Celebrate 2010
A decade of progress for children and youth with special health care needs
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October 2010
Welcome to Celebrate 2010, a commemorative reflection on a decade of progress in achieving a family-centered system of services for children and youth with special health care needs and their families.

This book celebrates the experiences of families, professionals, organizations, and entire communities who have worked hard for more than a decade to achieve key elements of a responsive system of care characterized by: (1) family-professional partnership at all levels; (2) access to comprehensive, coordinated care through the medical home; (3) early and continuous screening and intervention; (4) access to adequate insurance and financing for needed services; (5) organization of community services for easy use by families; and (6) transition to adult health care, work, and independence. There is a section for each of these systems constructs, but it is important to remember that they are interdependent and, only when achieved together, create a system of services that assures children and youth receive the care they need for optimal health and well-being.

How appropriate that we’re celebrating our progress in the same year that marks the 75th Anniversary of the Social Security Act and the 20th Anniversary of the Americans with Disabilities Act. We’re also celebrating in a year that witnessed the passage of the Patient Protection and Affordable Care Act, which promises a number of improvements for our nation’s children and youth by assuring access to preventive health care, eliminating lifetime insurance caps and exclusions for pre-existing conditions, and allowing youth to remain on their parents’ insurance plans until age 26.

As we look forward towards 2020, we realize that the system goals we identified more than a decade ago for children and youth with special health care needs are the same needed for adults living with chronic health conditions and disability. The vision that has led us to this point applies equally well across the lifespan to all children, youth, and adults. Who of us doesn’t want health care that emphasizes patient/family centered care? Who of us, whether or not we have
special health care needs, doesn’t want a medical home that emphasizes prevention and well-being and helps us access and coordinate the services needed to maximize healthy living? Who of us doesn’t want to be sure that a mechanism exists to finance needed health care?

You will find that each and every contribution included in this book tells a unique and compelling story. Yet they represent only a glimpse into the many, many experiences that could be shared if space allowed. Our hope is that this commemorative book will mark a point in time and help us to reflect, from the perspective of those who have lived it, on where we’ve been, how far we’ve come, and where we will go together as we envision 2020. If we are anywhere near as successful in the next decade as we’ve been from 2000 to 2010, we will indeed reach the goal of ensuring that all individuals with special health care needs have access to care and services they need and deserve. We at the Maternal and Child Health Bureau feel extremely fortunate to be a part of this remarkable journey.

BONNIE STRICKLAND
Director, Division of Services for Children with Special Health Needs
Health Resources and Services Administration
Maternal and Child Health Bureau
Family-Partnership
Ten years ago when the Maternal and Child Health Bureau (MCHB) laid out its agenda to achieve a community-based system of services for all children and youth with special needs, much had already been done to promote partnerships between families who have children with special needs and the professionals who provide services and supports. During the past ten years, we have seen these partnerships bring extraordinary changes in health care systems for children. (cont.)
The concept of family-centered care, now widely used, originated with MCHB. Throughout the 1980s, MCHB supported many initiatives to develop partnerships between families, health providers, and other professionals to improve service systems for children. MCHB identified and gathered together family leaders and asked them for advice and direction.

The outcome of these initiatives was the development and dissemination of a model for family-professional partnership and the incorporation of this concept in all Title V programs and services. State Title V programs were encouraged to hire family leaders as staff and to seek family feedback on their programs. MCHB included families as partners in the evaluation of its own programs by training parents to become grant reviewers. Through its Special Projects of Regional and National Significance (SPRANS) program, MCHB provided funding to projects that encouraged the incorporation of family and professional partnerships. The Bureau required State Title V programs and these special projects to report on their progress in developing such partnerships. Finally, in 1989 the Omnibus Budget Reconciliation Act included legislative language that promoted the concepts of family-professional partnerships.

1992 saw the founding of Family Voices, a national network of families speaking at all levels of decision-making on behalf of children and youth with special health care needs. As the Family Voices network grew and strengthened, families of children with special needs and/or disabilities united, organized statewide and nationally, and brought diverse groups together. Family Voices provided an avenue for developing more effective partnerships with policymakers, MCHB, professional associations such as the American Academy of Pediatrics (AAP), and health insurance companies.

As we entered the 21st century, these strong family-professional partnerships shaped how professionals and families interacted and led to major changes in the way in which pediatric care was provided and community services were organized. The shift from treating the child alone to recognizing the key role families play in their children’s lives led to the creation of a set of principles that defined family-centered care and the development of self-assessment tools that articulate, from a family perspective, how to put those principles into action. Also, families and youth helped the AAP create the Bright Futures Pediatric Guidelines, which are infused with the principles of family-professional partnerships.

The National Survey of Children with Special Health Care Needs, implemented in 2001 and 2005/06, and the National Survey of Children’s Health in 2003 and 2007 documented the experiences of all families nationwide, as well as those who were raising children and youth with special needs. Families helped design and refine these surveys, interpreted the data, and created effective tools to distribute the data in an accessible manner. Family leaders were then supported to use their states’ data to advocate for improvements and obtain the funding needed to implement change.

Also gaining momentum early in this past decade was the concept of providing funding for family groups at the state level to prepare families to become effective partners and leaders at the individual, program, and policy levels. At the federal level, after seven years of effort, Congress passed the Family Opportunity Act in 2005. This legislation provided funding for family-run, Family-to-Family Health Information Centers (F2FHIC) in every state. In February 2010, an additional three years of funding for these F2FHICs, along with many critical health coverage protections for children, were secured through the Patient Protection and Affordable Care Act.

The past decade has witnessed revolutionary changes in both attitudes and actions.
The past ten years have been an exciting time for maternal and child health programs, and the Association of Maternal and Child Health Programs (AMCHP) has been a part of the many positive changes affecting the lives of children and youth with special health care needs and their families.

There is so much to celebrate—the evolution of medical home, major policy changes with the re-authorization of the Children's Health Insurance Program (CHIP), the recent passage of health reform, and true progress within the states to promote family-professional partnerships. But the most positive, concrete way that AMCHP has changed in the past decade is in the evolution of our activities to support family involvement and family leadership within states and territories, and within AMCHP itself.

Ten years ago, the AMCHP Board of Directors did not have any directors specifically appointed to represent families. Today, we have two Family Representatives, elected by AMCHP's delegates, who serve as full members on our Board. The inclusion of family representatives on our Board has brought great opportunities to ensure that families and youth are included in our programmatic and policy discussions. Including families in our work at AMCHP has made us "walk the walk" and not just "talk the talk" when it comes to promoting family-professional partnerships among our members. It has challenged us to live our commitment to serve and support children and youth with special needs and their families. As an organization, we are dedicated to the vision of healthy children, healthy families, and healthy communities. It has made the work of inclusion real to our Board, to our staff, and to our members. I can honestly say that, without the active involvement of family leaders in the governance of AMCHP, we would be a much weaker organization. With the active involvement of families, we are much, much stronger.

AMCHP is on the move with families as true partners. We celebrate this important decade of change. Join us for another decade of change—positive, concrete change—for children and youth with special health care needs and their families!

Submitted by
MICHAEL FRASER,
Association of Maternal and Child Health Programs,
Washington, DC
We have known for decades that families caring for children with special health care needs have valuable experience and critical expertise to offer to public health agencies, health plans, pediatric practices, and others who affect children’s care.

When New England SERVE began working to document family perceptions of barriers to quality care in 1983, family leaders were hard at work in Massachusetts and across the country advocating for improved services. But only a small number of health care organizations, mostly hospital settings or state Title V agencies, could demonstrate any participation by consumers in advising, let alone designing or evaluating programs or services. As we joined the growing national movement to build family-centered systems of care, we committed ourselves to developing a range of policy-level opportunities for family members in all of our work and to expanding the types of places and roles in which families could make a meaningful difference.

In 2004, after nearly twenty years of promoting policy-level partnerships with families, New England SERVE and the Title V Program at the Massachusetts Department of Public Health launched the Family-Professional Partners Institute (Institute) to harness the power of a diverse set of family experiences. The vision was to impact a wide range of organizations that deliver care, educate the next generation of caregivers, and shape programs and policy for children and families in Massachusetts. Acting as a partnership broker and a matchmaker, the Institute set out to market the value of partnerships and demonstrate their impact on a variety of organizations. Then we documented and evaluated what happened.

The Institute brokered and supported 16 policy-level partnerships in academic, research, hospital, private pediatric practices, and health plan settings. We also built a partnership network that linked all participants, facilitating the exchange of ideas and providing ongoing training to all partners. It was like watching a fire catch every time the group gathered. Small sparks of energy lit by eager young physicians were fanned by thoughtful comments and feedback from new immigrant families; challenges identified by family leaders were often answered by state agency staff; and researchers left with new ideas for their work. Partnerships within each organization grew stronger and more effective due to their connection to a larger movement.

While the concept of establishing partnerships between family members and health care providers and policy makers was not new, the Institute experience changed our state’s vision of how to promote systems change and engage new members on the “2010” team. We helped demonstrate that:

• Family partners can operate effectively not only in medical practices and health plans, but also in academic and research sites, as well as community-based organizations with very limited staff and financial resources.
• Family members can assist in designing and conducting research, participate in graduate-level curriculum review, help build disease-management programs for health plans, and find ways to support minority families in cultures where disability is often kept hidden.
• Third party brokers can facilitate and promote partnerships.
• Linking partnerships to the national goal of systems change can help sustain these efforts.

Institute partners have seen their work as part of a larger agenda, to improve systems of care for CYSHCN by 2010. With that goal in mind, they continue to be part of the national movement.

Submitted by
SUSAN EPSTEIN,
New England SERVE,
Boston, Massachusetts
Currently there are over 35 chapters and numerous start-up efforts. One of the founding principles of Hands & Voices is its unique philosophy of being parent driven, yet collaborative with the professionals who serve our families and children. This philosophy has been epitomized through our parent leadership and representation, over the last ten years, in the Universal Newborn Hearing Systems established through the efforts of the Maternal and Child Health Bureau (MCHB) and the Early Hearing Detection and Intervention Systems grants.

Ten years ago, the “first wave” of parent voices began to clamor for a change in the status quo—the late identification of hearing loss of young children. Loudly and clearly, families expressed their desire for the chance to have their children screened early on so that they could effectively intervene. As one parent from Pennsylvania put it,

"With my first deaf child, before there was newborn hearing screening, what a challenge it was to find help and a good diagnosis and support! With my second deaf child, I had appointments lined up before I left the hospital and a test in my hand and I didn’t have to wait to “convince” anyone that something wasn’t right. The screening did it for me! We were completely ahead of the game, prepared, and READY to go because of the screening."

One state Early Hearing Detection Initiative and Intervention Program (EHDI) Coordinator reflected:

"It has been one of the highlights of my career to see how families lead the process from screening through early intervention at the local, state, and national level. We did a parent satisfaction survey of our program several years ago, and the one wish families had was more parent support. They wanted to meet parents who had children who are deaf and hard of hearing. Since 90 percent of our identified children are born to hearing parents, their baby is often their first experience with hearing loss."

Parent leaders from Hands & Voices have emerged as meaningful partners with the professionals in state EHDI systems to improve the process for the next families to come.

Submitted by
JANET DESGEORGES,
Colorado Families for Hands & Voices,
Boulder, Colorado
Frankly, it should have been out of view and out of our consciousness. At this moment, I was grateful that my 12-year old daughter Holly was unable to read—I could shield her just one more time. Retarded? Why that word, and who said it was okay to blanket the entire community with such blasphemy? I wondered if any families had been asked for input.

The message of that yard sign represented the emotional dichotomy families of children with special health care needs face every single day. Families like mine know the game all too well: tell a sad, pitiful, tragic story, and maybe some funding will come your way. Use the right words to describe your kid's challenges, and there just may be a way to pay for treatment. It is true, families who have children with special health care needs learn early on when to speak the language of deficit.

This yard sign was also my invitation to meet the professionals of Title V. In my quest to find out who was involved in the “Retarded Children” campaign, I attended a community meeting. It was at that meeting that I met families, young adults, and professionals who cared about this issue. One of the ladies attending that evening was the Family Coordinator for my local Title V agency. She explained to me how much her agency cared about what families think; that families should be included in efforts that are so emotionally charged. She put words to what I knew was right. Families should always be invited to engage in activities that directly impact their children—it is just the right thing to do. What I heard that evening was an acknowledgment of dignity, respect, partnership, and honor. It came from Title V.

So I became involved with my local Title V agency. I attended trainings, learned about Medicaid funding, heard the words medical home for the first time. I was hooked. I had a deep appreciation for what Title V was trying to do, chipping away at the concept of family-professional partnership. I wanted to be a part of it and I wanted to contribute to the vision of Title V that families of children with special health care needs will partner in decision making at all levels.

Together with MCHB and my state Title V program, I remain committed to integrating the voice of families and youth in all levels of program development, implementation, and evaluation. I now serve as the Director of Colorado’s Medical Home Initiative and Family Leadership Initiatives, braiding family leadership and health services. My daughter Holly still can’t talk, but I assure you she is watching, along with her brothers and sisters, keenly aware of how change happens on behalf of all kids and youth.

Nearly ten years later, a new yard sign might blanket my community and our country. The yard sign would read; “Promoting Partnerships Because All Families Matter.” This is the legacy of our work, and together we’ll find the way!

Submitted by
EILEEN FORLENZA,
Director, Colorado Medical Home Initiative,
Highlands Ranch, Colorado

It was the spring of 2001. The yard sign in my neighbor’s lawn read, “Vote Yes on 3A, Support Retarded Children.” The sweet photo of the “retarded child” was strategically positioned in the center of the small billboard, allowing plenty of room for the word “Retarded” to be unobstructed.
A decade ago in New Jersey, families of children and youth with special health care needs (CYSHCN) who reached out to Family Voices of New Jersey were helped by a volunteer parent who had another full-time job. In only half of New Jersey’s counties could families speak with a Statewide Parent Advocacy Network (SPAN) Family Resource Specialist.

With one call, families can connect to a myriad of family support and empowerment programs.

