

Moving On: How Providers can Successfully Help Families of Children with Special Needs Transition to Adult Care



Michelle Jiggetts, MD,MS,MBA and TjaMeika Davenport

Parent Navigator Program

Children's National Hospital

Pediatric Health Network



A few notes about today's Grand Rounds

- All lines are muted throughout the presentation.
- Please use the Q&A to ask questions or make comments.
- We will be recording the session.
- Today's recording and materials will be posted to the PHN website 3 business days following the presentation:

<https://pediatrichealthnetwork.org/>

Speakers



Michelle Jiggetts, MD, MS, MBA
Program Administrator
Parent Navigator Program



TjaMeika Davenport
Parent Advisor
Parent Navigator Program

No conflicts to disclose:

- No financial or business interest, arrangement or affiliation that could be perceived as a real or apparent conflict of interest in the subject (content) of their presentation.
- No unapproved or investigational use of any drugs, commercial products or devices.

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Objectives

- Review the steps to successful Transition from Pediatric to Adult Care
- Describe Supported Decision-Making Options
- Develop strategies to improve Transition planning in your practice

Children's National Parent Navigator Program

- Established in 2008
- Staffed by parents of children with special health care needs
- Housed within the Goldberg Center for Community Pediatric Health
 - Eligible Criteria: Child must receive services through our Primary Care Dept.

Children's National Parent Navigator Program

Mission:

- To provide non-medical assistance and peer-to-peer support to families of children with chronic medical conditions and special health care needs
- Empower families to be strong partners with their providers while providing guidance for families to advocate for themselves.
- Seek to inform, educate, support, and advocate for families of children with special health care needs

How Navigators Help

- Provide a listening ear
- Help families make and prepare for appointment
- Assist in communication with doctor, nurses and healthcare professionals
- Accompany families to sub-specialist visits
- Build partnerships with organization and community agencies

How Navigators Help

- Link families to services and other supports such as:
 - Educational Services
 - SSI Enrollment
 - Health Insurance
 - Respite Care (LISS-Low Intensity Support Services-MD), HSCSN-DC
 - Transportation i.e. Metro Access etc
 - Home Repairs (occasionally)
 - **Transition to Adult Healthcare Services**

Healthcare Transition

Moving from Pediatric to Adult Care

5 Steps to Successful Adult Healthcare Transitioning

1. Communicate, Communicate, Communicate
2. Assess Capacity of Child
 - Transition Readiness Assessment
3. Review Supported Decision Making Options
4. Discuss other Considerations to Familiarize Family About
5. Office Strategies for Transition Implementation

Step #1: Communication is Key

- Start the conversation with families at 16 years old
 - Legal Ramifications
- Encourage Parents to 'Prepare for Changes'
 - Office Policies
 - Portal Access
 - Adult Model of Care
 - Transition Policy
- Help families understand mental capacity of child:
 - Provide opportunities for adolescent to make decisions so they can develop capacity
 - Encourage young adult to be more independent
 - Encourage young adult to ask questions of their providers
 - Encourage young adult to understand their diagnosis, medications, allergies

Step #1: Communication is Key

- Help adolescent understand what's expected of them as an adult
- Encourage young adult to be more independent
- Encourage young adult to ask questions of their providers
- Encourage young adult to understand their diagnosis, medications, and allergies

Step #2: Assess Capacity

Definitions:

- Lacks ability to meet essential requirements for physical health, safety, or self-care
- Unable to receive and evaluate information or make or communicate decisions
- Inability to make decisions or perform certain functions
- It's **not** “all or nothing”
- It's **not** solely based on diagnosis or IQ



Transition Readiness Assessment



Children's National

Transition Readiness Assessment for Parent/Caregiver and Youth/Young Adult

Navigator will fill out this form to identify if the youth or young adult is aware of their health needs, how to access services and identify goals for them to learn more about.

