

Autism Grows Up: Transitions to Adulthood

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Agenda

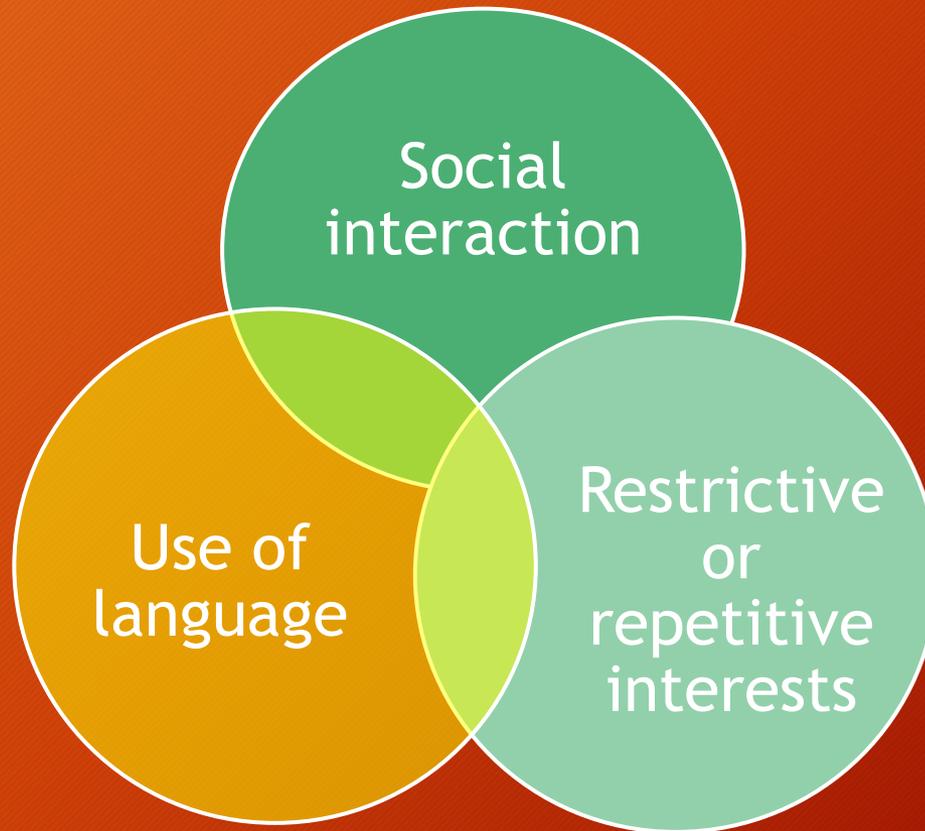
- Brief overview
- Transition issues
 - Impact on person with autism
 - Impact on the family
- Community resources



What is Autism?

- Autism is a *syndrome* of atypical neural development characterized by significant dysfunction in social interaction, communication, range of interests and repetitive behaviors.
- It is a cluster of different symptoms which may range from mild to severe, many to few, and is variable from person to person

Triad of Impairments



Medical definition: DSM 5

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

Deficits in social-emotional reciprocity

Deficits in nonverbal communicative behaviors used for social interaction

Deficits in developing, maintaining, and understanding relationships

Medical definition: DSM 5

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

Stereotyped or repetitive motor movements, use of objects, or speech

Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior

Highly restricted, fixated interests that are abnormal in intensity or focus

Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

What Causes Autism

- No one knows
- Autism “runs in families”
 - It is “genetic”
 - No specific gene has been located
- About 20% of cases are related to specific disorders
 - Fragile X syndrome, Tuberous Sclerosis, other genetic abnormalities

What Causes Autism

- Most common theory involves inheriting a genetic risk of some level which is then “turned on” by some type of environmental stress
 - Toxins, birth trauma, viral illness
- If your genetic risk is very high, the environmental stress needed may be low
- If your genetic risk is low then the environmental stress may need to be high

Epidemiology

- Male/female ratio
 - More males than females
- Current prevalence is difficult to pinpoint
- Increase in rate seems to primarily in the higher functioning end of the spectrum

Specific Symptoms Impairing Young Adults with Autism

- Repetitive behaviors and restricted interests
 - Limited social relatedness and conversations
- Concrete thinking
 - Persons with autism take things literally and assume you mean exactly what you say
- Lack of filters
 - All things have equal value and minor experiences/actions/sensory events cannot be "tuned out"
- Slowed processing
 - In spite of normal overall intelligence slowed processing restricts their ability to be academically successful

What Does “Transition” Mean?

