

***Supporting
Adolescents and
Young Adults with
Autism to Achieve
Independence***

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Disclosures

Book Royalties

Practitioner's Guide to Social Skills Training in Children with Asperger's Syndrome and High Functioning Autism. Guilford Publications. White (2011)

Cognitive-Behavioral Interventions for Children and Adolescents with High-Functioning Autism Spectrum Disorders. Guilford Publications. Scarpa, White, & Attwood (2013)

Handbook of Autism and Anxiety. Springer. Davis, White, & Ollendick (2014)

Oxford Handbook of Clinical Child and Adolescent Psychology. Oxford University Press. Ollendick, White, & White (2018)

Oxford Handbook of Autism and Co-Occurring Psychiatric Conditions. Oxford University Press. White, Maddox, & Mazefsky (2020)

Psychological Therapies for Adults with Autism: Theory and Practice. Oxford University Press. Spain, White, & Musich (2021)

Research Funding

NIMH

Department of the Army

NICHD

Roadmap

1. The challenge

1. What predicts adult outcome? What is the nature of the challenge? Also, what are ASD-related strengths?

2. Summary

1. What do we know? How can it guide our work?

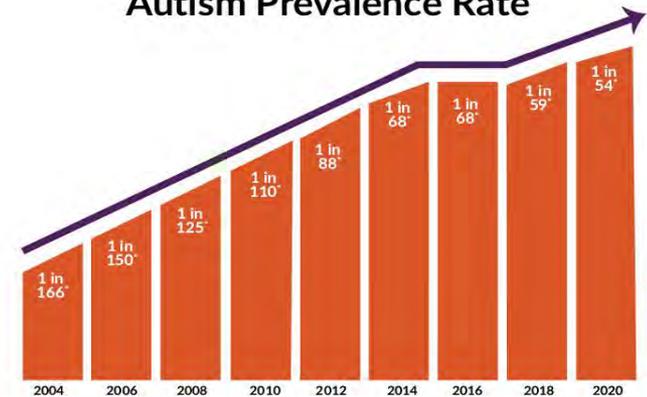
3. Application

1. Specific strategies and suggestions for families and service providers



Overview

Through the Years: Autism Prevalence Rate



*Centers for Disease Control (CDC) prevalence estimates are for 4 years prior to the report data. I.e 2020 figures are from 2016.

- 1 in 54 youth has the diagnosis
- 80-90% of individuals continue to meet diagnosis in adulthood
- More recognition in those without ID
- >70,000 more teens with ASD enter adulthood each year
- ASD is denoted as a spectrum condition because of diversity of those affected
 - Intellectual ability
 - Language/communication
 - Behavioral changes



