

MENTAL HEALTH AND SOCIAL SUPPORT DURING THE TRANSITION TO ADULTHOOD FOR INDIVIDUALS WITH NEURODEVELOPMENTAL DISORDERS

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1/25/21

Tarjan Lecture Series

TRANSITION TO ADULTHOOD

- Increased recognition as a distinct developmental period



Buchman & Kriesi, 2011; Schulenberg, Sameroff, & Cicchetti, 2004; Arnett, 2000; Cicchetti & Rogosch, 2002; Sameroff, 2000; Cohen, Kasen, Chen, Hartmark, & Gordon, 2003

TRANSITION TO ADULTHOOD

- Increased recognition of a distinct developmental period
- Characterized by exploration and continued identity development
- Diverse paths and outcomes



Buchman & Kriesi, 2011; Schulenberg, Sameroff, & Cicchetti, 2004; Arnett, 2000; Cicchetti & Rogosch, 2002; Sameroff, 2000; Cohen, Kasen, Chen, Hartmark, & Gordon, 2003

TRANSITION TO ADULTHOOD

- Increased recognition of a distinct developmental period
- Characterized by exploration and continued identity development
- Heterogeneous pathways and demographic diversity

- Person-Context interactions
- The transition period is developmentally salient
- Critical juncture



Buchman & Kriesi, 2011; Schulenberg, Sameroff, & Cicchetti, 2004; Arnett, 2000; Cicchetti & Rogosch, 2002; Sameroff, 2000; Cohen, Kasen, Chen, Hartmark, & Gordon, 2003

TRANSITION OUTCOMES FOR PERSONS WITH ND

- The service cliff



Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Shattuck et al., 2012; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Grigal, Hart, & Migliore, 2011; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; McIntyre, Blacher, & Baker, 2000

TRANSITION OUTCOMES FOR PERSONS WITH ND

- The Service Cliff
- Fundamentally Different



Jackson, Hart, Thierfeld Brown, & Volkmar, 2018; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Shattuck et al., 2012; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Grigal, Hart, & Migliore, 2011; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; McIntyre, Blacher, & Baker, 2000

TRANSITION OUTCOMES FOR PERSONS WITH ND



- The Service Cliff
- Fundamentally Different Experience
- Pervasive Negative Outcomes

Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Shattuck et al., 2012; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Grigal, Hart, & Migliore, 2011; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; McIntyre, Blacher, & Baker, 2000

MENTAL HEALTH

- Epidemiologically: 1 in 4 young adults (18-24 years old)
- Increase from adolescence
- Unmet needs
- Functional impairments
 - More likely to be NEET
 - Lower GPA, dropping out, substance use
 - Long term economic impacts



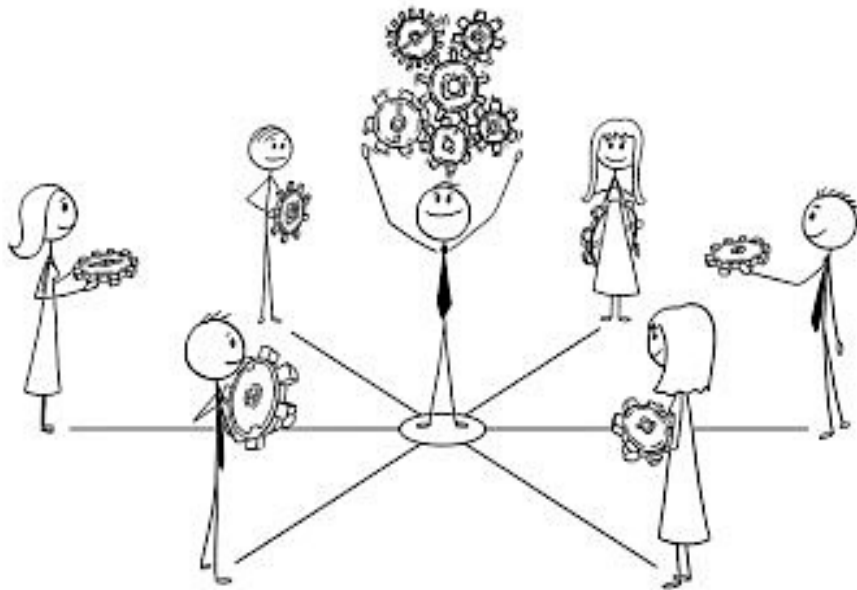
Cannon, Coughlan, Clarke, Harley, & Kelleher, 2013; Gibb et al., 2010; Holloway, Rickwood, Rehm, Meyer, Griffiths, & Telford, 2018; Baggio et al., 2015; Patel, Flisher, Hetrick, & McGorry, 2007; Cheung & Dewa, 2007; Eisenberg, Golberstein, & Hunt, 2009; Prince et al., 2007

MENTAL HEALTH & SOCIAL SUPPORT IN ND

Elevated rates of mental health problems in ND

- Estimates: 75% of adults with ASD
- Estimates: 50% of adults with ID

SOCIAL SUPPORT



- Strong support for its relationship to mental health and physical health in general population
- Multidimensional –
 - Perceived vs. Received
 - Size, composition
 - Function: emotional, belonging, practical, informational

Viswesvaran, Sanchez, & Fisher, 1999; Barnett & Gotlib, 1988; Kawachi & Berkman, 2001; Uchino, Cacioppo, & Kiecolt-Glaser, 1996; Leavy, 1983; Haber, Cohen, Lucas, & Baltes, 2007; Barnett & Gotlib, 1988

MENTAL HEALTH & SOCIAL SUPPORT IN ND

Elevated rates of mental health problems in ND

- Estimates: 75% of adults with ASD
- Estimates: 50% of adults with ID

Diminished social support in ND

- Smaller network size
- More reliance on professionals, less reliance on friends
- Less connection and lower satisfaction

PREDICTING SUCCESSFUL TRANSITION OUTCOMES

- Individual-level disability characteristics are most widely studied
 - IQ, Social-Communication Skills, ASD severity, Adaptive Behavior

Davis & Vander Stoep, 1997; Neece, Kraemer, & Blacher, 2009; Magiati, Tay, & Howlin, 2014; Taylor & Seltzer, 2011; Lounds Taylor, Adams, & Bishop, 2017; Chiang & Wineman, 2014

PREDICTING SUCCESSFUL TRANSITION OUTCOMES

- Individual-level disability characteristics are most widely studied
 - IQ, Social-Communication Skills, ASD severity, Adaptive Behavior
- Contextual Factors?
 - Social Support

Shattuck, Lau, Anderson, & Kuo, 2018; Davis & Vander Stoep, 1997; Neece, Kraemer, & Blacher, 2009; Magiati, Tay, & Howlin, 2014; Taylor & Seltzer, 2011; Lounds Taylor, Adams, & Bishop, 2017; Chiang & Wineman, 2014

PREDICTING SUCCESSFUL TRANSITION OUTCOMES

- Individual-level disability characteristics are most widely studied
 - IQ, Social-Communication Skills, ASD severity, Adaptive Behavior
- Contextual Factors?
 - Social Support
- Mental Health?
 - Differentiates functional outcomes concurrently
 - Review: only 1 paper looked at mental health longitudinally

Mason, Mackintosh, McConachie, Rodgers, Finch, & Parr, 2019; Davis & Vander Stoep, 1997; Neece, Kraemer, & Blacher, 2009; Magiati, Tay, & Howlin, 2014; Taylor & Seltzer, 2011; Lounds Taylor, Adams, & Bishop, 2017; Chiang & Wineman, 2014

THE CURRENT STUDIES

COLLABORATIVE FAMILY STUDY (CFS)

