Building Strong Clinical Connections with Youth Living with Autism Spectrum Disorders and Intellectual Disabilities

Mari Radzik, PhD, Sara Sherer, PhD, Sari Glassgold, PhD
Division of Adolescent and Young Adult Medicine
Children's Hospital Los Angeles
USC University Center for Excellence in Developmental Disabilities
USC Keck School of Medicine

March 9, 2017
Society for Adolescent Health and Medicine
Cultivating Connections Conference
New Orleans, Louisiana
Disclaimers

• Presenters have a special affinity for AYA with Autism Spectrum Disorders and Intellectual Disabilities
• No financial obligations
• Services rendered and supported by the Department of Mental Health, Los Angeles County, California
Educational Objectives

1. Identify the prevalence, co-morbidities and differential diagnoses among adolescents and young adults living with autism and intellectual disabilities.

2. Better communicate with their adolescents and young adults diagnosed with autism and intellectual disabilities in the medical and psychological setting.

3. Employ effective interventions useful in clinical settings and become aware of applicable linkages and community services.
Why Is Appropriate Communication With Youth Living with ASD/ID Important?

• Misinterpreted medical information
• Poor follow up and adherence to medical direction
• Patients may be unaware of harmful behaviors
• Patients may have different thresholds for pain
• Can reduce the need for emergency department use
• Can increase the utilization of prevention services
• Can increase satisfaction with patient-provider relationship
A Brief History of Autism Spectrum Disorder

- Steve Silberman - we are in “a perfect storm of autism awareness”
- “The Geek Syndrome” - 2001 Wired Magazine article
  - Silicon Valley confluence of Asperger's and autism
- 1944 - Hans Asperger's - ‘little professors’
  - Coined “Autistischen Psychopathen” - autistic psychopathology
- 1940-50's - Leo Kanner - the “refrigerator parents”
- 1964 - Bernard Rimland - disability rather than psychosis
- 1981 - Lorna Wing - describes a ‘spectrum’
- “making peace with autism” - acceptance rather than cure
- Causes - brain abnormalities, genetic vulnerability - no current biologic markers. We HAVE to rely on pt and parental reports
- Communication between patient and provider is key to success
Prevalence of Autism Spectrum Disorder Among Adolescents

• CDC estimates that about 1 in 68 children has been identified with ASD (or 14.6 per 1,000 8-year-olds).
• 2007 - 1 in 150 children had ASD (based on 2002 data from 14 communities).
• 2009 - 1 in 110 children had ASD (based on 2006 data from 11 communities).
• 2012 - 1 in 88 children had ASD (based on 2008 data from 14 communities).
• 2014 - 1 in 68 children had ASD (based on 2010 data from 11 communities).
• The estimated prevalence of ASD increased roughly 123% during 2002 to 2010.
Autism Spectrum Disorder
Prevalence Facts

• The percentage of children identified with ASD ranged widely across geographic area. For example, they range from a low of 1 in 81 or 1.2% in areas of South Carolina to a high of 1 in 41 or 2.5% in areas of New Jersey.

• Boys were 4.5 times more likely to be identified with ASD than girls.

• About 43% of children identified with ASD were evaluated for developmental concerns by age 3 years.

• Even though ASD can be diagnosed as early as age 2 years, most children were not diagnosed with ASD by a community provider until after age 4 years.

• Among children identified with ASD who had IQ scores available, about a third also had intellectual disability.
Prevalence of Intellectual Disorders in Adolescents

According to CDC’s analysis, the prevalence of intellectual disabilities range from:

• 1.55% to 1.83% internationally are diagnosed with ID
• .5% for children under 18 years old (from the National Health Interview Survey, 2006, and supported in a 2010 U.S. Census Bureau (.4%))
• But the 2009/2010 Natl Survey of Children with Special Health Care Needs finds approx. 5.8% children under 17 have ID
• And, in the 2014-2015 school year, .12% of 3-5 year olds and .62% of 6-21 year olds were served under IDEA (Individuals with Disabilities Education Act)
• In summary, we know that the overlap between ASD and ID can occur a 3rd of the time
• As a provider, being aware that not all ASD youth have ID is crucial, while understanding that a third do will inform your care
Prevalence of Autism Spectrum Disorder Among Youth of Color

- Diagnosis of autism may be related to cultural understanding of the diagnoses.
- 30% White children were more likely to be identified with ASD than black or 50% more than Latino children. Black children were more likely to be identified with ASD than Hispanic children.
- Black and Hispanic children were less likely to be evaluated for developmental concerns by age 3 years than white children.
- Co-morbid ASD and ID was significantly lower in non-Hispanic White children (3.3 per 1,000) than non-Hispanic Black children (5.8 per 1,000) who were less than 8 years old (Christensen et al., 2016).
Impact Of The ASD/ID Diagnoses On Culturally Diverse Families

