Advocacy for Adults with Intellectual and Developmental Disabilities

Assisting in the Transition from Pediatric to Adult Medical Services

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Richard McChane, M.D.
rick.mcchane@twc.com

Objectives

- Understand the rational for transitioning from child-oriented to adult-oriented health care for young adults having SHCN/IDD.
- Identify some of the barriers to successful health care transition.
- Review components of health care transition from the perspectives of pediatric and adult health care providers.
- List some tips for adult health care providers to integrate young adults with IDD into your practice.
- Discuss proposed future initiatives in the transitioning and care of adults with IDD.
- Review some resources.

What is meant by “HEALTH CARE TRANSITION” for young adults with Special Health Care Needs?

- “The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system.”
- Maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.
- Patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination. *AAP 1997, AAP/AAFP/ACP-ASIM 2002*

Anticipated Outcomes of Successful Transitioning

- Enhanced patient and provider satisfaction.
- Optimize patient's ability to assume adult roles and functioning.
- Reduce potential for gaps in medical care and prescription renewal, duplication of tests and services, medical errors.
- Reduce health disparities typically seen for this population.

Background

- 10.2 million Children and Youth with Special Health Care Needs (CYSHCN, SHCN) under 19 years of age.

- Each year 500,000 adolescents with SHCN cross into adulthood.

- About 65% of CSHCN experience more complex service needs that go beyond a primary need for prescription medications to manage their health condition.

- One generation ago, most of those with severe disabilities died before reaching maturity; now more than 90% survive to adulthood.

- More than a third of youth with special health care needs have been diagnosed with a developmental, emotional or behavioral disability or condition.

Developmental Disabilities

- A group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.

- About 1 in 6 children in the U.S. had a DD in 2006–2008.

- The prevalence of parent-reported DDs has increased 17.1% from 1997 to 2008.

- The prevalence of Autism increased 289.5%; ADHD 33%

Prevalence of Developmental Disorders in the US

- Intellectual Disabilities 1.5 / 100
- Autism Spectrum Disorders 1/68
- Cerebral Palsy 3.3/1000
- Down Syndrome 1/1000
- Fetal Alcohol Syndrome 1/1180
- Fragile X Syndrome 1/2500

Most young people with special health care needs are able to find their way into and negotiate through adult systems of care.

However, many adolescents and young adults with severe medical conditions and disabilities that impact their ability to function independently experience difficulty transitioning from child to adult health care. There is a substantial number whose success depends on more deliberate guidance. *AAP 1997, AAP/AAFP/ACP-ASIM 2002*

Potential Barriers to Transitioning Youth with DD

- Preference for pediatricians to continue to provide care rather than an adult provider.
- Health care coverage in adults with disabilities is inadequate and complicated.
- Time consuming visits-evaluation of patient is longer and coordination takes more time.
- Inadequate reimbursement in relation to time required.
- Adult physicians often cite minimal formal training in developmental disabilities, also inexperience in managing childhood onset diseases in young adults.
- Perceived challenges caring for young adults with complex neurobehavioral, emotional and medical conditions.
- Perceived shortage / difficulty identifying adult primary care providers and subspecialists willing to see persons with DD.

Barriers to Transitioning – Care Delivery Models

- Complex care populations, i.e. Cerebral Palsy, Spina Bifida, etc. often receive care in multidisciplinary settings.
- Multidisciplinary team care is not nearly as well developed in adult health care sector.

Critical Components to Ensure Successful Transitioning to Adult-Oriented Health Care

- Identify health care professionals who attend to the unique challenges of transition and coordination of care.
- Identify core knowledge and skills required by primary care clinicians to provide developmentally appropriate healthcare transition services.
- Prepare and maintain an up-to-date medical summary that is portable and accessible.

AAP/AAFP/ACP-ASIM

2002

Critical Components to Ensure Successful Transitioning to Adult-Oriented Health Care (cont.)

- Create a written health care transition plan by age 14 together with the young person and family.
- Apply the same guidelines for primary and preventive care for all adolescents and young adults, including those with special health care needs.
- Ensure affordable, continuous health insurance coverage for all young people with special health care needs throughout adolescence and adulthood.

AAP/AAFP/ACP-ASIM 2002

Basics of Transitioning – Pediatric Provider

- Transition Policy
- Transition Tracking and Monitoring
- Transition Readiness
- **Transition Planning**
- **Transfer of Care**

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Medical Summary and Emergency Care Plan

- Contact information – young adult, parent / care providers.
- Shared decision making status, advanced directives
- Diagnoses and current problems, including associated medical and behavioral health conditions.
- Assessment of functional skills, communication style, assistive technology and adaptive equipment, medical devices / appliances.
- Current and pertinent prior medications, prescribing physicians, medical allergies.
- Prior hospitalizations, operations, common emergent problems and treatment plans.
- Recent laboratory and radiology studies, EEG, EKG, etc.
- List of medical sub-specialists and therapists, contact information, current treatment plans.