- Longitudinal study of children and families
 - Typically Developing
 - Intellectual Disability
 - Autism Spectrum Disorder
- **Current Study: Young Adult Follow-Up (~age 22)**
- **N=93**
 - 44 TD, 49 ND



	Typically Developing (TD) n=44	Autism Spectrum Disorder (ASD) n=20	ASD + comorbid Intellectual Disability (ID) n=14	Intellectual Disability (ID) n=15	F or χ^2
Full Scale IQ – WISC (age 13)	112.55 (11.43)	110.00 (13.82)	62.00 (13.06)	60.00 (12.69)	98.67***
Adaptive Behavior – Vineland (age 13)	97.42 (8.74)	78.84 (7.99)	68.00 (8.22)	75.00 (6.69)	58.93***
YA age	22.13 (0.80)	21.65 (0.81)	21.64 (0.75)	21.53 (0.74)	2.27
YA Sex (% male)	43.2	95.0	64.3	60.0	15.53**
YA Ethnicity (% Caucasian)	59.1	65.0	64.3	60.0	0.10
Family Income (% <95,000k)	37.1	33.3	58.3	46.2	2.20

PROCEDURE

- Parents and young adults completed:
 - Online Questionnaires – Qualtrics
 - Semi-Structured Interviews

- ASD and/or ID
 - In person

<u>YOUNG ADULT MEASURES</u>	<u>Respondent</u>	<u>Subscales/domains</u>	<u>Length</u>
Transition Outcome Composite	Self (and parent)	Professional Activities, Social, Independence	Derived from 9 items
WHOQOL-BREF (Quality of Life)	Self	Physical, Psychological, Social, Environment	26 items
Adult Self Report (ASR) / Adult Behavior Checklist (ABCL)	Self & Parent	Total Problems, Internalizing, Externalizing	126 items
Interpersonal Support Evaluation List - Short (ISEL)	Self	Appraisal, Belonging, Tangible	12 items
Social Support Network	Self	Practical, Informational, Companionship, Emotional	4 items

Whoqol Group, 1998; Skevington, Lofty, & O'Connell, 2004; Power & Green, 2010; Eaves & Ho, 2008; Howlin et al., 2004; Achenbach & Rescorla, 2003; Tenneji & Koot, 2007

<u>Domain</u>	<u>ADOLESCENT PREDICTORS</u>	<u>Respondent</u>	<u>Subscales/ Domains</u>	<u>Time point</u>
Mental Health	Child Behavior Checklist	Mother	Total Problems	15
Parenting	Parent Child Interaction Rating System	Coded	Positive & Negative Parenting	15
Student-Teacher Relationships	Student Teacher Relationship Scale	Teacher	Total	13, 15
Peer Relationships	Parent/Teacher Rating of Social Acceptance	Mother & Teacher	None	13, 15
Peer Relationships	Bullying Survey	Mother & Self	None	13, 15
Self-Efficacy	Children's Hope Scale	Self	Agency, Pathways	15

Elgar, Waschbusch, Dadds, & Sigvaldason, 2007; Prevatt, 2003; Pianta, 2001; Jerome, Hamre, & Pianta, 2009; Pianta & Stuhlman, 2004; Harter & Pike, 1984; Snyder et al., 1997; Valle, Huebner, & Suldo, 2004

Functional Outcomes

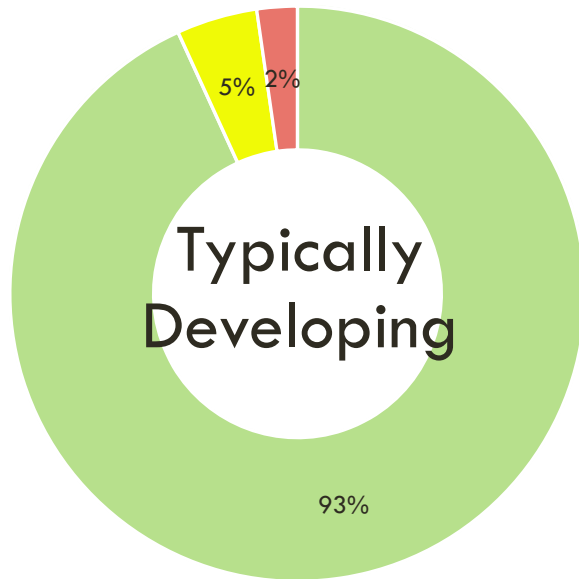
(as measured by the Transition Outcome Composite - TOC)

- Professional Activities:
 - higher education, paid employment
 - Independent Functioning:
 - living situation, autonomy
 - Social Relationships:
 - number of close friends, satisfaction with social network
- 0-3 scale (0 is best outcome)
 - Integrated Parent- and Self-Report toward a final rating
 - Double coded with high inter-rater reliability

RESULTS

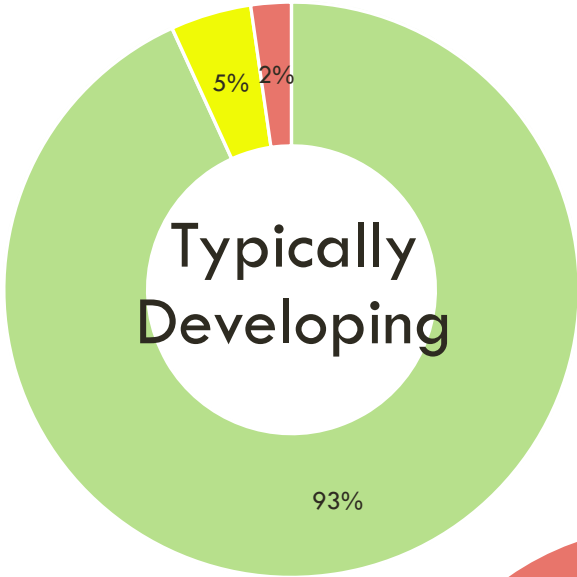


Functional Outcomes (as measured by the TOC)

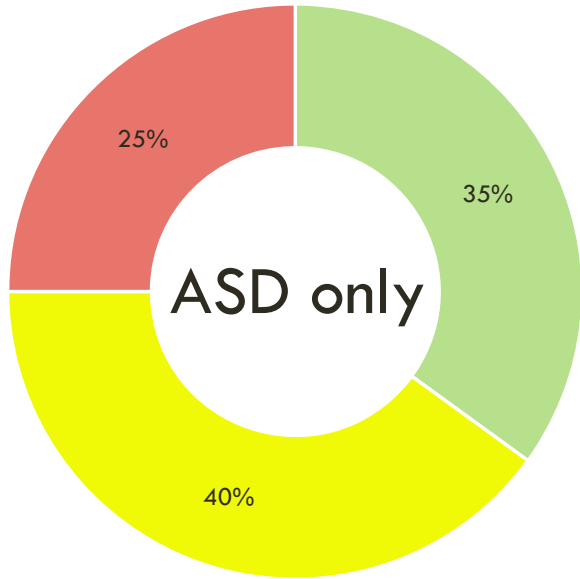
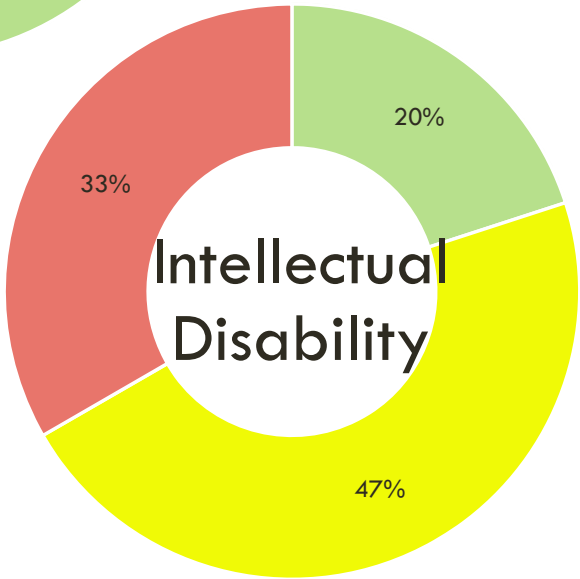


