#### **Preparing For and Living In** a Brave New World

LaSalle/GTP Autism Conference May 3, 2013

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#### Today's Agenda

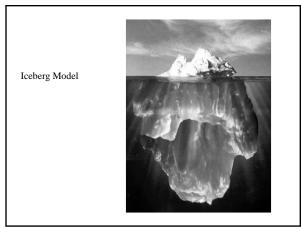
#### Workshop Description:

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.

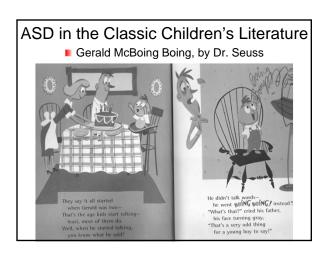
- Participants will understand the ingredients needed for innovative, cutting edge training and education that prepares for the transition to adulthood.

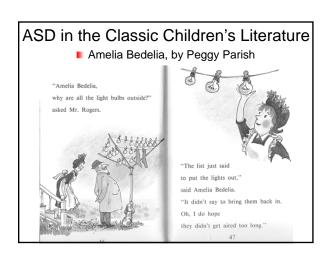
  Mobilize grassroots efforts to utilize the strengths of the ASD community and other
- stakeholders
- Participants will understand how to develop financially sustainable models for business development and employment centered on the strengths of autistic people.
- Participants will learn about the services 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.



REPRESENTING...





#### 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 overdeveloped areas related to social behavior.

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

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. .http://isnt.autistics.org/



#### 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



Amanda Baggs, self-advoca

Carly on panel about technology and autism with



#### Autistics to **Autistics**



Here are some tips from 15 y/o Haley Moss, 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
- 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." In middle school, everyone just cares that you're like them, and if you're different, you get picked on," Haley said. "No one accepts different appeals."
- 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





interview, "coming out"



interview, "advice"

#### Self-Advocacy



Alexis Wineman, 2012 Miss Montana

#### Parts Versus Whole

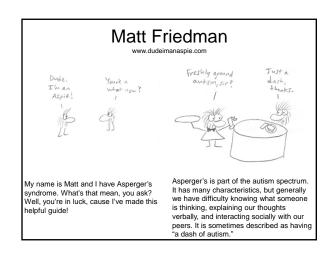
- •Move: part => whole
- Eye gaze studies
  Social awareness
- . Mozart and the whale





- Response focused on Pieces, not whole Schmuck

  - •Plateau
  - baby chickens
  - •Watercolors
  - •swimming bovines
  - •Eels
  - •two green fish



#### ASD Culture: Labels

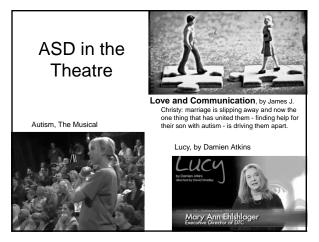
- Why I dislike "person first" language
  Jim Sinclair
  I am not a "person with autism." I am an autistic person. Why does this distinction matter to me?

  1) Saying "person with autism." I am an autistic person. Why does this distinction matter to me?

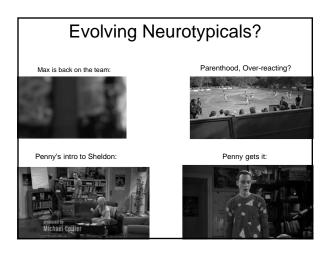
  1) Saying "person with autism." I am an autistic person. Why does this distinction matter to me?

  1) Saying "person with autism." suggests that the usince may be superaised from the person. But this is not the case. I can be separated from things that are not part of me, and I am sail be the same person. I am usually a "person with a but shirt" on edg, and a "person with a yallow shirt" he next day, and I vould sail be the same person, because my clothing is not part of me. But autism is part of me. Autism is hard-wired into the ways my brain works. I am autistic because I cannot be separated from how my brain works.

  2) Saying "person with autism" suggests that even if autism is part of the person, it land a very important part. Characteristics that electron with a substitution of the person with a substitution of the substit



#### **HELPING TO REPRESENT**



#### Advocating for Autistic People Joining with family members, and supporting family members and self-advocates who advocate for needs within the family among those who are less savvy with autism.

