



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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Health Information Technology

The term Health Information Technology (HIT) can be interpreted narrowly and broadly. Narrowly interpreted, the term refers to electronic medical records (EMR) at the patient and practice level, as well as integrated child health data sets at the systems level. More broadly, it refers to the use of innovative technology to improve systems (e.g., common application) and provide care (e.g., telehealth).

For medical homes, HIT, through patient registries, offers enormous potential to track CYSHCN and build stronger and more effective linkages between primary and specialty care (see Pennsylvania Medical Home model). At this point, however, only a small percentage of practices have adopted this technology, in some cases because of the relatively small size of their practices and also because of the lack of good pediatric models that can capture the type of information (e.g., growth charts) necessary to track child health. Ideally, the EMR will be able to interface with public health through integrated child health information systems. A number of states have developed linked child health data systems such as immunizations and newborn hearing screening that pediatric providers can access through a web-based system.

At the broad end of the spectrum, Utah presents an example of a common application and Florida offers telehealth specifically for CYSHCN. The examples provided in this section provide a sense of the possibilities of HIT, although in all cases, leaders say more investment is necessary to reach more families and better meet the needs of CYSHCN.

UTAH: INTEGRATED CHILD DATA SETS

Public

Emerging Practice

System of Care: Child Health Advanced Records Management, CHARM, is part of the Utah Department of Health's (UDOH) data integration effort. It links child health information from several programs that currently include: Vital Records (birth and death certificates), USIIS (Utah's Immunization Registry), Newborn Hearing Screening and Baby Watch/Early Intervention. Future developments will include the Newborn Screening (heelstick) program and the Birth Defects Network. CHARM provides access to information that is stored in specific program databases to track and monitor child health status, such as screening results, immunization status, referrals, assessment, treatment, and outcomes for children and their families.

CHARM acts as an electronic broker (middleware). It does not replace existing UDOH databases. The participating programs are fitted with their own front-end "agent" that plugs in to the CHARM infrastructure. CHARM is taking a modular approach to integrating systems, beginning with a core of programs and leveraging funding and incremental successes to achieve a long-term vision for a statewide integrated system.

Evaluation: The management approach of CHARM has resulted in a tightly integrated plan with a high degree of accountability. Due to its complex

nature, CHARM was organized into three phases: Needs Assessment, Planning and Implementation.

Will it Work in California: California may want to consider the planning approach used in the CHARM data integration system, should it embark on an integrated data planning initiative. It is important to note that it may require significant and blended funds to undertake such a project.

Source in addition to expert interviews: <http://charm.health.utah.gov>. Retrieved August 6, 2009.

COLORADO: INTEGRATED CHILD HEALTH REGISTRIES

Public

Emerging Practice

System of Care: Colorado is working to develop integrated registries and data bases. A Centers for Disease Control and Prevention (CDC), Early Hearing Detection and Intervention (EHDI) grant awarded the Children with Special Health Care Needs Unit funding to integrate newborn hearing screening, newborn metabolic screening and the Colorado Responds to Children with Special Needs (CRCSN) birth defects registry data. CRCSN is Colorado's birth defects monitoring and prevention program. CRCSN maintains a database with information about young children with birth defects, developmental disabilities, and risks for developmental delay. CRCSN and the Health Care Program for Children with Special Needs (HCP) share data so that local HCP offices can provide health care coordination and /or link children and families who have been identified with birth defects and related disabilities with early intervention services. Information is transmitted securely and electronically to an HCP public health office in every county of the state.

Evaluation: The IT system began in 2000 and will eliminate duplication of records for more efficient follow-up, reducing duplicate contacts for families. The project has also developed database software for numerous agencies. In addition to HCP, software has been developed for the metabolic clinics at Children's Hospital, and the Traumatic Brain Injury program. In 2010 the system will be web-based and the EHDI program will be fully automated, allowing hospi-

tal coordinators and audiology providers to update screenings and diagnosis information. Early interventionists currently can log into the system and provide early intervention information. Future integrating of screening results and birth defects with primary health care offices through the state's Immunization Registry is planned.

