

# Leaving Never Neverland

## A Transitions Roadmap to College



JOHNS HOPKINS  
M E D I C I N E

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# College Bound

- 69% of 2015 high school graduates enrolled in college
- Prevalence of children with special health care needs\*

*\*those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally*

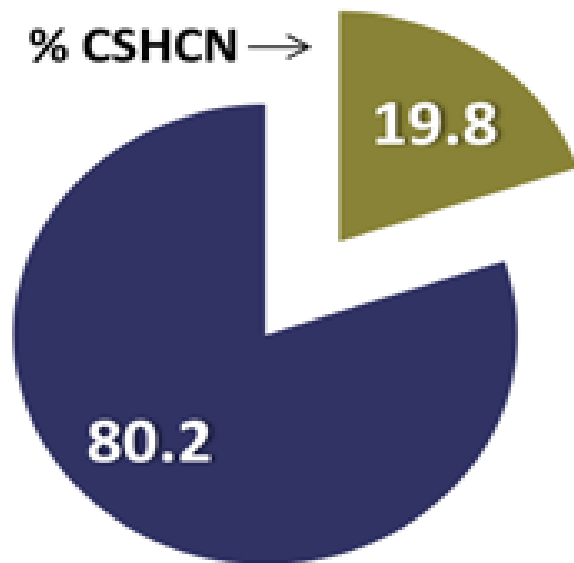
- 15.1% of children nationwide
- 18.4% age 12-17

*National Center for Education Statistics, 2015*

*National Survey of Children with Special Health Care Needs, 2009-10*

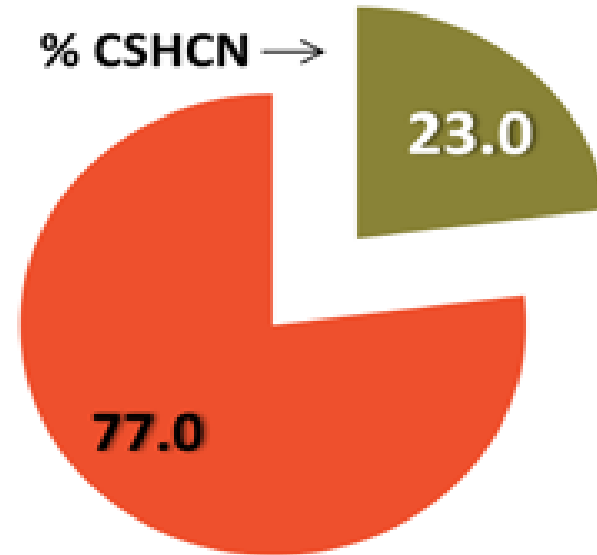
# Children with Special Health Care Needs (CSHCN)

Source: 2011-12 NSCH



**Children 0-17 years**

Source: 2009-10 NS-CSHCN



**Households with Children**

Child and Adolescent Health Measurement Initiative (2013). "Who Are Children with Special Health Care Needs (CSHCN)." Data Resource Center, supported by Cooperative Agreement 1U59MC0698001 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).

# Emotional, behavioral, & developmental disorders

Across the list of 18 specific health issues asked about in the **2011/12 NSCH**, 78.4% of CSHCN were reported to experience at least one of the conditions that was asked about; 41.1% experienced two or more

<b>Health Issue Asked About*</b>	<b>% Among CSHCN</b>	<b>Health Issue Asked About</b>	<b>% Among CSHCN</b>
Learning Disability	27.2	Speech Problems	15.6
ADD/ADHD	32.2	Tourette Syndrome	0.2
Depression	8.5	Asthma	30.2
Anxiety Problems	13.4	Diabetes	1.4
Autism, Asperger's, ASD	8.0	Epilepsy	3.1
Behavioral Problems	13.6	Hearing Problems	4.2
Developmental Delay	14.7	Vision Problems	3.2
Intellectual Disability	4.8	Bone, Joint or Muscle Problems	7.7
Cerebral Palsy	1.0	Brain Injury	1.1

# 2009-10 National Survey of Children with Special Health Care Needs (CSHCN)

- Only 40% of youth 12-17 years old received services needed for appropriate transition to adult care, work, and independence
- Adolescents with behavioral, emotional or developmental conditions were less likely to receive transition preparation (28.9%)

