The Transition Age Young Adult with ASD

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More than one in 100 Americans has Autism.
More than one in 100 Americans has Autism.

Where are the adults....?
Transition to Adulthood: A Critical Developmental Period

• Later adolescence through the 20's
• Developmental tasks include
  - Acquiring adaptive self-care skills (everything from grooming and driving to banking)
  - Developing mature social judgment
  - Separating emotionally from family of origin
  - Learning to behave appropriately in adult world
  - Forming an adult identity
  - Completing education and finding adult work
  - Living independently
  - Forming adult relationships
The Desired Trajectory?

High School  College  Job/Independence
But something isn’t working...

Currently, the employment outcomes for adults with ASD are not encouraging. Some studies suggest that as few as 6% of individuals with ASD have full-time employment.

(Barnard et al., 2001).

Employment Rate of Youth with ASD

32.5%

Of the 32.5% with employment

- 42% worked < 20 hrs/wk
- 37% worked 20-34 hrs/wk
- 21% worked > 34 hrs/wk

(National Longitudinal Transition Study 2009)
Limited Full-Time Employment

A 2002 study of 405 adolescents and adults with ASD indicated that:

- Those in supportive employment worked an average of 15 hours per week
- Those in competitive employment spent roughly 27 hours per week at their jobs
- Those in sheltered workshops worked an average of 24 hours per week

(National Institute on Disability and Rehabilitation Research, cited in Seltzer & Krauss, 2002)
“James”
- Presents to the clinic at age 19
- Does well academically in high school
- Supportive family and school
- Has few friends but involved successfully in some activities such as Eagle Scout
- Enrolls in a selective college
- In second semester takes medical leave due to severe depression and anxiety
- Returns home and has trouble moving forward or returning to school
- Begins using marijuana regularly
• “Dora”
  o Presents to the clinic at age 24
  o Attended college at a selective school in the northeast
  o Returned home after two years with severe anxiety
  o Enrolls in a less selective school but is bored after one year
  o Returns home and lives there for the next several years without employment, school or learning to drive
  o Spends most of her time caring for pets
  o Admits to being unhappy living at home but prefers it to having the responsibility of supporting herself.
“Simon”

- Presents to the clinic at age 26
- Completed four years of college while living at home
- Since college has been unable to find a job that he likes or can keep more than a few months or that reflects his level of education
- Family is concerned that he will soon be ineligible for coverage on their health insurance
- He is less concerned and is fairly content living at home and playing video games.
- He is considering applying for SSI.
• “Jeanette”
  o Presents to the clinic at age 22
  o Completed two years of college at a selective school before returning home with severe anxiety
  o For past two years has lived at home without a job
  o Spends days working on hobbies that have some potential for relating to a vocation, but is unable to take the next steps to achieve this.
  o Has mood swings and can become abusive toward mother.
  o Does not drive and is afraid to learn.
“Jonas”

- 30 years old, intelligent and has completed some college
- Has had a series of jobs that he has been fired from or has left voluntarily after a short time, none of the jobs reflected his education
- Often conflicts with bosses and co-workers because of volatile temper and insistence that he is right
- Lives with parents in their 60’s
- Drives a car but does not own one
- Frequently conflicts with stepfather at home
- States a desire to be independent but has difficulty following through on activities that will lead to his goals
What Factors Contribute to Difficulty Transitioning to Adulthood?

- Characteristics associated with ASD: cognitive, social, emotional, motivational
- Family system/relationships
- Lack of specific skills
- “Behavior problems”: both learned maladaptive behaviors and psychopathologies
- Lack of supports and opportunities
<table>
<thead>
<tr>
<th>Common Obstacles Associated with ASD</th>
<th>Potential Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional/Behavioral Obstacles</strong></td>
<td></td>
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<tr>
<td><em>Difficulty self-regulating emotion and behavior</em></td>
<td>Avoidance of social situations; isolation and withdrawal; loneliness; lack of initiative; depressed mood; other acquired problems such as substance abuse or compulsive behaviors (e.g., gaming); low self-esteem; might be content living like a younger person; “Behavior problems” - meltdowns, outbursts, shutdowns, aggression</td>
</tr>
<tr>
<td>Social immaturity/ Lack of age appropriate skills, motivations and interests</td>
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<tr>
<td>Severe anxiety, especially social anxiety</td>
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<tr>
<td>“Sensitive” temperament – more easily upset by experiences</td>
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Emotional Immaturity