- Refers to any time of change
- In this discussion “transition” refers to the time between the end of high school and the start of employment or further education
- In general the time of transitioning from adolescence to adulthood is lengthening for all students

School Transition Services

- Students who have not yet met their IEP goals are eligible for post high school transition services until the age of 21 years
- Services may include life skills, job skills, further academics or combinations of the three
- Families have incredible anxiety about “what next”

Transition Services

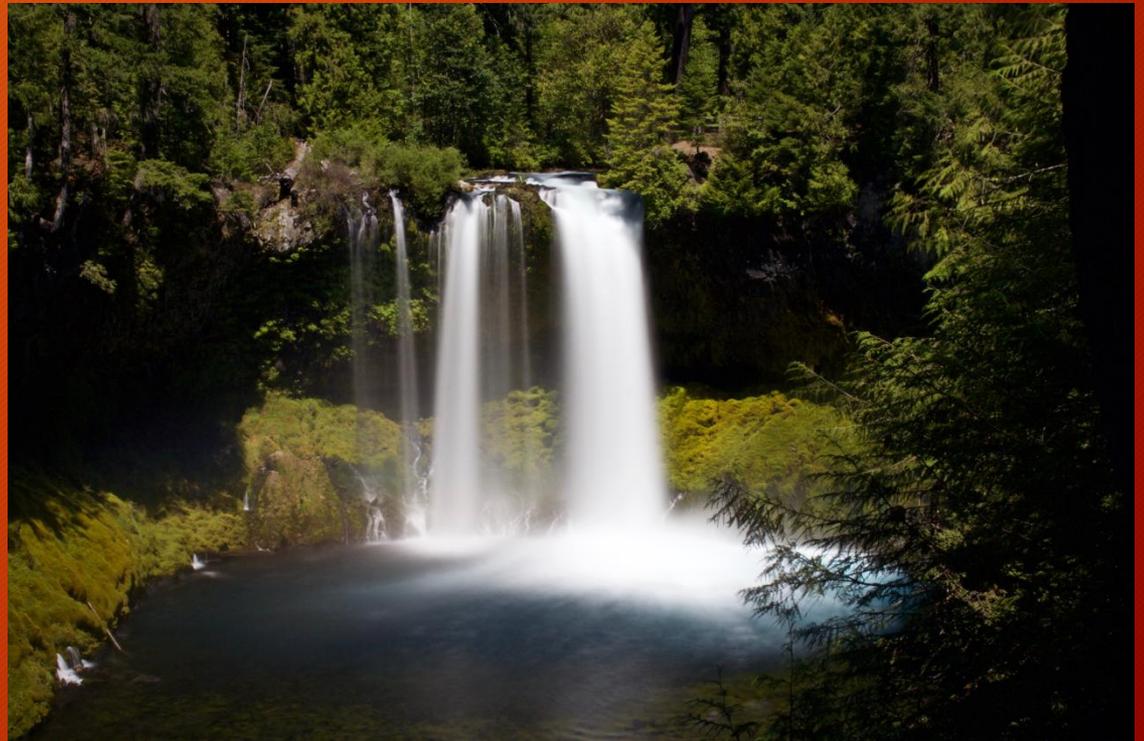
- Lower functioning students seem to have a clearer path
 - Post high school services until the age of 21 followed by some typed of structured adult programming after school based services
 - Clearer need for supports at home
 - Better able to qualify for social supports such as Social Security, Medical Assistance etc

Transition Services

- Higher functioning students have more decisions and options
 - College or other education
 - Special college support programs
 - Work
- Often do not qualify for support services
- At high risk for failure when the structure of school based services end

ASD Service Options

- ASD Cliff of Services



Services for Adults with Autism

- Jobs are difficult due to need to find specific jobs that meet the persons needs
- May not have the organizational and regulatory stamina to work full time
- Social aspects of employment challenging
- Often impacted by transportation issues

What Does the Literature Say?

