

# Advancing the Understanding of Life Course Outcomes: The Autism Transitions Research Project

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# Welcome

- ATRP Priorities
- Goals
  - Timely, targeted, and impactful findings
  - Inform service planning, benchmarking and policy *at the population health level*
  - Expand the evidence based on factors associated with healthy life outcomes to improve transition care



# NATIONAL AUTISM INDICATORS REPORT:

## Mental Health

[drexel.edu/AutismOutcomes/MentalHealth](https://drexel.edu/AutismOutcomes/MentalHealth)



# Why mental health in autism

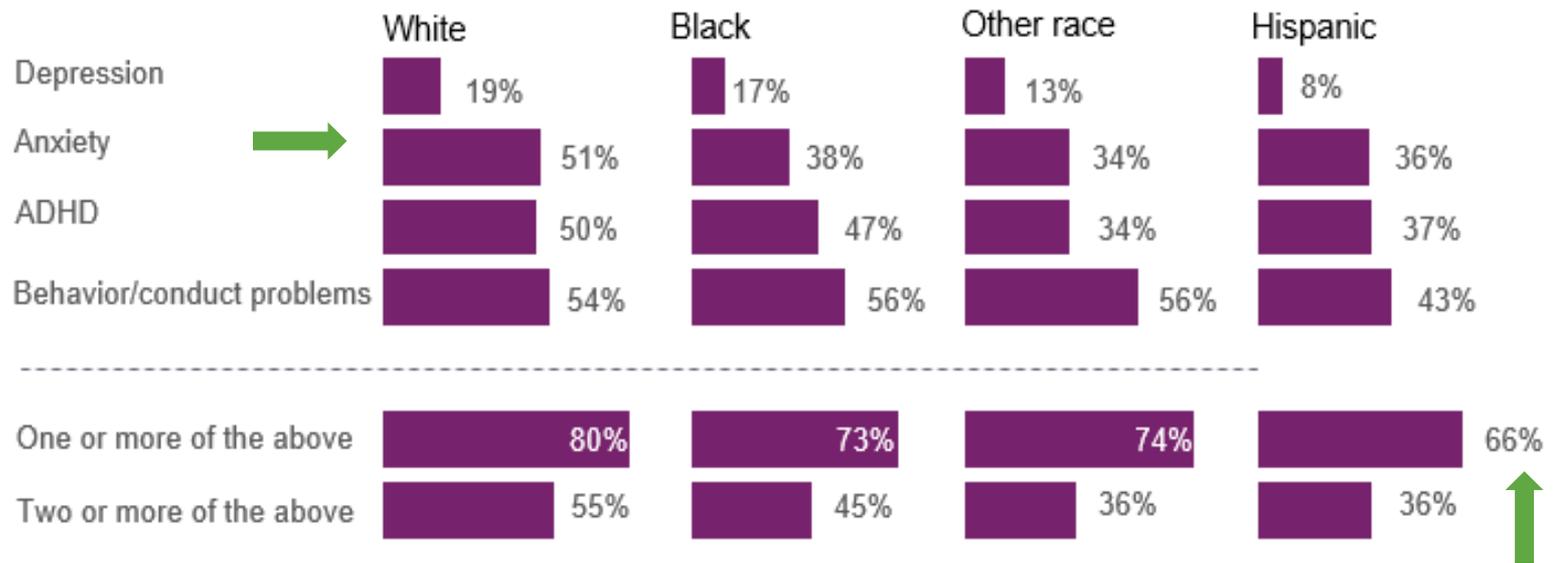
- Autism = family history, ACEs, discrimination, isolation, uncertainty
- Supporting mental health requires accessible and appropriate mental health care