F MINUS

By TONY CARRILLO

THE GROWN-UP TABLE IS NOT ABOUT AGE, IT’S ABOUT ATTITUDE.
<table>
<thead>
<tr>
<th>Common Obstacles Associated with ASD</th>
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<tbody>
<tr>
<td><strong>Cognitive and Motivational Obstacles</strong></td>
<td></td>
</tr>
<tr>
<td>Rigid thought patterns; literal and concrete; insists things be a certain way; no compromise; believes own way is the “right” way</td>
<td>Difficulty in managing daily tasks without much support (e.g., managing money); Unrealistic goals or no goals; Trouble starting and finishing tasks at school or job; May work slowly; Often frustrated; “Underachieving” despite high ability; Can be perfectionistic or upset if things are changed from expectations; Likes to know in advance what will happen at all times; Gets negative feedback for being “smart but lazy”; Has focused interests and spends a lot of time on them; Trouble learning certain “adult” tasks like driving; Poor judgment; Fails (apparently) to learn from experience</td>
</tr>
<tr>
<td>Difficulty planning and organizing; trouble initiating activity or knowing where to start on a task</td>
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<tr>
<td>Difficulty doing tasks when not highly motivated</td>
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<tr>
<td>Concentration and attention are difficult, unless focusing on something highly motivating</td>
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<tr>
<td>Trouble thinking of alternative strategies or imagining consequences</td>
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<tr>
<td>Hard to “multitask”: prefers to work on one thing at a time.</td>
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<td>May be impulsive; acts or speaks without thinking about consequences</td>
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Adjustment in Adulthood

I SIGNED YOU UP FOR A CLASS TO TRY AND GET RID OF THAT THING YOU HAVE.

WHAT THING?

THE THING. YOU KNOW. THE THING THAT MAKES YOU THE WAY YOU ARE.

MY PERSONALITY?

EXACTLY. BUT WE CALL IT COMMUNICATION SKILLS BECAUSE IT SOUNDS LESS RUDE.
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<td><strong>Social and Communication Obstacles</strong></td>
<td>Misses social cues; says or does inappropriate things; talks too much or too little; gets off topic; misses jokes; can’t tell when it’s their turn to talk; offends people without meaning to; seems to have “lack of empathy”; interprets people as angry, threatening or hostile when they are not; poor judge of safe/unsafe people and situations; viewed as odd or eccentric or “nerdy”; lack of gesture or unusual gestures; has trouble communicating feelings to others and being understood; trouble being aware of own feelings; May be perceived as rude, hostile, uncaring, unfriendly or merely eccentric; <em>Chronic isolation and loneliness</em></td>
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<tr>
<td>Difficulty interpreting facial expressions, “body language”, tone of voice in others</td>
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<tr>
<td>Finds eye contact aversive or distracting</td>
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<tr>
<td>Can either listen to what you’re saying OR pay attention to your expressions, but hard to do both at same time.</td>
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<tr>
<td>Difficulty gauging effect of own actions on others, changing behavior in response to feedback</td>
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<tr>
<td>May process language, social information slowly</td>
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<tr>
<td>May be less facially expressive than others</td>
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<tr>
<td>Motor control and coordination often impaired, may not be adequately connected with communication</td>
<td></td>
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<tr>
<td>Communication style tends to create social distance, promote misunderstanding and social rejection</td>
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Understanding the Social World

ONE BIG HAPPY

MY REPORT ON THE PUPPET SHOW,
BY RUTHIE.

FIRST, THIS BIG OLD PUPPET HEAD TALKED.
THEN A LITTLE WEASEL STOLE A LOT OF MONEY,
AND THEN A BUNCH OF PEOPLE YELLED AND RAN AROUND.

THEN THIS OLD PUPPET NOBODY LIKED MADE A SPEECH,
AND EVERYBODY COMPLAINED ABOUT STUFF.
THEN A COW DANCED WITH A CAT AND THE BIG PUPPET HEAD LAUGHED.

