

Transition from Pediatric to Adult Services:

What should a parent know?



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Characteristics of Adults with Autism Spectrum Disorders

- The core symptoms of autism continue into adulthood
 1. Problems with communication ranging from being non-verbal to having difficulties with the more subtle aspects of communication (verbal and non-verbal)

Ex: difficulty with abstract thought; inability to listen to others; inflexible thinking; literal interpretation

Characteristics of Adults with Autism Spectrum Disorders

2. Problems with social interaction ranging from lack of social interest to social awkwardness
Ex: difficulties with empathy for others or in taking other's viewpoint; difficulty with the hidden rules of courtship and sexual relationships; may be painfully shy or extremely outgoing and "in your face"; problems managing appropriate social conduct/interactions; lack of empathy; visual thinking; unacceptable sexual behavior; misinterpretation of cues from others

Characteristics of Adults with Autism Spectrum Disorders

3. Repetitive and stereotyped behaviors or restricted interests and adherence to routines

Ex: repetitive routines may provide them with a sense of security and it is stressful when routines suddenly change; specialized areas of interest; resistance to change; increase in compulsions

Characteristics of Adults with Autism Spectrum Disorders

Other symptoms: problems keeping track of time once they are involved in a task they enjoy; lack of emotional control; sensory sensitivities; problems with executive functioning; difficulty with anger management or feelings of anxiety and/or depression; aggressive or self-abusive behaviors; tantrums; concerns about exploitation; sleep problems



Recent long-term studies

- There is a small number of adults who achieve what would be considered a “good” outcome in the that they are living independently, hold jobs, had some sort of friendship with another person in their age group – sexual relationships and marriage continue to be infrequent
- The majority of adults with an ASD, despite normal or near normal intelligence, continue to be dependent on their families or other support



continued

- The only consistent childhood predictors of long-term outcome remain language development and IQ
- An IQ of 70 or higher appears to be related to more positive outcomes

continued

- **Developmental course of Autism**
 - Improvement – most studies show there are improvements in core symptoms – increase in communication and social interactions as well as general symptom reduction
 - Deterioration – there are some studies which suggest cognitive or behavioral deterioration in a small portion of adults with an ASD – recent studies have been looking at the development of catatonia in these adults



Other issues needing attention

- In addition to the core symptoms, other areas may come into the forefront for adults with an ASD. These include:
 - Difficulties with independent living
 - Difficulties being a partner or a parent
 - Difficulties in the workplace
 - On-going mental health issues



Difficulties with independent living

- What does the research tell us?
 - Studies have found that around 1/2 to 3/4 of adults with an ASD are unable to live independently, regardless of intellectual level
 - Around 1/2 continue to live with their families
 - Around 1/3 live in residential
 - <10% hold full time jobs
 - <5% live independently
 - Approximately 1/2 will have a comorbid psychiatric disorder in adulthood



What are independent living skills?

- Self-care and hygiene
- Budgeting and managing a bank account and credit account
- Housekeeping and cooking skills
- Safety skills and safety awareness
- Appropriate dress in the workplace
- Work-related social skills including understanding “office politics”

What are independent living skills?

- How to look for a job
- How to share living or office space
- Battling inertia
- Planning social and leisure activities
- Dating and sexuality
- Knowing resources available to them

Potential living arrangements

1. Independent living – living in own home, working and managing own finances
2. Semi-independent living – living in own home with support for solving major life functions such as finances and dealing with agencies
3. Living at home with family (parents or siblings)- there may be various levels of independence in this setting

Potential living arrangements

4. Foster home or skill development home – a family home that cares for unrelated adults – usually there is training in independent living skills such as self-care and housekeeping – leisure activities are arranged by the home
5. Supervised group living – group home staffed by professionals – help is provided for basic needs such as meal preparation, self-care – the amount of autonomy or number of visits per week varies depending on level of functioning



Potential living arrangements

6. Institutions – long-term care for those needing intensive and constant supervision
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Daily Activities