- Very Good or Good
- Fair
- Poor or Very Poor

Functional Outcomes (as measured by the TOC)

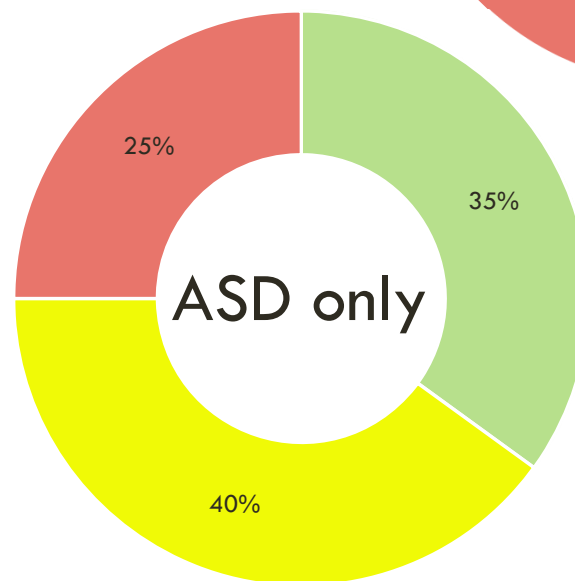
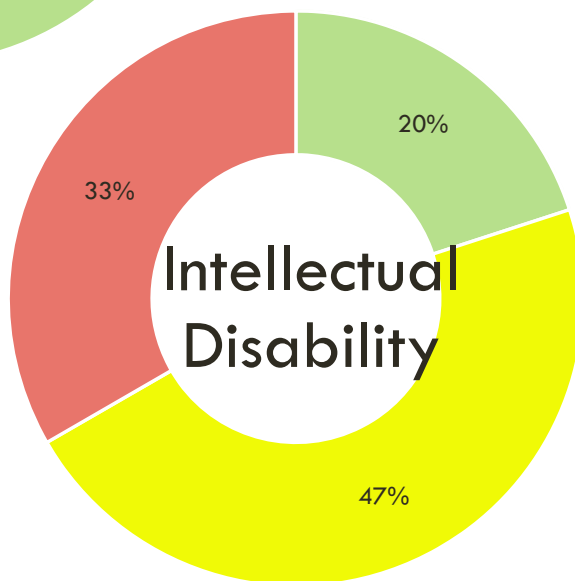
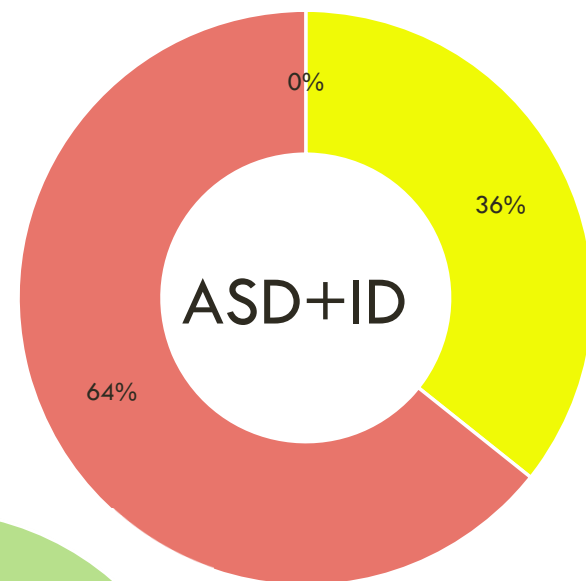
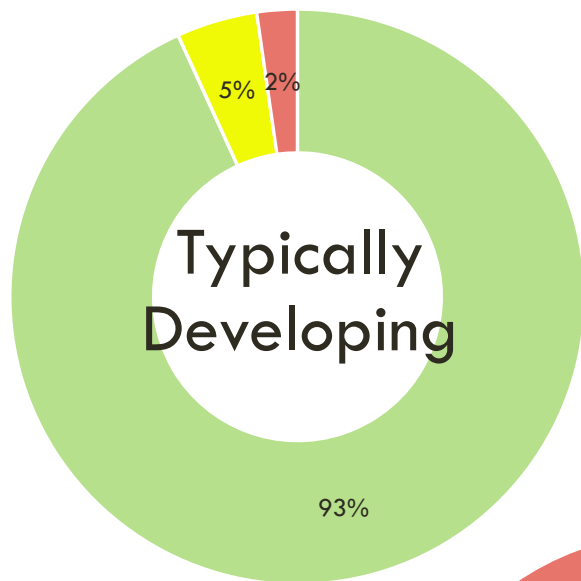


- Very Good or Good
- Fair
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Functional Outcomes (as measured by the TOC)

- Very Good or Good
- Fair
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MENTAL HEALTH FOCUS

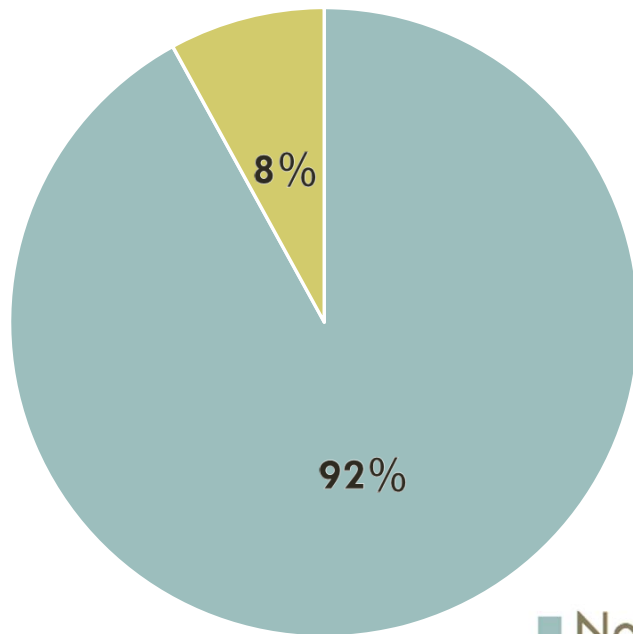
Moderator:
Diagnostic Status

Aim 1: To what extent does mental health in young adulthood relate to functional outcomes and quality of life?

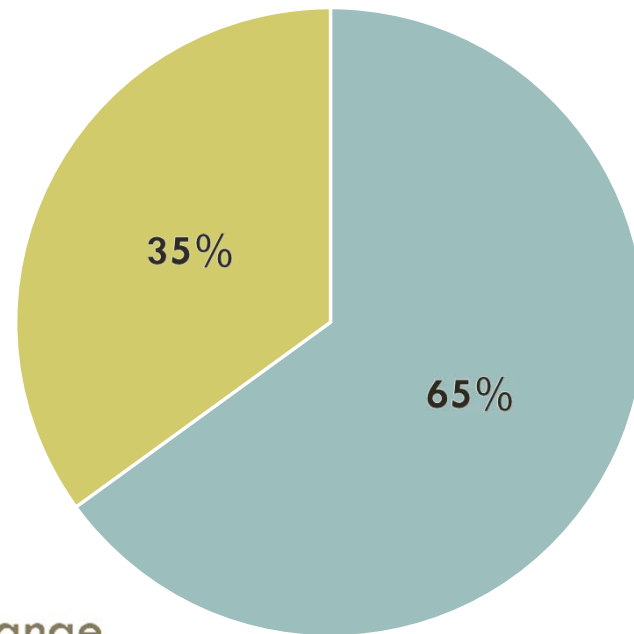
Aim 2: Which relationship factors in adolescence predict mental health outcomes in young adulthood?