Will it Work in California: The program in Colorado is noted for its consistent software across agencies. Using such a model could be applicable to California and other states as well.

Source in addition to expert interviews: State of Colorado Title V Block Grant Application Narrative, FY 2009. <https://perfddata.hrsa.gov/mchb/tvisreports/>. Retrieved August 12, 2009.

UTAH: UTAH CLICKS—A COMMON APPLICATION

Public

Emerging Practice

System of Care: Based on the Universal Application System (UAS) technology, Utah Clicks is a web-based interagency application process designed to help families apply for multiple programs. Families can complete paperwork online in a non-duplicative manner and submit their applications electronically to participating programs, such as Medicaid, WIC, CHIP, Head Start and others. The objective of this program is to create a streamlined process for families and children with special health care needs to apply for multiple services and programs. This program is targeted to Utah families who need to access multiple services.

Parents, state and local program staff for multiple agencies, and evaluators were involved throughout the grant cycle. State programs that are included as part of the Utah Clicks program are: Medicaid, CY-SHCN, WIC, Baby Your Baby, Early Intervention, Division of Services for Persons with Disabilities, Part B Preschool, Mental Health, and Head Start. Although not all of these partners' paperwork/application is currently available via Utah Clicks, their collaboration has been vital for the success and promotion of Utah Clicks.

Financing: This program was originally funded by a Maternal and Child Health Bureau grant. Additionally, participating programs in Utah (e.g., Medicaid, WIC, etc.) contribute a portion of the annual funds needed to maintain Utah Clicks.

Evaluation: Utah Clicks was launched in Utah in May 2005 and is currently available to all families statewide. A survey connected with Utah Clicks indicates that only 2% of consumers using Utah Clicks actually go into agency offices to use the system. With only word-of-mouth publicity during the initial five-month period, approximately 600 applications were submitted via Utah Clicks. In October 2005, two newspaper articles introduced Utah Clicks to the public, thus providing slightly higher visibility. During the second five-month period, 4600 applications were submitted via Utah Clicks, a 780% increase in usage. These results suggest that there is a high demand for this service. Additionally:

- 97% of UAS users who completed the online survey would recommend the UAS to other families.
- 40% of the electronic submissions are sent before/after business hours, indicating that 24/7 availability is of value to consumers.
- More than 50% of those surveyed use the program on their home computers and less than 5% use computers at agency offices to access service.

Will it Work in California: While cost savings information is not yet available, such a statewide common application program could potentially save money by reducing on-site visits. In addition, it could provide a mechanism to identify CYSHCN earlier and more efficiently.

Source in addition to expert interviews: Utah Clicks website: www.utahclicks.org. Retrieved August 11, 2009.

FLORIDA: A TELEHEALTH MODEL

Public

Emerging Practice

System of Care: Florida's Children's Medical Services (CMS) program operates a number of tele-

health programs to support child protection teams, pediatric endocrinology, and genetics.

- **Child Protection:** In the area of Child Protection, the CMS Telehealthogram works with the Child Protection Teams (CPTs) to provide medical examinations of alleged child victims who are located in remote areas. A U.S. Department of Agriculture, Rural Utilities Services grant was awarded to CMS in 2004 to enhance capabilities at the current seven telemedicine sites and added two new remote sites in middle/north Florida. A grant was secured to support expansion of telemedicine services into three locations in the Florida Keys region. CPT is now available at 14 services sites. In FY 2006-2007 the CPTs handled 27,470 cases involving child victims and their families and provided 37,008 team assessments, 1,684 staffing, and 797 court testimonies.
- **Endocrinology:** The Children's Medical Services Network (the special health care plan for CYSHCN) works with the Special Technologies Unit to maintain the CMS contracted program with the University of Florida's (UF) pediatric endocrinology staff that provides telehealth services for CMS enrollees with diabetes and other endocrinology diagnoses served by the Daytona Beach CMS area office. The use of two-way interactive video technology has proven to be an effective way of ensuring the availability of expert medical services to outlying rural areas.
- **Genetics:** A genetics telemedicine project enables a pediatrician and a University of Florida geneticist to communicate via two-way interactive video technology. This project has reduced the wait for a genetic screening consultation from one year to less than two months. A similar telemedicine project has been implemented at the University of Miami where the genetics team uses video conferencing to provide consultation for the Ft. Pierce and West Palm Beach CMS area offices.