- **Parental issues include** -
  - language barriers
  - Not being comfortable with in home service providers
  - Thinking autism symptoms are behavioral
- Understanding services by both the provider and parents
- Youth of color underrepresented in any research on autism
  - Underrepresented in the Autism Genome Project
- Spending on non-medical services for people with autism in California (Leigh, et al., 2016)-
  - Most spent on white individuals - the most on 18+
  - the least amount of money on Latino individuals
  - Authors advise that budgets need to prepare for large influx of young people moving into adulthood.
Social (Pragmatic) Communication Disorder 315.39 (F80.89)

Diagnostic Criteria include-

A. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:

1. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.

2. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on the playground, talking differently to a child than to an adult, and avoiding use of overly formal language.

3. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.
4. Difficulties understanding what is not explicitly stated (e.g., making inferences) and nonliteral or ambiguous meanings of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).

B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.

C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).

D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains or word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.
Key Differences Between ASD and SCD

• **SCD** -
  – more interest in others - sustained and affective relationships with others
  – Initiate interactions with others
  – Understands non verbal cues and facial expressions
  – Difficulties with interactions due to speech problems

• **ASD** -
  – Not interested in others
  – May reject contact
  – Little symbolic play with toys or items
  – Perseverative interest areas or repetitive behaviors
DSM V Autism Spectrum Disorder
299.00 (F84.0)

Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
A. (cont)

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify current severity:*

- Severity is based on social communication impairments and restricted repetitive patterns of behavior
B. Restricted, repetitive patterns of behavior, interest, or activities, as manifested by at least two of the following, currently or by history (ex. are illustrative, not exhaustive):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat the same food every day).
B. (cont)
3. Highly restricted, fixated interests that are abnormal in intensity (e.g., perseverative interests)
4. Hyper-or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., excessive smelling or touching of objects).

Specify current severity:
• Severity is based on social communication impairments and restricted, repetitive patterns of behavior
Autism Spectrum Disorder - Criteria C, D, E

C. **Symptoms must be present in the early developmental period** (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. **Symptoms cause clinically significant impairment** in social, occupational, or other important areas of current functioning.

E. **These disturbances are not better explained by intellectual disability** (IDD) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.
Autism Spectrum Disorder Specifiers

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor
- Associated with another neurodevelopmental, mental, or behavioral disorder
- With catatonia
Severity Level, Social communication, Restricted/Repetitive behaviors

**Level 3- Requiring very substantial support**
- severe deficits in verbal and nonverbal communication
- inflexibility of behavior, extreme difficulties coping with change or other restricted behaviors.

**Level 2- Requiring substantial support**
- Marked deficits in verbal and nonverbal social communications skills, social impairments apparent even with support in place, limited initiation of social interaction
- Inflexibility of behavior, difficulty coping with change, or other restricted behaviors.

**Level 1- Requiring Support**
- Without support in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions.
- Inflexibility of behavior causes significant interferences with functioning in one or more contexts.
DSM V Intellectual Disability (Intellectual Developmental Disorder)

Criteria -
- Onset during the developmental period that includes both intellectual and adaptive functioning in conceptual, social and practical domains.
- A. Deficits in intellectual functioning - reasoning, problem solving, planning, etc. confirmed by assessment
- B. Deficits in adaptive functioning - difficulties with independence and social responsibility
- C. Onset of the intellectual and adaptive functioning issues occurs during the developmental period.
- Coded by severity - mild, moderate, severer and profound
The Autism Experience
Youth on the Autism Spectrum present differently -

- They might have social skills difficulties and challenges learning how to make friends.
- Some appear “neuro-typical” much of the time but may have differences in the way they learn or in their interests.
- Some may have special gifts and talents but not all.
- Many often go to school and participate in activities just like their peers.
- And others may have special educational plans — due to their communication or behavioral issues; i.e. difficulty speaking or interacting with others.
The Social Experience of Autism

Socially, youth with autism -

- May appear to want to be **left alone** because they have trouble looking at, talking to, or hanging out with people.
- Sometimes they may appear rude or act like they're not interested in others.
- It can be difficult for some to **look at people** while they talk.
- They may have **trouble understanding jokes** or sarcasm.
- And since they've been taught by other people how to talk, they may **imitate what** they have learned making their voices sound flat, blunted or boring.
- They may appear socially awkward due to lack of awareness or may have just enough awareness about their lack of social awareness.
Social Interactions

• Unusual or repetitive activities -
  – Repeating the same word over and over or moving a body part in a certain way - but often have a hard time controlling it.

