A CHALLENGING TRANSITION: MANAGING YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER

BY: DR. CELIA ROBICHAUD B.SC., M.D.
PGY4 RESIDENT, DEPARTMENT OF PSYCHIATRY
DALHOUSIE UNIVERSITY

OBJECTIVES

- Review the diagnosis of Autism Spectrum Disorder (ASD), etiology, epidemiology, and major psychiatric comorbidities (specifically with attention to transition aged youth)
- Present cases of a young adults with ASD preparing for transition to adult services
- Review the basic components of the transition from adolescence to adulthood, as they apply to youth with ASD
- Review an approach to managing psychiatric comorbidities in young adults with ASD in the adult mental health system

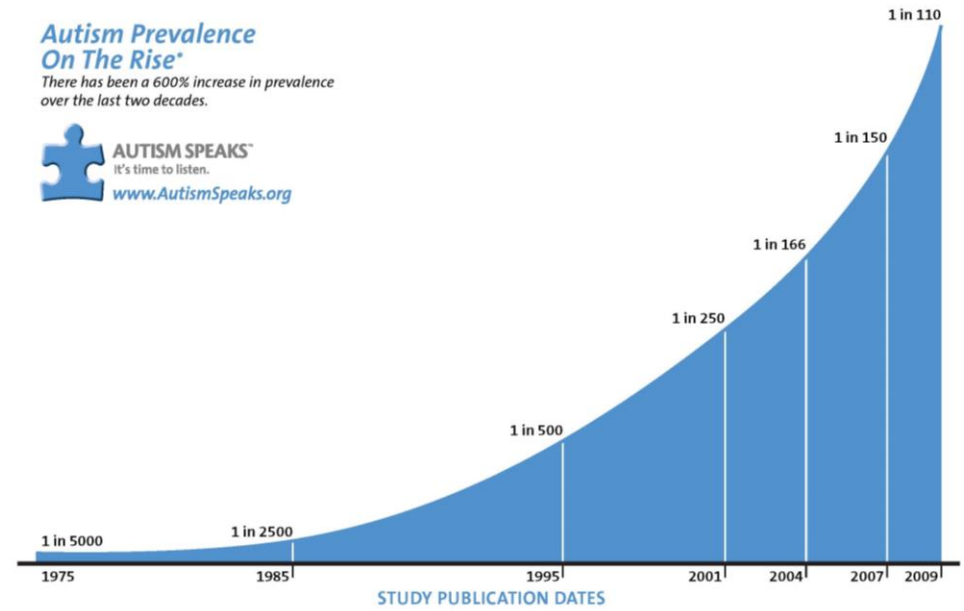
WHEN YOU THINK OF "YOUNG ADULTS WITH AUTISM"…





AUTISM SPECTRUM DISORDER

- **Lifelong neurodevelopmental disorder with detrimental impact on functioning**
- **A triad of symptom domains that represent impairments in:**
  - Quality of reciprocal social/emotional interactions
  - Verbal and non verbal communication
  - Repetitive stereotyped behaviors and interests
- **Represent ~1% of the general population**
- **Heritability ~90%**
- **Sex ratio 4:1 (male:female)**
  - 2:1 with comorbid intellectual disability