Families seeking parent-to-parent support had to search through disability-specific organizations or hospitals. Military families were lost trying to navigate unfamiliar systems of care. Families whose children were in the child welfare and juvenile justice systems floundered as they experienced these systems’ lack of knowledge about families’ right to participate in decision-making for their CYSHCN. Families—and most health professionals—had never heard of “medical home.”

Now, families of CYSHCN (including those with mental health needs) have available to them a wide array of new services that are improving their children’s access to quality care and their access to supports. SPAN’s once small staff of 14 has grown to 60 parents in every corner of the state. In one year alone, 2008 to 2009, more than 40,000 families and professionals accessed SPAN workshops, 30,000 received technical assistance, and 107,500 received information and materials through our website or publications. More than 200 parents participated in leadership development or Resource Parent training. SPAN-trained parent leaders, including a cadre of immigrant parent leaders: helped in the creation of a CHIPRA (Children’s Health Insurance Program Reauthorization Act) buy-in program for families of any income; worked on passage of legislation that established family leave insurance; impacted the recommendations of the Blue Ribbon Panel on Immigrant Affairs on language access for state and contract agencies and cultural brokers; and helped eliminate a proposed Medicaid co-pay in the state budget.

Today, parents in every New Jersey county can talk with a Family Resource Specialist, a parent just like them, to help their children transition from early intervention to school to adult life. With one call, families can connect to a myriad of family support and empowerment programs. A volunteer Support Parent can provide them with emotional support and resource information. Parents of children with emotional disabilities can get in-person, intensive advocacy and support from Family Support Organizations in every county. Military Resource Specialists help families become familiar with and secure services from New Jersey’s systems of care—on and off military bases. Families of CYSHCN in the child welfare and juvenile justice systems can get help with their children’s education and health rights and with their own decision-making rights. Families and health practitioners are learning strategies to increase access to medical homes, early and continuous screening, easy-to-use community-based resources, adequate public and private insurance, and transition to adult systems of care.

Submitted by DIANA AUTIN,
Statewide Parent Advocacy Network of New Jersey,
Newark, New Jersey
In many ways, Lori is a typical Alaskan, born and raised in Juneau. She is confident, motivated, independent, and deeply committed to her family, community, and neighbors.

As a family specialist, she is a professional in her field, working for a local non-profit agency. However, there are other aspects of Lori’s life that only a certain group of people can truly understand. Her life was changed by a mysterious, though increasingly common event. Lori is the mother of a young woman with autism.

Mothers in support groups “tagged” Lori’s daughter at age five, although diagnosis didn’t happen for another three years. Lori recalls that her daughter’s terrible tantrums and aggression—behaviors she hadn’t seen in her other children—made her feel like a “terrible mother.” There were no answers. In fact, no one seemed to understand or could explain what was happening. Kindergarten was a rough year for the family. The school called 25 times that year asking Lori to come and get her daughter.

Despite the limited services available in Juneau, Lori and her family decided to tough it out, advocate loudly, and effect as much change as possible for her daughter and future generations of Alaskan children with autism. The struggle continues even today since Juneau, like many other places, simply does not have enough high quality services to meet the needs of those affected with autism in their home communities. But, Lori states, life has improved, thanks to advocacy and the grassroots efforts of families, care providers, and community members who are contributing to an ever growing awareness of autism and neurodevelopmental disorders.

“I think we really, really need to publish and advertise where parents can go,” Lori states confidently. “There is nothing to be embarrassed about and ashamed of. I think we really need to get it out there that there are people with neurological differences and they need different types of support.” Despite slow progress and setbacks, Lori believes there have been important strides in parent and family inclusion in system change over the past 10 years. “The system is finally starting to recognize parents as a huge part of the team,” she reflects. “When I started this 20 years ago, that wasn’t really the case. Parents are often more personally invested than providers, and this is finally being recognized.”

And how has life changed for Lori’s daughter? As one of the older kids in the Juneau area diagnosed with autism, Lori states her daughter is “sort of a legacy. Many of the things we advocated for her (e.g., social skills training in schools, etc) are finally happening now for other kids. We are proud of the leadership role our daughter had, even though she doesn’t realize it.”

“It certainly has been a life changing experience,” Lori concludes, “but, I must add, a good one.”

Submitted by
JIMAEI LAWSON,
Autism Services, State of Alaska,
Anchorage, Alaska
Utah County, south of Salt Lake City, has a long history of working together to support children and families. This collaboration is supported by the leadership and vision of a family-initiated program called Kids on the Move (KOTM), an early intervention program that meets the needs of children from the time they’re born.

KOTM was started by two mothers of children with Down syndrome as a volunteer program to provide developmentally appropriate, family-centered early intervention services. From the beginning, these early family leaders spread a philosophy among the community that was inclusive of all children and supportive of families. When the State of Utah requested proposals from interested parties to provide the formal Early Intervention (EI) services under a state contract, Kids on the Move won the contract. KOTM also became the Early Head Start provider for Utah County. Although this brought organizational changes, the family focus has been maintained over the years as the number of children enrolled grew to its current level of more than 500 per month.

Family leadership has been sustained at multiple levels. Three parents whose children were in KOTM, but have moved on to the school system, are part of the governing board of directors of the organization, which also includes parents of minority cultures. Family input regarding the program is gathered via a monthly telephone survey. To connect parents throughout the community, the five-year old Utah County Special Needs Conference, which is now funded and supported by multiple community partners, is spearheaded by parent leaders.

There are other “doors” that families in Utah County may enter to network with other families and find support. The Family-to-Family network has a strong presence, providing families with training, as well as a way to network informally and provide support for one another. KOTM is still the community’s hub for coordination of early childhood services, with numerous community partners, including agencies providing special education, primary health care, and mental health services. KOTM works with organizations such as National Alliance on Mental Illness (NAMI), Brigham Young University Department of Psychology, local school districts, the Utah County Council for Partners for Infants and Children, and the Department of Health to provide comprehensive services. One of KOTM’s most successful endeavors is participation in the “Sib Shop,” monthly meetings for siblings, between ages 7 and 17, of children with disabilities.

Utah County is an inspiring example of what a strong history of family leadership and sustained collaborative relationships within a large community can do to further the work of coordinating care for families of children and youth with special health care needs.

Submitted by EILEEN A. CHAMBERLAND, Kids On the Move, Inc. and BARBARA LEAVITT, United Way of Utah County, Utah County, Utah
Nearly 20 years ago, I received a graduate degree in speech-language pathology from the University of Kansas. One of the reasons that I chose that program was to gain a traineeship at the University Affiliated Program (UAP) that focused on interdisciplinary evaluation and family-centered care.

At that time, it was still novel to include families in diagnostic testing, solicit and value their opinions, and help connect them to resources.

Fast forward 10 years to the diagnosis of my first son at age three with autism. At the end of the diagnostic visit, my husband and I were asked whether we wanted to know about the future. Without waiting for our response, the physician proclaimed, “Most of these children end up institutionalized.” I wondered whether he had ever heard of family-centered care and if he realized how his words affected our hope, our most precious resource.

Fast forward another five years to a visit with a specialist. I wanted to learn more about managing co-occurring disorders, as my son’s diagnoses had grown to include autism, ADHD, anxiety, and Tourette’s syndrome. Without even asking what I hoped to gain from this visit, the physician said, “Mrs. Roux, you have obviously seen all the best people in this state. I don’t know what I could possibly have to offer you.” I simply smiled and said, “I’d be happy to tell you why I’m here, if you would just ask me.” I thought to myself that this was an excellent example of what family-centered care does not look like and laughed inside, grateful for having learned to apply humor.

The year is now 2010. I have retained the unique privilege of wearing multiple hats. My family member hat is a large sombrero. Underneath I wear the hat of executive director of Missouri Families for Effective Autism Treatment. The feather in that hat is the family partner role on our state’s autism implementation grant, my favorite aspect of my job. From my 2010 perspective in Missouri, I am thrilled to see key members of our state’s autism implementation grant bringing families with them to their rightful place at the table. Families are still not always viewed as equal “experts” at the table; nevertheless, they are at the table and seen as capable of making valuable contributions.
Examples of progress abound. A family member leads the Individual and Family Supports Committee of our Missouri Commission on Autism. Our Missouri Autism Centers now have family mentors working side-by-side with professionals to provide immediate support and resources for families after diagnosis. A family-professional task force has been implemented at the Thompson Center for Autism and Neurodevelopmental Disorders in mid-Missouri. This task force is a crowning example of families and professionals working as equal partners to improve family-centered care. Yet, it’s not the products of the task force that will be the treasure; it’s the sharing of motivation and progress that will inspire the team’s members to continue this collaboration and teach others to do the same. It’s a glimpse of the future, and, yes, I finally do see family-centered care barreling down the road in Missouri!

Submitted by
ANNE ROUX,
Missouri Families for Effective Autism Treatment (MO-FEAT),
St Louis, Missouri
In Memory of Polly Arango, founding Executive Director of Family Voices. Polly will be remembered as a passionate visionary and tireless mother, advocate, mentor, and friend whose belief in the power of community was exemplified in her lifetime of work for families and children.

Within the pediatric world, federal and family community partnership was revolutionary.
During the last decade, without the unique and historic partnership between the Maternal and Child Health Bureau (MCHB) and a national network of family leaders, few of the achievements on behalf of children with special health care needs and their families would have been realized. How did this partnership come about? I trace it back to two individuals: the late Dr. Vince Hutchins, a venerated pediatrician who brought MCHB to its Bureau status and directed it for many years, and Dr. Merle McPherson, the wise pediatrician who ran MCHB’s Division of Services for Children with Special Health Needs (DSCSHN).

Merle and Vince, as we families came to know them, believed in the central role of families, not only in raising their children, but in helping to design and implement the policies that affect them. As visionaries, they knew that federal policies and programs would be enriched if developed through family-government partnerships. Beginning in the 1980s, Merle and Vince built that partnership by:

- Inviting family leaders to MCHB professional meetings and conferences to discuss problems and find policy solutions;
- Requiring MCHB-funded projects to include families as meaningful partners;
- Bringing families onto panels to review MCHB proposals and state Title V grant proposals;
- Funding projects and organizations led by families;
- Encouraging national organizations receiving MCHB funds to include families in their activities; and
- Seeking families’ ideas and expertise, no matter how “out of the box” they might have seemed.

Within the pediatric world, federal and family community partnership was revolutionary—for all parties. Families were nervous and surprised to find themselves working as peers with physicians, researchers, and policymakers. Professionals were equally astonished by the family presence, passion, and expertise. The leadership of Vince and Merle not only quieted fears, but modeled the nascent partnership.

In the last decade, the MCHB-family partnership led to achievements that changed the world of children and youth with special health care needs and their families—and set the stage for future accomplishments. Thank you, Merle and Vince. May the partnership endure!

Submitted by
POLLY ARANGO,
Algodones, New Mexico
During the last decade, we have seen medical home evolve from a visionary concept in pediatrics to a full-fledged movement to transform primary care for all Americans. The groundwork for this was laid by many years of collaborative work between the Maternal and Child Health Bureau (MCHB), Family Voices, and the American Academy of Pediatrics (AAP) to develop the medical home concept for children with special health care needs. (cont.)
It all started in the 1960s, when the American Academy of Pediatrics began to focus on the need for a single repository for all patient health information, including information on a child’s history, physical findings, immunizations, consultations, medications, therapies, support services, and anything pertinent to the patient’s health status. Out of this work came the core principles of a medical home. A medical home:

- operates within a 24/7 system of care that is well-resourced with primary care, subspecialty care, emergency department, community supports, and hospital-based care to which the child has ready access;
- depends on the collaboration among physicians, families, and all of those working in the public health arena to make the changes necessary to optimize and coordinate the care of children and youth, especially those with special health care needs;
- elicits trust from families in that they know there is one place where their child is seen as a whole, where all aspects of physical, mental, social, and emotional health are addressed over the child’s life, and where doctors, nurses, and staff know the child, community services, and family well.

At the core of the medical home is the idea that care should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. According to Dr Errol Alden, AAP Executive Director, “With the aim of improved health outcomes for children and youth, the goal is straightforward and possible—all children must have access to appropriate, quality health care within medical homes.” And, in the last ten years, medical homes have become the standard of care—acute, preventive, and chronic—for all children and adults.

**Does medical home work?**
Consider the recent study conducted by the University of California, Los Angeles. Data was gathered on implementation of a medical home model that included one-hour intake appointments and 40-minute follow-up visits, a bilingual liaison for families, and a binder to help families store their child’s medical records in a single place. The study indicated that implementing these medical home practices resulted in a 55 percent decrease in the number of visits to the hospital emergency department by chronically ill children.

**How do we ensure medical homes for all children?**
With support from AAP, MCHB, and families, the National Center for Medical Home Implementation has developed practical materials and resources to help pediatric practices, allied health professionals, and families improve care for all children through medical homes. Whether by downloading a patient brochure template from the National Center Web site, or personalizing a care plan via the *Building Your Medical Home* toolkit, or having a direct conversation with National Center staff about how and who to partner with in their communities, providers and families have demonstrated that, with information and support, the medical home approach to care can be achieved in every state, in every type of practice setting, and for every child.

We are inspired by the remarkable outcomes that result from providing a medical home to children and youth, including improved health status, timeliness of care, and enhanced family satisfaction. We look forward to the future when medical homes are available to individuals throughout their lifespan.

Submitted by **ANGELA TOBIN**, National Center for Medical Home Implementation, American Academy of Pediatrics
As a full-time, primary care pediatrician in Hawaii, I have witnessed, first hand, the vital role that the American Academy of Pediatrics (AAP) and Maternal Child Health Bureau (MCHB) have played in the evolution of the medical home concept over many decades. And, in the last decade, I have seen the concept being implemented at the national level.

In 1977, Drs. Vince Hutchins and Merle McPherson from the federal Maternal and Child Health Bureau sought changes to revise and update “the Crippled Children’s Program’s” mission nationally and statewide. The AAP Board collaborated in this effort by asking each state’s AAP Chapter to develop a Child Health Plan. In Hawaii, I chaired our Chapter Child Health Planning Group, which focused on the medical home concept and early childhood system of care.