Date: _____ Form Completed by: Youth/Young Adult
 Parent/Caregiver
 Legal Guardian

Name: _____ Date of Birth: _____

Transition and Self-Care Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it for the young adult to manage their own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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How confident do youth feel about their ability to manage their own health care?

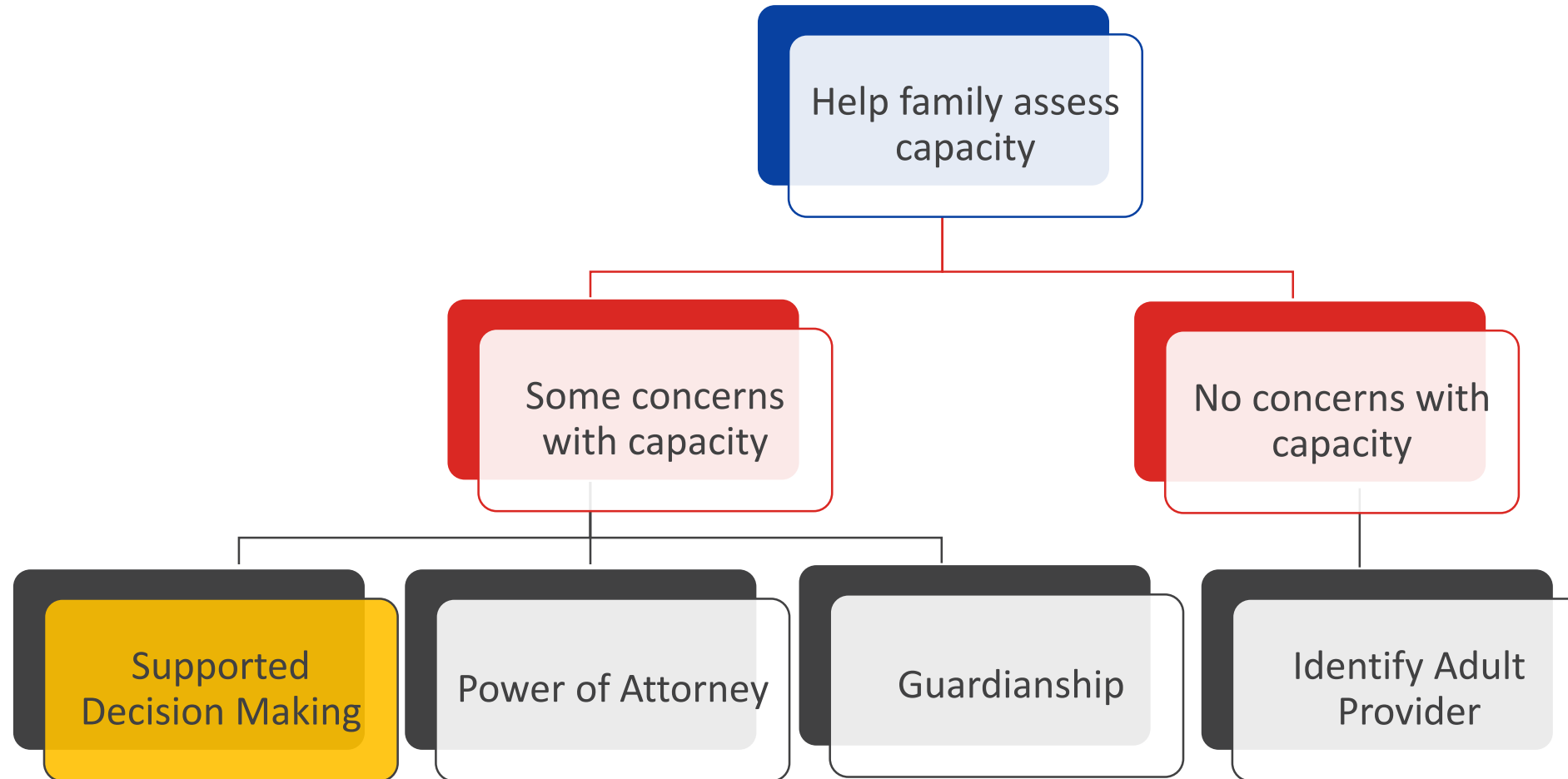
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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My Health	<i>Please check the box that applies to you right now.</i>			
	<i>Yes, I know This</i>	<i>I need to learn</i>	<i>Someone needs to do this...Who?</i>	<i>Does not apply</i>
1. Knows their own diagnoses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Knows how to explain their diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Knows their own medical needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Knows how to explain their medical needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Knows their symptoms including ones that they quickly need to see a doctor for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Knows what to do in case of a medical emergency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Knows their own medicines, and why their taking them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Knows their allergies to medicines and the medicines they should not take	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Knows what to do in the event of an allergic reaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Knows their assistive devices and medical equipment needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Knows the name/person of who can help with their health goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Sample Readiness Assessment Questions