• Looking unemotional or insensitive -
  – “Mindblindness” - not understanding another’s thoughts.
    • Theory of mind: understanding mental states in self and others
  – It doesn't mean they don't have feelings – it can just be more difficult for them to show those feelings or understand the feelings of others.
Due to their concrete thinking, communication and making personal connections are difficult for those living with autism.

- Facial expressions are often hard to read.
- Trouble understanding what emotions look like and what another person is thinking (the “mindblindness”).
- Their behaviors/communications may be unusual, and hard to understand.
- And they can easily misinterpret caregivers' communications such as teachers, health care and mental health providers and others.
• Parents of children with developmental disabilities report higher levels of stress than parents of children without such difficulties

• Raising a child with Autism has been associated with increased parental stress and increased family chaos.
Parental Stress & Reasons For Family Support

• Parents report difficulties coping with dx and coping with teens’ symptoms (i.e., behavioral problems).
• Parents of children with ASD and ID have high levels of depression and other mental health problems.
• Better communication with parents may improve parenting skills and parents’ overall well-being.
• Parents can also learn new tools and techniques to help their youth cope more appropriately.
Parents Need Support As Well

• Psychoeducation
• Improved parental skills for more effective interactions with their adolescents
• Reduce isolation and normalize experience
• Social support
  – Learning from other parents in a group setting
• Resources and linkages to community support
Jesse and his family received individual and family therapy, medical care, psychiatry, school advocacy and group interventions at CHLA-DAYAM.
Interview Quotes and Discussion

- **Jessie:**
  - “Autism is like having an ability. Like having a power.”
  - “Don’t be afraid...We do have some emotions.”
  - “Look me in the eye. Tell me what I have. Don’t keep secrets. When someone comes to therapy let them be themselves.”

- **Mom:**
  - “If they told me the truth in the moment...with that I could have educated myself.”
  - “I prefer the truth. If we train the professionals and the parents that he has this, it’s better.”
  - “Give me the correct names for everything...”
  - “The visual contact is very important for me and him. Then I feel like they understand.”
Communication Tools for Providers
Initial Connection And Establishing Rapport-Helping Your Patient Feel Safe

• Significant social skill deficits make it challenging for people with ASD to connect to care providers, teachers, doctors, etc.
• Casual conversations and routine interactions (i.e. checking in with doctors) can be extremely overwhelming, confusing and frustrating.
• Even casual conversation requires effort. Thus, youth may refuse and avoid these appointments.
• **Prepare patient for the clinic appointment** -
  • Pre-visit if possible
    – Review for any behavior or sensory issues
    – Inform your team
  • Ask for any information about cognitive functioning, verbal ability and medical history
    – **Review prior history of medical follow up.**
  • Review consenting and conservatorship
  • Determine role of the parent or guardian in care
    – **What is the capability of the youth to determine their own treatment**
Establishing Rapport

• Those living with ASD experience the world differently.

• Spend some time first getting to know their interests, then use those interest to engage them.
  • Try to connect on interests they have such as video games, TV shows, music, movies, Disney characters, anime, etc.

• Building rapport, allows for a better medical relationship and a more accurate sharing of medical information.

• Expressing emotions and asking questions can be very challenging –
  – Therefore- they may need several appointments to ask a question or let you know about certain symptoms.
  – Even though they are a young adult, they may need or want the parent to be in the room to help explain symptoms.
Communication And Encouragement

Dr. Temple Grandin - “Different not less”

- Important to try to speak, interact, communicate and encourage youth living with autism
- Parental encouragement and support is needed as well

https://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds#t-803765
Difficulties in Healthcare Settings

• Don't expect the patient (or family) to always understand what you are saying
  – Especially if English language learners
• Be more concrete, direct and repeat information
• Some youth present as understanding the information offered
  – However, they may nod or answer yes when in actuality they do not understand what is being said
Factors Impacting ASD/ID Care In The Health Care Setting

Nicolaidis, C., D. M. Raymaker, et al. (2015) reported on factors affecting health care communications-

**Patients with autism related the following difficulties**-

- Verbal communication skills - how to answer “on a scale from 1 to 10”?
- Sensory sensitivities in the clinic - bright lights, walls, noises
- Body awareness - how to describe pain when we ask about ‘shooting’ or ‘radiating’ pain?

