

Transition to Adult Primary Care for Young Adults with Complex Chronic Childhood Conditions

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Transition from pediatric health care to adult health care for young adults with chronic childhood conditions is challenging and can lead to poor outcomes. In June 1999, the Cystic Fibrosis Foundation (CFF) convened a consensus conference to discuss the state of adult CF care¹. The CFF has long been a champion for improving outcomes in the care of patients with CF, beginning in the 1970's with the establishment of multi-disciplinary CF care centers with doctors, nurses, dietitians, social workers, and respiratory therapists trained in the care of CF. As outcomes improved, patients began living into adulthood and the CFF recognized a need to replicate the multi-disciplinary care team in the adult care arena. Through the efforts of the CFF, and the dedicated staff of accredited CF Centers around the US, transition of young adults with CF to adult CF Care Centers has been greatly improved. CF Centers begin teaching self-care to patients as early as 8 years of age, teaching the pathophysiology of the disease, medications, and their rationale, seeing the teen individually to get the history and assess their knowledge, before the parent joins the session, and having teens call for their own refills and appointments. However, this model is not adequate for young adults with other complex, chronic childhood conditions associated with significant developmental and cognitive delays. These young adults have multi-system medical needs, requiring GI, pulmonary, neuro, rehab and ortho involvement.

The number of young adults with chronic childhood conditions requiring multi-specialty care, and who are technologically dependent, with significant developmental and cognitive delays such as cerebral palsy, autism, Down's syndrome, neuromuscular disorders (Duchenne Muscular Dystrophy, Spinal Muscular Atrophy, etc) and other genetic syndromes (Angelman, Turner, Fragile X, etc) have increased in recent decades and many of these children now live into adulthood². The degree of developmental delay can range from mild to global; thus, the need for many different sub-specialists to address various needs: chronic respiratory failure, chronic aspiration, gastrostomy tube dependence, obstructive sleep apnea, and/or seizures. Additionally, most of these patients have Medicaid (known as MediCal in California) as their primary insurance. Medicaid reimburses at a lower rate and does not reimburse for the extensive time and effort it takes to coordinate care for these complex patients².

Case management and care coordination for these complex patients requires a multi-disciplinary team including nursing, social work, and often a dietitian and respiratory therapist. California Children's Services (CCS), which provides medical coverage for many of these conditions, requires such a team approach and reimburses each member of the team seeing the patient. Unfortunately, one is only eligible for CCS coverage until the age of 21. Once 21, these patients are generally covered by Medicaid alone. Medicaid does not require, nor reimburse for a multidisciplinary team approach. Thus, the primary care provider must be willing to provide the

care coordination alone, at reduced reimbursement, or provide a team approach at their own expense. In addition, these patients are often technologically dependent requiring coordination with one or more durable medical equipment companies that require extensive documentation to justify the equipment to Medicaid for payment. Many of these patients require wheelchairs, suction machines, non-invasive and invasive positive pressure ventilation, mechanical cough assist devices, nebulizers, feeding pumps, baclofen pumps and ventriculo-peritoneal shunts².

In 2002, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine produced a consensus statement on the importance of health care transition for young adults with special health care needs³. The consensus statement focusses on providing “uninterrupted, comprehensive and accessible care within their community”; identifying core knowledge and skills required to provide healthcare for this population and to make it part of training and certification requirements for primary care providers; fostering collaboration between pediatric and adult health care providers; and emphasizing primary care and preventive care³.

However, there are not enough physicians available with an interest and an expertise in this population. In 2005, Baylor College of Medicine (BCM) developed the Transition Medical Clinic (TMC) to provide primary adult care for special needs patients. The TMC became the medical home for these patients as they found a paucity of community internists with the training to care for these complex patients, and/or with the ability to accept new Medicaid patients². The TMC hired a social worker to assist with the case management and under-insured issues. However, some of this funding came from grants, philanthropic donations and in kind support from BCM².

Baylor’s TMC experience did provide comprehensive care for patients that otherwise would have been seeing their pediatrician or would have been seeking care through the emergency department (ED), with no regular health care provider². Thus, it is clear that the easiest way to transition these adults with complex chronic childhood conditions requiring multi-specialty care and case management is through academic facilities with both pediatric and adult care providers. The pediatric care providers can establish transition programs in affiliation with the adult care providers. Collaboration can provide reduction in health care costs through seamless transition, continuity of care and reduced need for ED visits. These academic facilities are better able to absorb the influx of Medicaid patients than the independent internist and can provide training to upcoming doctors in the care of this population. Additionally, these academic facilities can provide instruction to community providers via grand rounds, in-services or conferences.

It is the recommendation of the Pediatric Committee of the *California Thoracic Society (CTS)* that California’s academic facilities (UC system, Stanford, Loma Linda, USC) should take on this cause. These academic institutions have the sub-specialty and multi-disciplinary professionals needed to provide adequate care to these complex patients in the outpatient setting, reducing hospitalizations and their associated costs, and providing these patients with a patient-centered medical home (PCMH).

References

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- (3) American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 2002; 110(6 pt 2): 1304-1306.