What's Next: Transitions to Adulthood for Medically Complex Youth

Celinda Carr, LCSW-C, CCM
Alyssa Stoffel, MS, BSN, RN, CPN, CCM

1

Objectives

- Recognize the differences between pediatric and adult healthcare and when the transitioning youth process should begin.
- Identify components of the transitioning youth process, in addition to health care.
- Learn how Social Work Case Managers and Nurse Case Managers can empower youth and their caregivers toward achieving optimal health and wellness throughout the transitioning youth process.
- Integrate a transitioning youth assessment into your current practice.

2

Disclosures

- No disclosures to report

3

Who's Who:

- The Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB)
- The National Alliance to Advance Adolescent Health
- Got Transition
- Maryland Department of Health Office for Genetics and People with Special Health Care Needs

Source: GotTransition.org. About Got Transition. http://www. gottransition.org/about/index.cfm. Accessed March 21, 2022.

The National Alliance to Advance Adolescent Health (2022, March 22). Got Transition. Six Core Elements of Health Care Transition. https://www.gottransition.org/six-core-elements/

4

What's What:

- Got Transition defines a health care transition as "the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care."

Source: GotTransition.org. About Got Transition. http://www. gottransition.org/about/index.cfm. Accessed March 21, 2022.

5

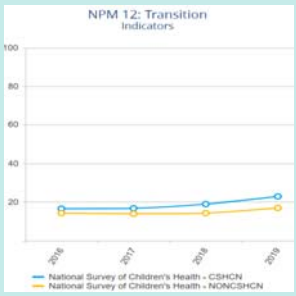
What's What:

- Title V Maternal and Child Health Services Block Grant Program:
  - Federal-state partnership to improve the health and well-being of mothers, children (*including children with special health care needs)* and their families in all States.
  - Utilizes national data sources, including the National Survey of Children's Health.
  - National Performance Measures (NPMs) -- the key metrics of health behavior or health care access and quality.
  - Transition to adult health care is NPM 12.

Source: https://mchb.tvisdata.hrsa.gov/

6

NPM 12: Transitioning Youth



Source: https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures

7

- In 2009-2010, the National Survey of Children with Special Health Care Needs, used a nationally representative sample of 17,114 parent respondents who had youth with special health care needs (YSHCN) ages 12 and 18. They were asked about:
  - (1) transition to an adult provider;
  - (2) changing health care needs;
  - (3) increasing responsibility for health care needs, and
  - (4) maintaining insurance coverage.
- **Results**: Most YSHCN were not receiving needed transition preparation. Although most providers were encouraging YSHCN to assume responsibility for their own health, far fewer were discussing transfer to an adult provider and insurance continuity.

Current Status of Transition Preparation Among Youth With Special Needs in the United States Margaret A. McManus, MHS et al., Pediatrics Vol 131, Issue 6, June 2013

8

- In 2016, the National Survey of Children's Health (NSCH) conducted a survey of over 20,000 youth (12-17 years old). They asked parents/ caregivers if transition planning occurred based on three things:
  - (1) doctor or other health care provider discussed the eventual shift to an adult provider,
  - (2) a provider actively worked with youth to gain self-care skills or understand changes in health care at age 18; and,
  - (3) youth had time alone with a provider during the last preventive visit.
- **Results:** Nationally, 17% of youth with special healthcare needs (YSHCN) and 14% of youth without SHCN met the overall transition measure.

Transition Planning Among US Youth With and Without Special Health Care Needs, Lydie A. Lebrun-Harris, Margaret A. McManus, Samhita Ilango, Mallory Cyr, Sarah Beth McLellan, Marie Y. Mann, Patience H. White, Pediatrics Vol 142, Issue 4, October 2018.

