Transitioning to Adulthood:

Special Challenges in Individuals with Intellectual and Developmental Disabilities and Comorbid Psychiatric Disorders

Cassie Karlsson M.D.

Child and adolescent psychiatrist, neuropsychiatrist

Associate Professor

Department of Psychiatry & Behavioral Sciences

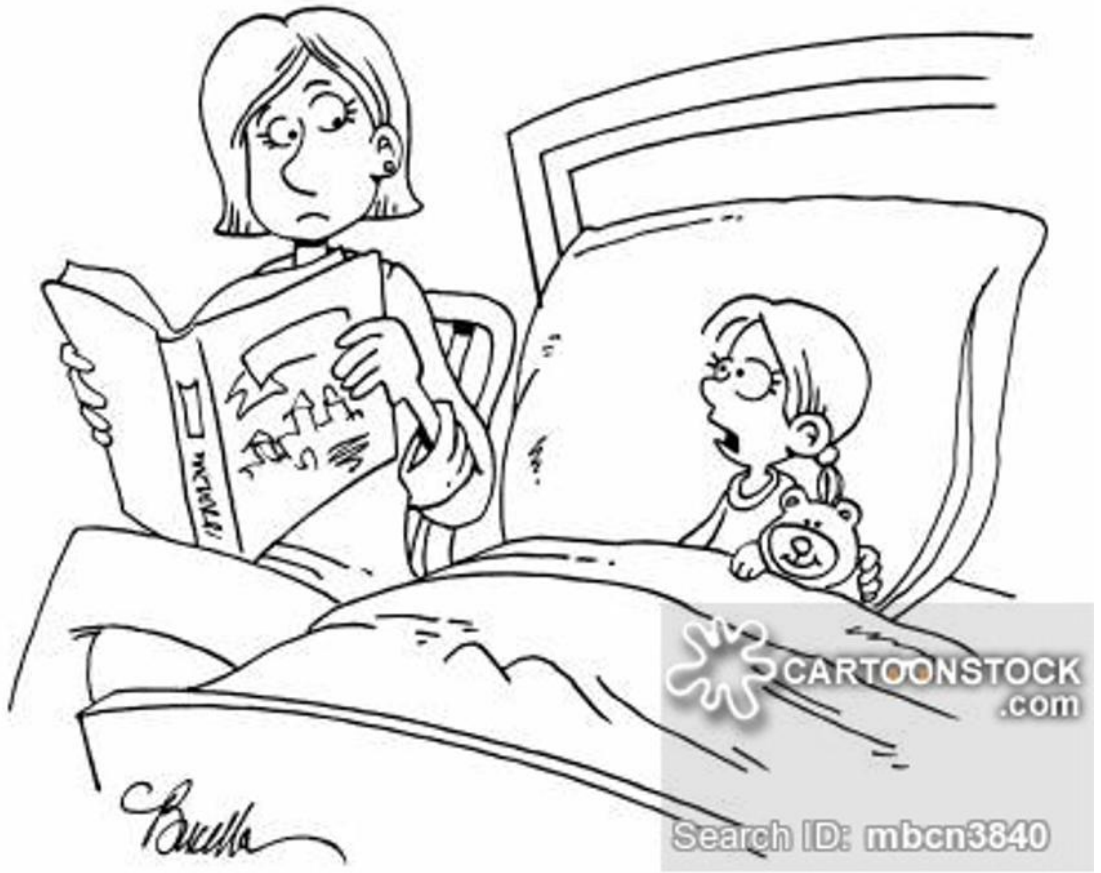
KU School of Medicine-Wichita

Learning Objectives

- Summarize the prevalence of psychiatric illness in individuals with intellectual and developmental disabilities, including autism spectrum disorder.
- Identify the factors involved in transitions to adult care for this population, including goals and barriers.
- Describe the importance of an individualized approach to transitions which focus on maximizing autonomy and independence.

Growing up is hard to do…

- The transition from adolescence to adulthood is a challenging time with profound physiological, psychological, and social changes
- For example…(let's name a few!)



"Mom, how many more years until I reach that awkward age?"

Growing up is even harder for some

- Globally, one in seven young people between 10 and 19 years of age experience a mental health condition, of which depression and anxiety are the most common.
- About 70% of adolescents with a mental health condition experience challenges that persist into adulthood and will require ongoing mental health services and support beyond adolescence.
- Neurodivergent adolescents are at greater risk for the onset and persistence of these mental health conditions than their neurotypical peers.

