Evaluating Adults for an Autism Spectrum Disorder

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Adults with ASD

Prevalence of Autism Spectrum Disorders

• 25 years ago 1/10,000
• Current (2012): 1/88

Centers for Disease Control

Prevalence in adult populations closely parallels that found in children (Brugha et al. 2011)—1%
70% of people with ASD are over 14 (Gerhardt & Lainer, 2011)

Autism Facts

• Autism can be reliably diagnosed by or before age 3
• Increasing number of adults are presenting for evaluation—underserved and understudied
• Male:Female = 3-5:1
• No effective means of prevention
• No fully effective treatment
  • Early intervention effective and improves prognosis
  • Intervention at any age can improve outcome

Autism Spectrum Disorder (DSM-5)

• New name for category which previously included autistic disorder, Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder NOS
• Three domains become two:
  1. Social/communication deficits
  2. Fixated interests and repetitive behaviors

DSM-5 Criteria

Must meet criteria A, B, C, & D including all 3 in A

A. Persistent deficits in social communication and social interaction across contexts; deficits in:
  • Social-emotional reciprocity (e.g. conversation, joint attention)
  • Non-verbal communicative behaviors (e.g. eye contact, body language, facial expression, gestures)
  • Developing and maintaining relationships (e.g. imaginative play, making friends)
DSM-5: Criteria (cont)

B. Restricted, repetitive patterns of behavior, interests or activities; at least 2 of the following:
   • Stereotyped/repetitive speech, motor movements or use of objects
   • Excessive adherence to routines/rituals or excessive resistance to change
   • Highly restricted interests, abnormal in intensity or focus
   • Hyper/hypo reactivity to sensory input or unusual interest in sensory aspects of environment

DSM-5: Criteria (cont)

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning

Also 3 levels of severity – requiring support, substantial support, or very substantial support

What do we know about young adults with ASD?

Through the use of national data completed by caregivers and young adults with ASD (n=500), results indicate:

- First 2 years out of high school are very difficult—very high risk of being disengaged
- 34% attended college
- 55.1% had paid employment; this is a lower employment rate than those with other disabilities

(Shattuck et al., 2009)

Employment Challenges

- Communication and social difficulties with coworkers are cited as the top causes for job termination (Hendricks, 2010)
- 50-75% of adults with ASD are unemployed (Howlin, 2005)

Is the ASD evaluation process useful as an adult?

Perhaps…

- Enhanced understanding of strengths, challenges, and a possible explanation for lifelong struggles.
- Sharing diagnosis with others may result in increased understanding and support
- Guidance in terms of therapies or services
- Can be useful in determining whether current treatments or medications are appropriate
- Potential eligibility for certain supports

Common Reasons for ASD Referral During Adulthood

Variety of Reasons for Referrals

- Having a child with ASD
- Marital/family difficulties
- Life long social difficulties
- Treatment of psychiatric symptoms not sufficient
- Loss of employment/unemployment
- Media
Supports
- Academic accommodations at the college level
- Extended time on a parent’s medical insurance or potential eligibility for SSI
- Autism Society of Colorado, national agencies (Autism Speaks), and other adults with ASD through local support groups (GRASP, DASAM)
- Community supports (depending on your cognitive abilities and daily living skills) through a community centered board

Supports Cont’d
- Vocational support/job coaching through Vocational Rehabilitation Services
- Placement on waitlists for waivers and housing supports

Best Practice Assessment Guidelines
- Developmental history:
  - Early social-communication behaviors and medical history, ideally with information from a parent/care provider
  - Direct observation
- Other assessment areas:
  - Psychiatric assessment
  - Intellectual assessment
  - Adaptive behavior assessment

Gold Standard ASD Assessment
- Clinical exam guided by DSM-5 that is supported by two standardized assessments:
  - Autism Diagnostic Observation Schedule (ADOS)
  - Autism Diagnostic Interview-Revised (ADI-R)

Both instruments require substantial training

More on ADOS
- Semi-structured assessment of communication, social interaction, and play (or imaginative use of materials) – four modules
- 45 min to administer module 4—module for adults with complex spoken language

More on ADOS
- Algorithm items in:
  - Communication: stereotyped language, conversation, descriptive gestures, emotional gestures
  - Reciprocal Social Interaction: eye contact, directed facial expressions, emotion/empathy, responsibility, quality of social overtures/response, amount of reciprocal communication
More on ADI-R

- Semi-structured clinical review for caregivers of children and adults
- 93 items (scored with “current behavior” and “most abnormal” ratings) in three content areas:
  - Quality of social interaction
  - Communication and language
  - Repetitive, restricted and stereotyped interests and behavior

