



The Importance of Integrated Services

A system of services is a family-centered network of community-based services that is designed to promote the health and well being of CYSHCN and their families. Ideally, community-based service systems are organized so families can use them easily. Care coordination, access to a medical home, family-centered and culturally competent services are considered key elements of coordinated services for families of CYSHCN. However, many families of CYSHCN face frustration accessing services. Eligibility requirements, policies, procedures, and multiple locations of services can leave families feeling overwhelmed. There are often gaps in services due to agencies that provide limited services or duplication in services from multiple coordinators and service plans. Families may also need to travel great distances to obtain specialized services.

The examples in the following sections, from medical home, care coordination, family-centered care, to cultural competency, as well as the common application forms found in the health information technology section, all address some piece of a coordinated system of care—although no state or community addresses all issues equally well. The following models of care often use strategies recommended by Champions for Inclusive Communities for developing coordinated services: including the use and development of interagency councils, partnerships with coalitions, supporting the development of family leadership and family-directed programs, and promoting linkages at the local and state level. For local level examples, please refer to the Star Communities on the Champions website: www.Championsinc.org.

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Transition

Among youth with special health care needs, transitioning into adulthood in terms of both health care and career planning/secondary education has added complexities. Therefore, it is vital for this population to have services in place that are appropriate and easy to navigate in order to ensure a successful transition into independent adult living. The most common recommendations among transition experts are that transition should start early (at the minimum age of 13) and should involve the youth, their pediatrician and a primary care doctor, so that everyone is included in the discussion of the expectations and goals for this process. The four models discussed below incorporate many of these recommendations into their programmatic approach to transition and may serve as promising examples.

FLORIDA: YOUTH AND YOUNG ADULT TRANSITION—CHILDREN’S MEDICAL SERVICES

Public

Emerging Practice

Florida, a state with a large and diverse population, is a leading model in terms of services for their CYSHCN population, with a long history on transition as well as positive evaluation data. Currently, Florida’s Children’s Medical Service (CMS) is working to establish a State Office of Health Care Transition to provide technical assistance and support for the development of local coalitions, implementation of education and training activities for both consumers and providers, and advocacy for improved health care financing strategies and policies. One of the goals of CMS transitions program is to help youth and young

adults with special health care needs learn self-determination and develop strategies for a successful transition into adulthood.

System of Care: Each of the 22 CMS area offices in Florida has designated a care coordinator (either a nurse or social worker—some offices have teams) as a point of contact for communications about youth and young adult transition. The care coordinator identifies national, state, and community resources for the successful transition of youth and young adults with special health care needs to all aspects of adult life, including health, work, and integration within their community.

Financing: These activities are funded and sustained through Medicaid.

Evaluation: Preliminary evaluation data show that the percent of youth 12 and older, who have received transition education increased to 51.5% in 2008 compared to 40.7% in 2007. Additionally, the percentage of youth aged 16 and older, whose regular source of primary medical care facilitates the transition from pediatric to adult providers increased to 44.4% in 2008 compared to 33.7% in 2007. Finally, according to a survey given to CMS families, 72% of CMS families reported that their primary care provider discussed transition and adult health care with them; a significant improvement from previous years. The CMS transition information and workbooks, both English and Spanish, are available at <http://www.cms-kids.com>.

Will it Work in California: California could explore this type of transition piece through a larger care coordination demonstration program or through CCS (California Children’s Services) case management.

Source in addition to expert interviews: AMCHP's collection of best practices as well as information taken from <http://www.cms-kids.com/cmsnetwork/transition.html>. Retrieved July 24, 2009.

OREGON: YOUTH TRANSITION PROGRAM (YTP)

Public

Promising Practice

System of Care: Oregon's Youth Transition Program is repeatedly mentioned by experts as a model of care with a strong evaluation, diverse funding sources and the potential for replicability. The program was created from a partnership between the state's Vocational Rehabilitation Services, local school districts and the University of Oregon. The purpose of the program is to prepare youth with disabilities for employment or career related post secondary education or training. Vocational rehabilitation counselors meet with students to discuss career planning, job training or other resources that are available. The YTP provides services to youth that begin during the last two years of high school and continue into the early transition years after leaving high school. More than 50% of youth served by this program come from low income families. This program, which began in seven schools in 1990, is currently operating throughout Oregon in approximately 103 high schools. During the 2007/09 biennium, YTP was funded in 38 local sites, serving 1,556 youth. YTP currently operates in 45% of Oregon high schools.

Financing: The YTP is funded through a combination of state and local education funds as well as money from Oregon's Vocational Rehabilitation Service. Additional funding has been provided through a new collaboration with the Oregon Masonic Charitable Trust.

