Integration and the Role of the Psychologist in the Early Detection and Treatment of Autism

Terry Matteo, Ph.D.
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Arizona Autism Coalition
4th Annual Conference

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Today's Discussion

- What is Integration?
- What we know about autism in young children
- Why multidisciplinary perspectives are so important in working with children and adults with autism
- The role of the psychologist with a specialization in autism, child development, and developmental disabilities

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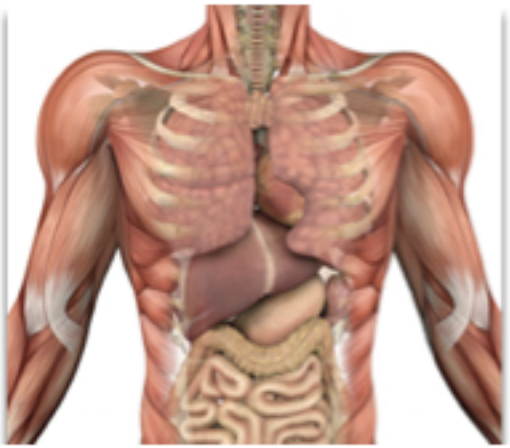
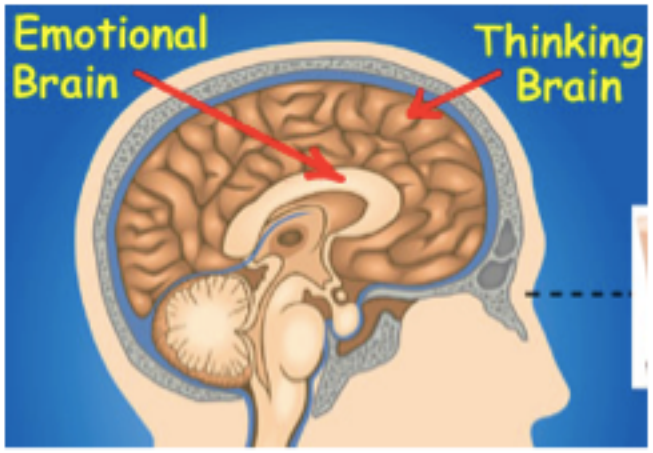
What is Integration?

- Integration is the way of the future for medicine and behavioral health services





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What is Integration?

- According to SAMHSA: (MH/BH + PC)
- The systematic coordination of primary care medicine and [mental health/] behavioral health care.
- Most people see their primary care physician first to discuss behavioral health issues (and behavioral health issues often co-occur with medical issues).
- Integration has been shown to be an effective approach to caring for people with multiple healthcare needs [including disabilities].

www.samhsa.gov

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What is Integration?

- According to policy experts – The Patient Protection and Affordable Care Act (ACA) will likely have a huge impact on the health care of individuals with mental/behavioral and physical health challenges

(Croft & Parish, 2013)

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What is Integration?

- Integration has been shown to enhance the health care for individuals with medical and behavioral or mental health conditions, particularly in the areas of:
  - Quality of care
  - Patient satisfaction
  - Cost

(Druss et al., 2001)

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What is Integration?

- Health Care Integration focuses on improving the 4 C's:
  - Communication (both between provider and patient *and* among various health care providers)
  - Collaboration – among treatment providers
  - Comprehensiveness of care (access to all care that is needed)
  - Continuity of care (a shared understanding of the problems and treatment goals)

(Horvitz-Lennon et al., 2006)

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What is Integration?

- Integration makes a difference! (surprise?)
- Studies have demonstrated:
  - Improvements in physical health (Druss et al., 2001)
  - Improvements in Mental/Emotional Health (Alexopoulos et al., 2009)

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What is Integration?

- We know why integration is so necessary:
- Individuals with multiple challenges – including physical health conditions, behavioral/mental health problems, and developmental challenges (such as autism)…
  - Experience a fragmented system of care
  - Systems are disjointed and difficult to navigate
  - Lack of information sharing between providers and systems
  - Separate funding, regulatory, and payment systems

(Institute of Medicine, 2006)

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What is Integration?

