



**Children and Youth with
Special Healthcare Needs in
Healthy People 2020:
*A CONSUMER
PERSPECTIVE***





Introduction

This document examines *Healthy People 2020* objectives and serves as a companion to *Envision 2020*, the 10-year strategic plan for the Division of Services for Children with Special Health Needs in the Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB). Genetic Alliance and Family Voices collaborated with MCHB to create this family and consumer perspective on the national health promotion agenda and how it relates to CYSHCN and their families. Children and youth with special healthcare needs (CYSHCN) deserve effective, efficient services and support. A passionate and powerful community has emerged over the last century to help make that goal a reality. However, though many excellent services exist, the network of programs that deliver them is complicated, often lacking both coordination and baseline data against which to measure their success.

Over the past decades, many federal, state, and community programs have begun to focus on creating a shared infrastructure for systems of services rather than focusing solely on providing direct services for individuals with particular diagnoses. This shift is reflected in the *Healthy People* objectives for the nation. For example, one objective in *Healthy People 2020* (HP2020) focuses specifically on increasing the proportion of children and families that receive care in comprehensive, coordinated systems of services (MICH-31). This Consumer Perspective underscores the role of individuals, families, communities, government agencies such as MCHB, and other stakeholders in monitoring and implementing HP2020, including developmental objectives for CYSHCN.



Background

In 1979, *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention* presented a health agenda for the nation. The document set forth health goals for the population based on life stage and laid out action items for disease prevention as well as health protection and promotion. Since then, every ten years, the U.S. Department of Health and Human Services (HHS) updates, reports progress, and expands the national health promotion agenda through its *Healthy People* publications

HHS collaborates with states, communities, and organizations in the public and private sectors to establish a series of objectives to bring better health to all people in this country. Each successive *Healthy People* document builds upon previous years' goals and objectives, adding new measurable objectives and expanding the tracking systems used to assess changes. HP2020 focuses on improving the health of all Americans, with four overarching goals¹:

1. Attain high quality, longer lives free of preventable disease, disability, injury, and premature death
2. Achieve health equity, eliminate disparities, and improve the health of all groups
3. Create social and physical environments that promote good health for all
4. Promote quality of life, healthy development and healthy behaviors across all life stages

Healthy People 2020 objectives fall into two main categories: measurable and developmental objectives. Every measurable objective has an established data source, such as the National Survey of Children with Special Health Care Needs (NS-CSHCN). Each measurable objective also has a baseline value, from a previous year, which is used to set the target goal for 2020. Developmental objectives do not have a baseline data point, but do have a nationally representative data source that could provide baseline data for the future.

Healthy People 2020 Mission

- Identify nationwide health improvement priorities
- Increase public awareness and understanding of the determinants of health, disease, and disability and the opportunities for progress
- Provide measurable objectives and goals that are applicable at the national, state and local levels
- Engage multiple sectors to take actions to strengthen policies and improve practices that are driven by the best available evidence and knowledge
- Identify critical research, evaluation, and data collection needs.

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There are nearly 600 objectives in *Healthy People 2020*. After a thorough assessment of all objectives, the list was narrowed, for the purposes of this document, to approximately 100 objectives that relate to CYSHCN. Collaborators from Genetic Alliance, Family Voices, and MCHB then selected 46 objectives we felt were most important to be featured in this companion document, including many new objectives related to medical home, healthcare transition, and genomics that directly affect CYSHCN and their families. We examine these objectives, outline progress to date, and envision how the objectives might influence CYSHCN as they grow and mature into adults with the possibilities of becoming a part of the nation's workforce.

By highlighting a small portion of the many community and organizational accomplishments related to CYSHCN and systems of care, we hope to generate discussions of the gaps that remain, as well as equip families and providers to better advocate and care for CYSHCN and their families. The goals of this document are as follows:

- Identify HP2020 objectives that directly relate to or support systems of services for CYSHCN and families, as well as those that impact CYSHCN across the lifespan.
- Relate HP2020 to each of the six MCHB outcomes included in the Envision 2020 strategic plan for CYSHCN.
- Demonstrate how HP2020 objectives can influence and provide direction for improving systems and services for individuals with special healthcare needs.
- Promote the importance of HP2020 to improving the health of families and communities and foster collaboration between families and other stakeholders, including federal and state agencies as well as nongovernmental organizations, to inform public policy.



New Objectives in HP2020: How are they selected?

Several federal agencies drafted the HP2020 objectives, which were then open for public comment. Individuals, families, communities, and organizations submitted comments during public meetings and online. A federal work group then selected the final objectives. This broad participation ensured that the topics people care about – those that affect their daily lives and health – were included.

Chapter 1

*Children and Youth with Special Healthcare Needs,
Then and Now*



For most of the 20th century, most congenital organ and systemic problems proved fatal early, so “children and youth with special healthcare needs” – a term that was not fully defined or used until the late 1990s – consisted mostly of those with relatively stable motor, sensory, or neurological conditions². The Federal Children’s Bureau, established in 1912, was the first government program to formally serve children with these complex, chronic health issues.

The next major development for CYSHCN, and all children and families, occurred more than two decades later, in the form of the Social Security Act of 1935. Through Title V of this Act, the federal government pledged its support to states to extend and improve programs that promote the health of mothers and children. In addition to overall care for women and children, Title V specifically funded services for “crippled children.” (Infectious diseases such as meningitis and polio caused long-term difficulties, so early programs to provide assistance to these children and their families were called Crippled Children’s Programs³.) This set the stage for decades of Title V-funded programs that support core public health functions, such as resource development, capacity and systems building, information dissemination and education, knowledge development, outreach and program linkage, technical assistance to communities, and provider training.

Even with the advent of Title V, into the 1970s, children with special healthcare needs were classified by their particular diagnoses. This led to condition-specific services, benefits, and research priorities. However, as public health and healthcare advanced in the 1970s and 80s, people realized that there are common access, service, and coordination challenges across conditions.

CYSHCN: Who are they?

Children and youth with special healthcare needs are defined as “those who have or are at 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.”¹³

Rather than narrowly defining the needs of children by their disabilities, it became clear that children and youth with special healthcare needs and their families:

- Often require complex, long-term health services;
- Spend more on healthcare than other families;
- Are vulnerable to access, cost, quality, and coverage weaknesses in the healthcare system;
- Experience disparities in accessing care, especially in minority, non-English speaking populations.

Across conditions, CYSHCN require similar types of programs, services, and supports^{2,4-8}. With the new inclusive concept of special needs came a new, cross-disease kind of advocacy organization, including Genetic Alliance and Family Voices.

During the 1980s, the U.S. Surgeon General’s Office and HRSA’s MCHB worked to set up a systems approach to services for CYSHCN and their families⁹⁻¹¹. This means that services – from help with financial issues related to medical costs to after school programs for CYSHCN – were made available to people with similar special health needs, regardless of their diagnoses. While direct services are still provided in many cases, this approach helps reduce duplication of services and promotes understanding and a sense of community across disorders. Parent and family organizations, public programs, professional organizations, elected officials, community leaders, and more came together to create a system that could most efficiently respond

to the needs of different families, communities, and cultures.

In 1989, this new model, with an emphasis on partnership, was incorporated into authorizing language for the Title V Maternal and Child Health Services Block Grant. That year, Congress used the Omnibus Budget Reconciliation Act (OBRA)¹² to require that Title V programs take leadership roles in helping CYSHCN to achieve family-centered care and family-professional partnerships.

A decade later, the definition of CYSHCN was formalized based on family and consumer needs rather than a specific diagnosis¹³. The term is not limited to those who qualify for particular programs, and it goes beyond insurance. CYSHCN are a diverse population with a wide range of diagnoses and abilities. Their common denominator is an increased need for services, which they often receive in multiple settings by a variety of professionals and service agencies.

In 2000, MCHB and key stakeholders, including families, state Title V programs, and other national partners, identified six core performance measures for CYSHCN¹⁴. These measures represent the essential elements needed for high-quality systems of care for CYSHCN:

1. Family/professional partnership in decision-making
2. Coordinated, comprehensive care through a medical home
3. Adequate health insurance and financing for needed services
4. Early and continuous screening for special health care needs
5. Community-based services that are organized for easy use by families
6. Effective transition to adult health care, work and independence

These performance measures are the standards to which all programs should be held. Better health for individuals, families, and communities depends on achieving these measures.

To date, programs have made strides toward realizing these performance measures. MCH CYSHCN programs in every state, territory, and the District of Columbia recognize these measures and report annually on strategies for implementation. Similarly, since the launch of *Healthy People*

CYSHCN: How many are there?