IT WAS A LOT LIKE WATCHING THE EVENING NEWS, BUT WITHOUT THE COMMERCIALS.
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<td><strong>Other Obstacles</strong></td>
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<tr>
<td>Lack of supports and opportunities; does not qualify for needed services or cannot access; difficulty getting employment; lack of transportation</td>
<td>Long term problems with behavior, emotions; does not access needed treatment; does not reach educational or vocational potential; struggles with emotional consequences of family dysfunction; traumatized by bullying, rejection, mistreatment, chronically stressed by environment</td>
</tr>
<tr>
<td>Education inadequate or disrupted by behavioral/emotional issues</td>
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<tr>
<td>Family and relationship discord</td>
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<tr>
<td>Rejection, exclusion by peers; bullying; mistreatment by adults who do not understand their needs</td>
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<tr>
<td>Sensory sensitivities</td>
<td></td>
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<tr>
<td>Fine and gross motor problems</td>
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Sensory Issues at Work

I'm wearing my anti-co-worker suit to work today.

It has noise-canceling headphones, blinders, and padding so I can't feel taps on my shoulder.

Mr. Watson - don't come here - I don't need you.

Heh heh.
Why Do Intellectually Able Young People with ASD Have Difficulty with Transition to Adulthood?
Cognitive Problems

Impaired Self-regulation

Impaired planning, organizing, initiating

Impaired attention

Concrete, rigid thought

Differences in information processing and perception

PLUS Emotional Dysregulation

PLUS History of Chronic Stress

PLUS Lack of Skills

PLUS Lack of Opportunities

Severe Problems in Life Adjustment
Adaptive Behavior: Skills for Life
Adaptive Behavior in Young People with ASD

• Cross sectional studies suggest youth with ASD have a greater discrepancy between mental age and adaptive skills than do other groups.
• This gap may continue to grow with advancing age so that youth with ASD increasingly lag behind peers.
• Longitudinal studies have found young people with ASD do gain more skills as they grow older, but that they progress faster when they have higher IQ and less autism symptoms.

A Ten Year Longitudinal Study of Adolescents and Adults with ASD

• Large sample (N=397) followed over 10 years using the Waisman Activities of Daily Living Scale
• Found a curvilinear trajectory of skills - growth followed by plateau and decline: gains in skills during adolescence into twenties, a plateau in late 20s, and decline beginning in the early 30s
• By the end of the study period, on average, the individuals with ASD were failing to complete over a third of the measured daily living skills independently.
• Similarly Taylor and Seltzer (2011) found that the rate of improvement in autism symptoms and behavior problems for adolescents with ASD slowed after high school.

Co-morbid Psychopathologies in ASD

Autism Spectrum Disorders (ASD) often co-occur with other psychiatric disorders (e.g., Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Morgan, Roy, & Chance, 2003):

- Bipolar Disorder (Kurita, Osada, Shimizu, Tachimori, 2004)
- ADHD (Goldstein & Shwebach, 2004; Yoshida & Uchiyama, 2004)
- OCD (Kamio & Ishisaka, 2002)
- Schizophrenia/Psychosis (Bojanin, Kolar, & Kolar, 2002)
- Anxiety and Depression (Bradley, Summers, Wood, & Bryson, 2004; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000)

Individuals with ASD are vulnerable to all the same mental disorders as everyone else.
Anxiety and ASD

• Growing number of studies show that anxiety may be even more common than other disorders, both in adults and children with ASD
  - In clinical samples about 55% of children with ASD met criteria for at least one anxiety disorder (deBruin, Ferdinand, et al, 2006)
  - Anxiety related concerns among most common presenting problems for school age children and adolescents with ASD (Ghaziuddin, 2002; White, Oswald, Ollendick & Scahill, 2009).
  - Infants and toddlers with ASD also had more anxious/avoidant symptoms than atypical children without ASD (Davis, Fodstad, Jenkins, et al, 2009)
Anxiety and ASD, continued

• Most studies have been on children with HFA, few on LFA or adults

• Studies have consistently shown higher rates of anxiety symptoms in those with ASD compared with those with
  o Typical development
  o Conduct disorder
  o ADHD

• Percent of school aged boys with ASD who had Generalized AD (20%) and Separation AD (7%) was comparable to rates in a general clinic referred sample (20%, 7%) but higher than a general community sample (both 3%) (Gadow, deVincent, Pomeroy & Azizian, 2005).
Psychopathologies in Children with PDD-NOS or Autism

- Children and adolescents with ASD aged 7 – 18 assessed using the PIC-R
- Clinically significant psychopathology was high in both groups.
- There were significantly more children with Autism than PDD-NOS who had clinically elevated levels of developmental problems, social withdrawal, and atypical behaviors.
- Although there were no differences in clinically significant psychopathology on other scales, nearly half the children in both groups had clinically significant depression, and over a third had clinically significant anxiety.