# College Student Mental Health

*Association for University and College Counseling Center Directors  
survey of counseling center directors, June 2015*

Presenting Concern	%
Anxiety	47.3
Depression	40.1
Relationship problems	32.5
Suicidal ideation	20.2
Self-injury	12.8
Alcohol abuse	10.6

- 26.1% student clients taking psychotropic medications
- 61.5% directors reported psychiatric services available on campus
  - 74.3% report that amount of psychiatric services are inadequate
  - 25% report services are non-existent
- Larger schools have more psychiatric service hours/week
  - <1500 students: mean = 9 hours
  - 35,000+ students: mean = 83 hours

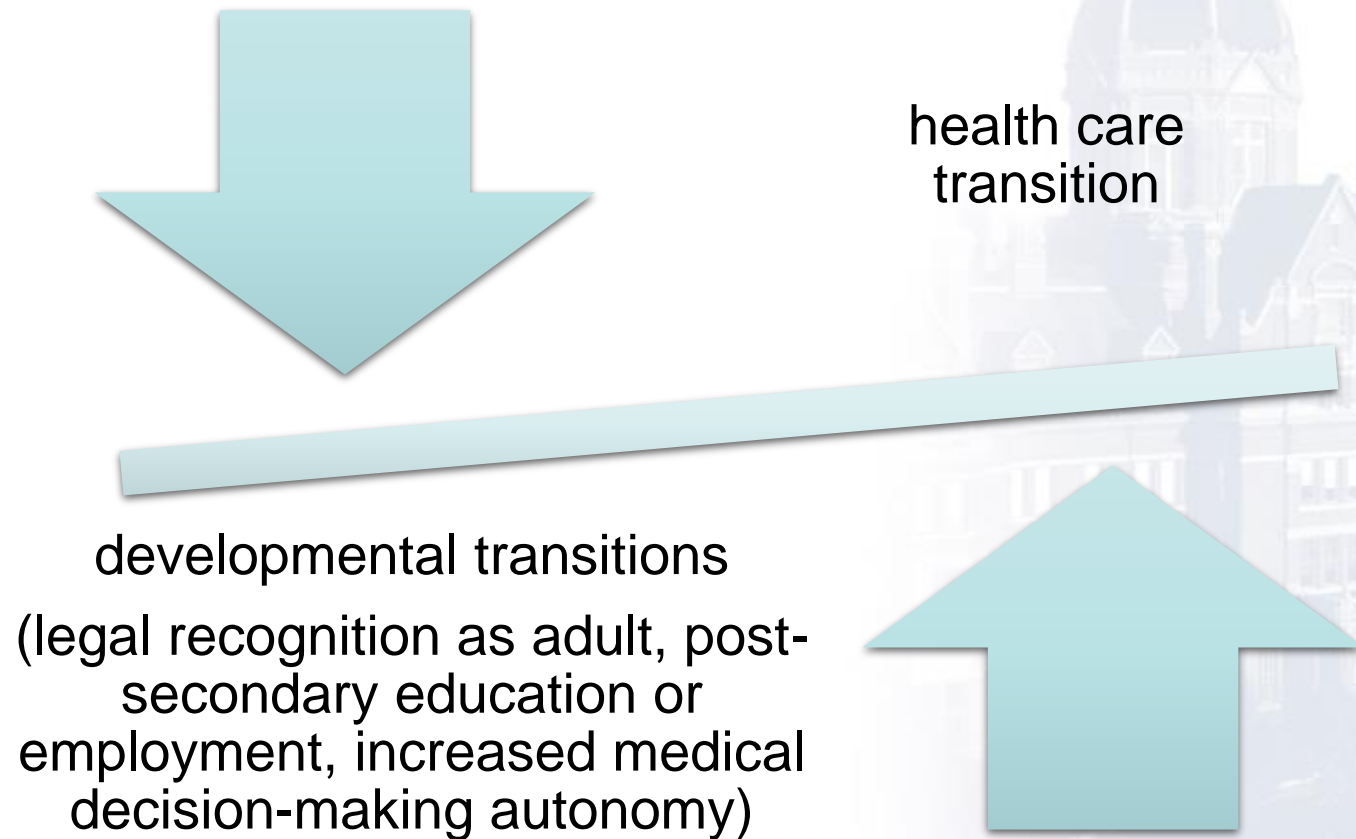
## ***Worsening mental health condition can significantly impact college success***