- Approximately 10.2 million children in the U.S. – 15 percent of all people under the age of 18 – have special healthcare needs.
- More than a fifth of U.S. households with children have at least one child with special needs.¹⁶



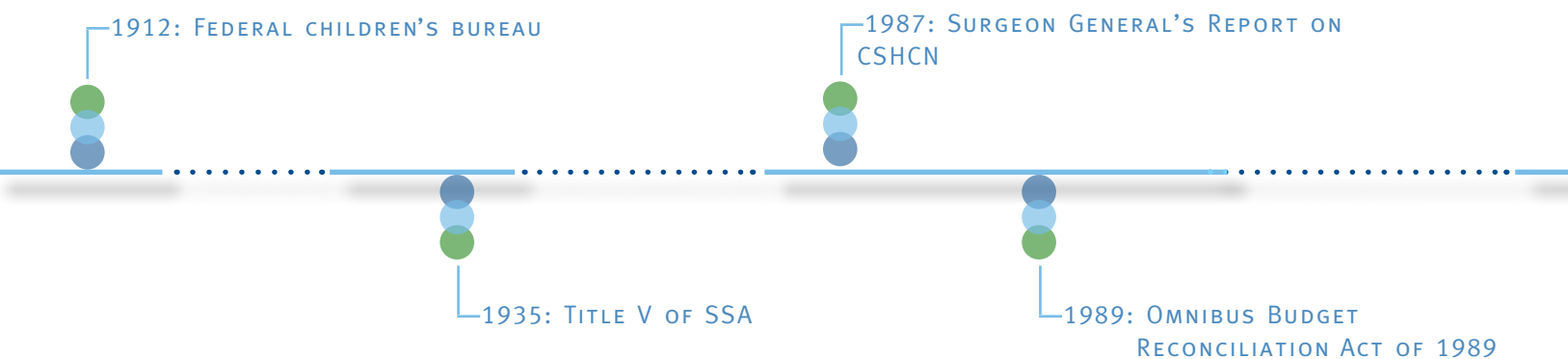
2000, a goal within the CYSHCN advocacy community has been to increase the number of objectives that focus specifically on the health of and services for CYSHCN and their families. With each successive *Healthy People* publication, the federal government has increasingly called for comprehensive systems of services for CYSHCN. Indeed, MCHB's basic mission is revealed in one recurring *Healthy People* objective (MICH-31): To increase the proportion of children with special healthcare needs who receive their care in family-centered, comprehensive, coordinated systems.

In 2001, the first National Survey of Children with Special Health Care Needs (NS-CSHCN) was conducted to establish prevalence estimates and assess and monitor the health status of CYSHCN. Data has been collected three times over the past decade (2001, 2005-6, and 2009-10). This survey complements the National Survey of Children's Health (NSCH), allowing comparison between the status of children overall in the country and the status of children and families with special healthcare needs.

Progress certainly has been made. Throughout much of the last century, it was commonplace for children and youth with special healthcare needs to be institutionalized or to not survive². Now, increased survival rates and effective interventions that address developmental and education needs can lead to satisfying, productive lives. However, there is still ample room for improvement. In 2009-10, the NS-CSHCN indicated that only 17.6% of CYSHCN received services in a high-quality system where all age-relevant outcomes were achieved¹⁵.

Each subsequent *Healthy People* publication is a step in the right direction, acknowledging successes to date and setting the bar for future improvement. Over the next three chapters, we will examine *Healthy People* objectives in the context of the six core performance measures promoted by MCHB; discuss the relevance of these objectives to at-risk populations; and forecast how the performance measures and objectives will extend into adulthood for transitioning children and youth with special healthcare needs.

TIMELINE



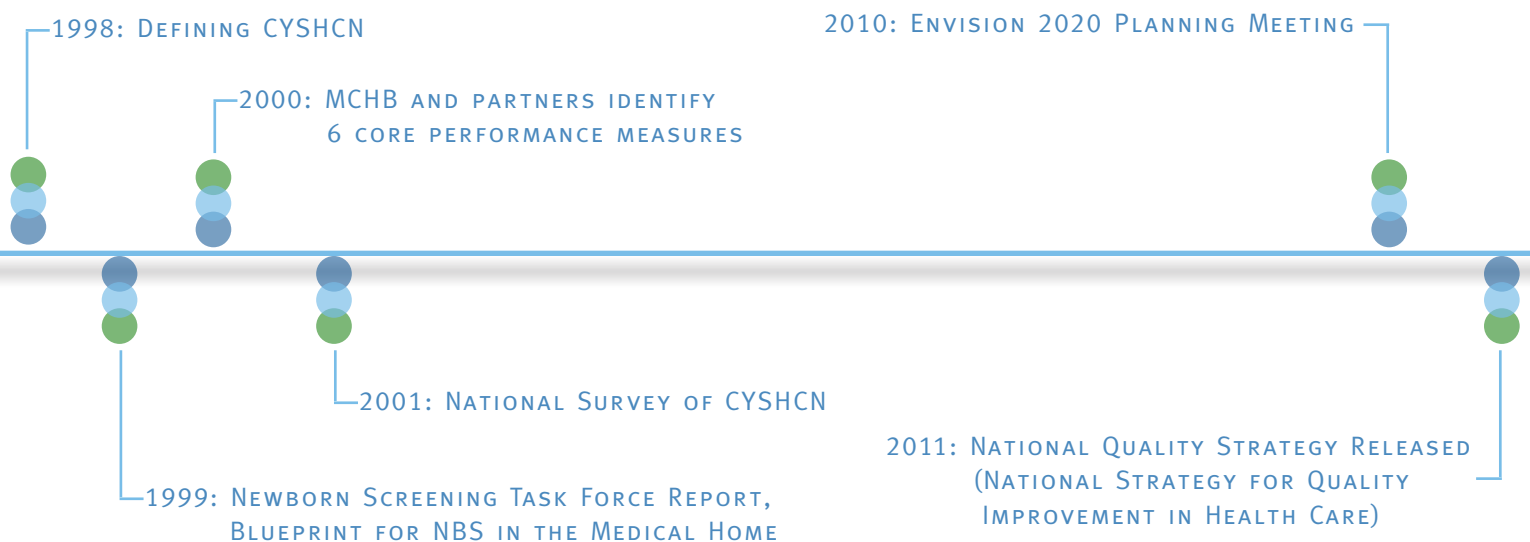
KATIE'S STORY¹⁷



At five months of age, a brain infection sent Katie Beckett to St. Luke's Methodist Hospital in Cedar Rapids, Iowa, where she stayed for most of the next three years. While Katie needed to use a ventilator to breathe for much of the day, she didn't need the level of care and expense that a continued hospital stay cost. When private insurance ran out, Katie's parents turned to Medicaid. Her mother, Julie, successfully advocated for a waiver of the rules that required children with special healthcare needs to be in the hospital in order to receive needed Medicaid funding. Keeping Katie in the hospital meant the government was paying \$10,000 to \$12,000 a month—five times what in-home care would cost. Thanks to an historic decision in 1981 by then President Ronald Reagan, Katie went home.

Over the next 30 years, Katie's mother, Julie, helped co-found Family Voices and create the first funding for Family-to-Family Health Information Centers. Katie became an advocate and board member of KASA, Kids As Self Advocates, a Family Voices project dedicated to empowering young people with special healthcare needs. Katie often spoke at conferences and testified before Congress.

The need for families to be actively involved in the care of technology-dependent children like Katie focused attention on the critical roles that families play in this process. Family/professional partnerships began to blossom. The Beckett's efforts also ensured that a broad array of families representing every group in our country would join this movement.





Chapter 2

Core National Performance Measures for CYSHCN

** HRSA funds national resource centers for the six performance measures described in this chapter. A list of currently funded resource centers is at the end of this document.*



Measure 1

FAMILIES OF CHILDREN WITH SPECIAL HEALTHCARE NEEDS PARTNER IN DECISION-MAKING AT ALL LEVELS

OBJECTIVE	HP2020	DATA SOURCE
Focus Objectives		
Increase the proportion of persons who report that their healthcare providers always involved them in decisions about their healthcare as much as they wanted	HC/HIT-3	Health Information Trends Survey (HINTS), NIH, NCI
Increase the proportion of persons who report that their health care providers have satisfactory communication skills	HC/HIT-2	Medical Expenditure Panel Survey (MEPS), AHRQ
Additional Objectives		
Increase the proportion of adults with disabilities who report sufficient social and emotional support	DH-17	Behavioral Risk factor Surveillance system (BRFSS), CDC, NCCDPHP
* Increase the proportion of patients whose doctor recommends personalized health information resources to help them manage their health	HC/HIT-4	Pew Internet and American Life Project, PEW

**Developmental objective, data sources listed are potential data sources*

Parents and guardians have ultimate responsibility for caregiving and overseeing their children’s health. However, support from professionals is necessary since care for CYSHCN involves multiple stakeholders, including primary and specialty care providers as well as non-medical service providers. For CYSHCN to thrive, partnership between care providers and families is critical.