Use of Self-Report

- Unlike the assessment of general mental health issues in adulthood, self report has not traditionally been the primary means of assessment for an ASD
- Language and cognitive abilities may be impaired
- Limited insight
- Misinterpretation of test items

More on ADI-R

- However, only 28 or so items are used for the algorithm:
  - Failure to use nonverbal behaviors
  - Failure to develop peer relationships
  - Lack of shared enjoyment
  - Lack of socioemotional reciprocity
  - Gestures
  - Conversation exchange
  - Unusual speech
  - Unusual interest
  - Rituals
  - Motor mannerisms
  - Sensory interest

Assessment Challenges—For Adults

- Disinterested family member
- Access to qualified provider
  - Insurance/payment issues, reduced number of qualified providers, Provision of mental health diagnosis that overshadows ASD etc.

Assessment Challenges—For Clinicians

- Access to early developmental history or school records
- Need for more standardized and streamlined assessment battery for this heterogeneous population
- Psychiatric comorbidity
- High rates of polypharmacy
- Challenges with self-report

Who are Adults with ASD

Turning to?

Primary care providers

Adults with ASD often:

- Have unmet physical and mental health needs
- Are less likely to receive preventative care
- Are more likely to end up in ER
- Are more likely to report poor communication with provider (Nicholaidis et al., 2013)
Screening Tools: Clinician Administered

- Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R, Ritvo et al., 2010)
- Adult Asperger’s Assessment (AAA, Baron-Cohen et al., 2005)

More on AAA

- It is a complete diagnostic system
- First complete AQ and EQ, then AAA
- Seeks to gather examples based on endorsed items from individual and informant
- 4 sections each describing a group of symptoms (A–D), and then a final section (E), describing 5 key prerequisites.

More on RAADS-R

- 4 subscales (per DSM-IV criteria)
  - Social Relatedness (39 questions): empathy, intimacy, social language
    - I can put myself in other people's shoes
  - Circumscribed Interest (14 questions): interests and social blindness
    - It can be very hard to read someone’s face, hand and body movements when they are talking
  - Language (7 questions)
    - I take things too literally; I often misunderstand what people say
  - Sensory Motor (20 questions)
    - I can’t tolerate things I don’t like (smells, textures, etc.)

More on RAADS-R

- Administered by clinician
- 64 symptom-based questions and 16 non-symptoms; scored on 4-point scale
  - “true now and when I was young” = 3, only true now = 2, true when I was young = 1, never true = 0
- Score > 65 is suggestive of ASD

Screening Tool: Clinician Administered Cont’d

Observational assessment:

- Autism Mental Status Exam (AMSE):
  - Structures the way physicians observe and document social, communicative and behavioral functioning
  - Designed for clinicians with competence in ASD
  - Excellent inter-rater reliability and strong classification accuracy compared to the ADOS (Grodberg et al 2012)

More on AMSE

- Online training curriculum (digital manual and video)
- Items scored on a 0-2 scale; cutoff score of ≥ 5 for verbally fluent adults
  - Eye Contact
  - Interactions
  - Pointing
  - Language
  - Pragmatics
  - Repetitive Behaviors
  - Preoccupations
  - Sensitivities
Screening Tools: Self Administered or Caregiver Administered

Self-administered to identify traits:
- Social Responsiveness Scale-Adult (SRS; Constanino and Gruber 2005)
- Social Communication Questionnaire (SCQ; Rutter et al. 2003)
- Autism Spectrum Quotient (AQ; Baron-Cohen et al. 2001)

More on SRS
- SRS-A contains 65 Likert-scaled (0–3) items, t-scores provided for age and gender with t-scores >76 strongly suggestive of ASD
- Two forms (one to be completed by spouse/caregiver, other self report)
- 5 Subscales:
  - Social Awareness
  - Social Cognition
  - Social Communication
  - Social Motivation
  - Restricted Interests and Repetitive Behavior.

More on SCQ
- Current can be administered to adults with ID, with a lower cutoff score
- Lifetime version--

More on ASQ
- Assumes ASD symptoms lie on a continuum and these traits are identifiable
- 50 items; each items scored at 1 point with agree and strongly agree merged and disagree or strongly disagree merged; scores >30 suggestive of further eval
- 80% of Baron-Cohen’s validation sample of adults with confirmed ASD diagnosis scored above cutoff
- In US samples, only 44% of adults with confirmed ASD and average IQ met cut off (Bishop and Seltzer, 2012)
  - Mean score ranged from 22.5-29.4 in three US studies of adults with confirmed ASD samples—should cutoff be dropped or questions modified given US samples are endorsing high social motivation? (Bishop & Seltzer, 2012; Ketelaars et al, 2008; Kurita et al., 2005)