- Day Program
- School

- Work



Day Programs

- 1. Day treatment – services to increase self-care, communication, mobility, independent living skills, learning and self-direction
- 2. Day Habilitation – Training in the above skills along with the provision of structured activities and specialized assistance – the goal is to keep the individual involved in non-vocational, community-based activities



Day Programs

- 3. Vocational services – this can include vocational assessments/evaluations, vocational counseling, work and personal adjustment counseling, job skills training, supervised or supported employment, job placement and follow-up
- 4. Day training and Sheltered Workshops – the worker is engaged in some type of productive activity for a reward (money, verbal praise, access to favored activity) and also



Higher Education

- Is actually two transitions
 - Transition to college
 - Transition to work



Key Skills Needed for College

- 1. Self-Advocacy Skills
 - A. Most schools have some disability support services
 - B. Understanding how to and how much information to disclose to professors
 - C. Understanding their rights and how to ask for academic accommodations
 - D. Ability to ask questions and understand instructions/rules



Key Skills Needed for College

- 2. Organizational and time management skills (how to break the day into chunks, create a schedule, skills for using an organizer, planning and problem solving)
- 3. Independent living skills (laundry, money management, interpersonal problem solving, sexual safety, exercising and cooking)



Key decisions

- 2 or 4 year school
- Remain at home, live in dorm, live in apartment
- Roommate or not
- In general, it may be best to start at a Community College in your area because many of them have nice services for young adults with disabilities



Key decisions

- In Texas, many of the Community Colleges have specific programs for young adults on the spectrum that includes course work or certification programs designed to develop the necessary skills for living independently, study skills, personal development, vocational skills, job readiness, social development



Key decisions

- For some young adults, it makes sense to remain in the community where they grew up in order to decrease the number of transitions associated with attending college
- Roommates are hard to deal with even when you are neurotypical
- Dorms can be loud and chaotic

Work

- When a young adult transitions into a work setting, there are a number of skills that are needed to be successful
 - 1. Basic academic skills
 - 2. Team and interpersonal skills
 - 3. Job search and application skills
 - 4. Job performance – understanding what others expect of you, spoken and unspoken
 - 5. Career and job development – need to be able to learn new skills, update established skills and apply new concepts



Transition Planning

- 1. You need a well developed transition plan
- 2. You need preparation for independent living
- 3. You need preparation for secondary education or employment
- 4. You need an understanding of the resources available and how to access them for on-going support



Transition Planning

- Transition planning needs to start early, around the age of 14
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- Services for adults with an ASD or an ASD and Intellectual Disability vary from state to state



Financial & Supervision Planning for Adults with ASDs

- There is a need:
 - Due to anticipated need for adult supervision for those also having an intellectual disability
 - Due to anticipated problems getting a job with appropriate income/benefits & problems holding a job for those with seemingly appropriate cognition/education



Financial & Supervision Planning for Adults with ASDs, cont'd

- Soon after receipt of diagnosis, no matter the age of their child, parents should:
 - Begin estate planning
 - Use trusted lawyer
 - Formulate special needs trust
 - Put back \$ for supervised living
 - Put back \$ for health/daily living needs not otherwise covered



Financial & Supervision Planning for Adults with ASDs, cont'd

- Soon after receipt of diagnosis, no matter the age of their child, parents should (cont'd):
 - Place their child's name on their state's Medicaid Waiver (MW) lists & any other state adult funding list for which their child would possibly qualify (Lists=long)
 - Ensure funding available when needed
 - For now, avoid moving to another state as these lists, even MW, do not transfer



Financial & Supervision Planning for Adults with ASDs, cont'd

- Soon after receipt of diagnosis, no matter the age of their child, parents should (cont'd):
 - Learn from their local autism support groups, local ARC, local ATN clinic, state council on developmental disabilities, state health department, state Title V office, state autism website, state & federal departments of disabilities/aging websites, Autism Speaks, etc. where to find guidance re special needs trusts, adult disability funding opportunities



