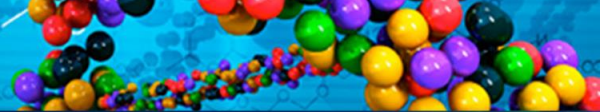


Transitions to adulthood for autistic youth: Improving outcomes by supporting families

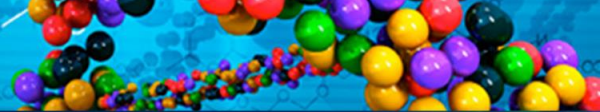
Julie Lounds Taylor, Ph.D.

Associate Professor of Pediatrics
Endowed Directorship in Autism Research
Vanderbilt University Medical Center



Agenda

- Why support families of youth with autism during the transition to adulthood?
- Development of a services advocacy intervention to help families better support their autistic youth in gaining services
 - Pilot work
 - Multi-state RCT
 - Feasibility and acceptability
 - Preliminary outcome analyses



Increased Attention Paid to Autism in Adulthood

Autistic Kids Learn To Survive, And Thrive, In College

by GRACE HOOD

April 13, 2011 2:52 PM

from KUNC



Listen to the Story

All Things Considered



- Playlist
- Download
- Transcript



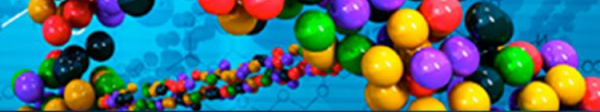
Lowell Austin, an autistic student at Marshall University in Huntington, W.Va., receives tutoring from Stephanie Hurly at the university's Autism Training Center, one of several college programs highlighted on the website College Autism Spectrum.

In many ways, Mark Heim is a typical senior at Colorado State University. He has the kind of smart humor you'd expect from someone who excels in computer science, engineering and math; his T-shirt reads, "Department of Redundancy Department."

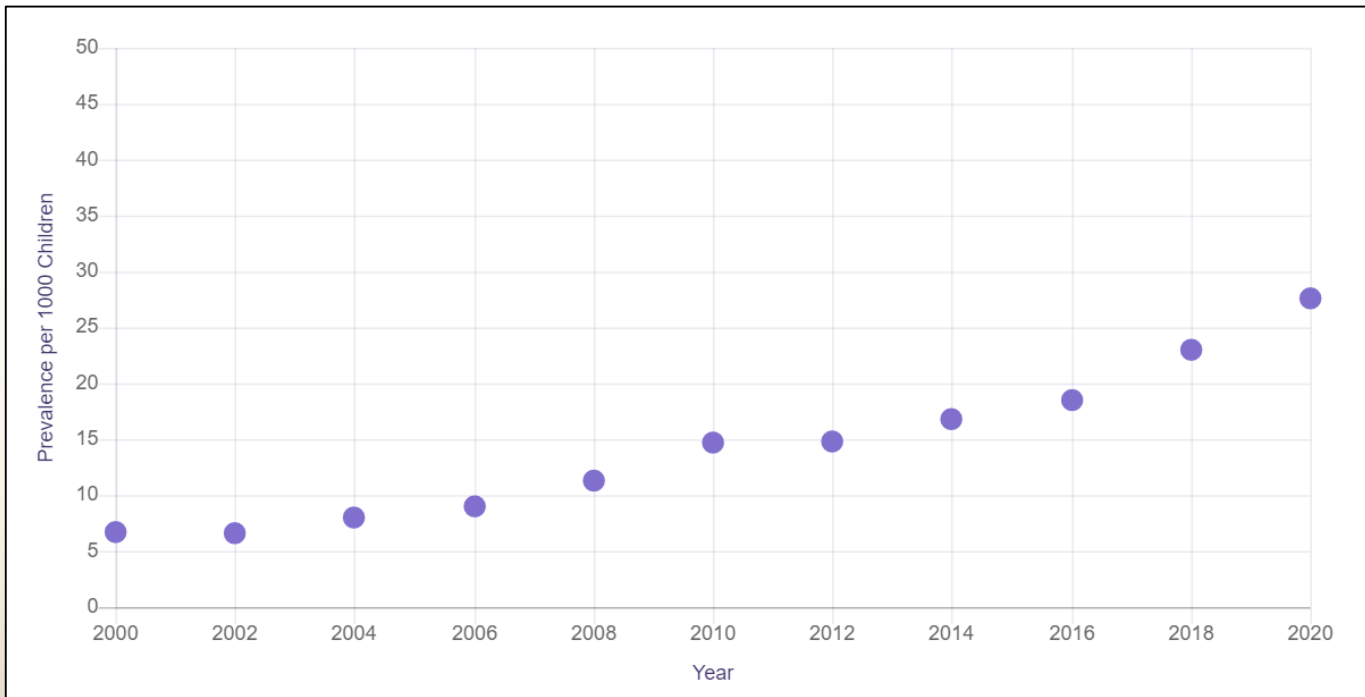
But as a student living with Asperger's syndrome, a high-functioning form of autism, the everyday social interactions of college life can be awkward. Heim is part of a new influx of kids with autism who are heading off to college, creating a new demand for college services to help students with autism fit in, graduate and find jobs.

Colorado State is one of a handful of schools that have adopted programs to help ease autistic students' transitions in and out of





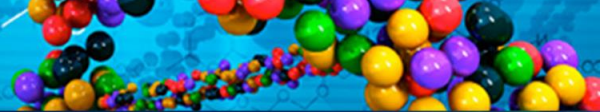
Why Focus on Autism in Adulthood?



