Stanford MEDICINE | School of Medicine

Mental Health in Young Adults with X and Y Chromosome Variations: Transition to Adulthood

AXYS Webinar
December 2025

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AGENDA

Brief Overview of Mental Health Conditions in X&Y Variation

- How common are they in SCA?
- What are the most common conditions?
- Does it change over time?

Transition to Adulthood

- What happens after the age of 18?
- Readiness for independence
- Transitioning responsibilities from family to individual
- Clinical resources

MENTAL HEALTH CONDITIONS IN X&Y VARIATION

High Prevalence of Mental Health Diagnoses in Youth with X&Y Variation

Brain, Genes and Puberty Study in KS

Original Article

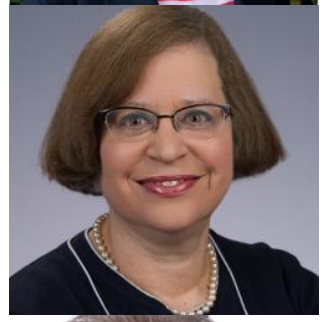
Social, Emotional, and Behavioral Functioning in Adolescents With Klinefelter Syndrome

Anja L. Jünger, MD*, Meagan Lasecke, MS*, Lara C. Foland-Ross, PhD*, Tracy L. Jordan, PhD*, Jamie L. Sundstrom, BS*, Vanessa Lozano Wun, MS†, Gregory A. Witkin, PhD‡,§, Chijioke Ikomi, MD‡,§, Judith Ross, MD‡,§, Allan L. Reiss, MD*,‖,¶

Original Article

Cognition, Academic Achievement, Adaptive Behavior, and Quality of Life in Child and Adolescent Boys with Klinefelter Syndrome

Tracy L. Jordan, PhD,* Lara C. Foland-Ross, PhD,* Vanessa L. Wun, BA,† Judith L. Ross, MD,‡ Allan L. Reiss, MD*§‖

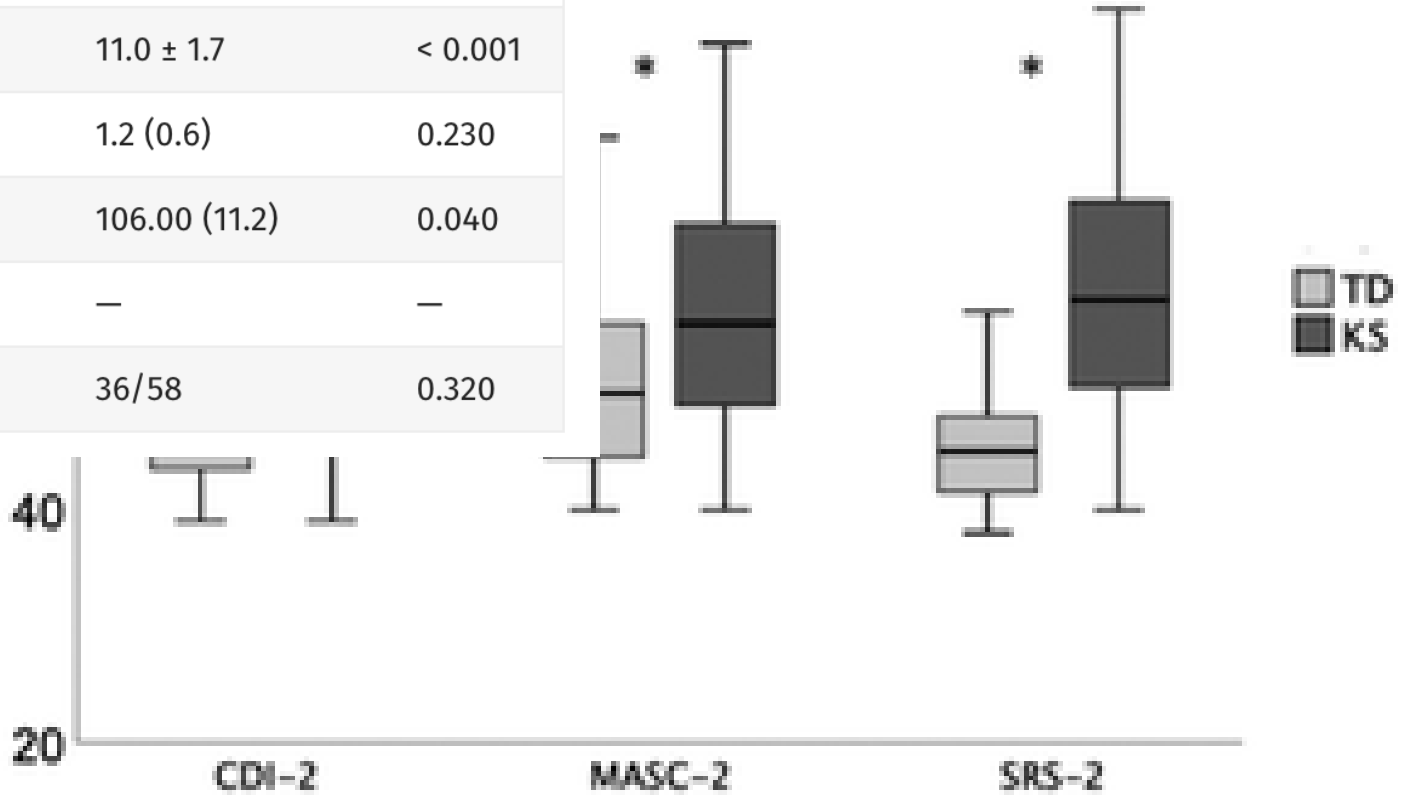


Early Adolescent Boys with Klinefelter Syndrome

Table 1. Participant Characteristics

Full Size Table

Characteristic	KS Group n = 52	TD Group n = 62	p
Age (years; mean ± SD)	12.2 ± 2.2	11.0 ± 1.7	< 0.001
SES score (mean/SD)	1.0 (0.5)	1.2 (0.6)	0.230
WISC-V VSI T score (mean/SD)	100.7 (15.5)	106.00 (11.2)	0.040
Timing of diagnosis (n; pre/postnatal)	27/25	—	—
Prepubertal/pubertal (N)	35/67	36/58	0.320



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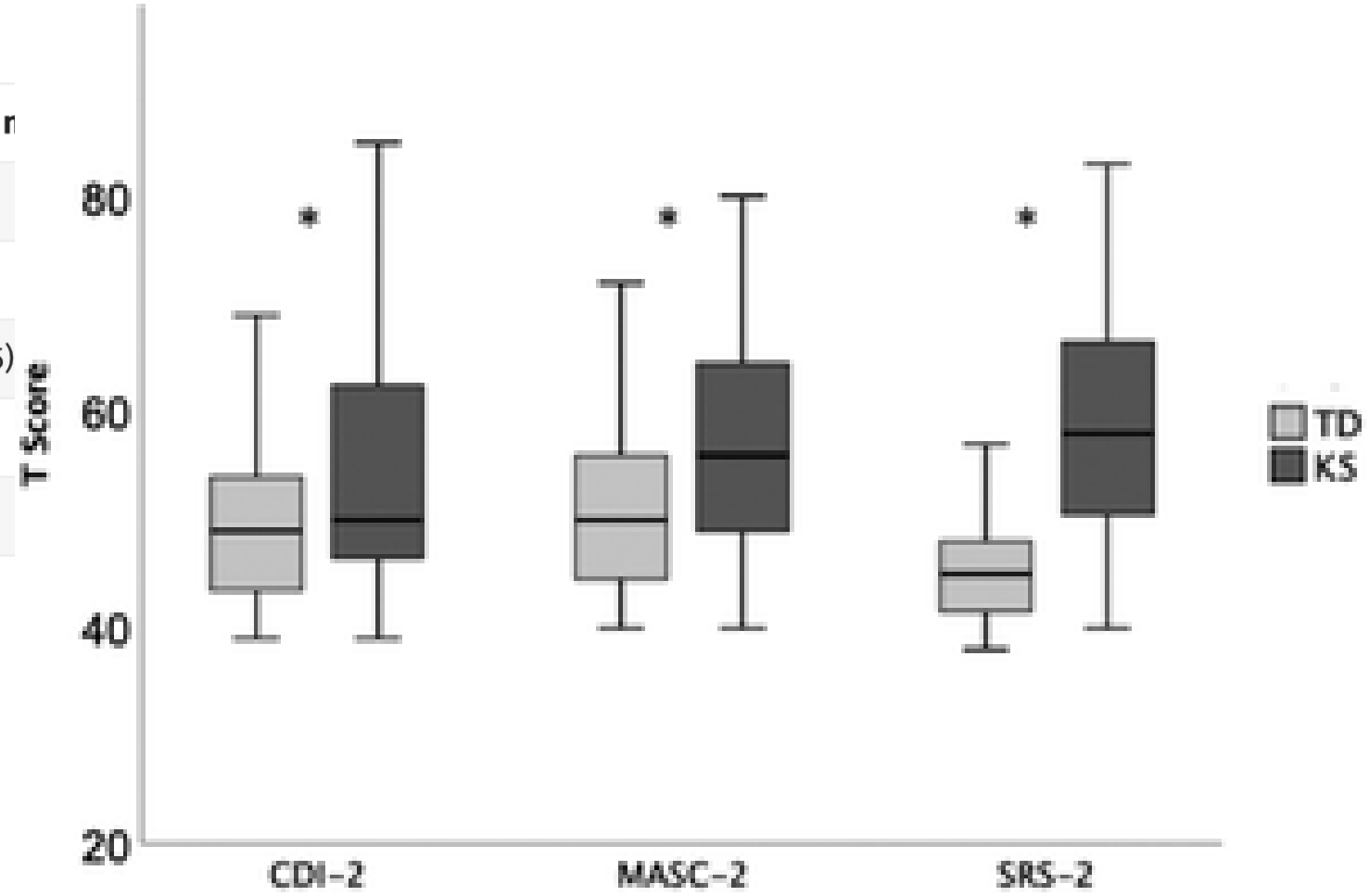


