Where Do I Go From Here? The Art and Practice of Providing Health Care Transitional Skills To Youth Living With Chronic Illness

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Learning Objectives

• At the end of this presentation, participants will:
  • 1) List at least 2 skills that assist with successful transition to adult care
  • 2) List at least 2 barriers to successful transition to adult care
  • 3) Describe the role that substance use and abuse plays in the care of medically complex youth
Transitions

Transitions are a part of normal development and occur across the lifespan
Transitions

Physical Transitions

Life Transitions

Congrats on your new job----
you deserved it!!
Transition of AYA With Special Health Care Needs

- More than 90% of teens with special health care needs (SHCN) survive to adulthood
- Nearly 500,000 adolescents with SHCN transition to adulthood each year
- Transition of youth with SHCN to adulthood is a dynamic, lifelong process
- Goal: maximize lifelong functioning and potential through developmentally appropriate healthcare services
Definition of Health Care Transition

- SAHM: The **purposeful planned movement** of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems
Definition of Health Care Transition

- Healthy People 2010 – all young people with SHCN will receive the services needed to make necessary transitions to all aspects of adult life, including health care, work, and independent living.
2011 AAP Statement on Transition

- Health care transition planning starts at age 12: assess for any SHCN
- Actual transition planning at age 14
- Age 16-17: transition planning well established
- Age 18: initiate adult model of care, even if no transfer of care
- Written transition policy should be prominently displayed
- Each practice should use a standard transition plan
- Review transition plans regularly and update
- Complete medical records delivered to adult provider, as well as portable health summary to youth/family
Transition Challenges

- Longitudinal and complex process
- Occurs during the challenging movement from adolescence to adulthood
- Requires the adolescent to become increasingly mature and independent
Transition Challenges

- Unpleasant and poorly organized transition experiences
- As many as 20% of young adults with SHCN are cared for in pediatric settings
- Only 15% of youth report that their transitions are well supported
Transition Challenges

- Parental overprotection
- Independently manage medications
- Communicate with health professionals
- Manage disclosure of a stigmatizing identity to friends and romantic partners
- Impact of illness on future childbearing
- Confront end-of-life issues
Transition Challenges: Adult Physician Expectations

- Young adult is fully autonomous
- Able to negotiate health care systems
- Make collaborative treatment decisions
Transition Challenges: Provider and Patients

- Young adult patients prefer pediatric centers
- Adult centers are found to be cold, hostile, and overly efficient
- Communication barriers exist between young adult patients and health providers
Transition Challenges: Provider and Patients

- Lack of time for transition by providers
- Lack of funding for transition programs
- Lack of understanding of illness by adult providers
Factors That Facilitate Transition to Adult Care

• Transition planning starts in early adolescence
• Discussions occur about changes in health insurance when the youth becomes an adult
• Future adult health care needs are addressed
• Discussions occur prior to transfer of care about where the youth will receive their adult care and from whom
  • Lotstein, DS et al 2009
Factors That Facilitate Transition to Adult Care

- Adult health providers are needed, who understand the needs of young adults with lifelong SHCN
- Youth with SHCN need the skills and knowledge to support their own care
- A medical summary to hand off to new providers
- Ongoing primary and preventive care
- Continuous health insurance
  - AAP 2002
Components of a Transition Program for AYA With SHCN

- Flexible
- Responsive
- Continuity
- Comprehensive
- Coordinated
- Supports emerging youth autonomy
What the Literature Says: Adult Outcomes for Youth with SHCN

- Youth with SHCN differ little from their healthy peers in achieving the milestones of adult life
- No difference in educational achievement or self esteem (Gortmaker SI et al, 1993)
- Chronic conditions have been associated with decreased income
- Other studies have found decreased educational outcomes for youth with SHCN (Maslow, et al 2011; Blomquist KB 2007)
What the Literature Says: Adult Outcomes for Youth with SHCN

- Higher depression scores have been found in youth living with serious medical conditions (Bussing R & Aro H, 1996)
- Youth with complex medical conditions have lower general educational achievement, more limited work experience, and lower incomes *
- Youth with multiple health problems or severe cognitive or mental health impairments have more difficulty transitioning to adulthood *
  - *Bloom, SR et al 2011
What the Literature Says: Patient’s Feelings and Concerns About Transition

- Patients describe their pediatric care centers as comfortable and familiar
- Reluctant to leave behind providers that know them
- Afraid to move to adult care
- Concerns that quality of care in adult systems not as good
- Adult providers may not know how to care for their disease
- Don’t like having to retell their story
What the Literature Says: Provider Characteristics