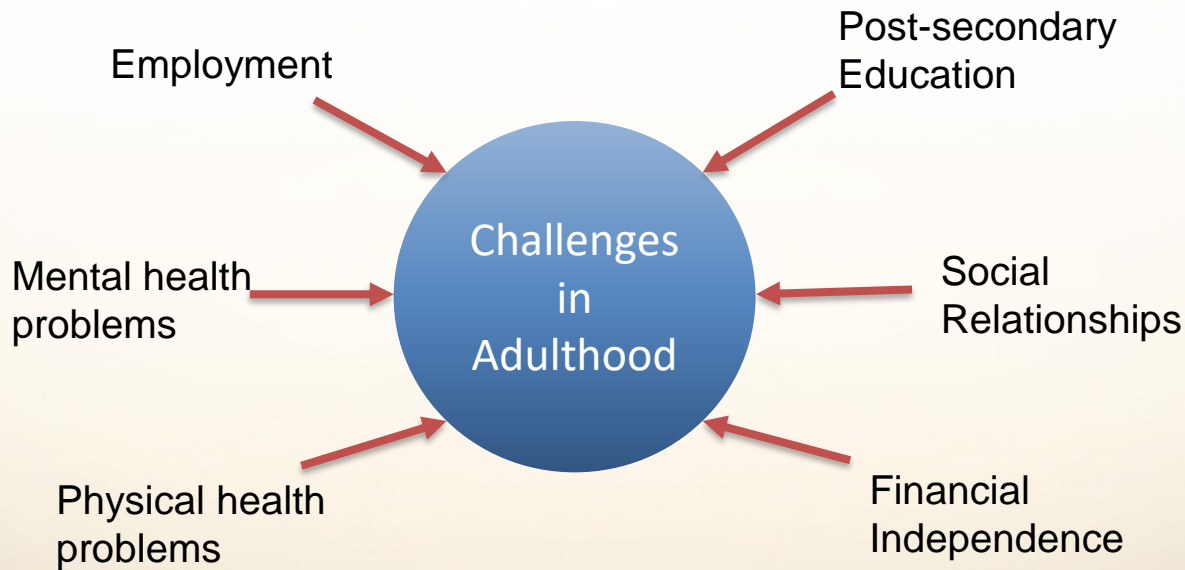


The Services Cliff

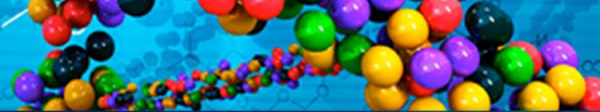




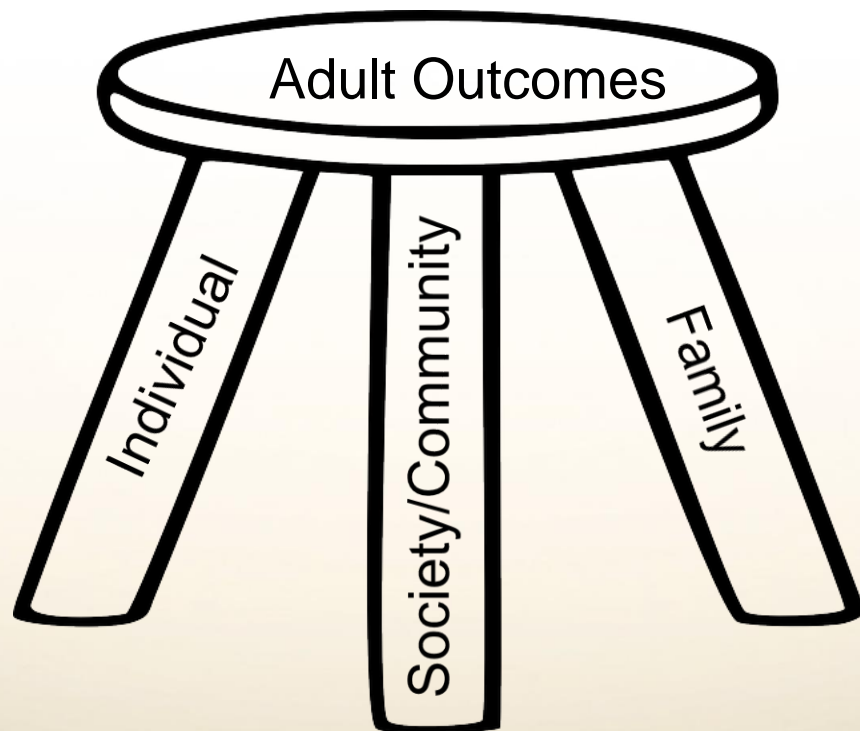
Many Autistic Adults Struggle

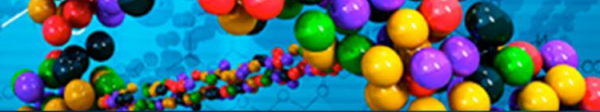


How can we improve outcomes?

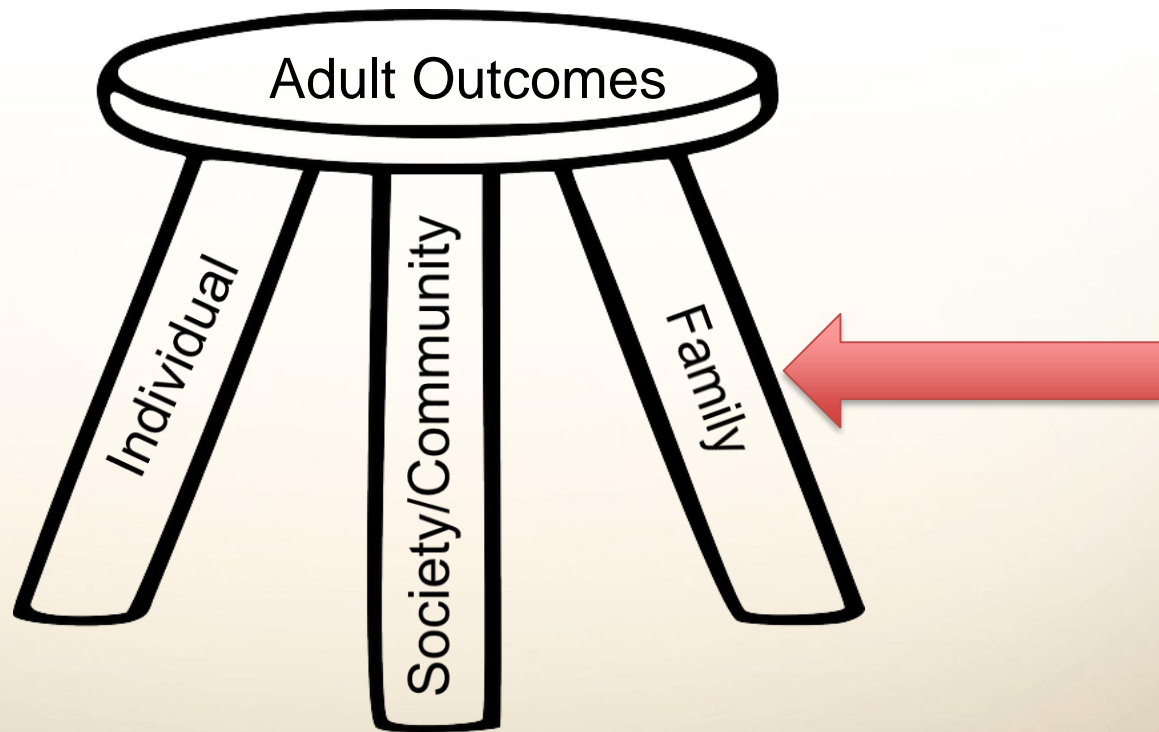


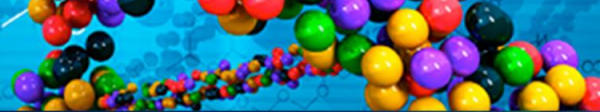
How can we improve outcomes?





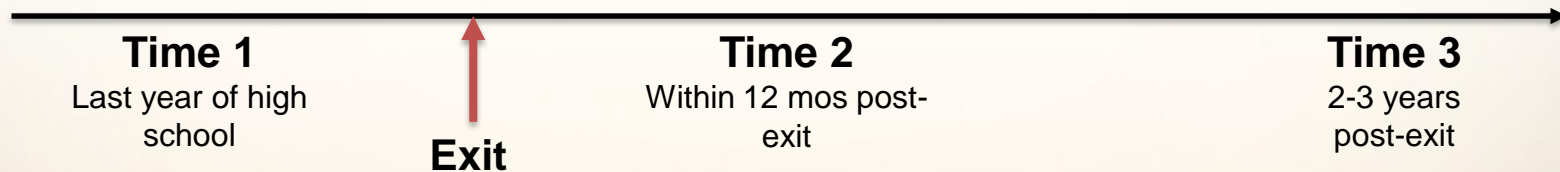
What does research tell us about the importance of families during transition?



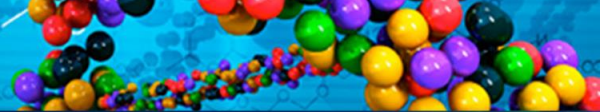


Families Support the Post-secondary Activities of Their Son/Daughter

- 38 families of youth with autism diagnosis who had data collected at 3 time points
 - Last year of high school, within 12 months after exit, about 2.5 years after exit