Federal legislation passed in 1984 funded Emergency Medical Services for Children (EMSC) to meet the unique emergency medical needs of children with special health care needs and disabilities. This legislation introduced the medical home concept as a coordinated system of care for children from crisis to hospital, follow-up care, and prevention of accidents and illnesses by the primary care physician. Hawaii received MCHB grants for physician training and technical assistance in order to spread the medical home concept for children with special health care needs throughout the state of Hawaii.

The first National Medical Home Conference was held in December 1987. Leaders from 26 AAP State Chapters attended and submitted state action plans that helped to spread the medical home concept beyond Hawaii’s shores. In 1992, the AAP officially adopted a policy statement on medical home and incorporated the concept in its Community Access to Child Health (CATCH) program. In 1993, with grant funding from MCHB, the AAP began providing medical home training and technical assistance.

As a primary care pediatrician in a two-person, full-time practice in Hawaii, this has been an interesting journey! And one that was only made possible by the support of many individuals, including local, state, and national leaders who recognized the importance of public/private partnership and were deeply committed to improving the provision of medical care for children with special health care needs. Today, the ideas that “every child deserves a medical home” and that “one pediatrician can make a difference in his/her community” have become realities.

Submitted by

CALVIN C.J. SIA,
Honolulu, Hawaii
With his anticipated extra chromosome in tow, our son Parker came into this world almost six weeks early. His first year included two life flights, three surgeries, various other invasive procedures, and more than his fair share of pediatric intensive care unit (PICU) stays.

Being the parent of a medically fragile child means carrying the weight of your child’s life on your shoulders and in your heart. You live in fear of overlooking something as you try to juggle medication schedules, unfamiliar equipment, doctor’s appointments, and hospital stays. Frustration kicks in as you try to mediate between specialists, in hopes of creating a team of medical advocates for your child. We found ourselves running from appointment to appointment, as one specialist would scratch his head and send us to another, who in turn would scratch her head and send us back from whence we came.

And then we got a new pediatrician and things changed—dramatically! Our first appointment with Dr. Conner found Parker’s PH levels dangerously high and his hematocrit exceptionally low. We explained that we were looking for someone to help us organize a medical team for Parker. Dr. Conner accomplished this the very next day. Quite simply said, we owe Parker’s life to her.

Being a part of a medical home means that Amanda (Dr. Conner’s Parent Partner) calls you when your child is admitted into the hospital. She follows your child’s progress. Since Amanda is also the parent of a child with special needs, she’s been where you are and she understands how you are feeling. She’s there to help you successfully navigate those medical land mines.

Being a part of a medical home means that when the hospital sends down copies of tests and reports written by specialists, your pediatrician reads them. It also means that your
My pediatric practice began with the vision of providing family-centered, coordinated care to children with special health care needs (CSHCN) by creating a medical home.

The process began with a focus on our office practices. We identified our patients with special health care needs, reviewed our office flow, and developed care coordination. As we became more involved with our Parent Advisory Group, we discovered we also needed to focus outside our practice. Our patients with special health care needs don’t live within our medical home. They live in our community and they often receive services from a number of different agencies.

We could have settled for developing a list of agencies with their phone numbers and handing it out to families. But how many times had we called local agencies to make a referral, given the patient’s name, and not really known what would happen next? So we developed the idea of a “lunch lesson.” We invited agencies to our office for lunch and asked them to give informal presentations about their services to physicians, nurses, and other personnel that made referrals. This was a great way to interact face-to-face and develop a real knowledge of the services that the agencies offered. It also afforded us the opportunity to get to know the people whom we would later be calling for assistance.

At first we were afraid we would have to beg the agencies to come to our office, so we started with a couple of agencies with which we had worked already. Soon, agencies in the community were calling our office, asking if they could come to us and do a lunch lesson. We also asked the parents who participate in our Parent Advisory Group to suggest agencies to invite. We have been hosting these lunch lessons for over five years now. It still amazes me that we find new agencies every year to come and present. It feels wonderful to refer families to providers whom we know personally, with whom we feel comfortable, and who we know will treat these families well.

Submitted by
KIM REILLY,
PrimeCare Pediatrics,
Zanesville, Ohio

pediatrician communicates with the specialists caring for your child and that each member of your child’s team is kept informed and updated on medical events and treatment. Within the medical home your pediatrician is a lot like a musical conductor, except she leads a medical orchestra.

Being part of a medical home means that if your child is too sick to be seen in the office, Amanda and Dr. Conner will come to you!

In a medical home setting, your pediatrician knows your child as an individual. She believes in his potential and wants to help him achieve it.

Submitted by
TAMMY HODSON,
American Fork, Utah

23
As a pediatrician, my interest in the medical home concept of care delivery began with my own growing dissatisfaction with how I was caring for my patients—children and youth with special health care needs.

I felt as though I rarely had the proper amount of time scheduled for their care and was always “catching up” with what the specialist had said, with the family’s stressors outside of the child’s health condition, and with the child’s medications. So, when two medical home pioneers, Carl Cooley and Jeanne McAllister, asked me to try out their Medical Home Index measurement tool, I asked 13 of our practice’s families of children with complex medical conditions to help me. The tool helps families and providers identify needed improvements in the care delivery system. Of course, I chose families with whom I worked well—but they opened my eyes! While they told us what we were doing well, they also told us they needed more help with referrals to community supports and with coordinating their child’s care with the many other providers involved. They needed meticulous communication when their child went in or out of the hospital or to a new school or camp. And they really wanted access to medical advice without waiting for a call back at night or the next day.

So, over the past six years, my partners and I have embarked on a process of small, steady changes to improve services in the areas that were weak and to build a medical home for all of our patients. Everyone on our staff, from those handling medical records and schedules to the lab technicians, nurses, and doctors, have improved how they work by problem solving for families. Our schedulers now have a protocol to schedule more time for children with complex conditions. By pairing our clerical and clinical staff with a specific doctor, we have gotten to know our families better and can customize their care. Our nurses are alert to children with conditions or equipment that might make a doctor’s visit more stressful for the family. We’ve identified those families who need more help, more time, or more services. To meet those needs, our care coordinators help with referrals, pre-visit planning, and communication with specialists. We’ve developed a directory of our local resources and an interactive website with a medical self-help link. Expanding our nurse phone advice program and extending our after-hours and weekend care capabilities help our families avoid emergency rooms and improves continuity of care.

For families whose children have less complex medical needs, a medical home with us may be well-baby checks or where you go on Saturday when your throat hurts. Other families, whose children have greater health care demands, must have more extensive support. With those families, we’ve shared news—both joyful and devastating. We’ve problem-solved everything from getting an inhaler into a child’s backpack at school to finding funding support for new hearing aids. Either way, the staff and physicians of a child’s medical home can be lifelong allies, who, from years of interaction, have a strong investment in that child’s life and health.

I’m proud to be involved in a medical community that is intent on improving quality care for children, and it is exciting to see the entire medical system embrace the concept of care within a medical home.

Submitted by JENNIFER LAIL, Chapel Hill Pediatrics and Adolescents, Chapel Hill, North Carolina
More than eight years ago, in partnership with the Maternal and Child Health Bureau (MCHB), we at The National Initiative for Children’s Healthcare Quality (NICHQ) began a groundbreaking program to promote the adoption of the medical home.

Ultimately, we worked with 22 states and dozens of front line practices. Achievements from this program included reducing unplanned hospitalizations for children with special health care needs by 63 percent, decreasing emergency department visits by 44 percent, and decreasing the combination of parental missed work days/children-youth missed school days by 49 percent. This program provided a major impetus to the current national focus on strengthening systems of primary care—for adults, as well as for children—through the medical home.

Beyond this groundbreaking program, NICHQ and the MCHB have developed ideas that have improved follow up from newborn hearing screening and improved access and quality of care for children with epilepsy. Together, we have also strengthened the capacity of state Title V programs to improve the systems of care in their states for children with special health care needs. Several tools have been developed, including a self assessment tool, the Title V Index, which Title V programs can use to identify their strengths and areas for focused attention to enhance their effectiveness. Another tool is a driver diagram and change package that illustrates how Title V and clinical programs can work together to improve services. Training in the fundamental methods of quality improvement is now being offered to state Title V leaders so they can apply these methods throughout their programs.

Submitted by CHARLES HOMER, The National Initiative for Children’s Health care Quality, Boston, Massachusetts
Parents of children and youth with special behavioral, mental, and physical health care needs accumulate vast stores of hard-earned, experiential knowledge.

However, these accomplished parents have little opportunity to share this knowledge with other parents facing similar situations, simply because it is unlikely that two families will ever find one another and make a connection at a critical time. To make knowledge-sharing and social connections easier, Educating Practices in Community-Integrated Care (the Pennsylvania Medical Home Initiative) created a web-based community where parents could connect, talk, blog, and share events and resources. Joining the “Especially for Parents” community at www.pamedicalhome.org helps parents stay “in the loop,” give or receive emotional support, communicate when it’s convenient for them, pool their experience with other parents, browse archived discussions or contribute to discussions, use the community to garner support for a policy or program, and found groups centered around a special area of interest.

Submitted by DEBORAH WALKER, Pennsylvania Chapter of the American Academy of Pediatrics, Philadelphia, Pennsylvania

Physicians at Southwest Pediatrics quickly realized that medical homes were a road map to achieving good quality of care for families.
In New Berlin, Wisconsin, a suburb of Milwaukee, success in implementing a medical home for every family is due largely to the collaborative efforts of Southwest Pediatrics, the Wisconsin Title V program’s Southeast Regional Center for Children and Youth with Special Health Care Needs, and Children’s Hospital of Wisconsin in Milwaukee.

Physicians at Southwest Pediatrics first became alerted to the benefits of medical homes five years ago when some of their staff members attended a medical home learning collaborative. They quickly realized that medical homes were a road map to achieving good quality of care for families, especially families of children and youth with special health care needs (CYSHCN).

The most exciting part of implementing the medical home concept has been the opportunity to partner closely with families. One of the first things Southwest Pediatrics did was form a parent advisory board. The advisory board has impacted the practice by doing everything from distributing a “special needs newsletter” that informs parents of CYSHCN about useful community resources to assisting in the design of a new office. With the development of parent information nights, parents have reached out beyond the practice to families living in the community. The best part is that the parents are committed to their work and to growing a strong family-centered medical home philosophy at the practice.

Another very successful collaboration has been forged with the local school district. Lori Karcher volunteers as a district parent liaison in a neighboring school district, acting as a conduit between Southwest Pediatrics and her school district. The message she wants to get across is that it is possible for medical homes to successfully partner with schools. The community has found that it’s not as difficult as some may think to involve children’s medical home providers when drafting IEPs (Individual Education Plans). Having medical professionals involved in these plans is important because, as Lori says, “As a parent, you don’t always have the medical background or the right words to say the correct information.”

Southwest Pediatrics also has a considerable hand in encouraging transition awareness throughout the community. Dr. Rohloff recently proposed a transition program to Children’s Hospital of Wisconsin that would involve many community partners. As the result of a statewide Transition Collaborative, physicians and case managers from Children’s Hospital and metropolitan Milwaukee physicians compiled a comprehensive, useful list of adult health care providers who would be willing to accept youth and adults with special health care needs. This information is shared with families and with pediatricians, encouraging communication among the pediatric and adult health care providers.

Southwest Pediatrics in New Berlin is a good model to all communities of family leadership, service coordination, and comprehensive care for children and youth with special health care needs. We are thankful for the strong community partnerships that exist and the emphasis on implementing the medical home concept.

Submitted by
MEG STEIMLE,
Southeast Regional Center and
ROBERT ROHOLOFF,
Southwest Pediatrics,
New Berlin, Wisconsin
The Minnesota pediatric medical home initiative for children with special health needs began, in part, as a result of a series of federal grants awarded as early as 1999 by HRSA’s Maternal and Child Health Bureau.
In the year 2000, when the federal government made medical home one of its core outcomes for children and youth with special health care needs (CYSHCN), there was no organized effort to bring medical home initiatives to Illinois.

In 2002, Dr. Charles Onufer, Director of the Division of Specialized Care for Children (DSCC) at Illinois’s Title V agency, began making presentations to primary care practices about the medical home concept. For more than two years he laid the groundwork for implementation of medical homes by teaching about this concept.

In 2004, the Maternal and Child Health Bureau (MCHB) funded the Illinois Chapter of the American Academy of Pediatrics (ICAAP) and DSCC to implement the Illinois Medical Home Project. Over the next five years, 19 practices learned how to use resources from the National Center for Medical Home Initiatives and the Center for Medical Home Improvement and pilot-tested this model.

With the success of the program, ICAAP and DSCC are currently working with nine practices across Illinois, including Federally Qualified Health Centers. Participating practices receive free medical home quality improvement support and resources, including a team facilitator. Four practices serve as mentor teams to the newest group of practices. The program has expanded so quickly that there is now a wait list for practices to join.

In 2008, we received a two-year grant from The Commonwealth Fund to improve communication and care coordination among primary care practices, early intervention, and families. A training curriculum was pilot tested and is now being implemented across Illinois; it will be shared with Part C Coordinators nationwide. A year later, we were funded by MCHB to implement the Integrated Systems of Services for Illinois Children and Youth with Special Health Care Needs project. The project is spreading the medical home model and improving access to quality, comprehensive, coordinated, community-based services for CYSHCN and their families, with a special focus on helping to transition youth into adult service systems.

During the past 10 years, Illinois has built upon the dedication of many individuals across the country to promote the medical home concept. Dr. Charles Onufer served as Illinois’ first medical home champion. Thanks to his work and the extraordinary partnerships he has formed with the Illinois Title V agency, the Illinois AAP Chapter, the Illinois Department of Healthcare and Family Services, families, and primary care practices, medical home has become a reality for many children and youth with special health care needs across Illinois.

Submitted by
KATHY SANABRIA,
Illinois Chapter,
American Academy of Pediatrics,
Chicago, Illinois
Our story began over 20 years ago with the birth of our daughter, Hali. Hali has faced both physical and cognitive challenges since her birth.

Her challenges have put our family on a journey that we never could have imagined—one filled with struggle, but also rich with blessing.