- Compared to peers young adults with high functioning ASD are:
 - Less likely to be on their own
 - More likely to still live with parents
 - More likely to require supportive living services
 - Less likely to drive
 - More likely to require county services
 - More often help to manage finances
 - More often help to manage hygiene

Employment Opportunities

- Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder
Shattuck et al, Pediatrics 2012; 129: 1042-49
- Data from 2007-2008
 - 680 youth with ASD, 470 with speech/language dysfunction, 460 with LD and 430 with MR
 - 55.1 % of the ASD youth had some type of paid employment since leaving high school
 - Average pay was \$8.10 per hour
 - 34% had attended a 2 or 4 year college
 - 9% had attended a vocational or technical program
 - 34.9% had not had any post secondary employment or education
 - ASD youth had significantly lower rates of employment than the other three categories
 - ASD youth had the highest rates of being disengaged from both education and work

Employment Opportunities

- Employment and Post-Secondary Educational Activities for Young Adults with Autism Spectrum Disorders During the Transition to Adulthood

Taylor and Seltzer, J Autism and Dev Disorders 2011 May; May 41 (5) 566-574

- 66 young adults who had recently exited the school system
 - Average age 22.98 years
- 80% male and 60% still living at home
 - 56% were in sheltered workshops or day activity centers
 - 80% were verbal
 - 74% had cognitive impairment
- Risk was three times higher for having NO daytime activities if you did NOT have an intellectual disability
- Competitive employment was greater (12% vs 4%) if you did not have an intellectual disability

Autism Goes to College

- 80% of students with ASD who go from high school directly to a four year college do not complete college
- Attending a two year college and then transitioning to a four year school markedly increases the chances of graduating

A Comprehensive Survey of Current and Former College Students with ASD

- Anxiety, depression, and loneliness were the most common challenges at 71%, 53% and 47%
- 60% received formal academic support and 45% received non-academic supports

Impact of the Family

- Caring for a young adult with autism has long impact on families
- Impact is broad and across all aspects of life



Burden versus Strain

- Caregiver Burden

- Burden refers to the problems: physical needs, transportation needs etc
- Burden is objective

- Caregiver Strain

- Strain refers to the impact of the burden
- May be physical or emotional
- Strain=stress
- Strain is subjective
- Personal resilience impacts the tolerance of strain/stress

Mental Health Comorbidity and Autism

- Psychiatric Disorders in Children With Autism Spectrum Disorders

Simonoff et al; JAACAP August 2004, 47:8

- 112 ten-fourteen year old children with autism
- 70% had one comorbidity and 41% had two or more
 - 29.2% had social anxiety (44% had some type of anxiety disorder)
 - 28.2% ADHD
 - 28.1% oppositional defiant disorder
 - Of note is major depression with a rate of 0.9%
- Problem of “lumpers versus splitters”
 - Does it help or hinder to have more labels?
 - Will this increase the use of psychotropic medications?
 - Will this “confuse” the proposed treatment plan

Caregiving and Risk of Coronary Heart Disease in women

- Lee et al., Am j Prev Med, 2003; 24(2)
- 54,412 women in 11 US states aged 46-71
- During 4 years of follow-up we documented 321 cases of CHD
- Caring for a disabled or ill spouse for greater than 9 hours a week was associated with an increased risk of CHD. This finding was true only for caring for a spouse

The Health and psychosocial functioning of caregivers of children with neurodevelopmental disorders

- Lach et al, Disability and Rehab, 2009; 31(8)
- Caregivers of children with neurodevelopmental disorders and behavioral problems were the least likely to report good health and the most likely to report asthma, arthritis, back problems, migraine headaches and limitations in activity

Adults with autism living at home

- Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. Krauss et al., J of Intell Disablitiy Research, 2005 Vol 49 (2)
 - Mothers of 133 adults aged 22 or older with ASD
 - Mothers found co-residing with the disabled adult to be of greatest family benefit but living away benefitted the adult more
 - Mothers had greater negative impact then the family as a whole when the adult lived apart from the family

Caregivers: Grief and loss

- Grief and other feelings of loss occur both at the time of diagnosis and at the time of other major developmental milestones
 - School transitions
 - Kindergarten, Middle School, HS, College
 - Social events
 - Play Dates, Birthdays, Dances, Sports
 - Age specific events
 - Driving, Dating
 - Transitions to adulthood
 - Independence
 - Employment

Financial Stress and Change

- Higher functioning persons with disabilities have more struggles with housing and financial options due to lack of services targeting them
- Families have often exhausted personal financial resources providing care and services for their child as that child grew up
- Accepting disability services may restrict the disabled person to a life time of poverty and government assistance

Impact on Parental Retirement

- Loss of their “retirement dreams”
- Inability to save for retirement
- Restrictions of travel/housing
- Lack of time to themselves
- Parenting responsibility consistent with child
 - Higher responsibility
 - Longer duration

Final Thoughts

- Remember to consider the person with autism and the impact on the family
- Familiarize yourself with community resources
 - AusM: Autism society of Minnesota
 - Fraser
 - The Arc Minnesota
 - County social services
 - State vocational rehab services
 - College offices of student disabilities



The End