Autism and Anxiety
From stress to success!
Purposes of This Training

- Identify the signs and symptoms of anxiety, and explore the experience through the words of self-advocates
- Explore the neuroscience of anxiety, and its connection to sensorimotor challenges
- Recognize the factors that can trigger and intensify anxiety, and practical strategies to reduce their impact
- Consider approaches that can help people with autism become more resilient in the face of stress
- Build awareness of socially valued activities that use the positive aspects of vigilant behavior to achieve desired goals
Imagine....

A long-ago scene around the camp fire...

Lurking danger...

A vigilant youth...
3 responses to danger:

• Fight!
• Flight!
• Freeze!
What is anxiety?

• A hard-wired alarm system protecting us from life-threatening dangers

• With fewer real dangers, now it is triggered by perceptions of SOCIAL danger
“Hard-wired”?

• Do we run because we’re afraid?
• Or are we afraid because we run?
• Emergence of body changes due to threatening stimuli: measured in milliseconds (thousandths of a second)

• Emergence of a single, simple thought: measured in seconds
Anxiety Disorders

- Officially classified 1980:
  - Panic Disorder
  - Social Phobia
  - Specific Phobia
  - Post-Traumatic Stress Disorder (PTSD)
  - Obsessive-Compulsive Disorder (OCD)
  - Generalized Anxiety Disorder (GAD)

- May have more than one at a time
- Often accompanied by depression
GAD Symptoms

- Excessive, ongoing worry and tension
- An unrealistic view of problems
- Restlessness or "edginess"
- Irritability
- Muscle tension
- Headaches
- Sweating
- Difficulty concentrating
- Nausea
- Frequent need to go to the bathroom
- Tiredness
- Trouble falling or staying asleep
- Trembling
- Being easily startled
Who has seen the Temple Grandin biopic?

- What causes of **stress** or signs of **anxiety** did you notice?
  - Intensity?
  - Sensorimotor challenges?
People with autism can have too much or too little input from

- Vision
- Hearing
- Smell
- Touch
- Taste
- Proprioception
- Vestibular processing
Proprioception

- **Body awareness**: knowing where our body parts are in space and in relation to each other, to carry out coordinated movements
- May fluctuate and be unreliable
Vestibular processing

- Centered on the inner ear; involves ability to maintain stability, posture, orientation

- Malfunction leads to lack of balance, unstable visual field; movements of people and objects seem confusing
Awareness: what do you see?
Brain Research

• **Hyper-connectivity**
  - Amygdala: primary role in formation and storage of memories associated with emotional events, from fear to happiness

• **Hypo-connectivity**
  - Cerebellum: vital to motor learning, equilibrium, and posture; also has role in attention, language, and sensory regulation
Hyper-connectivity: The Amygdala

- Primary roles in forming and storing memories of emotional events; significantly enlarged
- Extra neurons (brain cells) = hyper-connectivity
- Atypical neurons arrangements exist before birth
- Brain networks for reacting and inhibiting reactions are delicately balanced, easily disrupted
- Neuron connectors (synapses and dendrites) have unusual form, function; when disrupted may lead to seizures
Hypo-connectivity: The Cerebellum

• Research: 40-50% fewer cerebellar Purkinje cells in individuals with autism

• These cells specialize for motor functioning, sensory regulation, speech, attention; fewer cells means they may have to multi-task

• When multitasking cells get conflicting demands, the person may have difficulty performing motor, sensory, attentional activities
• **Cerebellum**: part of the brain that “takes over” when movements become habitual or automatic

• **Research**: when practicing a task, activity in the cerebellum increased less in children with autism than in neurotypical children. Children with autism had greater activity in the higher brain region that exerts “top-down,” voluntary control over movement

• **Meaning**: typically developing children can rely more on motor habits; children with autism must rely more on willful control of movement

• **This is exhausting!**

D., Goldberg, M., Mostofsky, Powell, S., Simmonds, D., Goldberg, M., Caffo, B., and Pekar, J. Decreased connectivity and cerebellar activity in autism during motor task performance. 132(9), 2413-2415.
Peripheral Nervous Systems

• Gastrointestinal
• Circadian rhythms
  - Sleep
  - Hunger
  - Mood/hormonal
• Pain

• SEE: “Autism: The Movement Perspective,” Frontiers in Integrative Neuroscience
How do

► “ramped up” connections in the *emotion*-processing part of the brain
► *slower, less automatic connections in the movement regulation area*
► *inconsistent, inefficient sensorimotor processing of peripheral nervous systems*

impact everyday experience?
In the words of a self-advocate...