9

- In 2019-2020, the NSCH identified a National Performance Measure for transition to adult health care. In order to meet the criteria, youth with special health care needs 12-17 years old must meet three components:
  - (1) Doctor spoke with child privately without an adult in the room during last preventive check up,
  - (2) If a discussion about transitioning to adult care was needed it must have happened; and,
  - (3) Doctors actively worked with child to gain skills and understand changes in their healthcare.

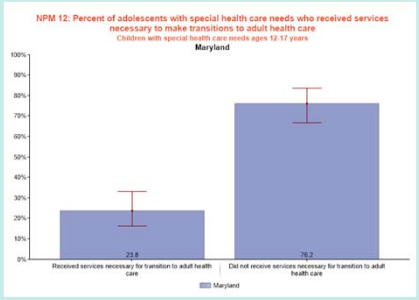
*If a child had at least one positive response to any of these components and the remaining were blank, they were categorized as having receiving adequate transition to adult healthcare

- **Results**: Maryland ranks 24th in the nation, as only 23.8% of CYSHCN have met this outcome.
- Glmph$Liepxl$Hexe

Child and Adolescent Health Measurement Initiative. 2019-2020 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 3/21/22 from [www.childhealthdata.org].

10

Maryland



11

More than just health care:

- Provision of a person/family-centered, comprehensive, and coordinated system for children with SHCN is a national priority.
- Healthy People 2030 Objectives
  - "Youth transition is beyond just healthcare, and encompasses a shift in educational, health, employment, and independent living services to ensure that youth with disabilities and special healthcare needs can fully participate in education, meaningful employment, and community living as adults."
- Challenges? Barriers?

https://health.gov/healthypeople/objectives-and-data/browse-objectives/health-care/increase-proportion-children-and-adolescents-special-health-care-needs-who-have-system-care-mich-20/data

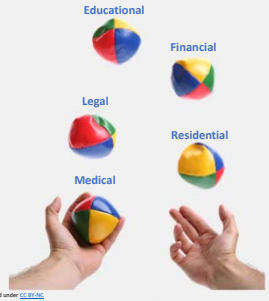
12

How can Social Workers and Nurse Case Managers Help?

- The Coordinating Center's history and approach
- Recognize and help educate clients and other health professionals:
  - increased levels of independence
  - choice
  - personal control
- Proper planning eases transitions
- Recognize the transition from youth to adulthood is critical and even more so for children with special healthcare needs.

13

The Juggling Act for Social Workers and Nurses



14

Parents in a statewide Maryland focus group reported that for children with special health care needs, they found managing all of the aspects for transitioning youth a challenge. One remarked, "I do everything myself. I drop lots of balls".

Source: https://www.ppmd.org/maryland-families-report-on-the-state-of-the-state-for-children-and-youth-with-special-health-care-needs/

15

How did COVID-19 affect the process?

Adverse Effects:

- Schools closed – Virtual learning
- Transitions were placed on hold
- Provider offices closed or had limited staff
- Community resources limited
- Staffing for services decreased

Positive Outcomes:

- Telehealth visits became easily accessible
- Medical documentation/ information – electronically
  - Patient Portals increased
  - Easily accessed
  - Virtual visits with case managers
  - Virtual meetings
    - Schools
    - Medical appointments
    - Collaborative meetings

16

The BIG Toss – changing providers…

Pediatric

- Pediatrician
  - warm and fuzzy
  - Known for two decades
  - Know the staff.
  - Easily reached and easy access
- Minor child
- Specialty providers
- Accessibility – accommodates family members
- Multiple appointments accommodated

Adult

- Adult Providers
  - bigger practice
  - less support staff
  - waiting rooms are different
  - billing codes are different
- Decision making changes at 18
- Less accepting specialty providers
- Less accessible (stretcher)
- Lack of sedation services for medical tests

17

Medical

- When should the Social Worker/Nurse start to discuss the pediatric to adult provider transition?
- What does this transition look like?
- How is information shared between these providers?
- What else is needed?