- Mental Health (MH) issues cited as major reason (64%) young adults withdraw from/don't attend college
- 73% of students with MH condition experienced MH crisis on campus
  - 65.8% of those: college unaware
  - Stigma, desire for self-reliance, lack of knowledge re: counseling process, fears of self-disclosure, and confidentiality concerns cited as reasons

*National Alliance on Mental Illness, College Students Speak 2012*

- Nondisclosure eliminates safety net
- Lack of planning creates difficulties accessing care if student become destabilized

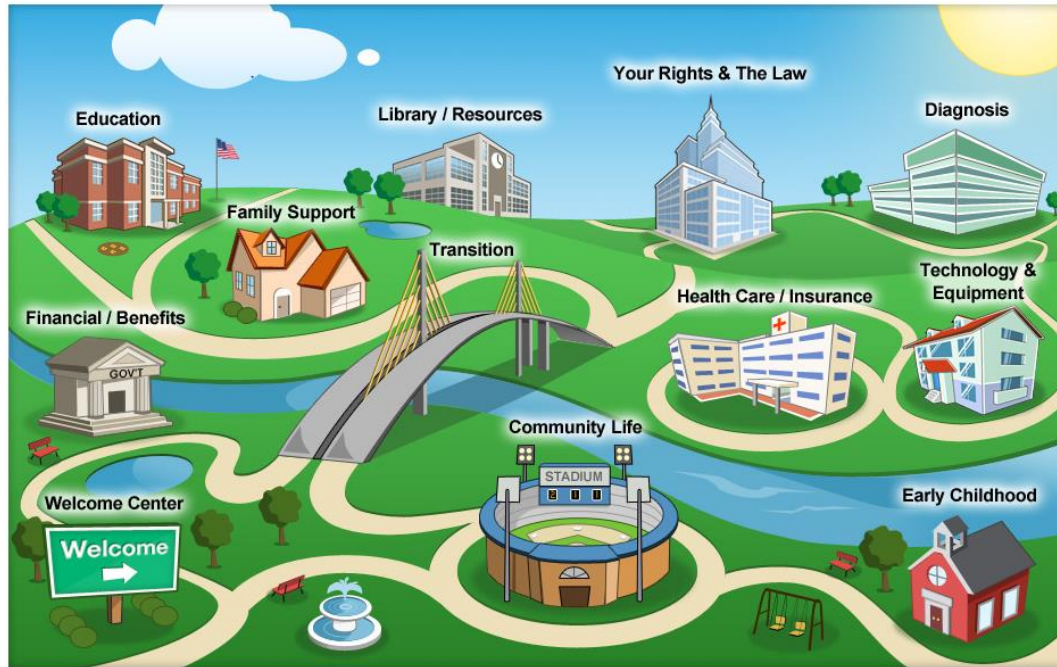
# Bumpy Road to College





# Preparing for the trip: *have a good map*

- Transition planning: multidisciplinary
  - medical home/primary care site, school nurses & counselors, specialists (including mental health team), social work, ancillary services, case management, student, and parent/guardian
- Self-management on campus
  - student health clinic, office of student disabilities, resident life, and local supports



# Transition Roadmap for College:

addressing specific aspects of transition  
planning to optimize self-care management





## **Environment**

accessibility  
other students' experiences  
ADA

## **Medical**

campus health services  
community services  
insurance  
provider appointments  
medication management  
DME, self-care, managing health

## **Social**

sleep      alcohol & drugs  
sex        social supports  
stress management  
life skills

## **Academics**

selective service  
academic demands

# Environment

**Environment**  
accessibility  
other students' experiences  
ADA



Medical

Social

Academics

# Environment

- Accessibility
  - Living quarters, buildings, transportation
  - Available services: note takers, extended time, alternative testing environments, etc.
- Experiences of other students/families
  - Contacts through Office of Student Disabilities

