OBJECTIVES

- Review of diagnostic criteria for Autism Spectrum Disorders
- Identify transition challenges and concerns for students with Autism Spectrum Disorders
- Explore existing post-secondary education models of support
- Defining the case for providing expert support for students with Autism Spectrum Disorders in post-secondary education
- Identify challenges and solutions regarding program development
DIAGNOSTIC CRITERIA

- Infantile Autism, Early Infantile Autism, Autistic Disorder, or Kanner’s Syndrome
- First defined by Dr. Leo Kanner in 1943
- Autism comes from the Greek word “autos” or “alone”

1. Qualitative impairments in Social Interaction
2. Qualitative impairments in Communication
3. Stereotyped/Repetitive Interests and Behaviors
4. Onset prior to age 3
QUALITATIVE IMPAIRMENTS IN SOCIAL INTERACTION

EVIDENCE

- Lack of imaginative play early in life
- Difficulty relating to others
- Fears that are difficult to overcome
- Limited awareness of feelings of others
- Abnormal seeking of comfort when distressed
- Impaired imitation
- Impairment in ability to express or understand emotions
- Difficulty understanding social cues
- Avoidance or odd use of eye contact
- Want and need to be left alone at times
- Will initiate touching but may not accept from others
- Inappropriate giggling or laughing

INTERVENTIONS

- Must teach social skills and social interaction (role play, social stories, cartoon strips)
- Structure social interchanges
- Utilize and support non-disabled peers or peers who are more outgoing
- Respect needs and personal space
- Build in time to just observe
- Plan for desensitization to fear
- Prepare for social situations
- Allow time to build trust
- Reinforce positive self concept
- Facilitate initiation of interactions
- Teach specific social rules
- Facilitate interaction through shared activities
QUALITATIVE IMPAIRMENTS IN COMMUNICATION

EVIDENCE

- May be nonverbal
- Impairment in nonverbal communication
- Low spontaneously initiated communication
- Restrictive modes of communication
- Echolalia
- Difficulty understanding concepts, long sentences, etc.
- Difficulty answering questions
- Inappropriate timing and content
- Trouble staying on topic unless it is one of their favorite subjects
- Difficulty in conversing through comments and ongoing exchanges

INTERVENTIONS

- Know each person’s abilities
- Teach a functional communication system
- Use pictures and visuals often
- Set up opportunities to practice and elicit communication
- Reinforce communication
- Talk in short sentences
- Be direct and concrete
- Demonstrate, gesture, and sign when needed
- Listen to what they are trying to tell you / determine what their behavior may be communicating.
STEREOTYPED AND RESTRICTED/REPETITIVE BEHAVIORS

EVIDENCE

- Impaired response to sensory stimuli
- Act as if deaf or very sensitive to some sounds
- Resist change in routine
- Lack fear of real danger
- Inappropriate attachments to objects
- Repetitive movements (rocking, flapping)
- Stare at lights, shiny objects, patterns
- Impaired response to temperature or pain
- Enjoy rocking, jumping, swinging
- Insistence on talking about a particular subject

INTERVENTION

- Control stimuli when necessary
- Plan appropriate stimulatory activities use visual means to instruct when possible
- Prepare and explain changes
- Provide “breaks” from high stimulation
- Provide private time, place when self-stimulation is allowed if needed
- Reinforce new activities and interests
AUTISM AND ASPERGER’S SYNDROME

ACCORDING TO THE DSM-IV AUTISM AND ASPERGER’S ARE DISTINCT AND SEPARATE DIAGNOSES. CLINICIANS OFTEN ERRONEOUSLY USE THE TERMS HIGH FUNCTIONING AUTISM AND ASPERGER’S INTERCHANGEABLY. THERE IS CONTROVERSY, HOWEVER, OVER WHETHER ASPERGER’S IS A SYNDROME IN ITS OWN RIGHT OR IF IT IS A FORM OF AUTISM.

