

Autism Spectrum Disorder: Transition to Adulthood

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Topics

- **Autism basics:** Definition
History
Differential diagnosis
Comorbidity
Treatment
Criteria for diagnosis
Epidemiology, risk factors
Course and outcome
Biology
- **Adult ASD:** Changes in adulthood
Adaptive functioning
Transition results
Services for youth and adult ASD
Comorbidity in adults
Transition challenges
Adult ASD and health care

Definition:

- Autism Spectrum Disorder is a complex, behaviorally defined, static disorder of the developing brain.
- It is a broadly impairing, brain-based, neuro-developmental, highly heritable condition occurring on a spectrum of type and severity of symptoms and impairments.

Autism Spectrum Disorder: DSM 5 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 (social approach, conversation, sharing of interest, emotions, affect, failure to initiate or respond to social interactions).
 2. Deficits in nonverbal communication behaviors used for social interactions (integration of verbal and nonverbal communication, eye contact, body language, understanding and use of gestures, lack of facial expression)
 3. Deficits in developing, maintaining, and understanding relationships (adjusting behavior to suit social contexts, sharing imaginative play, making friends, absence of interest in peers)

Autism Spectrum Disorder: DSM 5 Criteria

B. Restricted, repetitive patterns of behavior, interests or activities as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects or speech (stereotypies, lining up or flipping objects, echolalia, idiosyncratic phrases)
2. Insistence on sameness, inflexible adherence to routine or ritualized patterns of verbal or nonverbal behavior (distress with transitions or changes, rigid thinking, rituals or rigid preferences)
3. Highly restricted, fixated interests that area abnormal in intensity or focus (attachment to unusual objects, circumscribed interests)
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (indifference to pain/temperature, adverse response to specific sounds or textures, smelling or touching of objects, visual fascination with lights/movement)

Autism Spectrum Disorder: DSM 5 Criteria

- 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 later in life)
- D. Symptoms must cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability or global developmental delay.

Specify if: 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; or with catatonia

ASD: History

- First formally described by Kanner, 1943 who noted change intolerance, lack of social interest, impaired language with echolalia, concreteness, and repetitive behaviors/stereotypies
- Kanner and others considered ASD as a form of childhood psychosis; differentiated as a developmental disorder in 1970s
- First specified with criteria in DSM III
- Hans Asperger 1944 described precocious, pedantic youth with conversational impairment and circumscribed interests, associated social deficits; Asperger Disorder deleted in DSM 5

Youth ASD Epidemiology:

- CDC estimates: 1 in 68 children
- >500% increase in 25 years (case finding)
- Male: Female 4-5:1
- Average or better intellect in 46%; Intellectual disability in 25-33% or more; ID in 75% of narrow spectrum ASD
- All SES represented
- Narrow-spectrum ASD: 1 in 500 children

Risk/Contributory Factors for ASD:

- Older parents
- Prematurity/low birth weight
- Tuberous Sclerosis (36%), Down (16%), Fragile X (30%)
- Velocardiofacial (22q11 deletion, 25%); Rett (60%)
- Rubella, CMV, PKU; MTHFR?
- Prenatal exposure: valproate, alcohol, thalidomide?, misoprostol?, cocaine?, SSRIs?
- Pre-eclampsia, maternal influenza, diabetes, fever
- Pollutants (Hg), pesticides? (organophosphates)
- No evidence for childhood vaccine toxicity

Youth ASD Differential Dx/Comorbidity

Comorbid psychiatric conditions in up to 80%

- Intellectual Disability, ADHD, Learning Disorders, Coordination Disorder, Communication Disorders, Stereotypic Movement Disorder, tics
- Anxiety Disorder, OCD, Mood Disorder
- Seizure disorder, Landau-Kleffner, Rett
- Severe deprivation; vision, hearing deficits

Youth ASD Developmental Course

- **First year:** nonspecific (irritability, passivity, eating and sleeping); deficient eye contact, voice response, sensory and motor
- **12 months:** atypical visual attention, imitation, social response, motor control, reactivity; delayed language
- **24 months:** atypical language trajectories apparent; 15-40% show **regression** of language, social, cognitive, motor at 12-24 months
- **36 months:** core symptoms apparent (lack of social communication, restricted/repetitive behaviors)
- **Late preschool/early school age:** full syndrome visible

ASD Etiology

Genetic: genes regulating CNS development:

Growth (transcription, methylation)

Connectivity (synapse, dendrites, microglia)

Organization (white matter long tracts)

Brain regions: Limbic (hippocampus, amygdala), fusiform gyrus, cerebellum, frontal cortex abnormalities; brainstem?