- Families of children with disabilities often navigate through three, four, five or more different systems:
  - Medical (often with multiple specialists)
  - Insurance System
  - Behavioral/Mental Health
  - Developmental Disabilities
  - Educational
  - Social Security

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What is Integration?

- ACA may help to encourage these disjointed systems to move towards an integrated model of care by influencing 3 areas:
  - Increasing access (Medicaid expansion, parity laws, tracking disparities in special populations including people with disabilities)
  - Improving finance and reimbursements
  - Developing incentives for community based collaboratives

(Croft & Parish, 2013)

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What is Autism?

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First, let's imagine what it's like to have Autism?

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Imagine - when you see a group of objects… you notice the small details but miss the big picture?

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What if sensory input such as sound, touch, movement, and light felt painful or frightening?

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Or you feel confused and frightened because you don't understand other people's gestures and facial expressions…

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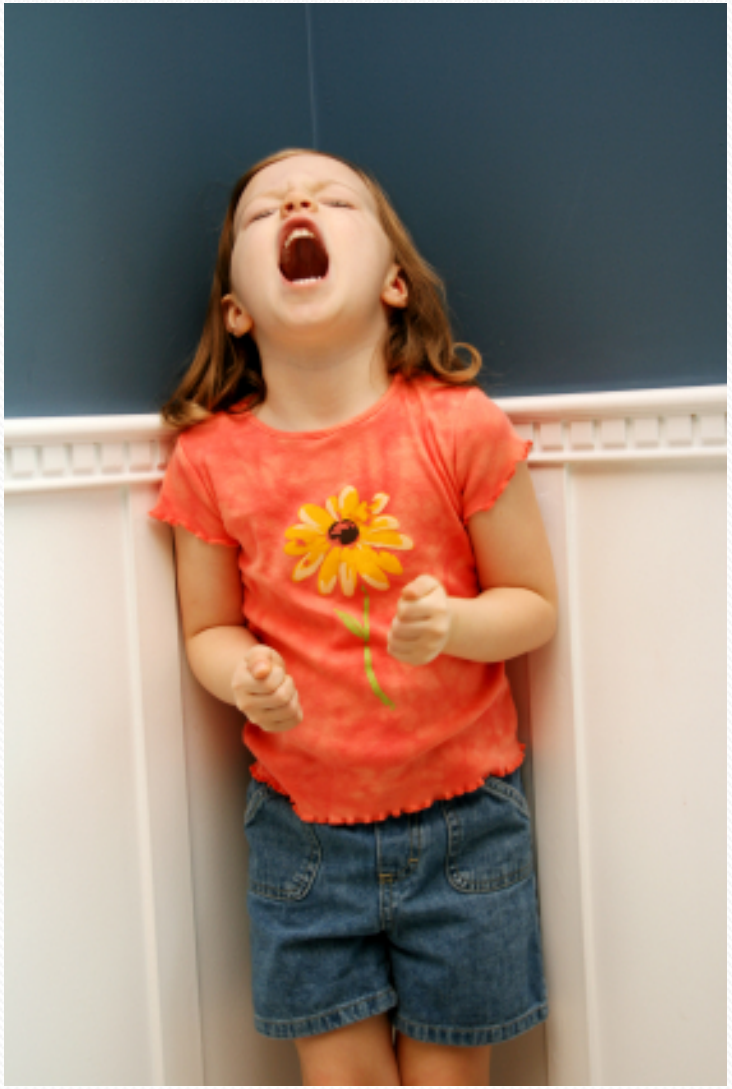

And tolerating frustrating feelings is impossible for you…

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What if - learning to move your body like others do - is difficult and embarrassing?