Pearson Loveland Lachar Lane et al, 2005
Anxiety Disorders in Youth with ASD

- 85 youth with ASD aged 7 – 18 years assessed using the DICA and CBCL
- Anxiety disorders were extremely common in the sample of children and adolescents
- Phobias were highest in number
- Anxiety highest in higher IQ persons

Study by Loveland, Pearson et al 2006
Overlaps?

- Autistic traits and internalizing traits (such as anxiety and depressed mood) have been found to have low genetic overlap even though they often occur together (Hallett, Ronald, & Happé, 2009).

- Sensory over-reactivity is also commonly diagnosed in ASD and is associated with anxiety, but it is unclear the direction of causality if any (Green & Ben-Sasson, 2010).

- Irritability a major trait in children with ASD, but less so in non-ASD anxious children (Mayes, Calhoun, Murray et al, 2011).
Self-regulation

• Emotional self-regulation: ability to modify own emotional reactions in response to perceived challenge (Denham et al., 2003).

• Emotional self-regulation important to social skills (Calkins, 1994; Bradley, 2000; Denham et al., 2003) and begins very early in life: re-establish equilibrium after an arousing or upsetting event (Als et al., 1977).

• Wide individual differences in the irritability of infants, reactivity to events, and capacity to self-regulate and return to baseline state.

• Children described as 'high-reactivity' or 'high inhibition' are predisposed to anxiety and depression (Kagan et al., 1999).
Reactivity and irritability?

• Highly reactive or behaviorally 'inhibited' children find environmental events more arousing than other children do.

• Highly reactive children function best when they learn to use self-regulatory strategies that buffer the effects of stressful experiences, rather than simply withdrawing (Manassis and Bradley, 1994; Stewart and Rubin, 1995).

• Difficulties in self regulation therefore expose children with ASD to long term and repeated effects of stress on the developing brain, and leave them vulnerable to developing anxiety and mood disorders.
Transition Age and Older Adults with ASD

- Is the presence of a greater number of diagnosed psychopathologies associated with lesser attainment of life milestones in intellectually able adults with ASD?
- Do older and younger cohorts of adults with ASD differ in their attainment of life milestones or in the type and number of psychopathologies?
- Do comparably aged males and female adults with ASD differ in their attainment of life milestones or in the type and number of psychopathologies?

Loveland & Harrison, 2013.
Methods

- Participants were 93 intellectually able adults with ASD (23 F, 70 M) aged 18 to 65 years, all clinic referred.

- Assessed with the Ritvo Autism Asperger Diagnostic Scale, the Autism Spectrum Quotient, the Empathy Quotient, developmental and psychiatric history and clinical interview.

- Groups did not differ in mean scores RAADS, AQ, EQ.

- Demographic information was used to identify level of attainment in relationship status, residential status, education, and employment.
Co-occurring Psychopathologies

- DSM-IV criteria were used to classify participants by presence or absence (1, 0) of clinically diagnosed
  - Generalized Anxiety Disorder
  - Depression
  - Obsessive Compulsive Disorder
  - Social Anxiety Disorder
  - ADHD
<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Coding</th>
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</table>
| Employment            | 0 – Not Employed  
                        1 – Student  
                        2 – Part time or underemployed  
                        3 – Full time employed |
| Relationship status   | 0 – Has never dated or had relationship  
                        1 – Has dated or had a BF/GF  
                        2 – Previously married or in a long term relationship  
                        3 – Currently married or in long term relationship |
| Residential Status    | 0 – Has never lived independently  
                        1 – Transitional  
                        2 – Lives independently |
| Educational Status    | 0 – Has not completed HS  
                        1 – Completed HS  
                        2 – Completed college  
                        3 – Completed a graduate degree |
Comparison of Younger and Older Adults on Diagnosed Psychopathologies

Younger and older adults showed similar patterns of diagnosed psychopathologies, although there was a trend for older adults to have less.
Comparison of Younger and Older Adults on Outcome Variables

Multivariate GLM: Wilks’ Lambda .562, $F(4,88)= 17.15$, $p=.000$; All group differences significant at $p = .000$

By contrast, older and younger adults differed significantly on all life milestones.
Findings Within the Transition Age and Older Groups

• In the transition age group only, older age was associated with higher educational, residential and relationship status.