“My brain always gets there in the end. It’s just that it takes the scenic route!”

-- Barbara Moran
Sensory Reactivity: hypo and hyper

1. NON-FIRING (of nerves and neurons in sensory system) – person not getting feedback, not perceiving or connecting with feelings

   • “Everyone chattered about school but I couldn’t really hear them -- there was a kind of hum inside me that I later realized was happiness.” -- Sean Barron, “There’s a Boy in Here”
• “I think my son experiences the world like a person in a space suit.”
  » a parent

• “My body goes away.”
  » a person with autism
2. OVER-FIRING -- person is hypersensitive to sensation, has overwhelming sense of self and of others (e.g. caution feels like terror, happy feels like manic)

• “Too good!”
  -- Jessie Park in “The Siege”
Barbara Moran, Self-Advocate:

"It was much easier getting my wisdom teeth pulled than to be in noisy surroundings."
“How can I practice self-control when there is so much self to control?!”

- Barb Moran
3. MIS-FIRING – emotion is felt, but the brain hasn’t processed its context (e.g. physiological responses of affection, such as deep breathing and rapid heart rate, are misread as responses to danger, resulting in aggression against a person one likes)

-- Donna Williams, self-advocate and author

NOTE: This condition also occurs in victims of post-traumatic stress disorder (PTSD)
Temple Grandin, Self-Advocate:

"Tactile stimulation for me and many autistic children is a no-win situation. Our bodies cry out for human contact but when contact is made, we withdraw in pain and confusion. It wasn't until I was in my mid-twenties that I could shake hands or look directly at someone."
How do sensorimotor challenges look?

- Movement breakdowns at transition points: initiating, sustaining, inhibiting/stopping, shifting
- Difficulties with bodily feedback; “self-injurious behavior”
- Repetitious movements
- Repetitious vocalizations
- Clumsiness
- Uneven performance
- “Good days” and “bad days”
- Intense sensitivity to environment, conditions
Motor reactivity: hypo and hyper

- Difficulties in initiating or sustaining voluntary and automatic movements
- Over-abundance of movement
- Involuntary repetitive movements, e.g. motor and vocal tics, which grade into obsessions and compulsions
• “My body is not who I am.”
• “My body goes away.”
• “My body has a mind of its own.”
What happen when we lose "connection to intentional action"?

• Actions and results may not reflect intent or choice

• The person may be seriously misunderstood
• Recall the *Croquet Game* in *Alice in Wonderland*

• What can it tell us about sensorimotor challenges?
Suppose your live game is **REALLY** alive...
Do anxiety and challenges to sensory processing go hand in hand?
Research: “Sensory Over-Responsivity” (SOR) connected with Anxiety

- 3 Theories
  - SOR → Anxiety
  - SOR ← Anxiety
  - SOR ←→ Anxiety
    (separate causes, but amplify each other)
Research:

- **Occupational Therapists** more likely to diagnose **Sensory Over-Reactivity**
  - Recommend Sensory Integration therapy, sensory diet, etc.