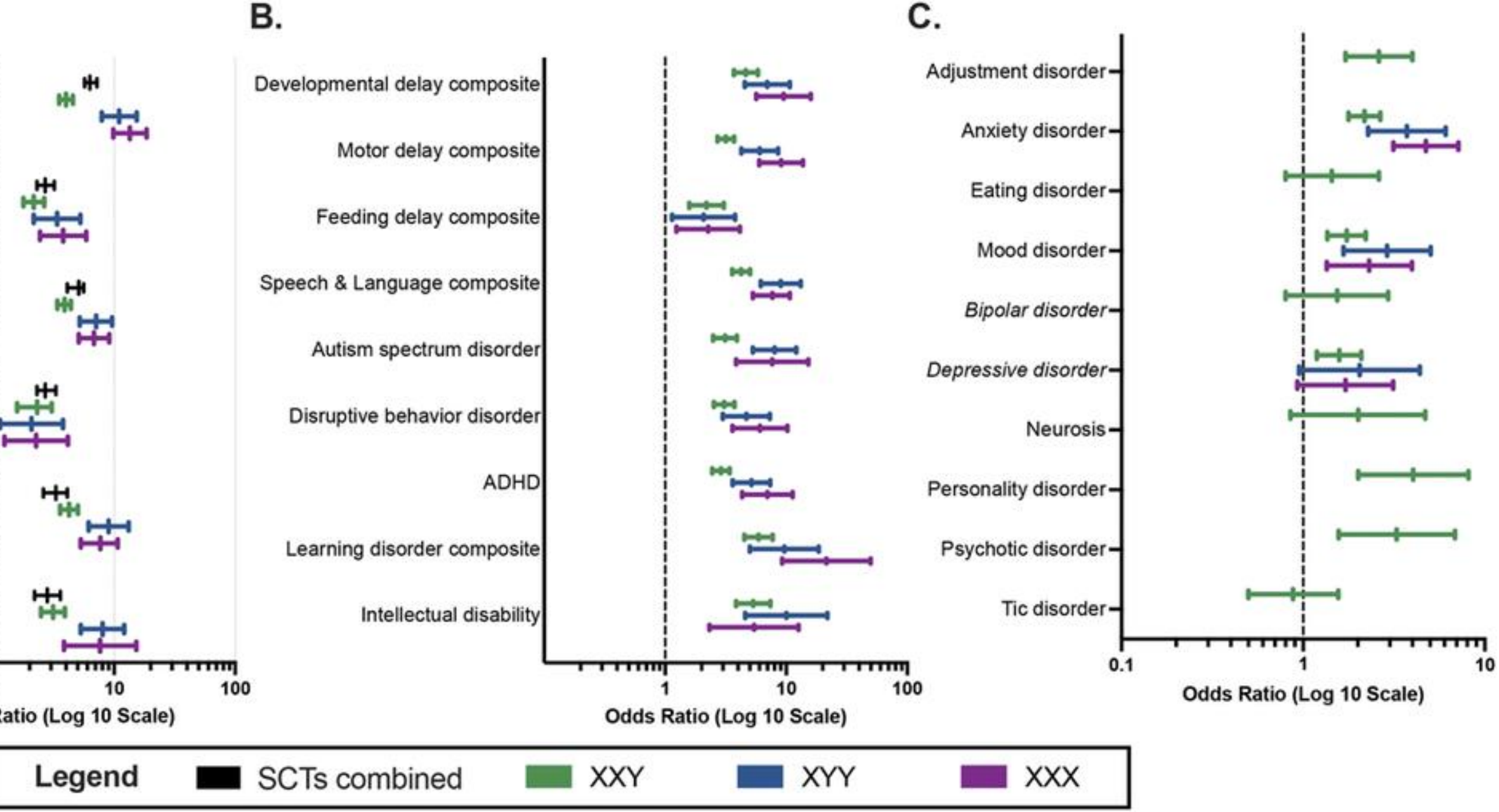
Broader Data in Electronic Medical Records

Original Article

SDC

Neurodevelopmental and Mental Health Outcomes in a National Clinical Sample of Youth With Sex Chromosome Trisomies Compared With Matched Controls

Adriana Hall, MD*, Anna Furniss, MS†, Nicole N. Tartaglia, MD, MS‡,§, Jennifer Janusz, PhD‡,§, Rebecca Wilson, PsyD‡,§, Caitlin Middleton, PsyD‡,§, Sydney Martin, MS, OTR/L, BCP‡, Jacqueline Frazier, MA, SLP‡, Michele Martinez-Chadrom, MA, SLP‡, Jennifer Hansen-Moore, PhD‖, Chijioke Ikomi, MD¶, Judith Ross, MD¶, Maria G. Vogiaski, MD**, Leela Morrow, PsyD††,‡‡, Dimitri A. Christakis, MD, MPH§§,‖‖, Rachel E. Lean, PhD¶¶, Natalie Nokoff, MD, MS§, Laura Pyle, PhD§,***, Shanlee M. Davis, MD, PhD‡,§


B.
C.
Developmental delay composite
Motor delay composite
Feeding delay composite
Speech & Language composite
Autism spectrum disorder
Disruptive behavior disorder
ADHD
Learning disorder composite
Intellectual disability
1
10
100
Odds Ratio (Log 10 Scale)
Adjustment disorder
Anxiety disorder
Eating disorder
Mood disorder
Bipolar disorder
Depressive disorder
Neurosis
Personality disorder
Psychotic disorder
Tic disorder
0.1
1
10
Odds Ratio (Log 10 Scale)
Legend
SCTs combined
XXY
XYY
XXX

Also Common in Adults with X&Y Conditions

RESEARCH ARTICLE

Mental Health Diagnoses Associated With Sex Chromosome Anomalies

Adaiah Soibi-Harry[1] | Oumaima Kaabi[1] | Doris Fadoju[2] | Melissa D. Gardner[3] | Darios Getahun[4,5] | Timothy L. Lash[1] | Peter A. Lee[6] | Joshua May[4] | Courtney E. McCracken[7] | Behzad Sorouri Khorashad[3] | Nancy Sokkary[8] | Suma Vupputuri[9] | Rami Yacoub[1] | David E. Sandberg[3] | Michael Goodman[1]

Prevalence for Conditions in Adults with Klinefelter Syndrome

Mental health diagnosis [b]	KS patients (*n* = 282)		Male referents (*n* = 2820)		KS patients vs. male referents	
	n [c]	%	*n*	%	PR [d]	(95% CI)
Any diagnosis	205	72.7	1198	42.5	1.63	(1.40, 1.89)
Schizophrenia spectrum and other psychotic disorders	16	5.7	42	1.5	3.15	(1.73, 5.74)
Bipolar and related disorders	18	6.4	83	2.9	2.04	(1.22, 3.41)
Depressive disorders	70	24.8	352	12.5	1.81	(1.39, 2.35)
Anxiety disorders	114	40.4	634	22.5	1.64	(1.34, 2.00)
Dissociative disorders	NR				8.21	(1.10, 61.25)

Prevalence for Conditions in Adults with Klinefelter Syndrome

Disruptive, impulsive-control, and conduct disorders	34	12.1	93	3.3	3.35	(2.25, 5.01)
Substance-related disorders	76	27.0	435	15.4	1.61	(1.26, 2.06)
Personality disorders	14	5.0	41	1.5	3.03	(1.62, 5.68)
Any neurodevelopmental disorder	97	34.4	334	11.8	2.82	(2.25, 3.54)
Intellectual disabilities	NR				3.31	(0.62, 17.77)
Communication disorders	47	16.7	145	5.1	3.31	(2.38, 4.62)
Autism spectrum disorder	14	5.0	43	1.5	3.15	(1.71, 5.77)
ADD/ADHD	53	18.8	183	6.5	2.70	(1.98, 3.68)
Specific learning disorder	36	12.8	46	1.6	7.61	(4.90, 11.80)
Motor disorders	12	4.3	29	1.0	4.25	(2.16, 8.36)
Neurocognitive disorders	NR				0.91	(0.27, 3.07)

Do Differences Emerge Over Time or Between Conditions?

TABLE 3. Age-stratified prevalence ratios for Klinefelter syndrome (KS) patients versus matched [a] male referents.

Mental health diagnosis [b]	KS patients (*n* = 105) vs. male referents < 25 years of age [c]		KS patients (*n* = 177) vs. male referents 25 years of age or older [c]	
	PR [d]	(95% CI)	PR [d]	(95% CI)
Any diagnosis	1.77	(1.38, 2.27)	1.53	(1.27, 1.85)
Schizophrenia spectrum and other psychotic disorders	0.54	(0.07, 4.09)	4.63	(2.40, 8.91)
Bipolar and related disorders	1.73	(0.58, 5.12)	2.12	(1.19, 3.79)
Depressive disorders	1.26	(0.68, 2.32)	1.97	(1.48, 2.63)
Anxiety disorders	1.74	(1.19, 2.55)	1.58	(1.25, 2.01)
Dissociative disorders	NC		16.77	(1.46, 192.66)
Feeding and eating disorders	1.47	(0.33, 6.64)	19.82	(3.59, 109.35)

TABLE 3. Age-stratified prevalence ratios for Klinefelter syndrome (KS) patients versus matched [a] male referents.

Disruptive, impulsive-control, and conduct disorders	3.09	(1.89, 5.05)	3.16	(1.57, 6.35)
Substance-related disorders	0.64	(0.23, 1.79)	1.78	(1.38, 2.29)
Personality disorders	2.55	(1.16, 5.60)	3.80	(1.29, 11.23)
Any neurodevelopmental disorder	2.73	(2.08, 3.59)	2.50	(1.64, 3.82)
Intellectual disabilities	2.40	(0.25, 23.44)	3.80	(0.31, 45.85)
Communication disorders	2.74	(1.92, 3.91)	9.00	(3.11, 26.02)
Autism spectrum disorder	2.46	(1.21, 4.98)	5.07	(1.46, 17.69)
ADD/ADHD	2.84	(1.90, 4.24)	2.18	(1.34, 3.57)
Specific learning disorder	6.82	(4.11, 11.33)	7.55	(3.10, 18.40)
Motor disorders	3.80	(1.88, 7.72)	4.85	(0.43, 54.53)
Neurocognitive disorders	NC		1.12	(0.32, 3.85)

TRANSITION TO ADULTHOOD

What are the potential **challenges** associated with the transition from adolescence to adulthood?

…Why might this be particularly relevant when you have a lifelong medical condition?

…And especially so when those conditions are associated with mental health diagnoses.