Diagnosis & Developmental Course



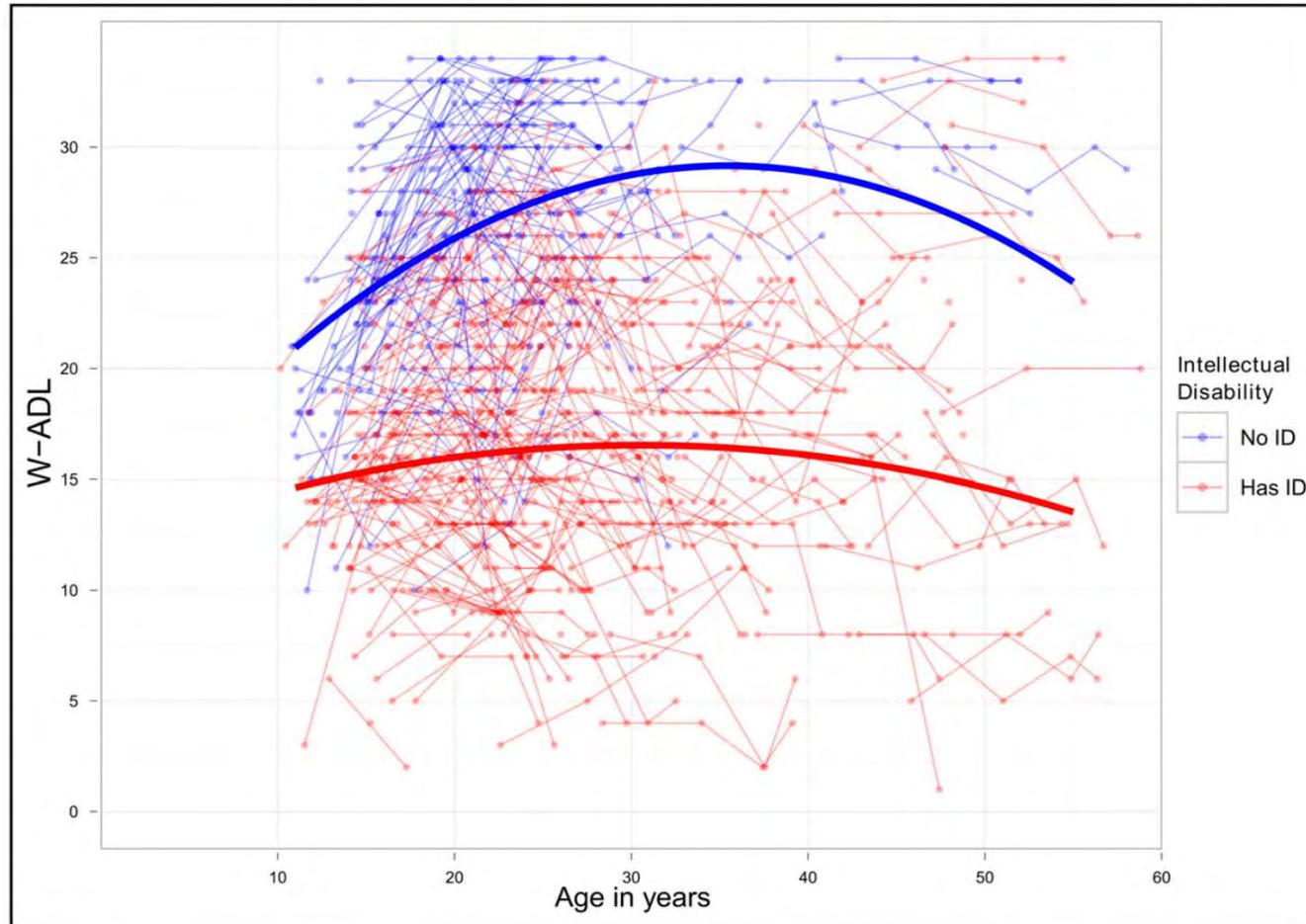
Developmental Course of ASD

- Often identified around age 2, with most kids identified by age 5**
- Often gradual improvements with age, but likely to continue to experience many problems
 - Less obvious, but still socially impairing
- IQ and language development are the strongest predictors of adult outcomes



Smith, Maenner, & Seltzer (2012)

FIGURE 1 Change in Waisman Activities of Daily Living (W-ADL) scores over time for autism spectrum disorder sample, individual and group trajectories. Note: Quadratic (age^2) mixed-model parameterizations displayed.



Best Estimates of Psychiatric Disorder Prevalence

	ASD	Non-ASD
Anxiety	40%	6.5-32%
Depression	12-52.8%	8-12%
ADHD	25-75%	28.2%
Psychotic disorder*	DK (6.6%)	0.75-0.87%
ODD	4-37%	3.3%
Eating disorders, SUD, Bipolar	???	

Challenges and Service Needs Most Frequently Endorsed from Online Survey



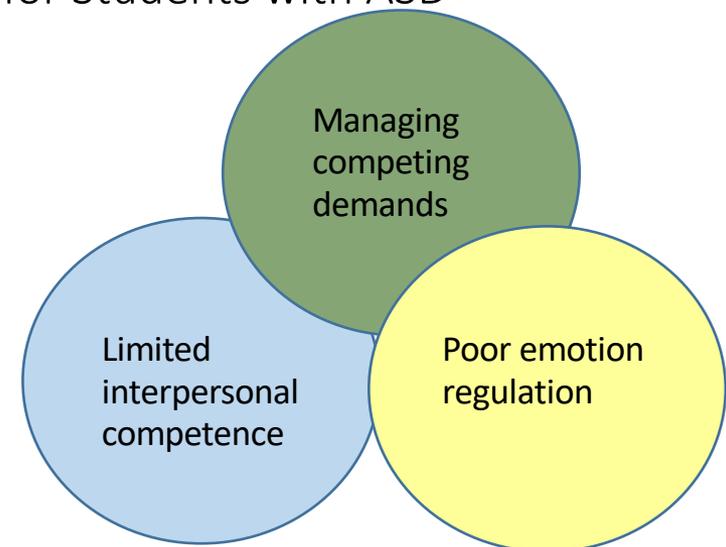
Stakeholder	Greatest Challenges		Most Helpful / Needed Services	
	Challenge	n (%) ¹	Service	n (%) ²
School Personnel (n = 30)	1. Social Interaction	27 (90.0%)	1. Transition Services	28 (93.3%)
	2. Social Supports	26 (86.7%)	2. Social Interaction Training	28 (93.3%)
	3. Self-Advocacy	22 (73.3%)	3. Emotion Regulation Therapy	23 (76.7%)
Parents (n = 32)	1. Social Interaction	21 (65.7%)	1. Social Opportunities	25 (80.7%)
	2. Social Supports	16 (50.0%)	2. Transition Services	24 (77.4%)
	3. Adaptive Skills	16 (50.0%)	3. Independent Living Training	23 (74.2%)
Students (n = 5)	1. Social Supports	3 (60.0%)	1. Career Counseling	4 (80.0%)
	2. Academic Stress	3 (60.0%)	2. Weekly Supportive Therapy	3 (60.0%)
	3. Intense Emotions	2 (40.0%)	3. Social Interaction Training	3 (60.0%)

Primary Needs Identified by Needs Analysis across Online Surveys and Focus Groups

Over-arching construct	Specific facets
Social integration	<ul style="list-style-type: none">Navigating social interactionsFinding social supportHandling conflict with others
Self-determination	<ul style="list-style-type: none">Finding transition servicesSelf-advocacyTime managementSustaining or developing social motivationGoal attainmentSelf-awareness and knowledgeIndependent living skills
Self-regulation	<ul style="list-style-type: none">Managing social, daily living, and social concernsNavigating inconsistencies and changes in routineManaging intense emotionsExecutive functioning (e.g., managing inattention)Coping with academic stress

Transitions: Adolescence to Adulthood, High School to College

- Adults with ASD who do not have co-occurring ID are at greatest risk – limited to no supports and services
- At point of HS exit, the entitlement-driven system [IDEA] ceases, replaced with a system that requires self-advocacy
- High School → College or Employment = Big Changes for Students with ASD
 - **Increased Demands**
 - Academic/ Performance
 - Interpersonal
 - Executive Functioning