- I can explain my medical needs to others
- I know what to do in case I have a medical emergency
- I know or can find my doctor's phone number
- I make my own doctor appointments
- I know how to fill out medical forms

Step #3: Supported Decision Making Options (Informal vs. Formal Decision Making)



Informal Supported Decision Making

- Open Dialogue with adolescent
- A process used to assist individuals in making choices about t family, friends, and other trusted people
- Helps clarify issues and choices
- Allows opportunity to ask questions and receive explanations in plain language
- Facilitates communication of decisions to others



Case Study Presentation: Case #1

- 17 yo male
- DD, ADHD, Epilepsy
- Multiple specialists
- Medication non adherent
- High School diploma

Formal Supported Decision Making

Power of Attorney – Legal document where an adult voluntarily authorizes another person to act on his/her behalf with making decisions in certain areas and under certain circumstances

Durable Power of Attorney for Health Care – Legal paper outlining who you trust to make medical decisions for you

Characteristics:

1. Less restrictive Formal option
2. Young adult doesn't lose any of his/her rights
3. Young adult must have capacity to decide
4. Attorney not need for POA
5. Notarized document only required

Case Study Presentation: Case #2

- 18 yo female
- ASD, non-verbal
- Therapies: OT, PT, ABA
- Assistance with ADL's
- In school until age 21
- Need for additional adult support

Formal Supported Decision Making

Guardianship – A legal relationship whereby the court appoints a person to care for and make decisions for an adult with disabilities who is unable to make decisions for themselves

Characteristics:

1. Most restrictive Formal option
2. Young adult loses **his/her rights**
3. Young Adult does not have the Capacity to decide
4. Legal Fees may be incurred

Process to Obtain Guardianship

Legal Guardian of Minor vs. Legal Guardian of Adult

1. Teen must turn 18 yrs of age
2. Family should contact the Court system in their jurisdiction
 1. Petitioning for Guardianship for an adult
 2. Obtain Court Date
 3. Will Appoint Attorney for the child

Process to Obtain Guardianship (continued)

3. Family should obtain Guardianship Documentation Forms

1. Medical Documentation (PCP)

- a. **Must be dated within 21 days of the Court Date**

Example: Court scheduled for July 1, medical form completed between June 7-June 30th