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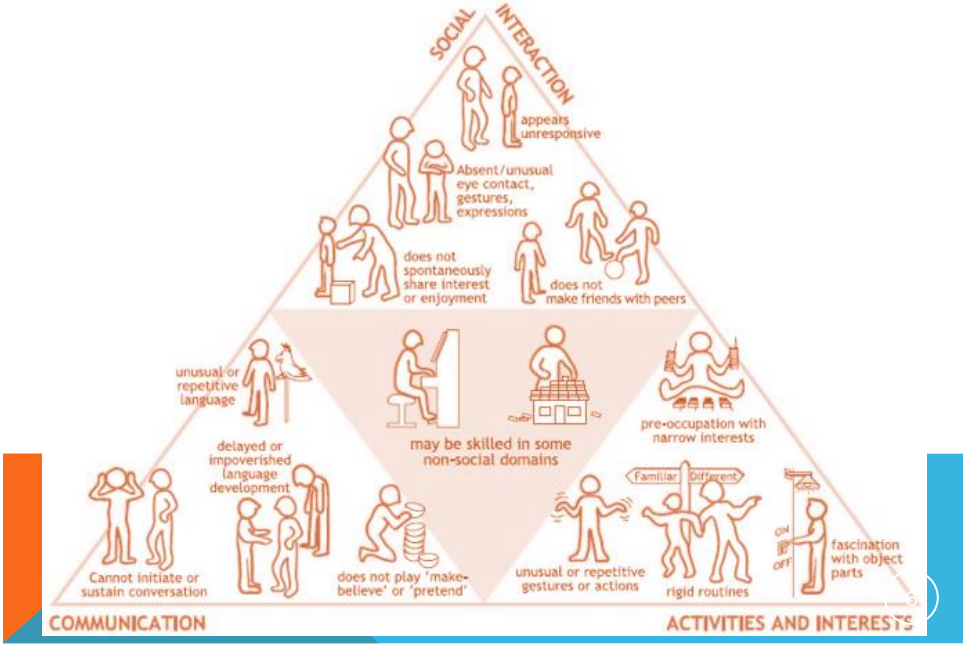
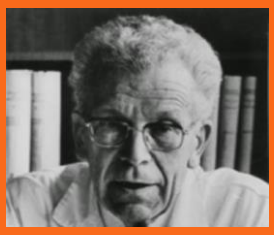
THREE MAJOR DOMAINS OF IMPAIRMENT



AUTISM: A HIGHLY HERITABLE, HETEROGENEOUS, NEURODEVELOPMENTAL DISORDER



Hans Asperger 1906-1980

Leo Kanner 1894-1981

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HOW IS A DIAGNOSIS OF AUTISM MADE?

- **A behavioral diagnosis: symptoms MUST begin in early childhood developmental period (12-24mos), but may become more apparent with increased social demands**
  - I.e. may not fully manifest until social demands exceed capacity
  - Later in life may be masked by learned strategies
- **Specifiers:**
  - With or without intellectual impairment
  - With or without language impairment
  - Associated with known medical or genetic factor (~15%)
  - Associated with another mental, neurodevelopmental or behavioral disorder
  - With or without catatonia

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TOOLS

- **Use of structured diagnostic tool important**
  - ADI-R: Autism diagnostic interview for caregivers or adults
  - ADOS: Autism Diagnostic Observation Schedule
    - Four modules tailored to age group and verbal ability
  - CARS: Childhood Autism Rating Scale
- **Ideally, coupled with detailed developmental history from a caregiver**

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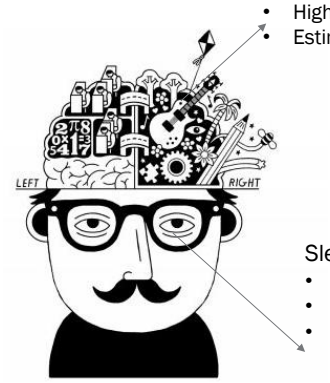
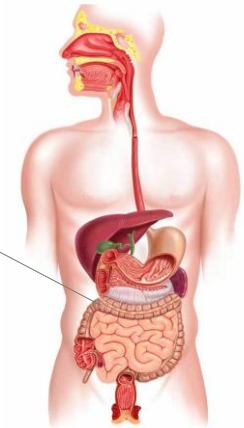
COMORBIDITIES: PHYSICAL

Epilepsy
- Higher rates of seizures
- Estimates 2-46%



Gastrointestinal
- 3x more common to have complaints of abdominal pain, constipation and diarrhea
- Feeding and eating problems

Sleep
- Sleep latency
- Night awakening
- ?abnormalities in melatonin production and circadian rhythm?



Altered sleep, anxiety, irritability, and self injury may all be indicative of a physical health problem!

