All Grown Up: Autism Spectrum Disorders in Adults
Controversies and Opportunities

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Faculty Disclosure

- **Dr. Bennett**: Grant/Research Support—Autism Speaks, Discovery Roche Pharmaceuticals, Neurim Pharmaceuticals, Stemina Biomarker; Employer (spouse)—Pfizer.
Disclosure

• The faculty have been informed of their responsibility to disclose to the audience if they will be discussing off-label or investigational use(s) of drugs, products, and/or devices (any use not approved by the US Food and Drug Administration).

• Applicable CME staff have no relationships to disclose relating to the subject matter of this activity.

• This activity has been independently reviewed for balance.
Challenge #1

*Person-First vs Identity-First Language*

Learning Objectives

• Identify common medical and behavioral health difficulties faced by transition-aged youth with autism spectrum disorder (ASD) and autistic young adults

• Discuss potential medical, mental health, educational / employment, and functional needs of autistic young adults

• Assess current and new potential transition programs for individuals with ASD
Autism Spectrum Disorder
Autism Spectrum Disorder

• Neurodevelopmental disorder presenting as a “spectrum” of symptoms, skills, and difficulties
  – Deficits in social interaction and communication
  – Restricted, repetitive, sensory-based patterns of behavior
• Presents in early childhood and not better explained by intellectual disability or global delay
• More prevalent in male than females (4:1)
  – More women getting diagnosed as adults

Symptom Presentation

- Majority diagnosed in preschool years
- May present at any time when social demands exceed individual skills
- Many co-occurring symptoms
  - Developmental
  - Medical
  - Mental health/behavioral
- Co-occurring symptoms often persist into adulthood

Challenge #2: 
*Functional Difficulties*
Cognitive/Executive Dysfunction

- Intellectual disability 40% to 75%
- Executive function deficits
  - Planning
  - Cognitive flexibility
  - Inhibition (self-regulation)

Adaptive Function Deficits

- Skills necessary for age-appropriate daily living
  - Communication
  - Daily Living Skills
  - Socialization
  - Motor Skills
- Discrepancy between IQ and adaptive skills
  - Discrepancy widens with age

Challenge #3: Medical Comorbidities
Pediatric Comorbid Medical Conditions

- Gastrointestinal – 8× more likely in ASD
  - Constipation/loose stools
  - Encopresis (withholding bowel movements)
  - Feeding difficulties (transitioning to solids, trying new foods)
  - Selective diets (texture, color, brand)
- Sleep disturbance ~70% to 80% in ASD
  - Insomnia / delays in sleep onset
  - Early / night waking
  - Bedtime resistance
- Epilepsy ~ 5% to 40%
- Metabolic and/or mitochondrial disorders

ASD = autism spectrum disorder.
Adults with Medical Comorbidities

Kaiser Permanente Records
- Adults > 18 years old (01/2008–12/2012)
- Documented diagnosis of ASD (N=1507)
- Controls (N=15,070)
- Documented diagnoses, laboratory results, medications
- Odds Ratios compared with typical controls

Seizure Disorder: 16.34
Parkinson's Disease: 32.73
Low Vision/Blindness: 7.85
Hearing Impairment: 2.35
Diabetes Mellitus: 2.18
Cardiovascular Disease: 2.54
Organic Sleep Apnea: 1.54
Dysomnia: 2.5
Constipation: 3.11
Vitamin Deficiencies: 2.35
Adults with Medical Comorbidities (cont’d)

- Rochester Health Status Survey
  - New York State
  - Massachusetts
  - Missouri
  - Italy
  - Israel

- 18+ years w/ ASD diagnosis (N=255)

- Controls
  - National Health and Nutrition Examination Survey (NHANES) and National Health Interview Survey (NHIS)

Adults Have Unmet Health Needs

- Physical health — OR=1.9
- Mental health — OR=2.2
- Prescription medication — OR=2.8
- Higher rates of emergency room usage — OR=2.1

Challenge #4: 
*Psychiatric Comorbidities*
Mental Health

• 54% to 79% autistic adults have co-occurring mental health condition
  – Anxiety 29% to 65%
  – Depression 26% to 52%
  – Bipolar disorder 1%
  – OCD 8%
  – Schizophrenia 8%

OCD = obsessive-compulsive disorder.
Mental Health (cont’d)

• ↓ adaptive function associated with ↑ severity
  – Anxiety
  – Depression
  – ADHD
  – Social difficulties
• ↑ discrepancy between cognitive and adaptive scores associated with
  – Depression
  – Anxiety
  – Social impairment