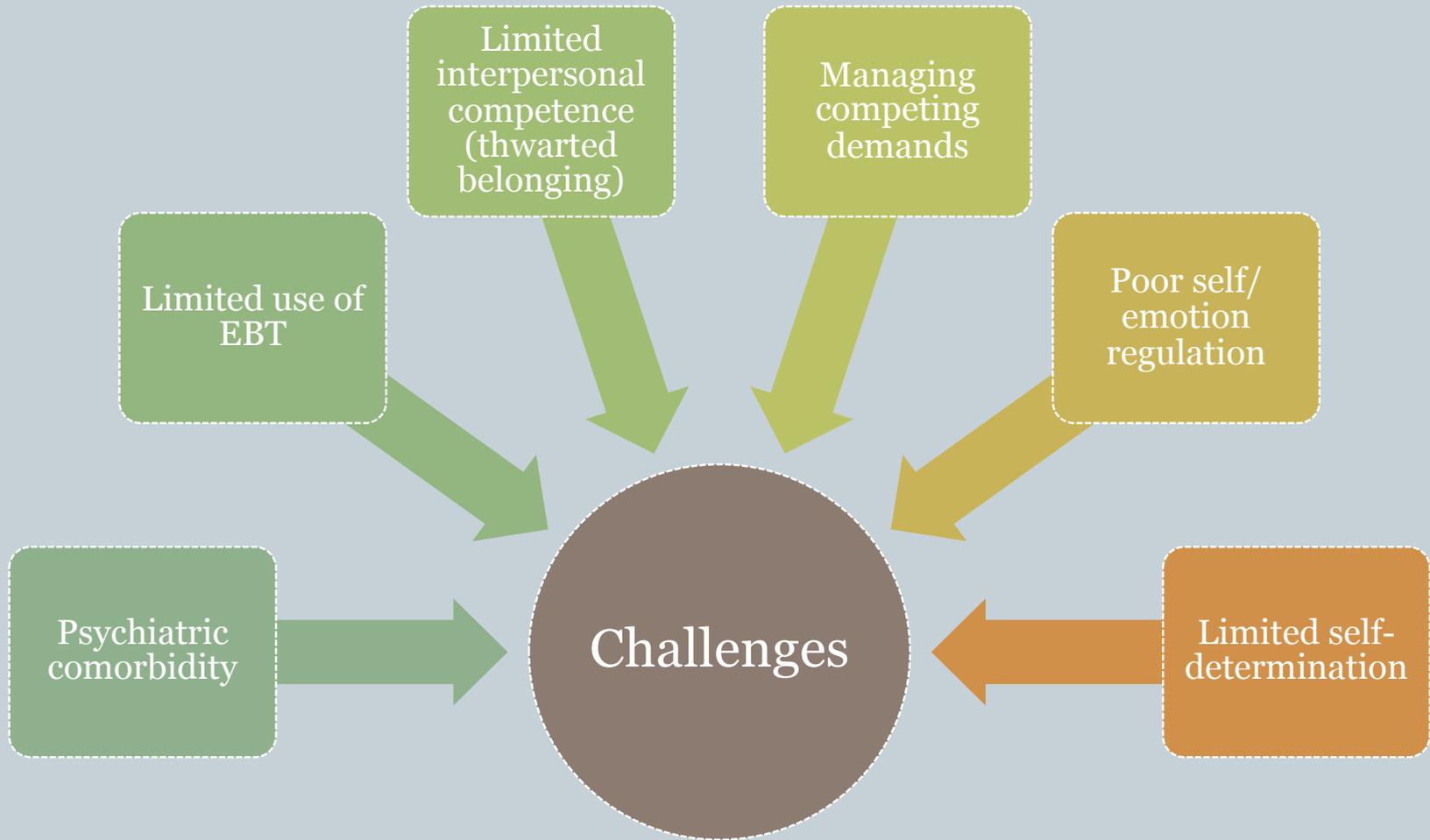


It's not all a challenge

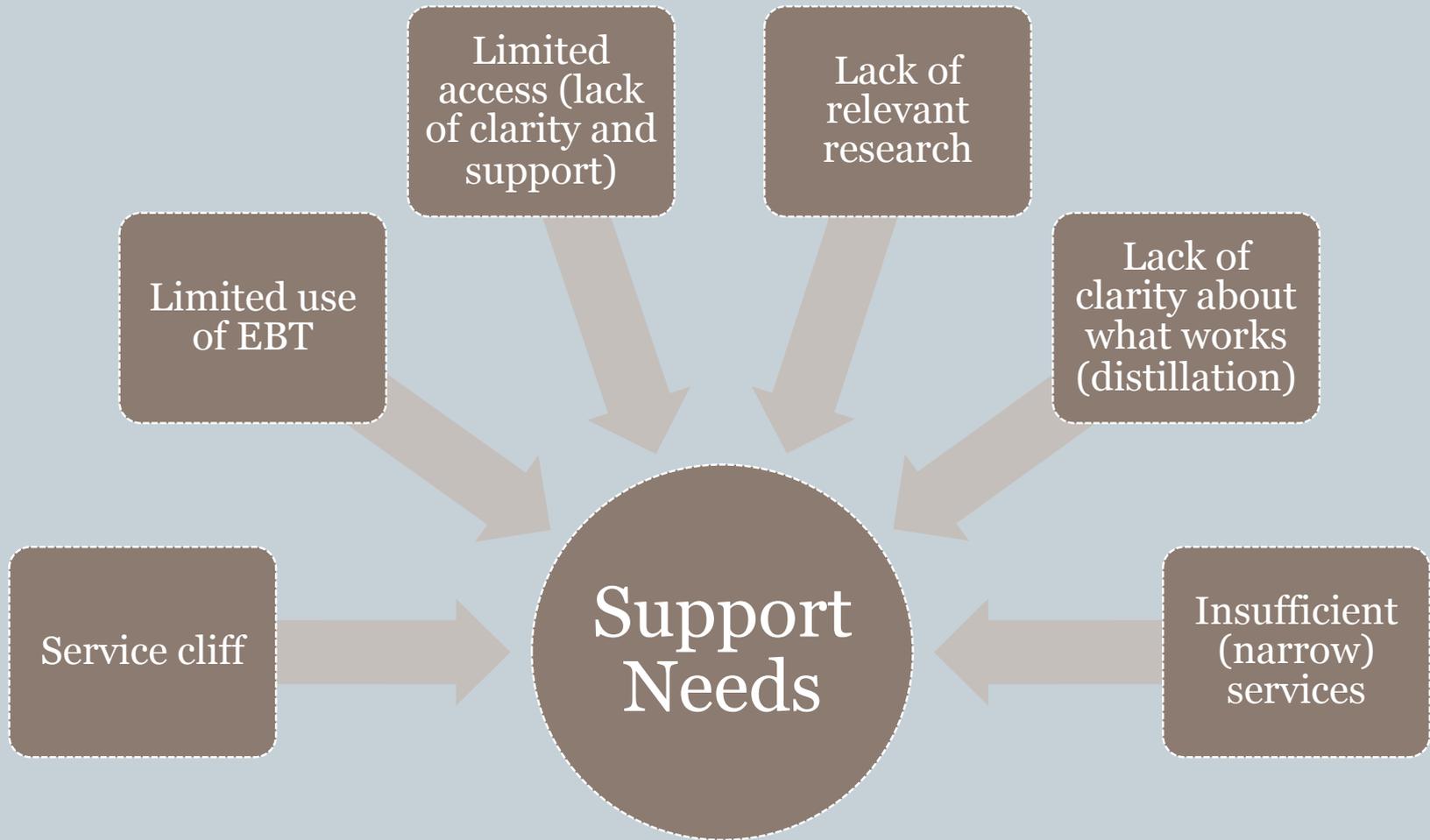
- We often think in terms of 'deficits' but there is more to it.
 - Ability to focus
 - Attention to detail
 - Unique humor
 - Honest, forthright
 - Fair, oriented toward social justice
 - Good memory
 - Logical