results

# MENTAL HEALTH CONDITIONS

# Prevalence of mental health conditions varied by race and ethnicity in autistic children

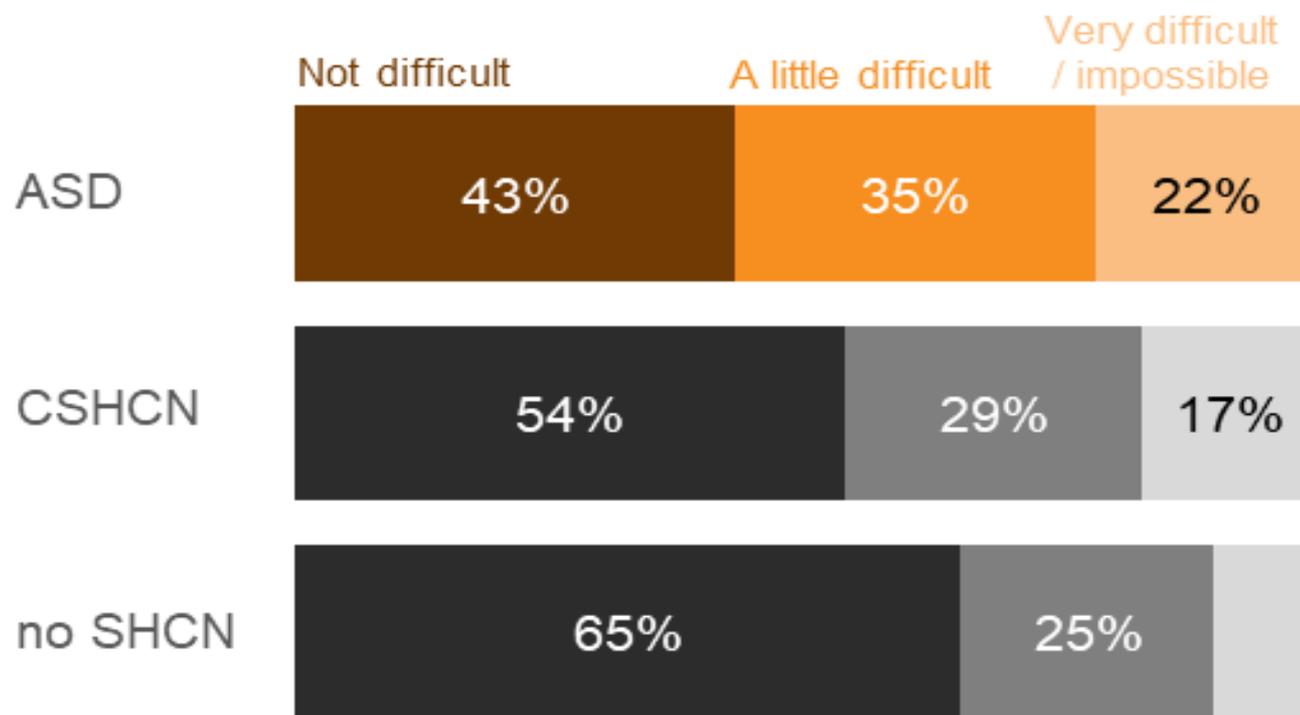


Source: National Survey of Children's Health 2016-19

results

# MENTAL HEALTH SERVICES

# More than half of parents of autistic children reported difficulty getting mental health care

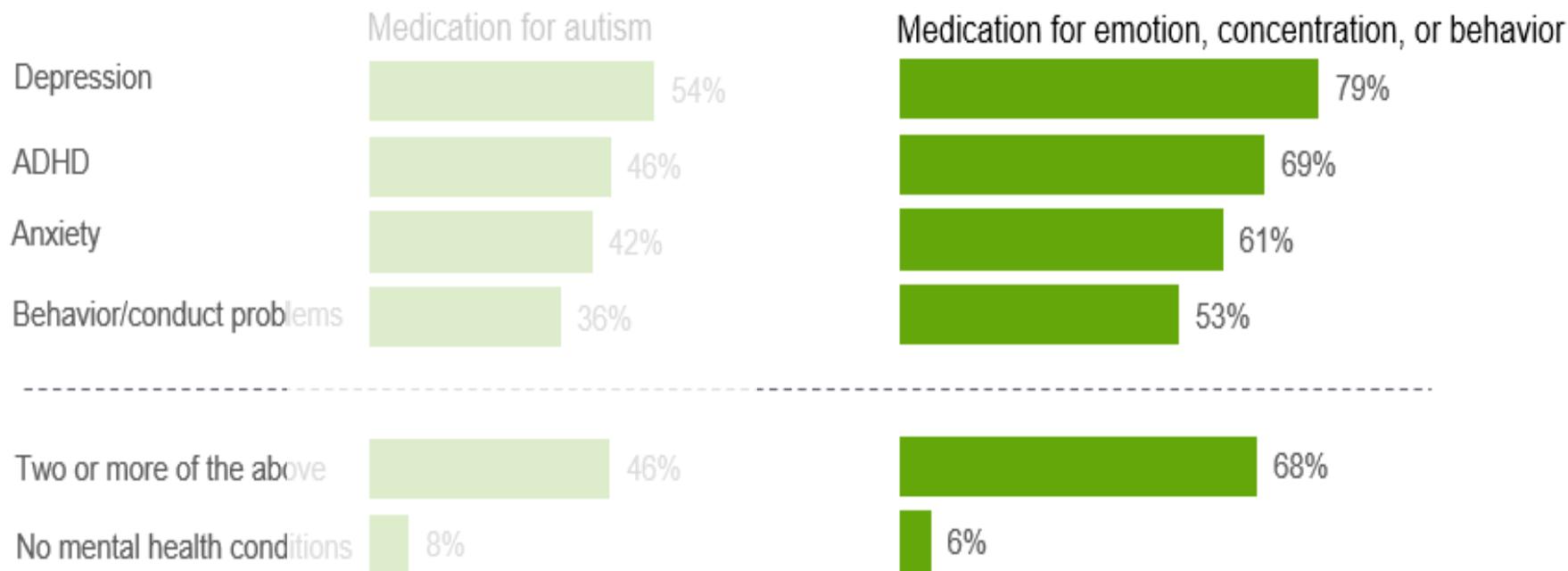


Source: National Survey of Children's Health 2016-19

results

# MENTAL HEALTH AND MEDICATION

# Medication use was more common in autistic children with co-occurring conditions



Source: National Survey of Children's Health 2016-19

# CONCLUSIONS

# Recommendations

- Make access more equitable
  - Racialized communities
  - Evidence-based practices
- Address location problems
- Improve systems of care
- Train providers