**AUTISM**
- First described by Kanner in 1943
- Cognitive development within normal OR MR range
- Language development is delayed
- Qualitative Impairment in Social Interaction
- Stereotyped/Repetitive Behaviors and Interests

**ASPERGERS**
- First described by Hans Asperger in 1944 (unaware of Kanner’s work)
- Cognitive development within normal to above average range
- Language development is within normal limits and may be a relative strength
- Qualitative Impairment in Social Interaction
- Stereotyped/Repetitive Behaviors and Interests

**RECENT CONSIDERATIONS:**
- DSM V elimination of Asperger’s Syndrome
‘RED FLAGS’ FOR HFA/AS

- deep focus on a special subject or area (or consecutive areas)
- described as “eccentric”
- tend to have one-sided conversations, or none at all
- difficulty in understanding human interactions and human social codes
- lack traditional peer relationships (i.e. ‘friends’ are people with whom they only have contact online.)
- difficulty with changing environments, or tendency to maintain routine
- difficulty with problem solving
- sometimes hypersensitive to various stimuli such as light, noise and pain
- motor skills may be less developed than the norm (and may have an awkward gait)
- may have repetitive motor movements
IMPORTANT STATISTICS

- According to the Centers for Disease Control and Prevention, 1 in 88 children is currently being diagnosed with an Autism Spectrum Disorder.
- Autism is nearly 5 times more likely to occur in boys (1:54) than in girls (1:252).
- Autism is ubiquitous (it occurs in all racial, ethnic and socioeconomic groups).
- Autism is a behavioral diagnosis.
- Although there is no known cause, Autism without a specified genetic etiology is widely recognized to be a neurologic disorder and is the result of environmental and genetic factors.
- About 10% of children with autism are also identified as having Down syndrome, fragile X syndrome, tuberous sclerosis, and other genetic and chromosomal disorders.
- The incidence of a second child being born into a family with an autistic child is at least 25% more likely than in the general public.
- 5-10% of persons with autism have savant abilities.
<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of ADDM Sites Reporting</th>
<th>Prevalence per 1,000 Children (Range)</th>
<th>This is about 1 in X children...</th>
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<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>6.7 (4.5-9.9)</td>
<td>1 in 150</td>
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<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>6.6 (3.3-10.6)</td>
<td>1 in 150</td>
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<td>2004</td>
<td>1996</td>
<td>8</td>
<td>8.0 (4.6-9.8)</td>
<td>1 in 125</td>
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<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>9.0 (4.2-12.1)</td>
<td>1 in 110</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>11.3 (4.8-21.2)</td>
<td>1 in 88</td>
</tr>
</tbody>
</table>
TRANSITION CONCERNS AND CHALLENGES

- Interpretation of ADA/Rehab Act (‘reasonable accommodations’) in higher education

- FERPA (Family Educational Rights and Privacy Act)

- There are many post-secondary options becoming available that provide a continuum of support services (which one, if any, are the right fit?)
INTERPRETATION OF ADA/REHAB ACT

- After high school IDEA no longer applies
- Must self-identify to receive accommodations under ADA
- Disabilities Resource Services is required to provide ‘reasonable accommodations’ for accessibility
- Students are responsible for communicating his/her accommodations to each faculty member
FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT

- FERPA/Buckley Amendment
- gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level.
- schools must have written permission from the student in order to release any information from a student's education record.
TRANSITION PLANNING

- Can never start too early!
- Is a team effort
- Should address skills relevant to success in post-secondary education/life in the community:
  1. Academic/Employment Responsibilities
  2. Life Skills/Domestic Responsibilities
  3. Social/Communication Skills

- Self-Advocacy
- Attendance
- Respect for Classmates/Colleagues
  personal space and property
- Organizational Skills
- Seek assistance/feedback from trustworthy source
- Diet
- Personal Appearance/Hygiene
- Negotiating campus/community
- Money Management
- Respect for Law/Authority
- Safety
TRANSITION CONCERNS AND CHALLENGES

- Interpretation of ADA/Rehab Act (‘reasonable accommodations’) in higher education

- FERPA (Family Educational Rights and Privacy Act)