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And sitting down at a table to eat a meal with your family – creates tension because all you want to eat is the same thing all the time…

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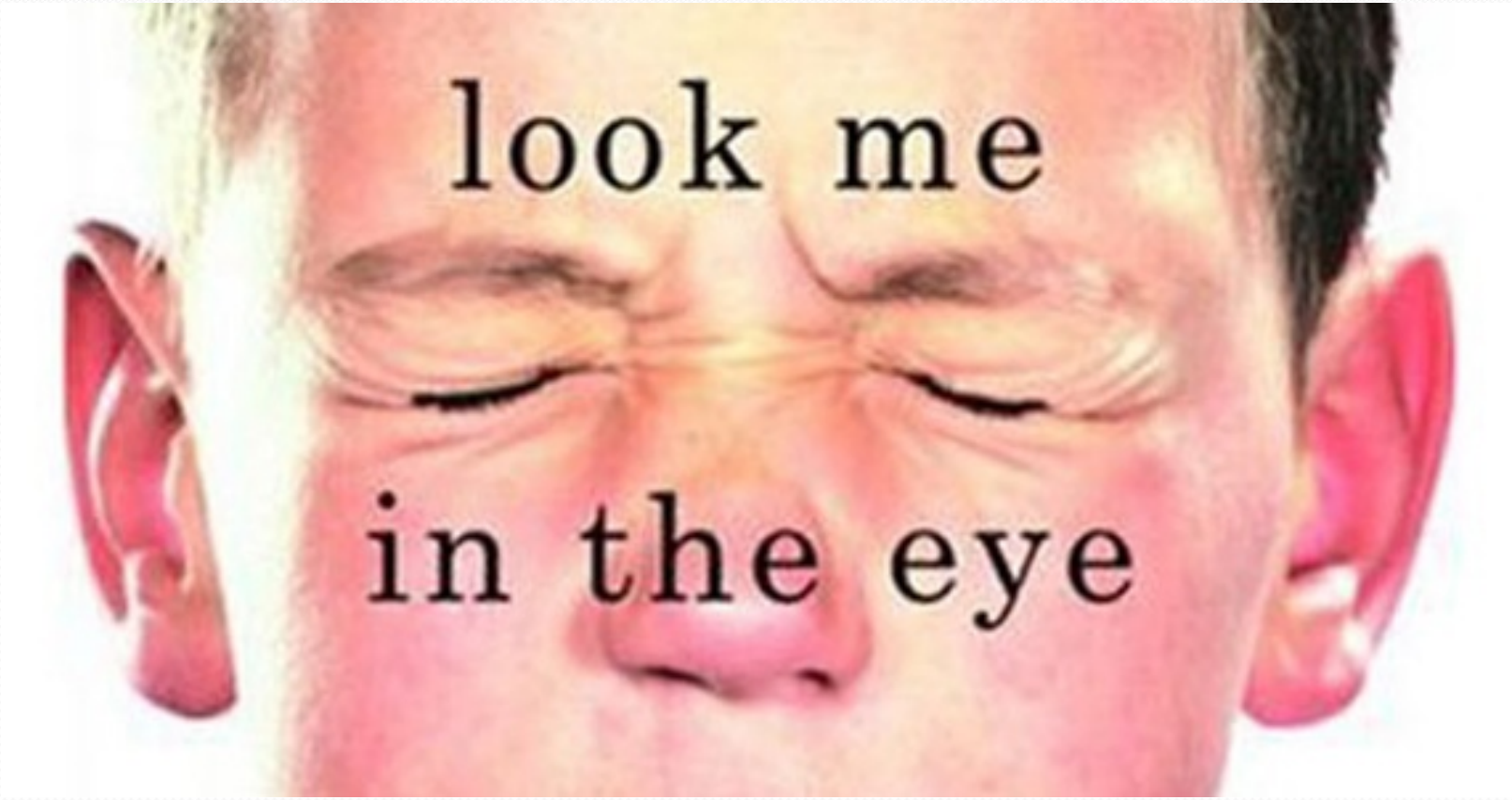
What if faces were confusing and you did not understand a person's eyes speak to you?



