents at “information night.” Their approach to working with students with autism is one-on-one.

Rider University  
*Shirley Mersky, Learning Specialist, Services for Students with Disabilities*  
“We have face-to-face meetings with the students over the summer,” said Shirley.  
- They don’t disclose the incoming students because of privacy issues.  
- They offer a support group (mostly Asperger students).  
- Provides a disability workshop for residence life people and show the movie ‘Intricate Mind.’”  
- Three full-time people to work with students w/ disabilities.  
- Has an anime club.  
- One dorm where one floor has many students with Asperger Syndrome.

Community College of Philadelphia  
*Lisa Burton-Grika, Counselor, Center on Disability*  
*CCP has a few students with Asperger Syndrome or PDD taking classes on a part-time basis. Since there are no dormitories, they do not have the issues with housing that other colleges encounter.*  
- The usually receive documentation of the disability prior to a first meeting with the student. Almost all of the students with ASD come to the initial meeting with their parents. At the hour-long interview, these items are discussed: documentation, past educational experiences, managing their disability in an academic setting.  
- Each student's unique challenges and special needs are assessed when determining appropriate accommodations. While communication can challenging, CCP insists that these students present their accommodation forms to their instructors and talk about their needs. Help is offered when necessary.  
- Although there are myriad social events throughout the college, CCP is a large commuter school, not conducive to building social relationships among students. The Center on Disability serves as a place for students to socialize before or after classes. Students with ASD are not usually part of the regular group of "socializers"; however, they have on occasion sat in the room while conversations were going on. The staff will at times invite or encourage students who are not participating in the discussion to do so. They also sponsor a few social activities throughout the year including birthday celebrations and a talent show.  
- Some CCP students with ASD have particularly strong interests in Asian cultures. The college’s course offerings in humanities, culture, and civilizations as well as foreign language courses are appealing to these students. In addition, the Office of Student Life organizes more than 40 different student clubs including anime and others that students with specific interests may join.
St. Joseph’s University  
**Vana Zervanos, Assistant Coordinator, Services for Students with Disabilities**  
“We only a handful of students with autism: two on campus and two commuters,” said Vana. “We know of their arrival the summer before.”  
- Disability coordinators meet with student and parents/  
- Students meet with counselors.  
- A problem is that parents don’t always share behaviors, i.e., inappropriate sexual comments. The student mentioned would have been more successful as a commuter, but was asked to leave after two months.

Bucks County Community College  
**Marie Stevens Cooper, Director, Disability Services**  
“BCCC’s more significantly impaired student has an aide to help him get from place to place,” said Marie. “He’s in a learning community class, which works well for him because he gets support from other students. Also, the teacher is very helpful. This arrangement seems to work well with this student.”  
- Sometimes the teachers feel overwhelmed by the needs of the students.  
- A learning community allows the students to support each other.

Villanova University  
**Nancy Mott, Learning Support Services**  
“We were specialists, but we now we need to be generalists,” said Nancy. “We’re trying to take a more general view.” Nancy does many transition workshops at schools, noting that one middle school had seven students with Asperger Syndrome.  
- Villanova invites families in over the summer. “Parents are key to getting info you need.”  
- Info is often not shared, especially with students with Asperger Syndrome, to the detriment of the students.  
- Offers a peer-mentoring program because support groups didn’t work out.  
- They match students on disability as well as major.  
- Offers one-on-one coaching sessions.