Transitional Age Youth and their Families

Readiness for Adulthood

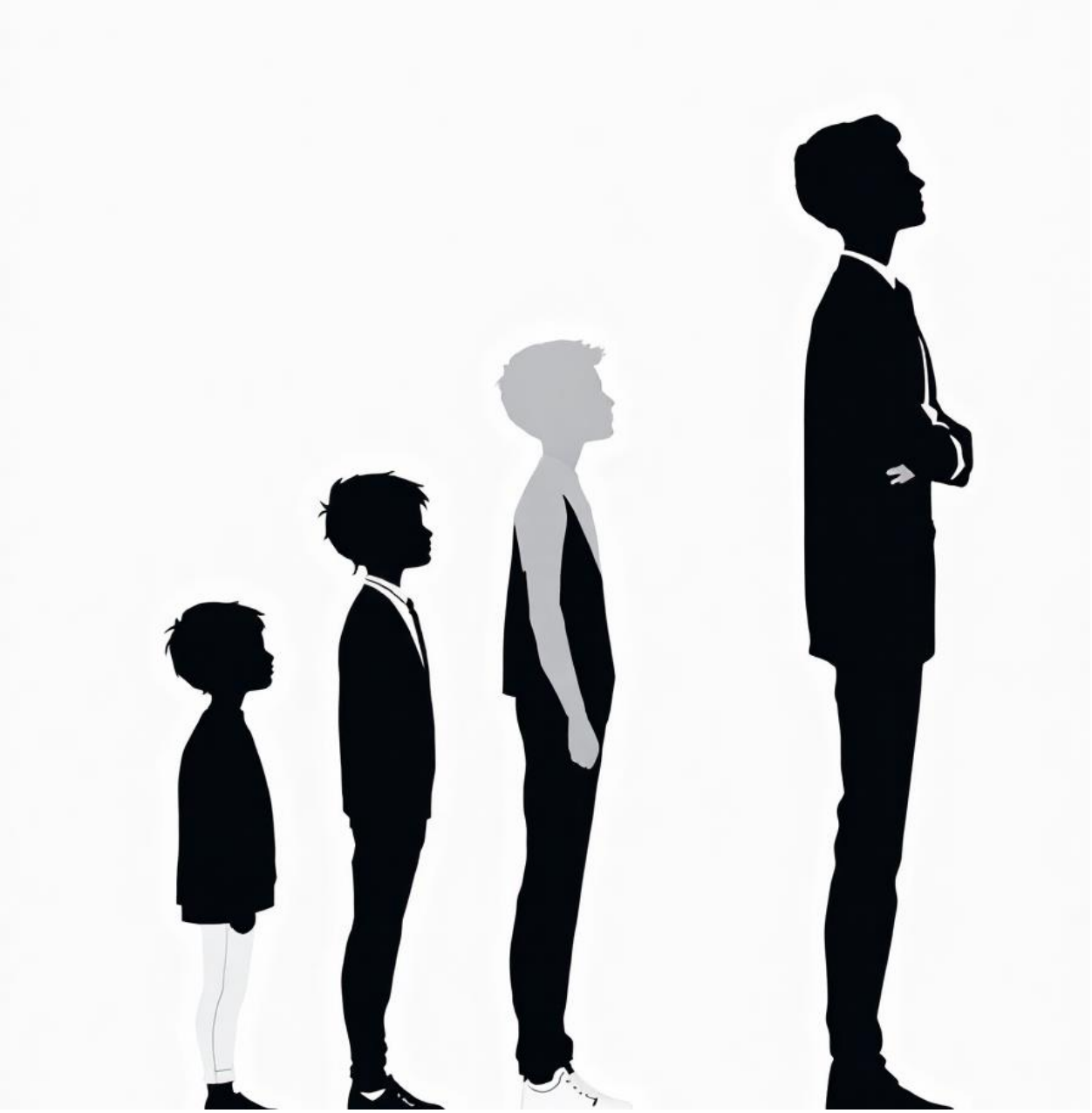
There is nothing magical about the age of 18 – transitioning to adulthood is an ongoing dynamic process that occurs over years.

Falling off the Service Cliff

Legally, and regarding support systems however, a number of things do change once an individual turns 18, that may interefere with development.

"Failure to Launch"

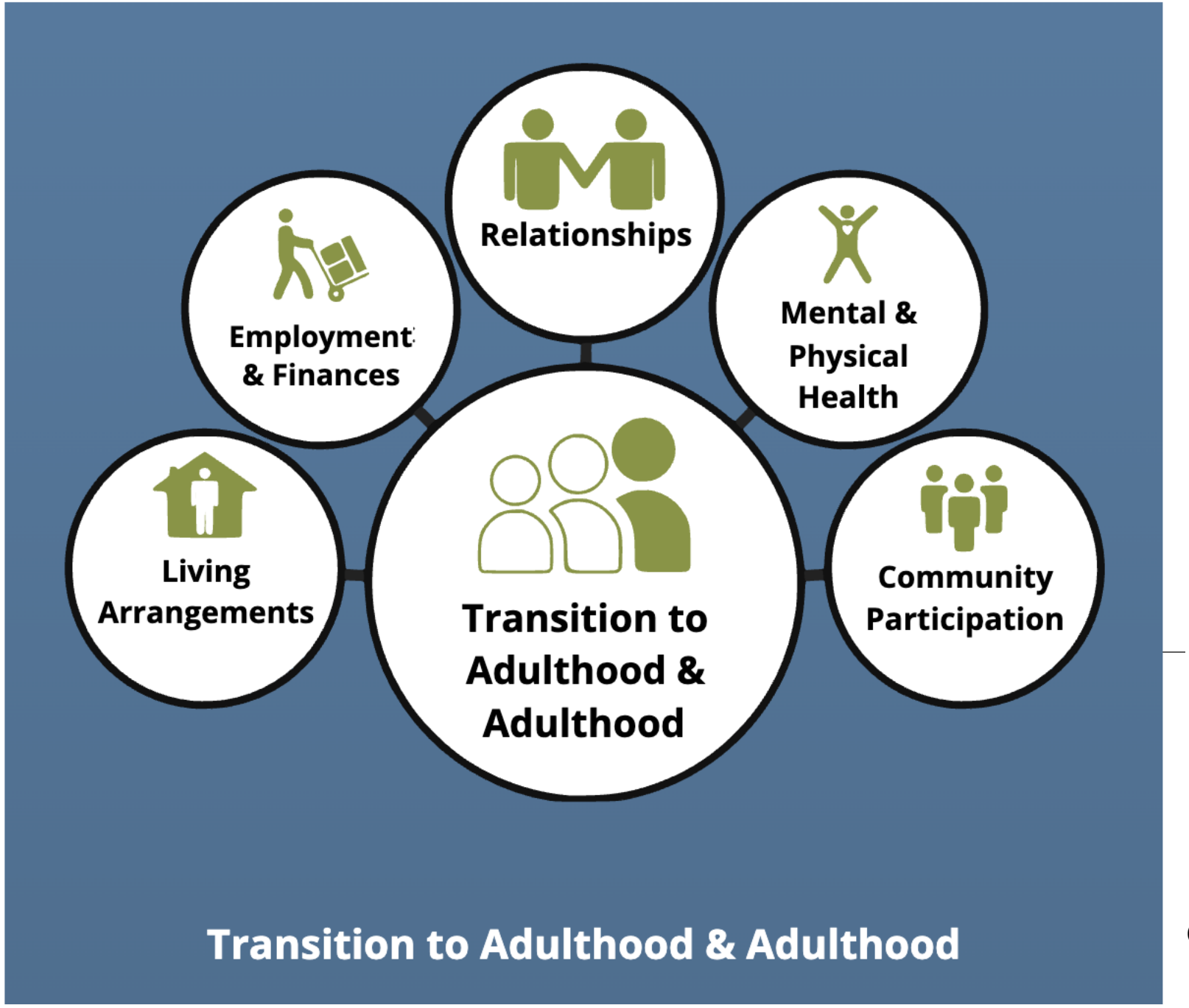
Strategies for when this transition period is difficult or may even feel unsuccessful at times.



Transition to Adulthood

Transitional Aged Youth (TAY) are generally considered as individuals between the ages of 16 and 25

- Right after significant biological and physical changes associated with puberty, associated impulsivity and risk-taking, increasingly complex social relationships, and formation of identity
- Unique period presenting social, educational, clinical and occupational demands, including possibly adjusting to college or employment
- Learning to navigate systems as a legal adult, with less guidance of family members



CHD, University or Oregon

Mental Health Challenges Associated with Transition to Adulthood

Estimated 75% of any mental health diagnosis will emerge before the age of 25 years

Critical Period: This developmental stage creates particular mental health challenges that need attention

Mental Health Vulnerability: The transition to adulthood can worsen existing mental health problems or trigger new ones

Information Gaps: Misinformation about mental illness prevents proper understanding

System Navigation: Young adults often don't know where to find appropriate mental health services

FAMILY SUPPORT

Advance Planning: It's essential to establish treatment plans before major transitions (college, employment, independent living)

Proactive Approach: Having support systems in place prevents gaps in care during vulnerable transition periods

Variability Between Variations and Between Individuals

Generally speaking, severity of symptoms or phenotypes tends to correlate with increasing number of sex chromosomes

- For example, individuals with 48 or 49 chromosomes may have a greater degree of symptoms than individuals with 47 chromosomes/trisomies
- Mosaic karyotypes are also generally associated with lesser degree of symptoms

There is significant variability even within the same condition or karyotype

- Some individuals will not be affected at all or only minimally whereas others may carry a much greater burden of symptoms
- We still do not fully understand why some individuals with sex chromosome variation are affected more or less than others

Falling off the Services Cliff

What Happens After 18 Years of Age?

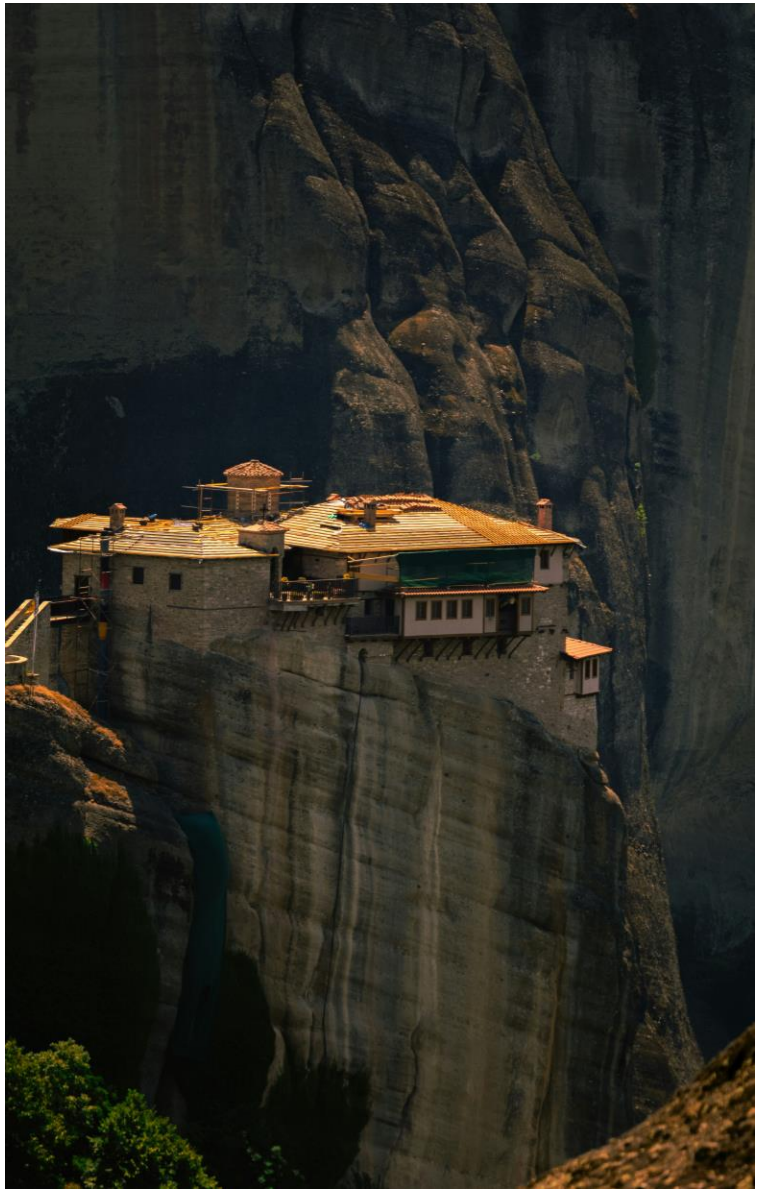
"Services Cliff": Often a dramatic drop in services after high school graduation; or up to 22 years of age after. Moving from youth to adult systems brings fewer resources and reduced support, making the transition difficult. In clinical settings, it may also be challenging to find adult providers as knowledgeable as pediatric providers on SCAs.