Cortical Circuits: impaired development, later “pruning,” apoptosis

AUTISM SPECTRUM DISORDER: Neurobiology

“Several lines of research indicate that ASDs are associated with disarrangement of neuronal organization, cortical connectivity, and neurotransmitter pathways. While the causes of these abnormalities are still being identified, it is generally believed that genetic as well as environmental factors are involved...autisms are disorders of neuronal-cortical organization that cause alterations of information processing at different levels of the nervous system, from synaptic and dendritic organization to pathway connectivity and brain structure.”

Pardo, Eberhart: *Brain Pathology*, 2007

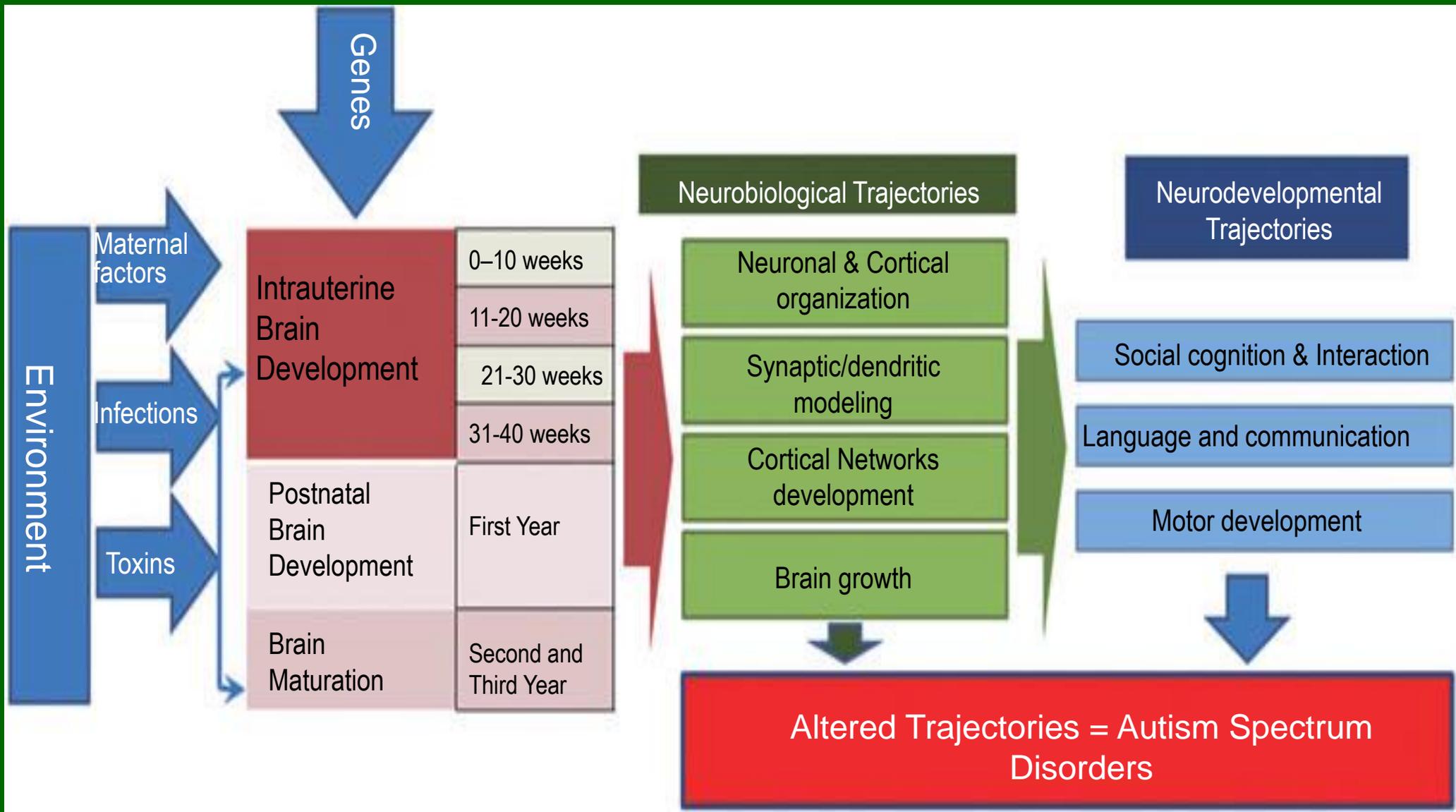


Figure 1. Genetic and environmental factors that influence intrauterine and early postnatal brain development likely alter neurobiological and neurodevelopmental trajectories that determine the clinical core of ASD.