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COMORBIDITIES: PSYCHIATRIC

- Approximately **70%** of individuals with ASD meet criteria for one additional mental health disorder, **40%** have two or more
- Higher rates of:
  - **Depression (70% in high functioning young adults with no comorbid ID, *Lugenard et al 2011*)**
  - Anxiety (56%)
    - GAD and SAD
  - Intellectual disability (38%)
  - ADHD (30%)
  - OCD
    - Controversial, given symptom overlap. Estimates 7-20%
  - Schizophrenia, solitary auditory hallucinations, Bipolar I

https://www.carautismroadmap.org/intellectual-disability-and-asd/

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DEPRESSION IN HIGH FUNCTIONING ASD

- Individuals with normal intelligence and verbal ability still may have core difficulties in social interactions and communication
- Vulnerable to negative life circumstances (bullying etc.)
- High level of alertness is recommended in these individuals for decline in mental health and psychosocial functioning

Lugnegård, Tove, Maria Unenge Hallerbäck, and Christopher Gillberg. "Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome." Research in developmental disabilities 32.5 (2011): 1910-1917.

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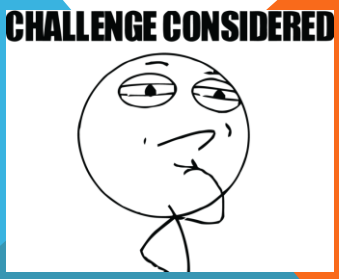
LET'S RECAP

- INDIVIDUALS WITH AUTISM HAVE DEFICITS IN COMMUNICATION, SOCIAL INTERACTION AND RIGIDITY
- MULTIPLE PSYCHIATRIC COMORBIDITIES THAT ARE DIFFICULT TO DISTINGUISH FROM THE PRIMARY SYMPTOMS OF ASD
- HOW MIGHT YOUNG ADULTS WITH ASD FARE WITH TRANSITIONING FROM ADOLESCENCE TO ADULTHOOD?



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CASES

- **Joe is a 19 year old male, lives at home with his siblings and parents**
  - Diagnosed with ASD as a toddler by pediatrics
  - Lower functioning, requiring substantial support with activities of daily living
- **First contact with psychiatry at age 12, referred by pediatrician for escalating aggressive behavior, tics and abnormal repetitive behavior**
  - Also struggles with hyperactivity and impulsiveness in the classroom
  - When stressed: self-injurious, touching mouth to various surfaces around the house, walking in circles
- **Comorbid medical conditions: Epilepsy, GERD/intermittent vomiting**
- **Medications**: risperidone, fluoxetine, lamotrigine

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CASES, CONT.

- Robert is a 19 year old male, adopted at age 2, lives independently in the basement of his parents home
- Diagnosed at age two with delayed speech, ASD and ADHD
- First seen by psychiatry at the IWK at age 14, seen by out of province psychiatrist prior
  - Main symptoms are anger, aggression, hyperactivity/impulsivity and inflexibility
- He has finished school and is working part time as a cleaner
  - His current clinician helps him with budgeting, meal planning etc.
- Biological family history of schizophrenia, bipolar and ADHD
- Comorbid medical conditions: Seizures
- Current medications: atomoxetine, fluoxetine, aripiprazole

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CASES, CONT.

- Joe and Robert have been followed by the ASD clinic at the IWK from age 12/14 until now
- What challenges do you foresee them facing with a move to the adult system? Will they be the same for both?
- What challenges do they face moving toward adulthood in general?