Financial & Supervision Planning for Adults with ASDs, cont'd

- Enable themselves to initiate what they need to do under current law/funding opportunities & to have contacts updating them regarding law/funding opportunity changes
- State laws/funding opportunities vary from state to state
- State and federal laws/funding opportunities may change



Financial & Supervision Planning for Adults with ASDs, cont'd

- Soon after receipt of diagnosis, no matter the age of their child, parents should (cont'd):
 - *Prepare their will(s) to include child care plans for all of their children if something happens to the parents when the children are <18 years old
 - *Prepare their will(s) to include adult child care for child with ASD, then update as needed

Financial & Supervision Planning for Adults with ASDs, cont'd

- Over time, parents anticipating that their child with an intellectual disability will need adult supervision even when the parents are elderly/deceased should:
 - *Arrange for personal care attendants/respite care workers to support adult child's care while living with elderly parents

Financial & Supervision Planning for Adults with ASDs, cont'd

- *Look for appropriate, stimulating, & safe small group adult residential places
- *Identify family members with whom adult child could live & prepare them along with the child as much as possible for the transition



Financial & Supervision Planning for Adults with ASDs, cont'd

- In the year before a child turns 18 years old, parents need to decide if their child will be able to independently make financial & medical decisions as an adult
 - *If not, get lawyer to help parents obtain guardianship
 - *If partial, get lawyer to help parents obtain partial guardianship, power of attorney...



Medical Care for Adults with ASDs

- Needs to be with primary care physician who:
 - Takes the insurance or Medicaid or funding plan of the adult with ASD
 - Treats adult with ASD with respect



Medical Care for Adults with ASDs, cont'd

- Needs to be with primary care physician who (cont'd):
 - *Does not see every health or behavior problem as simply something commensurate with autism
 - *Listens to the history
 - *Investigates each baseline deviance appropriately



Medical Care for Adults with ASDs, cont'd

- Needs to include routine annual preventive & health maintenance visits with a dentist & a primary care physician who:
 - follow all the preventive & health maintenance age-related guidelines



Medical Care for Adults with ASDs, cont'd

- Needs to include routine annual preventive & health maintenance visits with a dentist & a primary care physician who (cont'd):
 - recognize that an ASD is not protective against breast/cervical/colon/prostate cancer, pregnancy, high cholesterol, cardiovascular disease, diabetes, or osteoporosis

Medical Care for Adults with ASDs, cont'd

- Should consider the following:
 - *Individuals with an ASD do not suddenly lose their health problems upon becoming an adult

Medical Care for Adults with ASDs, cont'd

- If patient had GI problem, seizures, catatonia, anxiety, ADHD, aggression, etc. at 17 y/o or at 20 y/o:
 - Plan for an adult subspecialist in the problem area(s) who can advise patient's adult primary care physician
 - Make certain each adult subspecialist aligned takes the patient's insurance or Medicaid or funding source



Medical Care for Adults with ASDs, cont'd

- Should consider the following (cont'd):
 - Like with any adolescent entering puberty, those with an ASD are more likely to have new onset seizures than at any time since before they entered school or after they have completed puberty

Medical Care for Adults with ASDs, cont'd

- The likelihood of an adult with an ASD having a new onset seizure if that adult has never had seizures is not high
- If an adult with ASD who has never had a seizure has one, this needs immediate investigation

Medical Care for Adults with ASDs, cont'd

- Should consider the following (cont'd):
 - Like with any adolescent entering puberty, those with an ASD who have tics are more likely to have an increase in their tics but after completing puberty these tics continue to worsen in only 5% of individuals & seem to lessen in most others

Medical Care for Adults with ASDs, cont'd

- Should consider the following (cont'd):
 - If catatonia (new onset of rigidity with holding body in same position or new onset extreme slowing of movements or new onset of loss of muscle tone/increased flexibility) is going to happen, it is more likely to occur when someone with an ASD is entering puberty