A Model of Challenges for Transition-Age Youth

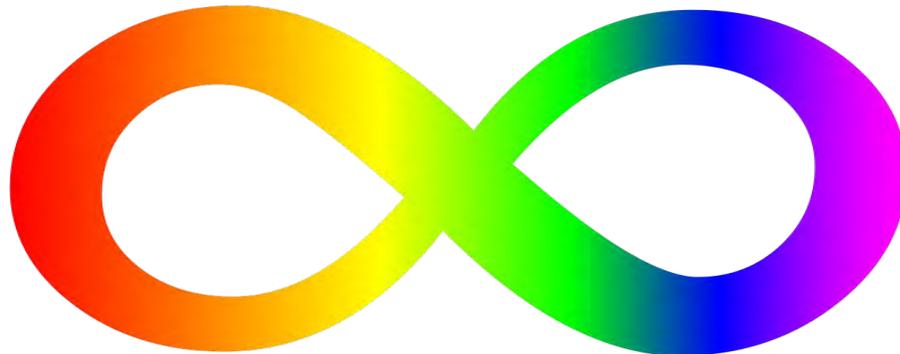


A Model of Support Needs



Inclusion & Access: Neurodiversity

- An approach to learning and disability that suggests that diverse neurological conditions appear as a result of normal variations in the human genome (Wiki)
 - Neurological differences should be recognized and respected socially (on par with gender, ethnicity, sexual orientation, or disability status)



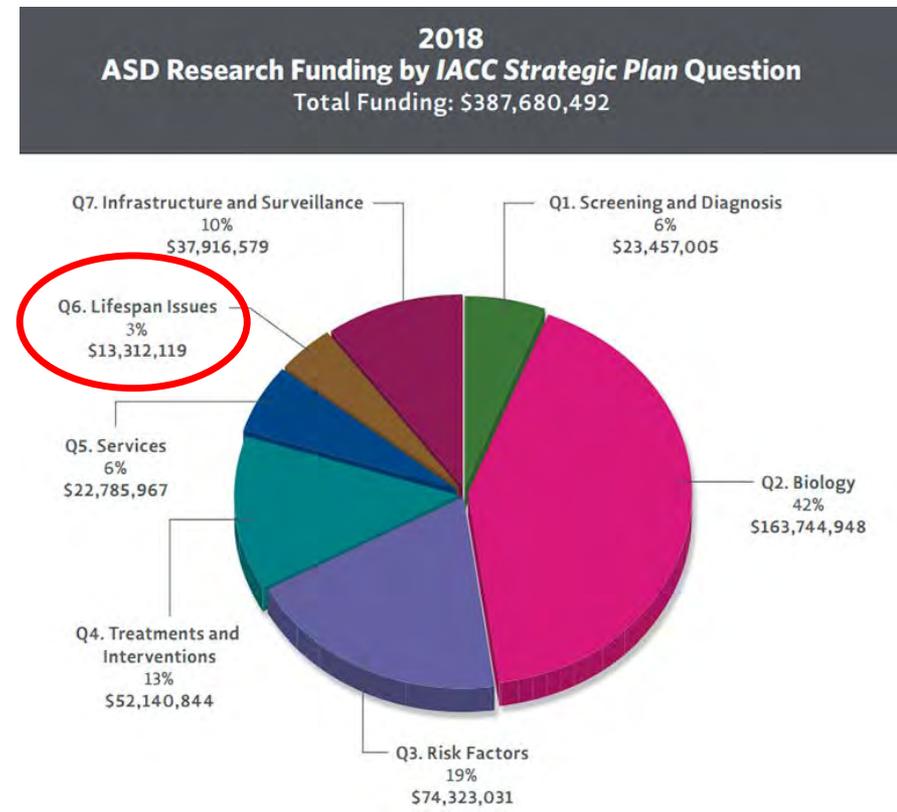
NOTHING

ABOUT US

WITHOUT US

Gaps in Treatment Research

- Most research is with cognitively able, verbal individuals
- Lower effect sizes – why?
- Long gap from efficacy to use (practice)
- Lifespan approach is rarely applied