Lack of Transparency: When adult services are available, families may struggle to understand what services they're eligible for, with social service organizations providing confusing or inadequate information

Access Difficulties: Extensive bureaucratic red tape, long wait times (up to a year), and unresponsive service providers create significant barriers

Inappropriate Services: Available programs often don't match individual needs, forcing families to choose between unsuitable options or no services at all

Impact on Opportunities: This sudden change can negatively affect education, employment, and quality of life for those affected.



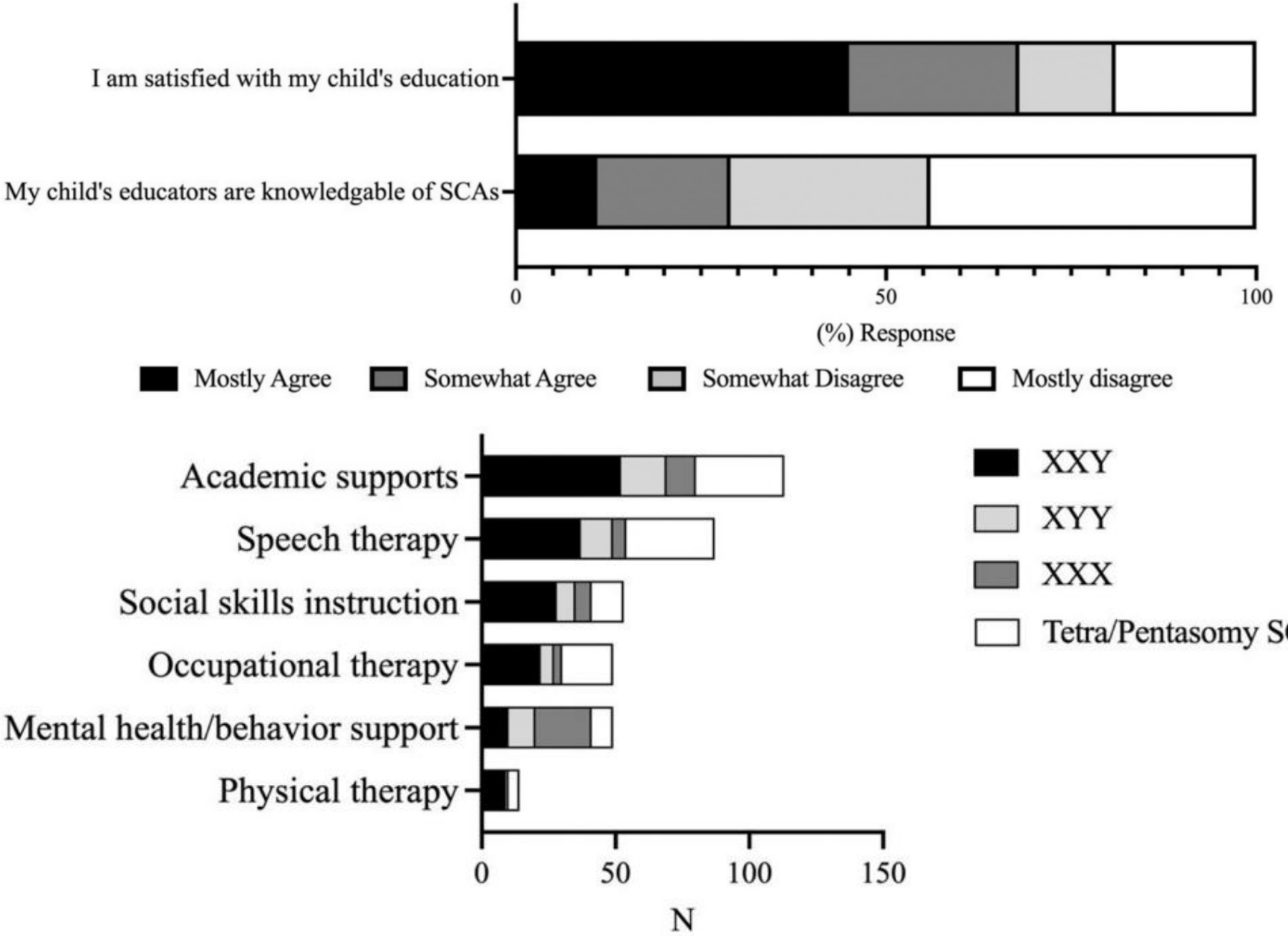
Contents lists available at ScienceDirect

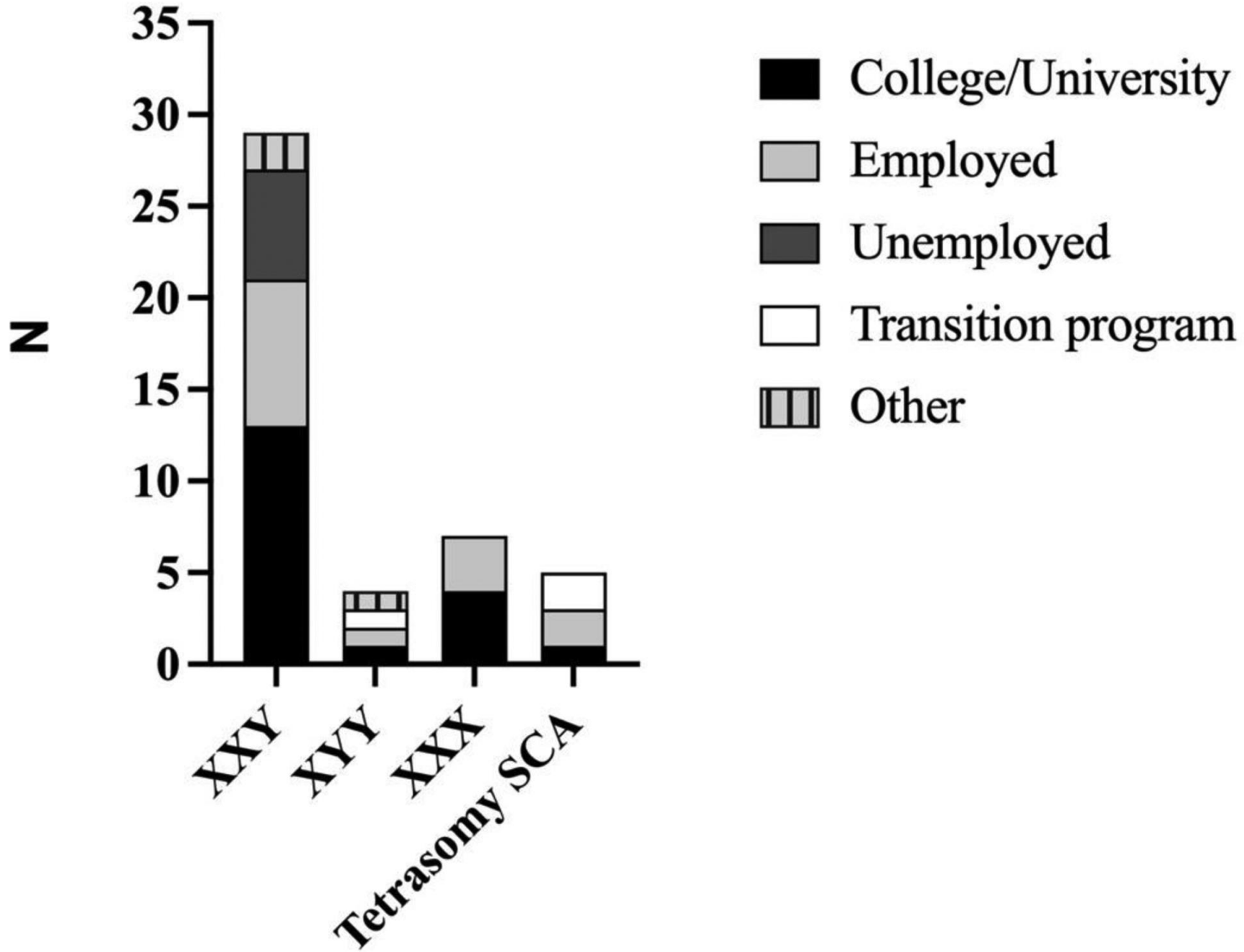
Journal of School Psychology

journal homepage: www.elsevier.com/locate/jschpsyc

Supporting students with sex chromosome aneuploidies in educational settings: Results of a nationwide survey

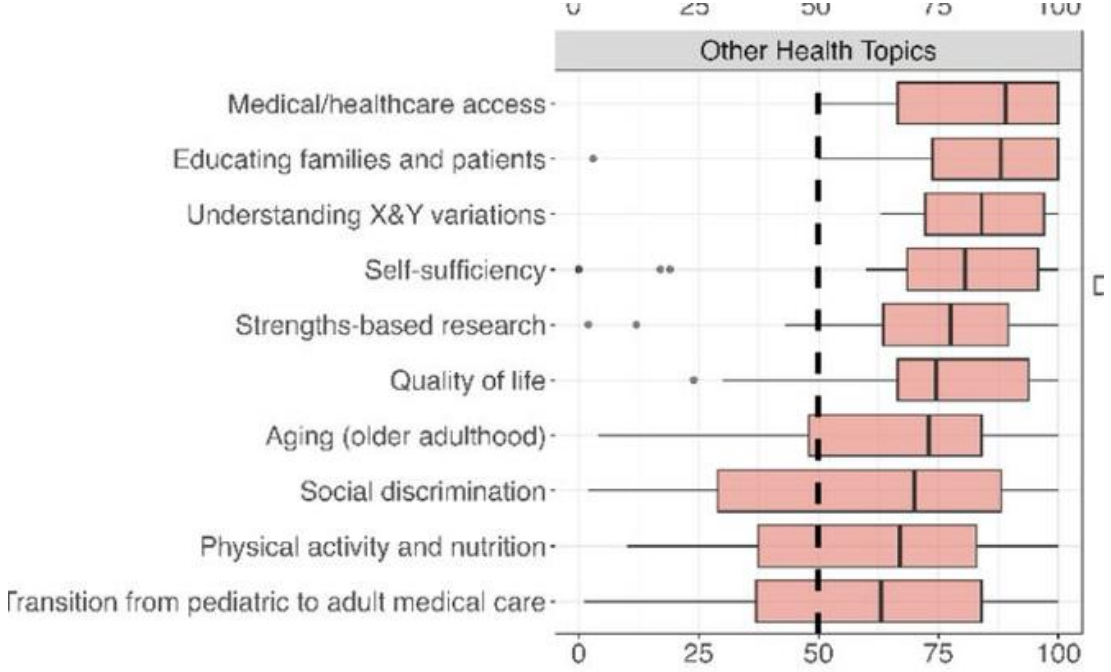
Talia Thompson [a,b,*], Shanlee Davis [a,b], Jennifer Janusz [a,b], Erin Frith [c], Laura Pyle [a,d], Susan Howell [a,b], Richard Boada [a,b], Rebecca Wilson [a,b], Nicole Tartaglia [a,b]