Unfortunately, it is often the already underserved groups that do not achieve the performance measure, and promoting full partnership and satisfaction in culturally and linguistically diverse communities is particularly challenging. Lack of a sense of partnership is correlated with lower income, no insurance, language other than English spoken in the home, and racial/ethnic minority¹⁸. Furthermore, parents of children with the greatest limitations are about three times more likely to report that this core performance measure and its components were not met.

On the other hand, across-the-board partnership, from the clinic to the city council, has wide-reaching effects. A sense of partnership has been associated with improved outcomes such as fewer school absences, higher rates of getting referrals for needed services, and reduced rates of unmet child and family health needs¹⁸.

Therefore, families need to play a part in the ongoing development and refinement of the system of services at the community and state levels, within the care setting and beyond. In addition, it is important for CYSHCN themselves, not just their parents and families, to participate in decision-making about their healthcare and program development related to the services they receive. Rather than passive recipients of information and services, CYSHCN should be stewards of their own health

and active participants in their care. The emerging generation of youth needs mentoring and assistance to develop confidence and build competencies working with issues and agencies for their special needs.

For many years MCHB has promoted the integration of family-centered care, family-provider partnerships, cultural competence, and language appropriateness into existing service systems⁹, and progress is ongoing. Family involvement in state and local program planning and operation is becoming more common, even standard of practice. For example, multiple organizations exist to provide information, training, technical assistance, services navigation, peer support, and leadership development [see call-out box] to youth and families and the professionals who serve them in every state, territory, and the District of Columbia.



TRISH'S STORY

Access to services can be very different, and difficult, when you come from a rural, diverse, depressed social economic area; speak a language – other than English – that has no words to explain a health condition or medical procedure; live in a society where traditions and culture are important and can govern individuals depending on what is being sought or needed. For example, when you live on a reservation or Pueblo.

It is not common knowledge, but it is important to know that we Native Americans have to deal with many levels of bureaucracy (Indian Health Service, contract health, Tribal 638 health programs, private health insurance, Bureau of Indian Affairs, traditional medicine) when trying to get needed healthcare services, more than the general public has to deal with.

Some Native people still use traditional medicine, and most have no insurance. Indian Health Service has been and continues to be underfunded, which leaves Native People with limited or no access to needed healthcare services for themselves and their families, including their children and youth with special healthcare needs. Many of our healthcare providers have little or no training on cross-cultural medicine, cross-cultural communication, and the cultural differences of the people they are working with. This makes access difficult, impacts trust, and can create delays in services or procedures. Often perceived failures are the result of both sides not asking or sharing their cultural differences.

For example, my son had to have numerous surgeries, including removal of body tissue from his eye (one of the Human Sense Organs). We chose to use both traditional medicine and western medicine, but the western providers did not understand the importance of doing our “ceremonies” before the western medical procedures and did not understand why it was important to us how the tissue was removed and disposed of. The western providers took offense to what they perceived as us getting a second medical opinion, when we were only following our culture and tradition when it came to our Human Sense Organs. It was made harder for us to reschedule and took longer as we had to go through a lot of red tape to have his removed tissue given to us so we could dispose of it in line with our culture and traditions. My son eventually had thirteen surgeries on his eye, but it took much longer than both sides thought it would.

The nurses played a key role and became our intermediaries or cultural brokers. Educating providers on cultural and linguistic competency is so important to improve access to needed services for diverse populations and their children and youth with special healthcare needs.

What Is Culturally Competent, Language-Appropriate Care?^{21,22}

To provide high-quality healthcare, providers need to recognize and respect the unique values, behaviors, attitudes, language, and health literacy of the patients and communities they serve. This helps diverse audiences—people with different racial, ethnic, and cultural backgrounds; persons with limited English proficiency or low literacy skills; and individuals with disabilities—to understand and accept information from healthcare providers.



Why Is Culturally Competent, Language-Appropriate Care Important?

Families of CYSHNC face a complex healthcare system that is hard to navigate. In this environment, effective communication is as important as clinical skill. When families receive services that are culturally competent and language-appropriate, it increases their ability to better care for their children and allows for family-professional partnership in decision-making, which means families working together with their children’s healthcare providers to improve health care services and access. As part of family-professional partnerships, culturally competent, language-appropriate care is necessary to eliminate healthcare disparities and improve the quality of services and health outcomes for CYSHCN.

RISE OF THE FAMILY MOVEMENT

Families of CYSHCN are true experts on the needs of CYSHCN. They have a wealth of knowledge, insight, and experience with healthcare and non-medical services based on years of living day-to-day with CYSHCN. As such, families are essential, valuable partners in shaping the system of services for CYSHCN. They support and educate each other and often facilitate partnerships with providers, policy makers, researchers, and other individuals and organizations with a stake in the health of CYSHCN.

However, it was not until the 1980s that parents and families became an influential presence in national decision-making as they began to form condition-specific support groups and advocate at the national level. A major early accomplishment of this movement was President Ronald Reagan’s 1981 decision to change Medicaid rules to allow in-home care. Previously, rules required CYSHCN to be in the hospital in order to receive needed Medicaid funding, but hospital care is significantly more expensive than in-home care.

Today there are thousands of support and advocacy groups for specific conditions as well as more general patient and family advocacy. Over the past two decades, virtual networks have catalyzed even more growth. Increased Internet use has made it easier for parents to connect with other families as well as key decision makers. Similarly, increased ability to access services, through both ease of travel and telemedicine, has transformed the parent movement, making it a more efficient—if not easier—process to educate and advocate for access and quality services.

RISE OF THE FAMILY MOVEMENT continued

Family support and shared decision-making are the pillars of the impactful organizations that help elevate the family and consumer voice in national healthcare conversations. For example

Genetic Alliance was founded in 1986 to support individuals and families affected by rare genetic conditions, which often lead to an array of special needs. Genetic Alliance's mission is to connect consumers to the information and smart services they need to make informed decisions about health and care.

Family Voices was created in 1992 as a national network for families of CYSHCN working to promote the inclusion of CYSHCN and their families' needs in anticipation of Health Care Reform, and to promote families as decision makers and partners in healthcare of their loved ones.

Family-to-Family Health Information Centers (F2F HICs) are staffed by experienced family members to provide support, resources and training to help families navigate available services and make informed decisions. Family Voices, through the National Center for Family/Professional Partnerships, provides technical assistance, training, and connections to other F2F HICs and partnering organizations.

Kids As Self Advocates (KASA) is a national, grassroots project created by youth with disabilities for youth. KASA youth help spread positive information about disability among their peers and participate in discussions about how to help each other succeed. They also help healthcare professionals, policy makers and other adults understand what it is like to live as youth with special needs. KASA is a Family Voices project

The Institute for Patient- and Family-Centered Care, a nonprofit founded in 1992, promotes collaborative, empowering relationships among patients, families, and healthcare professionals and facilitates patient- and family-centered change in all settings where individuals and families receive care and support. The Institute also serves as a central resource for policy makers, administrators, program planners, direct service providers, educators, design professionals, and patient and family leaders.

Parent to Parent USA was created in 2003 to ensure that families nation-wide whose children have special needs have access to parent support. Parent-to-Parent support – the matching of experienced, trained Support Parents with families seeking support – has been proven effective in helping families cope with their day-to-day lives, connect with community resources and navigate the healthcare system.

Family-centered care is based on the recognition that children live within the context of families and that families are the ultimate decision-makers for their children. Therefore, family-centered care promotes families participating as integral partners with healthcare providers in making decisions about their children's health.²⁰



Measure 2

CHILDREN WITH SPECIAL HEALTHCARE NEEDS RECEIVE COORDINATED, COMPREHENSIVE CARE THROUGH A MEDICAL HOME

OBJECTIVE	HP2020	DATA SOURCE
Focus Objectives		
Increase the proportion of children, including those with special healthcare needs, who have access to a medical home	MICH-30	National Survey of Children's Health, National Survey for Children with Special Health Care Needs, (CGIS,
Increase the proportion of adolescents who have had a wellness checkup in the past 12 months	AH-1	National Health Interview Survey (NHIS), CDC, NCHS
Increase the proportion of children with mental health problems who receive treatment	MHMD-6	NHIS, CDC, NCHS (National Survey of Children's Health)
Reduce the proportion of people with disabilities who report delays in receiving primary and periodic preventive care due to specific barriers	DH-4	NHIS, CDC, National Center for Health Statistics (NCHS)
Additional Objectives		
* Increase the proportion of persons with hemoglobinopathies who receive care in a patient/family-centered medical home	BDBS-3	RuSH, NIH, CDC
* Increase the proportion of persons with hemoglobinopathies who receive disease-modifying therapies	BDBS-5	RuSH, NIH, CDC
* Reduce hospitalizations due to preventable complications of sickle cell disease among children 9 years and under	BDBS-7	Sickle Cell Disease Treatment Demonstration Program (SCDTDP), HRSA; RuSH, NIH, CDC

**Developmental objective, data sources listed are potential data sources*

The “medical home” was developed as a record keeping mechanism in pediatric primary care. The first known use of the term appeared in 1967 in Standards of Child Health Care, which defined a medical home as one central source of a child’s pediatric records and emphasized the importance of centralized medical records for CYSHCN²³.