Basics of Transitioning – Adult Provider

- **Young Adult Transition and Care Policy**
- **Young Adult Tracking and Monitoring**
- **Transition Readiness/Orientation to Adult Practice**
- **Transition Planning/Integration into Adult Practice**
- **Transfer of Care/Initial Visit**
- **Transfer Completion/Ongoing Care**

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Transition Tips for Adult Health Care Providers

- Develop a Transition Policy or Statement
- Provide in-service staff training
- Identify interested clinicians, identify staff as “office champion”
- Perform and office “walkthrough” or “wheelchair ride through”
- Develop a brief welcome letter and FAQ about your office, post on website

Transition tips

- Obtain records from previous providers, information about the youth's specific condition.
- Ascertain the client's shared decision making status and implications.
- Ascertain the client's ability to communicate and communication method, also use of assistive technology and mobility devices; inquire about special accommodations.
- Schedule adequate time for first visit(s) to orient client to your practice and adult health care in general.

Transition tips

- Treat patient as an adult – greet patient first, speak and direct questions to the patient, encourage highest level of involvement in his or her care
- Ascertain name, contact information, role or relationship of any caregivers
- Explain what will happen during the visit, invite caregiver to translate if needed.
- Provide orientation to practice, accessing after hours care, electronic patient portal, process for prescription renewals.
- Perform same quality of care that you would provide for all clients – exam, treatment recommendations, health promotion and preventative screening.
- Determine status of specialty care, transition from pediatric to adult specialists.
- Perform ongoing readiness/self-care assessment and education for highest possible level of self management.

Transition tips

- Consider a follow-up call to review plan of care, medications, office procedures.
- Consider more frequent than annual visits to strengthen relationship, reinforce familiarity with office and practice.
- Follow-up with referring pediatric provider to confirm transfer, ascertain availability for future “reverse consultations”.

Solutions and Recommendations

- **Medicaid must remain affordable and comprehensive for adults with disabilities.**
- **Establish and promote Medicaid billing codes** that allow physicians to bill for the extra time it takes to serve individuals with complex needs.

  Chronic Condition Management (99214,99215, with counseling >50%)

  Care Plan Oversight codes 99374 and 99375 (> 30 minutes)
- **States should urge all Medicaid Managed Care Plans to work with their physicians and physician groups to develop more medical homes** for people

  with DD and SHCN.
- **Medical schools to include education about health care transition and medical care for young adults with DD and SHCN.**
- **Establish Loan Forgiveness programs to recruit and retain practitioners serving people with DD and SHCN.**

Achieva, April 2014

Future Directions in Education, Health Policy, and Outcomes Research

- Integrate transition curricula at the undergraduate, graduate, and postgraduate levels.
- Provide advance financial incentives and pilot the ACO model in centers providing care to youth during transition.
- Defining outcome measures of importance to transition and studying the effectiveness of current transition tools on improving these outcomes.

N. Sharma et. al., Academic Pediatrics

Resources / Bibliography

Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

Pediatrics 2011;128;182 http://pediatrics.aappublications.org/content/128/1/182

A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs
http://pediatrics.aappublications.org/content/110/Supplement_3/1304

Six Core Elements of Health Care Transition - Got Transition (gottransition.org)
http://www.gottransition.org/resourceGet.cfm?id=206

Integrating Young Adults with Intellectual and Developmental Disabilities into Your Practice: Tips for Adult Health Care Providers
http://www.gottransition.org/resourceGet.cfm?id=367

Resources / Bibliography

Transition from Pediatrics to Adult Medical Systems for Young Adults with Disabilities or Special Health Care Needs https://www.achieva.info/files/PDFs/4-14%20Transition%20from%20Pediatrics%20to%20Adult%20Medical%20Systems.pdf

Transition Readiness Assessment for Youth, Caregivers; Medical Summary for Young Adults with IDD – American College of Physicians https://www.acponline.org/system/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/gim_dd/idd_transitions_tools.pdf

Vanderbilt Kennedy Center Health and Development Resources http://vkc.mc.vanderbilt.edu/vkc/resources/healthdevelopment/

Transition Care: Future Directions in Education, Health Policy, and Outcomes Research https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4098714/

AP Committee on Genetics

(http://pediatrics.aappublications.org/collection/committee-genetics)

Health Supervision for Children with:

- Down Syndrome
- Fragile X Syndrome
- Prader Willi Syndrome
- Neurofibromatosis
- William Syndrome
- Turner Syndrome
- Marfan Syndrome
- Sickle Cell Disease

Care of Girls and Women with Turner Syndrome: A Guideline of the Turner Syndrome Study Group *Journal of Clinical Endocrinology and Metabolism* http://press.endocrine.org/doi/full/10.1210/jc.2006-1374