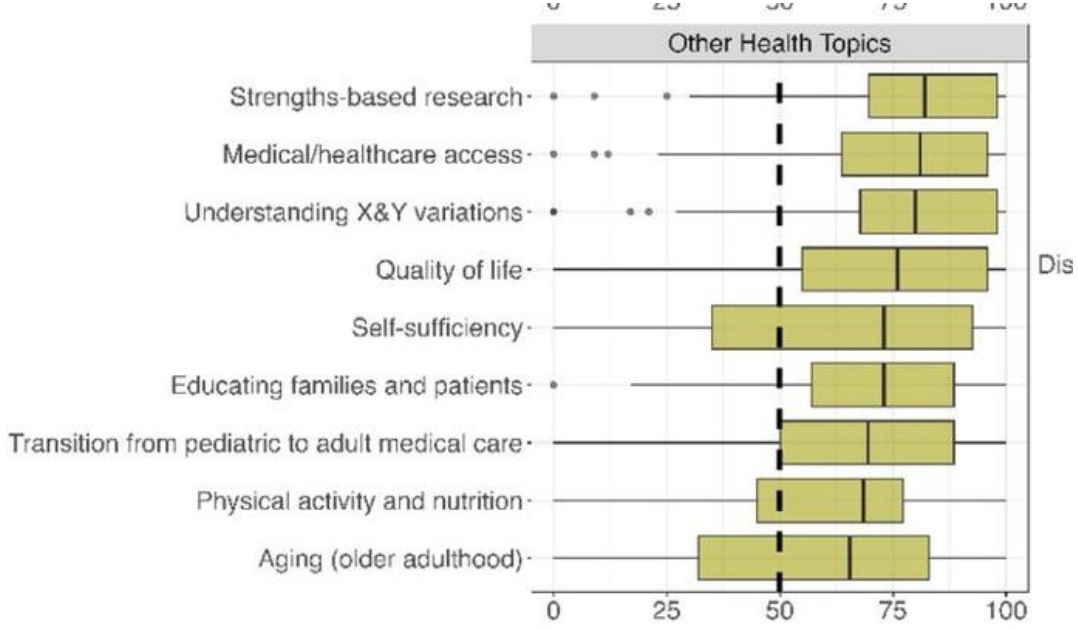

I am satisfied with my child's education
My child's educators are knowledgable of SCAs
0
50
100
(%) Response
Mostly Agree
Somewhat Agree
Somewhat Disagree
Mostly disagree
Academic supports
Speech therapy
Social skills instruction
Occupational therapy
Mental health/behavior support
Physical therapy
0
50
100
150
N
XXY
XYY
XXX
Tetra/Pentasomy SCA


N
35
30
25
20
15
10
5
0
XXY
XYY
XXX
Tetrasomy SCA
College/University
Employed
Unemployed
Transition program
Other

Survey Results for Research Priorities in SCA (Carl et al.)

- Parents and Individuals with SCAs reported in a recent survey that research in Medical Healthcare Access, Self-Sufficiency, and Transition from Pediatric to Adult Medical Care was a priority





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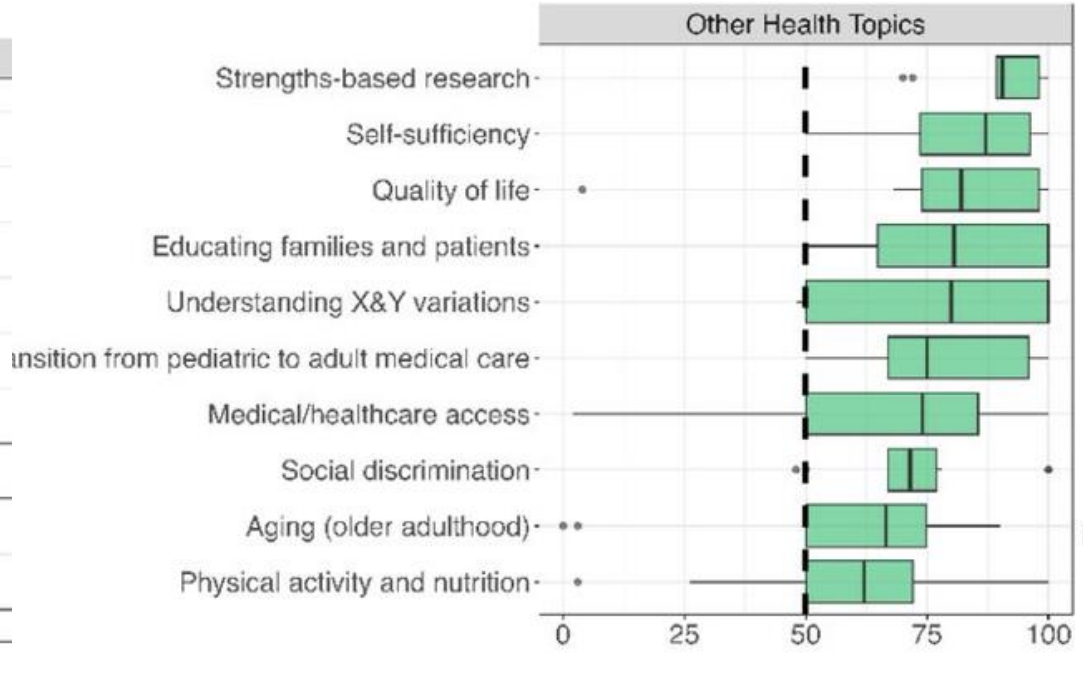
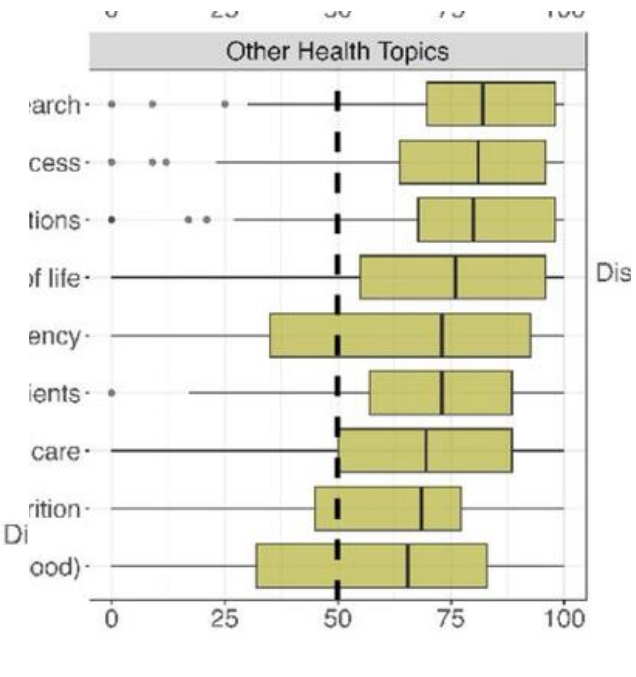




Service Interruptions

- Significant lack of data on service utilization in adults with SCAs
- Drawing from studies in the adult autism community, we do have some understanding of challenges in access to services, including:
- 9 out of 10 caregivers experienced a dramatic drop in services after high school graduation, with speech therapy rates falling from 66% at age 17 to just 10% post-graduation (Schiltz et al. JADD 2024)
- Unmet service needs for regular socialization opportunities (60.3% of caregivers), specialized primary health care with autism-trained staff (59.3%), social skills instruction (55.8%), life skills instruction (51.3%), and behavioral support (47.3%) (Ferguson et al. JADD 2024)

Preparing for Service Interruptions for College and/or Employment

AACAP Guide to College Readiness

Anticipate Academic Needs

Developing realistic expectations and plans about academic workload

Organizational skills needed to balance work and social life

Educational accommodations that can and should continue in college

Knowledge of IEP plan in secondary education and extent accommodations can be replicated in college environment

College "Fit"

Total number of students and class size

Housing options: residential (dorms), off-campus living, commuting from home

Educational environment: classroom, online, or a combination

Distance from home

Local friends and family

Ease of access to specialized treatment

Investigate resources available through Office of Access/Education/Disabilities

Educational Independence

Organizing study materials and knowing schedules for classes

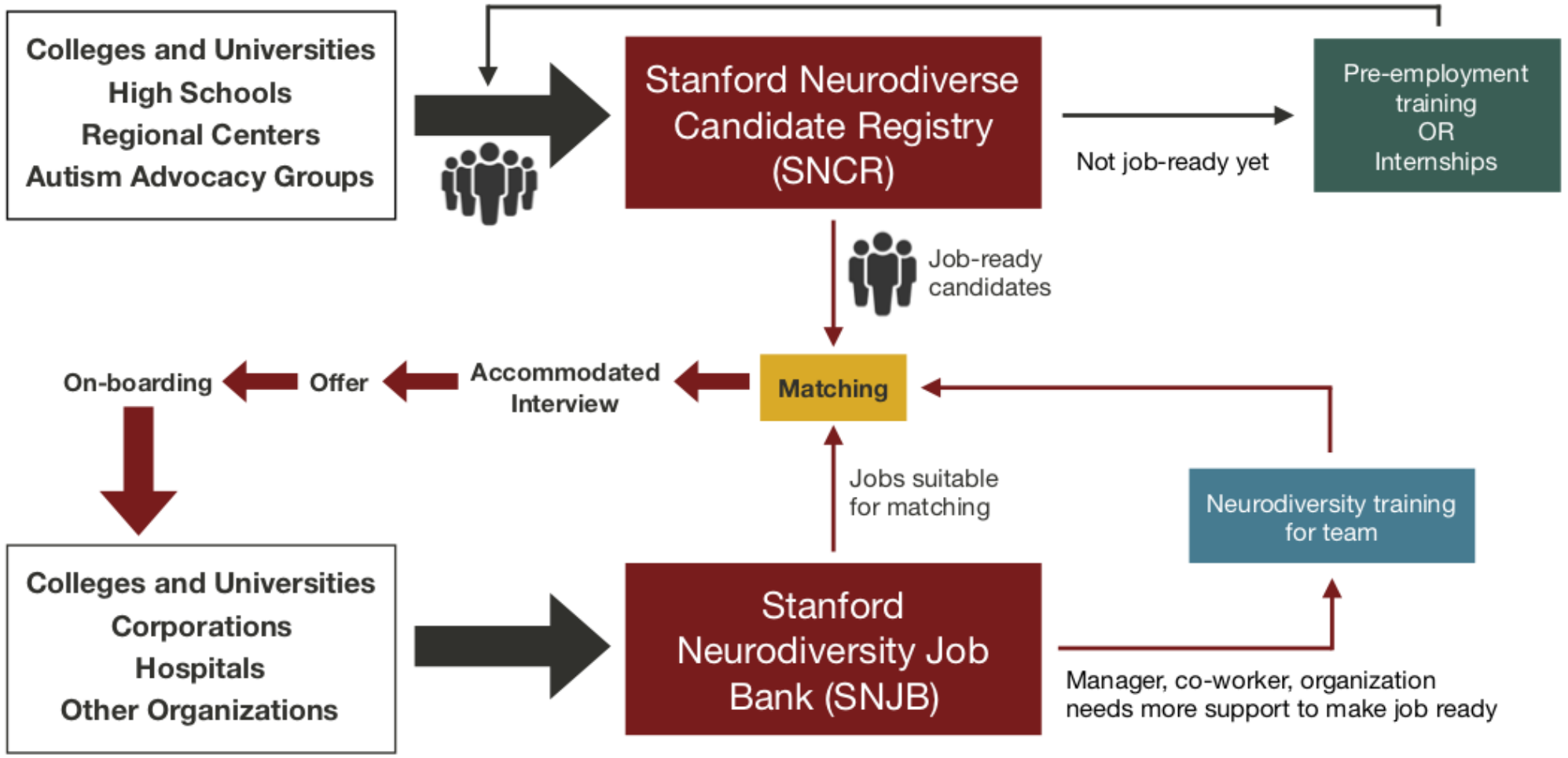
Completing homework, essays, and projects without reminders or involvement from parents, teachers, or tutors