- Pediatric care can be patronizing
- Adult care can be alienating
- Patients prefer services that fall between formality and “babying”
- Developmentally appropriate care
- Provider is knowledgeable, supportive, trustworthy, and flexible
What the Literature Says: Provider Characteristics

- Provider gives the patient choices
- Provider gives the patient a sense of control
- Provider expresses interest in the patient’s life other than their medical condition
What the Literature Says: Need for Independence

- Before transfer, patients want to be responsible for their health care
- Patients want to acquire skills pertaining to their health care, like scheduling their own appointments
- Want to speak to their doctor alone
- May still need their parents’ support and reassurance
- Parents and providers may give indirect messages that patients cannot take care of themselves
What the Literature Says: Preparation for Transition

- Patients like to talk about transition with their providers
- Want to feel involved in transition decisions
- Joint visits with pediatric provider and adult provider
- Longer initial visits with the adult provider or meeting more frequently than usual
- Patient mentor to assist with transition
- Encourage education about condition, treatment and self-care
Why Does Effective Transition Matter?

- Number of medical visits declines after transfer to adult care
- Patients self-report low adherence to treatment after transfer
- Difficulty in establishing rapport with adult provider
- Lack of appointment reminders
- Perception that adult providers don’t value them
Patient Characteristics Associated With Good Adherence with Transition

- Developmental maturity
- Older age
- Agree to the transfer
- High self efficacy
- Not highly dependent on parents
- Well prepared for transition
Elements Involved in Successful Transition

- Transition to adult care is viewed with positive meaning
- Clarify and discuss the patient’s expectations about the transition process
- Prepare for transition early, so that the patient has the necessary skills and knowledge
- Empower the teen or young adult
- Assist the teen with unexpected events that occur during transition
- Well planned
The Role of Transition Clinics

- Opportunity to create an optimal environment for successful transition
- Can be age-specific or condition-specific
- Should not simply be an extension of the specialty care center
- Patient education and empowerment emphasized
- Comfortable environment so that teens can become increasingly autonomous
Transfer of Care Does Not Equal Transition
Case: A Youth With Lupus

- Gemma is a 17 year old young woman with Lupus
- She is a senior in high school
- She plans on going to college
- Gemma states that she wants to be a nurse
- She has been dating her boyfriend for 6 months
- Gemma is sexually active and uses condoms 50% of the time
- She is not on hormonal contraception
- She takes her medications 75% of the time
What Are the Transition Issues That Gemma Faces?

- Assistance with medication adherence
- College planning
- Career planning
- Proximity of college to medical care
- Can she manage her own medications?
- What type of insurance will she receive as an adult?
How Would You Design a Transition Clinic/Program?

- What staff do you need?
- What are the goals of the program?
- What clinical partners do you need?
- How do you market the clinic?
- How do you fund the clinic/program?
The MyVOICE Transition Clinic in the Division of Adolescent and Young Adult Medicine at CHLA

- Youth and their families have a VOICE!
- V=Vocation/career
- O=Outcomes
- I=Individual
- C=Care (medical and mental health)
- E=Education/Empowerment
My VOICE Transition Clinic

- Always places the youth first
- Provides integrative care
  - case management
  - crisis management
  - health education
  - career planning
- Assists with medication adherence
How Do Others See Youth With Chronic Illnesses?
How Youth With Chronic Illnesses See Themselves
Medical

- Patient
- Meds
- Parent
- School
Teen

- Family
- School
- Medical
- Relationships
Transition

Transfer of Care

Mastery of young adult skills
My VOICE Program

- GI
- CF
- Rheum
- Renal
- Cards
My VOICE: The Transition Clinic

- Opened in November, 2010
- Accepts referrals from specialty care centers at CHLA that provide care to youth with solid organ transplants, youth with cystic fibrosis, youth with rheumatologic diseases, and youth with congenital heart disease
- Ages 15-21 years
- Currently serving 340 patients
My VOICE Transition Clinic Staff

- Social worker
- Case manager/patient navigator
- Psychologist
- Psychiatrist
- Program manager
Funding of Transition Clinics

- Grants
- Hospital support
- Philanthropy
My VOICE Transition Clinic: Medical Services

- In depth assessment of disease understanding by the MD
- Medication adherence assessed and assistance provided
- Referrals to mental health and substance abuse providers made, as needed
- Reproductive health care needs addressed
- End-of-life issues addressed
- Disease education provided
My VOICE Transition Clinic: Life Skills

