Preparing For and Living In a Brave New World

LaSalle/GTP Autism Conference
May 3, 2013

Eric R. Mitchell, Ph.D. Carol Moog, Ph.D.
ericmpsyc@yahoo.com focusmoog@aol.com

Today’s Agenda

Workshop Description:
• Today’s generation of autistic people at the precipice of transitioning into adulthood face great opportunity as well as great struggles ahead of them. This workshop will present grassroots personal and professional efforts to develop responsive educational/social programs that lead to quality transitions to college, work opportunities, entrepreneurship possibilities, and daily living/relationship success.

Objectives:
• Participants will understand the ingredients needed for innovative, cutting edge training and education that prepares for the transition to adulthood.
• Mobilize grassroots efforts to utilize the strengths of the ASD community and other stakeholders.
• Participants will understand how to develop financially sustainable models for business development and employment centered on the strengths of autistic people.
• Participants will learn about the services and supports available for successful transitions to higher education, work opportunities, adult living, and beyond.
• Participants will understand the needs and strengths that can be tracked for success beginning in early childhood through the lifespan of autistic people.

ASD in the Classic Children’s Literature

Gerald McBoing Boing, by Dr. Seuss

Amelia Bedelia, by Peggy Parish

REPRESENTING...

Iceberg Model

“Amelia Bedelia, why are all the lights bulbs outside?” asked Mr. Rogers.

“T’ll let just wait to put the lights out,” said Amelia Bedelia.

“It didn’t say to bring them back in. Oh, I do hope they didn’t get aired too long.”
NTs and Aspies/Auties

What Is NT?
Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs find it difficult to be alone. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviorally rigid, and frequently insist upon the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum. NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical is typically smaller than that of an autistic individual and may have underdeveloped areas related to social behavior.

* The Diagnostic and Statistical Manual of Normal Disorders: 666.00 Neurotypic Disorder

How Common is It?
Tragically, as many as 9625 out of every 10,000 individuals may be neurotypical.

Are There Any Treatments for NT?
There is no known cure for Neurotypical Syndrome.

Neurodiversity
Amanda Baggs
- Self-advocacy via internet
- Higher level of interaction with entire environment
- People may be seen as objects, but not necessarily less important as entire environment becomes important
- Blogging and social networking
- Second-life

Carly Fleischmann
- "Technology has allowed me to communicate, learn social skills, implement relaxing techniques and played a crucial part in helping me how to spell. To me, technology is the key to unlocking autism."
- Facebook, Twitter and blogging

Autistics to Autistics

Here are some tips from 15 y/o Haley Moos, autistic:

1. Seek help if you don't understand something: People with autism spectrum disorders are often detail-oriented and miss the bigger picture, Haley said. Her mother would read English books with her and discuss the themes to help Haley see them more clearly. Haley recommends consulting parents, siblings, teachers and textbooks if you are stuck on something.

2. Learn about trends to talk about them: Haley's approach to popular culture is methodical and detached. "Learn about the trends to fit in, even if you don't like them. She saw all the "Twilight" movies on opening night even though she doesn't like the franchise much. She can recognize a popular Jonas Brothers song. Being up on the fads helps with socializing and avoiding ridicule, she said."

3. Trust your parents: People with autism spectrum disorders tend to assume that everyone is trustworthy, and that can make them be easily manipulated, Haley writes. She recommends having a good relationship with your parents and entrusting them with your secrets instead of someone at school. Her parents help her with academic and social problems. Also, she looks to her mother to interpret classmates' comments that she didn't understand, instead of jumping to conclusions.

Heather Kuzmich
America's Next Top Model

Self-Advocacy

Alexis Wineman, 2012 Miss Montana

Parts Versus Whole

- Move: part \(\Rightarrow\) whole
- Eye gaze studies
- Social awareness
- Mozart and the whale

- Response focused on Pieces, not whole:
  - Schmuck
  - Geodes
  - Plateau
  - baby chickens
  - Watercolors
  - Trees
  - swimming bovines
  - Eels
  - two green fish
My name is Matt and I have Asperger’s syndrome. What’s that mean, you ask? Well, you’re in luck, cause I’ve made this helpful guide!

Asperger’s is part of the autism spectrum. It has many characteristics, but generally we have difficulty knowing what someone is thinking, explaining our thoughts verbally, and interacting socially with our peers. It is sometimes described as having “a dash of autism.”

---

**ASD Culture: Labels**

**Why I dislike “person-first” language**

On Broader

I am not a “person with autism.” I am an autistic person. Why does this distinction matter to me?