More on ASQ
- 5 conceptually derived subscales:
  - Social Skill
    - (74% “I find it difficult to work out people’s intentions”)
  - Attention Switching
    - (77% “New situations make me anxious”)
  - Attention to Detail
    - (77% “I usually notice car number plates or similar strings of information”)
  - Communication
    - (71% “People often tell me that I keep going on and on about the same thing”)
  - Imagination
    - (31% “I find making up stories easy”)

Psychiatric Comorbidity
- 80% of adult sample with HFA met criteria for an Axis 1 disorder (Hofvander et al. 2009)
- Mood disorder (65%), anxiety disorders (59%), ADHD (52%)
- PD: Obsessive (32%), Avoidant (25%), Schizoid (21%)
- Increased behavioral difficulties in adults with intellectual disabilities and ASD than in ASD alone (Smith & Matson, 2010)
- Higher rates of anxious/repetitive behaviors, ADHD symptoms, and depressive symptoms
Reasons for High Psychiatric Comorbidity

- Genetic loading
- Environmental factors
- Living with social-communication challenges that have been untreated can result in increased loneliness, isolation, and impairment

ASD vs. Other Psychiatric Condition...or both

- Onset of symptoms: ASD symptoms should be present from a very early age and often precede the onset of mental health symptoms
- Symptom profile: There are a unique set of social-communication behaviors often observed in ASD
  - Presence and/or history of unusual communication: echolalia, scripted language, neologisms, pronoun reversals, odd prosody, use of hand as tool
  - Poor integration of gestures, eye contact, spoken language

Behaviors That, Alone, Do Not Differentiate Autism

- Social anxiety or avoidance
- Delay in spoken language
- Repetitive motor behaviors
- Restricted interests
- Over-sensitivity or under-sensitivity to stimuli
- Problem behavior

Next steps when you suspect an adult has ASD:

- Discussion about whether a formal diagnosis might be appropriate and/or important
- Referral to clinician with ASD expertise

Next steps for adults who receive an ASD diagnosis

- Psychiatric supports—psychiatrist
- Mental health supports—psychologist, refer to JFK Partners and other community providers
- Medical supports—PCP may need to provide referrals

Social Supports

Support Groups

- GRASP – (303) 777-3117, a support group
- Autism Society of Boulder, monthly support groups

Skill Building

- Chris Burnes/Nancy Gann, 720-618-4502
- Craig Kippinburg – 303-716-4154, or
- Mike Roskey – 720-297-0736, 303-300-2990.
- Lauren Kerstein, LCSW, 303-284-5055 or email at lauren@comcast.net
- JFK Partners, Bev Markert at 303-724-7643
College Supports

- Disability services at college
- Thinkcollege! www.thinkcollege.net/
- Opportunities for Postsecondary Success: contact person is Cathy Schelly (catherine.schelly@colostate.edu), Front Range Community College (www.frontrange.edu) and the University of Colorado at Colorado Springs (contact: Christi Kasa-Hendrickson, chrrendri3@uccs.edu)

Job Coaching

- Colorado Division of Vocational Rehabilitation Services can be reached at (303) 866-4150 or on the Internet at www.cdhs.state.co.us.
- Community Centered Boards (each county has own CCB)
  - can be extremely useful, particularly for individuals whose IQ and adaptive behavior is below 70; new guidelines provide support for individuals without ID but with low adaptive behavior in two domains

SSI, Medicaid, Legal Advocacy

- Family Voices Colorado, a local chapter of a national organization designed to help individuals with a variety of special needs, can provide support with this process. They can be reached at (303) 733-3000.
- Legal Center for People with Disabilities regarding advocacy related issues: (303) 722-0300

Internet Supports

- Organization for Autism: Transition Guide
- Autism Speaks: Tool Kit about adult supports and resource guide specific to Colorado
  - http://www.udel.edu/bkibby/asperger/
  - http://www.autismcolorado.org/
  - http://www.naer.org/aboutaut/whats_id.htm
  - http://www.ucdmc.ucdavis.edu/mindinstitute/
  - http://www.asperger.net

In Summary:

- Adults with ASD are underserved and understudied
- Autism has a unique early developmental history and core presentation that is different from other developmental disorders and psychiatric disorders
- People with ASD are at higher risk for co-occurring developmental and mental health problems
- Assessment requires good knowledge of psychiatric conditions
- Intervention critical for skill development

Let's Join Together

"Let’s advocate, get involved, and work to improve the resources for adults in Colorado!"

Harriet Austin, PhD
Children’s Hospital

Audrey Blakeley-Smith, PhD