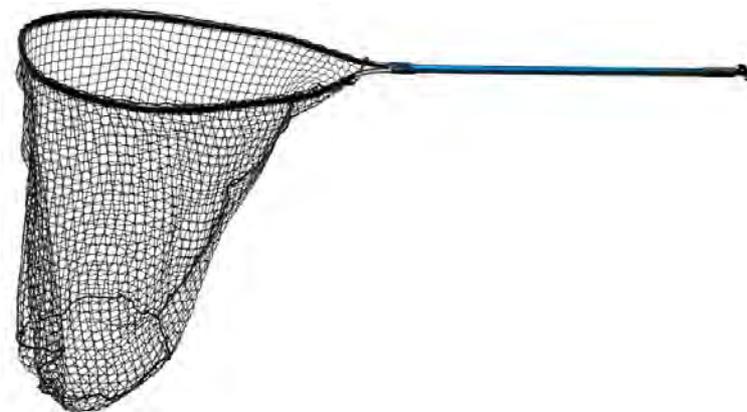
Cost of care

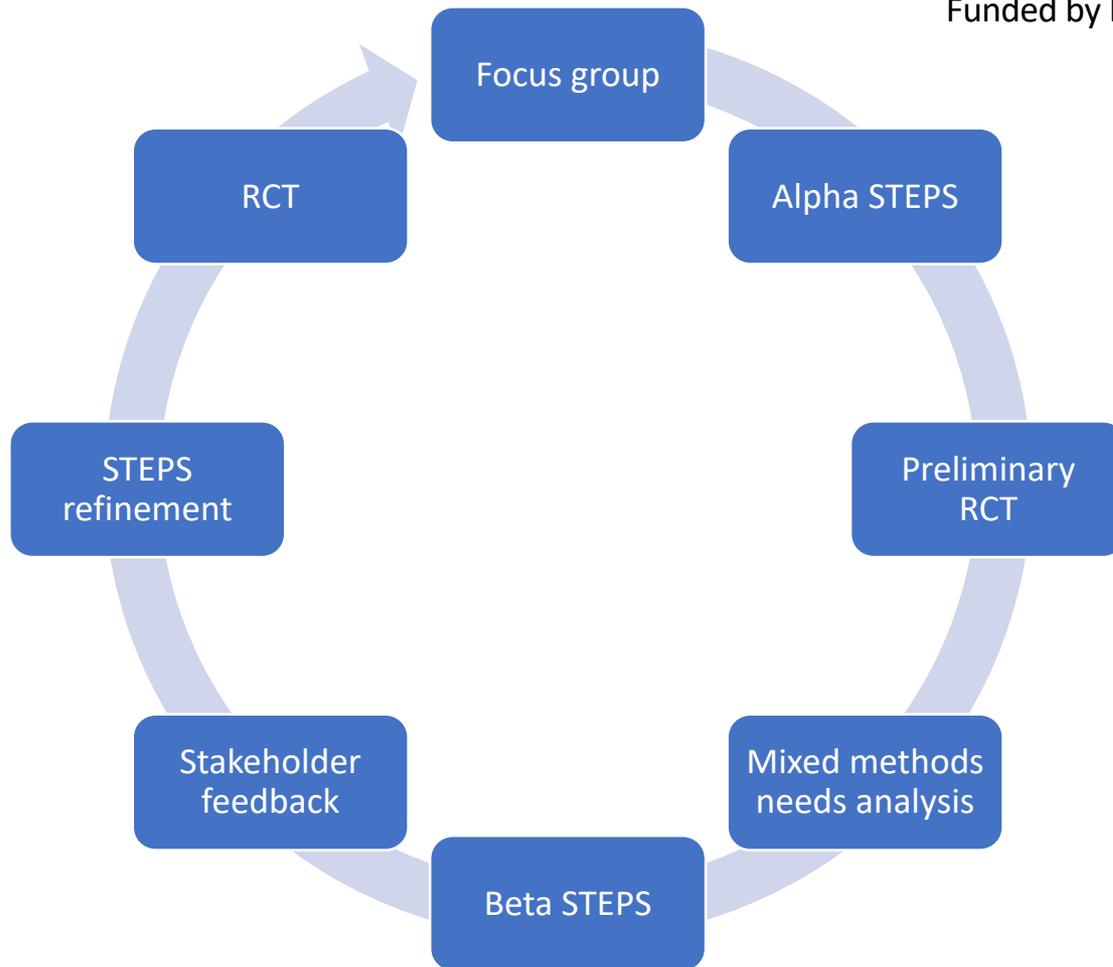
- Adults with ASD utilize health care services more than TD (double the cost) or adults with ADHD (20% higher)
- Adults with ASD have more Emergency Dept charges (2.3 times higher than TD adults)
 - Psychiatric disorder as reason for ED: 15% (ASD) vs. 4.2% (TD)
- Of the lifetime cost of autism (\$3.2 million), lost productivity and adult care are the largest contributors



Coordination of Services

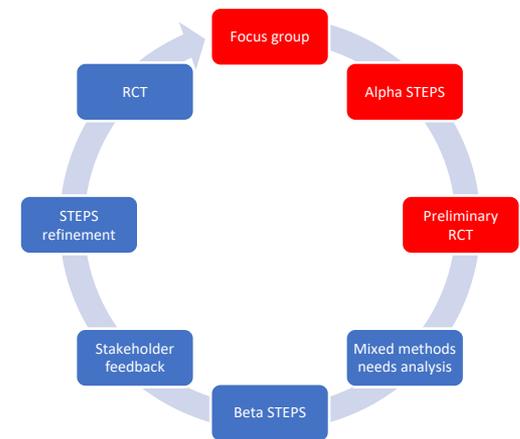
- Often not 'treating the autism' So hard to compare outcomes across interventions
- Family assumes role of case management after high school