Youth ASD Course

- Social/communication skills improve by age 6-12
- Adolescence: some gain markedly; some deteriorate (second pruning period)
- Predictors of better outcomes:
 - Communicative speech by age 5
 - Overall cognitive ability (IQ)
 - Early detection and provision of services
- Risk of shorter life spans, seizure disorder (28%)
- 33% achieve partial or full independence

ASD Treatment

Based on specific problems and needs as defined in assessment process; earliest possible intervention

- Speech and language therapy
- Occupational therapy (sensory and motor, skills training)
- Special education services including social skills training
- Parent education and training; support groups, advocacy
- Applied behavioral analysis (ABA) including social, behavioral and skill training
- Appropriate pediatric and adult medical care
- Problem-targeted medication



Autism? Not me!
That's for *children*.
I grew out of it!

ASD Changes: Child → Adult

- ASD is stable lifelong; clinical picture changes with age
- Modest improvement in ASD core symptoms over time:
 - ↓ repetitive behavior
 - ↓ stereotyped interests
 - ↓ social reciprocity deficits
- Also reduction in maladaptive behavior over time:
 - ↓ self injury
 - ↓ aggression
 - ↓ non-cooperation
- Biggest gainers include: ↑ SES, ↑ parental education
- Rate of gain ↓ by 50% after HS, mostly for non-ID ASD

Adult ASD Comorbidity

- ID, ADHD, SLD, motor disorders are the other neuro-developmental disorders commonly comorbid with ASD
- High-functioning ASD shows higher rates of ADHD, anxiety and mood disorders
- Asperger adults have up to 65% lifetime risk of depression
- ↑ comorbidity → ↓ autonomy, ↓ social, despite higher IQ

Vannucchi et.al., CNS Spectrums 2013; Van Schalkwyk, Volkmar Child Adol Psychiatr Clin N Am 2017; Taylor, Seltzer 2010; Attwood 2003

Comorbidity	Prevalence	Comment
Intellectual Disability	20-38%	Up to 70% in narrow-spectrum ASD
ADHD	11-30 %	May account for significant academic deficits in non-ID ASD
Depression	All ASD: 30% HFASD: 40%, 53-72% lifetime	May be the most common comorbidity; difficult to recognize; more frequent (or more recognizable) in HFASD; ↑ risk with ↑ cognitive skills & Hx Anxiety D/O
Anxiety Disorders	All ASD: 25% HFASD: up to 65%	Generalized Anxiety>Panic Disorder; Social Anxiety also
Obsessive Compulsive Disorder	7-35%	May worsen during depressive episodes; common in HFASD
Bipolar Disorder	7-18%	More likely in non-ID ASD
Schizophrenia	4-16%	Many overlapping diagnostic criteria; psychotic symptoms, regression in adolescents or young adults

Adult ASD Comorbidity: Depression

- Depression assessment is difficult in ASD due to deficits in expressive and receptive language, gestures, facial expression
- MDD rates increase after early adolescence
- MDD may increase OCD symptoms
- Risk factors for depression: Life events, FH of MDD
- ASD + Depression sequelae: withdrawal, opposition, aggression

HF-ASD Transition Challenges—College

- Shift from parent to personal responsibility
- Change in primary environment
- Change in legal mandates and services
- More social exposure, anxiety in social environment
- Complexity of social and sexual environments
- Shifts of academic context
- Necessity to develop routines, do chores
- Risks: victimization, inadvertent illegal/socially inappropriate behavior