2. Second Medical Provider (Specialist or Psychologist)

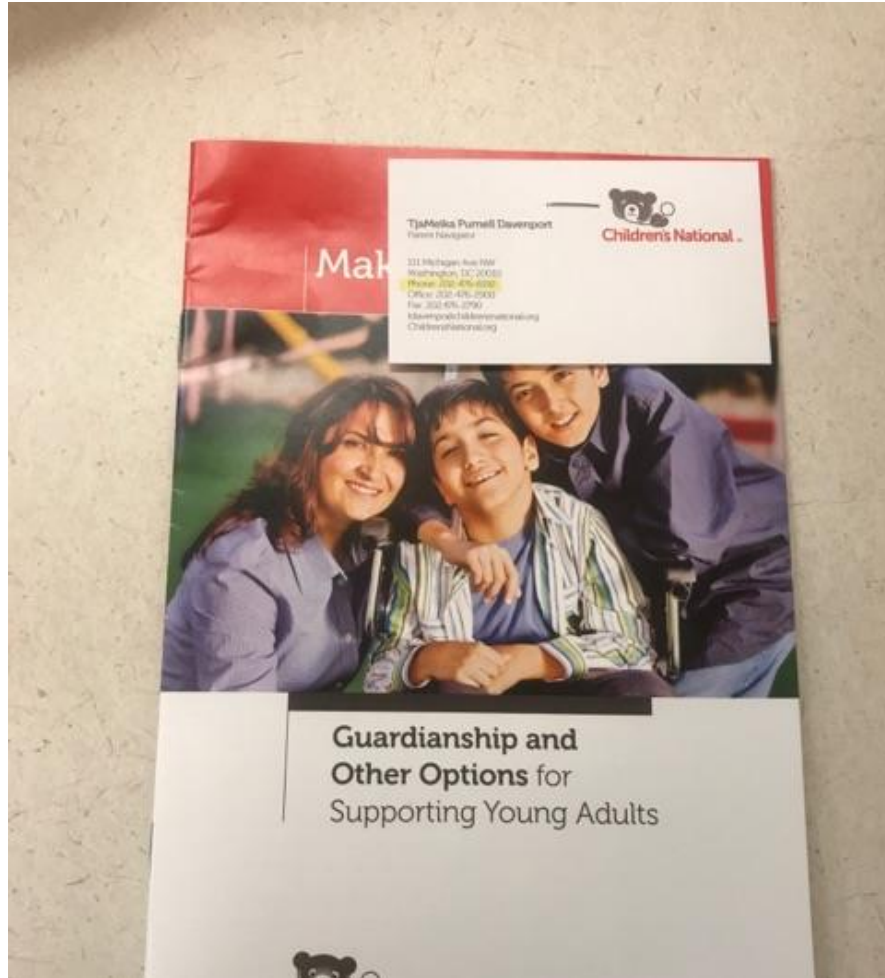
- a. **Should not be more than 9-12 months prior to court date**

3. Provide IEP Info

4. Parent and child must appear in Court

5. Court fees vary by jurisdiction

Decision Making Support Resources



Making Decisions: Guardianship and Other Options for Supporting Young Adults

Challenges to Transition

- Ability to release being their child's "case manager"
- Difficulty leaving their pediatric doctor
- Uncertainty about adult support services
- Community, College or Career track
- Locating Adult Provider

Step #4 Other Considerations for the Family

A. Community vs Hospital Based Primary Care Provider

B. Understand Insurance Coverage

- a. Verify coverage through insurance
- b. Verify Providers enrolled through the insurance
- c. Verify the type of services being cover.

C. Determine Disability Eligibility - *Apply for Supplemental Security Income (SSI)*

- For those already receiving SSI, they will be reevaluated as adults when they turn 18 (redetermination). Social Security Administration will send correspondence, so make sure demographic information is regularly updated.
- For those **NOT** currently receiving SSI, at 18 years old they can apply for benefits as an adult

Step #4: Other Considerations for the Family

D. Apply for Disability Services

- Provide required supporting documents
- Must be familiar with services requesting i.e.
 - housing,
 - employment,
 - day program,
 - individual family support.
 - Higher education...Community Colleges

Step #5: Practice Integration Strategies



1. Identify an administrative staff person to oversee project
2. Capture patients 16 years and older with special health care needs in practice
3. Develop Transition Policy
4. Implement a process for modifying and administering the Readiness Assessment
5. Formulate medical summary template
 - a. Problem List include Transition
6. Incorporate Decision prompts in the EMR