18

Legal

- Able to make own decisions?
- Which type of support does the client need?
- Guardianship
- Power of Attorney:
  - ❑ Medical
  - ❑ Financial

O'Sullivan et al. - University of Maryland Francis King Carey School of Law's Law & Health Care Program – 2011
https://www.guardianship.org/what-is-guardianship

19

Education/Vocation

- How long will the youth remain in the educational system?
  - ❑ 18 years
  - ❑ 21 years
- What track is the youth on in school?
  - ❑ Diploma
  - ❑ Certificate of Attendance
- What happens post-high school?
  - ❑ Day program/Medical Day program
  - ❑ College
  - ❑ Work- independent/supportive employment

20

Financial

- Income for the client:
  - ❑ SSI /SSDI
  - ❑ Employment
  - ❑ Special Needs trust
- Who will managing the finances?

https://www.ssa.gov/disability

21

Residential

- Where does the youth call home?
  - ❑Family home
  - ❑Separate space in the family home
  - ❑Group Home
  - ❑Supportive Living
  - ❑Independent living

22

Transportation

- How is the adult client going to navigate the community?
  - ❑Medical appointments
  - ❑Social activities
- Public transportation
- Medical transportation
- Private transportation

- Things to think about:
  - ❑ State ID card or driver's license

23

The Here and Now… assisting with the catch

- Assessment tool streamlined
- Realized that the start age needed to be 14 years for engagement
- Empowered the caregivers and clients to make their own decisions
- Created introductory letters for PCP and families
- Annual Transitioning Youth Assessment to see where they are and what is still needed
- Maintains a list of adult medical providers
- Developed Tip Sheets for the case managers to include transitioning youth goals
- Toolbox of community resources
- Acknowledged that while this started in one division in the organization, has evolved into an organizational movement with a committee to share ideas

24

Sample Assessment Questions

- **Medical**
  - Client/Caregiver can schedule appointments?
  - Client/caregiver understand medications including dosage and reason?
- **Legal**
  - Does the client require a legal guardian or power of attorney?
- **Education/Vocational**
  - What track is the client on in school? Diploma or Certificate of Attendance?
  - Where does the client/caregiver see the client after leaving high school?
- **Financial**
  - Does the client qualify for Supplemental Security Income?
  - Can the client manage any portion of their finances?
- **Residential**
  - Where is the client planning on living in the future?
  - What supports are needed for the client?
  - What supports are available for the client?

25

Sample Transitioning Youth Goal

- **Collaborate with:**
  - Client, Caregiver
  - Physician, Other Healthcare professionals
- **Description of Issue/Opportunity:**
  - John has entered the transitioning youth age range and needs to begin planning for adult care.
- **Long Term Goal:**
  - John will begin his transition from pediatric to adult care over the next 12 months
- **Barriers to Completion:**
  - John's caregiver is hesitant to leave the pediatrician's care
- **Possible Interventions:**
  - Client and caregiver to complete the Transitioning Youth Assessment during next home visit.
  - CM to provide Transitioning Youth education during all visits and contacts.
  - Pediatrician to be mailed an introductory letter regarding the Transitioning Youth process.
  - CM will collaborate with client/caregiver/pediatrician to provide education and identify potential adult healthcare providers.
  - CM to maintain contact with IEP coordinator to determine transition planning occurring at school.
  - Client and caregiver to research SSI application process.

26

Sample Transitioning Youth Goal

- **Collaborate with:**
  - Client/Caregiver/Physician
- **Description of Issue/ Opportunity:**
  - John is within the transitioning youth age range and needs to increase his ability to independently manage his health care.
- **Long Term Goal:**
  - John will increase his health care self-management over the next 12 months.
- **Barriers to completion:**
  - John lacks motivation to become more independent; Parent is reluctant to allow John more control of his health care.