- Social worker meets with the youth and assesses transition needs
- Transition milestones (TRAQ) completed by youth and social worker
- Case manager meets with the parents to identify their needs and goals
- Case manager works with youth to identify career and educational goals
- Social worker provides crisis management and assists with obtaining health insurance
Expectations of Youth in My VOICE

FULL PARTNERS IN THEIR CARE!
My VOICE Services

- AYA are given tools to assist them gain more independence
  - Medication apps
  - Pill boxes
  - Depart summaries of each visit
  - Coached on how to obtain medication refills & schedule appointments

- Tours are provided of the adult care clinic and they meet with the adult care physician, if possible

- “Health work” is assigned to the patient at each visit
### Transition Readiness Assessment Questionnaire (TRAC)

**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.

<table>
<thead>
<tr>
<th>No, I do not know how</th>
<th>No, but I want to learn</th>
<th>No, but I am learning to do this</th>
<th>Yes, I have started doing this</th>
<th>Yes, I always do this when I need to</th>
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<tbody>
<tr>
<td><strong>Managing Medications</strong></td>
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<tr>
<td>1. Do you fill a prescription if you need to?</td>
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<td>2. Do you know what to do if you are having a bad reaction to your medications?</td>
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<td>3. Do you take medications correctly and on your own?</td>
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<td>4. Do you reorder medications before they run out?</td>
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<td><strong>Appointment Keeping</strong></td>
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<td>5. Do you call the doctor’s office to make an appointment?</td>
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<td>6. Do you follow-up on any referral for tests, check-ups or labs?</td>
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<td>7. Do you arrange for your ride to medical appointments?</td>
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<td>8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?</td>
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<td>9. Do you apply for health insurance if you lose your current coverage?</td>
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<td>10. Do you know what your health insurance covers?</td>
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<td>11. Do you manage your money &amp; budget household expenses (For example: use checking/debit cards)?</td>
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<td><strong>Tracking Health Issues</strong></td>
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<td>12. Do you fill out the medical history form, including a list of your allergies?</td>
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<td>13. Do you keep a calendar or list of medical and other appointments?</td>
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<td>14. Do you make a list of questions before the doctor’s visit?</td>
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<td>15. Do you get financial help with school or work?</td>
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<td><strong>Talking with Providers</strong></td>
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<td>16. Do you tell the doctor or nurse what you are feeling?</td>
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<td>17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?</td>
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<td><strong>Managing Daily Activities</strong></td>
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<td>18. Do you help plan or prepare meals/food?</td>
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<td>19. Do you keep home/room clean or clean-up after meals?</td>
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<td>20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?</td>
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Health Passport
**Congenital Heart Disease**

This is where you put in your health information. Much of it will be known and the rest is available to the health care provider you are completing this with. If something doesn't apply to you, skip to the next section. There is no need to enter "none" or n/a, unless you want this section to print on the final version. An example of this would be if you want your card to say "Drug Allergies: None". At the end, there is a place you can put in anything that you would want an adult health care provider to know about you.

- **Name**
- **DOB**
- **Congenital heart diagnosis**
- **Important Medical History**
  - I have abnormal blood flow to my right arm
  - I have abnormal blood flow to my left arm
  - I have persistent right to left shunt
  - I have had heart rhythm problems
  - I have a high risk of stroke

**If you have had one stroke, please enter when and what part of your brain**

**If you have had more than one stroke, please enter when and what part of your brain, separate each stroke with a semicolon**

**If you have had endocarditis, enter dates**

**If you have had a heart rhythm problem what was the diagnosis and when was it diagnosed**

**Other current medical problems**

**If you have regular heart catheterizations, what was the date of your last one and what did it show?**

**If you have a pacemaker, please enter when you got it, what brand it is**

**If you have an implanted defibrillator, enter date implanted and brand**

**If you have an artificial valve, enter date inserted, which valve, brand & model, whether mechanical or tissue**

**What operations have you had? When were they?**
Medical Info App

EMERGENCY ACCESS

Show When Locked

Your Medical ID can be viewed when iPhone is locked by tapping Emergency, then Medical ID.

add photo

Name

add birthdate

Medical Conditions
None listed

Medical Notes
None listed

Allergies & Reactions
None listed
My VOICE Services

- Parent group
- AYA leadership group
- Keeping it Real With Your Doctor
- Insurance education group
- Career guidance groups
- Life skills outings
Issues That My VOICE Youth and Families are Encountering When Transitioning