Nature of the transition depends on level of functioning

Adult ASD Transition: Adaptive Functioning

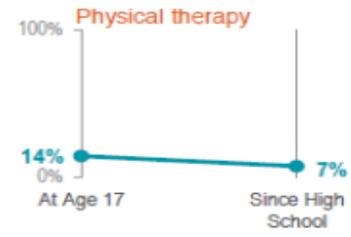
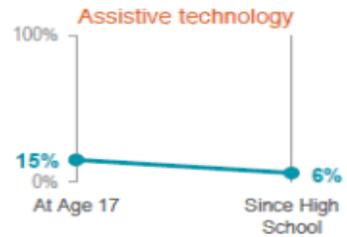
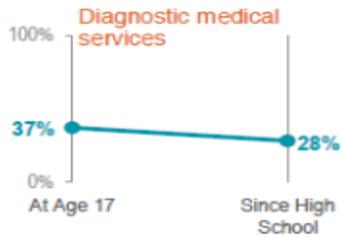
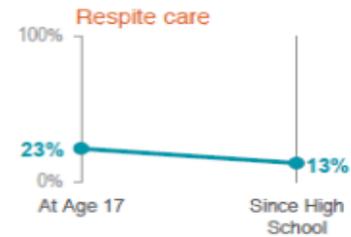
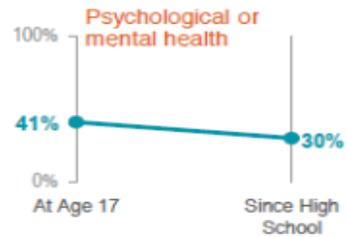
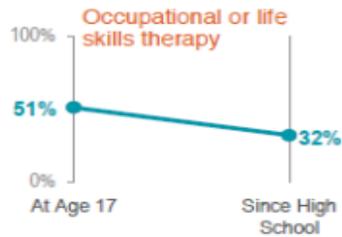
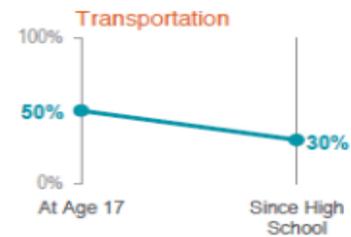
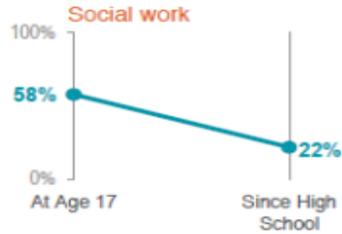
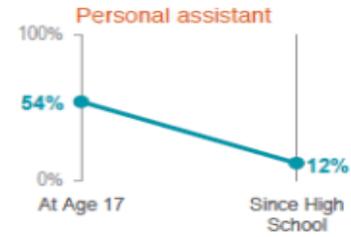
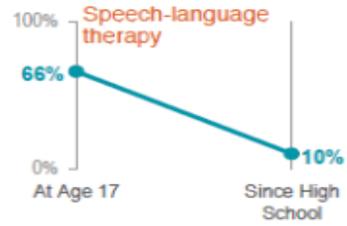
- IQ is not the only determinant of level of functioning; strong adaptive functioning predicts best outcome in ASD
- ASD-typical gap between cognitive and adaptive skills, which widens with age, uniquely in ASD; gains in adaptive skills during adolescence, but stagnation in adulthood
- Daily living scores gain, social and communication do not
- Study: In ASD adults with \geq average IQ, VABS composite scores were all <70

Adult ASD Transition Challenges: The “Services Cliff”

- Findings of longitudinal study, ASD adolescence → adult:
 - Adult day services: 75% of ASD + ID adults
6% of non-ID ASD adults
 - 25% of non-ID ASD adults had no occupational, educational or day activities of any kind (86% if comorbid condition)
- Services for non-ID ASD adults often are not available
- Parent role becomes that of service coordinator after high school
- Better services if higher SES (not so during high school)