- **Psychologists** more likely to diagnose **Anxiety Disorder**
  - Recommend Cognitive Behavior Therapy, medication

Anxiety Disorders and Sensory Over-Responsivity in Children with Autism Spectrum Disorders: Is There a Causal Relationship?
http://www.springerlink.com/content/t15371830474n060/fulltext.pdf
Incidence

- Anxiety is common among children with ASD, but incidence reports vary: 11% to 87%
- Anxiety disorders affect more than 23 million Americans, and 10% to 15% of American adults
- Rates are 3-24% in neurotypical children
- Sensory Over-reactivity is estimated to affect 56-70% of children with ASD; sensory differences in general are est. at 90%
- SOR may affect 10-17% in the general population of children
- SOR has been linked to anxiety in children with ASD in at least 3 studies
“Intense World Syndrome”
• **Intense World Hypothesis:** core challenge of brain in autism is
  - hyper-reactivity (*working harder* due to making more but less efficient connections)
  - hyper-plasticity (*heightened neural changes in response to experience,* esp. *heightened memories and intense responses to too many stimuli*)

• “Hyper-functioning” brain processes lead to hyper-perception, hyper-attention, and hyper-memory
“The lack of social interaction in autism may therefore not be because of deficits in the ability to process social and emotional cues as previously thought, but because a subset of cues are overly intense, compulsively attended to, excessively processed and remembered with frightening clarity and intensity.”
“Intense World Syndrome”: implications for treatment and support

• **Medication**
  - Avoid meds designed to increase neuronal and cognitive functioning
  - Emphasize meds to calm and slow down brain function

• **Behavior support**
  - Emphasize positive, rewarding, comforting approaches
  - Avoid direct punishment, which may lead to a lockdown of behavioral routines

• “It may well turn out that successful treatments could expose truly capable and highly gifted individuals.”

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518049/
Theory of Mind (ToM) or anxious mind?

Can ToM research tell us something important about anxiety?

The group with Asperger Syndrome (AS):  

- scored **lower** on the measures of “cognitive empathy,” the “process of understanding another person’s perspective and theory of mind”  
  - A more abstract, conceptual, cultural, language-based activity?
The group with Asperger Syndrome (AS):

- was no different from controls on one affective empathy scale, “empathic concern,” which measures an observer’s “emotional response to the affective state of others”
The group with Asperger Syndrome (AS):

• scored higher than controls on the other affective empathy scale, “personal distress” (PD).

• The PD scale assesses “self-oriented feelings of anxiety and discomfort resulting from tense interpersonal settings.”
Exposure Anxiety: A response to the “intense world”?

A type of social anxiety common in autism

Does it arise when sensorimotor challenges have been misinterpreted, and not accommodated?

Donna Williams video:
http://www.youtube.com/watch?v=bJNkYFuiv7g
Exposure Anxiety: **examples**

- Cannot bear to ask for birthday gifts or specify a desired item
- Shies away from directly addressing a loved one (by name or as “Mom,” etc.)
- Is pained even by GOOD attention for a job well-done
- “ Watches” favorite TV show from another room
- Would rather withhold work and get grade of “0” than earn anything less than “A”
Risk Perception research: new clues to anxiety prevention

- Risk feels scarier if:
  - Imposed (no opt out)
  - Created by a source you don’t trust
  - Human-made (not “natural”)

  Paul Slovik and Baruch Fischoff, cognitive psychologists

- Implications for practice?
  - Create choices (avoid: “Are you forcing me?”)
  - Beware “arbitrary” rule systems, e.g. competitive sports
  - Beware “arbitrary” consequences
  - Build relationships
Can people with autism develop PTSD?

**YES!** Diagnoses often follow the use of:
- AVERSIVES
- RESTRAINT
- SECLUSION

Some medical experts call PTSD among people with autism a *hidden epidemic.*
Effects of coercive techniques

- **Flashbacks**; intrusive memories
- **Hypervigilance**; “fight, flight, or freeze”
- Repetitive, **compulsive activity** patterns
- Reduced ability to control emotions
- Permanent **changes in brain**
- Loss of **skills**
- Reduced ability to pay attention and learn
These trauma responses can be **misinterpreted as**:

- Symptoms of the person’s original disability
- Worsening of the person’s original disability
- “Bad behavior”; willful noncompliance

The result is a **“vicious cycle”** of dependence on high-risk interventions.
Can people with autism develop depression?