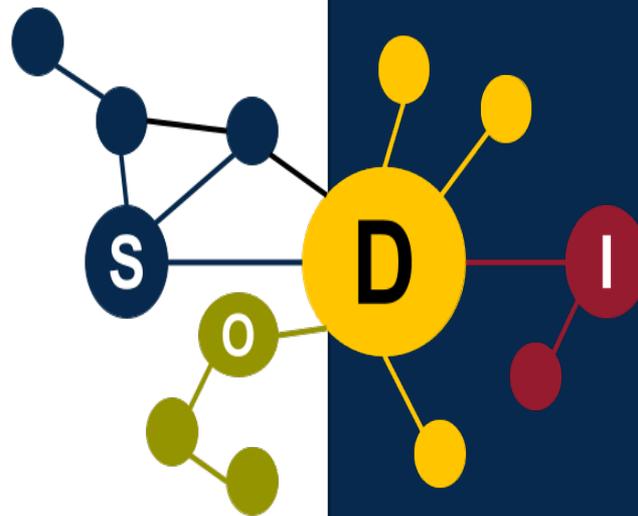
# ATRP

**Autism Transition Research Project**

**PI Paul Shattuck and Lindsay Shea**

**Co-I Elizabeth McGhee Hassrick**

# Transition Multi-centric Networks for Autistic Young Adults in Extended High School



By:

Elizabeth McGhee Hassrick

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Sara Murphy

Chau Nguyen

Mingyuan Low

Katie Bouvier-Weinberg

Jess Christian

# We are investigating how to build youth networks

**Population-level data** about unmet needs and outcomes

**Program models** for working with individuals

**Capacity-building models** for community organizations, employers, and systems

**Collaborative, community problem-solving** to convene, catalyze, mobilize and align resources across sectors



# Social Network Analysis

- **Captures heterogeneity** across the autism spectrum
- Identifies **personal strengths and gaps**
- **Rigorous measure** of informal support
- Pioneering **ecosystem measure** of informal support
- Captures **people and resources** in network
- Can **scale** complex interactional dynamics more effectively



# Table of Contents



Background



Objectives



Methods



Preliminary Results

Young autistic adults experience difficulties when they approach the service cliff. **Less is known** about autistic youth who participate in extended high school and how they experience transition.

Currently, research has focused on young adults' service experiences, **with little focus** on how transition impacts INFORMAL SUPPORT social capital, not just for autistic youth but also for their ecosystem of support.

## Background

# Measure Social Capital for Transition



# QUAL-QUANT Approach



**Life Course Outcomes**  
Research Program



# Study Aims

1

Adapt a measure of social capital for the postsecondary transition. We will use

- (1) qualitative semi-structured interviewing with TAYA, their families and providers (pre and post transition)
- (2) cognitive interviewing with TAYA to adapt the AIR-B-III measure.

2

3. Pilot test the adapted social capital measure with TAYA, their parents and transition coordinators before and after high school leaving.

# Study Aims

2

3. Pilot test the adapted social capital measure with TAYA, their parents and transition coordinators before and after high school leaving.
  - Focus on extended high school TAYA
  - Recruitment of 5 TAYA who applied for Vocational Rehabilitation (VR) funding / 5 YAYA who did not apply for Vocational Rehabilitation (VR) funding

# Testing Feasibility

- Adapt network measure for autistic youth and their key supporters
- Expanding from duocentric to eco-centric network measures
- Test feasibility of measure with extended high school students experiencing transition



# Participants

- Study Participants
  - Autistic Youth in extended high school (N=10), their parents (N=10) and employment support providers (N=XX)
- Longitudinal Data Collection Timepoints
  - T1: end of school year in extended high school
  - T2: post transition from extended high school

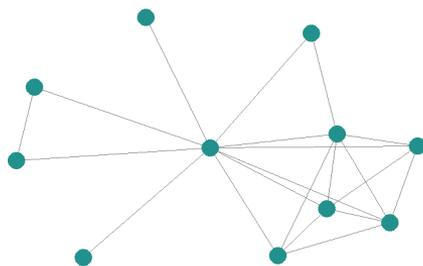
# Successful Measurement of Ecocentric Network