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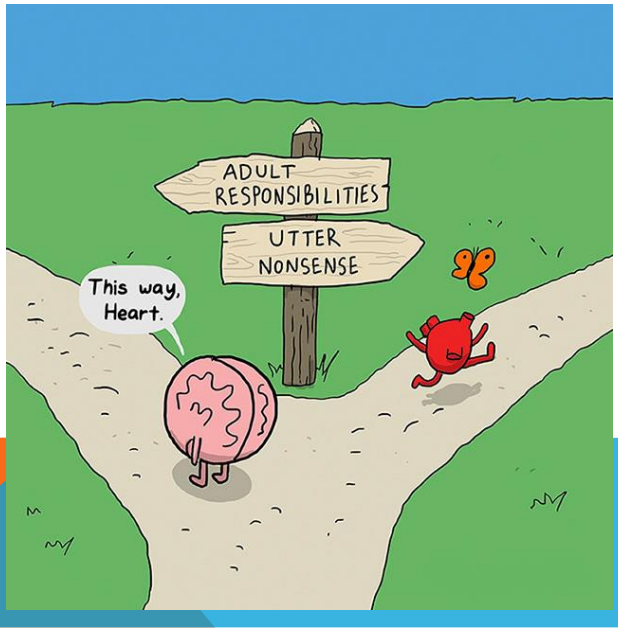
WHAT DOES IT MEAN TO BE AN ADULT?



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TRANSITION FROM ADOLESCENCE TO ADULTHOOD

- **Eriksonian stages**: identity v.s. role confusion, intimacy v.s. isolation

- **Activities of transition**: completing school, gaining employment, post secondary education, contributing to a household, community engagement, satisfactory personal and social relationships

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FOR A TEEN WITH ASD

- **School planning might mean:**
  - What services and supports are available to make post secondary goals attainable (such as assistive technology)?
- **Home planning might mean:**
  - Becoming more integrated into the community and more independent with age, a continuum of living arrangements and outside support
- **Employment planning might mean:**
  - Segregated training workshops, day programs, supported employment programs or entering competitive workforce

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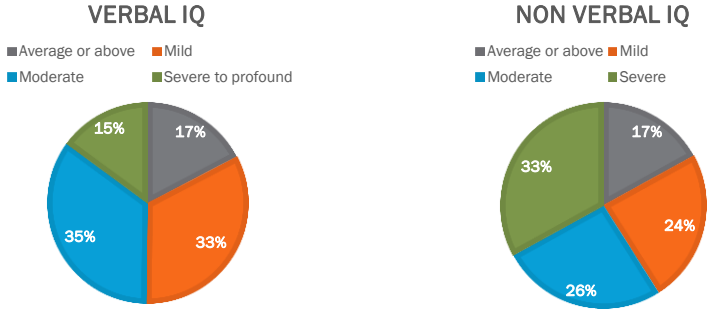
WHAT ARE THE OUTCOMES FOR YOUNG ADULTS WITH ASD?

- **Canadian study of 48 individuals diagnosed as preschoolers with ASD, followed up at mean age 6.8y, 11.4y and 24y**
  - Average CARS score 34 at time 1, 31 at time 2 (mild autism)



Eaves, Linda C., and Helena H. Ho. "Young adult outcome of autism spectrum disorders." Journal of autism and developmental disorders 38.4 (2008): 739-747.

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WHAT ARE THE OUTCOMES FOR YOUNG ADULTS WITH ASD?

- 30% attended some sort of post-secondary training, one individual at university
- 56% had ever been employed, averaging 5h/week in part time work
- 4% competitively employed (only one able to independently support themselves)

Eaves, Linda C., and Helena H. Ho. "Young adult outcome of autism spectrum disorders." Journal of autism and developmental disorders 38.4 (2008): 739-747.

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WHAT ARE THE OUTCOMES FOR YOUNG ADULTS WITH ASD?

- Those with ASD *without* intellectual disability three times more likely to have **no formal daily activity**
- **86% of young adults with no formal daily activity had a comorbid psychiatric diagnosis**
- At 24 years of age, 39.5% were on prescribed medication for behavior (most commonly risperidone)
- Obesity/metabolic side effects

Eaves, Linda C., and Helena H. Ho. "Young adult outcome of autism spectrum disorders." Journal of autism and developmental disorders 38.4 (2008): 739-747.