# Environment

- Accessing ADA accommodations
  - Include difficulties in communicating, reading, learning, thinking, and working problems
  - Section 504: if receiving federal funds, must modify policies, procedures and practices to allow reasonable accommodations for students with disabilities
- Post-secondary institutions: adjustments required as long as
  - Do not cause significant changes in requirements for the student's program of study
  - Do not create an undue burden for the university
- Interpretation of *reasonable accommodations* varies
  - Important to meet with Office of Student Disabilities during college vetting process

# Environment

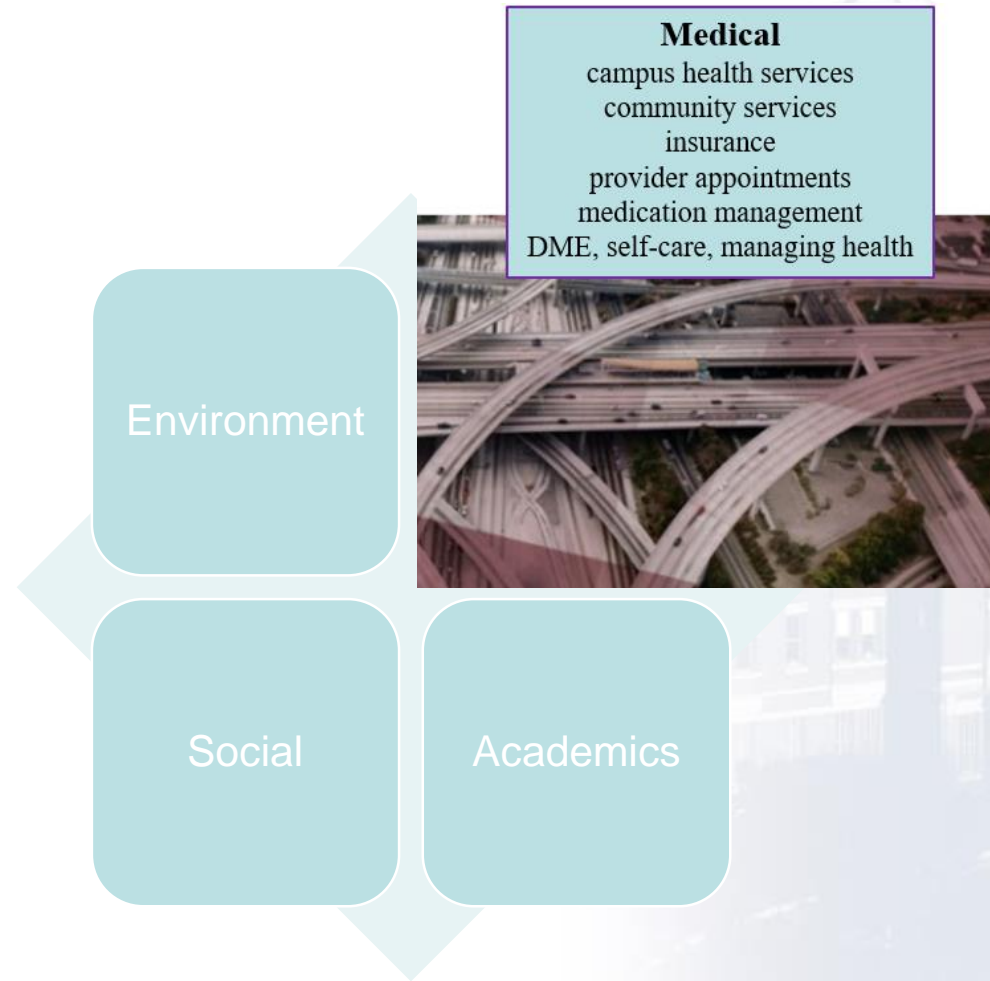
- Requesting accommodations
  - Crucial step for academic success
  - Students with MH diagnosis may hesitate
    - Majority of students (70%) with MH diagnosis did not file requests for accommodations due to concerns re: discrimination
  - Filing deadlines can impact access
  - Accommodation requests are not shared with course faculty without student consent
    - Therefore, no penalty for accommodations on file



# Case Study

- Kayla is a 17yo young woman with cerebral palsy who plans to attend college after graduation next year. She has a 3.2 GPA, uses a motorized wheelchair, and needs assistance with transfers. In addition, she has impaired speech which makes verbal communication challenging. She has come to clinic today to learn more about how to plan her transition to college. Her parents are extremely supportive of her independence and accompany her today to assist with putting plans in place as she explores college options.
- What transition plans need to be made for Kayla in regard to the college environment?
  - Accessibility
  - ADA accommodations
  - Other disabled students' experiences