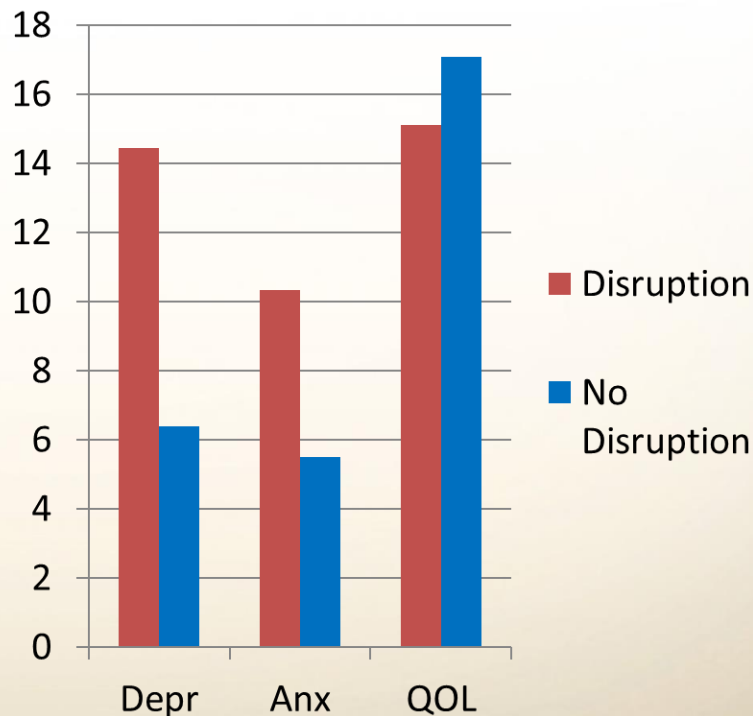


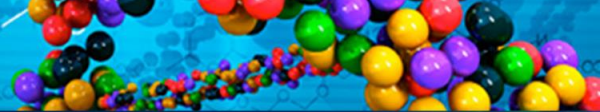
- Coded youth into “disruption” versus “no disruption” groups
 - 50% of youth had a disruption



Maternal Mental Health Predicts Disruption

- Usual cast of characters did not distinguish group
 - IQ
 - Autism symptoms
 - Problem behavior
 - Daily living skills
- Instead...
 - Maternal mental health mattered

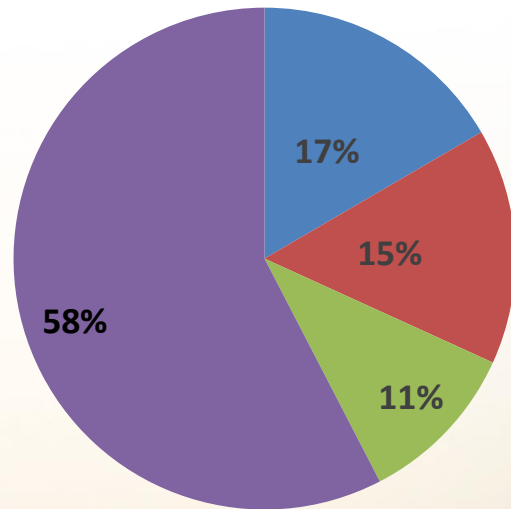




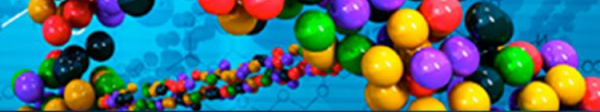
Role of Parental Advocacy

- 185 parents of transition-aged youth on the autism spectrum
- After controlling for known predictors of service access, how strongly does parent advocacy predict services?

(known factors = Intellectual disability, adaptive behavior, autism severity, high school exit, family income, race/ethnicity)



- Known factors
- State
- Parent advocacy activities
- Unexplained



To Best Support Individuals, We Need to Support Families

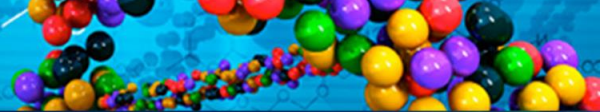
Families take over coordinating services after transition - often with little or no help





Agenda

- Why support families of youth with autism during the transition to adulthood?
- Development of a services advocacy intervention to help families better support their autistic youth in gaining services
 - Pilot work
 - Multi-state RCT
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 - Preliminary outcome analyses



The Services Cliff

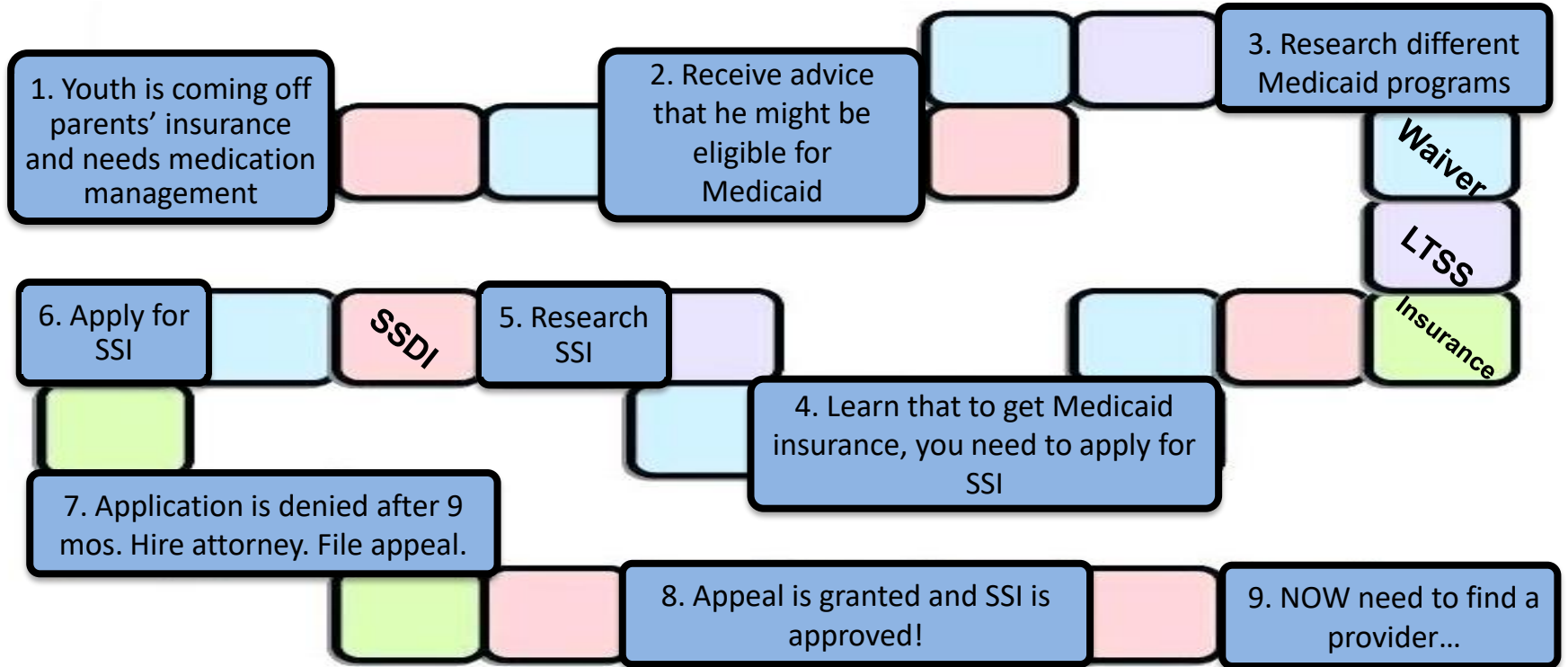


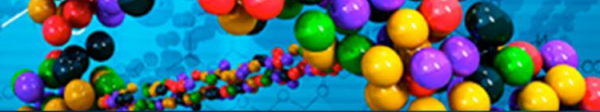
Adult services are:

1. Underfunded
2. Difficult to understand and navigate
 - Poorly integrated between school-based and adult services
 - Poorly integrated between agencies



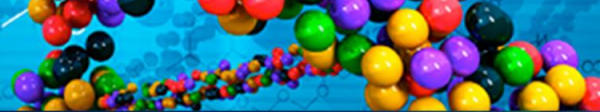
Example: The Winding Road to Medicaid Insurance





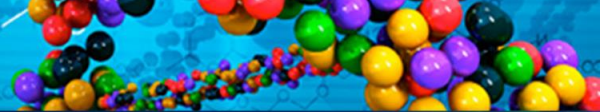
Volunteer Advocacy Program-Transition (VAP-T) 2014-2017

- Parent training to improve transition outcomes for youth on the autism spectrum (funded by NIMH)
 - Teaches parents about adult disability services and supports, how they interrelate, and the most effective ways to access them.
 - Based on Volunteer Advocacy Project (VAP)
 - Developed with extensive community input
 - In most session, program facilitator aided by local expert who present specifics of topic at hand.