PARENT-REPORTED TOTAL PROBLEMS (ABCL)

Typically Developing



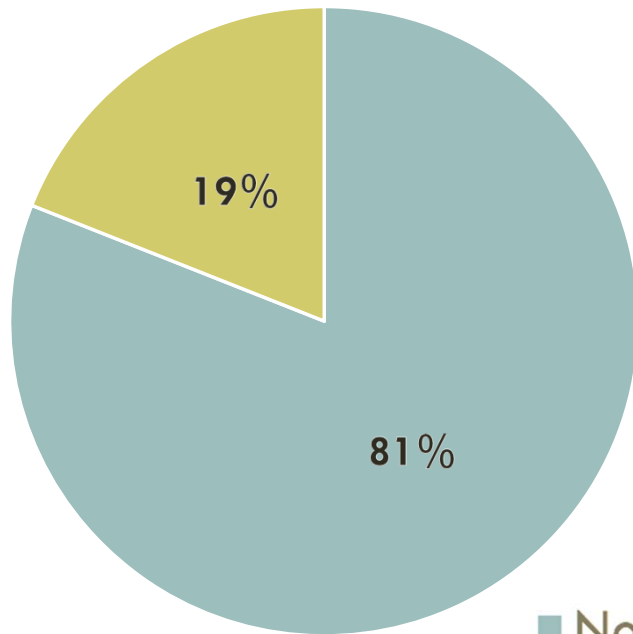
All ND (ASD and/or ID)



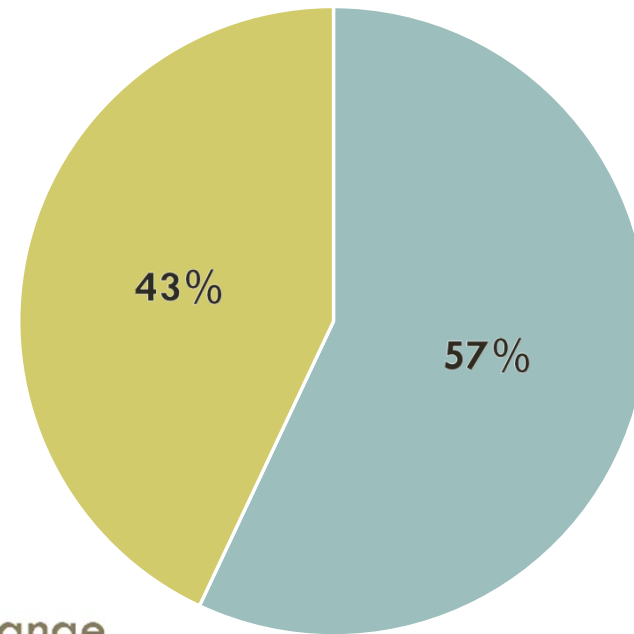
■ Normative Range
■ Clinically Elevated

SELF-REPORTED TOTAL PROBLEMS (ASR)

Typically Developing

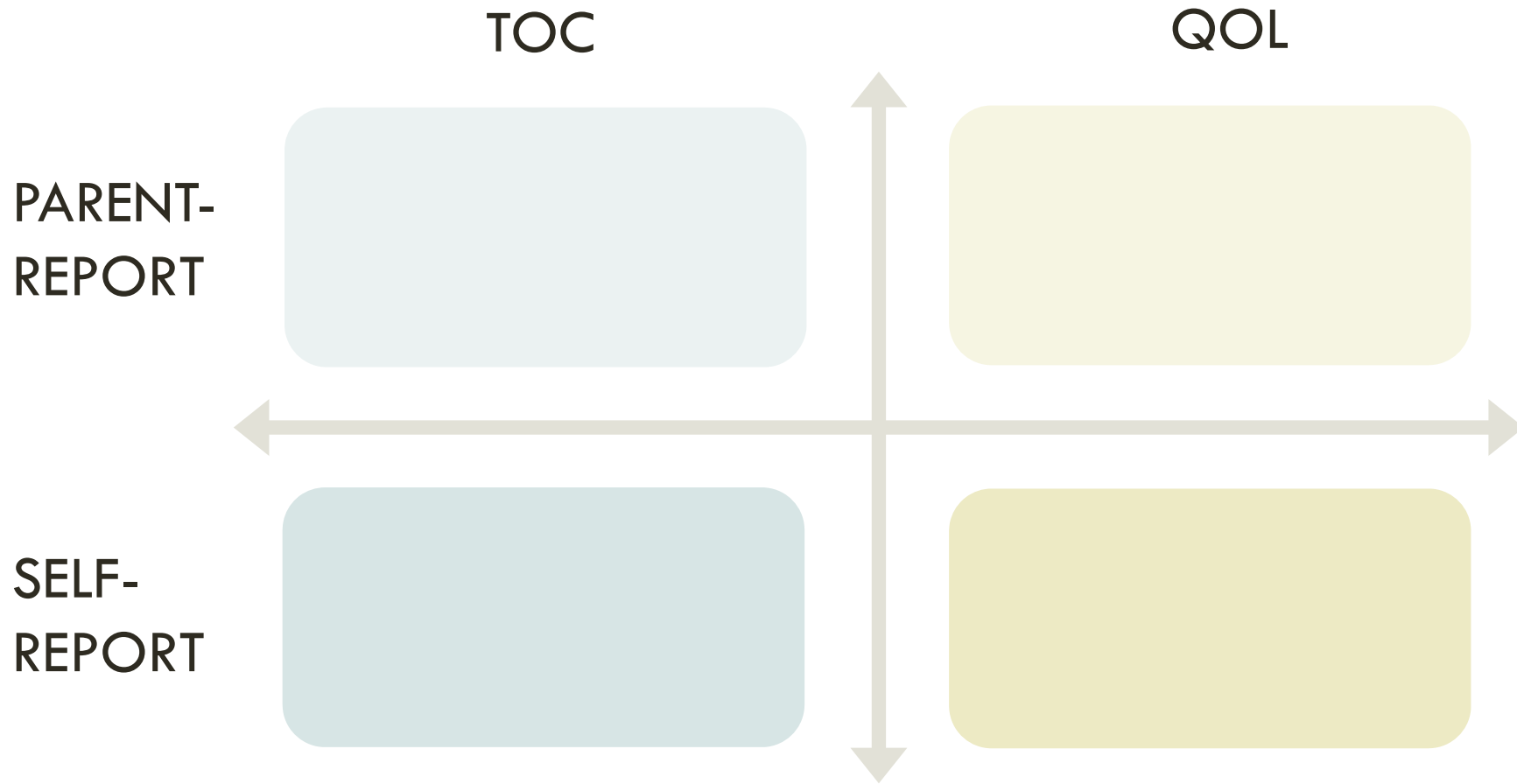


All ND (ASD and/or ID)

