The Transition to Adulthood for Individuals with Autism Spectrum Disorders and their Families

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Conflict of Interest: None
How do we define the transition to adulthood?

- Completing the “developmental tasks of adulthood”
  - Leaving the parental home
  - Finishing school
  - Starting employment
  - Marrying
  - Having children

- Autism Spectrum Disorders further complicate the picture
How do we define the transition to adulthood?

- Completing the “developmental tasks of adulthood”
  - Finishing school

- Autism Spectrum Disorders further complicate the picture
Why worry about the transition to adulthood?

Why worry about the transition to adulthood?
“I worry about him, where he’ll be in life down the road. Worry about him financially; him gaining friendships and not being lonely.”

“He lost everything then (when he exited high school). All the training was gone.”
What do we know about the transition to adulthood for youth with ASD?

• Under-researched

• Associated with loss of services
  – Youth with autism spectrum disorders (ASD) can stay in school until age 22
    • Services are often poor after high school exit

• Many young adults with ASD live dependent lives
  – Underemployed with jobs that do not provide a living wage

Ballabin-Gil et al., 1996; Eaves & Ho, 2008; Howlin et al., 2004; Howlin et al., 2005
How does this transition affect families?

• Writings of Patricia Howlin and others – very difficult

• Families taking over coordination of care at the same time that they are losing services

• Stressful family environments may put youth with ASD at greater risk
  – Parents may be less effective in procuring services
  – Family environments impact behavioral development
Factors Potentially Associated with a Positive Transition

• No comorbid intellectual disability (ID)
  – No ID = more independence in adulthood

• Family socio-economic status
  – Higher income = greater access to services (children)
  – For typically developing youth, Higher SES = greater decrease in depression and anger

Billstedt et al., 2007; Eaves & Ho, 2008; Galambos et al., 2006; Gillberg & Steffenburg, 1987; Howlin et al., 2004; Liptak et al., 2007; Lord & Bailey, 2002; Shattuck et al., 2007; Thomas et al., 2007
Research Questions

• How does exiting high school impact changes in the autism behavioral phenotype?

• How does exiting high school impact the mother-child relationship?

• Is that change moderated by characteristics of the youth with ASD (gender, ID), the family (family income, maternal education), or the service system?

Taylor & Seltzer (2010a; 2010b, in press), JADD
Adolescents and Adults with Autism Study (PI: Seltzer)

• Prospective, longitudinal study spanning 12 years in the life of each family (1998-2012), funded by the NIA (R01 AG08768).

• Repeated measures of the mother, father, siblings, and adolescent/adult with ASD.

• Aims: to investigate the course of change in the behavioral phenotype of autism during adolescence and adulthood, and its impact on the family.
Limitations of Past Research

• Small samples, possibly underpowered to detect change

• Primarily recruited from clinic populations

• Few studies extend beyond early adolescence
AAA: Research Approach

- Large sample (n=406)

- Recruited from the community (WI, MA)

- Wide age range -- 10 to 52 years of age at Time 1
  - 62% adolescents age 10-21
  - 38% adults age 22-52
AAA: Study Timeline

12 Years

Time 1
Time 2
Time 3
Time 4

Time 5
Daily Diary

Time 6
Time 7
Time 8

Daily Diary

18 Months
AAA: Focus of Research

- Reciprocal relationship between trajectories of the individual with ASD and the mother.
- Impacts on siblings and the marital relationship.
- Change in autism symptoms and behavior problems during adolescence and adulthood (measured at each point of data collection).
- Changes associated with the transition out of high school.
- Biomarkers of the impact of lifelong parenting.
Transition Sample

- Those in high school when the study began or had left during 18 months previous (n=242)

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<tbody>
<tr>
<td>In High School</td>
<td>92%</td>
<td>78%</td>
<td>66%</td>
<td>50%</td>
<td>8%</td>
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<tr>
<td>Exited High school</td>
<td>8%</td>
<td>22%</td>
<td>34%</td>
<td>50%</td>
<td>92%</td>
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Time 1 Transition Sample Characteristics

• Youth with ASD
  • Mean age = 16.3 years (range of 10.1 to 23.5)
  • 73% male
  • 63% with comorbid ID, 76% verbal
  • 81% living with parents at Time 1

• Family
  • 57% of mothers with at least a B.A.
  • Median household income between $50,000 and $60,000
Dependent Variables: Autism Behavioral Phenotype

• Autism symptoms
  – Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994)
    • Restricted interests and repetitive/stereotyped behaviors
    • Verbal communication impairments
    • Impairments in social communication and social reciprocity

• Maladaptive behaviors
  – Scales of Independent Behavior-Revised (Bruininks et al., 1996)
    • Asocial (offensive behavior, uncooperative)
    • Internalized (withdrawal, repetitive habits, self-injury)
    • Externalized (disruptive, hurtful to others, property)