As a result of Hali’s challenges, my wife, Karen, and I set out to use the lessons we have learned to help other families manage their situations and create the best lives possible for their children with special needs. In 2000, we founded the HALI Project. Through that project, we have developed programs to help parents learn how to come to terms with their situations, understand their emotions, and build positive relations with the people and institutions that can assist them and their children.

One of the great blessings of this work has been the opportunity to meet people from all over the country who share our passion for helping kids like Hali reach their potential. It began with an introduction to Family Voices, which led to an opportunity to serve on the American Academy of Pediatrics’ Medical Home Initiative. Being part of their project advisory committee for five years led to multiple speaking opportunities for us across the nation.

One of those speaking opportunities in Washington, D.C. in the summer of 2008 introduced us to the Genetic Alliance. Soon after that, we were invited to serve on the Consumer Workgroup for the Mountain States Genetics Regional Collaborative Center (MSGRCC). Since that time, we have had the privilege of being a part of a “Visiting Professor” lecture on the value of the medical home to the genetics community and of delivering the keynote address at MSGRCC’s 2009 annual conference.

The MSGRCC is now partnering with our project to put together a medical home training project for physician practices that want to improve the quality of care they deliver to families, but that lack the resources to provide some of the
The Epilepsy Foundation of Metropolitan New York (Epilepsy Foundation) is collaborating with the Charles B. Wang Community Health Center (Charles B. Wang) on a unique medical home initiative.

Charles B. Wang serves a Chinese immigrant population, the majority of whom have language barriers. These language barriers have made it difficult for many patients to obtain the health care they need, as well as to understand their diagnoses.

To promote the medical home concept at Charles B. Wang, assessments have been made to identify the changes needed to make the clinic a better place for patients and families. The Epilepsy Foundation translated the Medical Family Index into Chinese for the community and offered incentives to families to participate in family assessments of the clinic. A support group for parents of children with epilepsy now meets every month or two and allows parents to share their feelings and anxieties about their children’s condition.

Due to concerns about a lack of epilepsy knowledge in the Chinese community, the Epilepsy Foundation provided epilepsy-related education to families. The Parent Support Group developed an Epilepsy Care Book which helps many families to better organize and enhance care for their children with epilepsy. A Transition Plan was also developed for youth transferring into adult care.

The medical home initiative at Charles B. Wang has substantially increased families’ participation in their children’s health care.

Submitted by
RACHEL LIANG,
Epilepsy Foundation of Metropolitan New York,
New York, New York

The medical home initiative has substantially increased families’ participation in their children’s health care.

Submitted by
BRAD THOMPSON,
The HALI Project,
Amarillo, Texas

elements of the medical home. Our project brings together the strengths of the pediatric practice, local parent support organizations, and local philanthropy to create a “win, win, win” opportunity for the community.

The practice wins by partnering with the local parent support organization whose mission is to provide some of the components that make up the medical home. The parent organization wins by gaining almost direct access to the families they are trying to serve. And, most important, families win by receiving medical care, community support, and resources in one visit. They also receive the blessing of meeting other families who have children with special needs.
The past ten years have seen great progress in the evolution of systems of care for children and youth with special health care needs (CYSHCN), as measured by the six core outcomes.

With federal support, State Title V agencies have increasingly played a role in supporting change, and, in 2010, all 50 states have achieved at least partial success in achieving the six core outcomes. Many of the states are engaged in working across agencies to link their programs so that services are less fragmented and more easily accessed by families. For example, in some states, early childhood programs link with home visiting, Head Start, medical homes, early intervention, child care, and multiple other community-based programs to serve children, youth, and their families more efficiently.

I was hired by the federal Maternal and Child Health Bureau (MCHB) in 1977 with the understanding that the Title V “Crippled Children's Program” was outdated and must be revamped. From the late 1970’s to 1989, we engaged in a consensus-building process with former Surgeon General C. Everett Koop, who provided exciting leadership through a series of Surgeon General Conferences. As a result, Title V’s authorizing language was rewritten in 1989 to reflect a new mission. In place of its existing mandate “to locate, diagnose and treat crippled children,” Title V now had the responsibility “to provide family-centered care” and “to facilitate the development of community-based system of services for such children and their families.”
This new charge called for a concerted effort to transform the system—to move from serving “crippled children,” many of whom lived in institutions, to integrating children and youth with special health care needs into local communities and providing them with the services they needed, right there. Through years of consensus building, a strong research and development initiative was supported by public, private, and voluntary resources. MCHB funded a wide range of studies, work groups, and meetings that played a major role in developing this new field and building a base of knowledge. We enjoyed strong partnerships with all of the states, the American Academy of Pediatrics, the March of Dimes, and countless other organizations.

But our most important partnership was with families who were raising children with special health care needs. In years past, families had advocated to close the institutions and open the schools for their children. Now they told us, loudly and clearly, that the health care system did not work for them and needed fundamental change—and that they wanted to be drivers of that change. As a measure of how far we’ve come, in 2010 “family centered care” became an integral part of health care reform.

In 1998, a new definition of CSHCN was created collaboratively with the American Academy of Pediatrics (AAP), Family Voices, and key policy experts. We further refined and developed six outcomes for measuring success in implementing community systems. In 2000, multiple constituencies came together to develop action steps to achieve each of six outcomes, and a plan known as The 2010 Express was developed. The plan was not formally released, but a major summit was held, and the work generated by these efforts continued based on our legislative mandate. During the past decade, to achieve the six core outcomes, MCHB and its many partners:

- Provided the leadership that introduced the medical home concept and principles to the Department of Health and Human Services.
- Collaborated with the American Academy of Pediatrics to gain support for using the term “medical home” as a model for quality access to primary care.
- Insisted that the national standards called Bright Futures be inclusive of CSHCN and that families must participate in writing them.
- Worked tirelessly to strengthen early screening programs nationwide, including genetic, hearing, vision, developmental, and behavioral screenings.
- Funded the Healthy and Ready to Work Program to help adolescents and young adults move from pediatric to adult health care.
- Built a “Communities Can” Program that recognized model communities at a national event held on Capitol Hill.
- Defined family centered care and its core principles and financially supported the development of a national organization of families who have children with special health care needs, known as Family Voices.
- Focused on financing issues, including high risk pools, care coordination, and access to adequate insurance.
- Established a National Taskforce on Pediatric Supply, which documented the serious workforce deficiencies, described the very important role of specialists and subspecialists, and proposed new models of shared management in medical homes. This work continues in the National Center for Medical Home Implementation.

The most positive and concrete change that creates the vision for the next decade is the recently enacted “Patient Protection and Affordable Care Act.” Access to family-centered medical homes will assure universal, equitable, and sustainable comprehensive care for all children and their families in community systems of service. The foundation has been set. Let us continue to build on it.

Submitted by
MERLE MCPHERSON,
Former Director, Division of Services for Children with Special Health Needs,
Maternal and Child Health Bureau,
Arlington, Virginia

As a measure of how far we’ve come, in 2010 “family centered care” became an integral part of health care reform.
The first decade of the 21st century shall be known to the public health genetics community as the decade in which uniform universal newborn screening (NBS) became a reality for every child born in America. In 2000, babies born in the United States were screened for between three and nine conditions. (cont.)
The expert panel recommended a set list of conditions for which every state should test as part of their newborn screening programs.

(cont.) Screening panels were highly variable and determined on a state-by-state basis. In this same year Title XXVI, Screening for Genetic Disorders, became part of Public Law 106-310, The Children’s Health Act of 2000. This law established the Heritable Disorders program, to be administered by HRSA’s Maternal and Child Health Bureau (MCHB).

In 2002, the American College of Medical Genetics (ACMG) was commissioned by MCHB to convene an expert panel to undertake a multi-step, evidence-based review of newborn screening in the United States. The expert panel recommended a set list of conditions for which every state should test as part of their newborn screening programs. The Advisory Committee on Heritable Disorders in Newborns and Children endorsed these recommendations in September 2005, creating a recommended uniform panel of conditions that should be required in each state newborn screening program. The expert panel’s recommendations were published in 2006 in Genetics in Medicine.

As part of the newly authorized Heritable Disorders program, in 2004 MCHB began funding seven Regional Genetic and Newborn Screening Service Collaboratives (HRSA Genetics Collaboratives) and a National Coordinating Center (NCC), housed at ACMG. Since that time, the HRSA Genetics Collaboratives have helped implement the expanded newborn screening panel by addressing the maldistribution of genetic service providers, bringing high quality genetic services to local communities, building infrastructure and capacity, and improving collaboration between public health, specialty care, medical homes, and families.

Today, four years after the publication of the uniform newborn screening panel, 100 percent of babies in the United States are screened for 30 or more conditions. This remarkable achievement is attributable to many thoughtfully integrated, coordinated efforts at the local, regional, and national levels.

Submitted by
JUDITH BENKENDORF AND ALISHA KEEHN,
National Coordinating Center for the Regional Genetics and Newborn Screening Service Collaboratives
If a baby’s hearing loss is not identified early, it interferes with the infant’s ability to develop speech, language, and cognitive skills, to make friends, interact with family members, and ultimately to succeed in school and all other aspects of life.

Although various federal agencies had emphasized the importance of identifying permanent hearing loss in newborns since the 1960’s, it was not until the Maternal and Child Health Bureau (MCHB) funded the first clinical trial of a universal newborn hearing screening project in 1988 that notable progress began to be made. At that time, the average age at which permanent hearing loss among infants and young children was being identified in the United States was 2½ to 3 years of age. Based on early results of MCHB’s universal newborn hearing screening project, Surgeon General of the United States, Dr. C. Everett Koop, issued a challenge in 1989 that by the year 2000 all infants with permanent hearing loss would be identified before 12 months of age. Although it was an ambitious goal, and many people thought it was unrealistic, MCHB’s continued funding over the next ten years and its ability to engage the Centers for Disease Control and Prevention and the American Academy of Pediatrics as partners has allowed us to achieve and surpass that goal.

Now, more than 95 percent of all newborns are screened for hearing loss, universal newborn hearing screening has become the standard of care throughout the United States, and much of the world is striving to emulate what has been accomplished here. With modest financial assistance from the federal government, every state has established an Early Hearing Detection and Intervention (EHDI) program as a part of its public health system. In areas with EHDI programs, most infants and young children with congenital hearing loss are identified at less than three months of age. Importantly, research is now documenting that young children who are deaf or hard of hearing and who are identified early and given appropriate educational and health care services develop better language and achieve better outcomes in school.

There is still work to be done. Challenges such as lack of state and local funding, shortages of trained professionals, children lost to follow-up, inadequately coordinated services and programs, and lack of access to new technology sometimes interfere with the ability of children who are deaf or hard of hearing and their families to get all of the services they need and to make the progress of which they are capable. But these challenges are being addressed. MCHB continues to fund quality improvement activities, to develop and implement innovative strategies for achieving systems change, to engage other stakeholders in collaborative activities, and to make new technology available to continue to improve EHDI systems.

Submitted by
KARL R. WHITE,
National Center for Hearing Assessment and Management
When our first son, Joey, was born, and after we counted ten fingers and ten toes, we felt incredibly blessed and happily began our journey into parenthood.

Just a few weeks later, Joey began having thrush, usually an easily resolved nuisance. But Joe's thrush continued for weeks as we began another journey, a journey towards a diagnosis of Severe Combined Immune Deficiency (SCID).

SCID is commonly known as the “bubble boy disease” and is a genetic disorder caused by changes in the DNA encoding one of the many genes that make up the components of the immune system. We were lucky. Joey was diagnosed at five months of age and had unknowingly dodged a bullet by getting the attenuated polio vaccine when he was four months old. The live vaccine could have killed him. Joey had 22 matches in the bone marrow registry, great insurance, and a large extended family ready to help us.

At nine months of age, Joey received a matched unrelated transplant. Joey's transplant was a partial success—one part of his immune system is awesome and one part doesn’t work. Monthly infusions provide the missing immunity that he needs to stay healthy.

Eighteen years later, Joey is doing great. But we have heard many stories of children not as fortunate. Most SCID babies don’t survive long enough to have a transplant, or they die from complications during transplant. These transplants are most successful when performed before a baby is three months old—and since newborns are not routinely screened for SCID, many are diagnosed too late. But that is going to change.

I was nominated to serve on the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) in 2005 because of my expertise in genetics and in creating tests to detect changes in DNA. In completing my nomination packet, I did not mention that I was a parent of a SCID kid. At that time we had no test for SCID that would be a fit for newborn screening using heel sticks and dried blood spot cards. In spite of this, Dr. Rebecca Buckley of Duke University testified at our first committee meeting that SCID should be added to the newborn panel and that SCID was a pediatric emergency. I’ll never forget hearing her compelling testimony. Since that time, researchers and clinicians have worked to develop screening tests for SCID. A good friend, Dr. Mei Baker, developed one of the first tests and conducted the first successful pilot of newborn screening in Wisconsin.

In January 2010, after testimony from scientists and parents and months of study and deliberation, SACHDNC recommended that the Secretary of Health and Human Services add SCID screening to the core newborn screening panel. The Secretary quickly endorsed the addition, triggering the adoption of SCID screening across the U.S. and, most importantly, giving children like Joey the chance for a normal life and a healthy future.

Submitted by AMY BROWER, Dakota Dunes, South Dakota
My name is Nathan, and I was born here in Alaska. I just celebrated my first birthday, thanks in part to early newborn screening!

When I was born everything seemed normal. At one week of age my mom became concerned because I wasn’t acting right. I was irritable, gagged during feedings, and went a long time between feedings. That was the day my doctor called to tell my mom that my newborn screening test was abnormal and that I needed to be seen right away.

I was diagnosed with a condition called Maple Syrup Urine Disease (MSUD). My body lacks the enzymes to break down protein. When I take in too much protein, it makes me very sick, and can affect my brain. I can’t have any animal protein—that’s a no-no! I can have most fruits and vegetables. Because of the good care I receive and the early screening, I have met all of the developmental milestones doctors look for. I count myself lucky. I can’t imagine how life would be if I hadn’t received early newborn screening!

These findings, along with the expanded diagnostic panel, have saved lives!