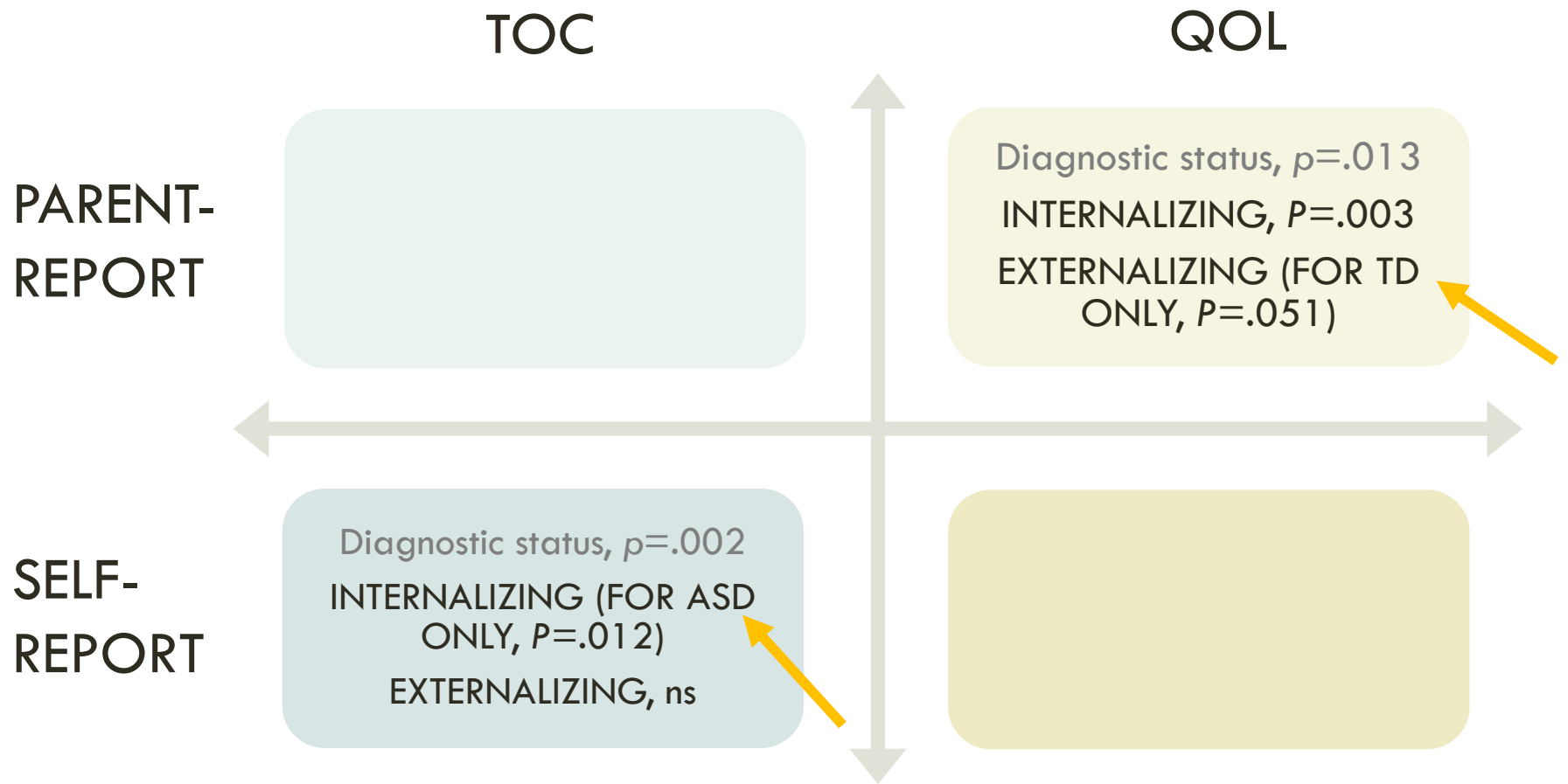


■ Normative Range
■ Clinically Elevated

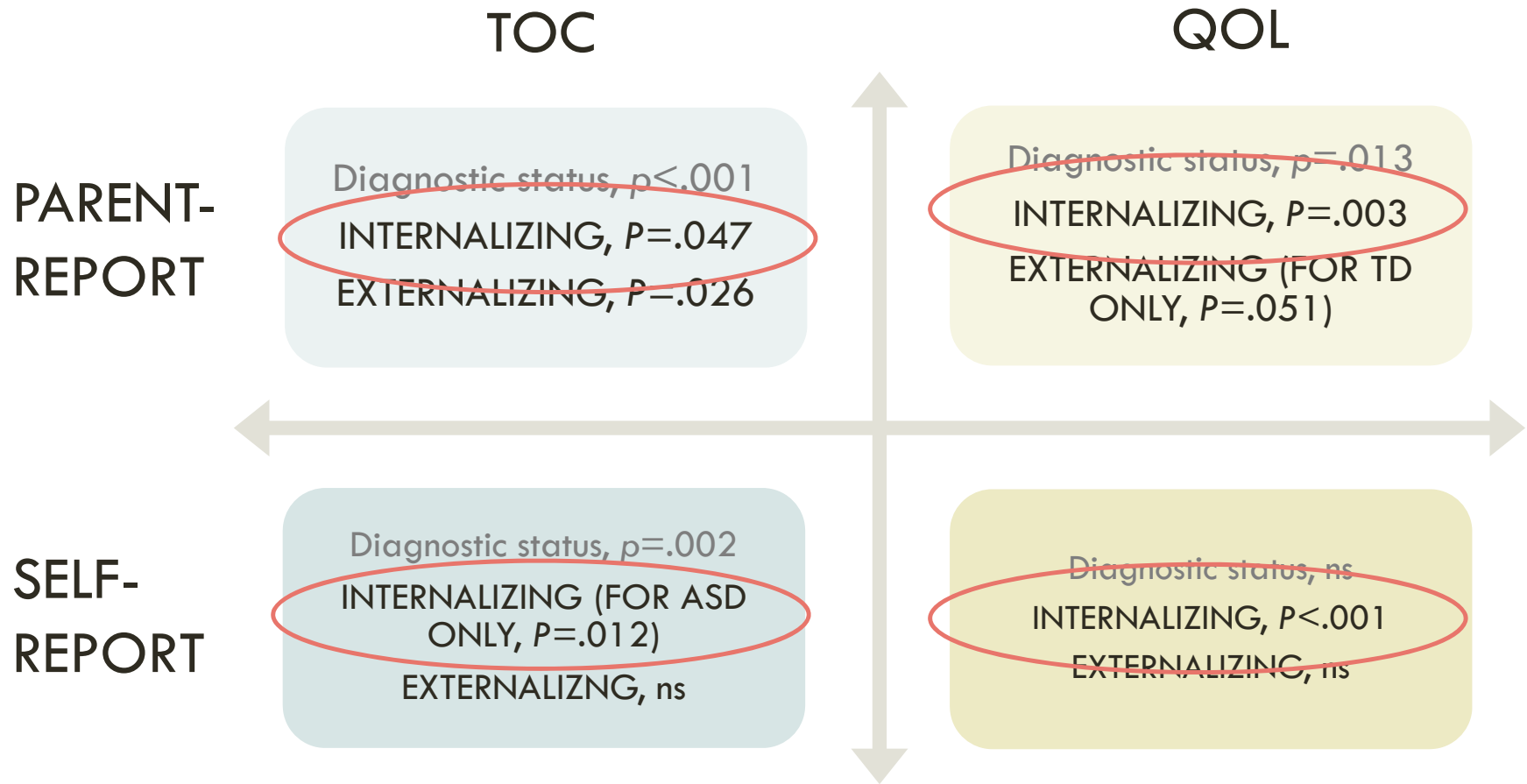
MENTAL HEALTH & YOUNG ADULT OUTCOMES



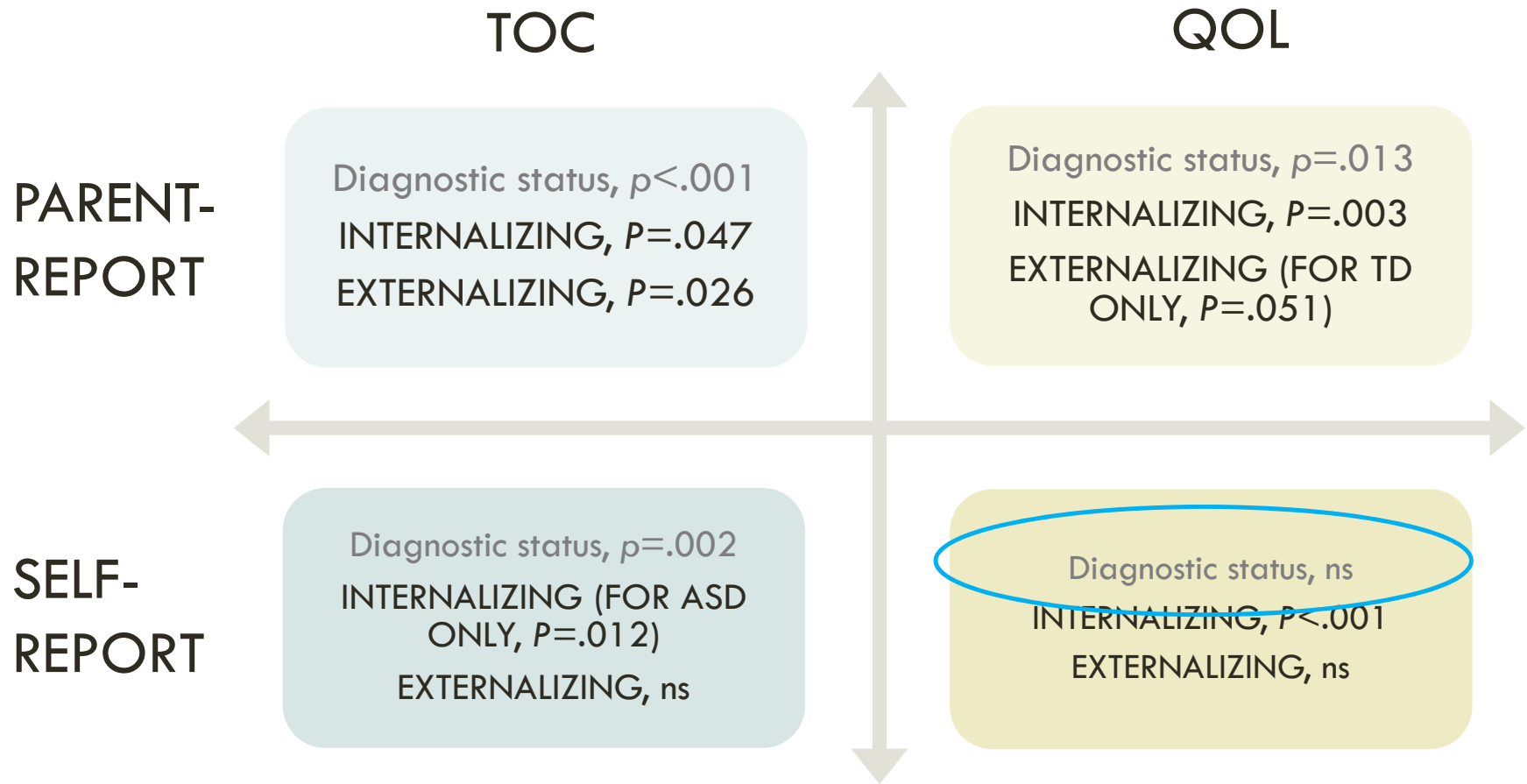
MENTAL HEALTH & YOUNG ADULT OUTCOMES



MENTAL HEALTH & YOUNG ADULT OUTCOMES



MENTAL HEALTH & YOUNG ADULT OUTCOMES



PREDICTING MENTAL HEALTH: PARENTING

Term	<i>F</i>	<i>p</i>	<i>R</i> ²
CBCL Total Problems (age 15)	14.23	<.001	
Diagnostic Status	4.48	.015	
PREDICTOR(S)			
INTERACTION TERM(S)			

PREDICTING MENTAL HEALTH: PARENTING

Term	<i>F</i>	<i>p</i>	<i>R</i> ²
CBCL Total Problems (age 15)	14.23	<.001	.37
Diagnostic Status	4.48	.015	
Negative Parenting (age 15)	3.85	.054	
Positive Parenting (age 15)	.061	.806	

PREDICTING MENTAL HEALTH: STUDENT TEACHER RELATIONSHIPS

Term	F	p	R²
CBCL Total Problems (age 15)	13.50	<.001	.30
Diagnostic Status	7.14	.002	
STR Total (age 13/15)	1.52	.223	