• Higher scores = more symptoms/behaviors
Independent Variables

- Study time
- Time since high school exit
- Characteristics of person with ASD
  - Gender, ID
- Characteristics of family
  - Maternal education, Family income
Multilevel Models Allow Us to:

- Look at individual change over time
- Use participants with missing scores by taking missing data into account
- Our model included:
  - Intercept (initial status)
  - Slope while youth with ASD were still in high school
  - Estimate of whether the slope changed after high school exit
Results: Autism Symptoms (ADI-R)

• All subscales improved while youth were in high school (symptoms became less severe)

• Improvement significantly slowed on all subscales after exit
Repetitive Behaviors

High School Exit

Years Since High School Exit

- 4 -3 -2 -1 0 1 2 3 4 5

No ID

ID

No ID - ID
Verbal Communication Impairments

Years Since High School Exit

High School Exit

- 4 -3 -2 -1 0 1 2 3 4

No ID
ID

No ID
ID
Social Reciprocity Impairments

Years Since High School Exit

High School Exit

No ID
ID
Results: Maladaptive Behaviors

• All subscales improved while youth were in high school (behavior problems became less severe)

• Improvement in internalized behaviors significantly slowed after exit
Asocial Behaviors

Years Since High School Exit

High School Exit

-4 -3 -2 -1 0 1 2 3 4

No ID ID

Years Since High School Exit

No ID — Blue Triangle
ID — Red Square

No ID vs. ID over the years since high school exit.
Internalized Behaviors

- Four lines representing Internalized Behaviors over years since high school exit for:
  - Lower Income with no ID
  - Higher Income with no ID
  - Lower Income with ID
  - Higher income with ID

Years Since High School Exit

- The graph shows a downward trend in Internalized Behaviors for all categories as years since high school exit increase.
- The line for Lower Income with no ID starts higher than the others and shows a steeper decrease.
- The line for Higher Income with no ID starts lower than the others and shows a slower decrease.
- The line for Lower Income with ID starts lower than the line for Higher Income with no ID.
- The line for Higher income with ID starts higher than the line for Lower Income with ID.
Externalized Behaviors

Years Since High School Exit

- Lower Income with no ID
- Higher Income with no ID
- Lower Income with ID
- Higher Income with ID
Summary: Behavioral Phenotype

• Leaving HS is a significant turning point
  – Similar to Esbensen et al. (2008) - worsening behavior problems after transitions for adults with ID

• Less improvement after exit = from lower income families
  – After exit only
  – Lower income is related to barriers to service access among families of children with ASD

• Less improvement after exit = without comorbid ID
  – The opposite of what would be expected from extant research
  – Lifestyle and services after HS?
Dependent Variables: Mother-Child Relationship

• Burden
  – Zarit Burden Inventory (Zarit et al., 1980)
    • Appraisals of burdens associated with caregiving (time demands, financial strains, lack of privacy)

• Relationship closeness
  – Positive Affect Index (Bengtson & Schrader, 1982)
    • Degree of understanding, trust, fairness, respect, and affection in relationship

• Warmth
  – Warmth rating from Five Minute Speech Sample
Independent Variables

• Study time
• Time since high school exit
• Characteristics of person with ASD
  – Gender, ID
• Characteristics of family
  – Maternal education, Family income
• Unmet service needs
Results: Mother-Child Relationship

• Relationship closeness and burden were improving while youth with ASD were in high school

• Improvement stopped after high school exit for relationship closeness

• Burden and warmth were getting worse after high school exit
  – EVEN after controlling for change in behavior problems
Warmth

[Graph showing data with axes labeled 'High School Exit']

- Blue line: No ID
- Red line: ID
Summary: Mother-Child Relationship

• High school exit associated with slowing of improvement in the mother-child relationship
  – Even after controlling for changes in behavior problems

• Less improvement after exit = those who have more unmet service needs
  – Tapping into the same thing as low income?
  – This might be even more of a problem if we looked at services after high school exit

• Less improvement after exit = without comorbid ID
  – Lifestyle and services after HS?
Percent in Employment Groups by Comorbid ID

No ID

ID

- College
- Competitive job
- Supported job
- Adult day services
- No activities
Going to Scale

• For service providers
  – Develop services geared toward the unique needs of youth with ASD without ID
  – Slowing of behavioral/relationship improvement
    + increased responsibilities after exit = high stress

• For families
  – Advocate for appropriate and stimulating day activities

• For researchers
  – First prospective study of the transition
  – Identifies risk factors and sets the stage for intervention research
  • We don’t know anything about the potential of intensive intervention for adolescents and young adults
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