- Depression is closely linked to anxiety
- People with autism may experience mental health challenges, but:
  - autism is NOT a mental illness
  - MH system has NOT proven a good place to serve people with autism
Mental health diagnoses are NOT ruled out by ID or DD diagnoses
How can we help?

1. **Medication** for anxiety

2. **Accommodation** for sensorimotor differences

3. **Education**
   1. of the body
   2. of the mind
Medication: what is the target?

• Research: 75% of people with ID/DD presenting psychiatric symptoms or behavior problems at a psychiatric facility had an underlying medical condition causing or contributing to it.
  • Ruth Ryan M.D. (2011)
• The role of **physical wellbeing** on behavior is too **often overlooked**

• **We ALL** act immature and difficult when we feel bad!
Possible causes of “behaviors”

- Hitting head → headache, toothache, infection
- Holding head and crying; wanting to be in dark place → migraine
- Confused behavior → urinary tract infection
- Forced regurgitation → acid reflux
• Shaking, irritability → thyroid problems
• Sad demeanor → thyroid problems
• Aggression, self-injurious behavior, undressing → sensory integration disorder

» Ruth Ryan Myers, MD
Accommodating Sensorimotor Differences

Accommodations are strategies and supports that help a person overcome or “work around” sensorimotor differences, reducing anxiety and fear. They must be personalized and able to be changed as needed.
When we accommodate differences we must start with the assumption that differences are okay.
While some people respond well to meds for anxiety, often the best outcomes arise from:

- Educating body and mind
- Fostering habits and attitudes of personal awareness and emotional resilience
- Creating accommodations that make the world a less anxious, more autism-friendly place
Educating the Body

- Sensory Integration therapy; Sensory Diet, desensitization, etc.
- Holistic physical disciplines: exercise, yoga, Tai Chi, etc.
- Activating “flow state”; play
- Animal companions
- Music, dance
- De-escalation techniques
- Mindfulness
Sensory Integration Approach

• Highly *individualized* body activities
• Rich in vestibular, proprioceptive, and tactile inputs - areas where many children with dd are challenged
• Encourages the nervous system to *process and integrate sensory input* in meaningful ways
• Encourages *organization* at increasingly higher levels
• Goal: person will be able to *interact and adapt to the environment* more successfully
Sensory tools for mental and physical wellness

SENSORY DIET: The daily round of activities and objects a person uses to regulate his or her sensorimotor system
Calming activities:

- Blowing (bubbles, balloons, blowing out candles)
- Sucking (straw, water bottle, etc.)
- Gross motor, deep pressure (jumping jacks, diving, trampoline, sit-ups)
- Putty, clay, squeezable or stretchable “manipulatives” (e.g. “Koosh Ball”)
- Weighted vest, shoulder pad, lap pad; heavy blanket or comforter
- “Compression” clothing (e.g. spandex athletic gear)
- Slow, linear movement (e.g. swing or rocking chair)
- Steady rhythms, vibrations (e.g. resting near air conditioner, car ride)
- Slow, steady visual patterns (e.g. “Lava Lamp”)
- Slow, steady sound patterns (e.g. desktop “waterfall”; music with base beat)
- Yoga or related “body work”
- Therapeutic brushing
- Deep breathing
- Gum or chewy foods
- Massage
Stimulating Activities

- Whole body movement, e.g. taking a walk, sweeping the room
- Foods that are sour, cold, or have strong aromas or textures
- Playing music with a fast tempo
- Raising the light level in the room
- Introducing forms of exercise that are challenging, such as sitting on a balance ball or walking a balance beam
- Trying activities involving tactile input, e.g. gardening or cooking
- Using intense colors, e.g. in clothing, décor, colored paper and ink
- Introducing humor; acting funny; encouraging laughter
- Introducing the unexpected, e.g. a hidden object, surprise in a bag, guessing game
- Focus on a “preferred interest”
Holistic Physical Disciplines

• Growing interest in autism community
• Shares many goals, methods with SI
• Low-impact physical exercise + emphasis on calming the mind (meditation)
• Has been studied as intervention for pain, stress, depression
• Yoga is 6th most commonly used alternative therapy in the United States
Activating “Flow State”; Play

Play: “A state of experience in which the actor's ability to act matches the requirements for action in his environment. It differs from anxiety, in which the requirements outnumber the ability, and from boredom, in which the requirements are too few for the ability level of the actor.”