- There are many post-secondary options becoming available that provide a continuum of support services (which one, if any, are the right fit?)
CONTINUUM OF SERVICES

College Internship Program
College Living Experience
Gersh

Drexel Autism Support Program, Mercyhurst AIM Program, Rutgers Developmental Disabilities Center, Midwestern State, St. Joseph’s Kinney Center

Boston University, U of Alabama ACTS Program, Eastern Michigan Autism Collaborative Center, Uconn SEAD, Marshall CASP

AHEADD, Private Professional Contract, Asperger Center for Education Coach (Lynda Geller)
The difference between providing accommodations for people on the spectrum and other disabilities is that, to at least some extent, you must connect with them in their world and go for the ride together.

-Stephen Shore
TRADITIONAL ACCOMMODATIONS

- Large print or Braille materials
- Help with learning strategies or study skills
- Tutors to assist with ongoing coursework
- Alternative exam formats
- Additional exam time
- Course substitution or waiver
- Priority class registration
- Disability resource handbook
- Sign language interpreters/translator
- Real-time captioning
- Oral interpreters/translator
- Readers
- Classroom note takers or scribes
- Faculty-provided written course notes or assignments
- Adaptive equipment and Audio Books
‘NONTRADITIONAL’ ACCOMMODATIONS

- establish network of support
- facilitated communication with professors
- self-advocacy skill development
- social skills instruction
- regular assistance with organization
- increased academic and personal accountability
- regular meetings with professors to discuss progress
- structured peer support
- life skills education
POST SECONDARY EDUCATION
MODELS OF SUPPORT

Key Elements of Any Support Program:

① Sustainable

② Professional Transition supports (entering into college and with each subsequent semester)
   Increased stress due to transition may cause substantial “difficulty with academic content, organization, time management and study skills” (Adreon & Durocher, 2007, p. 274)

③ Professional Academic supports
   Tutoring, as well as organizational and personal support services are essential components of effective supports (Adreon & Durocher, 2007; Luckett & Powell, 2005; Myles, 2005)

④ Professional and Peer Social Supports
   ‘where access to further education has been achieved, adults with autism have been provided with a general service for people with additional learning needs, rather than autism-specific provisions, and the educational infrastructure and support necessary for successful placement of those with more complex needs has often been lacking (Morgan, 1996, p. 145)

⑤ Accessible Community Resources
   a. Counseling/mental health services
   b. To meet general daily living needs
POST SECONDARY EDUCATION MODELS OF SUPPORT

- **Individual Professionals**
  - Credentialed or licensed professionals with specialized training (coaches, special education teachers, therapists)

- **Campus Based Programs**
  - Fee Based Support
  - Integrated Support

- **Private Organizations**
  - Residential
  - Community Based
MAKING THE CASE FOR DEVELOPING
SPECIALIZED AUTISM SUPPORT
PROGRAMS
NATIONAL DATA:

- According to the Autism and Developmental Disabilities Monitoring Network (CDC funded program), the majority (62%) of children the ADDM Network identified as having ASDs did not have intellectual disability (intelligence quotient \(\leq 70\)).

- In a longitudinal study published in 2005, 46% of the over 14,000 participants with autism reported enrolling in some type of postsecondary education or training (Wagner, Newman, Cometo, Garza, & Levine, 2005).

- 56% of degree granting postsecondary institutions enrolled students with an autism spectrum disorder (see chart 3. next page).

- Only 4% of post-secondary institutions provided nontraditional accommodations such as independent living supports. (The U.S. Department of Education, National Center for Education Statistics, Postsecondary Education Quick Information System (PEQIS), “Students With Disabilities at Postsecondary Education Institutions,” 2009.)
Table 3. Percent of 2-year and 4-year degree-granting postsecondary institutions enrolling any students in each disability category, by institutional characteristics: 2008–09