Young Adult

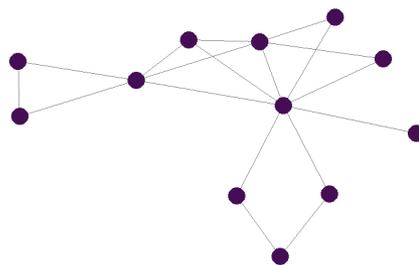
Caregiver

Provider

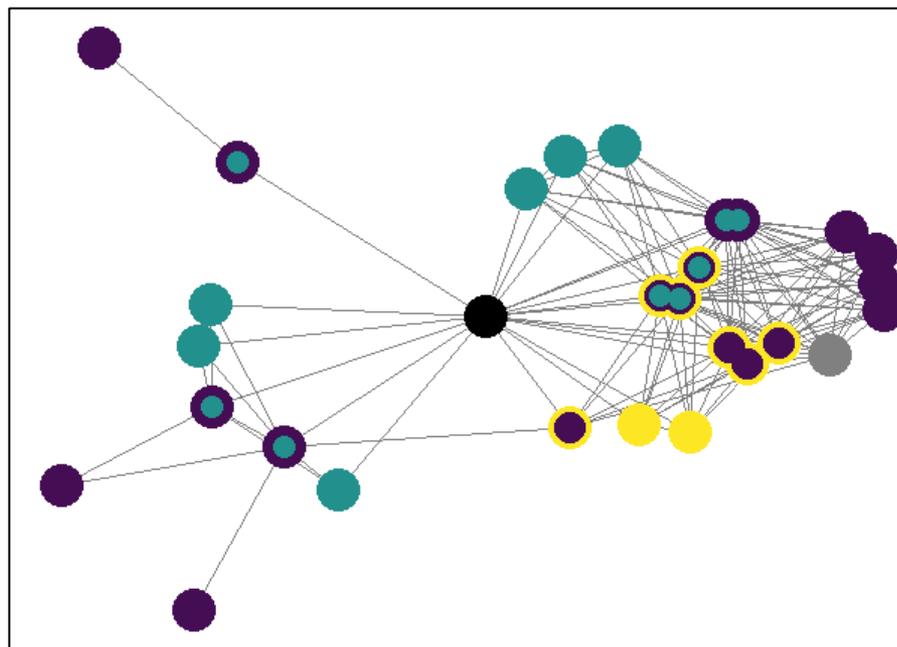
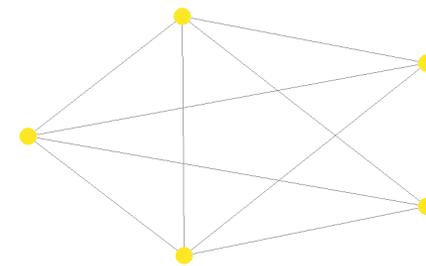
Youth



Caregiver



Provider



- Young Adult Alters
- Caregiver Alters
- Provider Alters
- Caregiver (Ego)
- Provider (Ego)

# Transition Network Changes

	(Youth) Youth-centric Data N = 10		Eco-centric Data N = 9	
	Mean	SD	Mean	SD
<b>Size</b>				
Time 1	11.10	3.31	20.11	4.26
Time 2	7.70	3.27	13.89	3.76
<b>Density</b>				
Time 1	0.49	0.19	0.27	0.14
Time 2	0.30	0.09	0.18	0.06

