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Meeting the Needs of Autistic Adults

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Learning Outcomes

1. Define autism and describe the lived experience of autistic adults, including common core strengths and challenges.
2. Discuss 5 strategies occupational therapists can use to improve occupational participation in autistic adults and enhance their quality of life.
3. Explain the role of technology, assistive devices/tools, and other supports for autistic adults to help manage daily living, social, and occupational needs.
Presentation sections (overview)

1. Define autism and describe demographics for autistic adults
2. Examine common strengths and challenges
3. Highlight findings from qualitative research studies focused on autistic adults
4. Share OT strategies to improve participation for autistic people and increase quality of life
5. Describe technological aids/devices and communication tools used by autistic people

Defining Autism

- Neurological developmental disability that originates in early childhood
- Estimated prevalence of 1-2%+ among children, youth, and adults\(^1\)

Core neurological areas of autism:
- Language and communication
- Social interaction and interpersonal relationships
- Sensory processing and motor skill coordination
- Executive functioning
Thinking Differently About Autism

Defining Autism in Adults

- Neurological developmental disability that originates in early childhood and...
  - Continues into adulthood with lifelong challenges
  - May often go undiagnosed until adulthood
  - No one is suddenly autistic in their late 20s
Defining Autism in Adults

- Studies of autistic adults frequently contain small sample sizes or use convenience samples
  - It is difficult to identify autistic adults to participate in research once they leave K-12 and youth systems
    - (This also makes it difficult to determine true prevalence in adults—HHS is focused on 8 year olds)
  - Existing studies are unrepresentative of the breath and diversity of the lived experience of autistic people
  - Studies do not capture diversity of race/ethnicity, socio-economic status, gender/gender identity, etc.

Demographics

- Lower scores on common quality of life domains, especially for social inclusion\(^2\) for community living
- High rates of unemployment and underemployment
  - Only 58% of autistic youth and young adults work for pay between age 18 and 25\(^3\)
  - Autistic adults often have atypical work histories with jobs of short duration\(^4\)
  - Autistic people frequently lack access to needed employment supports and resources\(^3\)
- High rates of co-occurring disabilities/conditions
  - Mental health disabilities, such as depression (37%+)\(^5\)
  - Chronic conditions, such as cardiovascular conditions\(^6\)
Diagnosis in Adult Life

- Accurate diagnoses in adulthood hinge on a solid understanding of childhood developmental history
- Challenges linked to subjectivity of clinical interpretation of atypical behavior in individuals
  - No reliable biological tests (e.g., blood tests) exist to diagnose autism for the full diversity of the disability
  - Few clinicians have training on diagnosing autistic adults
  - Occupational therapists may be more tuned to atypical traits in autism -> link to occupations and life functioning

Common Strengths and Talents of Autistic Adults

- Frequently think in detailed-oriented manners
- Commonly possess hyper-focused attention
- Highly focused interests abound among many autistic people, but vary widely in subject and scope
- Often share preferences for structure, routines, regularity, habits, and patterns
- Sometimes develop edge or out-of-the-box thinking
Frequent Challenges and Aspects of the Lived Experience

- Atypical processing of emotions and mental states
- Unusual expression and experience of pain and other sensory-related stimuli
- Processing of information at lower processing speeds and in neurodivergent ways and manners
- Difficulties with multi-tasking and managing demands of multiple competing tasks and attentional sources
- Challenges with handling novel social situations

Frequent Challenges and Aspects of the Lived Experience (Cont.)

- Challenges with organizing, planning, self-regulating, and self-managing life activities
- Atypical gait and slower reaction time
- Weaker grip strength and difficulties with coordinating fine motor skills
- Challenges with handling visual/motor integration and executing gross motor skills
FAMU Study on Perceptions of Quality of Life of Autistic Adults

- Qualitative survey with 3 analyzed questions on QOL
- Q3: How would you describe how autism affects your quality of life?
  - Theme 1: Mental State
  - Theme 2: Lack of Understanding of Non-autistic people
  - Theme 3: Communication Issues
  - Theme 4: Environmental Struggles
  - Theme 5: Barriers to Social Connections
  - Theme 6: Challenges to Occupational Performance
  - Theme 7: No Impact on QOL

FAMU Study on Autistic Adults’ Perceptions of Barriers to Work

- Qualitative survey with 3 analyzed questions on barriers to work and participation in employment
  - What does working in a job mean to you?
    - Be productive; make ends meet; work provides meaning; anxiety
  - How does autism affect your ability to work?
    - Executive functioning; social skills; sensory issues; stressful
  - What do you fear most about working regularly?
    - Fear of not finding a job; fear of social interaction; anxiety about workplace performance; transportation; no fear
FAMU Study on Autism and Pain: How Autistic Adults Perceive Pain

- Qualitative survey with 3 analyzed questions on perceptions and experiences of pain
- 3 Core themes:
  - Physical and environmental stimuli that cause pain are often difficult to control or unavoidable
    - Noise and loud sounds, lights, barometric pressure, extreme temperature and touch
  - Pain can affect daily participation
  - People experience pain in very different ways
    - Some pain experiences occur in unexpected and unusual ways

OT Strategies to Improve Participation and Enhance QOL

- Fine and gross motor skill strategies
- Self-advocacy skill development
- Stress management and reduction
- Assistance with creating helpful habits and routines
- Problem solving approaches to executive functioning for diverse situations (school, home, work, etc.)
- Promoting social participation and engagement
Strategies for Addressing: Fine and Gross Motor Skills

- Even though autistic adults may not appear to have issues with fine and gross motor skill, many do
  - We need to assess these areas carefully.
  - Things we take for granted may be difficult and cause unnecessary stress: i.e., tying shoes/ties, bending/stooping, handwriting, 2 handed tasks that require balance, etc.)