ADHD = attention-deficit/hyperactivity disorder.
Suicidality and Substance Abuse

- Swedish matched case-control cohort
  - Suicide cause of death in autistic adults vs neurotypicals — OR=9.4
- Increased rates of depression in autistic adults reporting suicidal ideation
- Swedish registries
  - Increased rates of suicide attempts in autistic adults = (3.4%) vs controls (0.8%)
  - Risk increased when comorbid ADHD and/or intellectual disability

Challenge #5: 
Post-High School Planning
Issues of Independence

- Power of Attorney vs Guardianship
- Education and Employment
- Social Relationships
- Independent Living
- Intellectual/Developmental Disability Systems
Power of Attorney vs Guardianship

• Many parents of children with ASD worry
  – Health care decision-making
  – Ability to consent

• Power of Attorney

• Guardianship

Power of Attorney

• Named by individual with decision-making capacity
• Assists with decision-making
  – Financial
  – Medical
  – Both
• Does not take away rights
  – Individual can override Power of Attorney decisions
Guardianship

- Individual deemed incapacitated for decision-making by court
  - Total (financial + medical)
  - Partial (only for specific decisions)
- 44% autistic adults reported having a “guardian”
  - Most often parent
  - Average IQ = 55.7
- Caregiver barriers
  - High cost
  - Confusing process
- Need to monitor that guardians are acting in autistic individual’s best interest

Education and Employment

• IDEA (Individuals with Disabilities Education Act)
  – Special Education (IEP)
    • Ends at 21 years (22 years in some states)
    • Transition plan must be included in IEP by 16 years old

• Transition options
  – Post-secondary education (college, trade school)
  – Employment

IEP = Individualized Education Plan.
Education

• Few autistic young adults attend college
  – Adults with ASD and average IQ (N=60)
    • 72% received no education beyond high school
  – US National Longitudinal Transition Study – 13- to 16-year-olds receiving special education services in 2000 (N=500 ASD)

• Many colleges are developing programs to support students with disabilities
  – Peer support
  – Social skills training
  – Social opportunities

Employment Outcomes in Recent Studies

- ASD w/ and w/o ID
- Identified 1950s–2012
- Mean age 23–44 years
- Published 2013–2017

- 30% ever employed
- 18% to 33% currently employed

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*Ever lived since high school graduation.
I = independently; ID = intellectual disability; NCI = National Core Indicators; NLTS2 = National Longitudinal Transition Study-2; PH = parent home.
Recent Education and Employment Outcomes

- US National Longitudinal Transition Study (NLTS2)
  - 13- to 16-year-olds receiving special education services in 2000
  - 500 w/ ASD

- 50% received no education 2 years out of high school
- 34.7% attended college
- 12.1% attended a 4-year college

- 55.1% with paid employment
- Most worked part-time

Employment Factors

• Success Factors
  – Higher educational attainment
  – Strong family support system

• Risk Factors
  – Severe ASD symptoms
  – Severe cognitive impairments
  – Severe language impairments
  – Psychiatric comorbidities
  – Epilepsy
  – Female

• Most common jobs for autistic adults
  – Clerical workers
  – Laborers
  – Teaching
  – Hospitality
  – Retail
  – Catering
  – Computers
  – Engineering
  – Sciences

Community Supports for Employment

• Workforce Innovations and Opportunity Act of 2014
  – Vocational rehabilitation agencies work with employers to increase competitive employment outcomes for adults with disabilities

• 36% of transition-aged youth receiving vocational rehabilitation services employed (2002–2011)
  – > 50% employed in 6 states
  – < 25% employed in 4 states

• 2013 follow-up
  – > 56% achieved competitive or supported employment

Evidence-based Supports

- Randomized trial of intervention – job placement, on-job supports, coordination between schools, vocational rehabilitation services, and employers
  - 49 students with ASD, moderate–high level of support
  - Academics < 3rd grade level
  - Independence with dressing, eating, personal hygiene
- Intervention
  - 9 months of training on-site at 2 suburban hospitals
  - Rotated through job internships
  - Participated in classes on job skills and social communication behaviors
- Controls – IEP high school accommodations

Intervention Outcomes

• At 3 months post-graduation
  – 90% competitively employed
  – 5.9% controls competitively employed
• 12 months post-graduation
  – 87% employed
  – 11.1% of controls were employed
• Working average 19 hours/week
• Average wage over $8.00/hour
  – State’s minimum wage $7.25/hour