\*\*\* *Mean difference of multi-centric is 6.2, almost twice that of ego 3.4.*



# Network Key



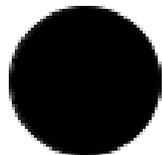
**Less Interaction**



**Same Interaction**



**More Interaction**



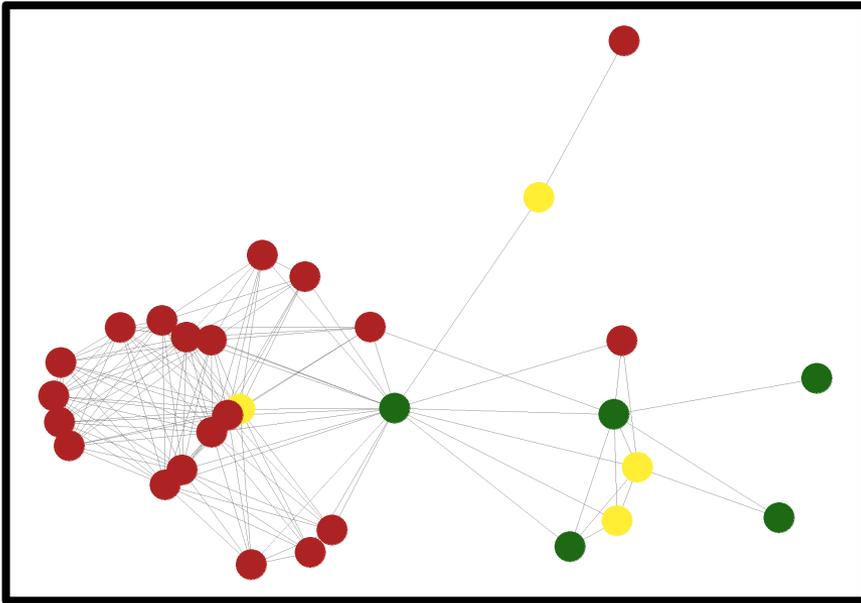
**Unknown**



# Finding 1: ALL Youth Networks were adversely impacted by COVID-19

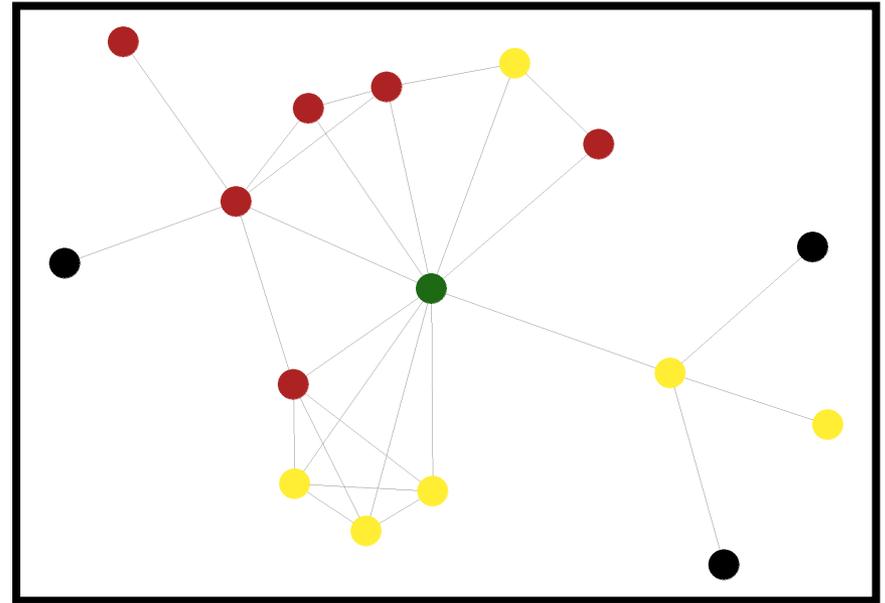
## YOUTH 1 EcoNetwork

Majority supporters have less interaction w/youth



## YOUTH 2 EcoNetwork

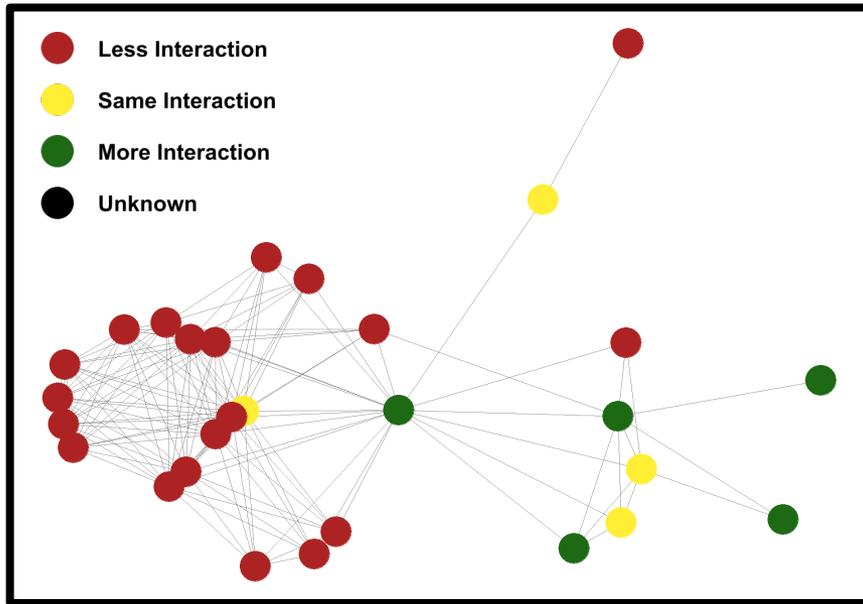
Majority supporters have less interaction w/youth



# Finding 2: Youth Networks were smaller, sparser post-transition

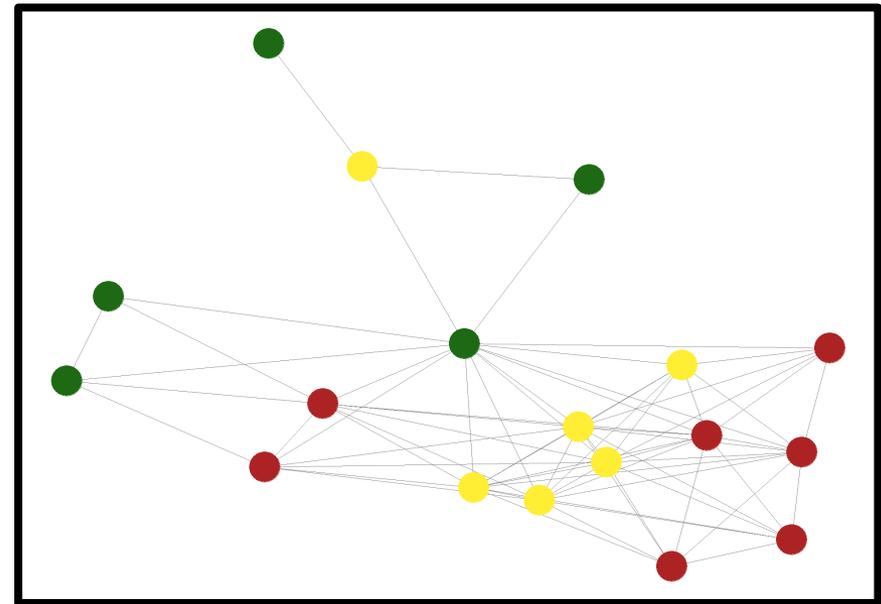
## YOUTH 1 PreTransition

Large, Dense



## YOUTH 1 Post Transition

Smaller, Sparser



# Multiple Role Ecosystems (N=299 Supporters)

## Pre-Transition

## Post-Transition

Pre-Transition			Post-Transition		
Role	Total #	Total %	Role	Total #	Total %
Community member	75	25%	Community member	53	27%
Family	65	22%	Family	43	22%
Healthcare	9	3%	Healthcare	8	4%
Peer	33	11%	Peer	20	10%
Romantic Partner	3	1%	Romantic Partner	6	3%
School Staff	109	36%	School Staff	67	34%
Other	5	2%	Other	0	0%
<b>Gender</b>			<b>Gender</b>		
Female	178	60%	Female	129	65%
Male	118	39%	Male	68	35%
Gender NC	0	0%	Gender NC	0	0%
DNK/DNWTA	3	1%	DNK/DNWTA	0	0%
<b>Age</b>			<b>Age</b>		
0-18	12	4%	0-18	4	2%
19-30	55	18%	19-30	27	14%
31-60	191	64%	31-60	144	73%
61+	32	11%	61+	19	10%
DNK/DNWTA	9	3%	DNK/DNWTA	3	2%