Strategies for Addressing: Fine and Gross Motor Skills

- Remember traditional and creative adaptive equipment will play a role for many, though it may not be obvious.
  - Reachers, built-up pens/pencils, elastic shoelaces, jar openers, buttonhooks, speech to text software, etc.
  - Rearranging things to convenient locations*** (keep in mind respect routine and need for sameness

36-inch-long-reacher
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Illustrating Examples of Fine Motor Tools Used by Autistic People

Yankz Sure Lace system
(tweet on Trizone Tuesday)

Button hooks
(public domain image)

Electric can openers
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(via Wikimedia Commons)

Strategies for Addressing:
Self-advocacy skill development

- Encourage the use of assistive devices and tools that help autistic individuals manage their daily lives
  - Assess and identify tools to match individual needs
  - Role play how to ask for them and how to ask to use them
- Connect with the autistic adult client and the individual’s circle of support (family, friends) to:
  - Identify useful community-based supports and services
  - Determine community organizations and resources to access needed supports and services
Strategies for Addressing: Stress management and reduction

- Coping with sensory issues, executive functioning, and social pressure can cause significant stress.
- Stress reduction strategies such as mindfulness exercises, practicing positive self-thought, and stress management activities can be very useful tools for autistic adults.

Strategies for Addressing: Assistance with routines and habits

- Occupational Therapy can work with autistic adults to create habits and routines for approaching demanding tasks.
  - e.g. observe and analyze existing habits and routines, roleplaying, problem-solving, etc.
- Occupational Therapy can troubleshoot stressors in an autistic adult’s life to develop stress management skills
  - Eliminate unnecessary tasks, improve organizational skills, incorporate checkpoints, or relaxation technique stops.
Strategies for Addressing: Assistance with routines and habits

- Model and demonstrate actions and steps for form, structure, and to maintain routines and habits
- Identify routine maintenance supports such as tools/devices, circles of support, etc.
- Connect routines and habits to focused interests

Strategies for Addressing: Executive functioning for life needs

- Need to address cognitive processing issues with compensatory strategies:
  - Break down the tasks so they are not overwhelming
  - Incorporate check points into task performance
  - Look at the big picture and help structure time and tasks
- Incorporate breaks in thoughts and performance
- Technology can help
Strategies for Addressing: Executive functioning for life needs

- Identify cognitive strengths and talents to mitigate major challenges with organization, planning, etc.
- Circumvent challenges by finding alternative approaches to manage tasks that fit the individual
- Integrate extensive use of customized and adapted tools, resources, and devices
- Seek ways to scaffold and structure management of tasks needed for executive functioning

Strategies for Addressing: Social participation and engagement

- Work on strategies including
  - Breaking down tasks for communication and social engagement into manageable steps so social situations are less overwhelming
  - Role playing challenging social scenarios and situations
  - Supporting the development of strategies and skills for social-related aspects of networking and work search

- Encouraging participation in mentoring by autistic and non-autistic people
Technological Aids, Assistive Devices, and Other Supports and Resources

- Think creatively for tools and devices (high, low tech)
- Recognize how autistic youth and adults benefit from assistive devices and tools to address barriers
- Consider how to address core challenges and difficulties from co-occurring disabilities/conditions
- K-12 agencies may purchase devices, but autistic young adults frequently lose access after high school\textsuperscript{10}

Communication Devices and Systems Used by Autistic People

- Sign language, letter boards, picture systems
- Computers, speech-generating devices, etc.
Sensory Tools and Systems

- Noise-cancelling headphones and smart hearing aids
- Smart captioning systems for language processing
- Fidget and stimming aids modulating sensory/emotional experience (e.g., mesh fidgets, fidget spinners*, etc.)
- Irlen lenses, smart glasses, visual scene apps, etc.

Executive Functioning Apps and Tools for Life Management

- Supports for multi-tasking, information processing speed, self-regulating, and self-management
- Gamified apps for productivity (e.g., Habitica, Bounty Tasker, Epic Win), finances, and fitness
- Customized high-tech and low-tech tools and software to enhance planning, organization, etc.

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Seeking sources for assistive tech and resources for autistic adults

- Organizations and groups run by and for autistic adults, such as:
  - Autistic Self Advocacy Network (ASAN)
  - Autistic Women & Nonbinary Network (AWN)
- Networking with other service professionals, such as speech-language pathologists, social workers, etc.
- Hearing the voices of autistic adults by reading blog posts and listening to podcasts (#ActuallyAutistic)

References


References (Cont.)


Questions?

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