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WHAT ARE THE OUTCOMES WITH RESPECT TO HEALTH SERVICES USE?

ARTICLE

Post–High School Service Use Among Young Adults With an Autism Spectrum Disorder

Paul T. Shattuck, PhD; Mary Wagner, PhD; Sarah Narendorf, MSW; Paul Sterzing, MSSW; Melissa Hensley, MSW

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YOUNG ADULTS WITH ASD: SERVICE USE

- Data from the National Longitudinal Transition Study 2 (U.S.)
  - 10 yr prospective study following youth enrolled in special education programs
  - 680 youth with ASD from a nationally representative sample, 410 of whom had completed high school in 2007/08
  - 6:1 (male:female)
  - Average age 21.5y
  - Compared rates of service use to data collected 6 years earlier, when all youth were enrolled in school

Shattuck, Paul T., et al. "Post–high school service use among young adults with an autism spectrum disorder." Archives of pediatrics & adolescent medicine 165.2 (2011): 141-146.

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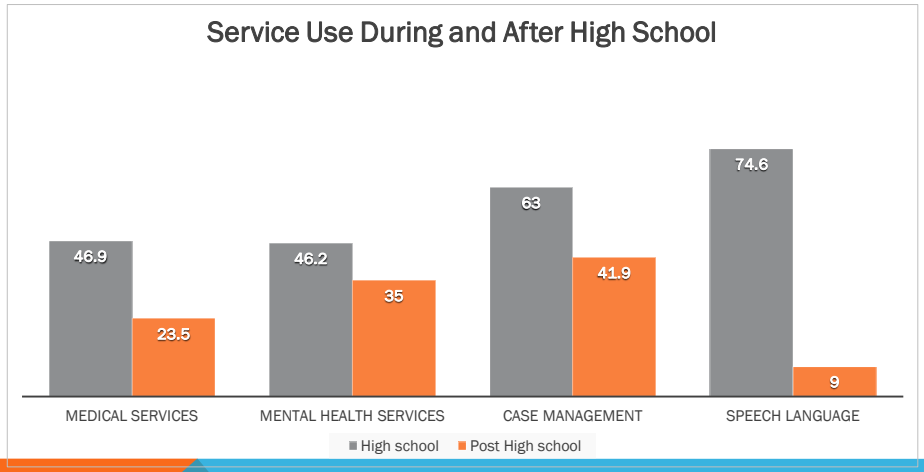
YOUNG ADULTS WITH ASD: SERVICE USE



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YOUNG ADULTS WITH ASD: SERVICE USE

- **While in school, only 6% of youth with autism received NO services at all**
  - This number climbed to **39%** after exiting school
- Other findings: those with no services after high school were more likely to have lower socioeconomic status, and were more likely to be African American
- Racial and economic barriers to continued service use

Shattuck, Paul T., et al. "Post–high school service use among young adults with an autism spectrum disorder." Archives of pediatrics & adolescent medicine 165.2 (2011): 141-146.

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How do we account for such a steep drop in service use?

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LIVED EXPERIENCE OF TRANSITION PLANNING

- Little evidence on mental health transition planning for youth with ASD
- Qualitative study on educational transition planning for youth with disabilities showed:
  - Youth themselves rarely engaged at all in planning, and if they are, too late in the process
  - Inadequate communication
  - Frustration with assumptions made about abilities/needs
  - Blind funneling into traditional adult programs

- A too little, too late, one size fits all approach

Sound familiar?

Hetherington, Susan A., et al. "The lived experiences of adolescents with disabilities and their parents in transition planning." Focus on Autism and Other Developmental Disabilities 25.3 (2010): 163-172.

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WHAT COULD BE BETTER?

- Early and active involvement of the youth
- Parent and family (system) involvement
- Individualized/contextualized relationships and plans
  - Especially in culturally or linguistically diverse populations
- Meaningful employment opportunities
- Outcome based, youth centered goals

Hetherington, Susan A., et al. "The lived experiences of adolescents with disabilities and their parents in transition planning." Focus on Autism and Other Developmental Disabilities 25.3 (2010): 163-172.