Stepwise evolution of the Intervention, consistent with ORBIT Moel (Czajkowski et al., 2015) and NIH guidance on ASD psychosocial intervention research (Smith et al., 2007)

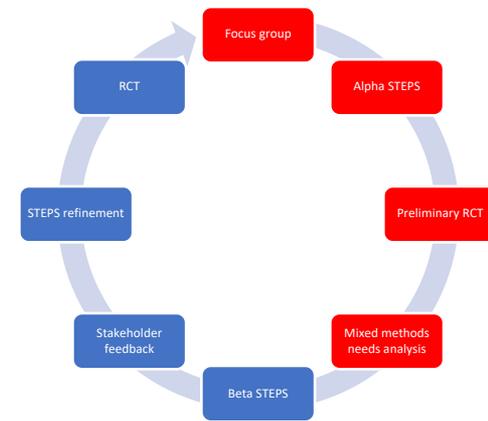
First steps



- Preliminary focus group (young adults with ASD) to identify the needs and challenges¹
- Used this information, along with theory, prior research, clinical experience, and expert consultation to develop first draft of STEPS curriculum
- Preliminary RCT (STEPS v BCI)²
 - N = 8; high feasibility (immediate recruitment, no drops), promising outcomes

¹Duke, Conner, Kreiser, Hudson, & White, 2013; ²White, Richey, Gračanin, Coffman, Elias, LaConte, & Ollendick, 2016

Mixed Methods Needs Analysis



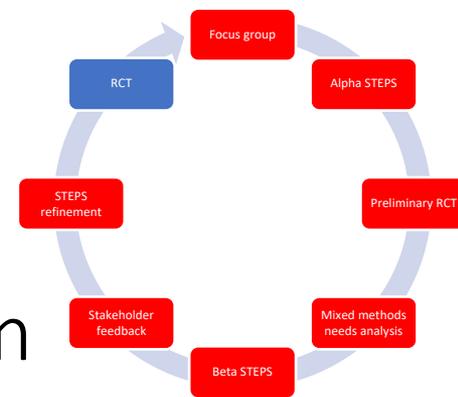
- Study 1
 - 2 focus groups; n=5 students, 10 school personnel and online survey (n=5 students, 30 SP, 32 parents)
 - Common themes across stakeholders: limited interpersonal competence, inability to manage competing demands in school, poor emotion regulation
- Study 2
 - Online survey with parents of adolescents & emerging with ASD (n=52) or ADHD (n=47)
 - Needs unique to ASD: social interaction training, independent living, self-advocacy, emotion management, adaptive/ self-care skills [a distinguishable pattern]
- Study 3
 - 4 focus groups (n=25 secondary and postsecondary educators)
 - Primary areas of difficulty: competency, autonomy/ independence, ability to sustain interpersonal relationships

STEPS Content



STEPS Content

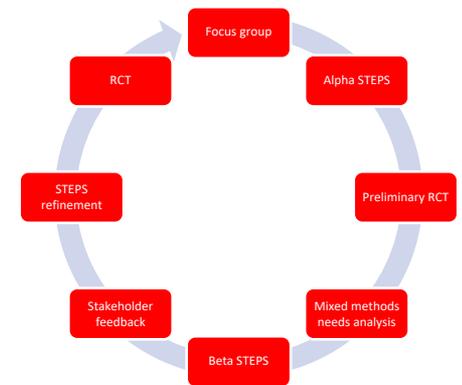
Skill	Activities
SK	<ul style="list-style-type: none">• Needs Assessment• Psychoeducation• Evaluate readiness for transition• Engage in age-appropriate tasks (e.g., driver's permit, job application)• Foster strengths and develop interests
SD	<ul style="list-style-type: none">• Identify integration opportunities/ supports• Identify and secure services, accommodations, supports• Immersion (practice self-advocacy and integration)
SR	<ul style="list-style-type: none">• Life skills coaching• Learn, practice emotion regulation strategies• Practice time management• Practice goal-setting and problem-solving related to goal attainment• Learn how to fade supports