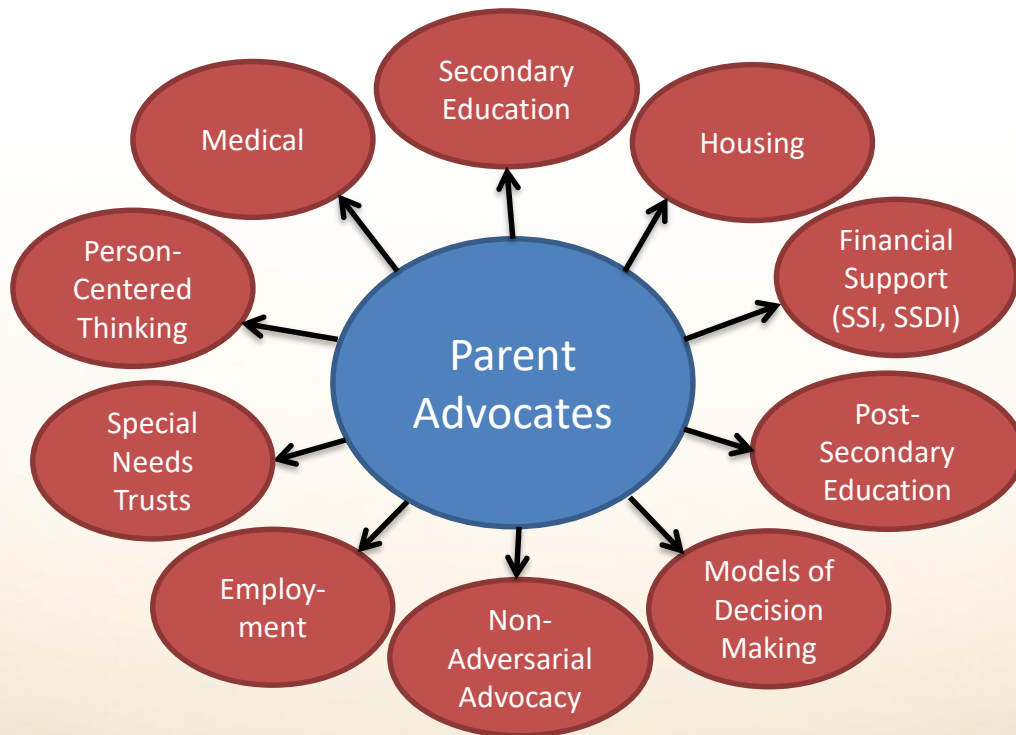


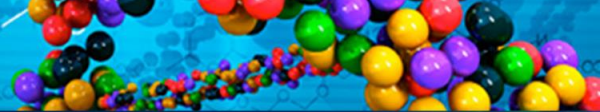
Our Approach

Parent
Advocates

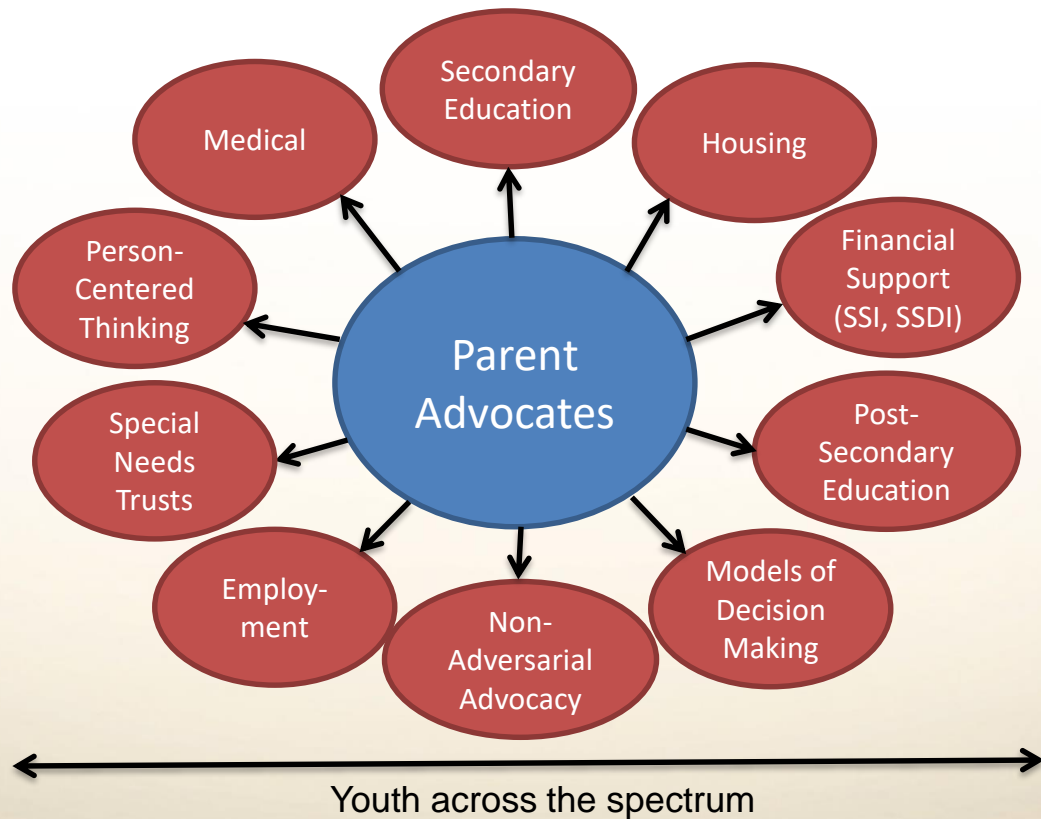


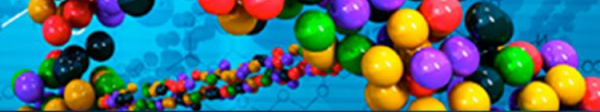
Our Approach





Our Approach





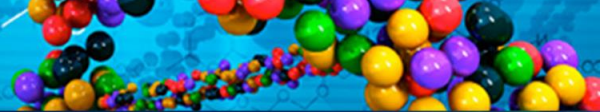
VAP-T Pilot Randomized Controlled Trial

- Recruited 45 families of youth with autism within two years of high school exit (in TN)
 - Randomized to treatment or wait-list control group (who got VAP-T after 12 months)
 - Families participated in groups in Nashville, Memphis, Chattanooga
 - 41 families were retained at post-test
- Does participating in the VAP-T lead to:
 1. Improvements in intervention targets of knowledge, advocacy skills/comfort and empowerment?
 - Measured at post-test (right after treatment)
 2. Improved services access?
 - Measured 6 months after treatment group took VAP-T



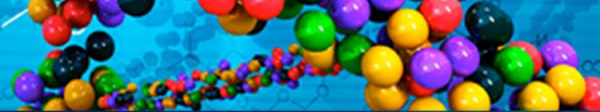
Participants

	Treatment (n=20)	Control (n=21)	T-value or X^2
Youth age	18.14 (1.74)	18.34 (2.02)	-0.34
Youth is in high school	80%	91.5%	0.90
Youth has intellectual disability	35%	28.6%	0.20
Youth sex= male	85%	81%	0.12
Parent sex = female	100%	95.2%	0.98
Parent has completed bachelor's degree	90%	61.9%	6.27
Parent race = white	90%	85.7%	2.31

