The Cliff at Childhood’s End

Helping Emerging Adults with ASD Make the Leap to College
**Session Learning Objectives**

**Objective 1:** At the conclusion of the session, participants will be able to identify and recall at least 5-10 strategies for increasing clinical effectiveness and connection in the treatment of individuals with autism.

**Objective 2:** At the conclusion of the session, participants will be able to identify and recall 5-10 challenges for emerging adults with autism (and their families) in transition to college.

**Objective 3:** At the conclusion of the session, participants will be able to state 5 supports and interventions that can aid emerging adults (and their families) with transition to college.

Mentor to University of Illinois students on the spectrum.

Medically diagnosed with autism at age 45.

Parent of a son diagnosed with Asperger’s at age 6 — now 17 and about to go to college.

This presentation is about Quinn and all the others with ASD who, like him, are about to take a leap of faith into their futures...

Kelly Searsmith
The Cliff at Childhood’s End

~50,000 students with ASD leave high school each year in the US — nearly half were bullied, more than a quarter engaged in wandering.

Students who are better able to converse, come from lower income households, or are African-American are at greater risk for delayed transition planning than other students with ASD, even if most get it in the end.

Of emerging adults with ASD, between high school and their early 20s...

60% have at least two physical or mental health conditions in addition to autism (such as ADHD, social anxiety, depression, OCD, disordered eating, epilepsy, GI problems, sleep problems, immunological disorders)

26% receive no further services for ASD (case management, mental health, medical care, speech therapy); it’s 28% for those who are not working or attending school.

Source: 2015 National Autism Indicators Report: Transition into Young Adulthood
Falling into the Services Gap

1 in 5 emerging adults with ASD ever live independently between high school and their early 20s, 87% with their parents.

1 in 4 emerging adults with ASD are socially isolated.

1 in 3 emerging adults with ASD have no community participation.

Only 42% of emerging adults with ASD worked for pay outside the home.

Within the next 10 years in the US, 550,000 children with ASD will transition to what is currently an under-supported adulthood.
Under-Represented in Postsecondary Education

“The only disability group with a lower rate of postsecondary education is youth with intellectual disabilities.”

- Just 36% received any postsecondary education in their early 20s, including vocational training (compared to 75% of general population)
- Of those who attended college, 70% enroll in 2-year colleges

Many postsecondary students with ASD choose not to disclose. Or can’t, because they haven’t yet been diagnosed.

Only 42% of postsecondary students who disclosed their ASD received accommodations / support.

For those in college who disclosed and received help, 73% felt the supports / accommodations made a difference.

Without transition support, students with ASD are at risk for...

- not receiving postsecondary education, leading to social disconnection, underemployment, and unemployment

- performing below their academic ability, despite “reporting high levels of academic comfort”

- increased rates of isolation / loneliness, stress, anxiety, and depression

- not completing their degree — rate of completion 38.8% (compared to the general population 52.4% and general disabilities 40.7%) (Jackson, Hart, Brown, & Volkmar, 2018)

- suicide — nearly three-fourths of postsecondary students with ASD reported “lifetime suicidal behaviors” (Jackson, Hart, Brown, & Volkmar, 2018)
Postsecondary Supports / Accommodations for ASD

**School Provided**

1. Testing  
2. Human aides  
3. Assignments modifications  
4. Material/technical adaptations  
5. Physical adaptations

Source: National Longitudinal Transition Study-2

**Parent Requested**

- Life skills training/support  
- Self-advocacy training  
- Social support networking (making friends)  
- Individual housing (singles)  
- Continued parent involvement  
- Academic organization assistance  
- Faculty trained with deep knowledge of ASD, sense of compassion, and willingness to provide individualized accommodations

Postsecondary Supports / Accommodations for ASD

Specialist Recommended

Resources to support social and emotional health (not necessarily academic resources)

Examples

- peer programs
- ASD housing/clubs
- highly available, high quality counseling / psychological services

Recognizing and Helping Students with ASD to Overcome Challenges to Development

a personal reflection on Chickering and Reisser’s Seven Vectors of Identity Development

- Developing competence
  motivated to achieve in three areas: intellectual, physical, interpersonal

- Managing emotions
  able to understand, accept, and express emotions

- Moving through autonomy toward interdependence
  values emotional independence but also cooperation with others
● Developing mature interpersonal relationships
accepts others, respects differences

● Establishing identity
gains an integrated, healthy self-concept

● Developing a purpose
makes a commitment to the future (to attain goals, overcome adversity)

● Developing integrity
moves from self-focused and rule-based to balanced and empathetic, gains core set of personal values with respect for others’ values, brings actions into line with beliefs

Review: Key Transition Challenges

- Loss of high school services for ASD and the need to re-disclose ASD (which students often resist) can lead to service discontinuation when support is still needed.

- The unfamiliar college environment and new demands significantly increase stress. They can lead to temporary developmental regression, a crisis in identity / belief in ability to succeed, and school withdrawal (failure to graduate).

- Colleges may mistarget supports due to focus in psychological disability services on ADHD (ASD supports should emphasize social and emotional over academic) and lack of ASD specialization (small population comparatively).

- Colleges may have weak or absent transition supports specific to ASD needs and individual needs (ASD is a population with diverse needs -- one size does not fit all).

- Students may also struggle with loss of family supports (moving far from home, with parents no longer able to advocate directly due to college policies that treat students as independent adults, which are reinforced by FERPA and HIPAA).
In visiting schools, students with ASD and their families should try to learn whether disability support and mental health counseling services on campus are provided for ASD specifically, with what level and kind of support, and with what level of expertise/specialization. They should ask whether student organizations for students with ASD exist and ask to meet with members to learn about the quality of supports on campus and the campus climate (especially faculty attitudes toward disability accommodations). If no related student organizations exist, they should ask to meet with a student ambassador on the spectrum.

Depending on need, students with ASD and their families should also consider postsecondary transition programming and/or enrollment in a community college or college close to home initially, in order to ease the transition to independent living and social-emotional challenge in college.

Initially, the primary focus should be on social and emotional supports, life skills development, and orientation to the new physical and social environment. The ability to live on campus in a single with bathroom privacy and low sensory impact may be of primary importance as well.
Needs and support assessments should focus on the whole person (ASD is a neurodevelopmental difference that affects the person in an integrated way and is lifewide as well as lifelong).

Emotional supports should focus on helping students to recognize, accept, and manage emotions, especially isolation, frustration, and stress / overwhelm.

Social supports should focus on training students to self-advocate, helping them to meet other students and form friendships, and guiding them in working with faculty. An early emphasis should also be on helping the student to identify and form a relationship with a mentor / trusted person in the student’s major / academic interest area (to help create a new academic home away from home).

An important initial secondary support for many students with ASD is help with organizing their schedule and workflow, as well as class materials (apps, links, websites, online resources).
Review: Key Transition Supports, concluded

- If the student welcomes it, parents should continue to be allowed to advocate for their child. Some colleges allow students to request parental involvement, especially for payment and housing purposes. However, broader privileges for parental involvement can be sought through “supported decision making” (the OAR college guide provides a sample universal form that can be submitted to the college). If the student does not welcome parent involvement, another trusted person can be designated.

Recommended Resource