# Network Employment Resources Pre-transition

	Yes	No	Unknown
<b>Encourage Job</b>	217 (73%)	64 (21%)	18 (6%)
<b>Employ Resources</b>	135 (45%)	157 (53%)	7 (2%)
<b>Dream Job</b>	161 (54%)	130 (43%)	8 (3%)
<b>Job Discussion</b>	188 (63%)	105 (35%)	6 (2%)
<b>Specific Job</b>	140 (47%)	150 (50%)	9 (3%)
<b>Job Advice</b>	208 (70%)	71 (24%)	20 (7%)
<b>Transition Talk</b>	215 (72%)	80 (24%)	4 (1%)



# Network Employment Resources Post-transition

	Yes	No	Unknown
<b>Encourage Job</b>	147 (75%)	46 (23%)	4 (2%)
Employ Resources	107 (54%)	89 (45%)	1 (1%)
Dream Job	135 (69%)	62 (31%)	0 (0%)
<b>Job Discussion</b>	142 (72%)	54 (27%)	1 (1%)
Specific Job	109 (55%)	87 (44%)	1 (1%)
<b>Job Advice</b>	132 (67%)	61 (31%)	4 (2%)
<b>Transition Talk</b>	158 (80%)	38 (19%)	1 (1%)

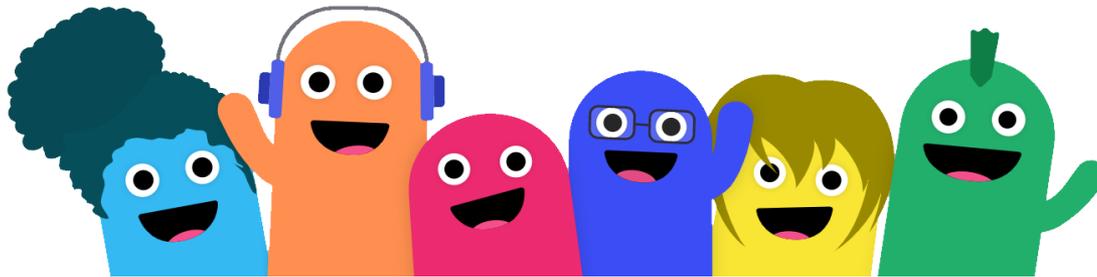


# Next Steps

- Developed Trestle App to Collect Network Data and Build Transition Support Networks based on ATRP findings - Currently conducting RCT Study



Trestle

The word "Trestle" is written in a large, bold, blue sans-serif font. Behind the text is a light blue network diagram consisting of several grey circular nodes connected by thin grey lines, forming a web-like structure.

# Trestle Study Recruitment

We are seeking **youth ages 13-29 on the autism spectrum** who are transitioning to adulthood. We are also looking for these youths' **parents/guardians and providers** to participate in a study about Trestle, an **application for transition planning and coordination**. If you're interested, scan the QR code to fill out the Interest Form at <https://tinyurl.com/TeamTrestle> or email our team at [sodi@drexel.edu](mailto:sodi@drexel.edu).



Scan me!



Life Course Outcomes  
Research Program

DREXEL UNIVERSITY  
A.J. Drexel  
Autism Institute

# Any Questions or Comments?



# Thank you for your time!

Dr. Elizabeth McGhee-Hassrick, Jonas Ventimiglia, Mars Potros,  
Sara Murphy, Toni Radcliffe, Isaiah Hoffman, Ming Yuan Low,  
Grace Quinn, Thao Nguyen



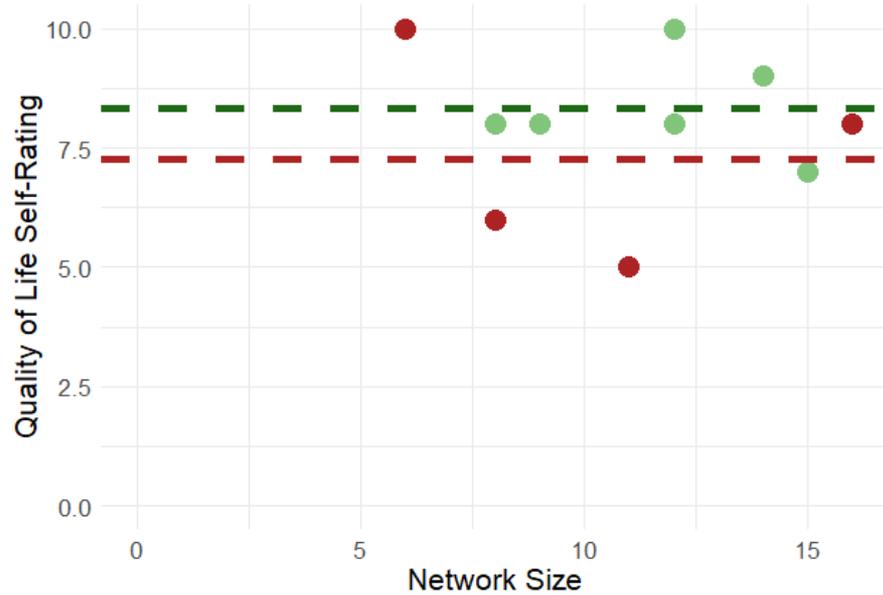
**Life Course Outcomes**  
Research Program