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And sleeping through the night is sometimes hard because your brain wants to be wide awake in the middle of the night!

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Or when someone wanted to share something with you… you had no clue they wanted to share an idea with you?

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And when people speak to you… you think they are speaking a foreign language?

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These are some of the challenges children with autism experience on a daily basis…

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DSM 5: Autism Spectrum Disorders

- Move from “Autism” to “Autism Spectrum Disorder” or ASD
  - To emphasize the wide range of symptom expression and variability over the course of development.
  - To acknowledge the degree of impairment in individuals who may not meet the traditional criteria for a full diagnosis

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Autism Spectrum Disorders:

DSM 5 Criteria for ASD:

- Three criteria became two:
  (Social communication and social interaction were combined)

  1. Persistent deficits in social communication and social interaction across contexts (not accounted for by general development)

  2. Restricted, repetitive patterns of behavior, interests, or activities
     - Sensory sensitivities are now included in this subcategory – ex. repetitive smelling, touching, looking, etc)

  - Symptoms must be present in early childhood
  - Symptoms together limit and impair everyday functioning

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Autism Spectrum Disorders:

Changes in DSM 5 :

- PDD -NOS– not helpful to say a person is not quite autistic
- Language disorders are not unique to Autism and are not included in the new criteria – seen as a modifier (along with cognitive abilities)- related to severity
- Need to Specify:
  - ASD - with or without language delay
  - ASD w/ Retts; ASD w/Fragile X; ASD w/ 15q11-15

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Autism Spectrum Disorders:

Surveillance Year	Birth Year	Number of Sites	Prevalence (per 1000)	About 1 in X Children
2000	1992	6	6.7	1 in 150
2002	1994	14	6.6	1 in 150
2004	1996	8	8.0	1 in 125
2006	1998	11	9.0	1 in 110
2008	2000	14	11.3	1 in 88
2010	2002	11	14.7	1 in 68

CDC, 2014

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Autism Spectrum Disorders:

Some facts about Autism numbers:

- Almost 12% of the records showed instability in diagnosis (i.e., multiple different diagnoses from different providers)
- Median age of diagnosis has remained fairly constant (≈4.5 years)
- Children with lower IQ scores – were more likely to receive a diagnosis of autistic disorder (versus PDDNOS or Asperger)
- Boys continue to be at higher risk (4 to 5 X more likely than girls)
- # of children who have average to above average intellectual ability are growing (responsible for some of the increase):
  - Steady increase from 2002 (32%) to 2010 (46%)
- Large increase in # of children with autism can be attributed to children with average to above average IQ (IQ > 85)

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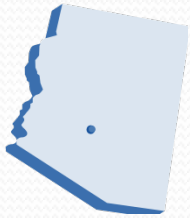
Autism Spectrum Disorders

Arizona - Autism Monitoring Data



- Results showed a slow down in the increase in prevalence here in Arizona:
  - 2006 - **12.1** in 1000 (9.0 in 1000 in US)
  - 2008 - **15.6** in 1000 (big jump)
  - 2010 – **15.7** in 1000

  - 1 in **64** in Arizona (1 in **68** on average in the US)
  - 1 in **40** boys in Arizona!

*Arizona continues to be higher than the 11-State median of 14.7 in 1000

(CDC, 2014)

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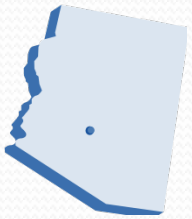
Autism Spectrum Disorders

Arizona - Autism Monitoring Data



For Autistic Disorder: Age of Diagnosis

- In 2008, Arizona had the **3rd highest median age** for an autism diagnosis (4 year, 8 months)
- In 2010, Arizona had the **2nd highest median age** for an autism diagnosis (4 year, 10 months)

(CDC, 2014)

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What we are learning about Autism:

- Autism thought to be a broad neurological and developmental disorder
- Referred to as a "neurodevelopmental disorder"
- Not just a social disorder