Possible Interventions:

- CM to provide Transitioning Youth education during visits and monthly contacts.
- Client and caregiver to complete the Transitioning Youth Assessment during next home visit.
- Client and caregiver will choose topics to work on from the Transitioning Youth Assessment.
- Client will demonstrate improvement in health care knowledge.
- Client will demonstrate improvement in health care self-management skills.
- CM will continue to provide education and encouragement to John and caregiver during monthly contacts throughout the transition process.

From the Transitioning Youth Assessment:

- John will be able to list all medications that he takes and their dosages.
- John will be able to tell others the reasons he takes each medication.
- John will take all medications correctly without mom reminding him.
- John will know his medications allergies and the medications he should avoid.
- John will refill his prescriptions on his own.

27

Sample Client Scenario:

- Paul is a 17-year-old male with a diagnosis of Muscular Dystrophy. He receives Supplemental Security Income (SSI). He hopes to graduate from high school at age 18 and attend college. He is dependent for all ADLs and requires use of a ventilator at night. Paul currently resides with his parents. His pediatric neurologist plans to retire in 2022.

28

Tools to keep the balls in the air:

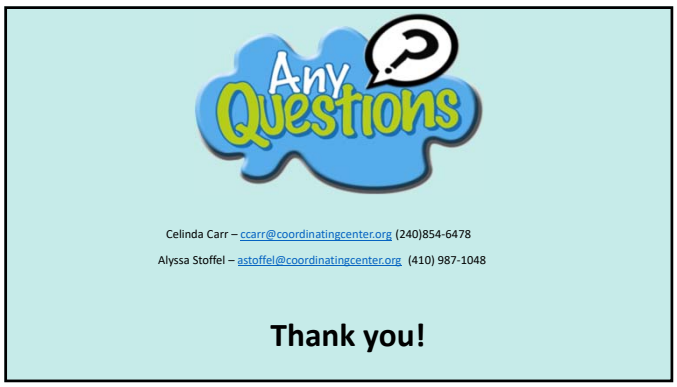
- Personal Health Record
- Community Services available
- State agencies for the Developmental and Intellectual Disability population
- Educational Advocate resources
- Legal Aid resources

29

References

- Source: GotTransition.org. About Got Transition. http://www. gottransition.org/about/index.cfm. Accessed March 21, 2022.
- The National Alliance to Advance Adolescent Health (2022, March 22). Got Transition. Six Core Elements of Health Care Transition. https://www.gottransition.org/six-core-elements/.
- Source: https://mchb.tvisdata.hrsa.gov/.
- Source: https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures
- Current Status of Transition Preparation Among Youth With Special Needs in the United States Margaret A. McManus, MHS et al., Pediatrics Vol 131, Issue 6, June 2013
- Transition Planning Among US Youth With and Without Special Health Care Needs, Lydie A. Lebrun-Harris, Margaret A. McManus, Samhita Ilango, Mallory Cyr, Sarah Beth McLellan, Marie Y. Mann, Patience H. White, Pediatrics Vol 142, Issue 4, October 2018.
- Source: https://www.childhealthdata.org/browse/survey/allstates?q=8571#.
- Child and Adolescent Health Measurement Initiative. 2019-2020 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 3/21/22 from [www.childhealthdata.org].
- Source: https://health.gov/healthypeople/objectives-and-data/browse-objectives/health-care/increase-proportion-children-and-adolescents-special-health-care-needs-who-have-system-care-mich-20/data.
- Source: https://www.ppmd.org/maryland-families-report-on-the-state-of-the-state-for-children-and-youth-with-special-health-care-needs/
- O'Sullivan et al. - University of Maryland Francis King Carey School of Law's Law & Health Care Program – 2011
- Source: https://www.guardianship.org/what-is-guardianship
- Source: https://www.ssa.gov/disability

30


Any
Questions
Celinda Carr – ccarr@coordinatingcenter.org (240)854-6478
Alyssa Stoffel – astoffel@coordinatingcenter.org (410) 987-1048
Thank you!

31