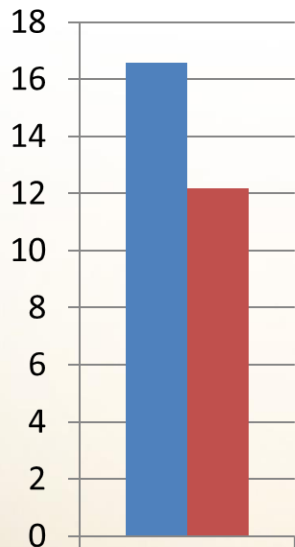


Measures

- Baseline and post-test
 - Knowledge measure: 22 multiple-choice questions about adult services and supports (Taylor et al., 2017)
 - Advocacy skills: 10-item, Likert-scale measure assessing parents' comfort and skills with advocating (Taylor et al., 2017)
 - Empowerment: Family Empowerment Scale (Koren et al., 1996)
- 6-month follow-up
 - Number of services from list of 22 services from NLTS-2 (e.g., mental health, speech/language, vocational training)
 - Post-secondary education (PSE) or employment (1 = enrolled in PSE or employed)
 - Just those who had exited high school

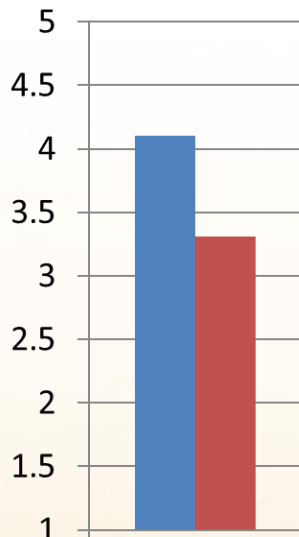


Question 1 – Effects on Intervention Targets



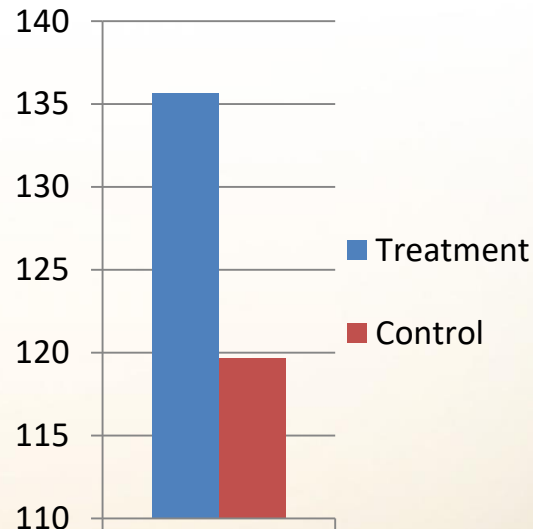
Knowledge

Intervention $F = 17.41^{**}$
Cohen's $D = 1.06$



Skills/Comfort

Intervention $F = 15.02^{**}$
Cohen's $D = 1.10$



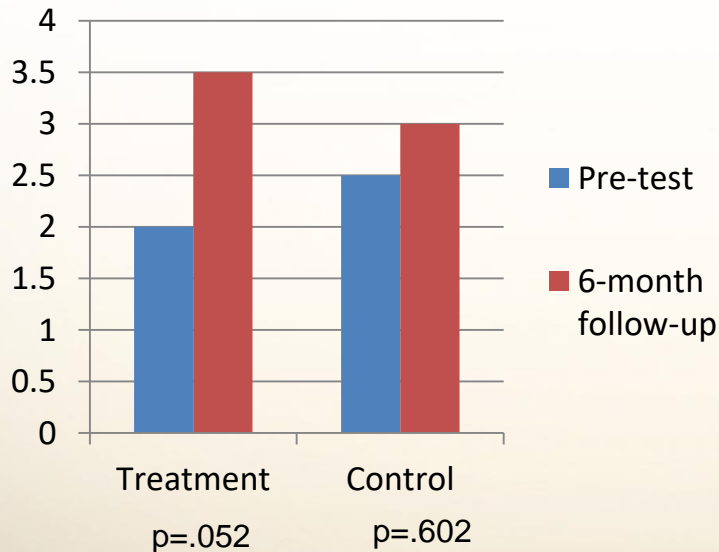
Empowerment

Intervention $F = 9.24^*$
Cohen's $D = 0.77$



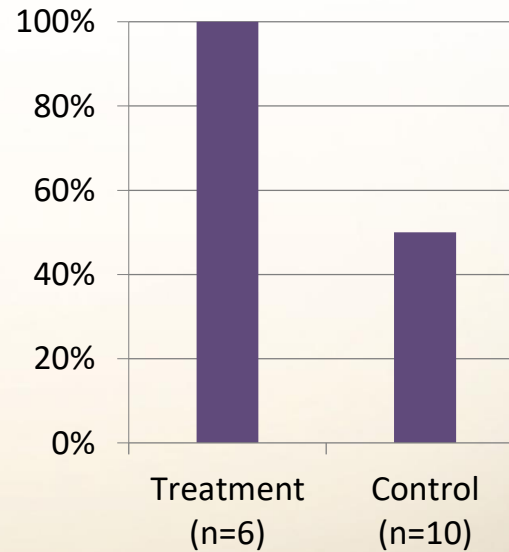
Question 2 – Group Differences in Service Access and Employment/PSE

Number of Services

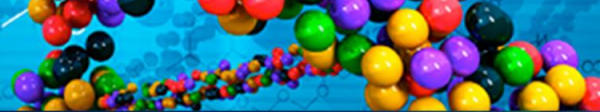


61% increased versus 35%

Employment or PSE

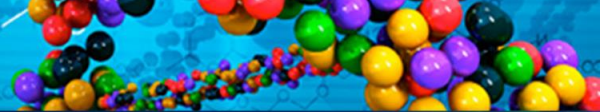


$X^2 = 4.36, p < .05$



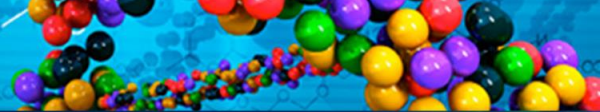
Challenges

- Curriculum only worked in Tennessee
- Need a more streamlined way to leverage expertise/experience of our community experts
- Control group was a challenge



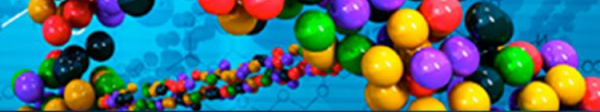
Next Step (funded by NIMH)

- Revise the curriculum to be nationally relevant
 - Called ASSIST - Advocating for SupportS to Improve Service Transitions
- Large-scale randomized-controlled trial of the parent advocacy program in three states (TN, IL, WI)
 - Control group gets all materials
- Focused on parents of transition-aged youth with autism both before and after high school exit
- Incorporating perspective of autistic youth into intervention and data collection
- Support community implementation



Collaboration

- ASSIST was developed through a collaboration with the
 - Vanderbilt Kennedy Center at Vanderbilt University Medical Center
 - University of Illinois Urbana Champaign
 - Waisman Center at the University of Wisconsin-Madison
 - The Arc Tennessee
 - The Autism Program of Illinois



Intervention Delivery Differences

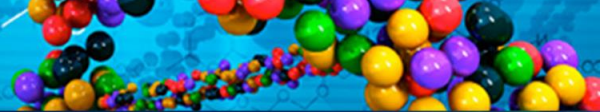
	VAP-T	ASSIST
Curriculum Delivery	PowerPoints <ul style="list-style-type: none"> developed by research team delivered by local subject matter experts 	<ul style="list-style-type: none"> 10-minute introductory video with nationally relevant information Local expert provides state specific information
Duration	12 weeks 2.5 hours each week	12 weeks 2 hours each week
Location	University	Community