Medical Care for Adults with ASDs, cont'd

- If what seems to be catatonia occurs in an adult, the primary care physician (PCP) should begin an investigation to make certain this is truly catatonia
- PCP should align subspecialist experienced in treating catatonia

Medical Care for Adults with ASDs, cont'd

- Subspecialists in this area are usually neurologists or psychiatrists
- The subspecialist should be one who takes the patients' insurance or Medicaid or funding source



Medical Care for Adults with ASDs, cont'd

- The subspecialist should be one skilled in prescribing and monitoring benzodiazepines which are considered the first line of treatment for catatonia

Medical Care for Adults with ASDs, cont'd

- Should consider the following (cont'd):
 - Of all the health issues seen throughout the lifespan of individuals with an ASD, anxiety & then depression are the ones that seem to worsen with time rather than remain the same or lessen

Medical Care for Adults with ASDs, cont'd

- Implication: all adults with an ASD should have adult psychiatrist
- Implication: all adults with an ASD should have a therapist who is appropriate for helping them at their specific cognitive deal with anxiety and depression



Medical Care for Adults with ASDs, cont'd

- Should address the following problems:
 - Medicaid waivers currently do not cross state lines and thus interfere with individual or family plans for moving to another state, including when an with an ASD needs to live with an adult sibling in another state upon the death of elderly parents



Medical Care for Adults with ASDs, cont'd

- Should address the following problems,
(cont'd):
 - *It is difficult to find an adult subspecialist
who takes Medicaid



Medical Care for Adults with ASDs, cont'd

- Should address the following problems (cont'd):
 - *Even when one finds an adult dentist or surgeon who takes Medicaid, the anesthesiologist needed for the procedure usually does not take Medicaid

Medical Care for Adults with ASDs, cont'd

- Should address the following problems (cont'd):
 - *It is difficult to find an Adult Psychiatrist willing to see someone with a “Dual Diagnosis” such as an intellectual disability (ID) and a “psychiatric diagnosis like anxiety or depression”...more likely to see someone with an ASD w/o ID, but not always



Medical Care for Adults with ASDs, cont'd

- Should address the following problems (cont'd):
 - Finding an ob/gyn willing to do a hysterectomy on an adult with severe/profound intellectual disability who cannot handle menses or have immense bleeding
 - Understandable due to this being abused in past, but ...
 - Long-term use of birth control injections can lead to bone thinning, so most ob/gyns want to limit this too

Medical Care for Adults with ASDs, cont'd

- Was improved with the January 2010 implementation of the Mental Health Parity and Addiction Equity Act of 2008
- Expanded rules requiring the insurance coverage for “mental health” problems as for “physical problems”
- Gives great help since biggest problem for adults with ASD = anxiety



Resources

- www.aspfi.org. Asperger Foundation International. Services throughout the U.S. for Adults on the Autism Spectrum: A Study by Asperger Foundation International.
- www.aspfi.org. AspFi's College Resource Guide – a directory of college's and universities and their services for college students on the spectrum – they also have a DVD on success in college



Resources

- A Journey Through Autism: A Guide for Transition to Adulthood by DANYA International, Inc. (www.danya.com), Organization for Autism Research (www.researchautism.org), and Southwest Autism Research and Resource Center (www.autismcenter.org)



continued

- WrongPlanet.net – web community for people with an ASD (or families, friends and professionals)

- Neurodiversity.org
- Asperger Foundation International
- www.faaas.org. Families of Adults with Asperger Syndrome
- www.aspires-relationships.com. About marriage and relationships with people on the spectrum



Resources

- AS Initiative: Advancing Futures for Adults with Autism
- http://www.autismspeaks.org/community/family_services/afaa.php
- AS Family Services: Age-relevant resources
- http://www.autismspeaks.org/community/family_services/



Thank you and Questions

