AUTISM IN ADULTHOOD: PREDICTORS OF POSITIVE OUTCOMES

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- AUTISM SPEAKS®
- Foundation of Hope
PRESENTATION OBJECTIVES

- Quality of life for adults with ASD:
  - Living Situation
  - Employment
  - Daily Living Skills
  - Physical Health

- Consistency and change from childhood to adulthood in symptoms, IQ, & daily living skills.

- What childhood measures predict a positive adult outcome?

- What do we know about older adults with ASD?
Prevalence increase from 1 in 150 to 1 in 59 8 year old children across the US.

The 2002 cohort is now 25 years of age.
- **TEACCH Autism Program**
  - Statewide community-based regional outpatient clinics established in 1965 by the University of North Carolina.
  - The longevity provides an opportunity to follow young children into adulthood.
# TEACCH ADULT OUTCOME STUDY


## Sample

<table>
<thead>
<tr>
<th>Sample</th>
<th>278 Surveys</th>
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<tbody>
<tr>
<td>Age</td>
<td>35.4 years</td>
</tr>
<tr>
<td></td>
<td>(range: 21-58)</td>
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<tr>
<td>Gender</td>
<td>80% male</td>
</tr>
<tr>
<td>IQ</td>
<td>63.3</td>
</tr>
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<td>(range &lt;40 – 130)</td>
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CURRENT LIVING SITUATIONS

- Living with Family: 53%
- Group Home: 14%
- Care Facility: 14%
- Care Facility: 14%
- Supervised Housing: 9%
- Independent: 10%
Understanding Service Usage and Needs for Adults with ASD: The Importance of Living Situation

Katerina M. Dudley · Mark R. Klinger · Allison Meyer · Patrick Powell · Laura G. Klinger

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0%

10%

20%

30%

40%

50%

60%

70%

80%

Employment Supports

Independent Living Skills

Mental Health

Allied Health

Transportation

Diagnostics

Family

Non-Family
DAILY SELF-CARE SUPPORTS NEEDED

- Financial: 84%
- Meals: 72%
- Health Care: 73%
- Hygiene: 54%
- Cleaning: 65%
- Social Activities: 76%
- Community Act.: 69%
EMPLOYMENT OUTCOMES

Currently Employed: 42%
Previously Employed: 42%
Never Employed: 16%

<table>
<thead>
<tr>
<th>Supports for Finding Current Employment</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Found Independently</td>
<td>18%</td>
</tr>
<tr>
<td>Family Member Support</td>
<td>20%</td>
</tr>
<tr>
<td>Agency Support</td>
<td>50%</td>
</tr>
<tr>
<td>Residential/Vocational Facility</td>
<td>12%</td>
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Increasing access to Vocational Rehabilitation (VR) services for adults with ASD has not improved employment outcomes much across the last decade.

In a review of over 35,000 transition-aged adults receiving VR services, only one-third of adults with ASD achieved successful employment.

(Burgess & Cimera, 2014)
PHYSICAL HEALTH

ASD Compared to United States National Sample
McKinney, Klinger, Powell, & Klinger
INCREASED RATES OF MEDICAL CONDITIONS IN ADULTS WITH ASD

- **High Cholesterol (**) - p < 0.01
- Diabetes (*) - p < 0.05
- Inflammatory Bowel Disease (**)
The health status of adults on the autism spectrum

Lisa A Croen¹, Ousseny Zerbo¹, Yinge Qian¹, Maria L Massolo¹, Steve Rich², Stephen Sidney¹ and Clarissa Kripke³
FEWER CASES OF PAIN-RELATED CONDITIONS IN ADULTS WITH ASD

- Migraines (**) - 8.7% vs 18.3%
- Ulcers (*) - 4.4% vs 1.9%
- Chronic Lower Back Pain... - 4.2% vs 26.9%
- Arthritis (**) - 4.2% vs 9.7%

(**) - p < .01
(*) – p < .05
Many adults with ASD live at home, are unemployed, need assistance with every day living skills, and experience increased rates of health conditions.
BUT ... THE NEWS IS NOT ALL DISMAL
BEING EMPLOYED IS ASSOCIATED WITH:

- Higher quality of life (Schalock)
  - Life Satisfaction
  - Sense of Belonging
  - Empowerment
- Increased contact with friends
- Fewer mental health symptoms
  - Anxiety
  - Depression
“What does TEACCH mean to me? Everything. Absolutely everything. We have been part of the TEACCH family for 47 years.”
COMMUNITY INTEGRATION

- Living in rural vs. urban areas across the state of North Carolina was associated with few community integration outcomes.