Temple University  
**Wendy Kohler, Associate Director, Disability Resources and Services**  
“We do not have one singular approach to working with students on the spectrum,” said Wendy. “This semester we have several new students on the spectrum and the gamut of the students is interesting, in terms of abilities, perspectives and presentation.”  
- We can learn from parents and we’re more likely to rely on them for suggestions on strategies with this particular population of students.  
- This population is challenging our thoughts on accommodations and what’s acceptable and what’s not.  
- We want to create more connections with counseling services at Temple, but doing it gingerly so as not ostracize the student. The suggestion of social skills groups and support groups has been met with resistance from the students.
University of Pennsylvania
1. Tony Rostain, Medical Director, Social Learning Disorders Program
   “There are many different kinds of learning disabilities,” said Tony. “AD/HD is a learning disability involving self-regulation. Asperger Syndrome is a social learning disability. I always encourage families to go to the disability office to get their assistance.”
   • We need to make explicit some of the skills and attitudes needed when these students are transitioning.
   • For many of these students, when they get to school, they get alienated quickly.
2. Annie Steinberg, Clinical Faculty, Department of Psychiatry
   Annie raised issues regarding how students identify themselves. With whom should they share information? And how much is the right amount of information to share? Also, it’s important not to overload the students.
3. Lisa Mimmo, Psychologist, Social Learning Disorders Program
   “I encounter those students who have failed,” said Lisa. “They’ve floundered and are underachieving.” Notes about social skills curriculum offered at Penn’s SLDP:
   • Helps with dating, interviewing, nonverbal language, role playing, etc.
   • All participants get a social coach so they can generalize what they’ve learned in places like the Penn bookstore and the train stations.
   • The program runs for 12 weeks.
   • It was developed by Mary Riggs Cohen, Ph.D.
   • It’s called a “seminar” and participants get a syllabus.
4. Alice Nagle, Office of Student Disabilities Services
   Penn offers a three-week program for pre-freshman with disabilities (and others) that runs each summer:
   • Small group, 150-200 students
   • Participants meet with advisors and discuss career goals
   • Offers social activities, which works well in small groups
   • Participants have an opportunity to learn what life on campus is like and take two classes each
Lebanon Valley College
Yvonne Foster, Director of Disability Services
Amy Ricedorf, M.S., Area Coordinator, Alcohol Education Programs
Amy works in residential life and as a mental health counselor. Yvonne said, “We do some really interesting things. We have 15 students with autism right now, mostly in the science curriculum. We are less about whether the student has AS and more about addressing behaviors. We want to take a holistic approach. Changing the environment is critical.” Some of what LVC offers:

- Written rules for the classroom and rules for the dorms that are different for each student.
- Issues are addressed behaviorally, i.e., “If your hand is raised, but the faculty member turns away, you’ve participated enough.”
- Faculty members email the problem, we create a rule.
- Example of a dorm rule: “When you walk by the door, you look in, you say hello, you move on.” (Don’t linger and look.)
- They allow parents to come in during admissions.
- Financial aid will flag the student and then they are met individually rather than in a group.
- Developing a “book” for residents life about how each side of a residential living situation should be handled.

The University of the Arts
Neila Douglas, Director, Disability Services
Neila’s department is one person, part-time. She had students on the spectrum last year and two more this year. Neila questioned what kind of documentation and identification is best practice to follow. Also, she would like to see some more collaboration and connection with other offices within the University.

Arcadia University
Andrea Coren, Disabilities Specialist, Educational Enhancement Center
Arcadia offers a mentoring program, but most students don’t want to participate. They have a disability resources guide for students and faculty members. Andrea’s concerns include:

- Academic advising; how to best advise students regarding more realistic areas of major study?
- Students with disabilities have high rates of unemployment after graduation. What supports or training can colleges and universities provide to facilitate the transition of students with disabilities into the work place?”

Swarthmore College
Tracey Rush, Coordinator, Student Disability Services
There are no formally diagnosed with autism on campus. At Swarthmore, Disability Services is a one-woman office and there are many quirky students at Swarthmore. Tracy wants to “prepare myself and faculty for ‘typical’ students.”
Shippensburg University
Anne Osowski, Graduate Assistant, Learning Center
Anne is pursuing her master’s in special education and completing her internship. Anne wants to learn about disabilities and how best to accommodate students with autism.