Intellectual Disability & Psychiatric Comorbidity

- Estimated that about **1/3** of individuals with an intellectual disability (ID) have a psychiatric disorder (about 2% of people with a psychiatric illness have an ID)
- Rate of schizophrenia in ID estimated between 3-5% (about 1% in the general population)
- Challenges:
  - Individuals with ASD, ID, developmental disorders do not always present with “classic” symptoms of a disorder
  - Can sometimes be difficult to differentiate between psychiatric disorder and “core features” of the developmental disorder

Autism Spectrum Disorders & Psychiatric Comorbidity

- **Mood Disorders:**
  - Suspected to be elevated in individuals with ASD
  - Higher rates of mood disorders in parents of children with ASDs (Mazefsky et al, 2008)
  - Significant psychosocial stressors (especially in higher functioning individuals aware of their social deficits) may increase risk of depression/anxiety
- **Anxiety Disorders**
  - Often considered the most common comorbid diagnosis - 40% comorbidity rate, has been cited up to 80% (Simonoff et. al, 2008)
- **ADHD**
  - Considered common in ASDs (often diagnosed prior to ASD diagnosis), can now diagnose with ASD in DSM-5
- **Intellectual Disability**
  - Estimates vary from 50-70%, learning disabilities also very common

Transitions in Mental Health

- Adolescents with mental health conditions, compared to those with chronic physical conditions, are especially likely to experience gaps in access to, and quality of, transitional care
- Patients with a severe mental illness, or those who have been admitted for inpatient services, are *more likely* to make the transition than individuals with co-occurring neurodevelopmental disorders

Transfer vs. Transition

Transfer = termination of care by a children's health care service, which is re-established by an adult provider

Transition = lengthy & seamless process with a beginning, middle, and end marked by joint responsibilities in multidimensional and multidisciplinary work to ensure a way to enable and support young patients continuing on into adult care

Barriers to Adult Mental Health Transition in NDD/IDD populations

- Separate access policies (CMHC vs. CDDO?)
- Lack of clarity of access procedures
- Lack of shared transition planning
- Not accepted by adult providers despite continued mental health needs
- Lack of mental health providers in general
- Adult mental health providers often lack training in treating individuals with autism and other developmental disorders
- Long wait times for services may create large gaps in care
- Many more…

Not just the United States…

2015 review paper in *European Psychiatry*, looking at transition to adult mental health services worldwide (L Reale, M Bonati)

- More than ½ of parents were unaware of any transition plan
- Only about ¼ were satisfied with the transition care their child had received
- At least 50% had various difficulties accessing services
- Difficult in finding adult services
- Consequent desire to continue care through the pediatric service
- Difficulty in defining the timing of the transition process

Family Role in Transitions

- Often responsible for finding, coordinating, and helping to finance adult services
- Must often be their own advocates for services & supports when the youth leaves high school
- Transition planning is mandated for schools by the Individuals with Disabilities Education Act (IDEA), but often falls short