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APPLYING THESE TRANSITION PRINCIPLES TO MENTAL HEALTH SERVICES

Barriers:

- **Differential funding of adult v.s. youth services**
- **Differing eligibility criteria for care**
- **Limited awareness or comfort among physicians and allied health professionals about neurodevelopmental disorders**
- **Dealing with transition requires adaptive skill**
- **Confusion among families and caregivers about how to navigate adult services**

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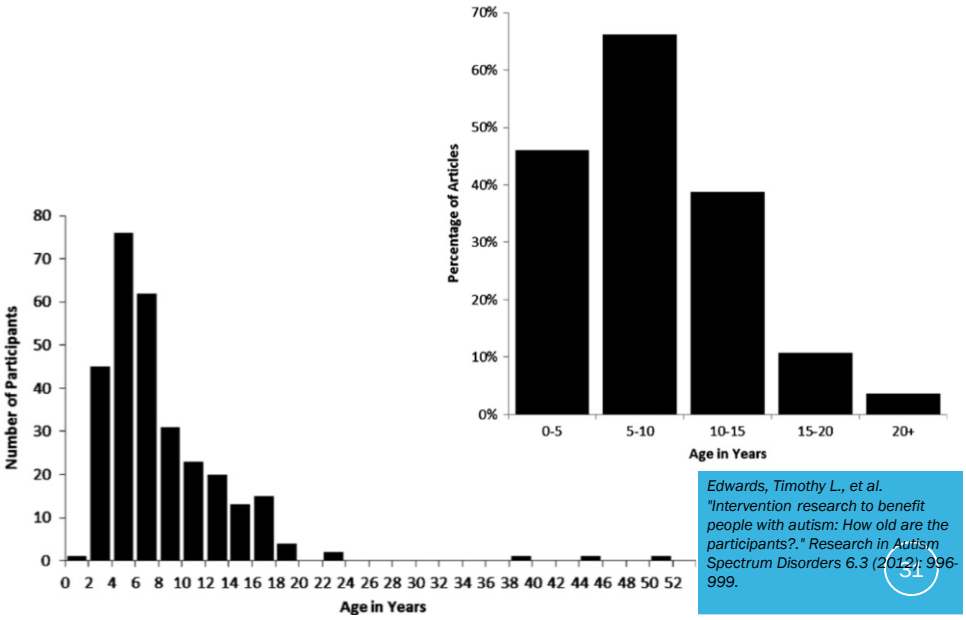
TREATING ADULTS WITH ASD: THE EVIDENCE



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IMPROVING AWARENESS AND COMFORT WITH ASD

http://www.thinkautism.co.uk/home

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IMPROVING AWARENESS AND COMFORT WITH ASD

- **NICE Guidelines for Diagnosis**
  - Multidisciplinary assessment
  - Focus on: Early developmental history, family history, behaviors, education, employment
    - Collateral history
  - Use of validated tools
  - Full Medical history
  - Physical exam
- Investigations: Genetic/metabolic workup (if family history, associated health problems or dysmorphic features indicate); hematological/immunological workup; neuro exam +/-EEG; renal u/s if 22q11del suspected

IMPROVING AWARENESS AND COMFORT WITH ASD

- **There is no medication treatment for core symptoms of autism**
  - Aripiprazole and risperidone approved for tx of irritability/aggression in autism by the FDA

- **For psychiatric comorbidities:**
  - NICE recommends treatment informed by existing guidelines for comorbid conditions, treating with the same algorithms (I.e. for ADHD/OCD)

MEDICATION MANAGEMENT

- **Important to consider: once an individual is started on a medication, they are very likely to stay on it**
- Longitudinal study of 286 adolescents with ASD, 57% taking psychotropic medication at the beginning, 64% 4.5years later

- **Potential reasons for this: increasing trend of polypharmacy, escalating complexity of issues, reluctance to discontinue effective medication, lack of medication review?**

Esbensen, Anna J., et al. "A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders." Journal of autism and developmental disorders 39.9 (2009): 1339-1349.