PREDICTING MENTAL HEALTH: PEER RELATIONSHIPS

Term	<i>F</i>	<i>p</i>	<i>R</i> ²
CBCL Total Problems (age 15)	8.42	.005	.38
Diagnostic Status	5.75	.005	
Bullying Average (age 15)	7.03	.010	
Peer Acceptance Average (age 13/15)	1.25	.266	

PREDICTING MENTAL HEALTH: HOPE

Term	<i>F</i>	<i>p</i>	<i>R</i> ²
CBCL Total Problems (age 15)	14.60	<.001	.41
Diagnostic Status	8.08	.001	
Hope (age 15)	10.60	.002	

TAKEAWAYS ON MENTAL HEALTH



1. Internalizing Problems

- ND young adults at greater risk
- More closely linked to impairment

TAKEAWAYS ON MENTAL HEALTH



1. Internalizing Problems

- DD at greater risk
- More closely linked to impairment

2. Long-lasting impacts of variables in adolescence

- Negative parenting
- Bullying
- Hope

RESEARCH QUESTIONS

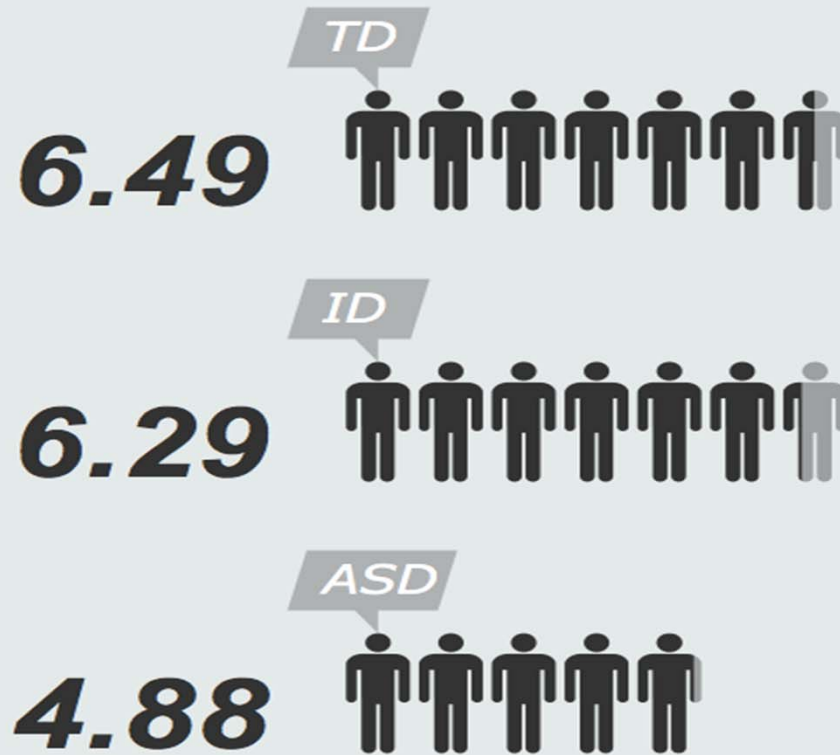
Moderator:
Diagnostic Status

Aim 1. What group differences are present in the composition and perception of social support networks in young adulthood?

