

ISSUE BRIEF

Outcome # 6: Youth with special health care needs will receive the services necessary to make the transitions to adult life, including adult health care, work, and independence.

*Michigan Department
of Community Health*



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CHILDREN'S SPECIAL HEALTH CARE SERVICES STRATEGIC PLANNING 2008

This background brief presents an overview of the **Transition to Adult Life** status for children and youth with special health care needs in Michigan. It has been prepared as a step in assessing the readiness, capacity, and barriers to a fuller implementation of transition to adulthood for children and youth with special health care needs (CYSHCN) in Michigan. Members of the **Children's Special Health Services Advisory Committee (CAC) and other partners** have compiled this brief to document the current status of transition activity in both the U.S. and Michigan. This brief was developed as background material in preparation for the April 16 and 17, 2008 Michigan CYSHCN Strategic Planning Meeting. The meeting will result in a five year strategic plan. The overarching goal is to address for Michigan the 10-year Action Plan to Achieve Community-based Service Systems for Children and Youth with Special Health Care Needs and Their Families (U.S. Department of Health and Human Services, 2001). The focus of the CSHCS Strategic Plan is on assessing Michigan's current status of reaching the 2010 outcomes for CYSHCN, exploring strategies with key stakeholders from across the state to achieve these outcomes and in developing a prioritized five year plan to get us there. This brief is specific to the federal Maternal and Child Health Bureau Outcome #6: **Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.**

Transition to Adult Life

Background

The 2010 Action Plan for Children with Special Health Care Needs (CSHCN) is a ten-year plan developed and promoted by the Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration of the U.S. Department of Health and Human Services, and is endorsed by the American Academy of Pediatrics (AAP), Family Voices, the March of Dimes and over 50 other national organizations.

The Action Plan includes the specific outcome of transition to adulthood for all children with special health care needs by 2010. Work on this outcome is proceeding at both the state and national levels. At the present time, the definition for CYSHCN by MCHB and Michigan CSHCS do not fully coincide (see box). Michigan's CSHCS program provides medical and support services to eligible children. Due to budget constraints CSHCS cannot currently open up eligibility for medical care and treatment. The CSHCS program can, however, provide education and outreach to the broader CYSHCN population.

The document, *Healthy People 2010*, offers a set of health outcomes for the nation and reflects current health planning at the national level. The nation's health plan recognizes the key to improving care for CYSHCN lies in a systems approach to organizing and delivering services. Healthy People 2010 objective 16.23 is to "increase the proportion of states and territories that have service systems for children with special health care needs." Achieving this objective has been further defined by the federal MCHB as accomplishing six core outcomes (USDHHS, 2001):

1. Families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.
2. All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
3. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. **All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.**

This Issue Brief focuses specifically on Outcome #6.

Definition:

Children and Youth with Special Health Care Needs

National (MCHB)

Children and youth who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Michigan CSHCS

Michigan's CSHCS eligibility criteria for children and youth focuses almost exclusively on physical health conditions and services provided by pediatric sub-specialists.

Transition has become a concern for many families and providers, as more children and youth with special health care needs live well into their adulthood. Because Michigan's Children's Special Health Care Services (CSHCS) assists children and their families with health care issues, the focus of the MCHB outcome of transition has been on medical transition thus far. Other transition-related issues being explored and important to this population are employment, education, and independent living. Often it is difficult for youth

Medical transition is defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to an adult oriented health care system". (Blum, et. al, 1993)

to find adult health care providers who understand their unique diagnosis and are able and willing to provide their medical care as they become adults. Furthermore, the prospect of moving from a pediatric-oriented health care setting to an adult-oriented setting is a significant life milestone. Leaving behind the

collaborative and team-centered world of pediatrics for the less collaborative environment of adult care can be unsettling and uncertain. Youth also feel increased pressure as they become more responsible for their extensive health care needs while dealing with typical adolescent issues such as completing their education, finding work, and living independently. Getting families and adolescents prepared for this transition has become a major focus through the following national initiatives:

- National MCHB Performance Measures
- Healthy and Ready to Work Initiative
- President's New Freedom Act
- AAP's Medical Home Model.

The Michigan Story

Michigan has a long and proud history of making children with special needs a priority, dating back to the late 1800's when organized state-run services first were made available to "crippled children." In more recent history, the focus of the program has been medical care, treatment and support services for eligible children and some adults with one or more of approximately 2,500 physical-health-related diagnoses. The treatment and supports that the program provides must be specific to the qualifying condition(s). Except in unusual circumstances, CSHCS focuses on the services provided by pediatric or other sub-specialists and does NOT cover primary care services or providers unless they directly relate to the qualifying condition (e.g. pneumococcal vaccine covered for a child with Sickle Cell Disease, or a urinalysis ordered by the local pediatrician for a child with kidney disease whose specialist is 400 miles away).