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MEDICATION MANAGEMENT

Maudsley Good Prescribing Guidelines for Adults with ASD

- Start at low doses
- Gradually titrate to maximal efficacy with regular monitoring /use of scales
- Routine health monitoring
- Stop any aversive or ineffective medication
- Seek expert second opinion as needed
- Avoid polypharmacy
- Schedule planned medication reviews

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AUTISM HEALTHCARE ACCOMMODATIONS TOOL

Autism Healthcare Accommodations Report

Name: John Doe **Date of Birth: 1981-6-6**

The purpose of this report is to help you, your staff, and John Doe have more successful visits. Due to the heterogeneous nature of autism spectrum disorders (ASD), the information and recommendations in this report have been **custom generated** to be specific to John Doe.

I Information to Assist with Patient Communication

Receptive speech: He can usually understand spoken language well.

Expressive speech: His ability to speak changes depending on the situation.

Alternatives to speech: He uses text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app).

Reading: He can read at a college level.

Writing: He can write or type at a college level.

Telephone: He cannot use the telephone.

Other important information about John Doe's communication.

- He may have difficulty communicating, even if his speech sounds fluent.
- He often takes langauge too literally.
- He can write or type better than he can speak.

To help John Doe better understand what you are saying.

- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Write down important information or instructions.
- Try not to talk to him while there are other noises.

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http://autismandhealth.org/?p=ahat

AUTISM HEALTHCARE ACCOMMODATIONS TOOL

V Recommendations to Help John Doe Comply with Recommendations

- Show pictures as much as possible.
- Have office staff help him schedule follow-up visits, referrals, or tests.

VI Information to Help You Better Understand John Doe

- He may have difficulty recognizing bodiliy sensations such as hunger, the need to urinate, or pain.
- If he fidgets, moves around, flaps his arms, or makes other sounds or motions, it does not mean he is not paying attention.
- He may have trouble processing more than one sense at a time, for example understanding what is said while looking at something.

Strengths: "Recognizing patterns; programming computers"

Interests: "Transportation systems"

Anxiety or overload triggers: "Unexpected changes in plans"

Ways that John Doe may show that he is anxious, upset, or overwhelmed: "I may stim or rock more or may shut down and stop talking"

Things that may help John Doe: "A quiet area; clear explanations"

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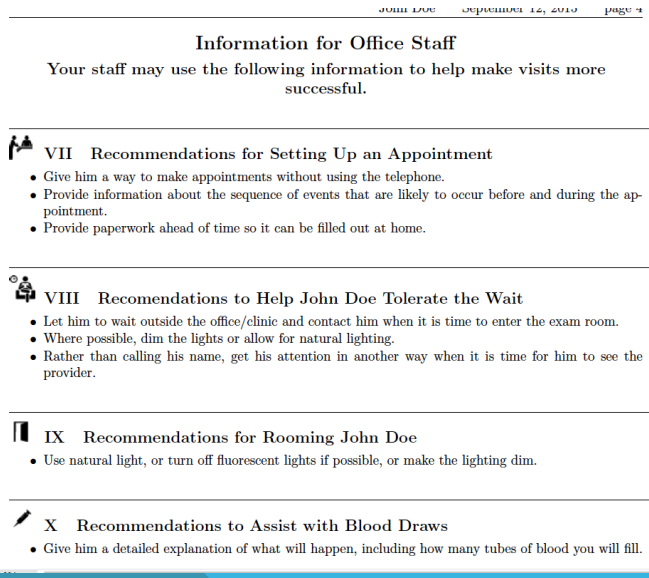
http://autismandhealth.org/?p=ahat

AUTISM HEALTHCARE ACCOMMODATIONS TOOL



John Doe September 12, 2015 page 4

Information for Office Staff

Your staff may use the following information to help make visits more successful.