1) Saying “person with autism” suggests that the autism can be separated from the person. But this is not the case. I can be separated from things that are not part of me, and I am still the same person. I am usually a “person with a purple shirt,” but I could also be a “person with a blue shirt” one day, and a “person with a job” the next day, and would still be me. The purple shirt and the job are parts of me. They are not things I can be separated from.

2) Saying “person with autism” suggests that even if autism is part of the person, it is not an important part. Characteristics that are recognized as central to a person’s identity are appropriately stated as adjectives, and may even be used as nouns to describe people: we talk about “blue-eyed” and “brown-eyed” people, and even about “short” and “tall” and “fat” and “thin” and “men” and “women.” But “people with asperger’s” and “people with Down’s syndrome” are aspects of people’s culture and medical identification. The adjectives in terms such as “blue-eyed” or “brown-eyed” or “fat” or “thin” or “men” or “women” do not describe one essential feature of the person. They are not characteristics that would define a person who otherwise is the same. The same thing holds true for “people with autism.” We describe important aspects of people’s personal identity such as “gender” or “gender identity” or “person with albinism” or “person with Down’s syndrome.” We exclude adjectives that describe any other central characteristics of identity, such as “purple-eyed” or “blue-eyed” or “short.” They are not attributes that describe who the person is.

3) Saying “person with autism” suggests that autism is something bad—so bad that it isn’t even consistent with being a person. Nobody objects to using adjectives to refer to characteristics of a person that are considered positive or neutral. We talk about left-handed people, not “people with left-handedness,” and about athletic or musical people, not about “people with athleticism” or “people with musicality.” It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person. I know that autism is not a terrible thing, and that it does not make me any less a person. If other people have trouble remembering that autism doesn’t make me any less a person, then that’s their problem, not mine. Let them find a way to remind themselves that I’m a person, without trying to define an essential feature of my personhood as something bad. I am autistic because I accept and value myself the way I am.
Training the Community
- Airport and Museum Accessibility Initiatives w/ Dr. Wendy Ross
- http://www.autismir.com

Sports and Disabilities
- January, 2013: US Department of Education indicates that similarly with Title IX (gender equality), all students with disabilities must be provided with opportunities for extracurricular athletics, and that additional athletic programs must be created if existing programs don’t meet the needs of students with disabilities, including clubs.
- According to a 2010 report from the Government Accountability Office, disabled students do not have equal opportunities to sports, a right that is protected by the Disabilities Act of 1973.
- Education Secretary Arne Duncan: Sports provide: “invaluable lessons in discipline, selflessness, passion and courage, and this guidance will help schools ensure that students with disabilities have an equal opportunity to benefit from the life lessons they can learn on the playing field or on the court.”

When Do I Tell My Kid About ASD?
- Identity formation
- As soon as they’re ready
- The earlier the better
- Positive aspects, with difficulties like others
- Before depression and/or behavioral difficulties
- They may let you know
- Connecting with others

When Do I Tell My Kid About ASD?
- Conversation between Siri and an 11-year-old boy who recently learned of his likely diagnosis of Asperger’s
- Critical mass
- “Coming out” to others
- Finding safe havens

TOOLS FOR WORKING WITH SOCIAL ANXIETY

Comic Strips & Smartboard
The Power of Video

- Social skills
- Favorite movies and parsing out emotions, intent, interaction, etc.
- Self-awareness, vocals, non-verbals
- De-escalation
- Posting on internet
- Team collaboration

Conversation Training

- Introduction w/reason for approach
- “Safe” compliment
- Repeat x 3:
  - Question @ what they might like
  - Wait for response
  - Self-disclosure
  - Wait for lack of response
  - See-you-later w/reason for ending

- Additional interventions:
  - Videotape
  - Mentoring
  - Real-life Confederates
  - Eye contact, nod, and facial recognition/memory

Social Skills Toolbox

- **Key Components**
  - Managing eye contact
  - Understanding social cues
  - Working with personal space in this culture
  - Reading non-verbal information
  - Taking in another’s perspective
  - Sharing the stage (Reciprocity)

- Most are aware of poor social skills and want to have relationships

The Gift of Time and Space

Simply offering time away from the situation (instead of critique or discussion) gives space for recovery, as depicted by this poem written after a student was able to take time away following a social meltdown:

My Sorrow

The crosswind blew, and the ship crashed.
The passengers became unsteady, and not all of them made it.
I was on a boat alone.
On a life boat.
I got home, apologized for my reckless driving, and returned to my conscience.