# Medical



# Medical

- Quality of student health & counseling services
  - Clarity re: types of services needed
  - Smaller university/smaller classes/individualized support may be desirable but health center services may be lacking
  - Student's ability to articulate needs
    - Medical summary on cell phone
    - Able to discuss condition, history, needs

# Medical

- Community health care services
  - Must arrange in advance, if needed
  - Proximity to large academic centers may increase options
- Understanding of insurance coverage
  - In-network vs. out-of-network
  - Gatekeeper concepts (prior auth, referrals)
  - Access website to determine limits
  - Limitations with state programs that don't transfer across state lines

# Medical

- Medical supplies, equipment, & support
  - Ongoing DME orders
  - Resources for equipment repairs
  - Service/emotional support animals
  - Personal care attendants
    - College requirements for documentation of need and certifications
    - Residence hall stipulations
    - Separation from academic support
    - Contract negotiations re: service payment, hours, etc.

# Medical

- Provider appointments
  - Identify new provider(s), transfer records before school starts
  - Optimal to meet provider in advance: warm hand-off
- Refilling medications
  - How/when to request a refill
  - Pharmacy services: local versus mail services

# Medical

- Medication adherence
  - Critical for certain health conditions, including MH
  - Adolescent adherence rates vary widely
    - from 10% to 89% for chronic illnesses
  - Most frequently-reported reason for non-adherence = forgetting (74.5%)
  - College students' additional potential barriers
    - Questioning necessity of medications, lack of known pathway for refills, need to schedule follow-up with prescribers
  - Use of daily reminders on cell phones helpful

# Medical

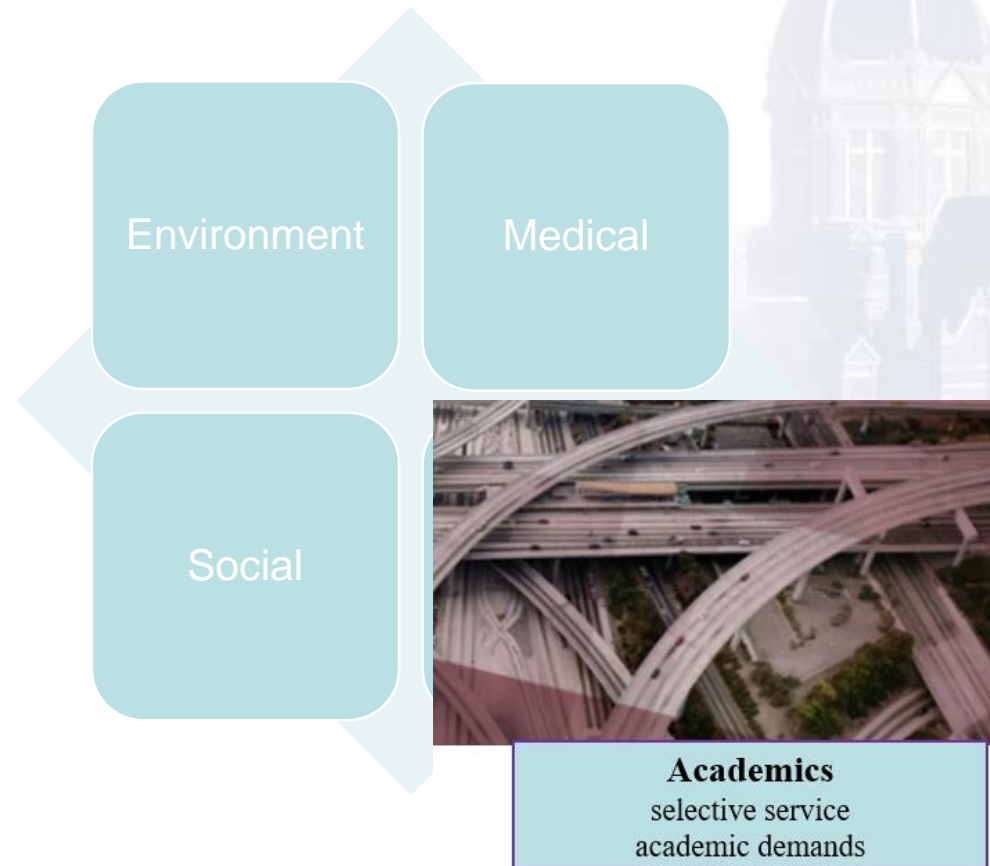
- Ability to manage health care
  - Self care needs (cathing, glucose monitoring, peak flows, etc.)
  - Health-promoting behaviors: exercise, limited screen time, sunscreen, oral health
  - Able to determine when condition is worsening
  - Able to seek assistance