The State of Alaska’s Newborn Screening Program began the 21st century screening for six conditions, in collaboration with the Oregon Public Health Lab, as part of the Northwest Regional Screening Program. In October 2003, the newborn screening panel was expanded to include the conditions recommended by the American Academy of Pediatrics (AAP). Within one week of implementation of the new screening panel, an Alaskan child was diagnosed with a potentially lethal metabolic disorder, not on the earlier panel, that could affect his ability to break down fats for energy. If that child had been born even a month earlier, he would not have been diagnosed as quickly. Additionally, an unexpected pattern emerged within a specific geographic area of the Alaska Native population. In what is now called “The Arctic Variant,” the program has more than 250 diagnosed infants with yet another metabolic disorder. These findings, along with the expanded diagnostic panel, have saved lives!

A cystic fibrosis screening added in 2007 gives families information much sooner for earlier intervention and treatment planning. When legislation was enacted in 2008, mandated hearing screening became the standard of care in Alaska’s birthing hospitals. This legislation also ensures that all children receive proper follow up for diagnosis and treatment. Newborn Alaskans are assured a better start in life due to these highly developed screening processes and follow-up systems, regardless of whether their families live in rural or urban Alaska.

Submitted by THALIA WOOD, Children’s Health Unit Manager, State of Alaska, Anchorage, Alaska
Since the early 1950s, it has been known that Congenital Adrenal Hyperplasia (CAH), a metabolic condition, is caused by adrenal insufficiency, and physicians have been able to treat it effectively.

The first screening test for CAH became available in 1977, when scientists found a way to detect infants affected by CAH through the collection of blood on filter paper. However, as recently as 2000, CAH was included in the newborn screens of only 18 states.

The tide began to change at the turn of the 21st century. Parents of children with CAH came together to establish the CARES Foundation (Congenital Adrenal Hyperplasia Research, Education, and Support). The expert panel on newborn screening recommended CAH as part of the uniform newborn screening panel. Through the combined efforts of family-professional organizations, the state newborn screening programs, and the Maternal and Child Health Bureau (MCHB), newborn screening for CAH has become a reality in all states. We celebrate the fact that, as of 2008, every child born in the United States was being tested for CAH at birth.

And we have more to celebrate. On April 24, 2008, President Bush signed the Newborn Screening Saves Lives Act (S.1858/H.R. 3825) into law. This legislation provides the funding necessary for states to expand and improve their newborn screening programs, as well as to ensure appropriate follow-up, treatment, and education. This landmark legislation is saving thousands of babies across America each year from dying unnecessarily or suffering cognitive impairment and severe disability from a disease that can be screened for at birth as part of a comprehensive screening panel.

Submitted by
GRETCHEN ALGER LIN,
CARES Foundation (Congenital Adrenal Hyperplasia Research, Education, and Support),
Union, New Jersey
In 2000, through a five year grant funded by the federal Maternal and Child Health Bureau (MCHB), the March of Dimes had the unique opportunity to work with several underserved and underrepresented communities of color to gain a better understanding of their perspectives on genetics and to develop genetics education programs tailored to their community needs.

They are committed to dispelling myths and teaching facts about genetics and health.

Ten years into this journey, there has been tremendous growth in the communities’ desire to learn about genetics. The journey began with the Genetics Education Needs Evaluation (GENE) project and continues as the Community Genetics Education Network (CGEN) project.

Community-based organizations are interested in engaging their constituents in discussions about the ways in which information about genetics can lead to healthier lifestyles. They are committed to dispelling myths and teaching facts about genetics and health. These projects focus on gaining a deep understanding of the communities’ needs and tailoring educational resources, while engaging community members throughout the process using principles of community-based participatory research (CBPR).

One program exemplifies how far we have come. In New York City’s Chinatown, Donna, a first time expectant mother, came to the Charles B. Wang Community Health Center seeking genetic counseling services. A friend had an abnormal triple screen test and was referred for genetics education. After Donna heard about her friend’s experience, she wondered why she had never heard of genetics education and why her provider had never discussed the subject with her. Her anxiety about being an older first time mother, coupled with her friend’s positive experience, drove Donna to seek more information about genetics. When she came to the health center, the health educator helped prepare her to see a genetics counselor and was very happy to provide her with educational brochures on thalassemia, advanced maternal age, and abnormal triple screen. She also took part in a “Genetics 101” workshop. Donna found this information very useful and was grateful to have the chance to discuss and ask questions about genetics. The availability of these resources in Chinese was a direct result of the health center identifying the need for genetics education products in its community.

We have learned over the past decade that culturally and linguistically appropriate genetics education can change people’s lives by teaching women and their partners about genetics and preparing couples to care for babies with a genetic defect. It has helped people make informed decisions about getting screening tests, such as Amniocentesis or the Triple Screen Test. The GENE and CGEN projects helped us learn how to work collaboratively with communities to better understand their cultural perspectives and provide the information about genetics that is most relevant to their needs. The educational products developed through these two MCHB-funded programs will continue to facilitate communication of culturally relevant and health literacy appropriate genetic educational materials to diverse audiences for years to come.

Submitted by DIANE GROSS, March of Dimes, White Plains, New York
With the completion of the Human Genome Project in April 2003 and the subsequent advent of the genomic era, genetic information has become a new “tool” used by researchers, providers, and industry to facilitate family management of health conditions.

The use and the potential for misuse of genetic information has been a concern of families for more than a decade. These concerns were substantiated by surveys and polls about the business practices of health insurers and employers. In 1996, Newsweek featured an interview with a mother named Jamie Stephensen, who shared how her health insurer discriminated against her family because of the results of her son’s positive genetic test for Fragile X Syndrome. Because of these concerns, even as genetic tests have become simpler to administer and their uses expanded, families have hesitated to use them.

Families of children with special health care needs have been vocal in their frustration at the inappropriate use of predictive genetic information, which can provide an incomplete picture of the impact of a particular condition, hinder access to health insurance, or pose a challenge to finding and keeping a job.

Genetic nondiscrimination legislation was first introduced in the U.S. House of Representatives in 1995 by Representative Louise Slaughter (D-NY) and in 1996 by Senator Olympia Snowe (R-ME). Subsequent legislative proposals took many forms, and various Congressional offices emerged as champions of the legislation. However, success in the fight for federal protections against genetic discrimination in health insurance and employment was largely due to the uniting of diverse stakeholders in the genetics and health community around this major civil rights issue of the 21st century.

The signing of the Genetic Information Nondiscrimination Act of 2008 (GINA) into law represents a nearly thirteen-year odyssey toward improved care for all families, including children, youth, and adults with special health care needs. Providing protections against genetic discrimination in both health insurance and employment, GINA signaled new opportunities for families to understand and make informed and personalized decisions about the management of health conditions.

To make good on the promise of GINA, organizations and agencies will now focus on ensuring that the law’s enforcement is transparent and actionable. With GINA’s crucial protections in place, families can now utilize genetic information without fear.

Submitted by ANDRIA M. CORNELL, Genetic Alliance, Washington, DC

The consumer-driven health care movement has helped create tools for provider and patient partnerships in the provision and coordination of care and in shared clinical decision-making.
Nine years ago my twins, Anthony and Alainey, were born prematurely at 27 weeks. I had no idea how dramatically this event would change my life.

Anthony did not pass his newborn hearing screening test and was referred for follow-up testing. Because he required constant oxygen, his pediatrician did not want to sedate him so he could undergo an auditory brainstem response (ABR) test. We were advised to wait until Anthony was off oxygen at age 11 months to have follow-up testing done. In the interim, we began early intervention services.

Anthony was diagnosed with a 75 dB bilateral hearing loss at his first ABR at 11 months of age. Looking back, my husband Brian and I are so thankful for universal newborn hearing screening. Even though we consider ourselves knowledgeable parents, we probably would not have recognized the severity of Anthony’s hearing loss until much later. I say “probably” because, while waiting until Anthony was off oxygen, we did the same “tests” at home so many parents do when they are concerned about a potential hearing loss.

We were also grateful that his twin sister, Alainey, passed her newborn hearing screening test.

Nine years after Anthony and Alainey’s birth, I founded an organization called Indiana Hands & Voices and am currently the Program Coordinator of the Hands & Voices Guide By Your Side Program. I’m blessed with the opportunity to help connect families of newly diagnosed babies and children to services and supports very early in their journey.

We were so thankful for newborn hearing screening in the year 2000 when our twins were born and have had the pleasure of watching additional advancements in screening since then. We were not offered an un-sedated ABR, and I’m so thrilled that families now have that option and it can be done prior to the baby being discharged from the neonatal intensive care unit! That is fantastic progress. I have been extremely impressed with MCHB’s encouragement of family support and equally impressed with how my state of Indiana has embraced and valued my experiences and expertise as a parent leader.

Submitted by
LISA KOVACS,
Indiana Hands & Voices,
Greenwood, Indiana
My son Henry, born in 2007, was referred for further testing by the newborn hearing screen and subsequently diagnosed with severe to profound bilateral hearing loss.

Henry is 3 years old now and thriving. Henry’s hearing screen triggered a sequence of events that ensured the timely delivery of services and resources for my son and has enabled my family to respond appropriately to his needs.

When Henry was first diagnosed with hearing loss, his audiologist gave us a “Parent Information Kit” developed by our state’s Universal Newborn Hearing Screening Program that we could explore at home. It contained information about hearing loss in children and services and resources available to us.

Learning all of this new information was daunting, but we didn’t have to do it all on our own. A few weeks after receiving Henry’s diagnosis, we got a call from the Parent Outreach Specialist at the Universal Newborn Hearing Screening Program. She was a parent of two children with hearing loss, and her job was to contact families struggling with their children’s newly diagnosed hearing loss. We talked about Early Intervention, specialty services, support groups for parents, sign language classes, and more. We talked about her experiences and learned that we weren’t the only family who had ever experienced this. The practical and emotional assistance we received on that call helped our family move forward. Once we connected with Early Intervention services, things started to fall into place, and we discovered opportunities to support Henry’s healthy development. The newborn hearing screening made this all possible.

A decade ago, Henry’s hearing loss might not have been diagnosed until later in childhood. Fortunately, the Massachusetts Legislature recognized that this was a public health concern and passed one of the most comprehensive state newborn hearing screening laws in the nation. Leadership at the national level from the Maternal and Child Health Bureau and the Centers for Disease Control and Prevention assisted states by providing grant funding and establishing national guidelines and recommendations. The past decade was spent developing and enriching the system of care to serve and support families with infants and young children with hearing loss.

A strong outreach component, including bilingual staff and a parent outreach specialist, follow families from screening through Early Intervention. In 2008, the Universal Newborn Hearing Screening Program documented that 99.5 percent of the more than 77,500 infants born in Massachusetts were screened for hearing loss. Of the 1.8 percent (more than 1,400) infants who failed the screen, almost 96 percent received appropriate audiological follow-up care. And, of the more than 200 infants identified with permanent hearing loss, almost 77 percent were enrolled in Early Intervention. Massachusetts continues its commitment to families with infants and young children with hearing loss by working to ensure that children with hearing loss are identified as early as possible and receive timely and appropriate services.

Submitted by RICHARD WENTWORTH, parent, and JANET FARRELL, Universal Newborn Hearing Screening Program, Boston, Massachusetts
Michael, who was born with spina bifida, was in first grade when, during a routine screening, done by the school, he was found to be in serious need of glasses.

It turned out that, in fact, he could hardly see the blackboard! Michael is paralyzed and uses a wheelchair. He was being seen by countless specialists—orthopedists, urologists, neurologists, and others—for his many ongoing health issues, but missing from this array of medical providers was a pediatrician. Yet that is exactly the kind of provider who would have readily discovered Michael’s easily correctible vision problem. For a number of years, Michael had been in an institution, without access to regular, routine care. His new adoptive parents were so busy coordinating all of his specialty care that they hadn’t noticed that he didn’t see well and was in need of glasses.

Before the Bright Futures Guidelines were developed, it was common for children with special health care needs (CHSCN) to be treated for their chronic conditions and disabilities, but not routinely screened or treated for vision, hearing, dental, behavioral health, or obesity issues. Thank heaven for medical homes and for Bright Futures, which ensure that all children, including those with special health care needs, receive well child health and dental health check-ups, immunizations, and all the other screenings and care that they need.

When the Patient Protection and Affordable Care Act passed in 2009, Bright Futures was included in it! Section 2713, in an “Interim Final Rule,” which became effective in September 2010, spells out the preventive care services outlined in the Bright Futures Guidelines. These include 31 well-child visits (birth to age 21 years), with regular ongoing screening (vision, hearing, developmental, behavioral, oral health), along with immunizations and the provision of information and advice to families. Bright Futures was initiated by the Maternal and Child Health Bureau and has been spearheaded by the American Academy of Pediatrics, along with many partners, among them Family Voices. And because of these guidelines, the future looks brighter than ever—for ALL children!

Submission from
BETSY ANDERSON,
Family Voices,
Boston, Massachusetts

Thank heaven for medical homes and for Bright Futures.
The nearest metropolitan areas of Oklahoma City and Tulsa are located hundreds of miles away. A community such as this can only be described as very rural, which is exactly how the citizens of Major County, Oklahoma see themselves. Yet this rural community has developed sophisticated solutions to meet the needs of families with CYSHCN.

One program is Sooner Start, Oklahoma’s early intervention program designed to meet the needs of infants and toddlers with disabilities and developmental delays. The program is a joint effort of the Oklahoma Departments of Education, Health, Human Services, Mental Health Services, the Commission on Children and Youth, and the Oklahoma Health Care Authority. Families come to the county health department and are referred to Sooner Start for developmental screening. They find Sooner Start convenient because screening assessments are often provided right in the family’s home, where the child is most comfortable. Sooner Start screens children for vision, hearing, developmental, and mental delays. Most special needs are identified by the time the child is three or four. Denice Haworth, County Coordinator for the statewide Sooner SUCCESS Program, works with the families to ensure children are directed to the right resources.

Picture a quiet community located in the northwest area of Oklahoma with a population of about 7,000, the residents distributed sparsely across 957 square miles.
The community of Hillsborough County, Florida has two large collaborative programs that have been instrumental in improving the system of services for children with special health care needs (CSHCN): They are the Early Childhood Council of Hillsborough County (ECC) and Children’s Future Hillsborough (CFH).