**And report the following providers communication challenges**

- Incorrect assumptions about skills or needs
- Unwillingness to allow pts to communicate by writing
- Accessible language - not talking down to the pt
- Openness to considering accommodations

Figure 1. Patient, provider, and system-level factors affecting the participants’ experience with healthcare
• **This study recommends** -
  – Respect for differing ways of communication
  – Accommodate the patient in the room - dim lights
  – Avoid open ended or vague questions
  – Recognize the broad range/spectrum of ASD
  – Ask about accommodations and allow
  – Advocate for their rights
  – Give information to patients about resources and information
  – Increased provider training on ASD/ID issues
Adolescent and Young Adult Health Care Information

• It is important to remember that youth living with ASD/ID need developmentally appropriate young adult information - puberty, sexuality, body development, etc.
  – this information may need to be presented in at an accurate developmental level (e.g., 3rd grade level), concrete and multiple times.

• Family Involvement may be necessary
  – Even if adult and over the age of 18
  – Conservatorship means you will have to review with conservator the above issues
• **Structure the visit** -
  – Determine how the patient communicates and utilize those modalities
  – Utilize visual tools-
  • write down information and don’t assume they will remember verbal information
  – Be brief and clear with request
  – At first, keep humor to a minimum, if at all
Communication Tools for Providers - 3

- **Structure the visit (cont.)** -
  - Ask the patient to repeat what you said and ask if they would like you to repeat it.
  - Give permission to not understand information right away
  - Allow for questions
  - Adult patients (18 and older) -
    - May have similar challenges to the younger patients
    - Sharing information with parent may be necessary
    - Utilize parents and family
• **Symptom review** -
  – May have difficulty describing symptoms
  – Physical complains may be expressed as mood symptoms
    • Aggressiveness, agitation, irritability or self-injury
    • Utilize parent reports, they know their children

• **Integrated care** -
  – Consultation with allied professionals -
    • Consult with or bring in therapist to appointments
    • Therapist can help family understand the medical information in following sessions and can address barriers to medical adherence
    • Therapist can assist with procedure anxiety - blood draws, shots
    • Families are often very appreciative of team approach
Collateral Treatment Services

- **Treatment for ASD includes**
  - **Behavioral and communication approaches**
    - Mental Health and Psychiatric Services (as needed)
    - ABA (Applied Behavioral Analysis)
    - Speech, OT and Physical Therapy
  - **School services**
    - Individuals with Disabilities Education Act (IDEA)
    - IEP, SSTs, 504 plans, NPS placement
  - **Dietary changes**
    - Seek nutritional consultation
  - **Complementary and Alternative Medicine (CAM)**
    - Be aware of parents seeking outside CAM care
  - **Case Management**
    - Regional Center (California) or Dept. of Disability
Advocacy Roles To Assist The Family

- **Roles of providers should include strong advocacy in the community, home and school setting** -
  - Linkage to Regional Center in California (Department of Disability Services)
  - Linkage to your state’s Department of Disability Services
  - Linkage to in home behavioral services
  - Linkage to School Services (IEP, accommodations)
  - Linkage to other community resources (i.e., legal services and learning rights services)
Steve Silberman

“The notion that conditions like autism, dyslexia, and ADHD should be regarded as naturally occurring cognitive variations with distinctive strengths that have contributed to the evolution of technology and culture rather than mere checklists of deficits and dysfunctions”

Strength based approach - rather then focus on the dysfunction, we focus on supporting patients and families

A supportive community is the “cure” for autism
Resources

- http://www.autisminblack.com/ - for African American families
- http://www.thecolorofautism.org/ - for African American families
- http://autismpdc.fpg.unc.edu/ - the National Professional Development Center
- https://www.autismspeaks.org/ - for families and providers
- https://www.autismspeaks.org/family-services/non-english-resources/spanish
- https://www.autism-society.org/
- https://aadmd.org - American Academy of Developmental Medicine and Dentistry
QUESTIONS AND ANSWERS

IF I CAN'T SEE THEM, THEY CAN'T SEE ME!
Thank You!

- **Mari Radzik** - mradzik@chla.usc.edu
- **Sara Sherer** - ssherer@chla.usc.edu
- **Sari Glassgold** - sglassgold@chla.usc.edu
References


References (Cont.)


• 2015 Steve Silberman Ted Talk https://www.wired.com/2001/12/aspergers/


• https://www.cdc.gov/ncbddd/autism/data.html


• Spending by California’s Department of Developmental Services for Persons with Autism across Demographic and Expenditure Categories. Leigh JP, Grosse SD, Cassady D, Melnikow J, Hertz-Picciotto I (2016) Spending by California’s Department of Developmental Services for Persons with Autism across Demographic and Expenditure Categories. *PLOS ONE* 11(3): e0151970. doi: 10.1371/journal.pone.0151970