# Young Adult Quality of Life – Self Report

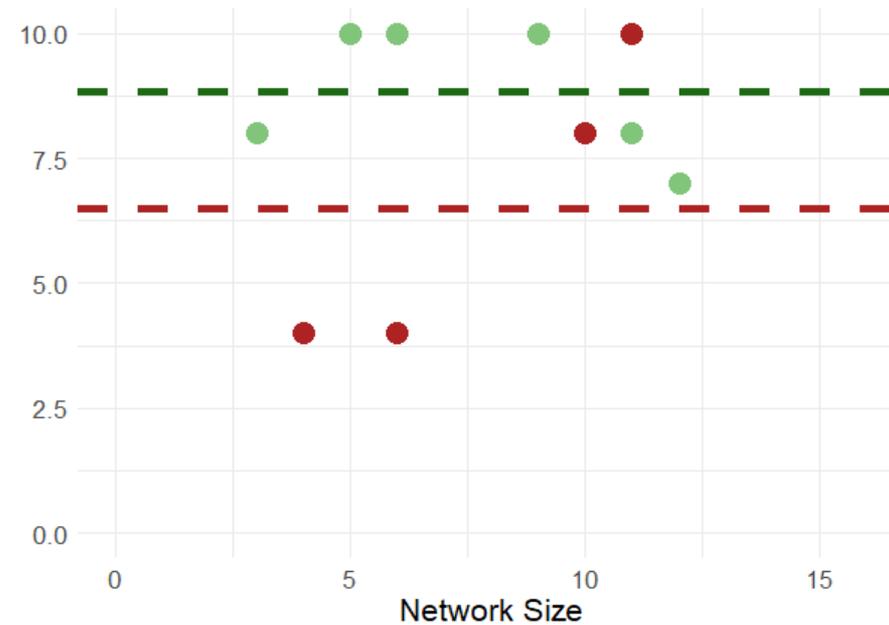
- Graduated
- Stayed on an extra year

## T1



Overall Mean 7.9 (SD=1.6)

## T2



Overall Mean 7.9 (SD=2.3)



# **The Transition Odyssey of Youth with Autism on the Road to Adulthood: A Pilot Study**

**Anne Roux, MA, MPH**



**Life Course Outcomes**  
Research Program



**DREXEL UNIVERSITY**  
**A.J. Drexel**  
Autism Institute

# Study purpose

- Develop a systematic, feasible, structured, economical approach to gathering useful data about the timing, sequencing and coordination of events related to accessing services during the transition process.
- With an eye on disparities in both access and outcomes



# Research questions

How do parents..

- Conceptualize the transition into adulthood?
- Experience the transition into adulthood?
- Recall information about the transition



# Characteristics

- Parents:
  - 80% Black
  - 40% Low-income (<185% FPL)
  - 50% had a 2-year or 4-year college degree or higher.
- Young Adults
  - 60% had co-occurring ID
  - 90% were using public health insurance when they left high school
  - Only 10% were seeing specialists for medical care.