Example: email to family members from sister of adult brother diagnosed with Asperger's (other family members would not support services, rejected diagnosis, and advocated for a "pull yourself up by your bootstraps" or "tough love" approach):

Perception:	Reality:
Stupid	He has an above average intelligence.
Lazy	He works hard at things he loves and get paralyzed by anxiety and stupefied by things that bore him.
Rude	He is having a righteous reaction to the fact that we are all abusive, inconsistent ***holes that bounce him around like a ball. None of us have good coping techniques to manage our own anger and pain. He is reflecting the behavior we model.
Immature	He is child-like and vulnerable because he is trusting.
Unmotivated	He is HIGHLY motivatedall he thinks about are his goalshe just doesn't know how to achieve them.
Forgetful	Sensory integration issues make it hard to focus on multiple data points. And difficulty with planning and long-term thinking make it hard for him to anticipate future needs, like needing a house key.



#### 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



- The earlier the better
- Positive aspects, with difficulties like others

Parenthood,

- Before depression and/or behavioral difficulties
- They may let you know
- Connecting with others

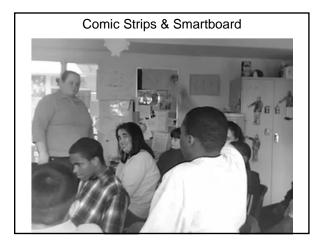


#### When Do I Tell My Kid About ASD?

- 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

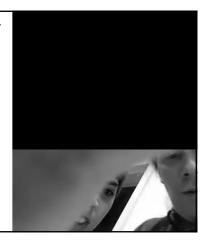


#### **TOOLS FOR WORKING** WITH SOCIAL ANXIETY



#### The Power of Video

- Social skills
- Favorite movies and parsing out emotions, intent, interaction, etc.
- Self-awareness, vocals, nonverbals
- 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.

## SUPPORTING TRANSITIONS THROUGH SOCIAL SKILL DEVELOPMENT

## Preparing for Changes in Routine Parenthood, Coaster, change in routine: Parenthood, Halloween:

Parenthood, camping with Grandpa:



Parenthood, sleepover:

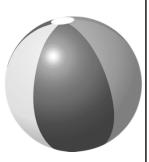


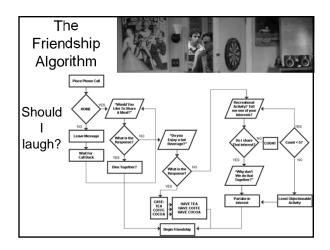
#### Improving Conversation Skills

- 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

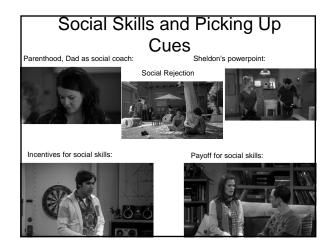
#### **CONVERSATION RECIPROCITY**

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









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?

#### <del>огоанну глоаноно осп</del> Perceptions:

#### - self-AssersอกุลไกBrand Identity

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)

Prepared answer to dreaded interview question: "Tell me about

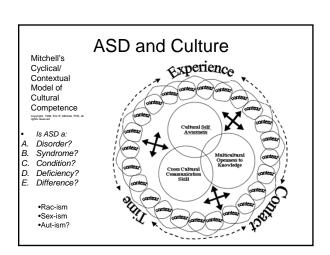
#### Criticism as "Offer" to Accept

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

#### Theatre Acitivities

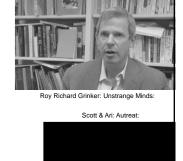
- Task analysis
- Music (ie, brushing teeth)
- · Movement (ie, triangle puzzle... first have leader conduct nonverbally, then only verbal, then tell group to come up with a shape and make it)
- Roleplay (ie, blowing your nose)
- Empathy, turn-taking, social skills, FUN!!!