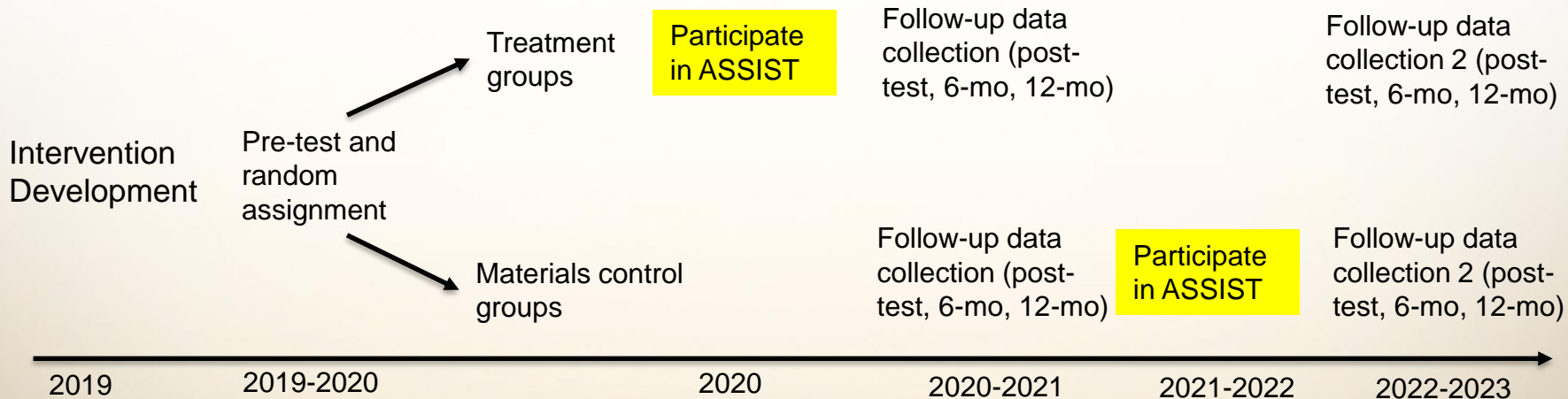
Participants for RCT

185 families of youth with autism ages 16-26 from TN, IL, WI

	Treatment (n=91)	Control (n=94)
Youth age	19.47 (2.85)	19.47 (2.59)
Youth gender = male	76%	73%
Youth race = white	69%	79%
Youth in high school	59%	61%
Youth has intellectual disability	40%	40%
Parent gender = female	88%	92%
Parent has bachelor's degree or greater	66%	72%

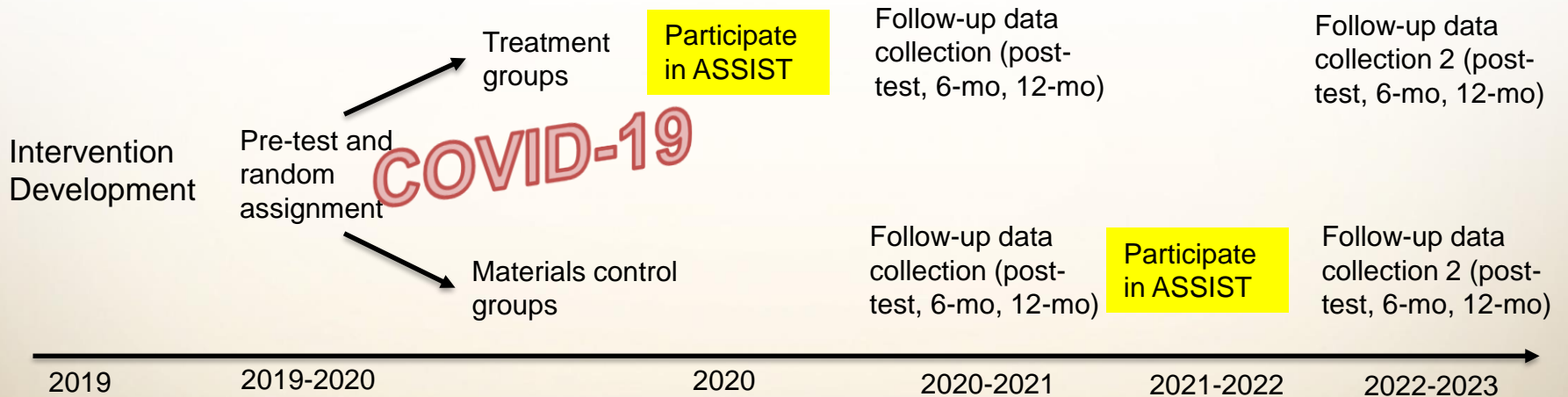


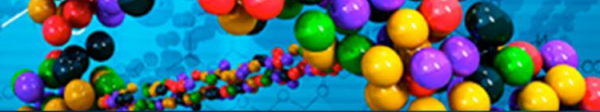
Project Timeline and Study Design





Project Timeline and Study Design



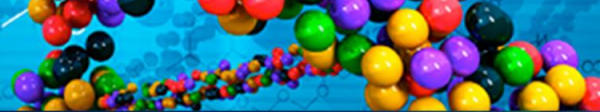


Implementation Outcomes

Do local experts cover the learning objectives? – YES!

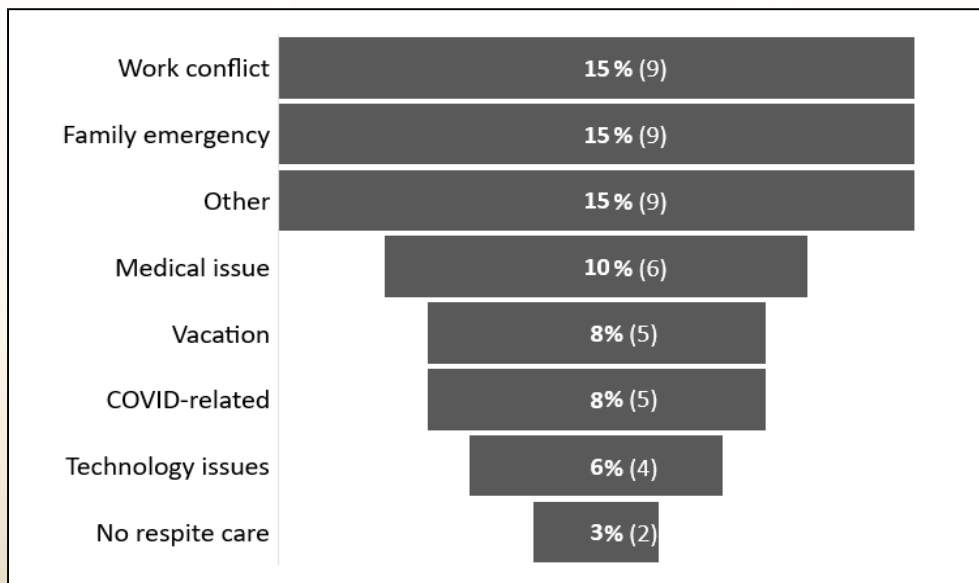
ASSIST session	% of local expert learning objectives met
Session 1- Intro and Person-Centered Planning	100
Session 2 - Models of Decision Making	98.1
Session 3 - Supplemental Security Income (SSI)	97.6
Session 4 - SSDI)& SNAP	100
Session 5 - Health Insurance Options	77.8
Session 6 - Medicaid Waiver	96.7
Session 7 - Employment 1	95.8
Session 8 - Employment 2	83.3
Session 9 - Post-secondary Education	100
Session 10 - Housing & Enabling Technology	100
Session 11 - Special Needs Trust & ABLE accounts	100
Session 12 - Advocacy	100