Accepting responsibility and consequences for actions (ex. missing a deadline) and learning how to plan for contingencies

Communicating with teachers/professors

Balancing educational and recreational computer use

Readiness for Employment



"Failure to Launch"

The transition to independence in young adulthood is complex and naturally difficult for both youth and parents

Young adults (particularly those with special needs) may require increased support from family systems. When it reaches levels of avoiding education and employment it represents a challenging, and often confusing, clinical problem

The term "failure" implies defeat; instead of focusing on failure, this process is likely better viewed as a starting point for growth and development

"Failure to Launch"

Stigma associated with this developmental challenge affect young adults:

- May be labelled as 'lazy' or 'unmotivated’
- Families may also be subject to social judgement about being 'overly indulgent'

There is a need for better clinical approaches that balance the necessity for additional supports for young adults with special needs, implements compassionate strengths-based approaches, while also utilizing evidence-based interventions for underlying issues that may be contributing to the issue.

Different Parenting Strategies Can Lead to Different Outcomes

vs.

Scaffolding: Providing parenting to support development

Core Elements:

- At every developmental stage, parents can model and teach positive behaviors, give corrective feedback, and increase self-esteem.
- This relationship is bi-directional.
- To a certain extent, 'mistakes' and 'failures' are expected and encouraged.

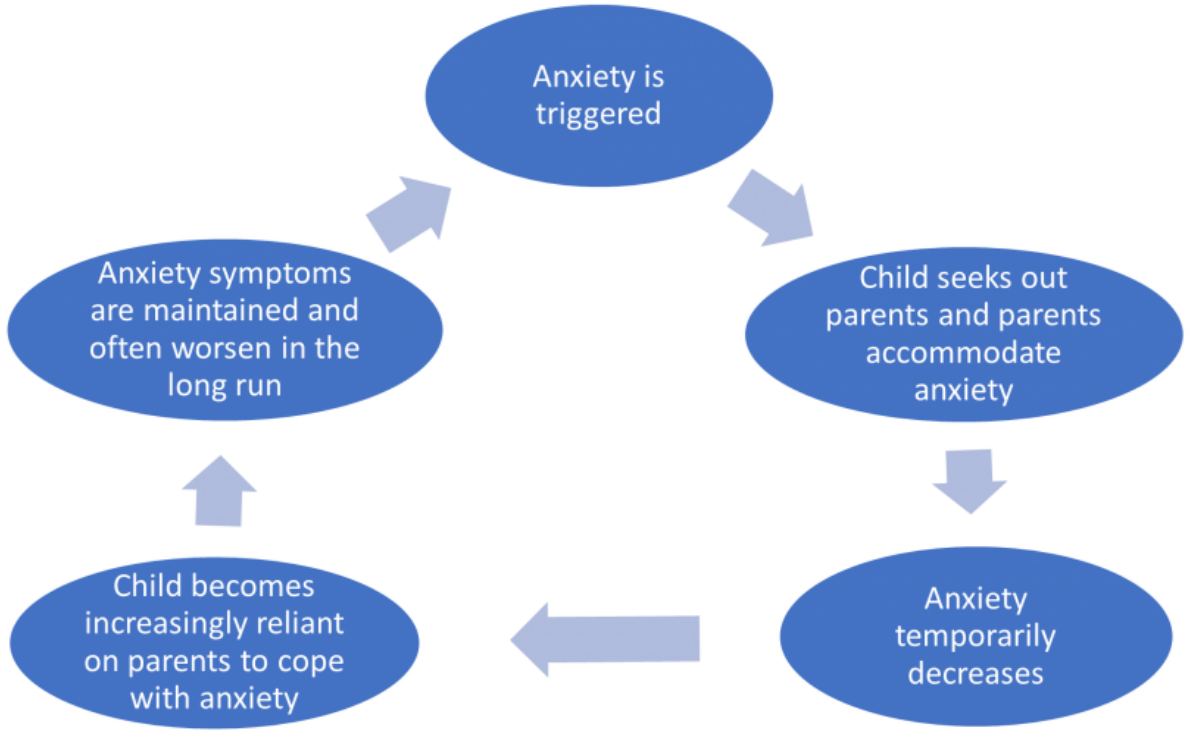
Temporary Support System:

- Parents act as "scaffolding" and "safety nets" to aid successful transition to adulthood, however in most cases this support is not meant to be permanent.

Gradual Removal:

- The scaffolding approach recognizes that never-ending parental problem-solving and involvement can have the opposite effect.
- Parental support should be gradually removed as the young adult develops their own capacity for independence
- This allows development of confidence and competence while providing support only when truly needed.

Accommodation: Short-term Wins at the Expense of Long-term Gains



OCD and Anxiety Center

Unintended Consequences of Accommodation

Normal Development vs. "Failure to Launch":

• Whenever possible, the developmental goal is for individuals to gradually transition from complete dependence to independence by late adolescence/early adulthood

• Some adults never achieve functional independence, avoiding productive activities, and relying heavily on caregivers for most needs

• This creates a cycle where social isolation and lack of function become increasingly entrenched over time

Challenges for Families:

• Parents experience frustration, helplessness, and severe burden (physical, emotional, financial)

• Adult children may refuse traditional therapy, making treatment difficult

• Families often become isolated due to challenges at home. Problems becomes more intractable as time passes

What can be done when a young adult doesn't want help?

Communication: Maintain open levels of non-judgmental dialogue between parent and adult child

Collaboration: Establish a shared agenda that will allow parent and child to work together to achieve goals

Coordination: Bring in other resources, family members, trusted individuals, professionals

Caregiver burnout and self-care: Providing effective parenting also means managing one's own mental health. Utilize respite when available, as well as individual/family therapy, support groups

Conservatorship: As a last resort – may also consider legal conservatorship or durable power of attorney. However this is typically a high bar.

What does supported decision-making look like?

SDM looks different for everyone. A person might have one or two supporters. Another person may have many more. Each supporter may take a different role. If you are the parent of an adult who uses supported decision-making, you will recognize that it is often the same things you are already doing.

Making sure your adult child gets to express their preferences in whatever way works best for them. That may mean something as big as creating a person-centered plan or something as small as a facial expression displaying a dislike of something.

Example: Every time one of Eileen's nurses came into her house, she would turn her head away and frown. But when a different nurse came in, Eileen would have a big smile. Eileen is expressing her preference for which nurse she likes better. A supporter should identify Eileen's nonverbal communication of her preferences, acknowledge these preferences, and help Eileen take action.

Explaining choices in a way that you know your child will understand, whether it's through pictures, words, or voice. It's important that you help your child think through the pros and cons of choices and whether there are consequences of certain decisions.

Example: Josh loves McDonald's. He wants to eat there every day for dinner. He is an adult who can make his own choices. His supporters can help him think about these choices by explaining the consequences, in a way that Josh will understand, of eating unhealthy food all the time, such as obesity and diabetes. They will help Josh work out a plan that he likes.

Not letting others make decisions for your child, or rush or force them to make a choice when they haven't considered all of the options.

Example: Emma went to the doctor and needed to have her blood taken. When she resisted, the doctor suggested they hold her down and force her to do the blood draw. Emma's supporter, her mother, communicated her daughter's concerns about needles and advocated for her to have more time to get used to the idea. Emma went home and used her supporters to understand why she needed to have her blood taken and then went back a few days later and agreed to the blood draw.

Providing examples of what a choice might look like, using an experience of something that has happened in the past to them or someone they know.

Example: Hamid loves to buy and play video games. He just got a part-time job and wants to spend all of his paycheck on video games. Instead of taking away that choice, a supporter might give an example of one of Hamid's friends who spent all of his money and had nothing left to go to Disneyland. A supporter might help Hamid open up a bank account and show him how to save money for something special.

Handbook. Disabilities Voices United.

Medical Model for Managing Mental Health Conditions

Value of Assessment and Diagnosis

•We know that risk for mental health conditions are elevated in X&Y variation

•For many of these conditions, accurate diagnosis aids in establishing a treatment and gaining understanding, including a general sense for an individual's expected level of functioning

•Diagnostic assessment via scales and clinical interview with pediatrician, primary care doctor, therapist, psychiatrist

•Typically involve screening scales and discussion with a medical provider

•Often classified in categories of mild, moderate and severe

•In more moderate or severe categories, may result in a referral to a mental health provider