Preparing for Changes in Routine

SUPPORTING TRANSITIONS THROUGH SOCIAL SKILL DEVELOPMENT

Parenthood, Coaster, change in routine:
Parenthood, Halloween:
Parenthood, camping with Grandpa:
Parenthood, sleepover:
Improving Conversation Skills

- Conversation “dance”
  - Topic Transitions
  - Implementing Conversations Skills

  - Scene Starters
    - Strangers at Starbucks
    - Seat Partners
    - Dorm Doldrums
    - Destination Dilemma
    - Orientation Day

  - Notice in self and in others:
    - Eye Contact
    - Body Posture
    - Voice
    - Mood/Emotion
    - Conversation Closing

CONVERSATION RECIPROCITY

- Keep balloon in the air activity (fun/needs all)
- Yes But vs Yes And…:
  - Pairs

The Friendship Algorithm

Should I laugh?

Social Skills

- Scripting
- Rehearsal
- Mentorship
- Shadowing

Social Skills and Picking Up Cues

Parenthood, Dad as social coach:

Social Rejection

Incentives for social skills:

Payoff for social skills:

BUILDING RESILIENCE FOR HANDLING CRITICISM
Counter-Criticism Exercise

- Think of your best trait
- Think of your worst trait
- Use traits to introduce self at "cocktail party"
- Experience?

Criticism as “Offer” to Accept

- Saying “yes” and noticing/enabling offerings (Yes, and…)
- “Criticism” as observation
- Difference between criticism and observation
- Tone
- Theory of mind

Creating Realistic Self-Perceptions: Personal Brand Identity

- Self-Assessment Form
  - Questions became catalyst for trusting curiosity, honest feedback, and group support (what do you value/how do you see yourself/think others see you)
- Personal Slogan
  - If you think of yourself as a brand what would your slogan be, one that characterizes you (share?)
    - Examples
      - "Know everything"
      - "Never quit"
      - "Whatever you are, be a good one"
      - "No regrets"
  - 30 second commercial
    - Develop a brief personal statement (aka 30 second commercial)
    - Why?
      - Prepared answer to dreaded interview question: “Tell me about yourself”

Theatre Activities

- Task analysis
- Music (ie, brushing teeth)
- Movement (ie, triangle puzzle… first have leader conduct nonverbally, then only verbal, then let group to come up with a shape and make it)
- Roleplay (ie, blowing your nose)
- Empathy, turn-taking, social skills, FUN!!!

FRAMING DIFFERENCE THROUGH DIVERSITY AND STRENGTH, NOT DIAGNOSIS

ASD and Culture
ASD Culture

- What is culture?
  - Language
  - Food
  - Common interests
  - Routines, etc.
- Critical mass
- Making connections
- Aspies
- Tech and computers
  - Podcasts
  - Websites
  - Discussion groups
  - Autreat, ASAN, etc.
- Between-group vs. within-group differences

ASD Strengths

- Lower degree of social self-consciousness
- Ability to focus on details
- Green Tree Talent Shows
- Logic and either/or thinking

Neurodiversity

ASD at Community College of Philadelphia rose from 3 to 25 from 2007-2011

"Colleges are seeing more people with autism spectrum disorders, the kinds of people who, in the past, wouldn't have gone on to college," says Felicia Hurewitz, director of the Autism Support Program at Drexel University. "We have a lot of diversity. Neurodiversity is the newest."

- Accommodations: copies of lecture notes, extended time, quiet testing area, tech supports, peer mentoring, single rooms, group supports, open mics, academic/organization support
- AHEADDD (Achieving in Higher Education with Autism/Developmental Disabilities)

Hyper-focus as a strength

Vast detail retrieved by client:

Strengths of Autistic People

Stephen Wiltshire
Temple Grandin

ACCOMMODATIONS FOR NON-PREFERRED EDUCATION AND WORK
Sensory Integration Issues
- Self-Regulation for students
- Lighting
- Proximal space
- Visual distractions
- Volume and chaos of classroom

Implications of Learning Style
- Learning Style Assessment
- Extended Time
- Augment audio recordings with digital photos
- Acquire any visuals used in class
- Visual strategies
- Feng Shui for ASD (a la Grandin… sort of)
- Organizational/Study Strategies
  - Keyword/picture columns
  - Question/answer columns
  - Regular meetings with counselor/tutor/organizer
- Social groups based on common interests
- Other accommodations based on need

Assistive Technology
- Ann Dolloff, Pennsylvania Institute for Assistive Technology
- AT evaluations
- iPad and other devices
- Microsoft High School for the Future
- Wretches & Jabberers
- Loving Lampposts

FACILITATING AND ENCOURAGING SOCIAL CONNECTIONS

Sites for and by Auties and Aspies

Social Skills: Ryuu
- Rebecca Klaw and Joel Shaul
RESOURCES FOR TRANSITIONS

Post-secondary options
- Day programs
- Work
- Trade-school
- College
- Online
- Paradigm shift!!