Through an Early Childhood Developmental Screening Program, the ECC and the Florida Diagnostic and Learning Resources System have developed unique interagency developmental screening clinics. An astounding number of professionals, more than 200 each year, from a wide variety of community-based programs, screen children from birth to age 5 for problems in vision, hearing, motor skills, speech, language, cognition, behavior, and growth. When needed, these children are referred for evaluation or other community services, such as family support, childcare, parenting classes, behavioral support, and health insurance, through Florida’s State Children’s Health Insurance Program (called KidCare). Faith-based entities also partner with the effort by offering their facilities as a place to conduct the screenings. This is beneficial in many ways, including helping to increase the trust level within the community. As many as 1,000 young children per year benefit from this noteworthy effort. And they reap these benefits for free.

Submitted by
DONNA PRISLEY,  
Children’s Future Hillsborough, Tampa, Florida
Health Insurance and Financing
Having a way to pay for health care is fundamental for children with special health care needs (CSHCN), who often need diagnostic testing, primary and specialty physician care, durable medical equipment and supplies, prescription medications, hospital care, therapies, and other essential health-related services. Access to these services is critical for detecting health problems, preventing the deterioration of physical and mental health, and maximizing a child’s potential for transition to a happy, healthy, and productive adulthood. (cont.)
Adequate insurance is important to the families of these children and helps reduce their risk of financial hardship, medical debt, and the negative impact of stress on family functioning. When parents are the “payer of last resort” (meaning there is no other source of funding for their child’s health-related services), they are often forced to make difficult choices with regard to the family budget. In the worst case scenario, a family with inadequate health insurance coverage may not be able to provide essential health care for their child or meet other needs for the entire family, like food, clothing, housing, and education.

Until recently, progress in meeting the Healthy People 2010 performance objective that “families of children with special health care needs (CSHCN) will have access to adequate public and/or private insurance to pay for the services they need” has sometimes appeared to take the form of “two steps forward and one step back.” However, in spite of economic and political challenges, modest but measurable improvement over the last ten years has shown that we have been moving in the right direction.

For example, the rate of uninsured children with special health care needs has been moving steadily downwards, thanks in part to expansions in Medicaid and the Children’s Health Insurance Program (CHIP). According to the 2001 National Survey of Children with Special Health Care Needs (www.cshcndata.org), 5.2 percent of CSHCN were reported by their families to be uninsured at the time the survey was done. In 2005, that percentage went down to 3.5 percent. These data represent a significant positive impact on many individual CSHCN and their families.

States have been working to offer innovative solutions to the problems of uninsurance and underinsurance among CSHCN. Examples of strategies currently in practice include:

- **State-based health care reform:** Prior to reform at the national level, several states—including Washington, Massachusetts, Vermont, and Illinois—implemented nearly universal coverage for children.

- **Medicaid buy-in programs for CSHCN:** Many states allow families to “buy-in” to their Children’s Health Insurance (CHIP) programs, but only if a child has no other insurance. Several states now allow families with income over the Medicaid income eligibility limit to “buy in” to the Medicaid program, even if the child has private coverage. The Family Opportunity Act’s Medicaid buy-in option now
makes it possible to implement buy-in programs without obtaining a federal waiver or demonstrating cost neutrality. This is particularly valuable to underinsured CSHCN.

- **Relief or trust funds:** Several states operate relief or trust funds that provide “last resort” coverage for medically-related expenses not covered by insurance, when these expenses represent a certain percentage (usually 10 percent or more) of a family’s annual income. These funds are administered by either state Title V programs or by independent commissions.

- **Premium Assistance Programs:** Some states provide families with financial assistance to purchase private insurance on behalf of their child. This is usually administered as part of a Medicaid or CHIP program, but in some states this role is assumed by the state Title V program for CSHCN.

February 2009 brought exciting news in the form of reauthorization of the Children’s Health Insurance Program, originally established in 1997. The new law offers significant new funding for states and allows them the option to expand their CHIP eligibility to uninsured children in families with higher income levels. It offers mechanisms and incentives to increase outreach efforts, reduces administrative barriers to enrollment, and helps families maintain eligibility. It also includes improvements in pediatric health care quality and the scope of benefits offered through CHIP, as well as new provisions for premium assistance.

At the end of the decade, advocates across the country are celebrating the recent passage of the Patient Protection and Affordable Care Act of 2010, also known as national health care reform. Several components of the new law have the potential to alleviate the effects of uninsurance and underinsurance for CSHCN.

While the full impact of the law will take time to be revealed, we know that, as of this year, parents will never again have to worry about leaving the neonatal intensive care unit with their newborn already having reached his or her lifetime benefit cap. We know that a child who gets sick or injured will not be denied coverage based on having a pre-existing condition. We know that young adults, the group with the highest rate of uninsurance, will have access to their parent’s insurance coverage until the age of 26. These three initial components of national health care reform, which will be implemented this year, offer encouragement that, as a nation, we are moving in the direction of finally providing CSHCN with the health care coverage they need to play, learn, and grow to their fullest potential.

Submitted by MEG COMEAU, The Catalyst Center
The Children with Disabilities Medicaid Coverage Program allows North Dakota families whose income is less than 200 percent of the Federal Poverty Level to purchase Medicaid coverage for their children with severe disabilities. While some people said health care financing policy is too complicated for regular people to influence, the resounding success of the family advocates of North Dakota proved otherwise. I am proud and humbled to have been part of this experience.

Prior to passage of the bill, many North Dakota families of children with disabilities were caught in the gap between being over-income for Medicaid and being uninsured or underinsured through inadequate private coverage. No one knew better than the families the impact this had on them and their children. Many regularly faced the difficult choice between paying for medical care and paying for groceries. Families didn’t want a hand out; they needed a rope to hang on to, to prevent them from drowning in medical debt. They knew that buying into Medicaid would allow them to access the comprehensive benefits their children needed, while sharing in the responsibility for paying for it.

Family Voices of North Dakota helped create a coalition with other advocacy organizations, such as Protection and Advocacy, Federation of Families for Children’s Mental Health, North Dakota Disabilities Advocacy Consortium, The Arc of Bismarck, and The Arc of North Dakota. As we worked for passage of the bill, we used data and technical assistance from the National Survey of Children with Special Health Care Needs and the Catalyst Center to develop publications that, enhanced by stories from real families, helped policymakers understand the benefits of a Medicaid buy-in program for all stakeholders. Children’s Special Health Services, Medical Services, and Family Voices participated in calls with the Catalyst Center to better understand the data and cost elements of implementation.

Individual family members, new to advocacy, were uncertain at times about the legislative process and whether they could make a difference. We worked with them on sharing their stories, taught them how the process worked, and gave them technical assistance to ease their fears. By providing written testimony and sending e-mails to their members as the process moved forward, these advocates were able

In April 2007, North Dakota became the first state to pass legislation establishing a Medicaid buy-in program through the federal Family Opportunity Act.
Beginning in the fall of 2003, Rhode Island began enrollment of children with special health care needs (CSHCN) into the Medicaid managed care program called RIte Care on a voluntary basis.

At that time, one health plan, Neighborhood Health Plan of Rhode Island, participated in the program. In September of 2008, an additional plan, UnitedHealthcare of New England, began enrolling CSHCN, and enrollment therefore became mandatory. There are currently 6,500 CSHCN enrolled in RIte Care.

The Department of Human Services works with both health plans to conduct a comprehensive quality and financial managed care oversight program. These activities include: the reporting and tracking of informal complaints, grievances, and appeals; monthly meetings to discuss financial, quality, and operational impact on CSHCN; and reports on the measures of the Healthcare Effectiveness Data and Information Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) relevant to CSHCN.

As a result of our efforts, CSHCN enrolled in RIte Care have access to the large network of primary care and specialty physicians and benefit from the health plans’ care management and care coordination.

Submitted by
PAUL CHOQUETTE,
Rhode Island Department of Human Services,
Cranston, Rhode Island

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Submitted by
PAUL CHOQUETTE,
Rhode Island Department of Human Services,
Cranston, Rhode Island
Whenever we have been successful in engaging a new physician leader, a hospital executive, or a colleague in the state Medicaid program in a meaningful collaboration, these individuals have become our “new best friends.” While there have been many “new best friends” over the years from a wide range of organizations, we can honestly say we never thought that we would use this phrase to describe a group of health plan executives.

In 1999, we launched the Massachusetts Consortium for Children with Special Health Care Needs, an informal group of 20 colleagues committed to improving the system of care in Massachusetts for CYSHCN and their families. They included Title V staff, other public agency personnel, families, clinicians, and researchers. Everyone in the room knew who and what Title V was. Indeed, most were receiving financial support in the form of grants from The Maternal and Child Health Bureau (MCHB). There were no commercial health plans at those early meetings, and we were quite sure that no one in that world knew what Title V was. In fact, managed care organizations were seen as the problem, if not the enemy. We knew that health care financing was a top concern for children and families in the state, yet we had no working relationships with any of the payers beyond Medicaid. How would we ever address the goal of improving the adequacy of health care coverage without partnerships with health plans?

Over the next eight years the Consortium grew to include more than 200 members. It developed a model that emphasized the power of partnerships in addressing gaps and barriers in the state’s service system. Gradually, we recruited and engaged more than thirty individuals from nine major health plans. In 2007 we published a booklet entitled, Making the Case for Coverage: Tips for Helping Children and Families Get the Benefits They Need from Their Health Plans. The product was the result of
two years of active collaboration with public and private health insurers and carried endorsements from nine health plans in Massachusetts. It explored the complicated territory of how things work inside health plans, how coverage decisions are made, and how to influence the decision-making process, including instructions to physicians on writing successful letters of medical necessity. We wrote it with our “new best friends,” our health plan partners. Looking back, the recipe for success included five critical ingredients:

- **Financial support:** The roots for these new partnerships began with the Shared Responsibilities Project, funded by MCHB, to develop a quality improvement process for CYSHCN in managed care.

- **Health plan champion:** From the beginning, we had a strong champion in the Medical Director of a respected Medicaid managed care organization in our state. Through this champion, families and providers worked together to develop a toolkit for public and private payers.

- **Leadership from the state public health agency:** The state Department of Public Health (DPH) had a track record of collaboration with health plans in the state on population-based issues such as smoking cessation and asthma guidelines. DPH leaders opened the door for us to this group and made the case for focusing on another critical population, CYSHCN.

- **Family-professional partnerships:** Health plan leaders worked side by side with families, providers, state agency staff, and researchers. Hearing real family stories about unmet needs increased their understanding of the gaps in care and health care financing for CYSHCN. Meanwhile, families learned more about how health plans really work.

- **Forum for communication:** Out of these discussions came a work group, reflecting the broad membership of the Consortium, to explore the medical benefit decision-making process, resulting in publication of *Making the Case for Coverage*.

It turned out that health plans, just like families and providers, were frustrated. They needed more complete information in order to make more informed decisions. They also wanted families and providers to better understand how decisions were made. There was a shared agenda to increase transparency in navigating the health care benefits process. All parties were committed to helping CYSHCN get the benefits they need from their health plans. We worked together, we gathered information, we put it in writing, and we’ve made real, positive improvements for CYSHCN and their families in Massachusetts. Best of all, we have some “new best friends” on our team.

Submitted by
SUSAN EPSTEIN,
New England SERVE,
Boston, Massachusetts
One family’s health insurance ordeal is almost over. In 2001, Sharon Mondry took her two-year-old son, Zev, to speech therapy.

Months earlier Zev had stopped talking, and his doctors eventually diagnosed him with autism, recommending speech therapy to help him regain some ability to speak. Zev’s speech therapy was initially covered through Wisconsin’s Birth to 3 Program. When Zev turned three, Sharon switched him to her employer-sponsored insurance to cover future therapy. Sharon carefully reviewed the health plan offered by her employer, communicated with human resources staff, and felt confident that the plan covered speech therapy. Sharon continued to get treatment for Zev. A few months later, Sharon received a letter from the plan’s claims administrator, denying coverage for Zev’s speech therapy.

When Sharon questioned the denial, she got the runaround. The claims administrator directed her to her insurance company, which directed her back to the claims administrator, which referred her to her insurance company again. Stymied, Sharon contacted ABC for Health, Inc (ABC). Inspired from a ABC for Health Project funded by the Maternal and Child Health Bureau in the early 1990’s, ABC is a nonprofit, public-interest law firm dedicated to linking families and
children, particularly children with special health care needs, to health care coverage and services. Since opening its doors, ABC for Health has assisted more than 31,000 family members across Wisconsin.

ABC fights for families on a variety of fronts. The firm trains advocates and raises public policy concerns about access to care and coverage for families. In addition, ABC provides health benefits counseling to help families determine eligibility for public and private health plans, manage medical debt, and appeal benefits denials.

ABC demanded that Sharon’s insurance company and its claims administrator produce the plan documents used to deny Zev’s speech therapy. ABC made phone calls, mailed letters, and sent emails to secure the documents to help Sharon understand and challenge the therapy denial. From the earliest correspondence, ABC warned the insurance company and the claims administrator that refusing to produce requested plan documents could result in penalties of up to $110 a day. Yet they both stonewalled Sharon and ABC for 27 months before finally releasing most plan documents.

In 2006, Sharon and ABC took her insurance company to court. In the lawsuit, eventually appealed to the U.S. Supreme Court, ABC’s Executive Director and public interest attorney, Bobby Peterson, argued that Sharon’s insurance company broke the law when it refused to require its claims administrator to respond to Sharon’s requests for the documents used to deny coverage of Zev’s speech therapy. The Seventh Circuit Court of Appeals agreed. The Court decision, which still stands today, noted that health plans cannot “hide the ball” from plan participants and withhold the documents they need in order to appeal benefits denials.

Sharon’s ordeal is not quite over. A few legal questions about fines and attorney’s fees remain to be resolved. But already her victory will ensure that other families fighting a benefits denial will not face similar refusals before they get the plan documents they need to appeal a denial of services.