Dickinson College
Jorja Waybrant, Assistant Director of Advising and Coordinator of Academic Resource Services, Office of Academic Advising
According to Jorja, "The file of a typical student with a disability is very small in comparison to that of a student on the autism spectrum. A tremendous amount of resources go into supporting a student with ASD. Schools should consider what they are required to do by law, along with the additional time and money involved in supporting these students. Transitional issues for these students are huge since many of them rely on major support systems to help them be successful at the elementary and secondary ed levels. Written information needs to be provided to these students so they can figure out a good fit when choosing a college. Written information will also allow these students to better navigate the college system by providing information on how to access available services when needed."
- Encourages self-advocacy.
- Encourages parental involvement while the student is in the transitional stage.
- Parents should be touching base with their student on a regular basis in order to provide guidance.
- Too much hand-holding will put these students at a disadvantage as they transition to the career world.
- Important to inform administrators and faculty, making sure they are aware of the accommodation process and know how to work with students with disabilities.
- Important to provide information and handbooks so students know how to navigate the system.
- Dickinson currently serves four students with Asperger Syndrome.

Boston University
Lorraine Wolf, Clinical Director, Office of Disability Services
“There’s no right way to do it,” said Lorraine. “There’s no road map and we need to be creative within campus culture.”
- We talk with parents frankly and draw up a contract.
- Sharing resources on campus helps to not overwhelm us.
- In the U.S., it’s a very "medical model"; overseas, more about respecting them vs. fix them and not “how do we get them to be more typical?”
- Results of the University of Minnesota campus study may show that we need to remove some of the emphasis on individual intervention and put more emphasis on campus-wide interventions.
PA Department of Public Welfare (DPW), Bureau of Autism Services (BAS)
Ryan Walters, Special Projects
BAS is working together with counterparts in NJ and other states on issues related to higher education. The state has called a meeting for October to discuss autism and higher education.

Penn State University
Scott Robertson, Ph.D. Candidate, V.P. of Autistic Self-Advocacy Network
“It’s important to get students to contribute to the dialogue,” said Scott. “We are the ultimate consumers of the education and want to get the most for our money. We’re a lot more open now.” (See resources from Scott on page 10.)

• How can we help faculty, too?
• A lot of accommodations would help a broader group of students.
• We need to share resources and get more schools and all parties on board.
• Essential to have students on the spectrum as part of the process.

NEXT STEPS TOWARD FACILITATING A NETWORK

Online Community
The group is interested in starting an online “Autism Goes to College Higher Education Network,” or “Community of Practice” like those found on SharedWork.org. We would start this group and open it to interested parties.
Action step: Deirdre Wright will work with Scott Robertson to initiate a “Community of Practice.”

Workshops
Ideas for possible workshops to offer in the future:
• Residential life initiatives
• Educating faculty to work with students with ASD
• Helping parents come up with successful strategies
Action step: The Penn Autism Network’s spring conference (3/22/08) will focus on autism and transitions to higher education and work. A planning meeting will consider these ideas.

Ideas for Exploration
• Talks out in the communities (school districts)
• Clarifying what we have to offer to each other
• Developing guidelines for parents to know what is a great college fit
• Best practices for being most effective in our own environments, as disabilities services providers
• Needs assessments
• Making the environment more open
• Reducing resistance to accommodations

NEXT MEETING: Tuesday, November 27, 2007, 6-9pm. Dinner included.
Thank you to SCOTT ROBERTSON for the following resources related to higher education and autism.

**Websites and Online Booklets**

- J. Coulter, "ASDs and Choosing College Courses", [http://home.att.net/~coultervideo/collegecourses.htm](http://home.att.net/~coultervideo/collegecourses.htm)
- J. Coulter, "First Year at College: Lessons Learned", [http://home.att.net/~coultervideo/FirstyrCollege.htm](http://home.att.net/~coultervideo/FirstyrCollege.htm)
- University Students With Autism & Asperger Syndrome: [http://www.users.dircon.co.uk/~cns/index.html](http://www.users.dircon.co.uk/~cns/index.html) (many articles & a FAQ)
- Brain.HE Video Gallery (many video/audio casts of neurodiverse college students in the U.K., including 6 who have Asperger's)

**Some Newspaper Articles on Autism Spectrum & College**


**Books on Autism Spectrum & College**

- "Realizing The College Dream With Autism Or Asperger Syndrome" by Ann Palmer
- "Succeeding In College With Asperger's Syndrome" by John Harpur, Maria Lawlor, Michael Fitzgerald
- "Managing Asperger Syndrome At College And University" by Juliet Jamieson and Claire Jamieson