Transition Planning
- IEP Team
- Mental Health Services
- Mental Retardation System
- Vocational Rehabilitation
- Occupational Therapy
- Social Skills Training
- Consistent routines
- Structured environments
- Attention to sensory integration

Elwyn Industries
Aston, PA
- 2012: Defense Logistics Agency contracts with Elwyn Industries: $7.7 million for making bandages
- Elwyn: nonprofit serves people with special needs
- adult day services
- Elwyn Industries already:
  - makes medals for armed forces
  - does maintenance on federal buildings
UCP Chestnut Hill
programming:

- OVR evaluation, Interest inventories, cognitive assessment
- Contract shop assessment for general work habits
- In-house training for areas of interest, food services, child care, janitorial
- OT assessment, Work adjustment training
- Funding for 14 weeks through OVR
- Post employment services
- Strength-based jobs and the match for disabilities, as opposed to drug addictions and other challenges of neurotypicals
- CLA’s and MR waiver funding

Placements & Resources

- Traditional:
  - Community Residential Rehabilitation (CRR)
  - Community Living Arrangement (CLA)
  - Outpatient services
  - Residential settings
  - Individual aide

- Next Steps:
  - Build-your-own Silicon Valley
  - Maximize strengths
  - Finding functional fixations
  - What CAN the individual do?
  - What CAN the group do?

New Programs for Working and ASD

- www.worksforme-pa.org

  - I am Daniel and I am looking forward to a career in finance or communications. I refuse to let being born with Autism stop me from going after my dreams. I serve my community by motivating others with disabilities to go after their dreams too! I take pride in being a gentleman and a minister at my church. I enjoy traveling, baseball games, and the internet. I did work study in high school and got paid. My college classes and my transcript do not cost us anything. And none of this hurt my social security check or stopped me from getting medical help. Some things are hard for me, but I have people from the Work Incentive Planning and Assistance program who believe in me and are helping me. I look forward to using the Ticket to Work program to continue my career path and show everybody my abilities!

  - JEVS: new program specifically supporting ASD... No job carving... yet.
  - Villanova Entrepreneur’s Network proposal

Job coaching Vs. Job carving

- Fitting a square peg into a round hole
- Underestimating abilities of those on the spectrum
- Splinter skills
- Strengths-based assessment and placement
- Filling a hole vs. finding a need
- Finding partner employers... often limited to corporations with executives who have family members on the spectrum
- Issues of possible exploitation

The Specialists

- Specialisterne: Software Testing in Denmark
- 60 consultants are considered best-in-class
- Paid industry-competitive wages
- Customers include LEGO, Microsoft, and Oracle
- 75 percent have Asperger syndrome or some form of ASD
- Consultants enjoy their work and are great at it
- Testing process—checking and rechecking outcomes, documenting test plans, and maintaining follow-through
- Making use of high intelligence, precision-oriented skills, deep concentration, and patience that can be positive features sometimes accompanying ASD
- “This is not cheap labor, and it’s not occupational therapy... We simply do a better job.”
- Model is taking off with public and private funding

ALAW:

- Roy Diamond & Becky Willmot
- 2 Phoenixville homes in 2000, 1 Media, 1 NE Philly
- Waiver Funding, LLC, PHFA Grant, Vouchers
- $500 Food Budget with $100 extra
- Partners: Northwestern, Keystone, Bureau of Autism Services
- Autism Waiver Impact... full spectrum?
- OVR: short term assistance with fading
- Social faux pas scenarios: unemployment
- Work too much: lose funding
- Farms
- Donating home to family members and others on the spectrum
**Neurodiversity**

- ASD at Community College of Philadelphia rose from 3 to 25 from 2007-2011
- "Colleges are seeing more people with autism spectrum disorders, the kinds of people who, in the past, wouldn't have gone on to college," says Felicia Hurewitz, director of the Autism Support Program at Drexel University. "We have a lot of diversity. Neurodiversity is the newest."
- Accommodations: copies of lecture notes, extended time, quiet testing area, tech supports, peer mentoring, single rooms, group supports, open mics, academic/organization support
- AHEADD (Achieving in Higher Education with Autism/Developmental Disabilities)
- Philadelphia University

**Transition Programs**

- Drexel Autism Support Program
- Carousel Connections (Haverford)
- Penn Social Learning Disorders Program
- Variety Club Autism Ambassadors
  - Marywood University
  - Lebanon Valley College
- AHEADD
- College Living Experience
- Y.A.L.E.
- NYIT

**LIVING A QUALITY LIFE**

**Dating**

- Stephen Shore’s “sleepover”
- Pitfalls and dangers

**Dating and Alternatives**

**THANK YOU… Questions?**

Focusmoog@aol.com
www.imagineact.com

Ericmpsc@yahoo.com
www.ericmitchellphd.com