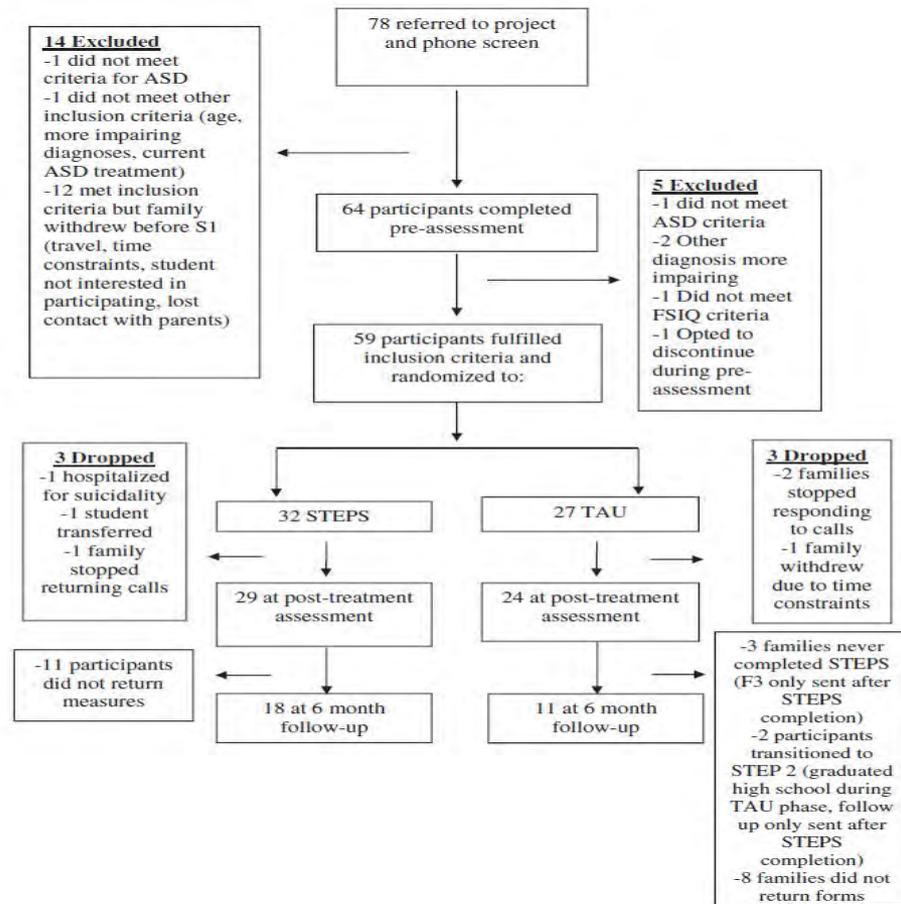
Stakeholder Feedback to Refine Program

- Feedback from stakeholders solicited
 - Expert panel comprised of clinical scientists and educators, ASD, treatment development
 - Parents of people with ASD
 - Students and adults with ASD
- Provided feedback on content, delivery, strategies to optimize learning and empower the client
- Example feedback from stakeholders
 - Help client consider potential benefits of non-traditional and 2-year cmtly college, prior to leaving home (staged approach)
 - Addressing fears of talking to people in authority
 - Increase comfort with and willingness to use technological supports such as apps

Preliminary RCT

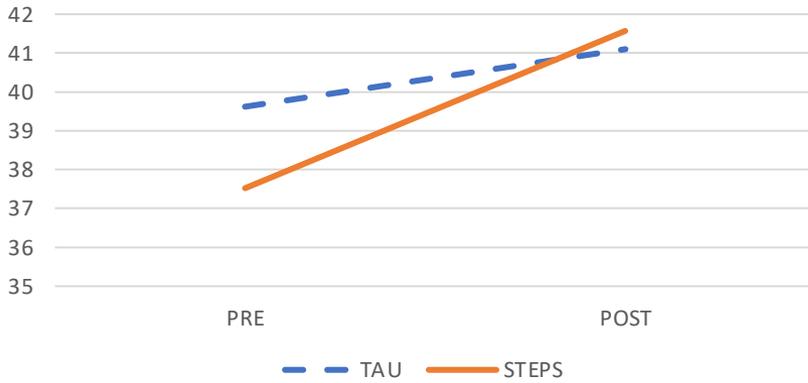


- N = 59, 16-25 yrs.
- High acceptability and fidelity
- STEP 1 (secondary students): significantly greater gains in readiness to transition
- STEP 2 (postsecondary students): significantly improved adaptation to college

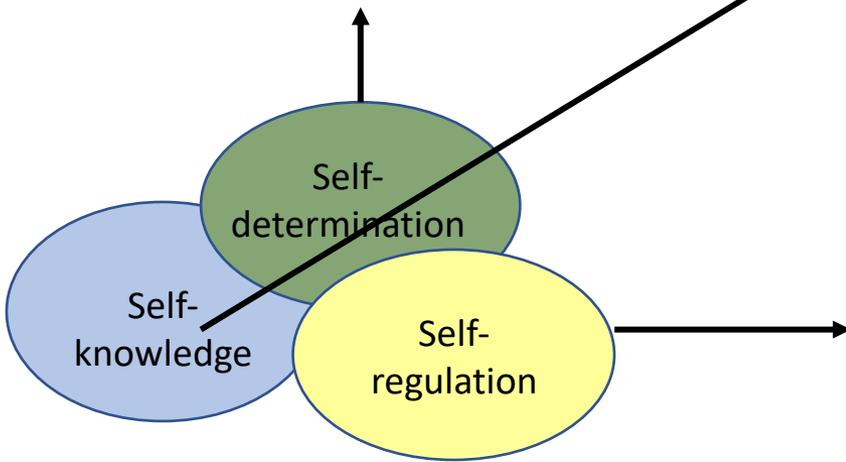
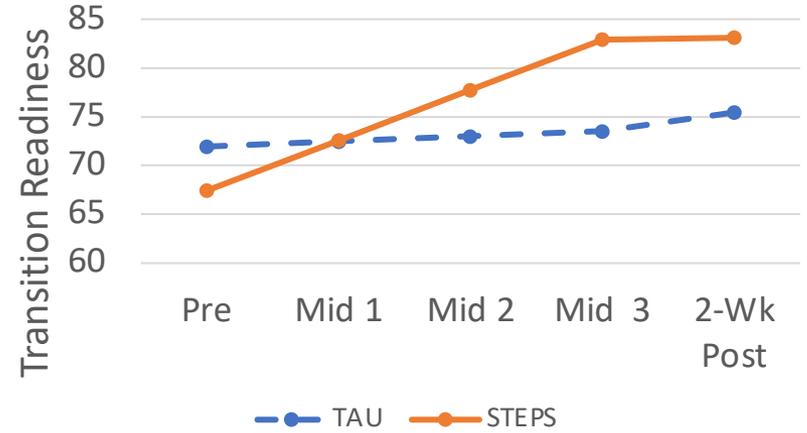