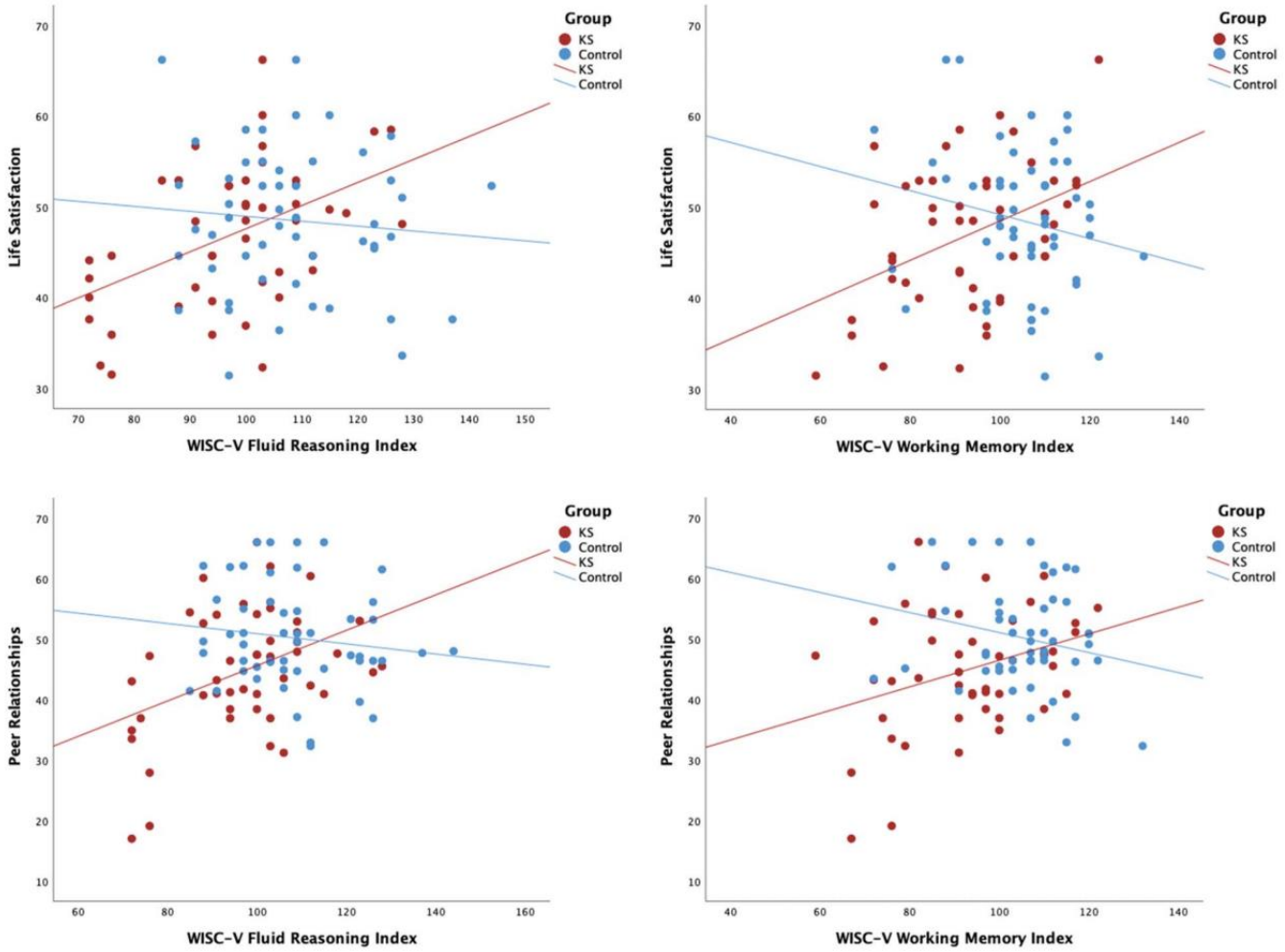


Figure 2. Pearson correlations between WISC-V Fluid Reasoning Index (FRI) and PROMIS Life Satisfaction, WISC-V FRI and PROMIS Peer Relationships, WISC-V Working Memory Index (WMI) and PROMIS Life Satisfaction, and WISC-V WMI and PROMIS Peer Relationships. KS, Klinefelter syndrome; PROMIS, Patient-Reported Outcomes Measurement Information System; WISC-V, Wechsler Intelligence Scale for Children, Fifth Edition.

Cognitive-Behavioral Therapy

•*Time limited, evidence-based*

•Learn to distinguish between thoughts and feelings

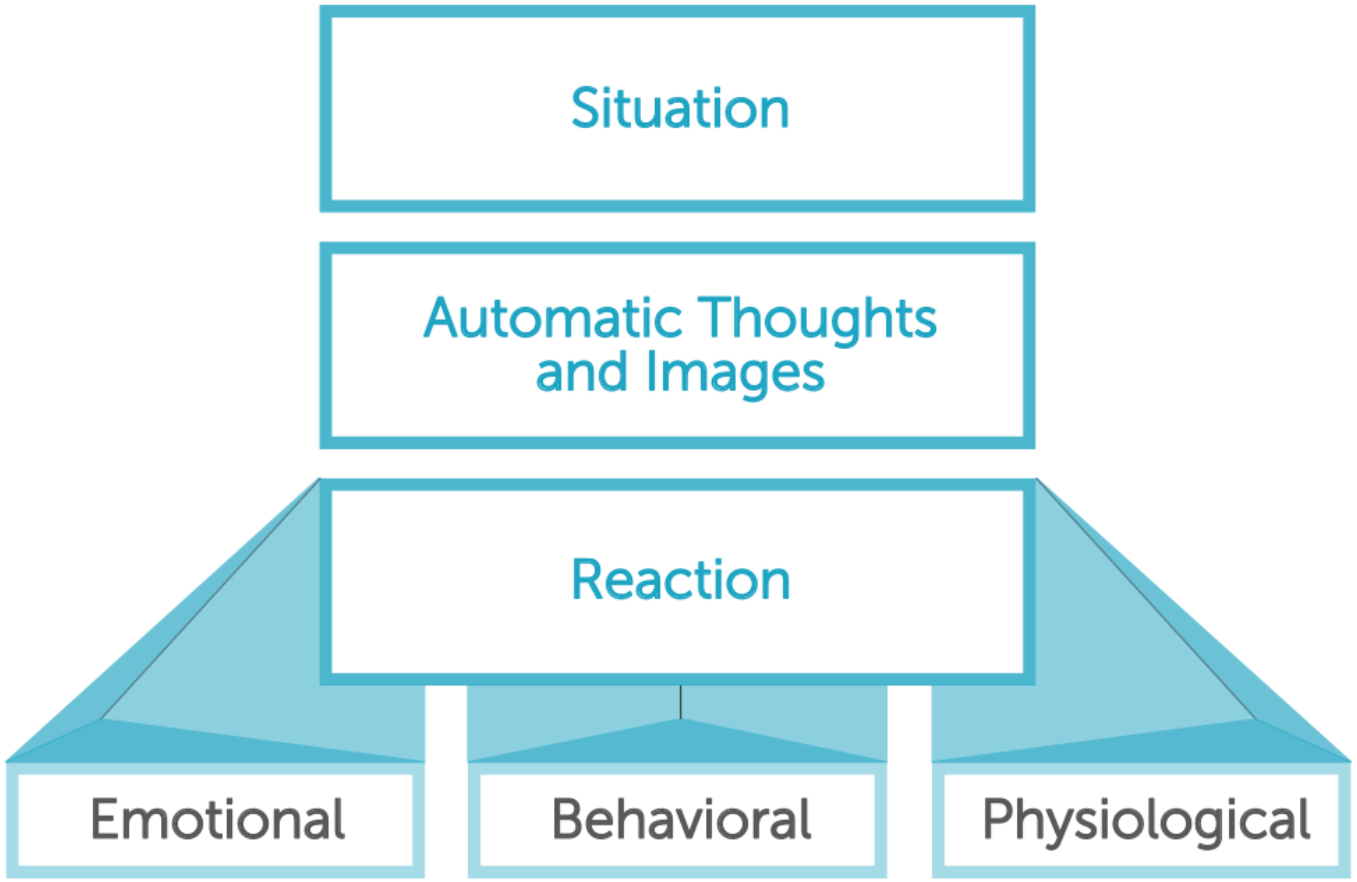
•Learn to see how thoughts can influence feelings in ways that sometimes are not helpful

•Learn how ‘automatic' thoughts may affect emotions

•Learn how to critically evaluate how ‘automatic’ thoughts can be accurate or biased

•Learn skills to correct these biased thoughts

•Teaching families how to manage unintentional reinforcements or rewards for ‘automatic’ negative thoughts



Social Skills Therapies

sion	Didactic lesson	Delivery
	Conversational Skills I: Trading Information	Face-to-face
4	Conversational Skills II: Two-Way Conversations	
	Conversational Skills III: Electronic Communication	Virtual meeting room
	Choosing Appropriate Friends	Virtual meeting room
	Appropriate use of humour	Virtual meeting room
	Peer Entry I: entering a conversation	Face-to-face
5	Peer Entry II: exiting a conversation	
	Get-togethers	Virtual meeting room
	Good sportsmanship	Virtual meeting room
	Rejection I: teasing and embarrassing feedback	Virtual meeting room
	Rejection II: bullying and bad reputations	Virtual meeting room
	Handling disagreements	Virtual meeting room
	Rumours and gossip	Face-to-face
5	Graduation and termination	

Social Skills Training

PEERS group counseling provides social skills training originally designed for individuals with autism, focusing on real-life interactions. It is now also widely considered to be helpful in a number of other diagnoses where social skills may be affected, such as ADHD.

Recently adapted for use in translational age youth with Turner syndrome (Wolstencroft et al. 2021)

Role-Play and Real Practice

Participants learn practical skills, such as making and keeping friends, through structured role-play and real-life exercises. It has a structured format implemented between adolescents and young adults during the group therapy sessions.

Parent Involvement for Support

Sessions include parent participation, reinforcing social skills at home to promote lasting personal development.

Other Evidence-Based Psychosocial Interventions

Acceptance and Commitment Therapy

Embracing Acceptance
ACT encourages accepting thoughts and feelings instead of avoiding or feeling guilty about them. Acceptance is the first step to psychological flexibility.

Values-Based Actions
ACT focuses on helping people clarify their personal values and commit to actions that align with those values.

Motivational Interviewing

Helping Teens Resolve Ambivalence
Motivational Interviewing supports adolescents in exploring and resolving mixed feelings about changing behaviors.

Empathy and Nonjudgmental Support
This approach emphasizes empathy, active listening, and providing a safe, nonjudgmental space for teens to discuss their challenges.

Proven Effectiveness in Treatment
Research indicates Motivational Interviewing increases engagement and reduces substance abuse in adolescents seeking help.

Medications for Depression and Anxiety

Clinicians may consider medications if moderate-to-severe symptoms are present. Medications may be an effective part of an individual's overall treatment plan.

Firstline treatments: SSRIs (and SNRIs)

- Fluoxetine (Prozac)
- Sertraline (Zoloft)
- Fluvoxamine (Luvox)
- Paroxetine (Paxil)
- Venlafaxine (Effexor)

May also use less common medications: buspirone (Wellbutrin), mirtazipine (Remeron) benzodiazepines, atypical antipsychotics, tricyclic antidepressants

A number of effective, newer treatments are now available, including transcranial magnetic stimulation (TMS), if symptoms are "treatment-resistant"