Beyond just medical records, though, the concept launched an approach toward developing a coordinated system of care, especially for CYSHCN. The medical home has evolved into a standard for all children and is now a major quality indicator for CYSHCN.

HRSA/MCHB, families, state programs, and other stakeholders have been strong proponents of the medical home concept. It is important to address the needs of the whole child and family in relationship to health, education, family support, and the social environment. The concept shifts medicine from treatment toward prevention, wellness, and early intervention.

Continuity of care (from visit to visit and from infancy to adulthood) is a core element of the medical home. Children with a regular source of care tend to use preventive and well-child services appropriately and have improved health outcomes. They are also less likely to experience delayed or foregone care and are less likely to have unmet needs for healthcare and family support²⁴.

However, while lots of children have a regular source of healthcare¹⁵, for CYSHCN it may be hard to get other components of a medical home, such as referrals, care coordination, and family-centered care. Reimbursement for the expanded role of medical home providers also can be a problem because of insurance limitations. There are even disparities within the CYSHCN community: Children with disabilities affecting their functional ability – their ability to complete activities of daily living – are less likely to receive care in a medical home in comparison to children whose functional abilities were not affected by their condition. Children living in poverty or rural areas are also less likely to receive care in a medical home²⁴.

Despite many challenges, there have been considerable successes, with Healthy People as a starting point. For example, the blood disorders community has demonstrated how medical home principles can be successfully applied to a diverse group of individuals and families with similar conditions and outcomes. In September 2006, the National Heart, Lung, and Blood Institute (NHLBI) held a working group to develop Healthy People objectives for sickle cell disease. The working group, which was a partnership with MCHB/HRSA, CDC, and other organizations, led to new developmental objectives for blood disorders and blood safety (BDDBS), including some around medical home, a foundational component of comprehensive systems for the delivery of needed services across the life span for individuals with blood and clotting disorders. While MCHB's Division of Services for Children with Special Health Needs has long supported programs focused on the needs of individuals and families with sickle cell disease, hemophilia, and thalassemia, inclusion in HP2020 put hemoglobinopathies and hemophilia on the national public health agenda. This helped to pave the way for improved health status, quality of life, and life expectancy of people living with hemoglobinopathies²⁵. New programs work collaboratively with treatment centers, consumer organizations, and others to increase the use and effectiveness of the patient-centered medical home model to manage and treat blood disorders.

BDDBS is only one of many new topic areas in HP2020, demonstrating that quality improvement is not just about asking, "Are we there yet?" It is a process over time. The appropriate question is, "Where are we now?"

Did you know?²⁶

A medical home has 7 essential components:

- Accessible
- Continuous
- Comprehensive
- Family-centered
- Coordinated
- Compassionate
- Culturally effective



ANDREA'S STORY

AcMy daughter's name is Angeles Leon, and she was diagnosed with spinal muscular atrophy (SMA), Type I. And what that means is that her muscles are atrophying.

Angeles has a trach (tracheostomy tube), she's on a ventilator 24 hours a day, she's G-tube (Gastrostomy tube) fed, and she has scoliosis. So, she has a lot of medical complications. But cognitively children with SMA are typically unaffected.

Children like Angeles require a lot of therapies and see many specialists. So, having information on where to take her and what kind of services were available in our community has made a complete difference. I remember when Angeles was having issues bringing up her secretions it was one of the parents that I met through the Family-to-Family Health Information Center who shared with me information about the cough-assist machine. I then went to Angeles' doctor and told her I had met that family and wanted a cough assist also. The doctor asked me a series of questions and then said, "I think it's totally appropriate for your daughter. Let's look at getting it." And so, we were able to get the machine to help Angeles cough.

Children like Angeles are typically expected to live a year and a half. Angeles is now nine and she's doing great. I believe that Angeles would not be where she is and doing as well as she is today if we hadn't received the information that we did from the F2F HIC around resources that were available and I also believe that having a "Medical Home" for Angeles has been vital in her health care wellbeing. A Medical Home is not a building, house, or hospital. It is an approach to providing high quality, coordinated health care that emphasizes the partnership between doctors and families. Children and youth who have a medical home receive the care they need from a pediatrician, family physician, or healthcare professional who partners with their families. A medical home identifies and helps coordinate all medical and non-medical services needed to help children reach their full potential.

Barriers to Medical Home for Children and Youth with Special Healthcare Needs

Insufficient time, insufficient reimbursement, and lack of support services were the most frequent barriers to care for CHYSHCN cited in a recent survey²⁷ of primary care pediatricians. Insurance issues – reimbursement, billing, and coding – all rank highly in barriers to care and affect the comfort of providers in caring for this population.

A medical home is not a location; it is an approach to care centered on partnership between family and providers of all services.



Measure 3

FAMILIES OF CHILDREN WITH SPECIAL HEALTHCARE NEEDS HAVE ADEQUATE HEALTH INSURANCE AND FINANCING TO PAY FOR NEEDED SERVICES

OBJECTIVE	HP2020	DATA SOURCE
Focus Objectives		
Increase the proportion of persons with health insurance	AHS-1	National Health Interview Survey (NHIS), Centers for Disease Control and Prevention (CDC), NCHS, (NSCS at CDC)
Increase the proportion of insured persons with coverage for clinical preventive services	AHS-2	Children’s Health Insurance Program (CHIP), CMS; Aging Integrated Database (AGID), AoA; CMS claims data and Medicare Current Beneficiary Survey (MCBS), CMS

**Developmental objective, data sources listed are potential data sources*

When you cannot finance your healthcare, it means that needed services are delayed or not delivered at all. This is an especially urgent problem for CYSHCN. Uninsured children are less likely to receive care in a medical home that addresses their comprehensive needs²⁸. And while most CYSHCN are insured, many are underinsured. Their coverage may be inadequate, leading to high out-of-pocket expenses.

For example, if a child is diagnosed with one of the inborn errors of metabolism that requires particular foods that are specially developed, the child must maintain a careful diet to avoid serious developmental complications or even death. However, it can cost \$1,000 per month more per individual to purchase the necessary medical foods. Public insurance such as Medicaid may or may not fund this diet, but many private insurance companies use loopholes to avoid covering the cost of medical foods²⁹. For many families, up to \$12,000 per year extra on specialized food is an insurmountable out-of-pocket expense.

HP2020 includes few objectives related to insurance in general, and no objectives related to insurance and CYSHCN. By design, HP2020 has a relatively clinical focus, emphasizing disease prevention. However, it is also important to include more objectives, like insurance, that facilitate access to care, and therefore better health. Simply having insurance does not make you healthy. But if you become unhealthy or have special healthcare needs, adequate insurance is critical to improving or maintaining your health.

CYSHCN receive care from many sources: physicians and nurse practitioners; speech, physical and occupational therapists; and other specialty providers. This can make reimbursement a continual challenge; it is hard to decipher referral requirements, coordinate the services from multiple providers, and interpret which services fall under what benefits. CYSHCN have particular difficulty with “out-of-network” specialty care, and because of time and reimbursement issues, pediatricians might limit the number of CYSHCN they see. Similarly, while insurance may cover medical costs, there are often high deductibles, copayments, and limitations for certain services such as mental health, medical equipment and supplies, and prescriptions. HP2020 lacks systems-oriented objectives that take this complexity into account.

Inadequate insurance coverage is not the only hurdle. A comprehensive system of care includes more than just medical services. Summer camp, respite care, after-school programs, and other recreational and educational services are all needed to provide the full spectrum of care and childhood experience. Health insurance cannot provide the full range of services CYSHCN rely on, so it is necessary to find other ways to pay for the activities and services that promote quality of life and create the social and physical environments that promote good health for all.



Did you know?¹⁵

According to the 2009-2010 National Survey of Children with Special Health Care Needs:

- 9.3% of CYSHCN were uninsured at least once during 2005-2006.
- 34.3% of currently insured CSHCN have inadequate coverage (i.e., insurance that did not cover the services they needed or the costs of those services).

Some states, including Maine, Michigan, New Mexico, and Utah, are developing strategies to fund new services for CYSHCN that are not typically covered by health insurance, such as care coordination, access to day care and camps, and catastrophic relief funds or trust funds that cover a wide range of non-reimbursable health-related expenses³⁰. For example, some states blend state Title V and Medicaid funding or Medicaid and private insurance funding to provide a safety net for CYSHCN³¹.

HRSA/MCHB's Division of Services for Children with Special Health Care Needs (DSCSHN) works with a broad range of partners to decrease disparities in access to care; disseminate innovative financing strategies at the

community, state, and national levels; and facilitate additional collaborations to enhance shared knowledge about coverage and financing issues³². With the passage of the Affordable Care Act, these programs also are monitoring the implementation of healthcare reform to ensure it meets the needs of CYSHCN. By expanding health insurance coverage and closing gaps in healthcare financing for CYSHCN, families will have access to the family-centered, comprehensive services that their children need.



