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Could a California-Specific Website Ease Transition to Adult Care?

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Introduction

Moving from pediatric to adult health care during adolescence is ordinarily a simple and successful process. For young people with special health care needs, however, transitioning to the adult care system can be complicated. It requires complex coordination by health care teams working to maintain delivery of high quality, comprehensive, patient-centered care. Much has been written about the difficulties of care transition, and a range of resources have been developed. In many states, health agencies have developed websites to facilitate planning and provide support for adolescents with special needs and their families during the transition. This paper highlights some of the more useful sites.

Background

Most children, especially those with chronic or complex health problems, have established long-term relationships with pediatric health care providers. For children with severe conditions, these relationships often are very close and very important to the child, family and providers. Further, the developmental context of child health care makes pediatrics qualitatively different from the typical organization of adult health care. Children require the involvement of a diverse team of service providers, and as they mature responsibility for their care frequently shifts from their parents to themselves. In addition, adult medical specialists may not be familiar with chronic conditions of pediatric onset and may be reluctant to accept responsibility for the care of youth with special health care needs.

Transitioning from pediatric to adult health care thus involves changes that are emotional, contextual and skill-based, and require much planning and preparation. In general, planning and support for care transition for children and youth with special health care needs in the United States is inadequate. Where transition is unsuccessful, care can be disrupted and children's health can suffer. In some cases the consequences are extreme. However, when transition is successful, health and functioning can be maintained and even improved. Successful transition requires planning and collaboration among the patient, his/her family and their current and future health care providers, as well as community service providers and agencies. Public policies and support for care transition are important to facilitate planning and implementation.

Thirty-nine states have a sponsored website dedicated to care transition for youth with special health care needs. California is one of the 11 states yet to create a site for its residents.

An estimated 4.5 million or 18.4 percent of US youth ages 12 to 18 have a special health care need, a rate double that of young children ages 0 to 5.[1] The National Survey of Children with Special Health Care Needs included a four-item index to measure the quality of transition services for youth with special health care needs (YSHCN). Only 40 percent of YSHCN reported having had the services deemed necessary to make a successful transition to adult care; in California only 37 percent report success, placing it 45th among states.

Even when efforts are made to facilitate transition, obstacles remain: a lack of available family physicians or general internal medicine physicians and adult medical specialists willing to accept YSCHN as patients; fragmentation of primary and specialty adult care services; lack of knowledge about or linkages to community resources that support older adolescents/young adults; absence of insurance reimbursement for transition services; and insufficient time and skills for staff to plan and provide transition services. About one-fifth of pediatricians surveyed reported that patients had insufficient knowledge about their health condition and/or skills to self-advocate at physician visits, making transition more complicated.[2]

Families with special needs children face a number of additional barriers to successful transition. These include financing health care services as their children age out of eligibility, fewer providers accepting Medicaid reimbursement, and problems sharing information due to the privacy of medical care and records.[3,4,5] A recent survey of families of children served by the California Children's Services program (CCS) found that among children age 14 and older, 71 percent reported that they would find more information on transition helpful. In particular, they would value a complete resource list including the various agencies and programs available to assist with transition. In those circumstances where CCS helped to find adult health care providers for the adolescent, they were successful in finding one 80 percent of the time.[6]

These myriad difficulties highlight the need for youth and families to have readily available resources to help them anticipate and plan for health care transition, taking into account topics such as enhancing self-management, health care planning, communicating with health care providers, insurance coverage and benefits, financing health care, continuing education, health care access, legal issues and advocacy strategies. Those wishing to assist families with transition, including health care providers, advocates, social workers and care coordinators, also need information and guidance.

[1] McManus et al. Current Status of Transition Preparation Among Youth with Special Needs in the United States. May 17, 2013. http://pediatrics.aappublications.org/

[2] AAP News. Survey: Transition services lacking for teens with special needs. 2009. http://aapnews.aappublications.org/

[3] Lindley, Lisa and Barbara Mark. Children with special health care needs: Impact of health care expenditures on family financial burden. 2011. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2872488/

[4] Center for Advancing Health. Young people with chronic illness face uncertainty when transitioning from pediatric to adult care. News Medical. August 2014. http://www.news-medical.net/news/20140822/Young-people-with-chronic-illnesses-face-uncertainty-when-transitioning-from-pediatric-to-adult-care.aspx

[5] Carey, Mary. CBO Projects Lower Medicare and Medicaid Costs. Kaiser Health News. August 2014. http://capsules.kaiserhealthnews.org/index.php/2014/08/cbo-projects-lower-medicare-and-medicaid-costs/

[6] CCS Family Survey for the Title V Needs Assessment: Preliminary Results. December 16, 2014.

Discussion and Recommendations

Fortunately, a great deal of information is available, but little of it has been vetted by knowledgeable people, and in many cases resources are not organized or consolidated. One reliable national resource is the organization Got Transition. Got Transition's[7] online index lists health care transition resources, which are organized and separated by topic. Categories include a summary of six core elements: transition policy; transition tracking and monitoring; transition readiness; transition planning; transfer of care; and transfer completion.

The circumstances in which transitions occur vary substantially by locale. Public policies and programs—including insurance programs, access to health care specialists, family support and educational resources—differ greatly among states, so state-specific information is of great value and importance to patients, families and providers. Fortunately, 39 states have a sponsored website dedicated to care transition for youth with special health care needs.