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What we are learning about Autism:

- Evidence of broad neurological impact:
  - Larger head circumference in early life (Shen et al., 2013)
  - Likely multiple genes involved – affecting proliferation, projections, and migration of neurons during fetal development (Pinto et al., 2010)
  - Language processing differences (Stevenson et al., 2014)
  - Neuronal connections may be decreased (Hardan et al, 2009)
  - Little or no symptoms at birth with more symptoms emerging between 12 to 36 months (as development progresses) (Ozonoff et al, 2010)

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What we are learning about Autism:

- Evidence of broad neurological impact: (cont.)
  - Motor planning and coordination (Fournier, et al, 2010)
  - Emotional Regulation/Amygdala (Bachevalier & Loveland, 2006)
  - Reward/Motivation systems (Kohls et al, 2011)
  - Mirror neuron matrix (Williams et al, 2006)

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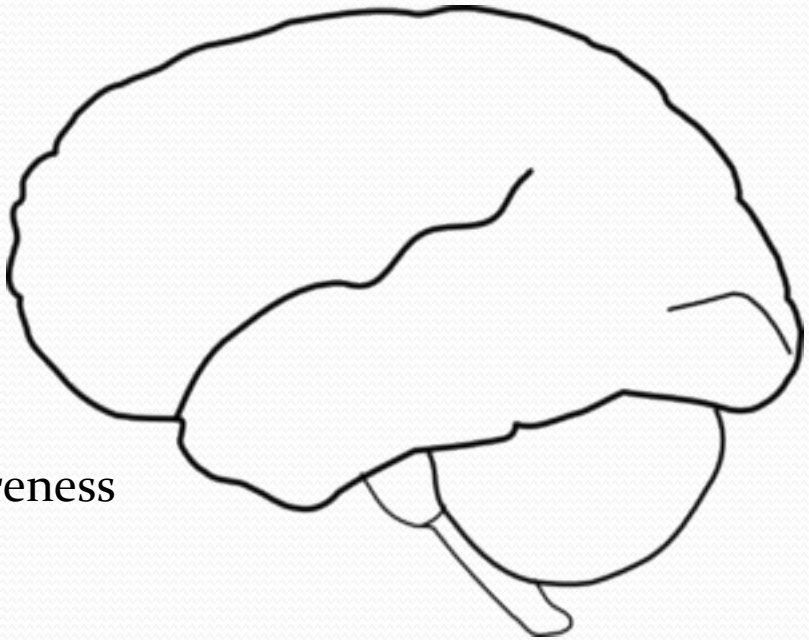
What we are learning about Autism:

- Many parts of the brain are thought to be affected:
  - Sensory
  - Motor
  - Language
  - Learning
  - Memory
  - Emotions
  - Social Awareness
  - Motivation
  - Attention



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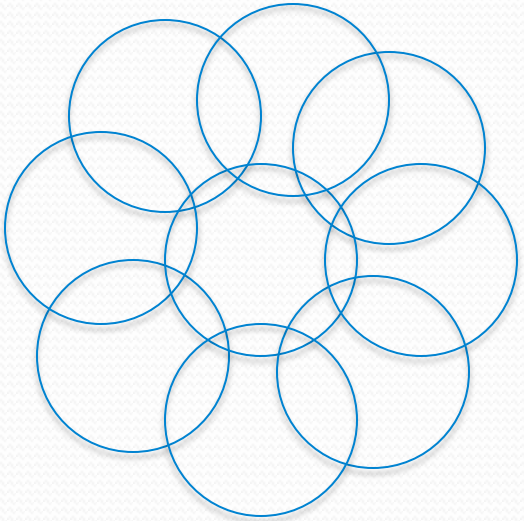
ASD: Presents A Multidimensional Challenge

- Medical/Physical
- Genetic
- Developmental
- Psychological
- Educational
- Occupational
- Family System
- Social



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Why we need a multidisciplinary/multidimensional approach to assessment and treatment:

- Many parts of the brain are thought to be affected
- Wide range of symptom expression
- Developmental differences over time
- Must address all aspects of a child's strengths and challenges
- No two children with ASD are alike: each individual needs a unique plan of interventions
- We need "all hands on deck"

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Why we need a multidisciplinary/multidimensional approach to assessment and treatment:

- No longer acceptable to operate from a single viewpoint!