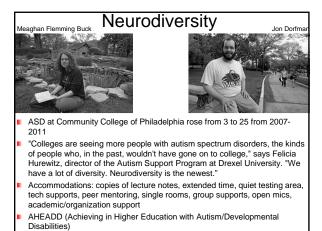
FRAMING DIFFERENCE THROUGH DIVERSITY AND STRENGTH, NOT DIAGNOSIS

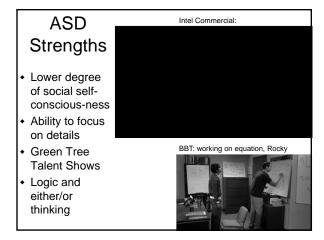




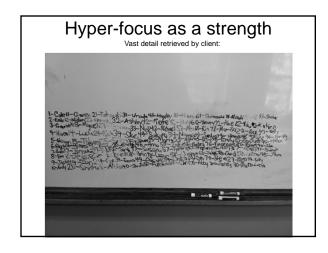
- · What is culture?
  - Language
  - Food
  - · Common interests
  - · Routines, etc.
- · Critical mass
- · Making connections
- Aspies
- · Tech and computers
  - Podcasts
  - Websites
  - Discussion groups
- Autreat, ASAN, etc.
- Between-group vs. within-group differences











ACCOMMODATIONS FOR NON-PREFERRED EDUCATION AND WORK

#### **Sensory Integration Issues**

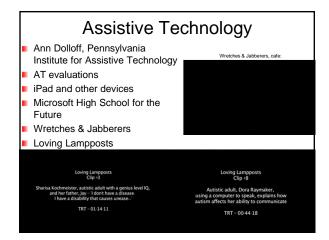
- ■Self-Regulation for students
- **■**Lighting
- ■Proximal space
- **■**Visual distractions
- ■Volume and chaos of classroom

Mercury...



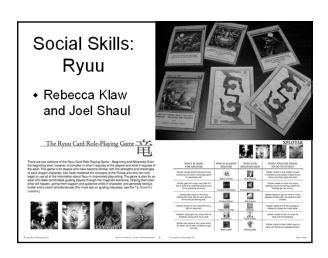
#### Implications of Learning Style

- · 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

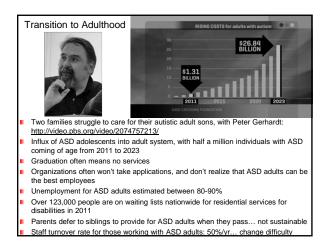


### FACILITATING AND ENCOURAGING SOCIAL CONNECTIONS



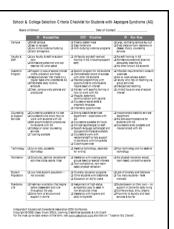


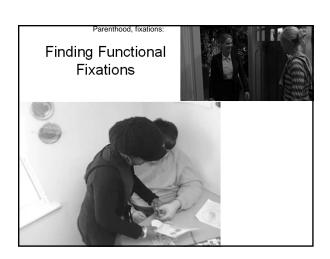
#### RESOURCES FOR TRANSITIONS



#### Postsecondary 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
- · 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-vour-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 tool I lake pride in being a gentleman and a minister at my church. I enjoy traveling, asseball games, and the internet. I did work study in high school and got paid, by college classes and my trans passes do not cost us anything. And none of his hurt my social security check or stopped me from getting medical help. Some hings are hard for me, but I have people from the Work Incentive Planning and sasistance 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...
- Villanova Entrepreneur's Network proposal

#### Job coaching Vs. Job carving

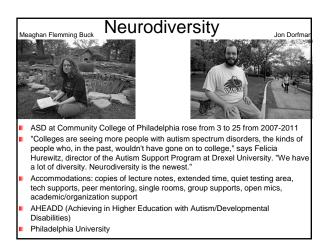
- · Fitting a square peg into a round hole
- Underestimating abilities of those on the spectrum
- Splinter skills
- · Strengths-based assessment and placement
- · Filling a hole vs. finding a need
- Finding partner employers... often limited to corporations with executives who have family members on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

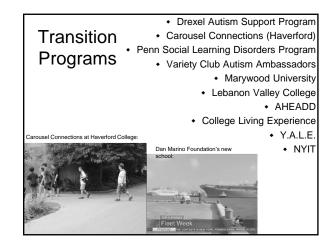
#### The Specialists

- •Specialisterne: Software Testing in Denma •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

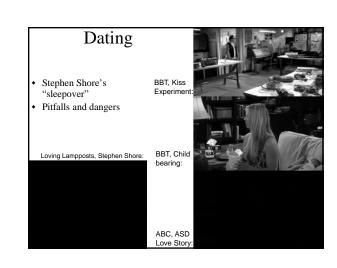
#### ALAW: Roy Diamond & Becky Willmot

- 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
- Donating home to family members and others on the spectrum





## LIVING A QUALITY LIFE





THANK YOU... Questions?

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