



Adolescents with Autism Spectrum Disorders: What Parents and Professionals Should Know

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Learning Objectives

- Participants will increase knowledge of..
 - characteristics of adolescents with an autism spectrum disorder (ASD).
 - the importance of continuous assessment to monitor changing needs and to inform supports and interventions.
 - the various strategies that can be used in the home, school, and community settings to support adolescents with an ASD through this difficult life phase.
 - the importance of home-school-community collaboration in supporting adolescents with an ASD.

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Adolescence

A life changing period.....

Adolescent Development

- Adolescent development is marked by many changes.....

– Personal

- Physical
 - Puberty and sexual development.
- Cognitive
 - Brain development and cognitive functioning.
 - Self-identity.
- Emotional
 - Changes associated with puberty and brain development.

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Adolescent Development

- Adolescent development is marked by many changes.....

– Social

- Peer
 - Friendships & Intimate Relationships
- Parent
 - Relationships-‘Parents as People’
- Home/School/Community
 - Increasing independence
 - » School work
 - » Personal care and domestic routines
 - Work/volunteer
 - Driving

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Adolescent Development

- Adolescent development is marked by many changes.....

– Expectations

- Personal Care
- Domestic routines
- School work
- Social skills
- Community activities
- Work experience
- Emotional and behavior regulation

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What does ASD look like in the adolescent years?

Adolescents with ASD

- Autism Spectrum Disorder (ASD) refers to a group of *neurodevelopmental* disorders characterized by...
 - Social impairments
 - Communication impairments
 - Restrictive, repetitive, & stereotyped behaviors & interests
- Adolescents with ASD may also have....
 - Intellectual disability or learning disability
 - Emotional-behavior disorders
 - Medical Disorders
 - Sensory-motor impairments
 - Sleep Disorders

Adolescents with ASD

- The neurodevelopmental nature of ASD affects brain development....
 - throughout the lifespan
 - *during critical developmental periods*
 - Early Childhood
 - **Adolescents/young adulthood**
 - multiple areas affected....
 - brain connections not made and/or are atypical.

Adolescents with ASD

- Atypical brain development affects....
 - cognitive abilities
 - social abilities
 - language and communication abilities
 - emotional status
 - behavior
 - sensory-motor abilities
- Results in less than expected 'age-appropriate' behavior in one or more areas of functioning.

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Adolescents with ASD

THE BRAIN-BEHAVIOR RELATIONSHIP



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Implications for Adolescents with ASD

Implications

- Developing brain and changes in bio-chemicals (puberty etc)....
 - Highly variable development ..
 - Studies show improvement for most in core areas of ASD.
 - Some children regress during adolescence.
 - Onset/worsening of anxiety/depression.
 - On-set of seizure disorder.
 - Sleep problems may persist.
 - Sensory problems may persist.
 - Gastrointestinal problems may persist.

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Implications

- Developing brain and changes in bio-chemicals (puberty etc)....
 - No good predictors of outcome across areas...
 - Higher cognitive and language skills are associated with slightly better outcomes than those individuals with lower cognitive and language levels.
 - Contextual factors may also moderate outcome.
 - Treatment/intervention-length of time/intensity.
 - Supports and services-quality/consistency.
 - Presence of related disorders (co-morbidity).

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Adolescent Issues

Considerations for supporting adolescents with an ASD....

Adolescent Issues

- **Social impairments** can affect the development of **self-awareness**.
 - Needed for self-regulation, self-determination, and self-advocacy, and development of self-identity.
 - Develops in some, but not all teens...some continue to show delays.
 - Relationship to behavioral, social, and emotional regulation.
 - May affect motivation to alter behavior to meet social expectations.
 - May be at increased risk of depression.
 - May be at increased risk/worsening of anxiety.

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Adolescent Issues

- Social awareness may continue to be delayed.
 - May appear immature.
 - May become target for bullying and victimization.
 - May engage in bullying behavior.
- May not understand concept of 'social rules.'
 - Puberty and sexual behavior.
 - Dating and group socializing.
 - Legal involvement may ensue.

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Adolescent Issues

- **Cognitive and sensory-motor impairments** can affect **personal self-sufficiency skills** in multiple areas.
 - **Personal**
 - Grooming & hygiene routines
 - Sexual behavior
 - Health behavior
 - Self-identity
 - Self-determination
 - Self-advocacy
 - Self-management

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Adolescent Issues

– Personal (cont.)

- May see difficulty...
 - initiating and completing tasks/routines.
 - » requires multiple prompts and supervision to complete.
 - keeping up with increasing and more complex demands.
 - with multi-tasking.
 - with efficiently processing increasingly complex information....
 - » Information overload → anxiety, meltdown, avoidance, behavior problem.

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Adolescent Issues

– School

- Self-management of work load.
 - Homework
 - Study behavior
- Peer interactions
 - ‘Fitting in’, groups, after-school activities/clubs, & other social activities.
- Participation in transition planning
 - Setting personal goals for future....
 - » College
 - » Work
 - » Residential

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Adolescent Issues

– Community

- Behavior
 - Personal self-regulation
 - Consumer skills
- Driving
- Volunteer work, summer employment
- Money management
- Safety skills

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Adolescent Issues

- High risk for onset/worsening of **emotional & behavioral disorders.**
 - Anxiety disorders & depression.
 - May not have well-developed coping & problem-solving skills to manage these disorders.
 - May not be diagnosed-not treated.
 - ‘Oppositional or defiant’ behavior may develop and/or worsen.
 - Irritable mood & low tolerance for frustration
 - » May not understand rationale for ‘rules’ and therefore, may challenge them.

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Challenges in Supporting Adolescents with ASD

Challenges

- Evidence-based guidelines for supports/interventions are limited in several areas...
 - Transition planning and preparation
 - Social and communication skills
 - Emotional and behavioral disorders
 - Sex education
 - Health behaviors
 - Safety skills

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Challenges

- Less than sufficient number of highly qualified professionals....
 - May not be familiar with ASD or the needs of adolescents with ASD.
 - Expectations may not be consistent with developmental levels and abilities.
 - Gap between age peers widens.
 - May not be trained in appropriate assessment and treatment practices for ASD.

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Challenges

- Limited or no services or resources....
 - Psychiatric, psychological, recreational, social..
 - For entire spectrum of ability
- Disconnected systems
 - Multiple service systems with different eligibility requirements, services, quality of staff and services etc.
 - Access to care issues-waitlists, location etc.
 - Current lack of guidelines for effective Care Coordination.
 - Parents often assume role of care coordinator.

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Challenges

- Primary caretaker may not be knowledgeable about the need to think and plan for the future...
 - Medical care
 - Transition to adult medical providers.
 - Multiple specialists may be needed.
 - Guardianship
 - Particularly for those with higher IQ this issue may be challenging.
 - Future care planning
 - Fiscal
 - Family

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Supporting Adolescents with ASD

Assessment Supports/Interventions

Assessment

- *Ecological assessment* is needed.
 - Assessment of the adolescent's current ASD/developmental profile.
 - Assessment of various settings/contexts to identify expectations and demands, and the skills needed for participation.
 - Identify gaps between adolescent behavior/skills and setting expectations.
 - Identifies gaps and informs specific support and intervention plans that may be needed.

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Assessment

Adolescent	Setting/Expectations
<ul style="list-style-type: none">• ASD symptoms• Cognitive/Neurocognitive• Adaptive Functioning<ul style="list-style-type: none">– personal, social, community• Co-morbid symptoms/disorders<ul style="list-style-type: none">– Medical, emotional, behavioral, sensory-motor.• School performance• Work/volunteer performance.	<ul style="list-style-type: none">• Home<ul style="list-style-type: none">– Personal care, domestic– Emotional-behavioral regulation• School<ul style="list-style-type: none">– Workload, social, communication, behavioral• Community<ul style="list-style-type: none">– Consumer behavior, recreation and leisure• Work<ul style="list-style-type: none">– Activities, social communication, behavior regulation

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Assessment

- These assessment data inform....
 - Support & intervention plans.
 - School program plans
 - Clinical service plans
 - Home/community support/intervention plans
 - Training needed for caregivers and personnel.
- Data also provides a historical record of...
 - Baseline levels of functioning.
 - Response to supports, interventions.

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Assessment

- On-going assessment is often needed to....
 - Monitor changes in development.
 - Monitor changes in demands and expectations for each setting.
 - Inform adjustments to the support/intervention plan.

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Supports & Interventions

Using data to inform support and intervention planning

Support/Intervention Planning

- Because of developmental changes and changes in expectations during adolescents....
 - Comprehensive supports/interventions may be required for *some* adolescents with ASD.
 - May require an increase in the type, frequency, duration and/or intensity of services.
 - Greater range of services from multiple service systems/providers.
 - » Greater care coordination responsibilities.
 - May require education and training of...
 - Parents/caregivers
 - School/community personnel

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Supports/Interventions

Home
School
Community

Home Supports

Developing Independence

Home

- Support the development of **independent living** skills..
 - Establish clear and consistent expectations or 'house' rules that include...
 - Specific responsibilities
 - Timelines for completion
 - Expected outcomes

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Home

- Support the development of **independent living** skills..
 - Develop a standard set of daily routines for **personal care** skills...
 - Grooming and hygiene
 - Puberty related routines
 - Health care
 - Sexual expression
 - Consider psychological/counseling services to assist with learning skills.

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Home

- Support the development of **independent living** skills..
 - Develop a standard set of daily routines for **domestic** skills...
 - Chores
 - Food preparation and meal planning
 - Money management:
 - Purchasing, budgeting
 - Consider Residential Habilitation services.

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Home

- Support the development of **independent living** skills..
 - Develop **home safety** skills....
 - Fire drills
 - Phone use
 - Internet and computer use
 - Stranger Danger
 - Swimming classes
 - First aid
 - Develop standard routines for completing **School work**...
 - Studying time
 - Homework & projects

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Home

- Support the development of **independent living** skills..
 - Develop **community** skills....
 - Community safety
 - Travel-driving
 - Recreation and leisure
 - Social club or group
 - Respite
 - Consumer behavior
 - Shopping
 - Banking
 - Volunteer and/or work experience

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Home

- Support the development of **functional and social communication** skills...
 - Adolescent may require specific training in functional and social communication.
 - School-based speech-language & counseling services.
 - Some insurance will cover these services from a licensed community provider, if deemed medically necessary to improve functioning.
 - Work collaboratively with community/school therapist on strategies to transfer use of skills to home setting.

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Home

- Various strategies can be used to teach skills...
 - Activity schedules
 - Task lists
 - Direct instruction
 - Modeling and role playing
 - Shadowing and graduated guidance
 - Communication Scripts/Augmentative/Alternative communication system.
- Reward system to motivate teen to use skills.
 - Contingency management
 - Social Stories to improve understanding of when to use skills.

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Home

- Set limits on repetitive behaviors & circumscribed interests.
 - Create opportunities for developing and using leisure/play skills and activities ('routines'.)
 - Consider developmentally appropriate activities.
 - » Consider peer group, setting, and expectations.
 - Establish activity schedules to assist the adolescent with learning and using these skills.

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Home

- Support the development of coping and problem-solving skills...
 - Adolescent may require specific training in emotional-behavioral self-regulation (coping and problem-solving).
 - Community-based psychological/psychiatric services.
 - School-based counseling.
 - Work collaboratively with community/school counselor to transfer use of skills to home setting.
 - Coping and problem-solving scripts.
 - Contingency maps.

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School Supports
Home-School Collaboration

- School**
- A variety of strategies can be used to support and teach the student skills...
 - IEP or 504 Plan
 - Interdisciplinary team: planning and problem-solving
 - Various educational and therapeutic supports
 - Transition planning and preparation.
 - Counseling
 - Focus on developing coping and problem-solving skills.
 - Identifying and managing feelings and behavior (emotional-behavioral regulation).
 - Focus on teaching social skills.
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- School**
- A variety of strategies can be used to support and teach the student skills...
 - Speech-language
 - Focus on functional communication training and pragmatics.
 - Focus on social skills and social communication training.
 - Peer Network
 - Club membership
 - Lunch buddies
 - Reading buddies
 - Peer network
 - Cooperative learning groups
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School

- A variety of strategies can be used to support and teach the student skills...
 - Structured after school activities
 - HW club
 - Individual sports
 - Other clubs (based on interest)
 - Parent-School Partnership
 - Establish regular meetings for collaborative planning and problem-solving.

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Community Supports

Home-Community Collaboration

Community

- Various community-based supports are likely to be needed for many adolescents with ASD....
 - Service Coordination
 - Should be knowledge of services, service system, and community resources to assist with Care Coordination.
 - Social Services
 - Individualized
 - Wrap around
 - Futures Planning
 - Guardianship
 - Futures Care

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Community

- Various community-based supports are likely to be needed for many adolescents with ASD....
 - Emotional-Behavioral Support
 - Cognitive-behavior therapy
 - Behavior therapy
 - Family therapy/Education
 - Psychiatric services
 - Community Recreation
 - Town & recreation centers
 - Place of worship

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Community

- Various community-based supports are likely to be needed for many adolescents with ASD....
 - Rochester Regional Center for Autism Spectrum Disorders.
 - Webinars
 - Educational resources
 - Technical assistance
 - Information & Referral

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Resources

- For information on various resources to assist in supporting the adolescent with ASD, visit these websites....
 - www.autismspeaks.org
 - This site contains various toolkits and guide for various topics including..
 - home, school, safety, medical etc.
 - www.golisano.urmc.rochester.edu/rrcasd-nyautism
 - Various resources on various topics including...
 - Self-study DVDs on Daily Schedules & Teaching Social Skills
 - Information Sheets

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Question & Answer

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