Specific to Health Care – Parent Concerns

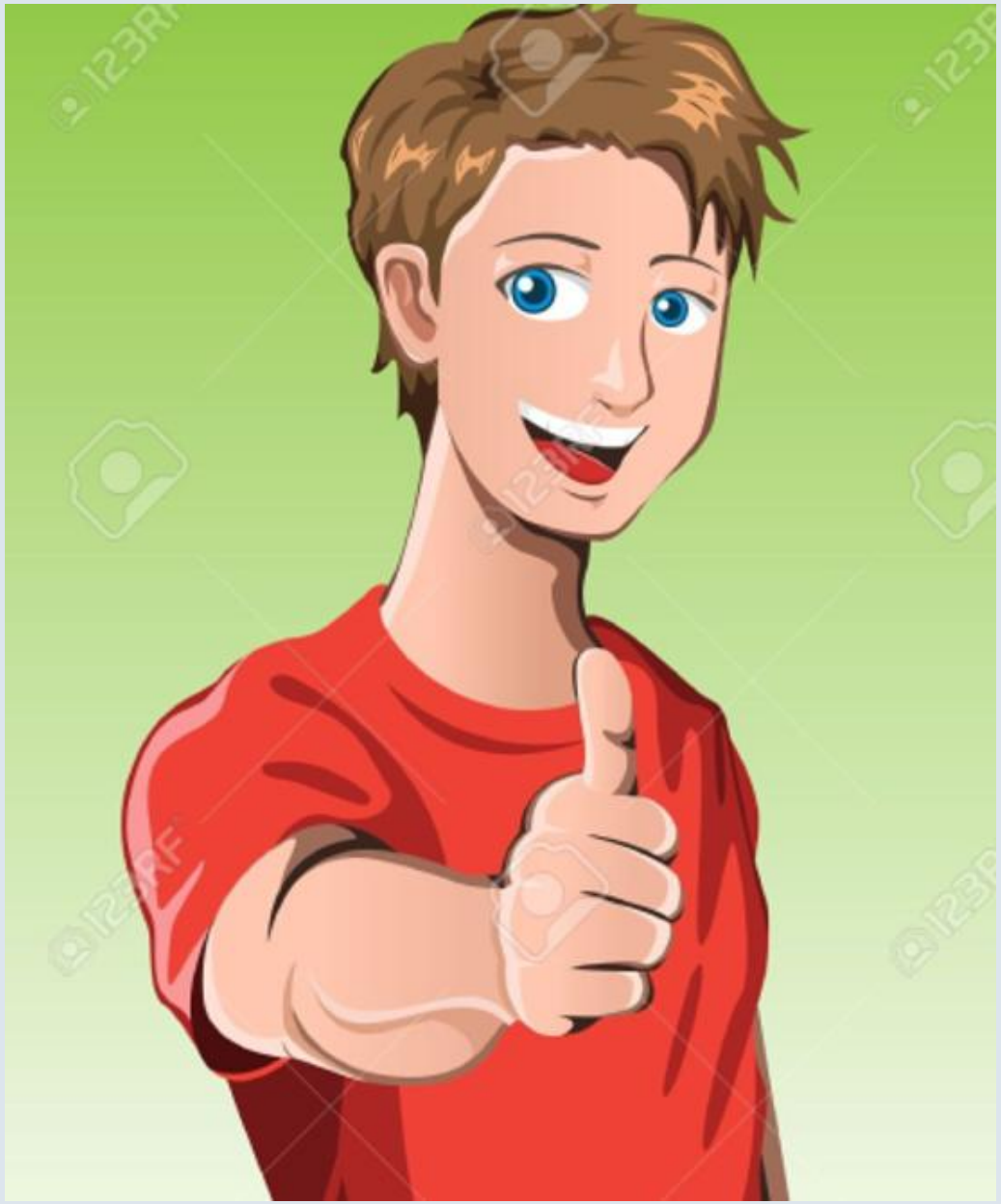
- Loss of relationship with provider and lack of support in transition to adult care
- Providers' lack of education & sensitivity
- Concerns about losing guardianship – worry that it would result in reduced access to care and poor outcomes in their youth
- Combined concern that youth lack competency to manage their own health care, and lack of trust in adult health care professional to manage child's health care

Specific to Health Care – Youth Concerns

- Often largely unaware about health care transition process, and what role providers would play in their lives
- Anxiety about lacking the skills (or experience) to talk to their provider
- Anxiety about taking on more responsibility
  - Idea that it would be their responsibility “overnight” at age 18, not a step-by-step process
  - Often about concrete things – needing to take pills on time
- Often could not identify why they saw a specific provider, or what kind of problems they helped them with
- Anxiety about being required to answer questions about their medications

Meet JOHNNY

- 21 years old
- Diagnoses: Autism, ADHD, History of depression (resolved), Cerebral Palsy, IQ below average but not intellectual disability
- Family: Lives with adoptive mom and dad at home (both successful professionals), younger bio sister. Multiple older siblings no longer in the home.
- Graduated from High School with a diploma (did receive additional services/IEP)
- Goals: “I want to live by myself, go to college, and have a job”
- Strengths: good with computers, technology



Parents, what would a successful transition look like?

Parent identified themes for “adult success”:

- Having an occupation or functional role in society
- Moving out of the home, apart from the caregiver
- Relationships with peers
- Skills required for successful daily functioning
- Continuing academic or intellectual pursuits
- Independence/Independence with support
- Constructive relationship with community
- Accessibility and transportation
- Psychological well-being
- Romantic relationships and/or starting a family
- Physical health or safety

KU School of Medicine-Wichita

Maximizing Autonomy & Independence

Maximizing Autonomy & Independence cont.