Evaluation: Other CMS telehealth and telemedicine initiatives include: a partnership with the Institute for Child Health Policy, University of Florida, to refer CYSHCN who are seen at three of the state's community health centers to a CMS office for enrollment; nutritional, neurological, and orthopedic consults for CMS enrollees in Ft. Pierce, West Palm

Beach, and Ft. Lauderdale; craniofacial team meetings; various educational presentations between CMS area offices; and numerous administrative and consultative meetings with CMS staff. Some CMS offices are beginning to work with the University of Miami (UM) to develop teledermatology clinics as well.

Will it Work in California: Florida's far-reaching telehealth program provides of model of collaboration between the state, academia and the hospital system that children's hospitals and universities in California may want to consider.

Source in addition to expert interviews: State of Florida Title V Block Grant Application Narrative, FY 2009. <https://perfddata.hrsa.gov/mchb/tvisreports/>. Retrieved August 12, 2009.

NEW YORK: PUBLIC-PRIVATE TELEMEDICINE PARTNERSHIP

Public/Private Promising Practice

System of Care: Health-e-Access is a telemedicine program located in Rochester, NY, in which childcare sites and schools can obtain off-site health-care from physicians through the use of computer technology. The Health-e-Access Telemedicine Model is guided by the concept of the medical home. The approach to sustainability is based on a model of organizational architecture that recognizes three key drivers: incentives, decision rights, and performance evaluation. Guidelines for care within the Health-e-Access Telemedicine Model detail expectations for certified telehealth assistants at child sites and for telemedicine clinicians in primary care practices.

The primary partners that were involved in the collaboration were health insurance organizations, community- and medical center-based primary care medical practices, child sites in both urban and suburban settings (childcare programs, elementary schools, day programs for developmentally disabled) and telemedicine systems from TeleAtrics, Inc.

Financing: Approximately \$4,000,000 has gone into the development and evaluation of Health-e-Access. Funding was received from federal agencies,

NY State, national and local foundations and from individual donors. The program was initiated in May 2001. Health-e-Access is an ongoing program and is currently sustained from reimbursement for telemedicine visits by all local payers, including Medicaid Managed Care.

Evaluation: Over 7,000 telemedicine visits were conducted through March 2009. The telemedicine program includes more than 30 primary care clinicians who have conducted visits. Approximately 96% of telemedicine visits are completed without the need for travel or any additional in-person visits. The evaluation demonstrated that 95% of parents would choose a child care program with telemedicine over one without it, and parents estimate that a telemedicine visit saves them 4.5 hours on average compared to an in-person visit.

The evaluation of this program also addressed the impact of telemedicine on: absence of children due to illness, parents' absence from work, utilization of traditional health services (e.g., emergency department) and overall cost of care. The results of the evaluation include the following:

- There was a 63% reduction in absence due to illness among children attending inner city childcare, which was attributable to telemedicine.
- There was a 22% reduction in emergency department utilization, which was attributable to telemedicine.
- Given that reimbursement rates for emergency department visits are much greater than for telemedicine visits (reimbursed at the same rate as office visits), the Health-e-Access telemedicine model results in substantial cost savings.

More information about this program is available at www.teleatrics.com. A success story can be found at www.teleatrics.com/media/.

Will it Work in California: California may be interested in the cost savings data and evaluation piece of the Health-e-Access program.

Source: Information taken from materials from AMCHP's Best Practices Program.