Evaluation: An evaluation for the years 2007-2009 found that 77% of the students who exited the program were engaged in either work, secondary training or some combination of work and training. This percentage remained the same when these students were contacted after one year.

Will it Work in California: The clear structure and strong evaluation of this program, in addition to its current private funding, could potentially be successfully replicated in California.

Source in addition to interviews with experts: Information taken from <http://www.ytporegon.org/node/6> on July 31, 2009.

MISSOURI TOP PROGRAM: BUILDING TRANSITION SERVICES IN SCHOOLS

Public

Promising Practice

The Missouri Transition Outcomes Project (TOP) is an example of improving transition services by building capacity within schools to address the transition needs among the student population by collecting and using baseline data to direct next steps. The Missouri TOP, which began in 2007, operates through the Division of Special Education and aims to increase the knowledge and understanding on the part of school administrators, educators, parents and students of the transition services requirements for the Individuals with Disabilities Education Act (IDEA). By law, states (i.e., school districts) are required to comply with the transition services requirements of IDEA (indicator 13) to receive funding. Indicator 13 ensures that children with disabilities have Individualized Educational Plans (IEPs), which outline educational goals for the student. IEPs are an important part of the transition process.

System of Care: Many states and local school districts have difficulty complying with indicator 13 due in part to a lack of understanding of the language and a lack of knowledge about how to address both the mandate and intent of the legislation. Also, there is often a disconnect between collecting transition related data (in the form of IEPs) and using that data to create action plans for youth with disabilities. Missouri has employed TOP contractors for the past two years to train staff at 60 schools. The two-day training includes a presentation on the IDEA legislation regarding indicator 13 using more comprehensible language. Staff members are also trained on collecting IEP data from their student population and enter-

ing these data into a central computerized database.

After this training, school staff is then able to pull the records for all the students with disabilities and analyze these data to determine whether gaps in transition services exist. If gaps exist, the staff can further use this information as baseline data from which to set future performance targets. TOP staff members follow up with the school districts 1-2 years later to evaluate the impact of the program in terms of addressing identified gaps in service.

Financing: TOP is typically funded and sustained through a combination of state funds, funds from the Vocational Rehabilitation Services and the U.S. Department of Education. In Missouri, TOP contractors are funded through federal money received by the Division of Special Education. TOP has been replicated in over 20 other states.

Evaluation: After the first year of implementation, preliminary evaluation data from many school districts has shown significant improvements in the way that IEP data are collected and used. These results are still being analyzed. Missouri plans to increase its TOP training to a total of 150 schools.

Will it Work in California: This program has been replicated in 27 other states and has some evaluation data to demonstrate its effectiveness. However, Missouri's success in the TOP program can also be attributed to a well-established infrastructure to support transition.

Source: For more information about the Transition Outcomes Project, visit the following websites: <http://www.rfcnetwork.org/content/view/205/47/> and <http://www.cuttingedj.net/resources.html>.

DISTRICT OF COLUMBIA: ENGAGING PHYSICIANS IN TRANSITION

Public Emerging Practice

The District of Columbia may be very different from California in terms of size and infrastructure, but its approach to transition by trying to improve the system of care by engaging physicians most affected by medical transition may still be of interest to California.

One of the most problematic issues surrounding medical transition for this population is that they are often under the care of a pediatrician past the age of 18, and when there is a desire to transition to more appropriate adult care, there may be a shortage of primary care doctors to provide services for CYSHCN for a number of reasons (e.g., the complexity of the cases combined with lack of insurance).

System of Care: The National Alliance to Advance Adolescent Health will work in collaboration with local medical universities, health centers, Family Voices-DC, and national partners at Healthy and Ready to Work and the Center for Medical Home Improvement to conduct a two year Action Learning Collaboration (ALC) focusing on engaging physicians around the topic of transition.

The main activities of this project involve surveying and convening a meeting with pediatricians and primary care doctors to solicit ideas and potential policies to address the difficult aspects of transitioning a young adult with special health care needs into adult care. The purpose of this project is to address transition by impacting the systems in which care is provided. In this case, the district is being used as a "system" due to its relatively compact and well defined population. The ALC is currently in its initial stages of development, but will collect evaluation and outcomes data as activities progress.

Financing: The National Alliance to Advance Adolescent Health, located in Washington, DC, recently received funding from the DC Department of Health to address the issue of transition among CYSHCN.

Will it Work in California: If California wanted to do a similar project, it might want to use one insurer, such as Kaiser Permanente as its "system" and conduct surveys and meetings with those physicians and try to impact the quality of medical transition among their CYSHCN clients.

Source: The information about Washington DC's transition activities was obtained during expert interviews with Margaret McManus, MHS and Patience White, MD, MA.