Taylor, Seltzer 2010; National Autism Indicators Report 2015

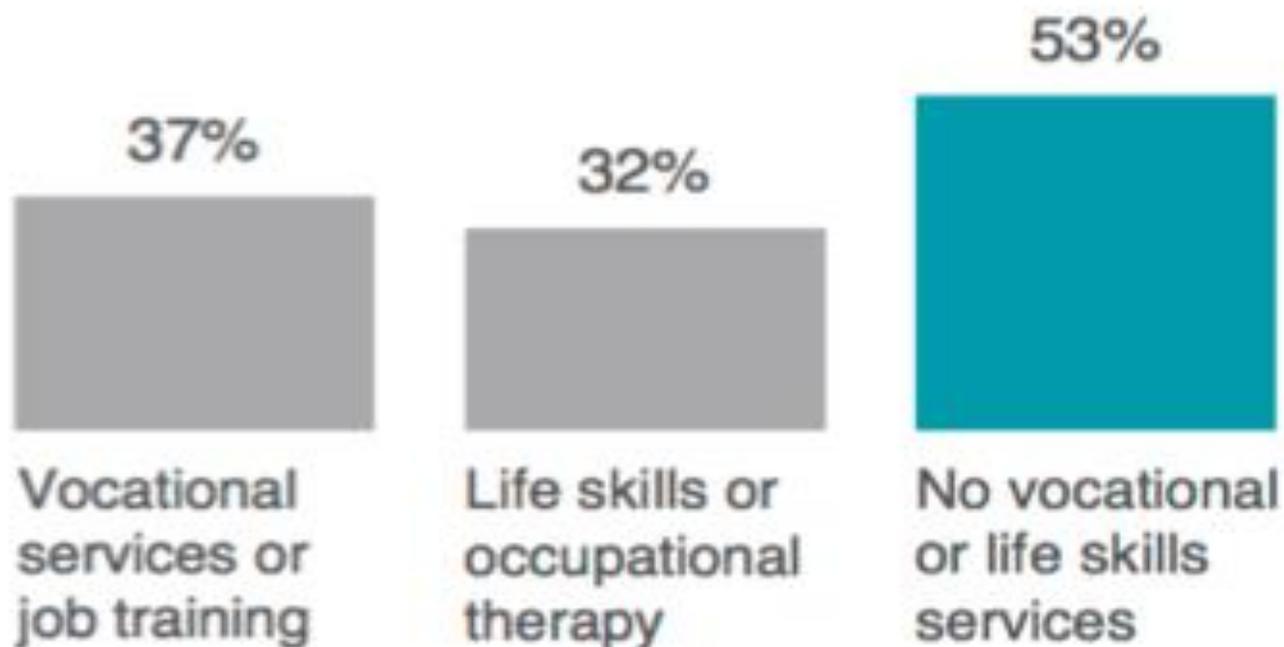
Services consistently decreased following high school.



Percent who received service at age 17 compared to percent who ever received service after high school.

Source: National Longitudinal Transition Study-2

Over half of young adults with autism received **no vocational or life skills services** during their early 20s.



Type of adult services received

Percent received service after high school

Source: National Longitudinal Transition Study-2

What happened to young adults with autism between high school and their early 20s?



Education
Attended any
postsecondary education

36%



Living Arrangements
Lived independently

19%



Employment
Had a job for pay

58%



Access to Services
Received any services

74%

What did young adults with autism do after high school?