VII Recommendations for Setting Up an Appointment

- Give him a way to make appointments without using the telephone.
- Provide information about the sequence of events that are likely to occur before and during the appointment.
- Provide paperwork ahead of time so it can be filled out at home.

VIII Recomendations to Help John Doe Tolerate the Wait

- Let him to wait outside the office/clinic and contact him when it is time to enter the exam room.
- Where possible, dim the lights or allow for natural lighting.
- Rather than calling his name, get his attention in another way when it is time for him to see the provider.

IX Recommendations for Rooming John Doe

- Use natural light, or turn off fluorescent lights if possible, or make the lighting dim.

X Recommendations to Assist with Blood Draws

- Give him a detailed explanation of what will happen, including how many tubes of blood you will fill.

http://autismandhealth.org/?p=ahat

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OTHER RESOURCES

- http://www.autismspeaks.ca/
- http://www.autismnovascotia.ca/

April is Autism Awareness Month!

Help us shine a light on autism as we illuminate buildings and landmarks blue and fundraise for Autism Speaks throughout the month of April.

www.lightitupblue.org

AUTISM SPEAKS LIGHT IT UP BLUE

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CASES

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  - Diagnosed with ASD as a toddler by pediatrics
  - Lower functioning, requiring substantial support with activities of daily living
- **First contact with psychiatry at age 12, referred by pediatrician for escalating aggressive behavior, tics and abnormal repetitive behavior**
  - Also struggles with hyperactivity and impulsiveness in the classroom
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- **Comorbid medical conditions: Epilepsy, GERD/intermittent vomiting**
- **Medications**: risperidone, fluoxetine, lamotrigine

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BACK TO THE CASES

Joe

- During his time at the IWK, Joe was involved with Applied Behavioral Analysis (ABA), OT, speech language pathology, psychology
- After turning 19 was referred to adult community mental health services
- Seen by RN + Psychiatrist for first assessment
  - Ongoing issues with property destruction, self-stimulation (slapping) and caregiver burnout/need for respite care
  - Felt that his needs would be best met elsewhere, referred to COAST (Dual Diagnosis)
  - Follow up by mental health RN in meantime

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CASES, CONT.

- **Robert is a 19 year old male, adopted at age 2, lives independently in the basement of his parents home**
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CASES

Robert

- Has yet to be transitioned!
- How can we (the mental health system) best prepare for his transition?

SUMMARY

- **Autism is a complex, heterogeneous, lifelong neurodevelopmental disorder**
- **Main impairments in social interaction, communication and activities/interests**
- **Multiple, COMMON, psychiatric comorbidities that can be easily confused with the primary symptoms of autism**
- **Young adulthood/ transition age represents an acute drop off in service use**
  - Attention needs to be paid to higher functioning individuals

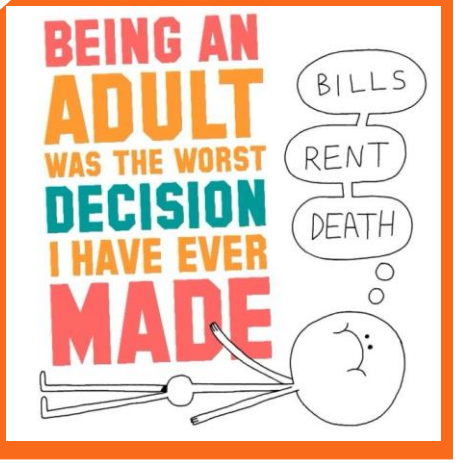
SUMMARY

- **Good Transition Practice**
- Early and active involvement of the youth
- Parent and family (system) involvement
- Individualized/contextualized relationships and plans
  - Especially in culturally or linguistically diverse populations
- Meaningful employment opportunities
- Outcome based, youth centered goals

- **A one size fits all approach doesn't "fit" ASD!**

THANK YOU

Special Acknowledgements: Dr. Lukas Propper, Dr. Jillian MacCuspie, Dr. Jillian Filliter



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