

Transitioning from Pediatric to Adult Care

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Objectives

- Correctly define transition vs transfer
- Identify what age to start the transition process
- Identify resources available during the transition period
- Identify at least one barrier to successful transition



“The health care system is a challenging maze for everyone, but it is a more daunting arena for youth with chronic health conditions and disabilities (CHCD).”



What IS the difference?

Pediatric

- Family focused
- Proactive approach
- Decisions with parents
- Fewer patients
- Transition=transfer from pediatric to adult

Adult

- Individual focused
- Reactive approach
- Decisions with patients
- Higher # of patients
- Transition=transfer of pt from home or community setting to facility/hospital or vice versa



Transition vs Transfer

- Transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare system” (Reiss, 2002)
- Transfer refers to single act of moving from one facility to another with no preparation or planning ahead of time.



“Hey in there...Let’s talk about transition to adult care...”



Suggested Transition Timeline

- Begin thinking and educating yourself when your child is 12 years old
- Written transition plan by age 14 years old
- Begin addressing career interests, living arrangements in-line with strengths ages 14-16
- Actual transfer to adult care should happen between ages 18-21 years old





Get ready...

Preparation is key

1. Identify health care provider to **coordinate** transition
2. Identify **core knowledge and skills**
3. Prepare and maintain concise **medical record**
4. **Written** transition plan by age 14
 - o Review and update annually
5. Apply preventive **screening** guidelines
 - o Prevent secondary complications
 - o Sexuality, aging, exercise, nutrition, mental health
6. Ensure affordable, continuous **health insurance coverage**





Keep getting ready...

- Provider readiness:
 - Explicit office policies
 - Receive training
 - ↑ capacity for adult providers
- Family readiness:
 - Ongoing education
 - Normalize transition process
- Youth readiness
 - In process
 - Foster self-management skills
 - Prioritizing and valuing independence



Get set...

4 Components of a Transition Plan

- **Assess** for transition readiness
 - Assess skills
 - Set goals
- **Plan** a dynamic and longitudinal process to accomplish realistic goals
 - Written transition plan
- **Implement** the plan through education of all involved parties and empowerment of the youth
- **Document** progress to enable ongoing reassessment and movement of medical information to the receiving provider



Go?





Adulthood=Adult responsibility

When your child turns 18, he/she is recognized as an adult who can make his/her own decisions.

Considerations:

- Power of Attorney
 - Medical
 - Financial
- Guardianship
- Advance Directives/5 Wishes





Power of Attorney

“Authorization to represent or act on another's behalf in private affairs, business, or some other legal matter”

- Medical Power of Attorney
 - Power of Attorney over Financial matters
 - Seek legal advice
 - Health Law Partnership
 - Wright's Law on-line
 - National Academy of Elder Law Attorneys (NAELA) Elder lawyer Referral Service
- 521-881-4005 or www.naela.org



Guardianship

- **Guardianship (regarding children)**- when a person (other than the child's parent or de facto custodian) has legal custody and control over your child. The guardian has the right to make all decisions concerning the child, and **is** legally responsible for the child.
- **Guardianship of an adult** - Guardians are granted only those powers necessary to accomplish what the disabled or incapacitated person cannot accomplish independently. These powers may include:
 - Assuring the availability and maintenance of care for the ward.
 - Making financial decisions for the ward.
 - Making medical decisions for the ward.
 - Making sure that educational and medical services are maintained and adequate.
 - Submitting updates to the court of the ward's condition.





Power of Attorney or Guardianship

The most important difference between a **power of attorney** and a person with conservatorship or **guardianship** is that a person appoints his or her **power of attorney** whereas a court proceeding is required to appoint a conservator or guardian; however, all are a fiduciary with essentially the **same** authority to make



Resources: Promoting Success in Transition

- Medicaid Waivers
- Vocational Rehabilitation
- Websites



Medicaid Waivers

- TEFRA/Katie Beckett
- Georgia Pediatric Program (GAPP)
- Service Options Using Resources in the Community Environment (SOURCE)
- New Options Waiver Program (NOW)
- Comprehensive Supports Waiver Program (COMP)



TEFRA/Katie Beckett

- Age 0-18
- The Tax Equity and Fiscal Responsibility Act (**TEFRA**) of 1982 is a federal law that allows states to make Medical Assistance (MA) available to certain children with disabilities without counting their parent's income.
- The Department of Family and Children Service offers the **Katie Beckett** (Deeming **Waiver**), an eligibility category for **Medicaid** when family's income is too high for them to qualify for SSI. ... “**Georgia Families**” provides health care services to enrolled members of **Medicaid** and PeachCare for Kids.