# Case Study

- Kayla is exploring college options. She has a cell phone but has some difficulty using it due to her CP. She qualifies for insurance with a REM diagnosis of quadriplegic CP. She wonders if her insurance will transfer if she attends an out-of-state school. Kayla is engaged in therapy to assist in coping with depression and takes Zoloft. She is considering an out-of-state college that caters to special needs students and will have a personal care attendant. During the visit, she shares concerns about how to manage her menses more independently.
- How do you counsel Kayla about her concerns?
  - Campus health services, community services, insurance, provider appointments, medication management, DME, self care

# Academics



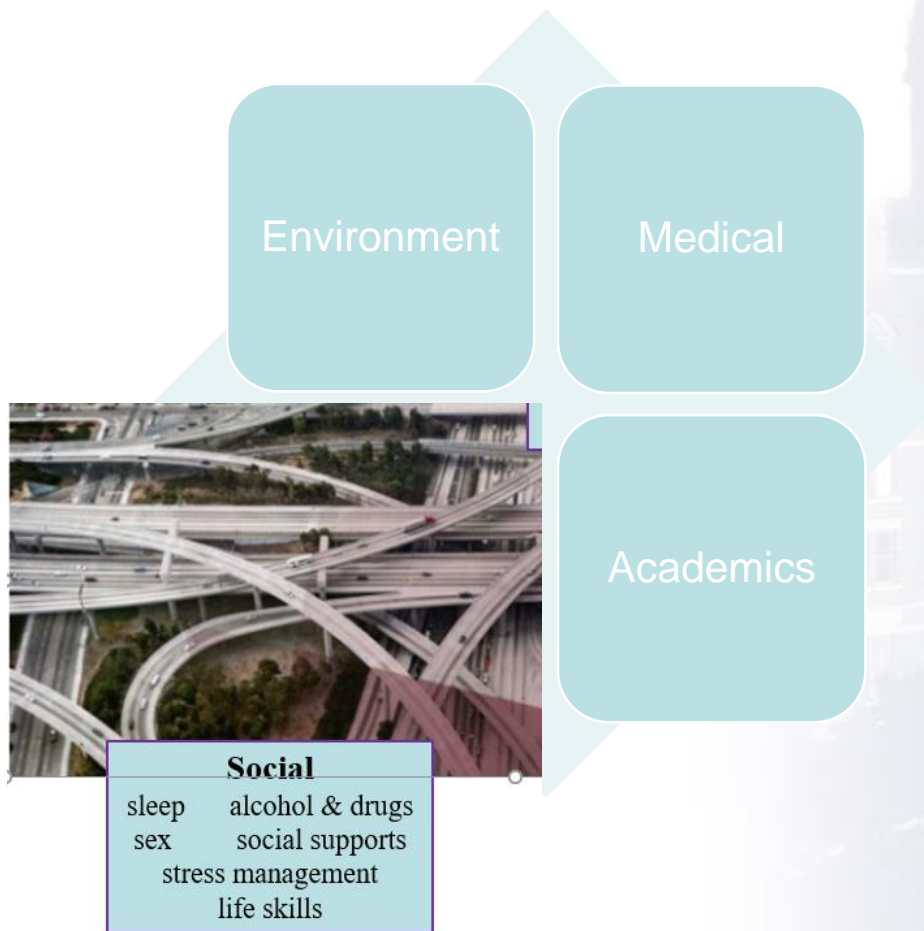
# Academics

- Males: register with Selective Service at age 18 (regardless of disabilities)
  - Impact on federal and state benefits, including federal loans, job training, and government jobs
- Ability to manage academic demands
  - Use/manage a computer
  - Time management
  - Emotional maturity
    - Reactions to emotional & social set-backs?
    - Able to deal independently & effectively?