• Social anxiety was less common in the older members of both groups.

• In the transition age group only, having social anxiety disorder was associated with lower residential and relationship status.
Males and females did not differ on any diagnosed psychopathologies.

Note the high rates of diagnosed disorders in both groups.
Females had significantly higher attainment in employment than did males. There was a non-significant trend for them to have higher relationship status as well. Note that chronological age was significant for all but employment.
Conclusions

• Results do not support a relationship between the number of diagnosed psychopathologies and adult outcomes.
• Overall, the older adults had attained more advancement in life milestones and had fewer diagnosed psychopathologies, although they had a very similar distribution of the type of disorders present.
• These findings, while based on a cross sectional sample, suggest that advancement in life milestones is possible for persons with ASD well into adulthood.
• Intellectually able adults at all ages with ASD had significant problems both with psychopathologies and with aspects of life adjustment. Many were living at home, were without employment or adult relationships at ages when these milestones would ordinarily be reached.
• However, others had attained long term relationships, full time employment and independent residence despite challenges.
• The mechanisms and characteristics contributing to their resilience will be a topic of further study.
“Samuel” – an older adult

- Came to the clinic in Houston from another city at age 58 seeking diagnosis of possible ASD
- Highly intelligent and verbal
- Talented professional artist, but spotty employment history
- Difficulty managing money, tracking time and other daily activities
- Married twice, recently divorced for second time, no children
- Living with friends who took him in
- Receiving federal disability for several years
- Extremely anxious, depressed, history of trauma and abuse, rejection by peers, school failure
- Severe ADD and other impairment of executive functioning
- Sensory problems
- Drives car but prone to accidents
- No family but some friends
- Tested and after exploration of history and present symptoms dx with Asperger’s Disorder (ASD)
Almost two years later:

- Samuel has a stable place to live
- Has regular income, though modest
- Has more friends and a faith community
- Has developed new skills in self-regulation of emotions
- Has learned new self-management skills and also learned to ask for help when needed from friends
- Has a girlfriend without ASD and the relationship is progressing well
- Has come to understand and accept himself better as a person on the spectrum
- Continues to have social-emotional challenges but has a greatly improved quality of life

Samuel attributes his improved adjustment to getting the diagnosis of ASD, understanding why he has experienced many challenges, therapy to improve emotion regulation, social supports. He wishes he had known earlier in life about his ASD.
How Do Intellectually Able Young People with ASD Get Past These Challenges?

- Parents and others must be aware of developmental immaturity and expect a longer timeline.
- Families must not “over-support”, creating an illusion of independence that crumbles when the individual moves outside the family (e.g., college).
- Seek supports outside the family to help with self-management skills at school and work.
- Gradually withdraw supports and allow the person to be more independent.
• Seek help for mental illness where it occurs
• Set realistic goals and challenge unrealistic thinking
• Do not “enable” destructive behaviors; do set limits
• Address family problems that may be affecting your child’s functioning
What Is Needed?

• Better treatments for mental illness in people with ASD
• More social and adaptive skills training for adults – e.g., driving, job related skills, age appropriate conversational skills
• Integration into social settings outside the family
• Policy that supports self determination and independence
• Research on adults and their needs.
• Fewer barriers to eligibility for services
• More providers trained to recognize and assist these individuals
• Better public awareness especially among potential employers
Changing Lives through Autism Spectrum Services (C.L.A.S.S.)
A UTHealth clinic for children, adolescents and adults with Autism Spectrum Disorders.

- Expert evaluation of
  - Autism Spectrum Disorders
  - Emotional and behavioral issues
  - Cognitive, adaptive, academic skills
- Medication treatment
- Individual therapy
- Therapeutic groups for adolescents and adults
- Opportunities for research participation

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