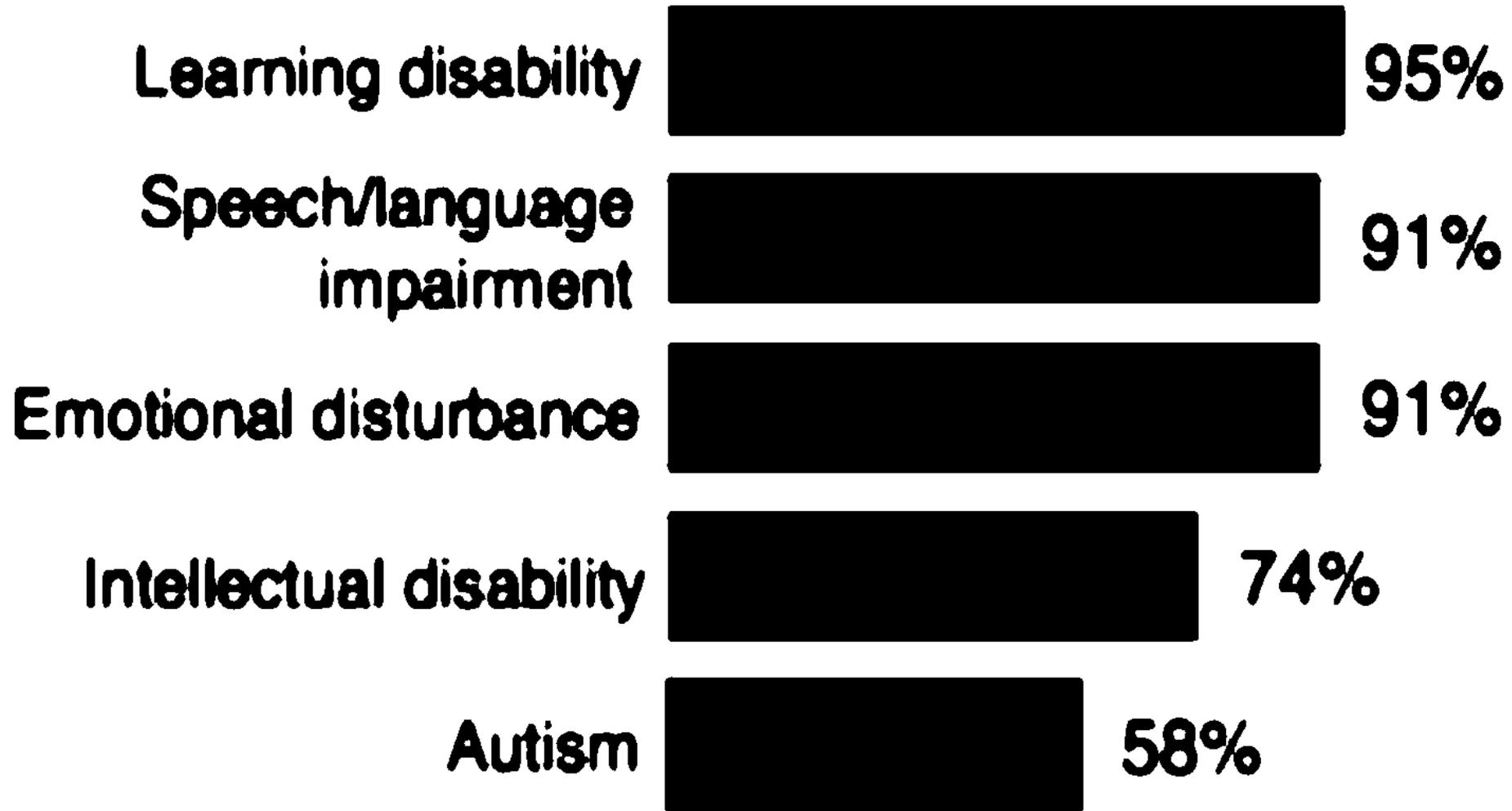


Source: National Autism Indicators Report: Transition into Young Adulthood. 2015. Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University. <http://drexel.edu/autisminstitute/>

Adult ASD Employment

- 37.2% of young adults with ASD report being employed
- However, only 4-17% of adults with ASD maintain employment over time

Taylor, Seltzer 2010



Percent ever worked after high school

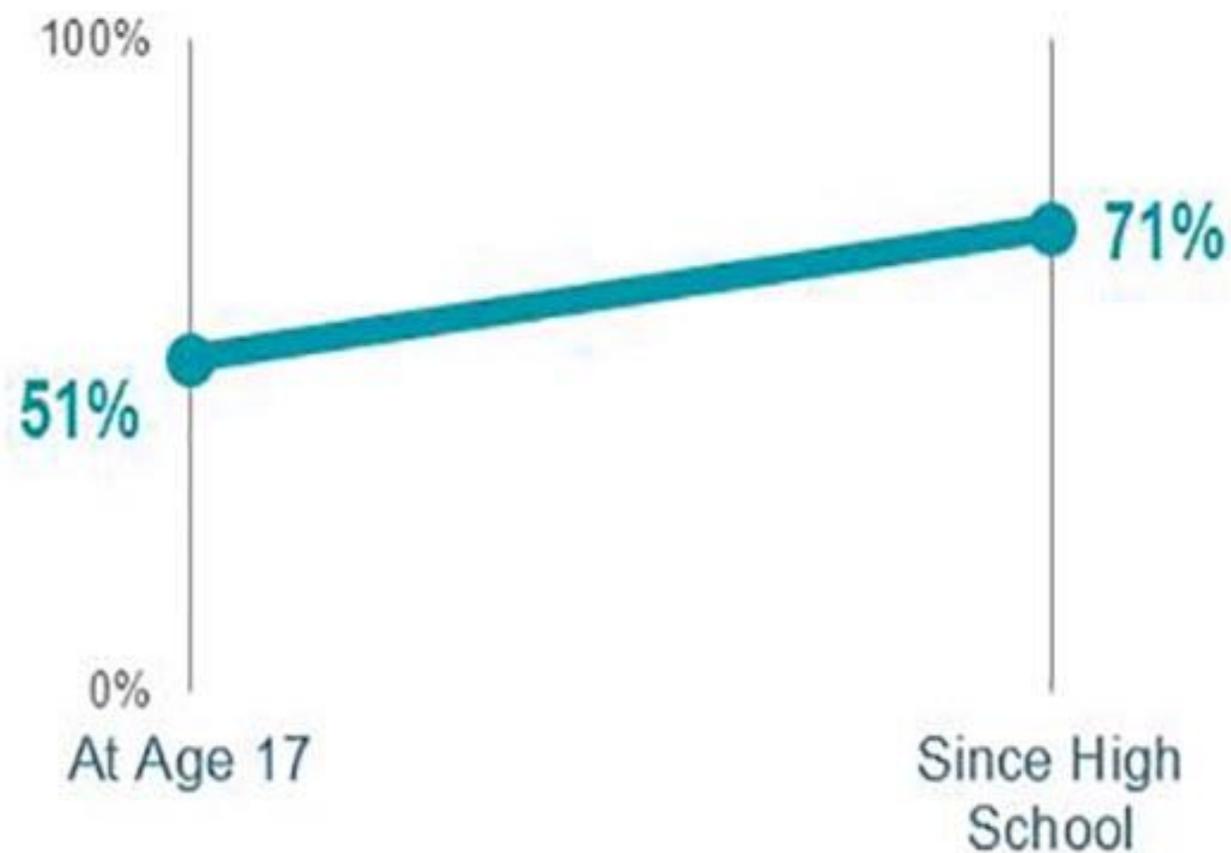
Source: National Longitudinal Transition Study-2