The focus on the transition to adult life for CSHCS-enrolled youth increased only recently; the topic was addressed when CSHCS-initiated Special Health Plans for children and youth with special health care needs in 1998. The Special Health Plans, or SHP's, were managed care plans CSHCS clients were able to enroll in. Clients enrolled in a SHP were provided with coordinated and personalized case management. The design of the SHP's created an opportunity for Michigan to

begin to implement transition planning for youth since each enrollee was assigned a Principal Coordinating Physician (PCP) and each enrollee participated in the development of an Individualized Health Care Plan (IHCP). The SHP model was never fully implemented (reaching a maximum of approximately 5,000 of the approximately 30,000 CSHCS enrollees) before it proved to be too costly and administratively burdensome for the CSHCS Division. This decision came after the federal Centers for Medicare and Medicaid Services rule changes resulted in much more stringent oversight requirements. As a result, the SHP initiative was discontinued on September 30, 2004. Michigan then began anew in its pursuit of meeting the MCHB 2010 outcomes for CYSHCN in the area of supporting clients' needs as they transition to adulthood.

Michigan and National Data

There are approximately 8,400 adolescents ages 14-20 enrolled in CSHCS that will need to transition to adult health care in the next 5 years. They will need to access multiple services to allow them to live as independently as possible.

The National Survey of CYSHCN (2005/2006) is a national telephone survey. Participants are those who report having a child with a special need. Persons beyond those with Michigan CSHCS coverage or eligibility for their children were interviewed. According to the National Survey:

- 44.7% of parents in Michigan reported that "Doctors or other health care providers have talked to you or your child about his/her health needs as he/she becomes an adult." This is slightly below the national average of 46.2%.

Other sources of data that CSHCS generated have been reviewed. Information about the needs and gaps in services for this group of children and their families has been put together as a result of major efforts by the CSHCS program to build a transition system of care. Information comes from the CSHCS Family Center Survey and the Champions for Progress Grant, Youth and Family Discussion Group Sessions.

From January through March of 2005, the CSHCS Family Center surveyed 7,000 Michigan families of 14- to 21-year olds enrolled in the program regarding their information needs, transition issues, missing services and transition needs.

- 70.3% indicated they needed information.
- 13.3% did not know what they needed because they did not know what was available.

The major types of information families need are regarding transition planning, health insurance, health care maintenance, employment, education, independent living, health care providers, legal, financial, housing,

Information Needs on Transition

- Transition planning
- Health insurance
- Health care maintenance
- Employment
- Education
- Independent living
- Health care providers
- Legal
- Financial
- Housing
- Support
- Transportation
- Recreation
- Community involvement activities

support, transportation, recreation and community involvement activities. **The most important issue identified was health insurance coverage.** Families are concerned about having insurance to pay for their youth's medical equipment and supplies, medications, hearing aids, therapies, glasses, ambulance bills, x-rays, out-of-state treatments and dental treatment after they age out of CSHCS.

According to the U.S. Census Bureau, in Michigan 24% of all young adults age 18-29 are uninsured. Because eligibility requirements are much different for adult health care programs than those for children, young adults who were once eligible for such services as a child are facing a difficult transition when they are not eligible for public health care programs as adults. Families are also concerned about their children developing the necessary skills to maintain their health and live independently.

Personal Narrative

The following story was written by a young woman who had aged out of CSHCS and encountered many difficulties transitioning her health care services. Her experience is common among young adults who, as children, qualified for CSHCS services but do not qualify for Medicaid as an adults. Primarily, this is due to Medicaid income and disability eligibility requirements. This narrative was written for other young adults with special health care needs.

I am diagnosed with type I diabetes, rheumatoid arthritis, hypothyroidism, and osteoporosis. I also have documented, but as yet undiagnosable, problems with my joints (besides arthritis), fine motor control, and neurological functioning. I have been diabetic since I was 2. I got on Children's Special Health Care Services when I was 11. I turned 21 July of 2005—and fell off the face of the Earth when I tried to get health insurance.

I use food stamps to eat; my parents are disabled and on a fixed income; I take about a dozen medications plus I need syringes and other medical supplies. Between maintenance appointments for diagnosed problems and specialist appointments to try to make headway with undiagnosed illnesses, I definitely run up doctor bills. I wanted not to turn 21 more than I've ever wanted anything else! But I did. My family was spending a lot of money trying to keep me able to walk. What about Medicaid? That's supposed to help poor people get health care, right? Well, folks, I become ineligible for Medicaid at 21 as well (grrr). I am lucky enough to live in a county with a county health plan (the Adult Benefits Waiver, ask about it at your local Department of Human Services office). It helps cover most doctor visits, and about half my meds. However, the expensive ones are not covered and I have to pay out of pocket. Also, I have to reside in my county, where there are no graduate schools in my field. I am required to go to a county doctor, and am in there a lot. So I can't go to, say, Virginia and come back for doctor appointments.