Healthcare Reform and CYSHCN³³

The Affordable Care Act has exciting potential for families of CYSHCN: children will be able to remain on their parents' health insurance until age 26 and cannot be denied coverage because of pre-existing conditions. Both these changes will provide some financial relief to un- or under-insured families who struggle with healthcare costs.



DAWN'S STORY³⁴

The second anniversary of the Affordable Care Act (ACA) forced me to reflect on some personal and painful experiences that followed the births of my full term twin sons, 26 years ago. I never imagined that landmark legislation like the ACA would pass in my lifetime, after years of advocating for what I refer to as “Justice for Jason.”

Jason, the second born of our twins, suffered a severe brain injury due to lack of oxygen during birth. What should have been a routine, healthy birth resulted in complications that left him medically fragile, technology dependent, and in need of round-the-clock nursing care. Jason died when he was 19 months old from complications of the injury he had suffered at birth.

One would think that this most devastating experience would be more than any family should have to face. Unfortunately, our experience with our health insurance compounded our nightmare. At that time, my husband and I had what we thought was the best, most comprehensive health insurance plan available. We soon learned that having “good” health insurance didn’t guarantee that the policy would provide the medical services Jason needed and were “covered benefits” under our health plan. The plan tried to limit his access to services and supports that should have been covered. After we negotiated with the plan for several months to get these services covered, the insurer withdrew from the health benefits program, citing the high cost of care for Jason and others like him. This was considered legal, as the company dropped the whole group as opposed to only our family. Our family and thousands of others throughout Rhode Island and southeastern Massachusetts were forced to choose another plan. None of these alternative plans included the complex care services that our son needed, especially, and most importantly, his home nursing care.

The ACA has provisions that contribute to universal, continuous coverage of children with special needs. There are no longer pre-existing condition exclusions for children (which will go into effect for adults in 2014). Insurers can no longer rescind coverage when an individual suffers a catastrophic illness or injury. If this provision of the ACA had been in place when Jason was still alive, my husband and I wouldn’t still be haunted by wondering if he would have survived that dreadful night when he went into cardiac and respiratory arrest, if there had only been a nurse on duty in our home. No one law can fix all of the challenges of our current health care system. Nevertheless, my family and I are relieved to know that other children like Jason and other families like ours can no longer be treated differently due to health status. Disability does not discriminate – nor should WE!



Measure 4

CHILDREN RECEIVE EARLY AND CONTINUOUS SCREENING FOR SPECIAL HEALTHCARE NEEDS

OBJECTIVE	HP2020	DATA SOURCE
Focus Objectives		
Reduce the proportion of children diagnosed with a metabolic disorder through newborn blood spot screening who experience developmental delay requiring special education services	MICH-26	Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), CDC, NCBDDD (NBSTRN)
Increase the proportion of screen-positive children who receive follow-up testing within the recommended time period	MICH-32.2	Title V Information System, HRSA, MCHB
* Increase the proportion of children with a diagnosed condition identified through newborn screening who have an annual assessment of services needed and received	MICH-32.3	National Newborn Screening and Genetics Resource Center, HRSA, MCHB
Increase appropriate newborn blood-spot screening and follow-up testing	MICH-32	National Newborn Screening and Genetics Resource Center, Title V Performance Measures, HRSA, MCHB, CDC
Increase the number of States and the District of Columbia that verify through linkage with vital records that all newborns are screened shortly after birth for conditions mandated by their State-sponsored screening program	MICH-32.1	National Newborn Screening and Genetics Resource Center, HRSA, MCHB
Increase the proportion of newborns who are screened for hearing loss by no later than age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months	ENT-VSL-1	State-based Early Hearing Detection and Intervention (EHDI) Program Network, CDC, and/or specific State data (DGIS, TVIS)
Increase the percentage of young children with an Autism Spectrum Disorder (ASD) and other developmental delays who are screened, evaluated, and enrolled in early intervention services in a timely manner	MICH-29	NS – CSHN, HRSA; Autism and Developmental Disabilities Monitoring (ADDM), CDC, NCBDDD
Increase the proportion of preschool children aged 5 years and under who receive vision screening	V-1	National Health Interview Survey (NHIS), NCHS, CDC

Additional Objectives		
*Increase the proportion of children who are ready for school in all five domains of healthy development: physical development, social-emotional development, approaches to learning, language, and cognitive development	EMC-1	PDS: National Survey of Children's Health (NSCH), HRSA, MCHS; CDC, NCHS; National Household Education Surveys (NHES), ED
* Increase the proportion of children with sickle cell disease who receive penicillin prophylaxis from 4 months to 5 years of age	BDBS-6	RuSH, NIH, CDC, (SCDTDP)
* Increase the proportion of persons with a diagnosis of hemoglobinopathies and their families who are referred for evaluation and treatment	BDBS-2	RuSH), NIH, CDC, (SCDTDP)
* Increase the proportion of persons with a diagnosis of hemoglobinopathies who receive early and continuous screening for complications	BDBS-4	RuSH, NIH, CDC, (SCDTDP)
* Increase the proportion of hemoglobinopathy carriers who know their own carrier status	BDBS-10	RuSH, NIH, CDC (SCDTDP, NNSIS)

**Developmental objective, data sources listed are potential data sources*

HP2020 objectives focus heavily on screening, including 16 objectives related to CYSHCN and developmental objectives related to specific conditions that were not included in HP2010. These developmental objectives are not clinical practice guidelines, validated indicators, or mandates. Instead, they are consensus indicators of where the field should be in 10 years.

Though it is promising that there are many screening-related objectives overall, there are few screening objectives for adolescents and young adults, and objectives related to childhood are separated from those related to adulthood. Of concern is the apparent lack of emphasis on continuous screening. Screening, and appropriate follow-up intervention, should be a regular part of health services for young people of all ages, and throughout the lifespan.

Our systems are set up to focus on short-term issues and sector-specific savings, rather than taking a long-term preventative approach, which could lead to lifelong benefits and savings. For example, if a patient comes in with an acute issue, doctors cannot put treatment on hold during the standard 15-minute visit to discuss lifestyle change and prevention. As was mentioned with regard to the lack of insurance objectives, it is important for the health of our nation that future Healthy People documents take a broader approach by including objectives related to follow-up services, continuity of care, and other systems and processes that have an indirect, but still significant, impact on health and wellness.

A child's first screenings may actually occur in the prenatal period, and as children grow, ongoing surveillance is necessary to promote healthy development and identify emerging issues. Collaboration and evaluation are needed to realize any of the objectives listed above, with a lot of the energy and initiative coming at the state level. States are working to address the comprehensive and continuous screening needs of children, starting from birth. State newborn screening programs continue to grow, but we still need better systems for adding conditions to existing screening panels and expanding screening throughout the lifespan.

Because screening should be evidence-based, data tracking systems are being developed to monitor screening results. For example, state chapters of the American Academy of Pediatrics are working to develop surveillance and screening approaches that align with Bright Futures Guidelines for Children and Adolescents, focusing on disease prevention, health promotion, effective communication, partnership, and family education and empowerment.



CYSHCN require screening and care based on their special needs. Referral and communication linkages should be in place between doctors, early intervention programs, and school districts to make sure that problems are identified early so that treatment can begin, if available. At the same time, CYSHCN are just children. They require the same care and services their peers need: age-appropriate well-child checks (for metabolism, vision, hearing, development,

behavior, and mental health), immunization, health supervision, nutrition and physical activity education, gun safety instruction, school adjustment, etc. Time and attention must be paid to identifying and reinforcing their strengths and promoting healthy emotional development.

Overall, the expansion of screening objectives in HP2020 underscores that screening is as important as treatment and care. In fact, early detection and intervention have significant academic, social, and economic benefits³⁵.

Some people describe the current state of early identification as “screen it and leave it,” meaning there is little follow-up if an issue is detected. This is not an acceptable philosophy. There are critical windows where children, youth, and adults need to get screened, with appropriate follow-up, ideally within the medical home. Appropriate follow-up after screening is essential, though it also is important to assess and address the costs and feasibility of follow-up when instituting any new screening system.

What screening should be done at birth?

Newborn screening and hearing screening ensure that all babies are screened for certain serious conditions at birth, and for those babies with identified conditions, it often allows doctors to start treatment before harmful effects occur. According to BabysFirstTest.org, screening tests are currently available for more than 60 conditions³⁶.