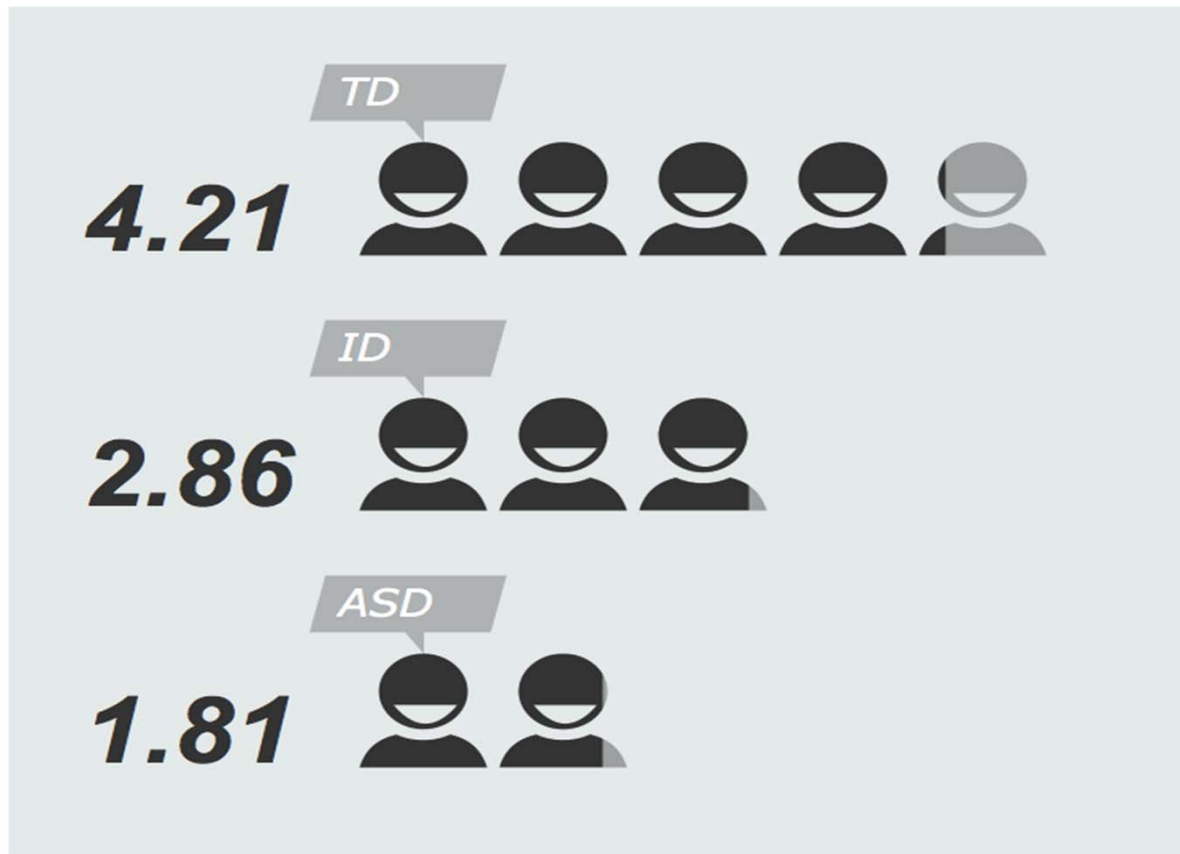
Aim 2. To what extent do specific aspects of social support concurrently relate to functional outcomes and mental health?

Aim 3. Do mental health and hope in adolescence predict social support outcomes in young adulthood?