What is a "medically challenged" person, who actually wants to work someday, to do? I'm a bit lost on that part still. But I'm working with the Early Adult Transition Task-force (EATT) to try to help all of you avoid falling off the face of the Earth. It's not like we're healed by 21st birthday cake—we would be if we could be! All of us (anyone 15 or older) who are or have been on CSHCS worry about transition/falling. If we work together, we can make sure we don't crash land."

Current Status in Michigan

CSHCS has made great effort since 2005 to coordinate efforts to assess and assure youth with special health care needs receive services necessary to make the transition to adult life including health care, employment, and independent living. A **Transition Analyst** was hired by the program to work full time on this 2010 outcome. A three-year plan was developed based upon work done in the area of

CSHCS Progress: Transition

- Transition Analyst hired.
- Three-year plan developed.
- Local health department transition resource manual developed and disseminated.
- Education and training provided to local health department staff.
- Ongoing technical assistance available to local health departments.
- Discussion groups held with youth experience transition.
- Early Adult Transition Task Force was created.
 - Quarterly newsletter produced
 - EATT Blog
- *Family Guidance* brochure developed and disseminated.
- Four anticipatory guidance letters developed and sent.

transition including the “**Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs**” published in the *Pediatrics Journal* (Dec. 2002). The CSHCS division is currently in the second year of the three-year plan for transition and is moving closer towards the goal of a coordinated system of care for youth and young adults with special health care needs.

To address the needs of local health department (LHD) staff who wanted more information and resource materials CSHCS created a transition resource manual. The ***Transition Resource Manual*** was created to serve as a single point at which LHDs could maintain reference information, handouts for youth and families, and planning material on the topic of transition to adulthood. The manual contains over 100 pages of information on the topic of transition, divided into easy to use topical sections. Over 300 *Transition Resource Manuals* have been distributed to LHD staff around the state of Michigan. Feedback from LHD staff has been

positive. Further education and training has been provided to them through semi-annual meetings and teleconference training calls. Technical assistance is always available to LHDs on any topic related to transition through the division’s Transition Analyst.

In January of 2004, the CSHCS division was awarded the **Champions for Progress Incentive Grant** to expand efforts to partner with families and develop a new effort to engage youth in decision-making and program planning for a coordinated transition system of care. Four discussion groups were held around Michigan with young adults experiencing the transition process. The young adult participants were asked to advise the CSHCS program on: (1) what they believed a good system of care for transition would look like; and (2) what type of information should be available as they make the journey from children’s services to adult services. As a result of the meeting, applications were taken to form a **Youth Advisory Committee** to provide input to CSHCS on decisions being made and policy/program development. A Youth Advisory Committee was formed and held its first annual meeting April 8th 2006. The group is comprised of 10

young adults from around the state with varying health care needs. The group soon re-named themselves the Early Adult Transition Task Force (EATT). The EATT currently has a delegate on the main CSHCS Advisory Committee. Annual EATT meetings and with new members are planned each year.

The EATT came up with the idea of creating a quarterly newsletter for young adults enrolled in CSHCS. Parts of the newsletter are written by EATT members, and all EATT members have the opportunity to edit the material. The main focus of the newsletter is to educate young adults about transition and planning for their future health care needs. The newsletter also includes resources that may be helpful to young adults of transition age. The newsletter is mailed quarterly to over 4,600 young adults receiving services from CSHCS. Another idea from the group was to provide education to young adults in a way that they will listen. An **Early Adult Transition Task Force Blog** has been created on the internet for young adults with special health care needs so they may connect with others in a similar situation, ask questions, and comment on certain transition-related topics.

Providing education and guidance to families on the topic of transition has also been a priority within CSHCS. A brochure titled “**Family Guidance: Transition Planning for Youth**” was created which outlines topics such as health care skills, insurance, education, employment, and independent living. These brochures have been circulated to all local health departments and are also included in all anticipatory guidance that is distributed on the topic of transition. CSHCS also educates young adults and family members on transition through anticipatory guidance in the form of letters. **Four anticipatory letters** have recently been developed and are currently being sent to clients and to family members.