DINA'S STORY



It was a long three and a half years to finally get a diagnosis for Alayna's chronic, painful tummy aches. There did not seem to be any rhyme or reason for when they would strike. We did food journals, tried various diets, including gluten-free, and she was given numerous medications that never seemed to help. She had dozens of blood and allergy tests. We even tried some alternative medicines, but those also did not seem to lessen her pain. Eventually, a doctor at Denver's Children Hospital said, "I only have one more test to try. If this does not work then there is nothing else I can do." Those are the last words a mother ever wants to hear when your child is in pain. But our final test was a breath test to see if she had intolerance to fructose. We did not even need to finish the three-hour test, because within the first hour it was definitely positive. We finally had our answer, and along with it came "mom's guilt." How did I not realize that the very things I thought were safe to give her, like apples, watermelon, and fruit juice, were the very things giving her so much pain? The first time I went grocery shopping after her diagnosis I spent three hours in the store and only went home with six items. It will be a continual learning process with only a limited number of resources available and lots of label reading to see if products are safe for her to eat. I would love to take her to a dietician that specializes in fructose intolerance, but our insurance does not pay for dieticians, and I also have not been able to find anyone locally who really has any knowledge of this condition. So, I am becoming the expert for the school and her primary doctor. We continually need to supply her own snacks at events such as softball and Girl Scouts when they have snack time.

What screening does your young child need?

- **Hearing Screening** for hearing loss at birth or by 1 month of age; audiologic evaluation by 3 month of age; enrollment in appropriate intervention services by 6 months of age
- **Developmental Screening** for age-appropriate skills at 9, 18, and 24 or 30 months to identify developmental or behavioral difficulties
- **Language Screening** for young children with phonological disorders, language delay, or developmental language problems
- **Vision Screening** for preschool children under the age of 5

The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program & Title V Collaboration to Improve Child Health

EPSDT is the child-health component of Medicaid³⁷. The program is designed to improve the health of low-income children, by financing appropriate and necessary pediatric services to meet their physical, emotional, and developmental needs. State Title V agencies can play an important role in fulfilling the potential of EPSDT by assuring better access to and receipt of the full range of screening, diagnostic, and treatment services. Collaboration can improve both access to and efficiency of services.



Measure 5

COMMUNITY-BASED SERVICES ARE ORGANIZED FOR EASY USE BY FAMILIES

OBJECTIVE	HP2020	DATA SOURCE
Focus Objectives		
Increase the proportion of children with disabilities, birth through age 2 years, who receive early intervention services in home or community-based settings	DH-20	Individuals with Disabilities Education Act (IDEA) database, DoED, Office of Special Education Programs (NSCH, DGIs)
*Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree they wish	DH-13	National Health Interview Survey Supplement, CDC, NCHS
* Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness program	DH-8	National Health Interview Survey (NHIS) Supplement, CDC, NCHS
* Reduce the proportion of people with disabilities who encounter barriers to participating in home, school, work, or community activities	DH-9	National Health Interview Survey (NHIS) Supplement, CDC, NCHS
* Reduce the proportion of people with disabilities who report barriers to obtaining the assistive devices, service animals, technology services, and accessible technologies that they need	DH-10	National Health Interview Survey Supplement, CDC, NCHS
Additional Objectives		
Reduce the number of children and youth with disabilities (aged 21 years and under) living in congregate care residences	DH-12.2	Survey of State Developmental Disabilities Directors, University of Minnesota
Increase the number of Tribes, States and District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers	DH-2	TVIS (Block Grant)
* Increase the proportion of community-based organizations (CBOs) that provide outreach and awareness campaigns for hemoglobinopathies	BDBS-9	Hemoglobinopathies (RuSH), NIH, CDC
* Increase the proportion of young children with phonological disorders, language delay, or other developmental language problems who have participated in speech-language or other intervention services	ENT-VSL-21	NHIS, CDC, NCHS

**Developmental objective, data sources listed are potential data sources*

To be of value, services need to be organized so that families know where to find them and can easily use them. This sounds intuitive, but complexities abound in our current disconnected system. Services are fragmented, with their own funding streams, procedures, and locations, leading to duplication or gaps of services and overall confusion. Professionals and families constantly learn how to “work with the system,” but in this environment, many CYSHCN and their families can fall through the cracks.

At its core, the issue is one of availability versus access. Just because a service exists – is available – does not mean that it is accessible – easy to use. There are many scenarios:

- Local services exist, but CYSHCN and their families do not hear about their availability or are unable to make it during business hours.
- Specialized services are not available in some communities, so families travel great distances to access them.
- Eligibility cut-offs are not clear, so families find out they are entitled to something after they are no longer eligible.
- The system of services is not streamlined, so multiple forms and appointments are needed to apply for programs and navigate the system.
- Services are not provided in a culturally competent, language appropriate manner, so non-native English speakers, racial/ethnic minorities, or others feel intimidated or offended, or cannot understand their options.

Coordination of multiple funding streams (health, education, business, and multiple private organizations) is critical because there are so many needed services: primary, secondary, and tertiary prevention of disabilities; transportation; housing; access to quality healthcare and insurance, especially for the working poor; personal care assistants and job supports; assistive technology that is affordable and portable³⁸; and more. For example, in addition to housing, transportation, and school and work support, CYSHCN and families have social and recreational needs, as well. Involvement with Scouts, 4-H, Special Olympics, local parks and recreation programs, and other independence and social skill building organizations can broaden their horizons beyond medical settings.



One strategy for making the service system easy to use is the community liaison/cultural broker model, where trusted members of a community provide linkages between individuals, families, and organizations and the healthcare system. Community liaisons and cultural brokers are able to expand the ability of community organizations to engage the community, involve families, deliver services, and meet the varied needs of families of diverse populations³⁹.

While the community liaison model addresses one important element of accessible services, it does not address office hours, location of service providers, marketing of services, availability of specialists, those specialists' knowledge of various diseases, or the efficiency of service delivery. Successful completion of MCHB's core performance measure 5 will be dependent on the leadership and work of state Title V programs and all community partners that support building services at the community level. No single agency has the expertise or funding to cover all needed services. Interagency workgroups are needed with representation from physician and other healthcare provider groups; the education field (child care through college); and programs focused on workforce development, business, healthcare funding, transportation, personal support, and issues related to poverty.

The shared goal for all service providers should be, "What you need, when you need it."

**Coordinated, barrier-free design is essential
for easy-to-use community services, and
this cannot be accomplished without
cooperation among multiple stakeholders.**



SALVADOR'S STORY⁴⁰

My three children were born with special needs. Ronald, my first born, who is six years old, is the one who has continued to require a lot of assistance for his development. Even now, we still have not received a complete diagnosis of his medical condition. The closest information that we have received is that he has Hajdu-Cheney Syndrome, a genetic condition that affects the growth and development of his bones as well as other aspects of his life.

As immigrants to this country it has not been easy to address the challenge of my son's special needs. Here the professionals seem used to treating every case or family situation the same way, and give news that can be very upsetting to a family, as if it were nothing of importance. They also seem to expect that children will obtain milestones and independence quickly.

Fortunately, we were able to overcome these barriers, and accepting our children's conditions has allowed us to participate in a support group for parents of children with special needs. We have also been able to obtain federal and state benefits for our children. Being able to navigate the system, respond to emergency situations or simply answering questions like: "Why is your child like that?" or "Papi, why don't I have fingernails?" have been the links in the chain of strength, knowledge and courage to fight for our children.

I have learned to advocate for my children. The birth of a child with special needs can make parents feel that the world is caving in, but the support of other families helps you to learn that you are able to face adversities. This has enabled me to support my other two children, three-year-old Frank and two-year-old Karina, both of whom have language delays.

With all of the experience that we have gained, we have been able to identify sources of evaluation and support to assist our children in their development. My son Frank has already obtained age-appropriate language skills, and my daughter is receiving speech therapy. In order to move forward, we have experienced sad, painful, anguished, fearful moments. As a result, you realize that you cannot do everything on your own.

My wife had to quit her job, and I had to miss work many times to take my son to the doctors or to the hospital for emergencies. Thank God, I have been able to keep my job. I have learned that help is available, but you have to look for it. Some of the services and supports that I have received include the following:

- Moral support- through a support group
- Economic support through SSI
- Educational support through programs such as early intervention, Head Start, etc.
- Technical assistance through supports such as medical, rehabilitative, therapeutic and psychological services
- Health services through health insurance
- Housing through housing programs, and
- Training through programs for parents.

All of these services and information helped us to not only find support and help at very difficult times, but also opened new roads so that we could continue to grow and be strengthened to face our challenge.



Measure 6

YOUTH WITH SPECIAL HEALTHCARE NEEDS RECEIVE THE SERVICES NECESSARY TO TRANSITION TO ADULT HEALTHCARE, WORK, AND INDEPENDENCE

OBJECTIVE	HP2020	DATA SOURCE
Focus Objectives		
Increase the proportion of youth with special healthcare needs whose healthcare provider has discussed transition planning from pediatric to adult healthcare	DH-5	NS-CSHCN
* Increase the proportion of adolescents and young adults who transition to self sufficiency from foster care	AH-4	National Youth in Transition Database (NYTD), ACF, ACYF
Additional Objectives		
* Increase the proportion of persons with a diagnosis of hemoglobinopathies who complete high school education or a General Education or Equivalency Diploma (GED) by 25 years of age	BDDBS-8	RuSH, NIH, CDC

**Developmental objective, data sources listed are potential data sources*

In the past, many youth and young adults diagnosed with special healthcare needs did not get to participate in all of the normal childhood activities – going to school, playing team sports, community activities. Instead, a typical day might include lengthy medical treatments, special nutritional support in-home and out, and assistance with other daily needs. If something happened requiring medical attention, it would take time from school and social interactions with friends. When few children with life-threatening diagnoses lived to be 18, talking about the future seemed unrealistic⁴¹. Today, much has changed.