Submitted by
BOBBY PETERSON,
ABC for Health, Inc.,
Madison, Wisconsin
In July 2000, Massachusetts passed legislation establishing the Catastrophic Illness in Children Relief Fund (CICRF) to help families bear the excessive financial burdens associated with the care of children with special health care needs.

It was modeled after the New Jersey Fund of the same name and was one of the first funds of its kind in the nation.

While virtually all children in Massachusetts have health insurance, many families find their child’s insurance inadequate. CICRF provides financial assistance to families with children experiencing a medical condition requiring services that are not covered by a private insurer, federal or state program, or any other financial source. The Fund is overseen by an 11-member Commission and is staffed by the Title V CYSHCN program at the Massachusetts Department of Public Health. It is funded through employers’ contributions to the state unemployment health insurance trust fund.

To be eligible, the child must be under age 22 and a Massachusetts resident, and the family’s out-of-pocket expenses related to their child’s condition must exceed 10 percent of the family’s annual income up to $100,000 and 15 percent of any portion of the annual income above $100,000.

From July 2000 through June 2009, CICRF provided $12.2 million to the families of 947 children with a variety of medical conditions. Types of expenses covered included: costs associated with medical supplies and equipment; therapies, hospital and physician services; travel and related expenses during hospitalizations; some alternative or complementary treatments; accessible vehicles; and home modifications.

CICRF has proven to be an invaluable resource for families struggling with the need to preserve family life in the face of unbearable financial obligations. The testaments of parents below speak to the remarkable differences the Fund has made in their lives:

I want to express to you the sincere joy and relief the CICRF has given me as a parent with a child with extensive medical needs. I am grateful in knowing that there is an organization that understands the overwhelming struggles of having a child with medical issues and has ensured funding is available to assist those in need. You have blessed us with giving my son the opportunity of having medical treatments that he would have been otherwise unable to receive.

Thank you for allowing my child to reach her full potential! She is doing amazingly well since her return from her therapeutic program. These successes have only been possible through CICRF, by allowing us to focus on our child’s needs, not the financial setbacks of her condition. Thank you again for contributing to our daughter’s success.

Having to deal with all these medical issues has definitely taken a toll on us. Thanks to the Fund, we have been able to keep our house and pay many overdue bills.

Over the years the Fund has supported us through several financial obligations that parents never expect or plan on when a child is born. The Fund has lessened our stress around providing our son the care he needs at home with us. With our handicapped van, ramp, and more appropriate bathroom, we can keep him safe and maintain our ability to be his caregivers!

Submitted by
NICOLE ROOS,
Massachusetts Department of Public Health,
Boston, Massachusetts
We suspect the response to this question for most youth and young adults with special health care needs—regardless of age, employment status, income, or education level—would be “D.” While we’ve certainly witnessed significant changes in paying for health care services over the last decade, it doesn’t seem to get any less complicated. The new federal Patient Protection and Affordable Care Act promises to further redefine our country’s approach to health care financing—hopefully for the better!

Young adults, ages 19 to 29, experience more difficulty accessing health insurance coverage than any other group of consumers and have the highest uninsurance rate of any age group. Almost half were uninsured at some time during the past year. Moreover, research shows that young adults with chronic health conditions or disabilities who don’t have adequate coverage are at much higher risk for poor life outcomes.

Fortunately, increasing awareness of the issues around health care transition, including adequate financing of adult health care services, has resulted in more focused attention on the needs of young adults. Under the leadership of FloridaHATS, a new “Health And Transition Services” program located within Children’s Medical Services (Florida’s Title V program), we developed a health insurance guide for all young Floridians ages 0 to 18, including those with complex medical conditions. The 64-page guide provides “just the facts” about health care coverage options in order to help young adults—with support from their parents, caregivers, or trusted allies—decide which plans might work best for their particular needs.

Using a matrix design, we list private and public financing options available in Florida, identify key eligibility requirements for each, as well as what to consider in choosing a plan, how to apply, potential out-of-pocket costs, monthly premiums, the good and not-so-good points about each plan, state and federal laws, and resources to learn more. Our hope is that the guide will help all young adults in Florida secure the health insurance they need to be healthy, happy, and productive. We also hope other states and communities will follow Florida’s lead and develop their own guides.

We’re looking forward to another 10 years of progress in improving outcomes in adulthood for CYSHCN, especially in improving health care coverage!

Submitted by
PATTI HACKETT,
Healthy and Ready to Work National Center,

JANET HESS,
University of South Florida
School of Medicine,
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PHYLLIS SLOYER,
Florida Department of Health,
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MEG COMEAU,
Catalyst Center

Our hope is that the guide will help all young adults in Florida secure the health insurance they need…

Question: How would you describe your experience getting, paying for and using health insurance?

a. Confusing
b. Frustrating
c. Anxiety-provoking
d. All of the above
To support federal and state level Children with Special Health Care Needs (CSHCN) programs in their efforts to implement effective systems of care, the Maternal and Child Health Bureau (MCHB), in partnership with the National Center for Health Statistics (NCHS), developed the National Survey of CSHCN.

The survey is designed to produce reliable state and national level estimates of the prevalence of special health care needs using MCHB’s definition of CSHCN. The questionnaire content was developed under the leadership of MCHB with input from state Title V programs, family organizations, professional organizations, researchers, and others. Because the survey was first conducted in 2001 and repeated again in 2005 to 2006 and 2009 to 2010, it is possible to analyze trends.

The survey, conducted by telephone, includes approximately 750 to 850 children with special health care needs in each state and the District of Columbia. Parents or guardians respond to a comprehensive set of questions on demographics, health and functional status, health insurance coverage, adequacy of health insurance coverage, public program participation, access to care, utilization of health care services, care coordination, satisfaction with care, and the impact of the child’s special needs on the family. A goal from the beginning was to make the data widely available to potential users. Chartbooks, dedicated special issues of journals, electronic data files, technical reports, and access to the MCHB supported Data Resource Center, which provides customized reports from the survey, are available at no cost to users.
The survey has many uses. It is used by state and federal Title V programs for program planning and evaluation purposes. State Title V agencies use the survey in conducting their five-year needs assessment activities. The survey is being used by MCHB to measure progress toward meeting the Healthy People 2010 objectives related to CSHCN. The survey has provided a valuable source of data for health scientists, health services researchers, practitioner organizations, family organizations, and advocacy groups. For example, advocacy groups use the data to illustrate the range of services needed by CSHCN and the numbers of uninsured and underinsured children with special needs. There are also rich research opportunities in the epidemiology, health services, and health policy areas. Some of the research questions that have been addressed using the National Survey of CSHCN include:

- Are the health care needs and concerns of families of CSHCN being addressed?
- To what extent do unmet needs exist?
- What is the level and type of health insurance coverage and how well does it cover special health needs?
- What factors are associated with the receipt of better quality, more comprehensive care?
- What proportion of CSHCN have a medical home?
- What is the impact of the child’s condition on the family finances?

Success rates in attaining the core outcomes in 2005 to 2006—the most current data available to this point—ranged from 41.2 percent (the core outcome on transition to adult health care) to 89.1 percent (the core outcome on ease of using services). At mid-decade, the U.S. was at the halfway point or beyond for four of the six core outcomes, and close to halfway on the other two. These results indicate that a foundation is in place for the nation to meet the six core outcomes. But these encouraging findings are tempered by the fact that only about one in six CSHCN met all six core outcomes and were therefore accessing high quality systems of care in 2005 to 2006. Hence, much more investment is needed on the part of all of the major players in the health care system before comprehensive systems of care are available for all CSHCN.

The National Survey of CSHCN offers a unique data source for individuals and organizations interested in understanding and improving service delivery for CSHCN. It is an accomplishment that reflects the contributions of state and federal Title V programs, family organizations, provider organizations, health services researchers, and the broader maternal and child health community.

Submitted by
PAUL NEWACHECK,
Philip R. Lee Institute for Health Policy Studies
University of California,
San Francisco, California
Over the past 10 years, tremendous progress has been made in achieving the Healthy People 2010 outcome that calls for community-based service systems that are organized so families can use them easily. This outcome has been the impetus to transform disconnected individual assistance, support, and medical care services into community-based systems providing services and supports that are inclusive, coordinated, family-centered, and culturally competent. (cont.)
Community Services
(cont.) These systems are designed not only to ensure that all children and families receive the educational and health services they need, but also to encourage their involvement in scouting, after school programs, religious or spiritual activities, playgrounds, and public transportation.

A community-based system allows for local decision making, ease of access within a geographic area, and coordinated services provided by people who embrace family-centered principles and can help guide families to available resources. Communities can organize services in many ways. These can include: using interagency applications; providing care coordinators, often via the medical home, who understand the needs of the child within the context of the family; or using technology, such as integrated data systems and telehealth. Communities can bring together public-private partners to develop policies and practices to integrate services or create innovative financing mechanisms, such as blended funding to fill gaps. And communities can ensure that services are cost effective, alleviating financial burdens on families and preserving family time by reducing the amount of time these families would otherwise spend on organizing services for themselves.
Achieving easy-to-use community systems also depends on achieving the other performance outcomes for children and youth with special health care needs (CYSHCN). Family partnership is essential in understanding the challenges families face in getting the services they need and the development of solutions to address these challenges. Medical homes play a key role in coordinating care. Families must have a way to pay for services they receive in the community. They must know where and when to go for continuous screening that can help identify children and youth in need of services. Access to transition services must be available in the community so that families and youth receive them in a coordinated way that fits with the vision of their future.

Community coalitions and wrap-around service teams make sure that families are at the table, serving as active participants. In San Francisco, California and Major County, Oklahoma, community coalitions bring key stakeholders together to develop practical solutions that fit their communities. The voice of all families, particularly those from under-represented populations, can be heard via the engagement of “cultural brokers” on service teams. Family-directed efforts such as the Family-to-Family Health Information Centers have been instrumental in helping families find out about services in their communities.

Strong state policies and practices focused on infrastructure building are providing support to communities. State funds provided through mini-grants and blended funding pools can help communities address unmet needs of families. Many state CYSHCN programs have created regional/community offices that provide care coordination to families of CYSHCN, as well as fostering collaboration with medical homes, schools, and other community partners. Wisconsin’s CYSHCN regional offices play a key role in coordinating services for the broad CYSHCN population, while supporting other providers, such as those offering medical homes.

Federal policymakers, particularly those within the Division of Services for Children with Special Health Needs (DSCSHN) in HRSA’s Maternal and Child Health Bureau (MCHB), have provided critical leadership in their support for family-driven, community-based service systems. Discretionary grants from MCHB have helped states create community-based service systems and provided funding to support innovative efforts.

Submitted by
DIANE BEHL,
Champions for Inclusive Communities National Center
I had the pleasure of co-directing with Dr. Richard Roberts a project funded by the Maternal and Child Health Bureau (MCHB) that was intended to integrate Utah’s services for CYSHCN and their families so that they could use them more easily. The ultimate outcome of this project was the creation and adoption of a cross-program, cross-agency online application system called Utah Clicks, which helps families complete and submit application paperwork to multiple state programs without having to enter duplicative information more than once. During the grant, Utah Clicks was piloted in six Utah communities to gain acceptance by families, as well as by administrative staff and intake workers from the participating agencies at the local level. Since 2006 more than 92,000 families have used Utah Clicks to apply for public services online.

With some additional funding, we were able to acquire the rights to the prototype to develop the full code for the Utah Clicks system. In 2006 Utah Clicks won an Innovation Award from the Council of State Governments. The system has been operating in Utah for five years. Families are able to complete and submit paperwork for a variety of programs such as Early Intervention, Children and Youth with Special Health Needs, Baby Your Baby, Head Start, and others. Medicaid and Utah’s Child Health Insurance Program (CHIP) were part of the effort until recently, when they were shifted to another online system.

Utah Clicks has maintained a 98 to 99 percent customer satisfaction rating for five years running. What most gratify me are the specific comments submitted by families about the Utah Clicks system. The following are just a few of the thousands of user comments.

- It saves a lot of time so you don’t have to go from site to site to find the right applications.
- I think this is an amazing website. It helps lost souls like myself that have no idea where to get help.
- I thought it was easy and provided all possible situations. I was able to enter lots of information very easily.

Submitted by 
ADRIENNE AKERS, Dynamic Screening Solutions, Inc., Logan, Utah

A vexing problem that families of children and youth with special health care needs (CYSHCN) across the nation have reported is the challenge of finding and applying for the myriad public services for which their family might be eligible.
Imagine, if you are a family member of a child with special needs, how helpful it would be to bring together a team of local health, education, and social services folks to discuss your child’s needs—everyone at the same table at the same time.

Then imagine how great it would be if at least one team member had walked a mile in your shoes, because they have a child with complicated needs in their own family. Some families in Oregon don’t have to imagine. Their children are served by the Community Connections Network and the Family Involvement Network.

The Community Connections Network (CCN) has been coordinating care for children and youth with special health care needs (CYSHCN) at the community level for over 15 years. Ten CCN teams around Oregon meet monthly to create plans of care for children who are referred to CCN. Family members, physicians, health and community service providers, and education professionals participate on each team. Together, they coordinate care, identify resources, and plan on behalf of these children. Along the way, team members improve their local systems of care by strengthening partnerships and finding solutions. They identify gaps and overlaps in services. This collaboration helps them leverage their resources to meet the most pressing needs of the community’s children and youth and their families. As Dr. Donna Rabin from Coos Bay, Oregon put it:

Our small community has a huge number of caring, knowledgeable individuals who are willing to come to the table to problem-solve. We have found that by working together we can often come up with creative solutions for children and families using our local resources. And although none of us has all the answers, together we have more answers.

As CCN teams took root in their communities, each developed its own character and style. But one thing they all had in common was a desire to better understand the needs of the families they served. To address that desire, the Family Involvement Network program was developed, and they launched a new CCN team member position in 2005: the Family Liaison. Family Liaisons represent the family perspective on CCN teams. The position can only be filled by a family member of a CYSHCN. Theirs is wisdom that can only be gained from first-hand experience. One of the professionals on a CCN Team noted: “We didn’t know what pieces we were missing until we had a family member on our team.”