- The year of the **client’s 17th birthday** a letter is sent to the responsible party outlining some important issues as they plan for their child’s future including guardianship and alternatives to guardianship.
- **Three months before their 18th birthday** a letter is sent to the responsible party to notify them of upcoming changes due to privacy and age of majority laws.
- The **month of their 18th birthday** a letter is sent to the client to notify them that they are now the responsible party for CSHCS. The letter also notifies them of the steps to allow CSHCS to disclose protected health information to family members if they wish.
- **Three months before the clients 21st birthday** an anticipatory guidance letter is sent explaining that CSHCS coverage is soon ending.

These letters provide guidance to youth and their family members with detailed information about steps throughout the transition process, steps such as planning for your child’s future as an adult, reaching the Age of Majority, HIPAA privacy laws after the age of 18, as well as guidance on health care skills and health insurance. This guidance addresses the concerns that were voiced by youth and families during the needs assessment phase that included comments such as “tell us where we are going” and “we need to know what is next.”

Challenges/Barriers

1. In the survey of CSHCS families, they identified the most pertinent missing services for transitioning CSHCS youth to adult services. These missing services included:
 - a. General transition information, names and contacts information for agencies to assist with transition, and health insurance options.
 - b. Transition information that outlines the process, discusses milestones of how families can prepare for transition, lists services available and contact information for transition specialists that will assist them (most common need).
2. Local health department staff, who are the local arm of CSHCS, were also surveyed and identified gaps in services for the young adult population. The resource they believed missing was information and education on adult programs and services for both families and local health department staff.
3. A major barrier for this population involves health insurance. As stated before the young adult population has the highest rate of being uninsured nationwide and statewide. The general feeling is that this population is considered “healthy.” For the population with special needs that CSHCS serves we know this is not the case. Without eligibility in a state-sponsored health care program many young adults find themselves without coverage. If a young adult is not on a parent’s health plan or has an employer that offers health coverage their choices of services are limited. CSHCS specifically sees this in the population of young adults with special needs that are not identified as a “disability” such as diabetes, asthma, cleft palate, and many other conditions that require ongoing health care maintenance to maintain health.
4. Co-Pays are unmanageable as they are very expensive for some insurance coverage.
5. Local Health Departments are not fully funded and do not have the staff to provide the needed coordination to each client aging off the program.
6. There is a disconnect between children and adult programs, and very little coordination between the two.
7. Different “language” between child and adult resources causes confusion and makes transition planning difficult.
8. There is a lack of prevention services in this population.
9. Parent sometime foster dependency when they do not let young adults take control of their own health care.
10. It is often difficult when transitioning to get services through Michigan Rehab Services (MRS) for employment supports.

11. There is little to no coordination/follow-up to see the transition has been successful.
12. Young adults and their parents are often overwhelmed when transitioning.
13. Diabetic other supplies—money
14. Transportation services are lacking, especially in rural areas of the State.
15. Families Struggle with the Department of Human Services when trying to get services and question answered.
16. There is no single point of entry for services, which causes problems because many people don't know where to go or who to talk to about available services.
17. There is little space available in adult community based waiver programs and they often have long waiting lists.

Strengths/Opportunities for Improvement

1. Having a full time transition analyst on staff at CSHCS.
2. The CSHCS program has good information distribution with the transition anticipatory guidance letters.
3. Interest and support within the program and MDCH is great.
4. Local health departments are able to provide Care coordination/Case Management for this population.
5. There is a transition process in place for young adults receiving private duty nursing.
6. The Early Adult Transition Task-Force blog was a great idea.
7. The CSHCS program addresses guardianship alternatives.
8. MDCH has a great data warehouse and because of it the CSHCS program is able to get enrollment and utilization data for the transition population.
9. Having the Early Adult Transition Task-Force (EATT), this is the youth advisory committee for the CSHCS program. The EATT provides an opportunity for consecutiveness/sharing/network
10. Local Health departments have access to a Transition Resource Manual for guidance and support.

11. There is much family involvement for the issue of transition.
12. The Center for independent living (15 within the state), are a wonderful resource.
13. The Department of Education provides transition planning for special education students at the age of 14.

Prioritized Recommendations (outcomes from Strategic Planning)

- *1. Create addition services to cover adults: health care, insurance coverage, CSHCS buy-in, pharmacy coverage, mental health
 - *2. All young adults with special care needs will initiate a transition plan by 14 (Local level through medical home and or care coordinator) Create standard requirements and training for all youth with special health care needs at age 14. Review at least annually and expand who would be eligible to bill for care coordination for transition planning.
 3. Create a collaboration between organizations and/or agencies that serve youth and those that serve adults
 4. Identify all available services and establish a state-wide point of entry
 5. Offer training/education awareness to providers and medical schools. Continue work to establish Medical Home concept. Provide incentives and or increased reimbursement rates for providers. (Emphasize transition)
- *High priority as determined by participants at the Strategic Planning session.