Adult ASD Transition

- Non-ID ASD adults pursue post-secondary education at a higher rate than other ASD groups
- Mother-child relationship measures in non-ID ASD adults show a steady improvement in high school years; after high school, those gains diminish or stop
 - consistent with unmet service needs
 - suggestive of rising demands on mother, increase in family frustration

Taylor, Seltzer J Autism Dev Disord 2011

The percentage of families who reported some or great effort to access services increased following high school.



Percent families of young adults with autism

Source: National Longitudinal Transition Study-2, Wave 5, 2009.

Adult ASD Health Care

- Health needs for adults with ASD are poorly met, as compared to pediatric care
- Complex issues of health decision making, guardianship
- Less than 25% of youth with ASD receive appropriate health services (including therapies) despite entitlement. Adult access to care is worse; many adult PCPs are at a loss on care for ASD
- ASD adults remain dependent on parents financially and otherwise; as parents age and become infirm, ASD adult health may suffer

Adult ASD Service Availability

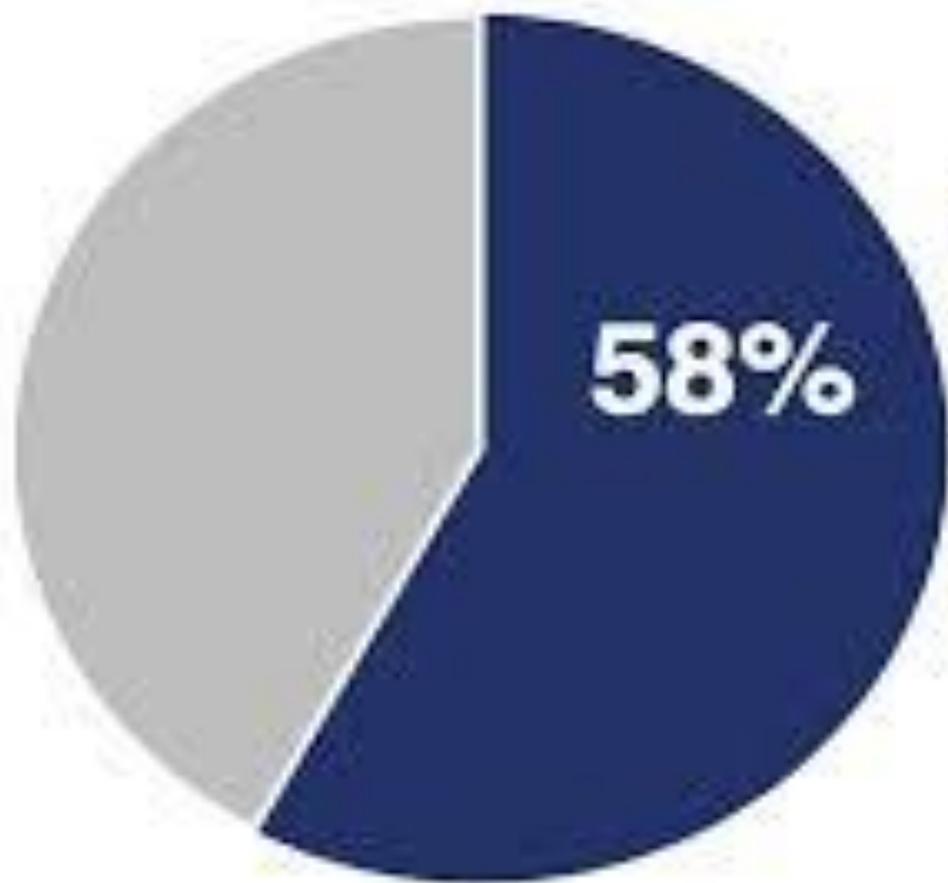
- School is the organizing service entity for ASD youth
- Entitlement in school years for education, health, social services
- Eligibility in adult years for housing, health, jobs; guardian or individual must initiate the eligibility process
- Eligibility does not guarantee services