- Lack of understanding of their medical condition
- Lack of understanding of how their medications work and why they were prescribed
- Challenges with medication adherence
- Immigration issues
- Unclear as to at what age they will transition out of care at CHLA
- New/changed role for parents/caregivers
Issues That My VOICE Youth and Families are Encountering When Transitioning

- Childbearing questions
- Ability to be sexually active
- Youth are engaging in sex (often unprotected!) as often as their peers who do not have special health care needs
- Unclear, or unknown, future plans, with regards to education, career, and independent living
### Six Core Elements of Health Care Transition 2.0

#### Transitioning Youth to Adult Health Care Providers
(Pediatric, Family Medicine, and Med-Peds Providers)

1. **Transition Policy**
   - Develop a transition policy/statement with input from youth and families that describes the practice’s approach to transition, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. **Transition Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning youth and enter their data into a registry.
   - Utilize individual flow sheet or registry to track youth’s transition progress with the Six Core Elements.
   - Incorporate the Six Core Elements into clinical care process, using EHR if possible.

3. **Transition Readiness**
   - Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.
   - Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.

#### Transitioning to an Adult Approach to Health Care Without Changing Providers
(Family Medicine and Med-Peds Providers)

1. **Transition Policy**
   - Develop a transition policy/statement with input from youth/young adults and families that describes the practice’s approach to transitioning to an adult approach to care at 18, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. **Transition Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry.
   - Utilize individual flow sheet or registry to track youth/young adults’ transition progress with the Six Core Elements.
   - Incorporate the Six Core Elements into clinical care process, using EHR if possible.

3. **Transition Readiness**
   - Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.
   - Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.

#### Integrating Young Adults into Adult Health Care
(Internal Medicine, Family Medicine, and Med-Peds Providers)

1. **Young Adult Transition and Care Policy**
   - Develop a transition policy/statement with input from young adults that describes the practice’s approach to accepting and partnering with new young adults, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the Six Core Elements and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care.

2. **Young Adult Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry.
   - Utilize individual flow sheet or registry to track young adults’ completion of the Six Core Elements.
   - Incorporate the Six Core Elements into clinical care process, using EHR if possible.

3. **Transition Readiness/Orientation to Adult Practice**
   - Identify and list adult providers within your practice interested in caring for young adults.
   - Establish a process to welcome and orient new young adults into practice, including a description of available services.
   - Provide youth-friendly online or written information about the practice and offer a “get-acquainted” appointment, if feasible.
Six Core Elements of Transition

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transition Completion
Do Youth With SHCN Engage in Risky Behaviors?

• Are they too ill to engage in risky behaviors?

• Are youth with SHCN aware of the health risks associated with risky behaviors?

• Does a sense of a limited lifespan impact on their willingness to engage in risky behaviors?
Risky Behaviors in Youth With SHCN

- Chronic conditions protective against risk-taking behavior
- Limited opportunities to engage in risky behaviors
- AYA living with chronic conditions are as likely, or more likely, than their peers to engage in risky behaviors
- AYA with SHCN engage in substance use, high-risk sexual behavior, and smoking
Risky Behaviors and Youth With SHCN

• 20% of childhood cancer survivors that smoke do not believe that smoking increases their risk of developing future health problems (Ford JS, et al, 2014)
• Young adult childhood cancer survivors are more likely to consume alcohol frequently and engage in binge drinking (Rebholz, CE et al 2012)
• 16-20 year olds with congenital heart defects (328 studied) reported recent and lifetime use of tobacco, alcohol, MJ and other illicit drugs that is comparable or lower than their healthy peers (Reid, GJ et al 2008)
Risky Behaviors and Youth With SHCN

- Childhood cancer survivors have been found to engage in equivalent rates of risky sexual behaviors (multiple partners, unprotected sex, early age of first intercourse), as their healthy peers (Klosky JL, et al 2012)
- Only 32% of female childhood cancer survivors initiated the HPV vaccine series & only 17.9% completed the series (Klosky JL, et al 2013)
Risky Behaviors and Youth With SHCN

• Females with congenital heart defects (CHD) are at increased risk for cardiovascular complications during pregnancy.

• Females living with CHD have been found to have their sexual debut at similar ages to healthy peers and have similar number of lifetime sexual partners (Loomba RS, et al 2014).