GAPP

- Medically Fragile Children or Technology dependent child that needs Medical day care or in-home nursing
- The GAPP medical day care program provides specialized pediatric skilled nursing services to medically fragile, ages birth to 3 years of age.
- Georgia Pediatric in-home nursing program is for children under the age of 21.
- Also provide aides (not qualified for skilled nursing needs) to assist with ADL's



SOURCE & CCSP

2 Medicaid programs to assist residents with paying for Assisted Living Services

- SOURCE (Service Options Using Resources in a Community Environment program) must be fully covered by SSI/Medicaid and meet other eligibility requirements
- CCSP (Community Care Services Program) provides assistance through Personal Care – Feeding, dressing, bathing and toileting, meal preparation, respite care, and more.



NOW (New Options Waiver)

- Designed for people who do not need 24 hour care and for people who need less intensive services and supports.
- All ages with MR or DD
- There is a limit of \$25,000.00 a year.
- Intake and Evaluation through DBHDD



COMP Waiver

COMPREHENSIVE SUPPORTS Waiver

- people who are transitioning out of institutions into community living
- designed for people who need 24 hour care
- Intake through Regional Offices (877-217-4462)



Services NOW & COMP Waivers provide

- Adult Occupational Therapy Services
- Adult Physical Therapy Services
- Adult Speech and Language Therapy Services
- Behavioral Supports Consultation Services
- Community Access Services
- Community Guide Services
- Community Living Support Services
- Community Residential Alternative Services
- (COMP only)
- Environmental Accessibility Adaptation Services
- Financial Support Services
- Individual Directed Goods and Services
- Natural Support Training Services
- Pre-vocational Services
- Respite Services
- Specialized Medical Equipment Services
- Specialized Medical Supplies Services
- Support Coordination Services
- Supported Employment Services
- Transportation Services
- Vehicle Adaption Services



ICWP

Independent Care Waiver Program

- Adults ages 21-64
- Physical disability or TBI
- Qualify for SSI
- Can direct their own care
- Intake through Georgia Health Partnership
 - 800-982-0411



Vocation Rehab services

How Vocational Rehabilitation Works

- Best to start while still enrolled in school – part of IEP
- Trained Certified Rehabilitation Counselors (CRCs) and other professionals work in teams to help eligible persons with disabilities prepare for, start, and maintain competitive employment, thus becoming tax-paying citizens in their communities
- Find the nearest local office online GVS.GA.GOV
- Call 1-844-367-4872



Vocational Rehab Services

More than 40 Local Offices offering:

- Counseling/guidance
- Postsecondary Support
- Supported Employment
- Work-readiness Training
- Job Placement Assistance
- Assistive Work Technology
- Vocational Training
- On-the-Job Training



Websites

- Got Transition www.gottransition.org
- ACP Pediatric to Adult Care Transitions Initiative www.acponline.org
- Healthy and Ready to Work www.hrtw.org
- Cerebral Palsy Guidance www.cerebralpalsyguidance.com/cerebral-palsy/living/transitioning-to-adulthood/
- Exceptional Parent www.eparent.com
- CDC www.cdc.gov/ncbddd/cp/links.html



Feeling stuck?



“I’ve decided you can stay after the transition period.”





Parent/Caregiver tips

- Ask about typical transition age
- Be understanding about feelings experienced (nervousness, excitement, hope, frustration) with patience and support
- Develop a list of goals for transition – review goals
- Talk with your child early and often
- Provide positive reinforcement for taking initiative with healthcare needs
- Use the resources at your disposal



References

- 2002: Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs - AAP, AAFP, ACP-American Society of Internal Medicine
- 2011: Clinical Report – Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home – AAP, AAFP, ACP
- *Transition of Care From Pediatric to Adult Clinics*
Megan A. Moreno, MD, MEd, MPH JAMA Pediatr. 2013;167(7):684.
doi:10.1001/jamapediatrics.2013.2657





**KEEP
CALM
AND
ASK
QUESTIONS**