<table>
<thead>
<tr>
<th>Institutional characteristic</th>
<th>Difficulty hearing&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Difficulty seeing&lt;sup&gt;2&lt;/sup&gt;</th>
<th>Difficulty speaking or language impairment</th>
<th>Mobility limitation/orthopedic impairment</th>
<th>Traumatic brain injury</th>
<th>Specific learning disabilities</th>
<th>ADD or ADHD&lt;sup&gt;3&lt;/sup&gt;</th>
<th>Autism Spectrum Disorders&lt;sup&gt;4&lt;/sup&gt;</th>
<th>Cognitive difficulties or intellectual disability</th>
<th>Health impairment/condition, including chronic conditions</th>
<th>Mental illness/psychological or psychiatric condition&lt;sup&gt;5&lt;/sup&gt;</th>
<th>Other</th>
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<td>All institutions ...............</td>
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<td>67</td>
<td>35</td>
<td>76</td>
<td>56</td>
<td>86</td>
<td>79</td>
<td>56</td>
<td>41</td>
<td>73</td>
<td>76</td>
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<td>Institutional type</td>
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<tr>
<td>Public 2-year ..................</td>
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<td>84</td>
<td>53</td>
<td>90</td>
<td>74</td>
<td>94</td>
<td>87</td>
<td>70</td>
<td>71</td>
<td>80</td>
<td>87</td>
<td>26</td>
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<tr>
<td>Private not-for-profit 2-year</td>
<td>29</td>
<td>26</td>
<td>18</td>
<td>35</td>
<td>26</td>
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<td>53</td>
<td>36</td>
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<td>56</td>
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<tr>
<td>Private for-profit 2-year ....</td>
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<td>35</td>
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<td>70</td>
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<td>60</td>
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<td>18</td>
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<td>Public 4-year ..................</td>
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<td>90</td>
<td>46</td>
<td>93</td>
<td>84</td>
<td>97</td>
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<td>Private not-for-profit 4-year</td>
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<td>Size of institution</td>
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<td>Less than 3,000 ...............</td>
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<td>47</td>
<td>22</td>
<td>63</td>
<td>37</td>
<td>78</td>
<td>69</td>
<td>38</td>
<td>31</td>
<td>61</td>
<td>62</td>
<td>8</td>
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<tr>
<td>3,000 to 9,999 ...............</td>
<td>96</td>
<td>95</td>
<td>51</td>
<td>96</td>
<td>84</td>
<td>98</td>
<td>94</td>
<td>82</td>
<td>58</td>
<td>92</td>
<td>97</td>
<td>26</td>
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<tr>
<td>10,000 or more ................</td>
<td>100&lt;sup&gt;5&lt;/sup&gt;</td>
<td>100&lt;sup&gt;5&lt;/sup&gt;</td>
<td>63</td>
<td>98</td>
<td>91</td>
<td>99</td>
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<td>84</td>
<td>57</td>
<td>93</td>
<td>98</td>
<td>41</td>
</tr>
</tbody>
</table>

SPECIALIZED AUTISM SUPPORT
PROGRAMS
PENNSYLVANIA NEEDS ASSESSMENT DATA:

- 29% of those surveyed are enrolled in higher education v. 46% from national survey

- Of the 19% of those who responded for themselves, only 37% completed their post-secondary education program v. national average graduation rates of 47.6% for general disability population and 50.7% for students with autism

- We know that retention is a priority across institutions

(SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Special Education Research, National Longitudinal Transition Study-2 (NLTS2), Waves 4 and 5, 2007 and 2009, unpublished tabulations. (This table was prepared July 2010.)
“Able autistic individuals can rise to eminent positions and perform with such outstanding success that one may even conclude that only such people are capable of certain achievements ... Their unswerving determination and penetrating intellectual powers, part of their spontaneous and original mental activity, their narrowness and single-mindedness, as manifested in their special interests, can be immensely valuable and can lead to outstanding achievements in their chosen areas.”

-Hans Asperger (1944)
REFERENCES

QUESTION AND ANSWER
SESSION

Points for Thought/Discussion:

① My college doesn’t see the need to develop a program
② My college doesn’t want to attract this ‘type’ of student
③ FERPA would interfere
④ We don’t have funding or the human resources to develop a specialized program
⑤ Students that need help don’t disclose