Variability in Employment Successes

- Vocational rehabilitation service provider reported 87% success rate in obtaining competitive employment for adults with ASD
- Study of 64 autistic adults referred to vocational rehabilitation for supported employment services
  - 98% employed
  - 63% maintained employment for more than 6 months
- Vocational rehabilitation services most consistently associated with employment
  - Job placement
  - On-job supports
  - Assessment services
  - Counseling services
  - Job search services

Challenge #6:
*Intimacy and Relationships*
Social Relationships in Autism Spectrum Disorder

• Autistic adults are entering long-term relationships
• Having more friends has a positive impact on subjective well-being
• > Two-thirds of autistic adults have sexual interests
  – More information from parents or media
  – Less information from friends/peers

Parents’ Advice on Sex/Relationships

• Topics discussed
  – Safety
  – Maturation
  – Sexual mechanics
• Less emphasized
  – Emotional intimacy
  – Why people have sex
  – Dating
  – Stalking/pre-stalking behaviors

Influences on Social Relationships

• Individual Characteristics
  – Employment
  – Housing
  – Financial security
  – Interests
  – Inappropriate or challenging behaviors

• Promising Interventions
  – Social Coaching – live discussions or mobile apps
  – Group/Psycho-educational skills trainings
    • PEERS® (Program for Education and Enrichment of Relational Skills)
    • TUNE In (Training to Understand and Navigate Emotions and Interactions)
  – Tackling Teenage Training
Challenge #7: Independent Living
Independent Living

• Young autistic adults vs typical or disabled peers
  – Less likely to live independently
  – More likely to live in parental home as adults
• Study of 21- to 25-year-olds with ASD vs ID, LD, ED
  – ED and LD 5× more likely to live independently
  – ID 2× more likely to live independently
  – Odds of ever living independently higher
    • Higher income households
    • Higher functional skills
    • Better conversational skills

LD = learning disability; ED = emotional disturbance.
### Independent Living

- Only 8% living unsupported
- 6% living in apartment with supports
- 30% to 47% living with family

#### Barriers
- Told it was not feasible by a health care provider
- Fear of loneliness
- Insufficient funds
- Need for assistance with planning day-to-day tasks

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<td>(additional 14% still in school)</td>
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Challenge #8:
(Limited) Resources to Support Transitioning Adults
Intellectual/Developmental Disabilities Systems

- Overseen by US Department of Health and Human Services (HHS) Administration for Community Living (ACL)
- State-run funding to supports individuals with I/DD
  - Independent living
  - Community integration
  - Employment
  - Respite for families
  - Behavior and psychological services
  - Assistive technology
- Eligibility and services vary by state
  - ASD (without ID) not always included as eligible

DD = developmental disability.
Accessing I/DD Supports

• Register with state’s I/DD office
• Wait list for Medicaid waiver → comprehensive service packages
  – Varies by state

• 65% autistic adults receiving I/DD services
  – ASD + high IQ does not always qualify
  – Barriers to accessing services
    • High turnover of service coordinators who assist with the development and implementation of the service plan
    • Available services not the right fit for the individual
    • Services provided not consistent with interests of skills
    • Staff unable to accommodate medical or behavioral issues

Supplemental Security Income (SSI)

- Some individuals with ASD can receive financial assistance through SSI
  - Monthly payments to individuals with disabilities acquired before 22 years of age
  - Must have low income and few assets (< $2000 for children/single adults)
  - Meet Social Security Administration definition of disability before 18 years or
  - Adult disability must “result in the inability to do any substantial gainful activity”

- 83% autistic adults receiving SSI benefits (1984–1988)
- SSI eligible usually receiving Medicaid
  - Medical and/or psychiatric health services

- Eligibility for SSI re-evaluated when children reach 18 years

Transitioning People w/ Autism Need Supports

- Understanding Diagnosis and Identity
- Adaptive and Executive Function
- Medical Conditions
- Psychiatric Conditions
- Education/Employment
- Intimate Relationships
- Independent Living
- Navigating Community Programs
On a Positive Note …
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Stephen Shore, PhD

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• Author of
  – *College for Students with Disabilities*
  – *Understanding Autism for Dummies*
  – *Ask and Tell*
  – *Beyond the Wall*
• Board of Autism Speaks
• Former head of Asperger’s Association of New England
• Former board member of Autism Society of America
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