• 54% of females with CHD received information on appropriate contraception by their health care provider and only 47% received this information prior to sexual debut (Vigl, M et al 2010).
Substance Use Among Youth Living With a SHCN

- 68.8% ever tried alcohol and 42.2% engaged in binge drinking
- 44.3% ever tried tobacco and 73.4% used cigarettes regularly
- 47.8% ever tried marijuana and 50.3% reported recent marijuana use
- Youth living with a chronic medical condition are more likely to engage in any and heavier substance use
- Young adulthood is the period of peak risk for youth with SCHN
  - Wisk, LE & Weitzman, ER 2016
### Substance Use Among Childhood Cancer Survivors

<table>
<thead>
<tr>
<th>Young adolescents (mean age 14 years)</th>
<th>Young adults (mean age 24 years)</th>
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</thead>
<tbody>
<tr>
<td>11% currently use tobacco</td>
<td>26% currently use tobacco</td>
</tr>
<tr>
<td>3% currently use MJ</td>
<td>10% currently use MJ</td>
</tr>
<tr>
<td>16% currently use alcohol</td>
<td>63% currently use alcohol</td>
</tr>
</tbody>
</table>

- Klosky, JL et al, Risky behaviors among adolescents in the childhood cancer study cohort 2011
Risky Behaviors in Youth With SHCN

The AAP, the American Academy of Family Physicians, and the American College of Physicians recommend counseling patients with SHCN regarding healthy lifestyles and advising against health risk behaviors.
Risk Behaviors and Youth Living With SHCN

- May engage in risky behaviors to fit in with peers or feel older
- More likely to engage in risky behaviors if their friends/peers are doing so
- Increased risk of using drugs and alcohol if depressed, or other untreated mental health issues
- Increased risk of sexual risk taking if depressed or other untreated mental health issues
Risky Behaviors and Youth Living With SHCN

- Adolescents and young adults with chronic illnesses do engage in health risk behaviors
- Includes high-risk sexual activity, smoking, and substance use
- High risk for negative health consequences
- Risk behaviors are under addressed by pediatric providers
- Screening for risky behaviors should be routinely performed by providers
How Do We Help Cara?

- 19 year old female living with CF
- Poorly adherent with her breathing treatments and taking her medications
- History of depression and anxiety
- What questions do you want to ask her?
How Do We Help Cara?

- Her pulmonologist reports that she has a mild form of CF
- Would you ask about substance use?
- Cara reports that she started smoking MJ at age 16 years
- She smokes several times a day
- Her pulmonologist reports that Cara’s lung function has significantly worsened, since she began smoking MJ
Risk Behaviors and Cystic Fibrosis

- 21% of adolescents with CF smoke
- 25% of adolescents with CF start having sex before the age of 15 years
- Have similar rates of sex without a condom, not using contraception, or having multiple partners, as peers
- Knowledge of reproductive health is often poor
- 30% of adolescent males with CF don’t use condoms

• Britto, MT et al 1998
How Do We Help Cara?

- Offer referral to substance abuse treatment
- Offer referral to mental health services
- Utilize MI to reduce Cara’s risky behaviors
- Provide information on the health impact of her MJ use on her lung function
19 yo male with a renal transplant in organ rejection

Abusing cough medicine and alcohol

17 yo male with a liver transplant and poorly adherent with medications

Cannabis use disorder

19 yo male with CHD, who has had surgery delayed due to substance abuse

Abusing crystal methamphetamine
What Do These Patients Have in Common?

- Living with a chronic illness
- Depression and anxiety
- Substance abuse
- Poor understanding of their disease
- Poor understanding of the long term consequences of poor adherence
Summary

• A well planned and organized transition process facilitates successful transition to adult care
• Barriers to a successful transition include poor organization, gaps in insurance coverage, or poor understanding of their disease and the transition process by youth
• Substance use by youth living with SHCN is found to be at rates similar to their healthy peers
“You’re off to great places!
Today is your day!
Your mountain is waiting,
So...get on your way!”

Dr. Seuss
References

- AAP Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home Pediatrics 2011;128;182
- Bloom, SR et al Health care transition for youth with special health care needs 2012 J of Adol Health 51, p 213-219
  Got Transition Six Core Elements of Health Care Transition 2.0
- Klosky, JL et al Risky health behavior among adolescents in the childhood cancer survivor study cohort J of Ped Psych 2012 57(6), p634-646
- Moola & Norman “Down the Rabbit Hole”: Enhancing the transition process for youth with cystic fibrosis and congenital heart disease by re-imagining the future and time Child: care, health, development 2011 37, 6, 841-851
References