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California is one of the 11 states yet to create a site for its residents. A detailed review of the existing 39 state websites identified 10 components or types of content that occurred frequently. Table 1 lists those topics that were found useful to those concerned about transition. These topics provide an outline of the potential content that might be incorporated into a California-specific website. In addition, the websites of five states (Indiana, Kentucky, Maryland, Michigan and Pennsylvania) are particularly good examples in terms of both content and ease of navigation. All of them include (1) planning guides, (2) information on health care coverage, (3) resources for children and adolescents, (4) resources for families, and (5) lists of local and national organizations that can be useful in planning and implementing transition. Their web addresses are listed in Table 2.

Recommendation

Using these state websites as models, leadership of California's health care programs serving children and youth with special needs should collaborate to create a state-specific website as a transition resource for patients, families, providers and those serving them.

[7] The National Alliance to Advance Adolescent Health. *Got Transition*. 2014. http://www.gottransition.org/

Table 1: Ten Common Transition Website Topics

Topic	Purpose
Advocacy, public policy, legal assistance	Support families in anticipating issues and planning transition; educate policymakers, service providers, and families on best practices; create options and opportunities for transitioning youth within their communities.
Counseling services	Provide or identify resources to address a wide variety of issues faced by transitioning youth including bullying, mental health and behavioral health services, therapies (e.g., physical, occupational, speech, hearing, and vision), physical and vocational rehabilitation.
Data	Increase awareness about the needs for service for youth and families during transition.
Education	Provide access to educational programs including remediation, certification programs, vocational training, college, and adult education. Provide information about financial aid and government/private programs in the state that offer aid and scholarships. Help youth achieve success by empowering students, families; foster effective learning and protect educational rights and opportunities.
Federal, state and local government programs and national networks	Identify supports offered by governments to help youth achieve independence and employment and to assist families in continuing to care for their adult child (e.g. Supplemental Security Income and Social Security Disability Insurance). Facilitate access to state and regional coalitions and grant resources, and provide assistance with the legal system.
Finance	Provide information about eligibility and availability of financial resources for insurance, health care bills, medical equipment, in-home care and other health and social service coverage and expenditures, including respite care, housing, etc.
Materials to assist with transition services	Provide materials to assist in the development of self-management capacity so the adolescent can learn to better promote and maintain his/her health and minimize disability. Enhance understanding of how to use the health care system. Provide specific guidance on how and when to introduce information about transition and related activities. List information on educational and training opportunities, webinars and archived videos for patients, families and providers. Offer examples of various forms, (e.g., family health history summary; referral for consultation and services; collaborative services charting; case management and care coordination; adolescent development chart; medical home fact sheet, appointment scheduling, goal setting, medical passport, etc.). Link to useful publications, research and news articles. Provide glossary of terms that relate to disabilities and transition services.

Resources for youth	Provide a variety of resources to promote community participation and encourage independent living if appropriate: • Planning for the future, self-care management including housing, transportation, money, emergency preparedness, skills, meals, personal and health schedule. • Highlight organizations that offer social and recreational opportunities including entertainment, creativity for adolescents to explore activities in sports and leisure and the arts, community recreational centers, and day programs. • Information about social development (e.g., sexuality, reproductive health, relationships); youth leadership, overall health and wellness. • Access to support services (peer and mentor), support hot-lines, and information on assistive technology, (e.g., devices and services that increase independence at home, school, and work).
Resources for families	Offer resources for caregivers and foster care families, including lists of health and human service providers, organizations, committees and councils that serve or represent youth with chronic and complex health conditions.
Resources for health care service providers	Provide resources to help health care providers, including pediatricians, adult physicians, nurses, and care coordinators, to organize and support transitions to adult health care.

Table 2: Exemplary State-Specific Transition Websites

Organization	Website
Michigan Department of Community Health: Transition to Adulthood	https://www.michigan.gov/mdch/0,4612,7-132-2942_4911_35698-135030--,00.html
Pennsylvania Department of Health: Transition Health Care Checklist	http://www.portal.state.pa.us/portal/server.pt/community/special_kids_network/14205/transition_health_care_checklist/558090
Kentucky Cabinet for Health and Family Services: Transition Resources	http://chfs.ky.gov/ccshcn/ccshcntransition.htm
Maryland: Transitioning Youth	http://mdtransition.org/ Resource Locator—http://specialneeds.dhmh.maryland.gov/

Indiana State Department of Health: Transition: Pathways to Your Future	http://www.in.gov/isdh/files/CSHCS_TransitionManual.pdf (PDF)

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1. McManus et al. Current Status of Transition Preparation Among Youth with Special Needs in the United States. May 17, 2013. http://pediatrics.aappublications.org/

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5. Carey, Mary. CBO Projects Lower Medicare and Medicaid Costs. Kaiser Health News. August 2014. http://capsules.kaiserhealthnews.org/index.php/2014/08/cbo-projects-lower-medicare-and-medicaid-costs/

6. CCS Family Survey for the Title V Needs Assessment: Preliminary Results. December 16, 2014.

7. The National Alliance to Advance Adolescent Health. *Got Transition*. 2014. http://www.gottransition.org/

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