# Case Study

- What do you need to know to optimize Kayla's transition planning around academic success?

# Social



# Social

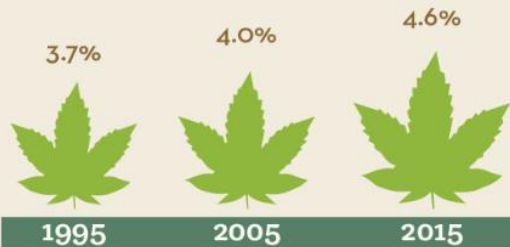
- Sleep deprivation
  - High school increase due to homework, extra-curriculars, and part-time work
    - Increased risk: poor academic performance, depressed mood, and drug use
  - College life increases risk for sleep deprivation
    - Academic demands, peer pressure to socialize, roommate's schedule, residence hall life
  - Anticipatory guidance
    - Develop sleep schedule
    - Review good sleep hygiene

# Social

## Drug and Alcohol Use in College-Age Adults in 2015

2015 Monitoring the Future  
College Students and Adults Survey Results

### Marijuana Use Among Full-Time College Students Remains a Concern



Daily marijuana use has steadily increased among college students in the past two decades.

### Heavy Alcohol Use Higher in College Students than Non-College Peers

**BINGE DRINKING**  
Five or more drinks in a row

**INTOXICATION**  
Having been drunk



College Student Group Non-College Group

# Social

- Alcohol & Drug Use
  - Regular cannabis use puts adolescents at risk for
    - Cognitive decline
    - Withdrawal from school (2 x non-users)
    - Using other illicit drugs
  - Alcohol + medications may amplify effects of both, making monitoring “safe levels” a challenge
  - Students with anxiety and depression at increased risk due to mood oscillation



# Social

- Exposure to alcohol and other drugs in college, in combination with increased autonomy, makes emerging adults more vulnerable for initiation or increased use
- Transition planning should include coping with increased exposure to alcohol and other drugs

# Social

- Sexuality
  - Often overlooked facet of transition planning
  - Menstrual management in females can increase independence
  - Risk reduction counseling, contraception, reproductive life planning
    - LARC methods

# Social

- Loss of social supports
  - Major shift in social supports with transition to college
  - Need to re-establish new networks
  - Importance of social networks among college students
    - High quality: lower incidence of depression, suicidality, self-harm, anxiety, eating disorders
    - Poor quality: 6 times more likely to experience depressive symptoms

# Social

- Social isolation more common among students with ethnic minority, international, and/or low SES status
- Importance of clubs, support groups

# Social

- Stress Management
  - College transition an exciting developmental milestone associated with new stressors
  - Existing coping mechanisms may require adaptation
  - Transition planning should address
    - Identifying known stressors
    - Previously-used coping strategies
    - Anticipatory guidance for new scenarios and how to cope

# Social

- Ability to perform life skills
  - Kitchen, food prep, shopping skills, food choices
  - Laundry & housekeeping
  - Emergency procedures (medical and general)
  - Community skills
    - Getting around, bank accounts & managing money, using community services, restaurant services, appropriate dress behavior, personal safety
  - Leisure time activities
    - Keeping calendar of events, arranging time with friends, participating in a sport or hobby

# Case Study

- Kayla is known for her sense of humor, has many friends, and likes to be part of an active social circle. She has tried alcohol once at a friend's party but denies other drug use. She is not sexually active but is interested in boys. She works hard to maintain her grades, often working late into the night. She is a bit worried about living in a quad apartment in a residence hall and her family wonders how she will manage regular activities of daily living like meal preparation and laundry.
- What transition plans need to be made for Kayla in regard to social concerns?
  - Sleep deprivation
  - Social support
  - Sexuality
  - Stress management
  - Life skills

# Conclusions

- Preparation for college transition is a multidisciplinary endeavor engaging medical, educational, and ancillary support teams.
- Transition planning should be an integral part of every youth with special health care needs' (YSHCN's) post-secondary plans and cover multiple domains (environment, academics, social and medical concerns).
- Students with MH concerns need comprehensive transition planning as they transition to college.
- School personnel are well-positioned to partner with a student's medical home to optimize transition planning for success in college.



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# References

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