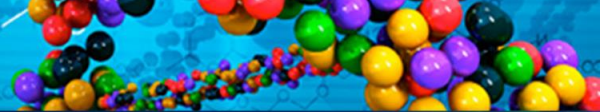
Taylor et al., JADD, 2022



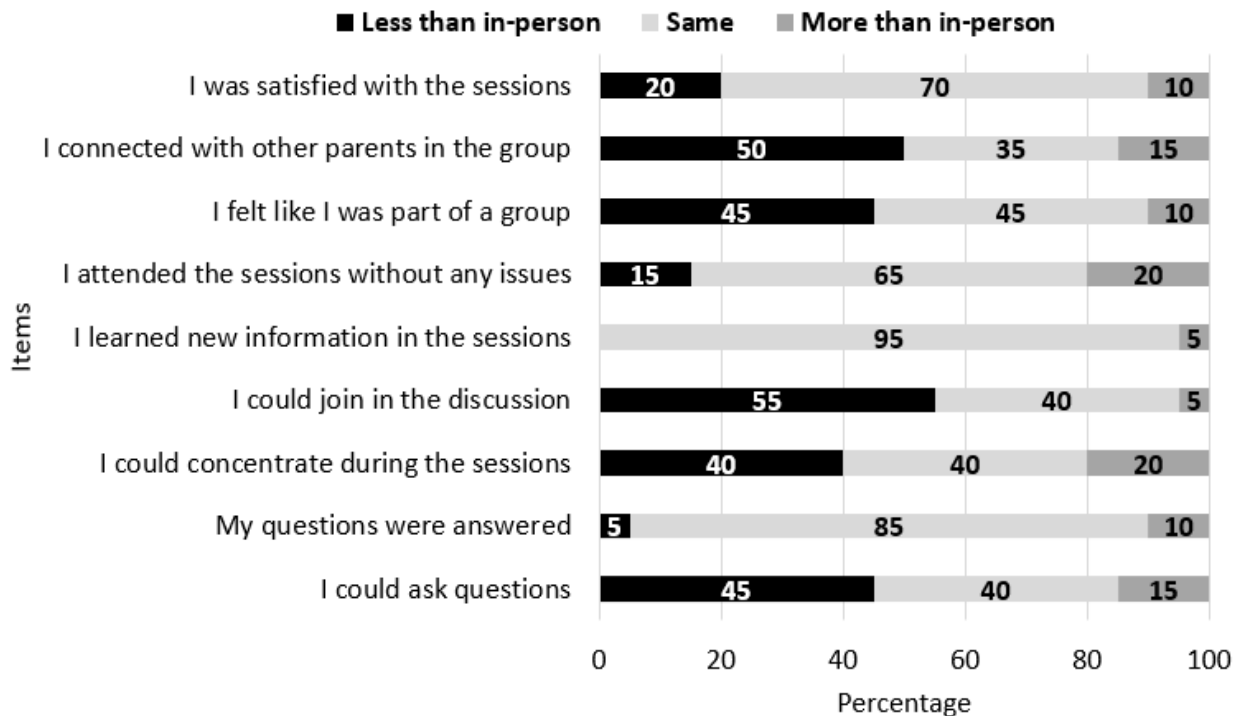
Implementation Outcomes

- Are participants able to attend?
 - YES! 86% of the participants attended 75% or more of the sessions





Overview: In-Person vs. Online Experience

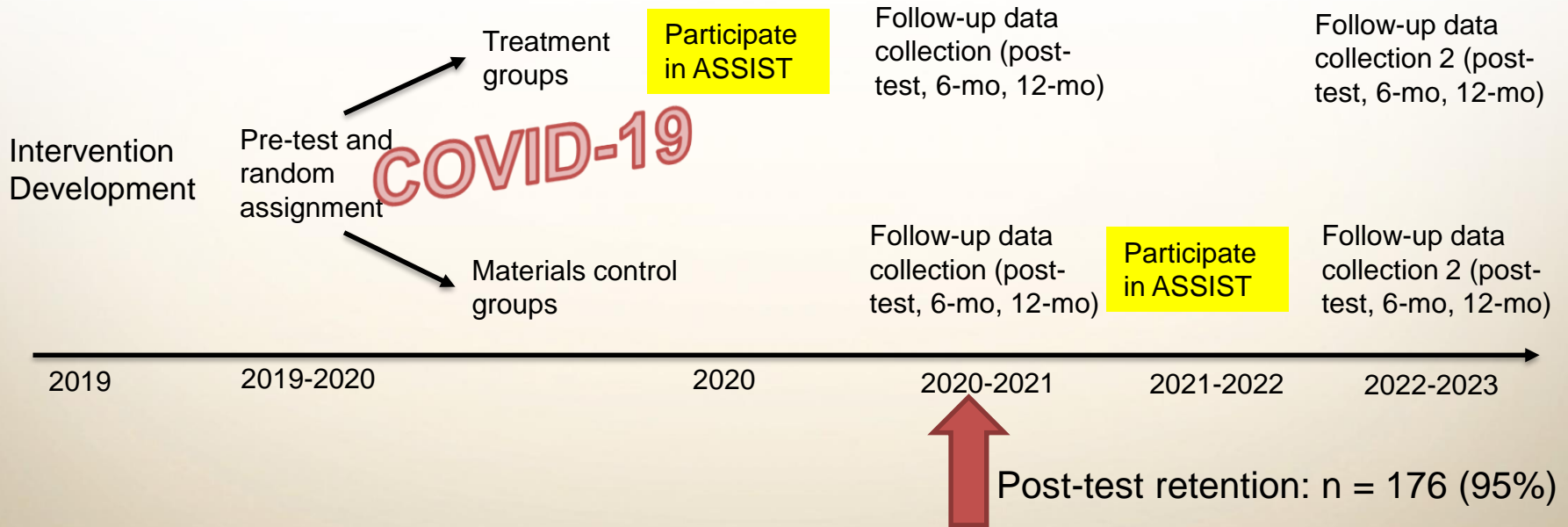


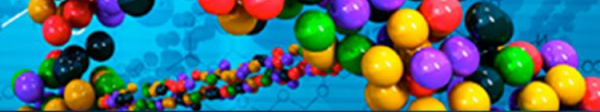
- 60% of those who had both methods of delivery would prefer in-person ASSIST
- 33% of those who only had online ASSIST would prefer in-person ASSIST