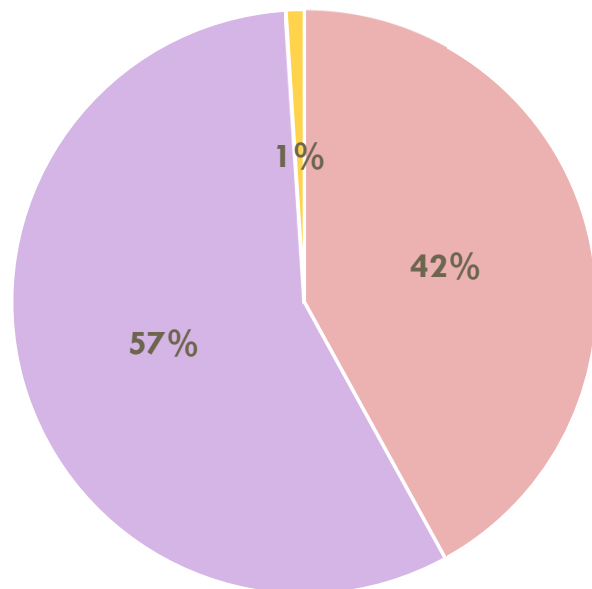
TOTAL NETWORK SIZE



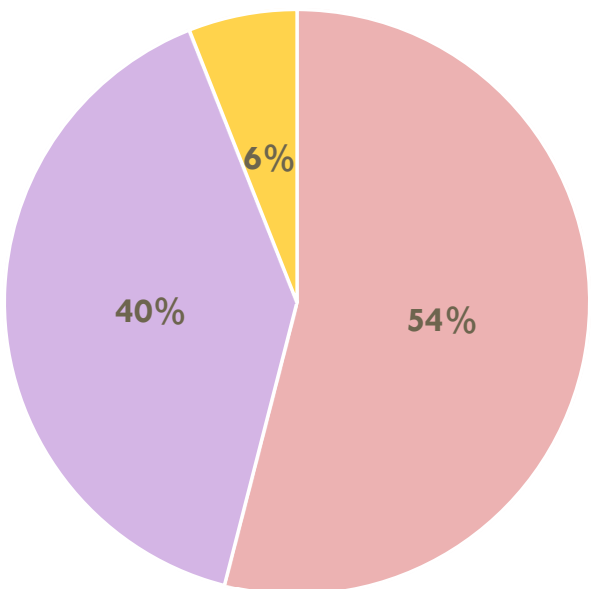
TOTAL FRIENDS IN NETWORK



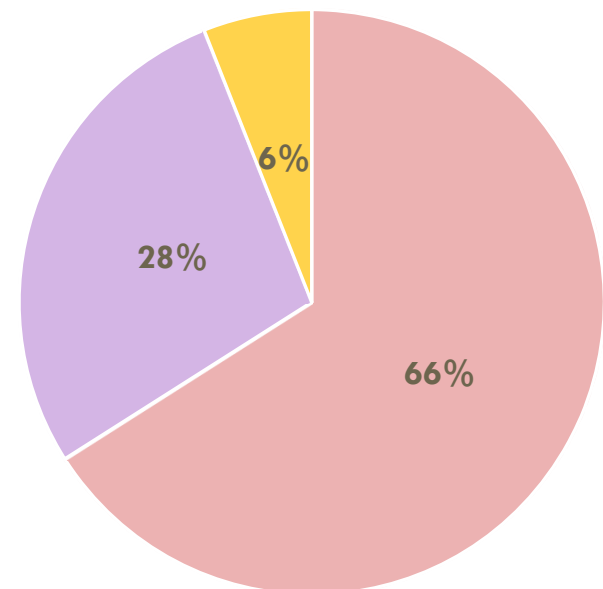
Typically
Developing



Intellectual
Disability

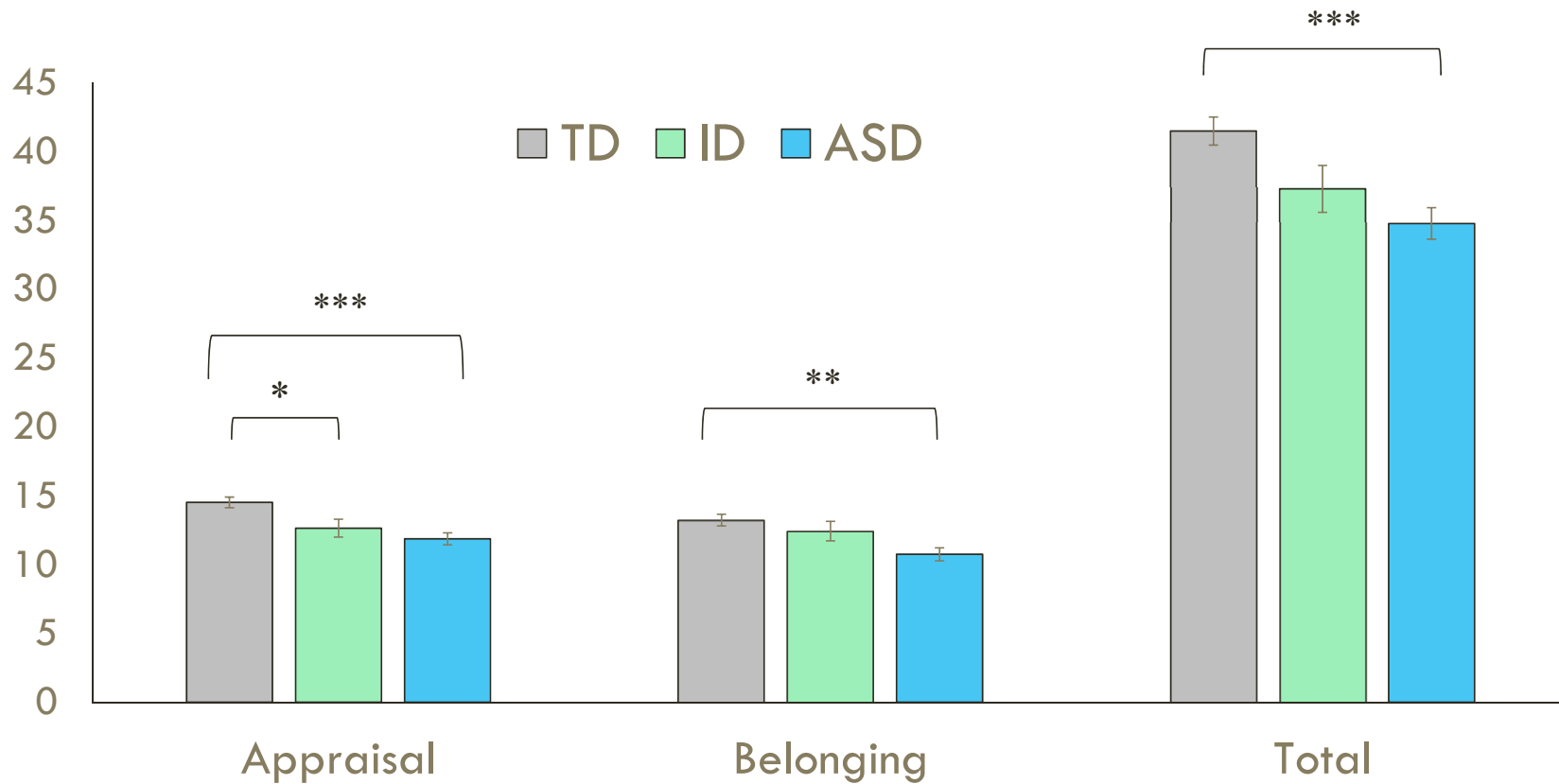


Autism Spectrum
Disorder



■ Family ■ Friends ■ Professionals

PERCEIVED SOCIAL SUPPORT



SOCIAL SUPPORT & YOUNG ADULT OUTCOMES

Functional Outcome

- Network size related to functional outcome as measured by the TOC
- Similar effect for all groups
- Those with more people in their support networks, had better functional outcomes
 - more likely to be involved in education/employment

SOCIAL SUPPORT & YOUNG ADULT OUTCOMES

Functional Outcome

- Network size related to functional outcome as measured by the TOC
- Similar effect for all groups
- Those with more people in their support networks, had better functional outcomes
 - more likely to be involved in education/employment

Mental Health

- Network size did not relate to mental health outcomes
- However, perceived social support (ISEL) was significantly associated with YA internalizing problems (ASR), $p=.001$.
 - Driven by perceived belonging support
- No relation to externalizing

PREDICTING SOCIAL SUPPORT IN YOUNG ADULTHOOD

Outcomes:

- PERCEIVED BELONGING AND APPRAISAL SUPPORT (ISEL-12)
- NUMBER OF FRIENDS AND NUMBER OF FAMILY MEMBERS

Term	<i>F</i>	<i>p</i>	<i>R</i> ²
Diagnostic Status			
Internalizing Problems (CBCL age 15)			
Externalizing Problems (CBCL age 15)			
Hope (age 15)			

PREDICTING SOCIAL SUPPORT IN YOUNG ADULTHOOD

Outcome: NUMBER OF FAMILY MEMBERS

Term	<i>F</i>	<i>p</i>	<i>R</i> ²
Diagnostic Status	5.16	.008	.16
Internalizing Problems (CBCL age 15)	0.35	.556	
Externalizing Problems (CBCL age 15)	6.08	.016	
Hope (age 15)	2.97	.089	

PREDICTING SOCIAL SUPPORT IN YOUNG ADULTHOOD

Outcome: PERCEIVED BELONGING SUPPORT (ISEL-12)

Term	<i>F</i>	<i>p</i>	<i>R</i> ²
Diagnostic Status	1.81	.170	.30
Internalizing Problems (CBCL age 15)	1.20	.277	
Externalizing Problems (CBCL age 15)	0.09	.766	
Hope (age 15)	9.85	.002	

SOCIAL SUPPORT TAKEAWAYS

1. No differences in overall network size



SOCIAL SUPPORT TAKEAWAYS

1. No differences in overall network size

2. Young adults with ASD are uniquely at risk

- Significantly fewer friends
- Lower perceptions of appraisal and belonging support



SOCIAL SUPPORT TAKEAWAYS

1. No differences in overall network size
2. Young adults with ASD are uniquely at risk
 - Significantly fewer friends
 - Lower perceptions of appraisal and belonging support
3. Specificity in multidimensionality
 - Network size → functional outcome
 - Perceived social support → mental health



SOCIAL SUPPORT TAKEAWAYS

1. No differences in overall network size
2. Young adults with ASD are uniquely at risk
 - Significantly fewer friends
 - Lower perceptions of appraisal and belonging support

3. Specificity in multidimensionality

- Network size → functional outcome
- Perceived social support → mental health

- Adolescent hope → perceived social support
- Adolescent externalizing problems → number of family members



DISCUSSION

PULLING IT ALL TOGETHER



1. Poor outcomes in young adulthood persist for ND populations
2. Relationships and mental health matter

PULLING IT ALL TOGETHER



1. Poor outcomes in young adulthood persist for DD populations
2. Relationships and mental health matter
3. Universal processes across neurodiverse groups
4. Poor outcomes may be a culmination of multiple risk factors

PULLING IT ALL TOGETHER



1. Poor outcomes in young adulthood persist for DD populations
2. Relationships and mental health matter
3. Universal processes across neurodiverse groups
4. Poor outcomes may be a culmination of multiple risk factors
- 5. Need for effective and accessible interventions**

FUTURE DIRECTIONS

Sample size

- Would be ideal to examine all 4 diagnostic groups separately
- Continuing recruitment to maximize sample

Self-report vs. Parent-Report + Qualitative Data

Demographic factors

- Higher income, Caucasian, gender

Developing and disseminating interventions

THANK YOU!

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Additional Acknowledgments:

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- All of the family and youth participants who give so generously of their time

QUESTIONS? |