- According to Dr. Matthew Siegel, coauthor of the AACAP Practice Parameters:

"But we've now seen that this is a disorder that touches multiple areas of functioning.

So to give children the best chance for a good outcome, it's not acceptable to operate from a single viewpoint."

(Brauser, 2014 – Medscape News)

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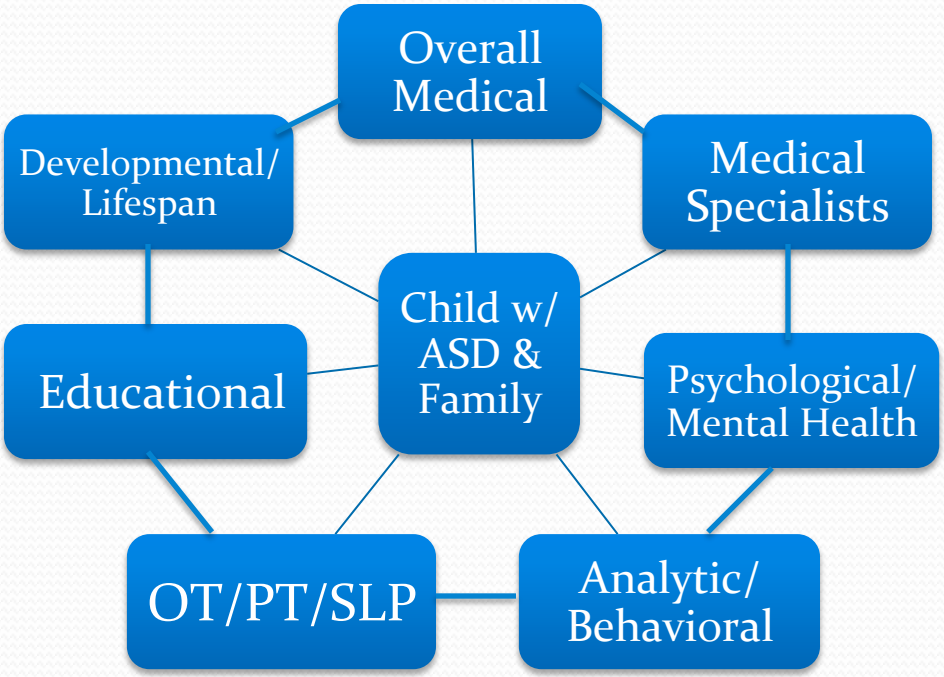
Why we need a multidisciplinary/multidimensional approach to assessment and treatment:

- We must begin to look at assessment and treatment from multiple viewpoints… and begin to integrate our perspectives:



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Psychologist's Role:

- Psychologists play an important role in a multidimensional/multidisciplinary approach:
  - Trained in the areas of:
    - Development
    - Human behavior
    - Diagnosis of psychological/developmental disorders
    - Testing and evaluation
    - Counseling
    - Systems/Organizations
    - Relationship-building

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Psychologist's Role:

- Consultation to Primary Care /Integration
- Early Screening/Detection
- Testing/Assessment - using scientifically researched interviews, test instruments, and structured observations (used in Autism Centers across the country)
- Counseling and Education
- Treatment – both relationship-based; behavioral approaches; hybrid approaches
- Parent Support
- Advocacy

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Role of the Psychologist:

- In an integrated system of care:
  - Use advanced skills to identify parents' concerns in primary care visits –
  - Identify "at risk" concerns
  - Make observations in office visit to identify "at risk" infants and young children
  - Screen in primary care for developmental, mental health, and other family risk factors
  - Do initial assessments and evaluations and refer to appropriate centers for next steps (AzEIP, DDD, Dept of Ed, etc)
  - Eligibility determination is faster – when identification, screening and evaluation are initiated at the primary care level

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Psychologist's Role:

- Comprehensive Diagnostic Picture:
  - Trained to integrate large amounts of information into a comprehensive diagnostic picture:
    - Medical
    - Developmental
    - Historical
    - Psychosocial
    - Behavioral
    - Educational
    - Test data
    - Observational

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Psychologist's Role:

- Use the ADOS - the "Gold Standard" in autism assessment
  - Systematizes and standardizes observation of multiple subtle social interactions – providing the child or adult opportunities (presses) to interact with parent and examiner
    - California Dept of Developmental Services (2002)
    - Filipek, et al (2000)
    - Filipek et al (1999)
    - NRC (2001)
    - AACAP (2014)

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Psychologist's Role:

- Psychologists use science to identify the most important predictors of autism in very young children
- Help to increase the accuracy of early detection of autism in very young children
- Early detection is the key to helping improve the outcomes of young children at risk of an autism diagnosis

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Role of the Psychologist:

- Developmental differences in symptom expression:

1) One of the earliest markers may be the impaired disengagement of visual attention seen at 3 to 4 months of age

Landry & Bryson (2004) found that visual attention deficits distinguishes typically developing children (including children with lower IQs such as Down Syndrome) from children with autism.

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Role of the Psychologist:

- Developmental differences in symptom expression:
  - Visual Attention
  - Lack of initiation
  - Developmental Language Differences

2) By 12 months of age - several researchers have found abnormalities in visual attention, passivity and lack of initiation, and delays in receptive and expressive language

(Zwaigenbaum et al, 2005)

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Role of the Psychologist:

- Developmental differences in symptom expression:

3) Very young children tend not to show obvious stereotyped behaviors but still do show abnormal repetitive behaviors:

Ozonoff et al (2008) - found prolonged visual inspection, spinning objects and rotating objects at 12 months were predictive of later diagnosis of autism at 36 months

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Role of the Psychologist:

- Developmental differences in symptom expression:

4) Response to name: no differences at 6 months but by 12 months – begins to be a predictor of possible autism.

Osterling & Dawson, 1994: Baranek, 1999) - home video studies of 12-month-olds found lack of response to name was a significant predictor of possible autism as early as 12 months

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Role of the Psychologist:

- Developmental differences in symptom expression:

5) Response to Joint Attention: high risk infants at 12 months of age make significantly fewer joint attention responses and predicts a diagnosis of ASD at 33 months

Presmanes et al, 2007 – found high risk infants have more difficulty interpreting communicative cues and do better with redundant cues (point, turn, verbal).

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Role of the Psychologist:

Refer if Infant is not…

- Before 6 months:
  - Looking at faces
  - Smiling at others
  - Cooing
- 6 to 12 months:
  - Responding to name
  - Babbling
  - Playing social games
  - Displaying bright affect
- 12 to 18 months:
  - Pointing and showing
  - Using single words
  - Using gestures
  - Imitating
  - Interest in peers

(Ozonoff et al, 2010; Ozonoff Presentation U of A 2012)

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Role of the Psychologist:

- Parent Support:
  - Decrease isolation:

    "Other parents don't seem to understand what we're going through"

    "Talk to other people who are "going through the same thing"
  - Share knowledge and resources
  - Gain more of an understanding:

    "Know more about how to help my child"
  - Give hope:

    "This was uplifting in a time of confusion"

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Summary of Today's Discussion

- We talked about Integration.
- We talked about ASD as a broad multidimensional neurodevelopmental disorder.
- ASD requires a multidisciplinary approach – not okay anymore to operate from a single viewpoint!
- Psychologists have important skills for an integrated team approach and can help with early identification and treatment of ASD

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