With advances in medical care over the last 30 years, it is now expected that more than 90% of children who have a chronic medical condition or disability will reach adulthood⁴². However, they are less likely than their non-disabled peers to finish high school, pursue post-secondary education, get jobs, or live independently. There are few coordinated services available to them to assist in transition from school to work, home to independent living, and pediatric to adult care. Therefore, they are forced to remain dependent on their families and pediatric services, stressing both systems of caregivers.

Initiatives approach transition from two angles: working with service providers and working with the transitioning youth and families. There are trainings, guidelines, and other resources for providers who coordinate transition services. Similarly, training materials

Transition to Adult Healthcare

Transition to adulthood is the ultimate outcome of all the Core National Performance Measures. In order for CYSHCN to meet core performance measure 6, their healthcare providers must:

1. Discuss transitioning to adult care if needed,
2. Discuss changing healthcare needs as child becomes an adult if needed,
3. Discuss transitioning insurance to maintain eligibility if needed, and
4. Encourage responsibility for self-care (such as taking medication, understanding his/her diagnosis or following medical advice). [NS-CSHCN, 2009-10]

Unfortunately, fewer than half of pediatricians are providing transition support services such as discussing insurance options, making transition plans, or offering educational materials, and few initiate transition planning early⁴³.

and workshops are available to prepare youth to make the transition to adulthood in the healthcare setting as well as in all other aspects of life. These resources make kids self-advocates; the programs aim to increase youth's understanding and ability to communicate with providers and understand the systems and services they receive and need. One example is the establishment of youth advisory boards, which give a unique perspective to program planning and build confidence and competence in the participating youth. When program planning involves youth, they are seen as more than simply patients and their voices and opinions are valued. These children and young adults educate each other as well as the myriad professionals—from healthcare, work, education, and other social services—who make important decisions about transitioning and other issues relevant to children and adults with special healthcare needs.

Still, only 40% of CYSHCN make successful transitions⁴⁴. A problem faced by many youth is the lack of provider capacity to serve their needs when they reach puberty. Youth and young adults are left with three scenarios. Many consider their specialist their primary care physician. So, first, they can continue being seen in the pediatric setting where they are well known and confident their care will be managed. However, this option often compromises the receipt of developmentally appropriate care. Beyond standard

Six Core Elements of Healthcare Transition⁴⁵

Healthcare professionals caring for both youth and adults have endorsed a set of highly specific guidelines to guide the transition process. The overarching elements are as follows:

1. Transition policy/Young adult privacy and consent policy
2. Transitioning youth registry/Young adult patient registry
3. Transition preparation
4. Transition planning
5. Transition and transfer of care
6. Transition completion

pediatric developmental milestones, age-appropriate and related services cannot always be met in the pediatric setting. Issues such as reproductive care and complications due to aging with a disability have not been seen routinely in pediatric offices.

An individual's health status affects his or her productivity, quality of life, and capacity to participate fully in everyday activities, so it is particularly important for people with special healthcare needs to receive age- and developmentally-appropriate care. Therefore, option two is for YSHCN to transfer to a welcoming adult care physician who has some level of expertise in coordinating services and care for complex health issues. In this case, "welcoming" is the operative word. Traditional adult care physicians have not "experienced" a population of emerging adults with long-term, complex, special healthcare needs. Most do not have training and lack confidence to serve these individuals, and may be reluctant to do so.

Finally, youth/young adults can guide their own care and hope for the best. This option may result in youth receiving sporadic and episodic care that is fragmented and uncoordinated. When services for CYSHCN are not coordinated or streamlined to begin with, it is an added challenge to prepare youth and families with the knowledge necessary for successful navigation of the adult system. For example, health skills development is a vast and crucial part of transition, including sexuality, safety, substance abuse, and risk taking as well as record keeping and planning for legal responsibilities at age 18.

Fortunately, states are increasingly including youth and families in the planning, development, and implementation of transition projects so that the experts on living with special healthcare needs – those who do it every day – can provide input into the policies that directly impact them.

Not about Us without Us⁴³

Disparities in healthcare are pervasive and based on many factors. Only 40% of CYSHCN aged 12-17 in the US receive the services necessary to make transitions to adult healthcare, work, and independence. This proportion is even lower among youth who are Hispanic or Black, with family incomes below 200% of poverty, and who are uninsured or publicly insured. In addition, males are less likely than females to transition successfully, and those without a medical home are at a significant disadvantage.

To combat the disparities, underserved and underrepresented individuals and groups must be engaged, from individual-level healthcare decision making to population-level research. As young adults with special healthcare needs transition to adulthood, their opinions and desires must be carefully considered.

BETSY'S STORY



The objectives for Performance Measure 6 sound so rational, so organized. Life is a lot messier.

Michael was born with spina bifida and is paralyzed just into the thoracic level. He spent much time in clinics, hospitals, and receiving care at home. There weren't really any guidelines, let alone prescriptions, for how to plan for transition. Consequently, many of us just made it up, taking bits and pieces from our own lives, and adding what we thought would be important. For example, it seemed a good idea for him to know how to cook, so one night a week in high school he planned and prepared a meal. That was a great success and we loved eating what he'd enthusiastically made.

We purposefully lived right near the Children's Hospital, so he could wheel there himself and go to appointments. Probably the staff didn't imagine that kids would move or live elsewhere so it was just assumed he'd continue care there. They continued to see teens as they grew to adulthood – his was the first generation that had actually survived. We didn't know adult care and neither did Michael's pediatric physicians. It was new for us and for Michael.

After high school Michael moved to California to attend junior college. We hooked him up with the SB clinic at UCLA. That had good points. However, the first time he went to self-admit to the hospital he was told he couldn't because he was too young: they said he had to be 21! On the phone to me in Boston came the realization that it was probably not possible to prepare for all (the absurd) things that would happen. (I told him to go back to the desk and tell them they were wrong. It worked.) After that Michael moved to various parts of the country, perhaps 6-8 times. Each time we'd try to link in the closest pediatric SB clinic, figuring they'd know where someone his age would go. His care became quite fragmented, mainly because he was less interested in care and didn't think he needed much. He preferred to seek help when he needed it, not proactively. Transportation, too, was often difficult. Further, none of the jobs he's ever had offered health insurance – though with Medicaid this wasn't the difficulty – and they did not allow paid time off from work for healthcare appointments. (If you're a low wage earner, this looms large.)

After years of a somewhat nomadic life, another big change occurred – Michael got married! He moved to the rural area where his wife's family was from, and has been there ever since. The area itself presents a number of challenges, familiar to many: few services, no nearby tertiary care services, caregivers unfamiliar with his condition, working with out-of-state specialists and sometimes hospitals – and getting used to using the emergency room on a regular basis. While Michael is, of course, in charge of his own life, having a caring spouse right there is a phenomenal asset. For us, his parents, when there are emergencies or problems it means having someone in addition to Michael to share information and insights with – someone who helps provide care and transportation as needed, as well as love and support.

Aging with disability - What's normal? What's new or becoming known for his health condition? What's just typical aging? There are relatively few adults with his condition older than he. . . little is known by adult caregivers and systems. Michael has transitioned to a life that is “pretty normal” by most standards – and we want him to keep living it!



Chapter 3

Who is at risk?

The healthcare needs of children exist on a dynamic continuum, from children who are healthy, with no chronic conditions or special healthcare needs to children with chronic conditions who do not have an increased need for services to children with chronic conditions and special healthcare needs. The same genetic, social, and environmental risk factors affect children in all along the continuum⁴⁶, and children may move from one place on the continuum to another in the course of childhood and life. The complex interactions of these risk factors, along with different patterns of exposure and our bodies' unique responses, impact the health of individuals as well as populations^{47,48}. A child's risk cannot be understood without knowing about the risks of his or her family and community.

In the context of CYSHCN, however, "at risk" is not clearly defined. "Children and youth with special healthcare needs are those who have or are at 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."¹³ It is a broad definition, including a large population with diverse diagnoses and needs. The definition does not address specific health conditions or an individual's functional ability; rather, it is focused on an increased need for services, which are often obtained in multiple settings from a variety of professionals and service agencies. Although the definition of CYSHCN recognizes the diversity of CYSHCN, it maintains a degree of ambiguity. An action step for the CYSHCN community is to formally define "at risk" so the needs of at-risk children and families can be better understood and addressed.