Transition Policy Template

- *We Care for Kids* is committed to helping all our patients make a smooth transition from pediatric to adult health care. This process requires working with you to plan and prepare your transition starting around your **16th** birthday. According to our policy, all patients are expected to transition from our practice to an adult primary care practice by age **21**.
- By law, you are an adult at age 18. We will only discuss your health information with others if you agree. Some young adults choose to still involve their parents/caregivers or others in their health care choices. To allow your doctor to share information with them, consent is required. We have these forms at our practice. For young adults who have a condition that limits them from making health care choices, our office will share with parents/caregivers options for how to support decision-making. For young adults who are not able to consent, we will need a legal document that describes the person's decision-making needs.
- We can provide you with resources as you take increasing responsibility for your own healthcare. We are also able to help you select an adult medical provider, to organize your medical records, and to support **all other aspects of transition planning** as part of preparation for a successful and well adult life.

Questions?

For more information visit: [GotTransition.org](https://www.GotTransition.org)

Supporting Teens and Families in Transitioning from Pediatric to Adult Health Care

Upcoming Family Focused Transition training workshops:

- May 20, 2021 from 2-3:15pm
- June 15, 2021 from 2-3:15pm

Please invite your patient families to attend either session! Both will include the same materials but be led by different navigators.

Advancing Asthma Care: A PHN Initiative

Upcoming Events

- **Data Champions Meeting Session 2**
 - Tuesday, April 27th from 12 – 1pm or Thursday, April 29th from 1 – 2 pm
 - To select a date please [click here](#) to complete the survey
- **Educational Webinar #3: *Social and Environmental Disparities Affecting Asthma Outcomes in the DMV Region***
 - Tuesday March 11th from 12pm – 1 pm
 - [Register Here](#)

CME

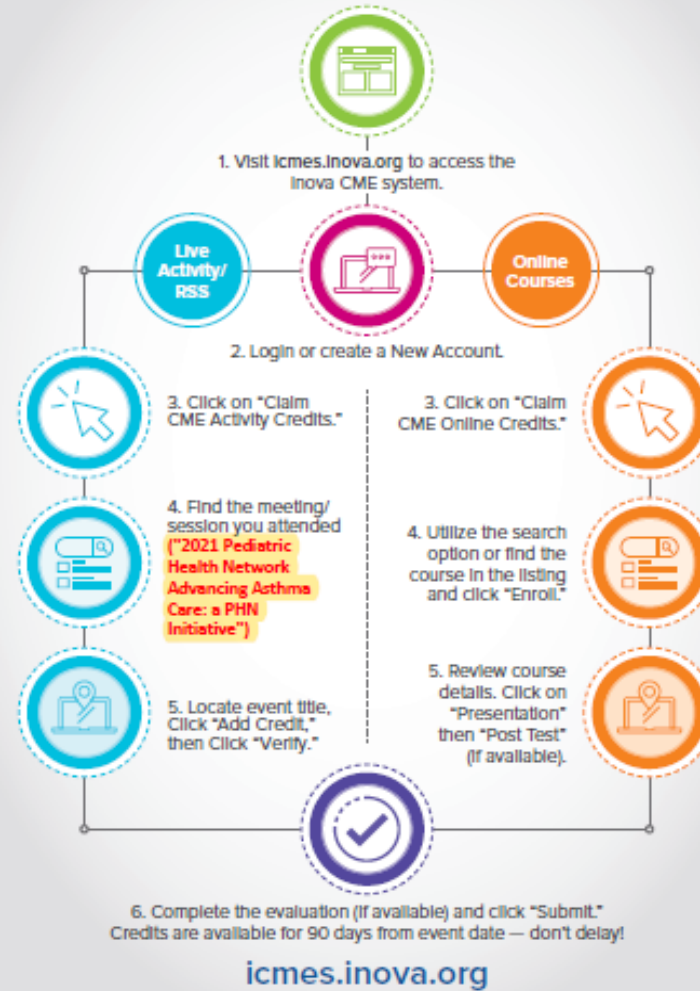
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✓ CME must be claimed within **90 days** of event!

Thank you

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