- Many individuals with Autism/ID and severe problem behaviors will not be their own guardian
- Some may not need a guardian, but will require extensive continued support
- Why is autonomy & ability to make decisions so important?
- What are ways to maximize autonomy & independence?
  - Providing opportunities for choice throughout the day
  - Not requiring that all enjoyable items/time is required to be earned by good behavior
  - Attending to problems in a developmentally appropriate way (which may differ for different things, ie boyfriends/sexuality vs. playing with baby dolls)
  - Neglecting structure or schedule because the individual is an “adult who can make their own decisions” is not always helpful

Back to JOHNNY

- Johnny started his transition volunteering at a local organization and taking 1 class at a local university.
- Problem behaviors that interfered with functioning:
  - Inconsistency with going to class, or leaving class early and spending the time in the computer lab on YouTube
  - Impulsive eating – especially sugar products (parents have always locked up these items at home) – cleans out the “candy jar” at his organization daily, takes sugar packets from the cafeteria, one incident of stealing food from the bookstore when forgot his wallet
  - Forgetting his wallet and phone at home – led to losing track of time, forgetting appointments, unable to afford lunch or to pay for other items/errands he was supposed to run

What might be leading to problems for Johnny in his current situation?

Steps to improve:

- Johnny needed more structure in his day, less free time
- Johnny needed help with remembering his belongings for the day
- Consultation with a psychiatrist regarding impulsivity, disorganization

Solutions:

- Enrolled in a very structured vocational rehab program with increased adult supervision
- Parents helped establish a morning routine where wallet, phone, and lunch were packed and ready to go the night before
- Psychiatrist started a stimulant to target ADHD symptoms

Can we make this process better?

- Talking about transition with families and patients before the youth is 17 or 21 (these are the usual “oh no!” moments)
- Identification of “adult providers” prior to discharge from child providers, consider creation of a “portable medical summary” of diagnoses/treatment
- Education of mental health professionals in treating individuals with developmental disorders
- Advocacy for increased mental health access
- Mental health providers partnering with primary care
- Recognizing the PCP or psychiatrist may not be the most knowledgeable about resources – importance of connecting to appropriate agencies, clinics, etc.
  - The ARC – local chapters (no state chapter in Kansas)
  - Capper Foundation (Easter Seals)
  - Families Together, Inc (Family Voices Kansas Affiliate)
  - Vocational Rehabilitation Services
  - CDDO
  - Independent Living Resource Center (ILRC)
  - KCDD Kansas Benefits Guide https://www.kcdd.org/kansas-benefits-guide

KU School of Medicine-Wichita

Join and access:

- Consultation Line
  - Case consults with child psychiatrists, child psychologists, social workers, and pediatricians
  - Resource and referral support
- Training events
  - Webinars
  - ECHO clinics
  - In-person symposia
  - On-demand

All services are 100% free, statewide

KSKidsMAP

Pediatric Mental Health

A Kansas Department of Health and Environment Program

KU School of Medicine-Wichita

References

1. World Health Organization . World Health Organization; 2021. Mental health of adolescents.https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health Available. [Google Scholar]
2. Cleverley K, Lenters L, McCann E. “Objectively terrifying”: a qualitative study of youth’s experiences of transitions out of child and adolescent mental health services at age 18. BMC Psychiatry. 2020;20:147. doi: 10.1186/s12888-020-02516-0. [DOI] [PMC free article] [PubMed] [Google Scholar]
3. World Health Organization . World Health Organization; 2022. Mental disorders.https://www.who.int/news-room/fact-sheets/detail/mental-disorders Available. [Google Scholar]
4. Accardo AL, Pontes NMH, Pontes MCF. Heightened Anxiety and Depression Among Autistic Adolescents with ADHD: Findings From the National Survey of Children’s Health 2016-2019. J Autism Dev Disord. 2024;54:563–76. doi: 10.1007/s10803-022-05803-9[DOI] [PMC free article] [PubMed] [Google Scholar]
5. Reale L, Bonati M. Mental disorders and transition to adult mental health services: A scoping review. Eur Psychiatry. 2015 Nov;30(8):932-42. doi: 10.1016/j.eurpsy.2015.07.011. Epub 2015 Oct 21. PMID: 26647869. DOI: 10.1016/j.eurpsy.2015.07.011
6. Henninger NA, Taylor JL. Family Perspectives on a Successful Transition to Adulthood for Individuals with Disabilities. Intellect Dev Disabil. 2014 Apr;52(2):98–111. doi: 10.1352/1934-9556-52.2.98. PMCID: PMC4128390 NIHMSID: NIHMS619021 PMID: 24725109

Thank you

ckarlsson@kumc.edu