Outcomes

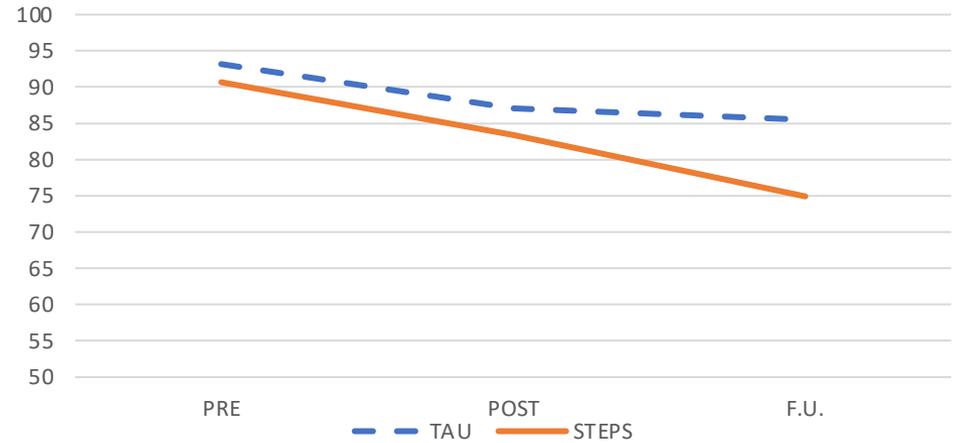
Parent-Reported SD



Change in Readiness for Transition from High School



DERS Total Score



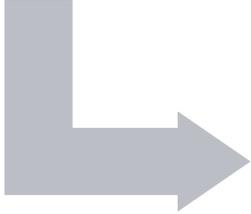
Stepped Transition in Education Program for Students with ASD



A multi-component, individualized program to targeting self-regulation and self-determination to improve educational outcomes for students with ASD

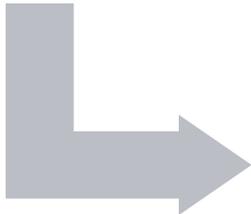
Phase 1

Identify barriers and facilitators to STEPS implementation



Phase 2

Initial refinement and pilot test of STEPS



Phase 3

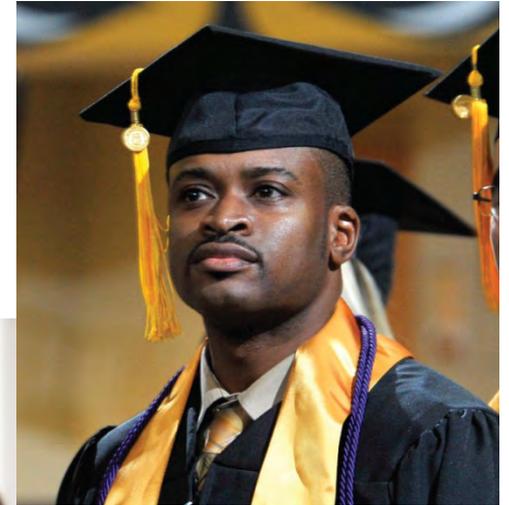
Optimize STEPS for future implementation



Discussion Points

- Is there a 'common practice'?
 - VRS – many either are not eligible or do not utilize services
 - Outpatient/Inpatient
 - Policies that prohibit treating ASD as primary diagnosis
 - A major obstacle is reaching the population, and the population reaching us (initiative?)
- Thinking proactively....
 - Housing needs
 - Employment training

Practical Suggestions





**SLOW
MINEFIELD**

**“In a minefield it is
wise to use caution”**
Ari Ne’eman

In the classroom and on the job



- **Inflexibility & Overload**

- Overload is dangerous: It leads to anxiety, impulsivity, inappropriate behavior
- It creates profound risk in context of social isolation, teasing and bullying
- Resistance to change; need for sameness [difficulty with traditional school curriculum]



In the classroom and on the job



- **Executive/Processing Deficits:**
 - Shifting attention, focus [~ADHD]
 - Active but unproductive – often need help distinguishing helpful from useless information
 - Perseveration/deficient solution generation
- **Strategies**
 - Help with understanding ‘unwritten rules’
 - Ensure assignment or task is understood
 - Refrain from extraneous (Extract the main idea first)
 - Identify a new patterns at the start of each semester
 - Build into routines, rather than fight against them

In the classroom and on the job



- **Socialization Deficits**
 - Difficulty relating to others
 - Poor stress management
 - Unusual behaviors, stereotypies, self-stimulatory behaviors
- **Possible Aids**
 - Be mindful of the demands [and perils] of working in groups
 - Identify social/networking groups of like-minded or accepting people
 - Recognize early distress signs
 - Be explicit but tactful, if necessary

In the classroom and on the job



- **Emphasize and build up the person's strengths**
 - Intelligent
 - Excellent focus and attention to detail
 - Sustained attention and focus (on topics of interest)
 - Strong long-term and rote memory
 - Reliable
 - Rule-following, good follow-through

thank you!

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Center for Youth Development and Intervention at UA

Center for Youth Development and Intervention



The CYDI's Mission is to improve prevention and treatment of youth mental health and behavioral problems and strengthen communities.

www.cydi.ua.edu

Parents: Do you or your child want to participate in research / interventions? Do you want to be informed of events?

Join our **CYDI registry** to give us permission to contact you with applicable information!

Are you an educator, clinician, organization, or professional and want to be a CYDI partner?

Complete our **CYDI partnership survey** to let us know you may be interested in partnering with us on future work and would like more info on workshops, events, and research.

Registry:



Partnership Survey:



Studies currently enrolling :

FAST: Facial Affect Sensitivity Training Study

Intervention for 6-11 year olds who struggle with empathy and concern for consequences

fastclinicaltrial@ua.edu

205-348-2472

ORED: Brain Research Study

Research study for 10-17 year olds who are neurotypical or who have been diagnosed with autism or social anxiety

b.rad.laboratory@gmail.com

205-348-4201

EASE: Managing Emotions for Teens and Young Adults with Autism

Intervention for 12-21 year olds with autism who struggle with managing their emotions

npowell@ua.edu

205-348-6551

R15: Social Attention Study

Research study for 11-13 year olds

b.rad.laboratory@gmail.com

205-348-4201

The FEELING Study

Online surveys for teens in high school and their caregivers

Email mxia3@ua.edu or visit our website at:

<https://mxia.people.ua.edu/feeling.html>