Van Schalkwyk, Volkmar 2017

ASD Course of Services

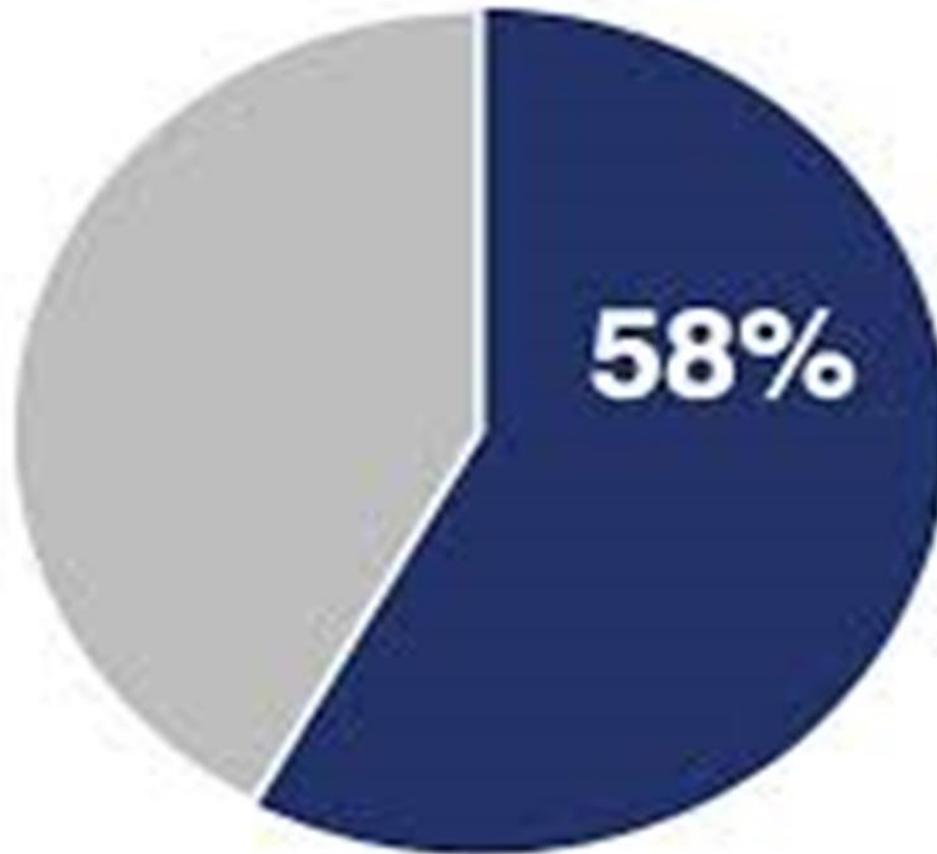
- Youth ASD: ECI in earliest years
School services guided by IDEA, FAPE
IEP, behavior support plans if eligible
504-based accommodations as
alternative
- After age 16, IEP must include documentation of plans
for post-HS education or training

Federal law requires schools to have a transition plan for every special education student exiting high school.



of youth with autism had a transition plan by the required age according to their teachers.

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Source: National Autism Indicators Report Transition into Young Adulthood. AJ. Drexel Autism Institute, Drexel University.

ASD Course of Services

- Adult ASD: Day services/training
Supported employment—training, job coaches, vocational placement
Mental health services
Residential services
Housing services
- Planning must start early, during high school
- Autism is a lifelong disorder requiring a consistent level of services

At a glance — Outcomes of adults with ASD (18-64 years) who received DD services



Summary: ASD Transition to Adulthood

- ASD is a lifelong condition that requires ongoing services
- Adult ASD has high rates psychiatric comorbidity; affects LOF
- Adaptive skills deficits may be bigger obstacles than cognitive capacity
- ASD adults have much worse access to health, mental health, habilitative, and family support services than youth (“services cliff”)
- Transition planning in high school is essential, too often absent
- Employment rates and job persistence are very low vs cognitive ability for ASD adults