



AUTISM SPECTRUM DISORDERS IN POST- SECONDARY EDUCATION

**ASERT Inaugural Conference
Postsecondary Programs
for Students with Autism Spectrum Disorders
Keynote Presentation: Carolyn Komich Hare
May 22-23, 2012**

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



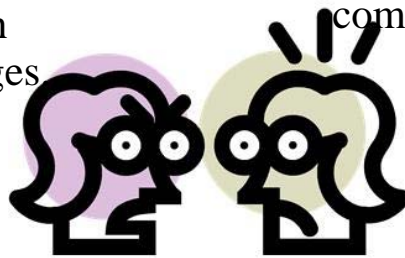
QUALITATIVE IMPAIRMENTS IN COMMUNICATION

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 using 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

RECENT CONSIDERATIONS:

- DSM V elimination of Asperger's Syndrome

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



'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 (ie. ‘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



Identified Prevalence of Autism Spectrum Disorders

ADDM Network 2000-2008

Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88



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



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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



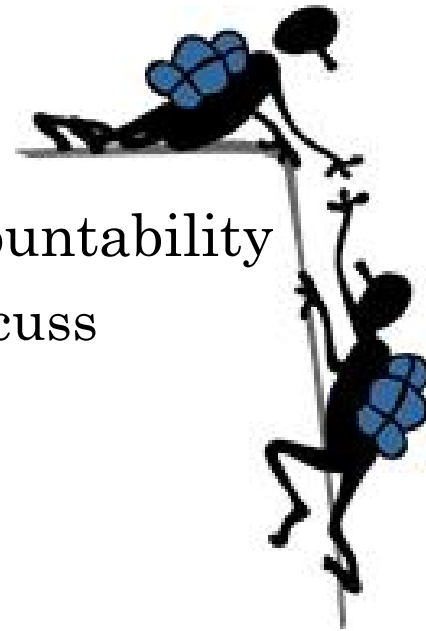
TRADITIONAL ACCOMMODATIONS

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; Lockett & 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



MEASURING 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 ≤ 70)
- In a longitudinal published in 2005 study 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

Institutional characteristic	Difficulty hearing ¹	Difficulty seeing ²	Difficulty speaking or language impairment	Mobility limitation/orthopedic impairment	Traumatic brain injury	Specific learning disabilities	ADD or ADHD ³	Autism Spectrum Disorders ⁴	Cognitive difficulties or intellectual disability	Health impairment/condition, including chronic conditions	Mental illness/psychological or psychiatric condition ⁵	Other
All institutions	73	67	35	76	56	86	79	56	41	73	76	17
Institutional type												
Public 2-year	90	84	53	90	74	94	87	70	71	80	87	26
Private not-for-profit 2-year	29	26	18	35	26	67	53	36	30	56	76	71
Private for-profit 2-year	32	35	18	70	25	60	40	18	26	47	53	31
Public 4-year	92	90	46	93	84	97	94	78	39	95	94	30
Private not-for-profit 4-year	65	59	25	68	47	84	78	49	26	72	69	11
Private for-profit 4-year	60	37	16	46	19	72	64	34	27	39	52	8
Size of institution												
Less than 3,000	57	47	22	63	37	78	69	38	31	61	62	8
3,000 to 9,999	96	95	51	96	84	98	94	82	58	92	97	26
10,000 or more	100 ⁶	100 ⁶	63	98	91	99	92	84	57	93	98	41

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SOURCE: U.S. Department of Education, National Center for Education Statistics, Postsecondary Education Quick Information System (PEQIS), “Students With Disabilities at Postsecondary Education Institutions,” 2009.



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

- Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders. *Intervention in School & Clinic, 42(5), 271-279.*
- Morgan, H. (1996). *Adults with autism. New York: Cambridge University Press.*
- U.S. Department of Education, National Center for Education Statistics, Postsecondary Education Quick Information System (PEQIS), “Students With Disabilities at Postsecondary Education Institutions,” 2009
- Lockett, T., & Powell, S. (2003). Students with autism and Asperger's Syndrome. In S. Powell (Ed.), *Special teaching in higher education (pp. 159-176). Sterling, VA: Kogan Page.*
- Myles, B. S. (2005). *Children and youth with Asperger Syndrome: Strategies for success in inclusive settings. Thousand Oaks, CA: Corwin Press.*



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