RISK FACTORS

While Healthy People 2020 does not provide an explicit definition for who is “at risk,” it does call attention to many risk factors. HP2020 includes objectives related to risk factors for CYSHCN to develop secondary conditions – conditions that a child is not born with, but might get as a result of having a special healthcare need. For example, objective MICH-27 is to reduce the proportion of children with cerebral palsy born as low-birth-weight infants (< 2,500 grams). This is important because with appropriate information, developmental guidance, and monitoring, families can be made aware of and even prevent secondary conditions in their children. All CYSHCN are at increased risk for some secondary conditions. But many other factors—genetic predispositions (family health history), exposure to various environmental or social risk factors, behaviors, and other circumstances related to the individual, family, and community—will impact some CYSHCN to the extent that they will require specific interventions for secondary conditions.

HP2020 also includes objectives focused on risk factors that otherwise healthy children have for developing chronic conditions later in life. For example, an abusive family situation can lead to traumatic brain injury (reduce fatal and non-fatal traumatic brain injury, IVP-2), and obesity can lead to chronic health problems such as heart disease and diabetes (reduce the



proportion of children and adolescents who are considered obese, NWF-10). Determinants of health are the medical and nonmedical factors that influence the health of individuals, families, and communities⁴⁹⁻⁵². Nonmedical determinants of health were not really recognized in the development of new health policies until the mid-1970s, but they are now known to be important⁴⁶. Social determinants of health—which include individual behavior, physical and social environments, and health services—play a large role in developing certain conditions. Outcomes of these social

risk factors include a higher likelihood of not graduating, being unemployed, and having challenges accessing healthcare services. If not addressed at an early stage, these risk factors can lead to complex, chronic conditions later in life.

To complicate their healthcare concerns, children and youth with special healthcare needs are more prone to missed days of school⁵³, having unmet healthcare needs⁵⁴, and mental and behavioral health issues^{13,55}. The latter in particular is a problem because of stigma around mental health. Often families or young people are reluctant to seek or accept mental healthcare, and funding and waiting-list issues loom large. Emotional or behavioral difficulties should be caught early to prevent their becoming secondary disabilities.

There are two points at which preventive measures can be taken: 1) before the onset of a chronic condition for children who are otherwise healthy, and 2) after a chronic condition has been identified but before it rises to the level of creating special healthcare needs⁴⁶. Unfortunately, in many cases, families have children (both with special healthcare needs and without) with several risk factors, but they do not receive any intervention or information until the child has crossed the line from at-risk to fully affected. To help families avoid excess stress and financial burden, healthcare and other service providers need to go beyond early detection to prevention by recognizing and addressing risk factors at an early stage. Many federal, state, and community programs are beginning to address social determinants of health to create social and physical environments that promote good health for the general population as well as at-risk individuals, families, and communities and CYSHCN.



We do not know all the risk factors for special health needs. We do know that it is as important to address risk factors to keep a child healthy and prevent secondary conditions as it is to treat many of the avoidable adverse consequences of having a special health care need. This is the reason for including “at risk” in the definition of CYSHCN, and why we must focus on promoting health and wellness throughout the life course.



PROGRAMS

MCHB supports many programs that provide interventions at different points along the at-risk spectrum, including the following:

Healthy Tomorrows Partnership for Children is a cooperative program between the American Academy of Pediatrics and MCHB to stimulate the development of community-based initiatives where identified child health needs are not being met. Healthy Tomorrows projects are new and innovative initiatives in a low-income community that they address four key areas: access to healthcare services, community-based healthcare, preventive healthcare, and service coordination.

Healthy Start works reduce infant mortality and improve perinatal outcomes, especially in communities of color. The program addresses significant disparities in the health of mothers and babies in at-risk communities that face many challenges including inadequate access to care and limited funding.

Traumatic Brain Injury Program helps state and local agencies develop resources so that all individuals and families of TBI will have accessible and appropriate services and support so that they can understand their diagnosis and develop a treatment plan. Many individuals with TBI are often faced with challenges, such as improper diagnosis, inability to access support or rehabilitation services, and lack of appropriate community-based services.

LEND (Leadership Education for Neurodevelopmental and Related Disabilities) is a leadership training program that trains health professionals in neurodevelopmental and related disorders to improve the health of children and youth who have or are at risk for neurodevelopmental or intellectual disabilities. The program trains a wide variety of health professionals so there are LEND leaders in different fields of healthcare. Over the past decade there has been an emerging role in LEND programs for a family faculty member to provide interdisciplinary teams with an invaluable perspective in the scope of their training: the perspective of the family. This role is unique in that the experience of being a family member or parent of an individual with a developmental disability cannot be learned in any university course and is known as the “family discipline.”

Collaborate for Healthy Weight is a project of HRSA and the National Initiative for Children’s Healthcare Quality (NICHQ). Obesity is one of the leading preventable causes of death nationwide, and it disproportionately affects disadvantaged and underserved communities. Obesity also leads to many secondary complications, such as mental health issues and diabetes. In order to address both the health disparities in the obesity epidemic as well as the nationwide problem as a whole, this program was created as a multi-faceted, community-based project with innovative partnerships between public health, primary care and community-based organizations.

Chapter 4

Preparing Individuals and Families for the Future



How can HP2020 influence health as individuals age and have to access different systems?

It is not enough to have two consecutive systems of care – pediatric and adult – even if both systems are good. Overlap is necessary to ensure connectivity and continuity. Disease does not simply appear or disappear when youth reach the age of 18. For individuals, families, and communities, particularly those with special healthcare needs, there should be a continuum of care, including screening, from infancy through the elderly period.

One approach that takes into account the social, economic, and environmental contributors to health across the lifespan is the Life Course Health Development model. Life Course Theory looks at health as a developmental process⁵⁶ and focuses on four key concepts⁵⁷:

1. **Timeline:** Today's experiences and exposures influence tomorrow's health. This is true for individuals as well as across generations. Our health risk factors accumulate across our lifespan and can impact our children and grandchildren.
2. **Timing:** Our future health is particularly affected during sensitive periods in our lives, especially during childhood. At these early developmental stages, health promotion interventions can have the greatest benefit.
3. **Environment:** Our community environment affects our capacity to be healthy. Environment is more than the physical spaces where we live, learn, work, and play. Safe housing, nutritious foods, and clean air are parts of the equation, but environment also includes social and economic factors, such as poverty, racism, job opportunities, violence, and culture.
4. **Equity:** One's genetic make-up offers both protective elements and risk factors for disease, and we often make lifestyle choices that do not guide us down the path to ideal health. However, external factors, such as those mentioned above, contribute greatly to health disparities.

Life Course Theory is a comprehensive, continuous approach to health that takes into account all our strengths and limitations. A lifelong focus on prevention is good for everyone: it will lead to healthier individuals, families, and communities as well as a healthier healthcare system.

MCHB’s core performance measures set the stage for a well-functioning system, one that screens during the prenatal period and continues screening throughout the lifespan; one that responds with appropriate follow-up care and provides necessary interventions; one where all the needs – health, social, recreational, spiritual, financial – of a growing individual and family are met. A well-functioning system allows children and families to thrive. When all measures are achieved, it can be assumed that CYSHCN and their families are part of a comprehensive, collaborative system of health and care. We are not there yet.

In this era of “outcome-based” programs, one may ask: What are the outcomes of all these federal programs for healthcare, education, and rehabilitation? How do we monitor and measure the progress of these activities and the successful transition of youth with special healthcare needs? And what do we know about outcomes, or even processes for federal programs, for adults with special healthcare needs?

As has already been stated in this document, a few decades ago these questions were not relevant. When few children with life-threatening diagnoses lived to be 18, talking about the future seemed unrealistic. Today, we must ask, is the future of children who happen to have special healthcare needs enhanced by the current system of federal, state, and community supports? HP2020 gives us a starting place to answer these questions. For Healthy People 2030 and beyond, consideration needs to be given to objectives that ensure that the system of services is constructed and functions to support children and families at every developmental stage of life. One service on its own is not enough. We need comprehensive, collaborative systems to create a woven fabric of services.



For now, though, we cannot afford to downplay the difficulties of growing up and living with diverse healthcare needs. Burdensome health and access disparities remain; navigating the complexities of specialized care is no easy task; and while many youth with special healthcare needs transition into productive, self-sufficient adults, they often need extra family support.

Our healthcare system is ever-changing, with uncertainties arising and new rules impacting us on a regular basis. Therefore, it is important that we have Life Course Theory to give us something to strive for, both for our individual health and for a health system transformation.

Organizations such as Family Voices, Genetic Alliance, and other organizations and family support networks can help educate and connect people with services through adulthood, encouraging a focus on quality of life rather than on disease. With early health promotion and prevention, we can shift our focus from health itself to what we can do with better health.

With early health promotion and prevention, we can shift our focus from health itself to what we can DO with better health.



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- Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs
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