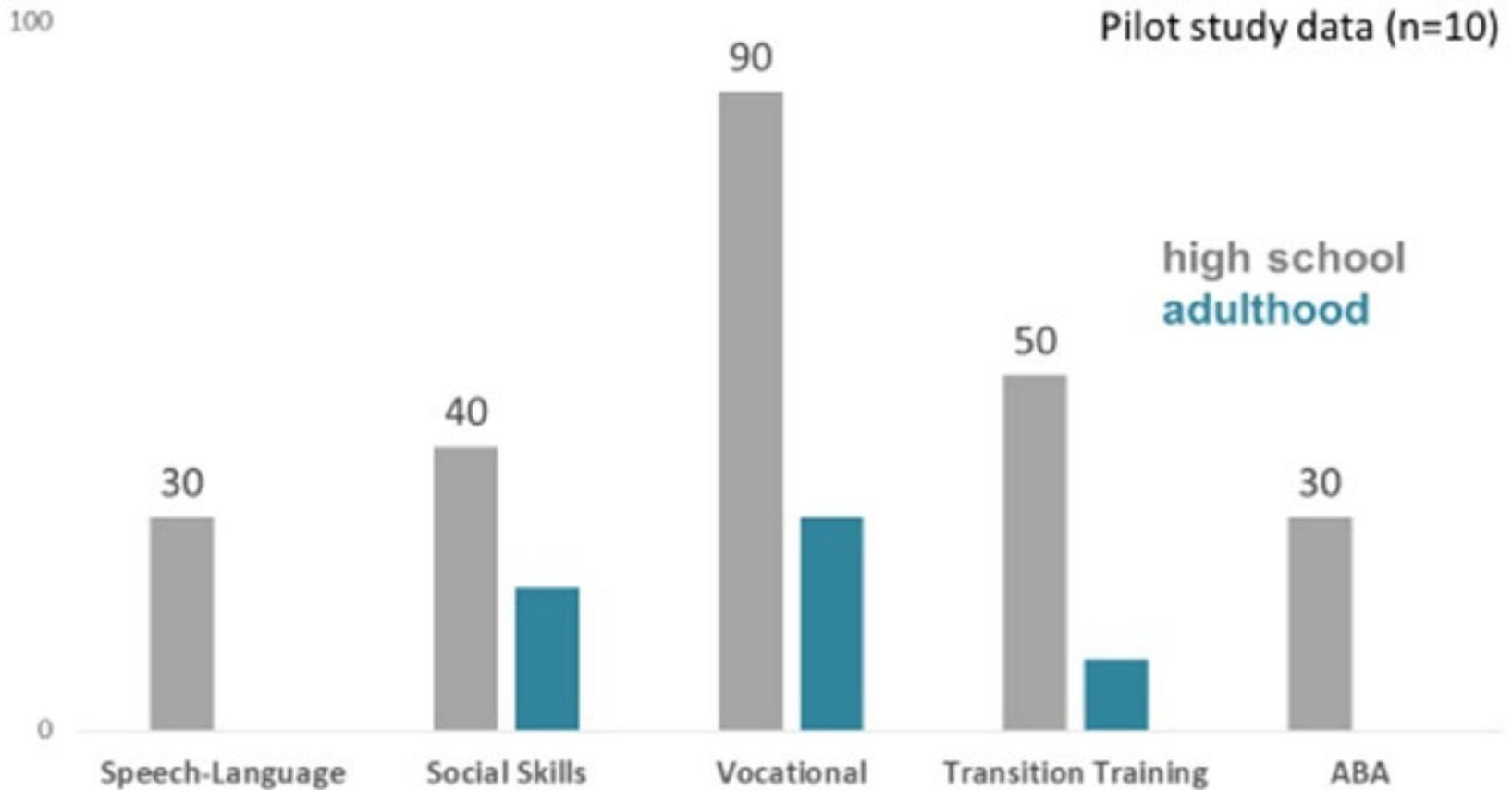


# Young Adult Outcomes

- 100% living in the parent's home.
- 50% were on Medicaid waivers.
- 50% had a service plan with an agency at the time of high school exit.
- 70% experienced a period of disconnection from daytime activities.
  - 30% said these gaps were frequent
  - 40% never had services to reconnect to activities.
- 0% received health care transition information.



# Service use declined dramatically over time.



# Parent perceptions

- 30% of parents felt transition services were appropriate.
- 40% felt somewhat or very dissatisfied about how life was turning out for the youth.
- Do you feel there is an active plan or a goal for continuing to improve [youth's] life?
  - Only 20% said Yes.



# Interview themes

## 1. Parents are not getting enough information.

- Rely on the school to direct preparation
  - “No one talks about it. No one lets you know.”
- Don't know what to expect
- Find out what they need too far down the road
- Obtain information from other parents
- Terminology is a barrier



# Interview themes

## 2. Parents internalize: Fight or Fault

- Take on responsibility to make up for lack of information (fight the system)
- Leads to self-blame if things go wrong
- Emotions run high.
  - Regrets about lack of knowledge -“If I could go back..”
  - “They will fight you. They will lie. They will tell you, “We don't do that... We don't have that.”
  - “How do you go five years and there's just nothing in place? It's just horrible.”



# Interview themes

## 3. Poor transition experiences impact how parents view youth's skills and abilities

- Limited/low expectations for the future
  - Few positive models
- Surprised when things go well
- Expectations sometimes changed over time when they saw things work out for the youth

# Other findings

- “Multiply-vulnerable” – low-income, marginalized populations face transition challenges that are exacerbated by changes related to COVID
- Relationships are key for families during transition (who helped them) versus structural aspects of transition (documents, meetings)
- Families appear to use multiple types of cultural wealth



“I mean there's a lot of help out there...  
There's a lot of resources, but if you don't  
know how to get to them, they might as well  
not be there.”



# ATRP Next Steps

- Future NAIR topics
  - Medicaid
- New data
  - Impact of COVID-19
  - Climate change
  - Medicaid and emerging service needs

# Questions?

The screenshot shows the website for the Drexel University A.J. Drexel Autism Institute. The header includes the university logo and name, a search bar, and navigation links for Giving Opportunities, Search, and a right-pointing arrow. A dark blue navigation bar contains links for RESEARCH, COMMUNITY PROJECTS, NEWS & EVENTS, RESOURCES, and ABOUT. Below this is a breadcrumb trail: Home / research / Research Program in Life Course Outcomes / National Autism Indicators Reports.

**RESEARCH**

- Overview
- Modifiable Autism Risk Factors Research Program
- Research Program in Early Detection and Intervention
- Research Program in Life Course Outcomes
  - National Autism Indicators Reports**
  - Social Networks and Autism
- Policy and Analytics Center

## NATIONAL AUTISM INDICATORS REPORT SERIES

The National Autism Indicators Report is a publication series produced by the A.J. Drexel Autism Institute's [Life Course Outcomes Program](#). The National Autism Indicators Report series presents our research findings in a clearly communicated, open-access, online format to speed the delivery of information to decision-makers while maintaining very high standards of scientific credibility. All reports are freely accessible as downloadable PDFs [here](#).

### TOPICS COVERED

- Access to Services
- Community and Social Participation
- Education
- Employment
- Health and Mental Health
- Living Arrangements
- Safety and Risk
- Transition to Adulthood
- Vocational Rehabilitation

### ACCESS THE FULL REPORT SERIES HERE

National Autism Indicators Report  
Transition into Young Adulthood

Life Course Outcomes Research Program

### LIFE COURSE OUTCOMES PROGRAM

The [Life Course Outcomes Program](#) is building a base of knowledge about things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their