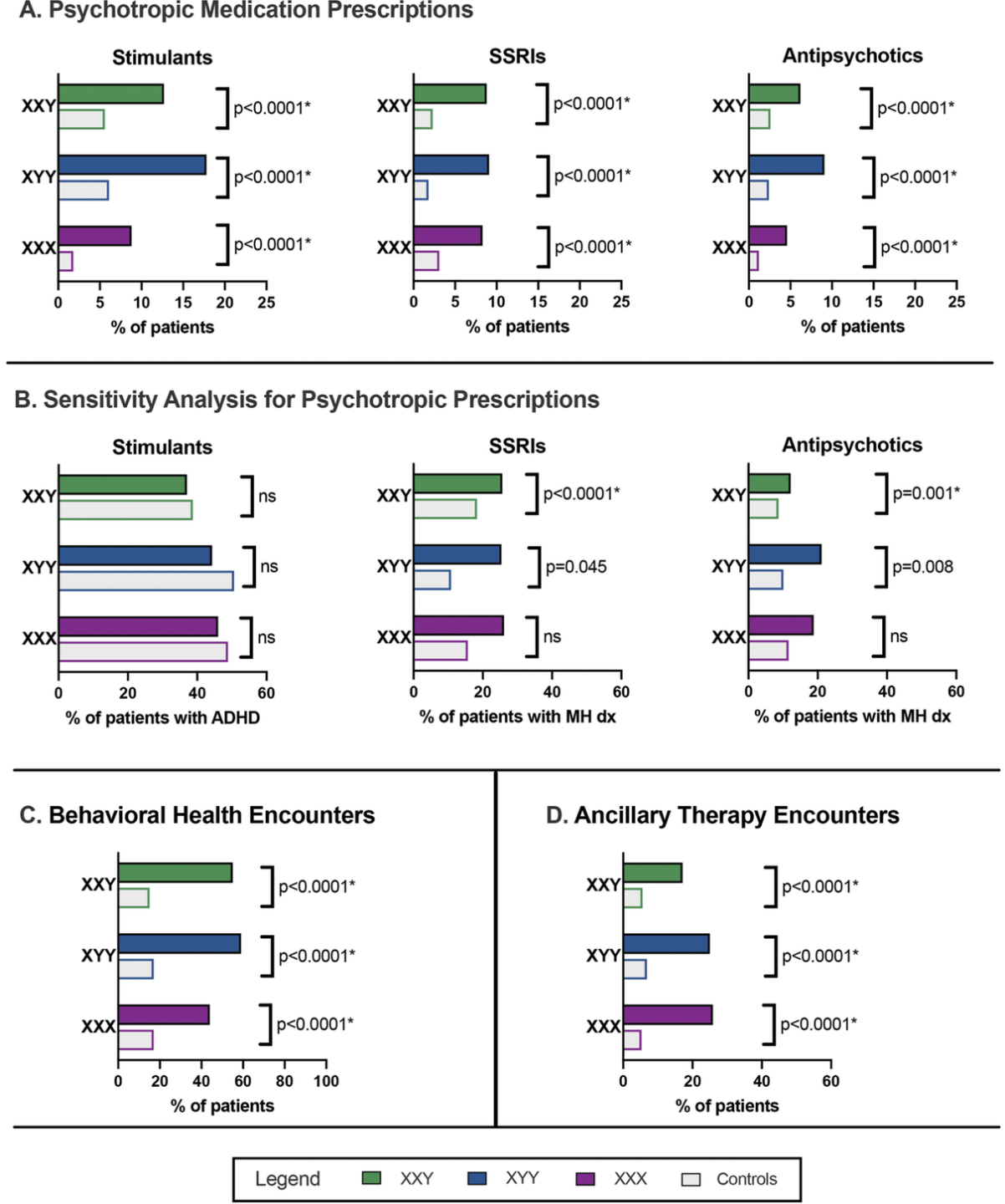
ADHD Medication Choices

Stimulant Medications

Stimulants like methylphenidate and amphetamines are the most common ADHD medications, enhancing specific brain chemicals for symptom control.

Non-Stimulant Options

Non-stimulant medications such as atomoxetine and guanfacine are alternatives for those who do not tolerate stimulants or need different therapies.



Hall A…Davis S. 2025 JDBP.

Additional Support Services

- Executive Functioning Coaching
- Tutoring and Educational Support
- Life Coaching
- Independent Living Skills Coaching
- Career Counseling Job Coaching
- Family Counseling and Support for Parents of Adult Children
- AXYS and Family Advocacy Organizations
- Respite Care or Group/Assisted Living

TOOLS FOR TRANSITION IN THE MEDICAL SYSTEM

Turner Syndrome

GENERAL

Patient's contact information	Patient's school/work
Name	School/employer
Address	Address
Primary phone	Phone number
Cell phone	**Patient's insurance**
E-mail	Provider
Fax number	Policy number

Demographic information and other

Date of birth	Current age
Karyotype	Today's date

EFFECTS OF TURNER SYNDROME, OTHER DIAGNOSES, AND TREATMENTS

Effects of Turner syndrome	Treatment	Start date	End date

Other clinical diagnoses	Date of dx	Current treatment

RECENT LABORATORY TEST RESULTS

	Result	Date
TSH		
Free T4		
Antimicrosomal antibody		
Antithyroglobulin antibody		

	Result	Date
Ambulatory BP monitoring		
Urinalysis		
Renal ultrasound		

TARGETED RISK ASSESSMENT

Cardiovascular risk factors	Yes	No
Family history:		
Type 2 diabetes mellitus		
Hypertension		
Dyslipidemia		
Early-onset of MI or stroke		
Increased BMI or hip/waist ratio		
Hypertension		
Insulin resistance/prediabetes/diabetes		
Dyslipidemia		
Bicuspid aortic valve		
Coarctation of the aorta		
Aortic root dilation		

Osteoporosis risk factors	Yes	No
Family history of osteoporosis		
Caucasian/Asian ethnicity		
Slight build		
Steroid use		
Low bone mineral density		
Low calcium intake		
> 2 servings of alcohol per day		
Other (specify)		
Cardiovascular/osteoporosis risk factors		
Sedentary lifestyle		
Smoking		
Other (specify)		

PSYCHOBEHAVIORAL RISK ASSESSMENT

Family history of mental health disorder
Family history of alcohol/substance abuse
Neurocognitive impairment
ADD or ADHD
Social immaturity
Eating disorders
Depression
Anxiety or obsessive-compulsive disorder
Smoking, alcohol or drug use, sexual activity
Driving history
Overall quality of life

LIFE GOALS

Educational goals
Vocational goals

TRANSITION OF CARE

	Transition care from:	To:
Primary care provider(s)		

My Klinefelter

Young Person's Clinic

Adult Clinic

Further information can be found online at: https://www.ksa-uk.net/

Karyotype	
Test Date	
Laboratory	

Birth			
Weight		Length	
Cryptorchidism		Penile size	

Mini Puberty (0-6 months)			
LH		FSH	
Testoseron		Inhibin B	
AMH		Other	

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THE KLINEFELTER SYNDROME CLINICS

NHS Guy's and St Thomas' NHS Foundation Trust

Medical Readiness - Transition to Adulthood Questionnaire

Clinicians can help guide adolescents with chronic conditions to prepare for increasing independence in managing their care

Some useful tools are in place, such as the Transition Readiness Assessment Questionnaire.

It covers topics, including:

- Managing Medications
- Appointment Keeping
- Tracking Health Issues
- Talking with Providers

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Transition Readiness Assessment Questionnaire (TRAQ)

Patient Name: _____ **Date of Birth:** ___/___/___**Today's Date** ___/___/___ **(MRN#**_____**)**

Directions to Youth and Young Adults: Please check the box that best describes ***your*** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.
Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***your*** skill level. **Check here** if you are a parent/caregiver completing this form. ☐

	No, I do not know how	*No, but I want to learn*	*No, but I am learning to do this*	*Yes, I have started doing this*	*Yes, I always do this when I need to*
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you reorder medications before they run out?					
4. Do you explain any medications (name and dose) you are taking to healthcare providers?					
5. Do you speak with the pharmacist about drug interactions or other concerns related to your medications?					
Appointment Keeping					
6. Do you call the doctor's office to make an appointment?					
7. Do you follow-up on referrals for tests or check-ups or labs?					
8. Do you arrange for your ride to medical appointments?					
9. Do you call the doctor about unusual changes in your health (for example: allergic reactions)?					
Tracking Health Issues					
10. Do you fill out the medical history form, including a list of your allergies?					
11. Do you keep a calendar or list of medical and other appointments?					
12. Do you tell the doctor or nurse what you are feeling?					
13. Do you contact the doctor when you have a health concern?					
14. Do you make or help make medical decisions pertaining to your health?					
15. Do you attend your medical appointment or part of your appointment by					

Specific Transition Readiness Assessment for Turner Syndrome

TRANSITION READINESS ASSESSMENT
FOR YOUTH WITH TURNER SYNDROME
BY THE ENDOCRINE SOCIETY

ENDOCRINETRANSITIONS.ORG

USING HEALTH CARE (CONTINUED)

Please check the box that applies to you right now.	Yes, I know this	I need to learn	Someone else needs to do this... Who?
I know how to fill out medical history forms.	☐	☐	☐
I know how to ask to be seen by other another doctor/therapist.	☐	☐	☐
I know where my pharmacy is and what to do when I run out of my medicines.	☐	☐	☐
I know where to get a blood test or x-rays if the doctor orders them.	☐	☐	☐
I carry my health information with me every day (e.g. insurance card, allergies, medications, and emergency phone numbers).	☐	☐	☐
I know that when I am 18 the rules about my health privacy change.	☐	☐	☐
I have a plan so I can keep my health insurance after 18 or older.	☐	☐	☐
(If applies) I have a plan so I can keep my disability benefits (SSI) after 18.	☐	☐	☐

SOCIAL/EMOTIONAL FACTORS

Please check the box that applies to you right now.	Yes, I know this	I need to learn	Someone else needs to do this... Who?
I have good strategies for managing my attention when I have trouble.	☐	☐	☐
I have good strategies for keeping up with work or job responsibilities.	☐	☐	☐

gottransition.org

Youth, young adults, and families:

Do you want to learn about transitioning to adult health care?

These tools can help you learn about moving from pediatric to adult health care.

What is health care transition (HCT)?

Watch the HCT 101 video

Are you ready to transition to adult health care?

Take our quiz

What transition topics should you think about each year?

Timeline

Is your health information on your smartphone?

Set up your "Medical ID"

List of questions to ask

What questions should you ask your doctor about transition?

What changes for your health care when you turn 18?

Turning 18: What it Means for Your Health

Here's how they differ

What are the differences between pediatric and adult

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Roadmap to Successful Independence

It is important to have a systematic road map, early preparation of families and youth about the array of adult transition services, and a centralized hub of information to be disseminated.

Practitioners need to identify locally available resources and channels for outreach and make available service more visible by producing transition-related materials with examples of current legislative information, problem solving, and best practices.

Practitioners should consider how young adults identify their needs and wants may be different than how service providers and parents conceptualize them.

It is critical to capitalize appropriate levels of caregivers/family support and engagement by provision of education about policies and guidelines for communication and collaboration.

Adapated from: **Chun et al. 2023. Disability and Rehabilitation.**

I want to...	Documents to bring/use
Support my child at school	• SDM Agreement* • Educational Disclosure
Support my child at the doctor's or hospital	• SDM Agreement* • Durable Health Care Power of Attorney • HIPAA Authorization • Health Care Passport • SUPPORT Tip Sheet
Help my child manage money	• SDM Agreement* • Durable Power of Attorney for Finances
Help manage my child's SSI payments	• Representative Payee Form
Help secure my child's financial future	• Durable Power of Attorney for Finances • Special Needs Trusts • ABLE account
Support my child in dealing with their regional center	• SDM Agreement* attached to your child's IPP plan • Regional Center Disclosure

* You may not need an SDM Agreement to support your adult child in these situations, but may find it helpful depending upon the individual situation.

Handbook. Disabilities Voices United.

AXYS
Stanford University Department of Psychiatry

Thank you!

Helpful Resources:
- **gottransition.org**
- **disabilityvoicesunited.org**