- Access to public transportation was associated with increased community integration:
  - Employment
  - Volunteer Activities
  - Contact with Friends
  - Service Use and Satisfaction
CONSISTENCY AND CHANGE FROM CHILDHOOD TO ADULTHOOD
SYMPTOMS ON THE CHILDHOOD AUTISM RATING SCALE ARE CONSISTENT ACROSS TIME

\[ p = .21 \]
CHANGES IN IQ AND ADAPTIVE BEHAVIOR FROM
CHILDHOOD TO ADULTHOOD

IQ

Vineland

Child  Adult  p = .04

Child  Adult  p = .001
Brief Report: Developmental Trajectories of Adaptive Behavior in Children and Adolescents with ASD

Allison T. Meyer\textsuperscript{1,6}, Patrick S. Powell\textsuperscript{2}, Nicole Butera\textsuperscript{3}, Mark R. Klinger\textsuperscript{4}, Laura G. Klinger\textsuperscript{5}

- 186 participants with ASD
- 1-33 years of age
CHANGES IN IQ AND ADAPTIVE BEHAVIOR FROM CHILDHOOD TO ADULTHOOD

![IQ Comparison](chart1)

IQ

Child: 72
Adult: 67

\[ p = .04 \]

![Vineland Comparison](chart2)

Vineland

Child: 61
Adult: 45

\[ p = .001 \]
ADAPTIVE BEHAVIOR IS LOWER THAN EXPECTED BASED ON IQ

- Bishop & Duncan, 2013
- 417 participants with ASD
- 10-18 years of age

*Figure 2.* Mean FSIQ-DLS difference score across three FSIQ groups.
PREDICTING ADULT OUTCOMES FROM CHILDHOOD

Poor Daily Living Skills in Childhood

Poor Employment Outcomes in Adulthood
DAILY LIVING SKILLS RELATED TO EMPLOYMENT

- Currently Employed (42%)
- Previously Employed (16%)
- Never Employed (42%)

Waisman-Activities of Daily Living

- Household Chores
  - Making bed
  - Cleaning
  - Laundry
  - Cooking
- Grooming
  - Dressing
  - Bathing
  - Brushing teeth/hair
- Independent Living
  - Shopping
  - Finances

F(2, 275) = 63.72, p<.001
Symptom severity and intellectual functioning are consistent from childhood to adulthood.

Daily living skills are lower than expected by intellectual functioning and plateau in adolescence.

Daily living skills are an important predictor of employment outcomes.
A NEW FRONTIER: AUTISM & AGING
WHAT DO WE KNOW ABOUT AGE-RELATED CHANGES:
COGNITION
ACTIVITIES OF DAILY LIVING
PHYSICAL HEALTH
MODELS OF AGE-RELATED CHANGE

Parallel Decline
Autism starts and ends lower but rate of decline parallels typical aging

Accelerated Decline
Autism starts and ends lower but rate of decline is steeper than typical aging
Patterns of Age-Related Cognitive Differences in Adults with Autism Spectrum Disorder

Patrick S. Powell¹ · Laura G. Klinger² · Mark R. Klinger³

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<thead>
<tr>
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<th>ASD (n = 29)</th>
<th>Typical (n = 30)</th>
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<tr>
<td></td>
<td>Mean (SD)</td>
<td>Range</td>
</tr>
<tr>
<td>Age (years)</td>
<td>49.0 (11.7)</td>
<td>30-67</td>
</tr>
<tr>
<td>Gender</td>
<td>Male = 24</td>
<td>Male = 23</td>
</tr>
<tr>
<td>WASI FSIQ</td>
<td>113.2 (9.5)</td>
<td>92-128</td>
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Montreal Cognitive Assessment (MOCA)
Montreal Cognitive Assessment (MOCA)

Pattern of Accelerated Cognitive Decline for Those with ASD

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<th>$R^2_{\text{change}}$</th>
<th>$F_{\text{change}}$</th>
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<tbody>
<tr>
<td>Age</td>
<td>0.13</td>
<td>$F(1,56) = 9.05, p = .004$</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>0.15</td>
<td>$F(1,55) = 11.85, p = .001$</td>
</tr>
<tr>
<td>Age by Diagnosis</td>
<td>0.05</td>
<td>$F(1,54) = 4.64, p = .04$</td>
</tr>
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ACTIVITIES OF DAILY LIVING: 14 YEAR LONGITUDINAL STUDY

- 406 **ASD** subjects
- 10-52 years of age (38% adults)
- assessed 9 times over 14 years
- compared to **Down Syndrome**

Smith et al., JAACAP (2012) (Mailick Lab)
Rates of Parkinsonism in Adults with Autism

Starkstein, Gellar, Parlier, Payne and Piven
Journal of Neurodevelopmental Disorders (2015)

- ASD adults without neuroleptic medications: N=20
- Mean age: 55.6 ± 8.6 (years ± SD), range 42-77 years
- All male
- Four (4/20) adults with ASD (20%) met criteria for Parkinson’s Disorder
- All four individuals with PD were 50+ years of age
- 1/1000 in the general population, 45 to 64 years
There is initial evidence for accelerated declines in adults with ASD with regards to daily living skills, cognition, and motor difficulties.

Possible Explanations:
1. True neurocognitive degeneration.
2. Less active lifestyle leading to greater declines.
**Caring for adults with ASD needs to take both a prevention (employment, daily living skills) and an intervention approach**

**Clinical targets:**
- Daily living skills
- Healthcare
- Active engagement (employment; community integration)
- Residential supports

**Need for professionals with expertise in both ASD and aging.**
ACKNOWLEDGEMENTS

TEACCH Research Team:

*L-R, back row:* Whitney Brooks, Dara Chan, Mark Klinger, Patrick Powell, Rachel Sandercock, Allison Meyer, Katerina Dudley, Laura Klinger

*L-R, front row:* Tammy Dawkins, Nancy Bagatell, Elena Lamarche, Elizabeth Schroeder, Danny Rahal

*Not pictured:* Joanna Mussey, Glenna Osborne, Paul Shattuck

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