Mihaly Csikszentmihalyi
"The opposite of play is not work. It's depression."

- Brian Sutton-Smith, folklorist
“In play a child always behaves beyond his average age, above his daily behavior. In play it is as though he were a head taller than himself.”
- Lev Vygotsky, psychologist

“Play is training for the unexpected.”
- Marc Bekoff, biologist
Animal Companions

- Increasing use of animal companions to support emotional development and regulation

- Communicating about and “through” pets relieves social anxiety

- Some states classify trained dogs as autism service animals, permit them in schools
Music and Dance

- Can be used to communicate and express emotion - especially when other channels of expression are compromised

- Music and dance therapy can help relieve psychological, emotional and stress-related conditions
De-escalation Techniques

What is in your “Prevention Kit”?

• **Plan ahead** to de-fuse “Fight-Flight-Freeze”

• **Avoid complex sensory input**: NO talking!

• **Back off**, give space, take time

• **Use breathing control techniques**, e.g. “3-3-6”

• **Model** needed actions; use visuals or hand signals
Mindfulness: bridging body and mind

• Mindfulness -- “paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally.” (Jon Kabot-Zinn, MD, UMass Medical School)

• NIH study: pain-related med use decreased, activity levels and feelings of self-esteem increased

• Techniques help focus and control rambling thoughts, teach calming use of breathing

• Increasingly used by people with autism!
Educating the Mind

• Psychological approaches combining verbal and experiential components
• Tools for making the physical and social environments clear
• Reframing: Positive uses of “hypervigilance” in recreation, employment
Psychological strategies

• Teaching positive **self-talk**
  - Positive interpretations, words, imagery created and practiced
  - Empowerment; confidence-building

• **De-sensitization; “exposure therapy”**
  - Activating anxiety/fear system under safe conditions to teach new responses
  - May utilize play activities, drama, scary movies, stories, amusement park rides, etc.

• **Routines for facing the unexpected**
  - Advance teaching and practice of calming phrase, activity, thought, response
  - Planned exposure to non-negative novelty
Cognitive Behavior Therapy (CBT)

• Recent studies suggest usefulness for treating anxiety in autism

• **Components:**
  - psychoeducation
  - cognitive restructuring
  - self-talk
  - relaxation
  - exposure to feared stimuli

• Some therapists adapt CBT by simplifying cognitive aspects, emphasizing concrete aspects such as relaxation and controlled exposure
"I wonder what kind of person I would have been if I had known all along that my sensory problems were neurological and what it would have been like if my complaints had been taken seriously and if there had been no shame."

- self-advocate Barbara Moran
Tools for making the physical and social environments clear

- **Lists, maps, charts** (for home and school)
- **Social Stories** (see Carol Gray’s books, web site)
- **Pictures, visual cues** (in strategic places)
- **Autobiographical materials** (photo albums, collages, bulletin boards, collections, personalized articles of clothing such as t-shirts, merit badges on sash, etc.)
Reframing: “vigilance” has many positive uses!

• In the home and school
  - Safety monitoring
  - Scheduling, reminding
  - Neatness
  - What else??

• In recreation
  - Score-keeping; timing
  - Knowing the rules
  - Computer games
  - What else??
• On the job
  - Medical professions (e.g. reading x-rays)
  - Data processing
  - Book-keeping
  - Inventory
  - Proof-reading
  - “Continuity”; quality control
  - What else??
The Wrap-Up!

• What will you do more of?
• What will you do less of?
• What will you try that’s new?
Resources  In addition to the published research cited in this training, you may wish to try:

