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.

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.

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

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
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.

Implications for Adolescents with ASD
Implications
• Developing brain and changes in biochemicals (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.

Implications
• Developing brain and changes in biochemicals (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).

Adolescent Issues
Considerations for supporting adolescents with an ASD....
Adolescent Issues

• **Social impairments** can affect the development of **self-awareness**.
  – 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.

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.

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
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.

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

Adolescent Issues

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

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
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.

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.

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
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.

Assessment

Adolescent
- ASD symptoms
- Cognitive/Neurocognitive
- Adaptive Functioning
  - personal, social, community
- Co-morbid symptoms/disorders
  - Medical, emotional, behavioral, sensory-motor.
- School performance
- Work/volunteer performance.

Setting/Expectations
- Home
  - Personal care, domestic
  - Emotional-behavioral regulation
- School
  - Workload, social, communication, behavioral
- Community
  - Consumer behavior, recreation and leisure
- Work
  - Activities, social communication, behavior regulation
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.

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.

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

Supports/Interventions

Home
School
Community

Home Supports

Developing Independence
• Support the development of independent living skills..
  – Establish clear and consistent expectations or ‘house’ rules that include…
    • Specific responsibilities
    • Timelines for completion
    • Expected outcomes

• 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.

• 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.
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

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

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.
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.

- 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.

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.
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.
  – 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
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.

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
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

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
Question & Answer