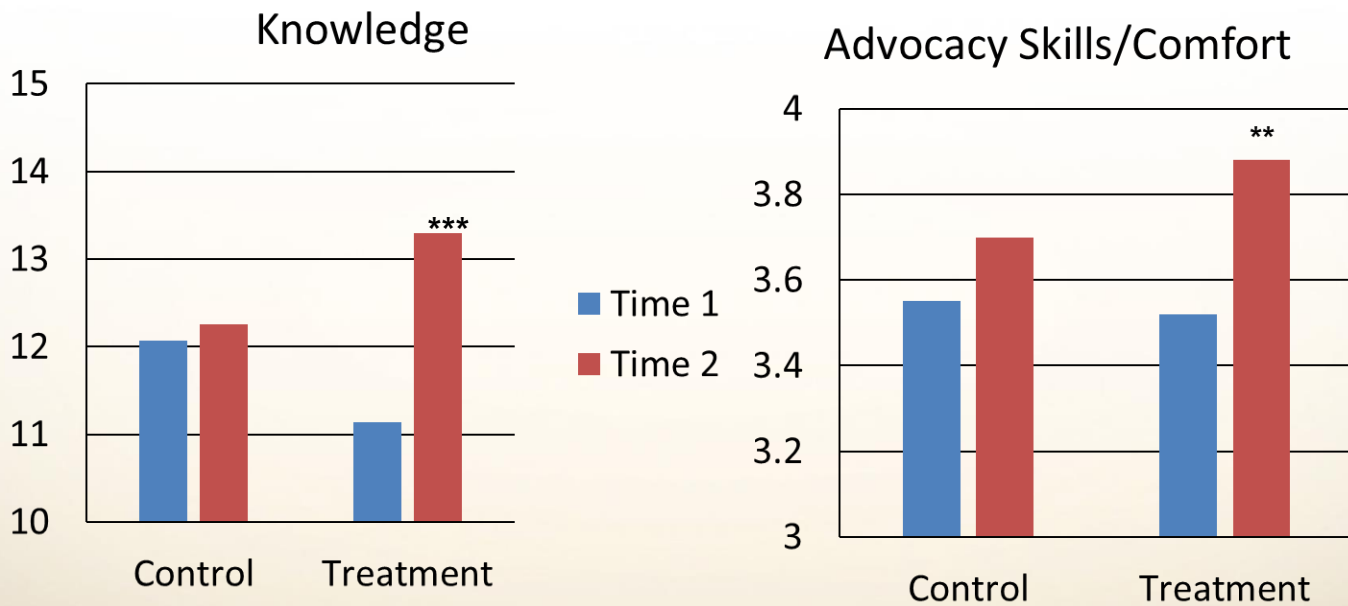
Project Timeline and Study Design

- 185 families of youth with autism ages 16-26 from TN, IL, WI





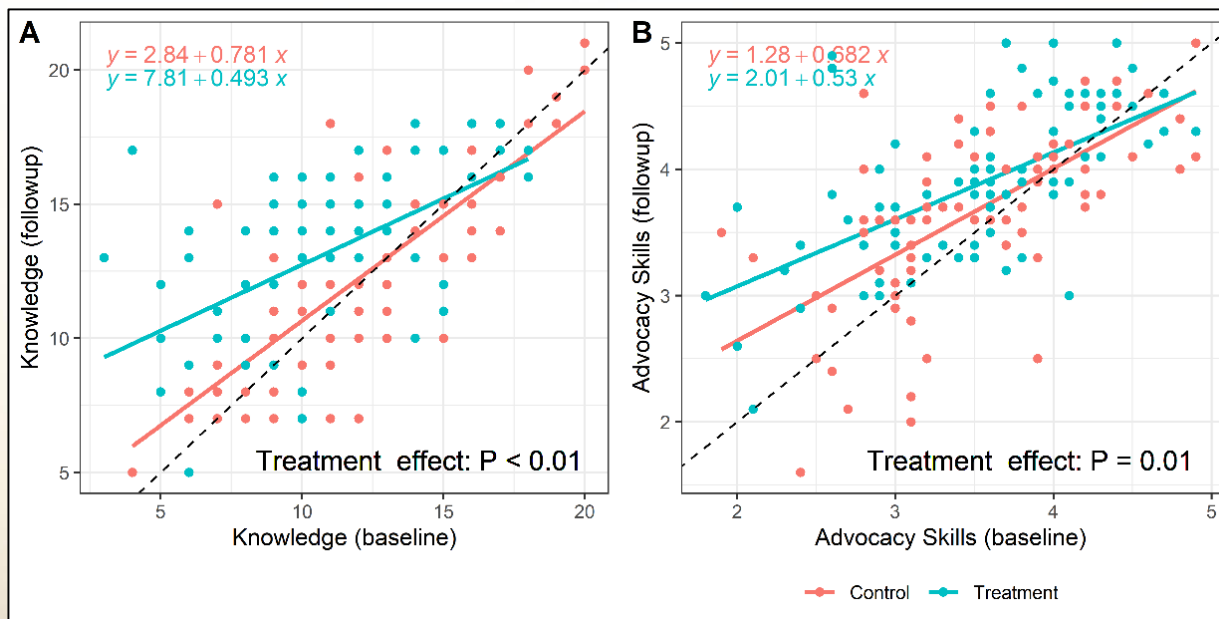
Are ASSIST Families Better Able to Advocate?

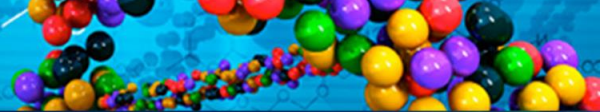


Those who took ASSIST knew significantly more about adult services and felt more skilled and comfortable using that information.



Those Least Prepared to Advocate Seemed to Benefit Most

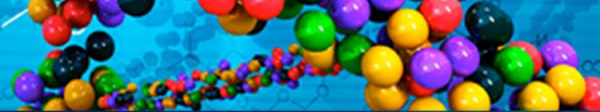




Next Steps

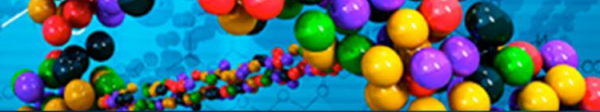
- Does taking ASSIST lead to better service access and youth outcomes?
 - Government programs and direct services
- Who seems to benefit most?
 - New grant (Burke, PI) to develop a culturally responsive version for Spanish-speaking Latinx families
- What are barriers to using this information to improve outcomes?





Summary

- Families play many important roles during the transition to adulthood
- Supporting families helps them better support their youth
- Promising program are available to support families
 - Teaching parents about adult services (soon)
 - Reducing parental stress (Parenting Stress Intervention Project: Dykens)
 - Psychoeducation to help parents understand the transition years (Transitioning Together: DaWalt)



Acknowledgements

Collaborators

- Meghan Burke (U of IL)
- Leann DaWalt (U of WI)
- Robert Hodapp (Vanderbilt)
- Carol Rabideau (Vanderbilt)
- Janet Shouse (Vanderbilt)
- Kate Szidon (U of WI)
- Molly Buren (U of IL)
- Carrie Guiden (The Arc TN)
- Loria Hubbard (The Arc TN)
- Linda Tortorelli (TAP IL)

Taylor Lab (past and present)

- Joanna Belland
- Sarah Carlson, PhD
- Eman Durrani
- Florencia Pezzimenti
- Grace Herbert
- Chung eun Lee, PhD
- Jordan Segal
- Ginger Sullivan
- Sidney Waitz-Kudla

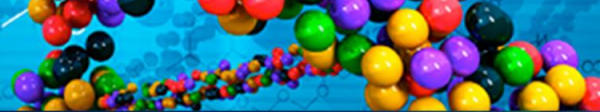
Community Partners

- The Arc TN
- TAP Illinois
- Wisconsin DD Council
- TN Boling Center
- Chattanooga Autism Center

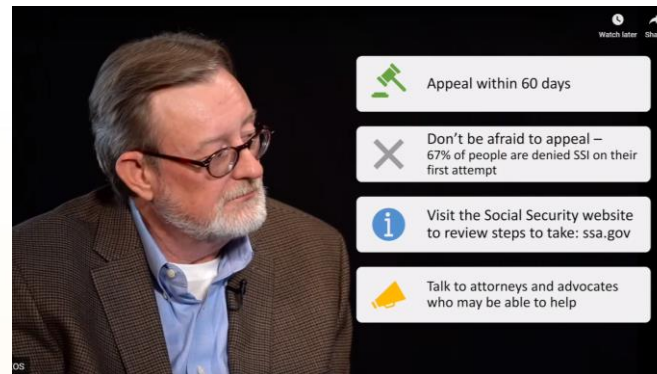
Research Funding

- NIMH – R34 MH104428
- NIMH – R01 MH116058
- NICHD - P50 HD103537
- Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (UCEDD)
- The Autism Project of IL

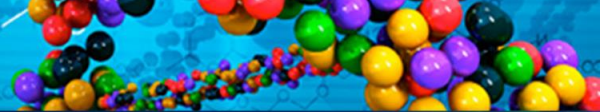
Many thanks to our
research participants!!



ASSIST Videos



<http://assist.vkcsites.org/preview/>



Local Expert Learning Objectives for SSI

LO 1. Share information about current SSI amount

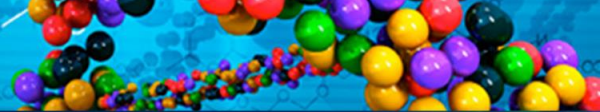
LO 2. Discuss specifics of applying and the importance of an appeal

LO 3. Dispel myths about employment and SSI

LO 4. Discuss how to keep benefits in place –effects of income, living expenses, in-kind support & avoiding overpayment

LO 5. Explain work incentives offered by SSI - 1619 A&B, Earned income exclusion, IRWE, PASS, EXR

LO 6. Discuss how representative payee should keep accounting of SSI



Other Promising Programs

- Parenting Stress Intervention Project
 - Elisabeth Dykens, Vanderbilt University
 - Tested MBSR intervention against a positive psychology intervention in reducing stress and distress among parents of children with disabilities
 - Both interventions were effective
- Transitioning Together
 - Leann Smith DaWalt, University of Wisconsin
 - Used group psychoeducational method aimed at educating parents about the transition to adulthood and problem-solving
 - Participating led to improvements in family climate and greater understanding of service systems and of son/daughter with autism