Family Liaisons are selected by local CCN teams. They are screened, trained, and mentored by families staffing the Family Involvement Network. Family Liaisons help support families before, during, and after CCN meetings. They help families get the most from CCN and they help CCN teams keep everyone’s focus on the common goal of meeting the needs of CYSHCN and their families. As one of the Family Liaisons said, “I know how I felt when I had complete strangers helping me at my lowest point. I try to offer what I was given: compassion, caring, and acknowledgement of my role as a parent.”

Submitted by GILLIAN J. FRENEY, Community Connections Network, Oregon Center for Children and Youth with Special Health Needs, Portland, Oregon

Together, they coordinate care, identify resources, and plan on behalf of these children.
Jackson has a unique and highly effective approach when it comes to organizing services so families can use them easily.

Jackson, Mississippi is routinely described as a “city with soul.” Located in the heart of the Deep South, Jackson is home to a rich array of people from different cultures. Because it is the capital of Mississippi and the most populous city in the state, the citizens of Jackson must pull together to form a united community. This is especially relevant when it comes to children and youth with special health care needs (CYSHCN).

Jackson has a unique and highly effective approach when it comes to organizing services so families can use them easily. It is home to the Jackson Medical Mall Thad Cochran Center, a once-shopping mall that was converted almost 15 years ago into a thriving hub of medical services. In the words of Zakiya Summers, Public Relations Manager for the Jackson Medical Mall Foundation, “We are a model facility of non-profit, community, retail, and human services—all in one safe environment. We are the mall with it all.”

The Jackson Medical Mall is lucky to have Mississippi’s Title V Children with Special Health Care Needs (CSHCN) program, the Children’s Medical Program (CMP), located right within its walls. The CMP provides financial and medical assistance to children and youth with chronic or disabling conditions. They have 14 community satellite clinics throughout the state, but their central one stop multi-specialty clinic, called the Blake Clinic for Children, is located at the Mall. The CMP provides services such as pediatric specialty care, durable medical equipment, and referral services to other community resources via pediatric social workers and family liaisons.

In addition, the local Family-to-Family Health Information Center is located close by in a part of the mall called the Resource Library. Jacqueline Washington serves as the Parent Liaison for the center and acts as a valuable resource by directing families to the appropriate service for their needs. Jacqueline also advocates for families in monthly meetings with the metro community, where she discusses any concerns and shares information about upcoming center events.

One of the benefits of the Jackson Medical Mall is the fact that a family’s medical home is essentially embedded within its walls. A child’s primary care provider and many of his or her specialists are often located right inside the mall. The Children’s Medical Program makes it a point to ask each family they see in their clinics who its primary care physician is so that communication and coordination is fostered with each child’s medical home.

The Medical Mall also helps families with insurance. When families express concern about financing their children’s medical needs, they are usually directed to the Medicaid office, a tenant of the Mall. Families who receive services from the Children’s Medical Program also have the added benefit of knowing the CMP has developed a network of providers that accept their rates for services rendered. CMP is the payer of last resort if patients do not have private insurance or Medicaid.

The idea to convert an ordinary shopping mall into a successful hub of medical services has been a relief for families in the area. The list of tenants in the Jackson Medical Mall is long, but each of them is working together to create an integrated community-based system of services for CYSCHCN and their families. The Medical Mall truly is a good example of how this “city with soul” takes care of its own.

Submitted by ZAKIYA SUMMERS, Jackson Medical Mall Foundation and JACQUELINE WASHINGTON, Family-to-Family Health Information Center, Jackson, Mississippi
The Children’s Partnership (CP) in Travis County, Texas focuses on providing services to children and youth with complex needs and their families, particularly children and adolescents with serious emotional disturbances, and on “changing the way business is done” in child, youth, and family organizations.

Instead of having one physical location, the CP operates virtually. This means the organization’s “location” is a P.O. Box, and services are provided at the families’ homes or at community locations.

The 44 team members that carry out the work of The Children’s Partnership are all employed by partner agencies that are spread throughout the community. These agencies include the Travis County Juvenile Probation and Health and Human Services Departments, the local Mental Health Authority, Casey Family Programs, and several Independent School Districts. There are more than 100 providers, partner agencies, and team members who work together to comprehensively meet the complex needs of children, youth, and families. Princess Katana, Director of CP, emphasizes that their unique approach is “truly a community-based way of serving and working with children and youth with serious emotional disturbances and their families.”

The Community Partners for Children (CPC) initiative, a key partner, serves as the single point of community access to services and supports for children, youth, and families. CPC provides a unique opportunity for youth and families to share their experiences and talk about their hopes and needs with representatives from approximately 30 public and private organizations who meet together twice a month. Families who attend CPC meetings leave with a plan of care that starts them on their way to accessing services in the community.

The Children’s Partnership collaborates extensively to expand existing resources and establish new services by including the investment of resources offered by grassroots providers to support youth and family access to non-traditional services. Such strategic investments have effectively reduced the service gaps in Travis County.

An important aspect of CP’s community-based approach to service delivery is the flexible funding pool to which partners contribute annually. This method ensures that categorical funding doesn’t drive the service delivery, but that youth and families have access to the full array of services and supports required for them to achieve their goals.

The Children’s Partnership is a truly successful initiative and a model for other communities. The clear message that The Children’s Partnership and its supporting community of Travis County emphasize is that, when resources are united and youth and families are supported in achieving their goals, they maintain their success. This results in children and youth with complex needs being able to live successfully with their families in their homes and participate positively in school and community. This, according to the staff at The Children’s Partnership, is the most important goal of all.

Submitted by PRINCESS KATANA AND CHRISTY KUEHN, The Children’s Partnership, Austin, Texas
For more than two decades, the High Risk Infant Interagency Council (HRIIC) has been working to improve the organization of services for young children with special health care needs in San Francisco.

HRIIC was created over 20 years ago when the state of California, along with other states, received federal funding (Part H of IDEA) to implement early intervention interagency groups that would coordinate services for infants and toddlers county-wide. When the original funding ran out, the county believed the program to be a vital part of the community and continued funding to ensure coordinated services. Today, HRIIC receives funding through the state cigarette tax and is stronger than ever.

HRIIC reflects strong partnerships among many agencies throughout the community. The Golden Gate Regional Center, Support for Families of Children with Disabilities (a Family-to-Family Health Information Center), San Francisco Unified School District, and California Children Services, among others, work with HRIIC to streamline services for families. They accomplish this through a very successful model of interagency collaboration evidenced through regular interagency meetings and interagency care coordination.

They also mentor them in their role as decision makers regarding the care of their children by providing information, support, and training.
HRIIC’s Roundtable meets monthly and is made up of a group of care coordinators working on behalf of families to better connect young children to services. The Roundtable discusses various options for services and collaboratively brainstorms and makes recommendations for services. According to Ann Carr, Director of HRIIC, the Roundtable is known for “constantly reaching out to bring the community services to families and their children with special health care needs.”

Support for Families of Children with Disabilities provides families with peer-to-peer support through community resource parents (CRPs). CRPs are there for families as empathetic guides to help them navigate the often confusing system of services within the community. They also mentor them in their role as decision makers regarding the care of their children by providing information, support, and training. Most parents find this support from other family members invaluable.

HRIIC convenes regular General Council and Steering Committee meetings of interagency stakeholders to address barriers that families experience in accessing early intervention services. It also develops interagency solutions to coordinate service delivery system for families.

Because San Francisco has such a diverse population, services must be offered in languages that families speak and with knowledge of family customs and values. To meet this need, Family Resource Centers, jointly funded by three San Francisco agencies, are located throughout San Francisco. They provide a range of family support services, including counseling, case management, referrals, parenting workshops, family-child activities, mental health services, and homework help in a variety of languages. “Here, families can enroll in health insurance programs and gather information about a variety of other services, such as food stamps and income taxes,” explained Laurel Kloomok, Director of First 5 San Francisco. HRIIC’s website also contains translations of all resources in Spanish and Chinese.

When asked how they are able to sustain their efforts over time, the community gives credit to the city government funders who recognize the importance of the work and are willing to make it a priority. Janice Polizzi, Early Childhood Special Education Director for the San Francisco Unified School District, also says, “I think we have a willingness to look at issues as they arise and figure out ways to bring partners together to address those issues.” HRIIC and its partners hope to continue to strengthen the community and families with CYSHCN by sticking together for many years to come.

Submitted by
ANN CARR,
High Risk Infant Interagency Council and JUNO DUENAS,
Support for Families,
San Francisco, California
Here, as in many other communities, providing services to children and youth with special health care needs (CYSHCN) depends on a large network of supporting organizations and programs, including the Early Intervention Program, Head Start, and Indian Health Services.

The reservation itself makes up a unique community. Governed jointly by two Native American tribes, the Eastern Shoshone and the Northern Arapaho, the Wind River Reservation is the seventh largest Indian reservation in the country. It spans 2.2 million acres, with the Shoshone occupying the western half and the Arapaho living in the central part of the reservation.

The Early Intervention (EI) Program is considered part of the Eastern Shoshone Tribe because the Shoshone Business Council acts as the program’s board of directors. The Early Intervention Program provides services to all children with disabilities and/or delays, birth through age five, as well as to their families, who reside on the reservation. Funding for the program comes from both the state of Wyoming and from federal funds. In other states, the 3 to 5 year age population is usually grouped within the school districts, but, in Wyoming, there are 14 regions that provide special education services to infants, toddlers, and preschoolers. The Wind River Reservation is its own region, Region 14.

Many of the families to whom the program provides services, whether they are of the Shoshone or Arapaho tribes, have little or no means of transportation and oftentimes don’t even have access to a phone. Therefore, the EI staff is constantly traveling around the very large reservation visiting children and families in their natural environment. Staff members are accustomed to doing whatever it takes—reaching out to the families on the reservation—in order to ensure families are receiving services for their children with special health care needs.

The EI Program, in conjunction with local school districts, conducts Child Find screening for children ages birth through five. Community-wide screenings are held in June and August every year all over the reservation. The program also receives referrals from other community members, such as those from Head Start, preschools, and daycare centers, all year round. When a potential problem is raised, the children don’t have to go far; the EI Program not only screens, they also provide many of the services children need right within their own walls. Full-time staff members include physical, occupational and speech/language therapists, social workers, special education teachers, and mental health clinicians.

Serving residents spread far and wide is time-consuming, frustrating at times, and challenging. However, staff members at the EI Program are a reflection of the culture of their community on the reservation and seem to view the challenges with a “that’s just the way it is” attitude. They find their own unique ways of reaching out to families of CYSHCN based on cultural norms to ensure they are receiving the services they need and don’t worry much about the extra effort that may be involved. There are recognizable benefits as a result of their steady stream of outreach. Families receive many services and are able to connect with staff members from the convenience of their homes, no matter how isolated those homes may be.

Submitted by LAURENE HINES, Wind River Reservation, Wyoming

Staff members are accustomed to doing whatever it takes.
The Special Kids Network in Pennsylvania initially began serving children and youth with special health care needs and their families by providing information and referrals in six regionally based offices.

In response to the needs of parents and providers identified through the network’s helpline, the Community Systems Development initiative was developed to provide technical assistance to local community-based organizations and families. Out of a desire to be able to provide callers to the Special Kids Network with more comprehensive information and referral resources, the helpline function was centralized at the Health and Human Services Call Center, where the Special Kids Network helpline was joined with eight other help lines servicing needs across the lifespan.

Within the last several years, the Community Systems Development initiative became centralized and was renamed the Special Kids Network System of Care. The mission of the Special Kids Network System of Care continues, as we work with communities to address the barriers families experience when trying to get needed information and services for their children and youth with special health care needs. Through collaborations like the Memorandum of Understanding for a Shared Agenda for Youth and Young Adults with Disabilities, we continue to work together with youth and young adults with disabilities, families, and caregivers to support the achievement of healthy lifestyles, post-secondary education, training and lifelong learning, and community participation.

The Special Kids Network System of Care takes every opportunity to identify gaps in services across Pennsylvania and to ensure that the needs of our children and youth are met and services are not duplicated. We accomplish this by aligning with organizations such as Military OneSource, Operation Military Kids, and the PA CARES Task Force.

The Special Kids Network System of Care has continued to meet its goal of developing more coordinated service systems in the community. Through the use of twelve Family Health Nursing Services Consultants, the Special Kids Network System of Care demonstrates its regional presence through community resource mapping, outreach, and statewide initiatives. Being part of the Bureau of Family Health in the Pennsylvania Department of Health offers the potential for collaborations with our Newborn Screening and Genetics Division as they provide up-to-date and expanded data on children identified at birth with special health care needs.

Submitted by
MICHELLE CONNORS,
Pennsylvania Department of Health, Harrisburg, Pennsylvania
Since the first National Survey of Children with Special Health Care Needs (NS-CSHCN) in 2001, families have become the most important source of data in the U.S. for driving improvements in the system of care for children and youth with special health care needs (CYSHCN).

Starting in 2001 with support from the Maternal and Child Health Bureau (MCHB), a group of family and Title V leaders, family-centered measurement experts, and other maternal and child health leaders collaborated to develop the MCHB-supported National Maternal and Child Health Data Resource Center for Child and Adolescent Health (DRC). Through an easy-to-use website (www.childhealthdata.org), hands-on technical assistance, and data skills building trainings, the DRC provides families, advocates, program leaders, policymakers, and researchers with direct access to data on more than 100 indicators from the NS-CSHCN and the National Survey of Children’s Health (NSCH).

Under the leadership and day-to-day operation of the Child and Adolescent Health Measurement Initiative (CAHMI), more than 400,000 visitors have accessed data and support through the DRC, representing over 20 million “data hits.” This has resulted in hundreds of data reports, media and research articles, and advocacy fact sheets that blend data with family stories to educate and motivate continuous improvement in health systems, as well as in the health status and quality of life of CYSHCN. Data summaries, technical assistance, and other resources obtained from the DRC have been used to develop grants, engage partners in efforts to advance health and system performance for CYSHCN, and advance the education and training of future maternal and child health advocates, researchers, and program leaders.

In addition to data from the 2001 and 2005 to 2006 NS-CSHCN, the DRC website allows point-and-click access to findings from the 2003 and 2007 NSCH on both health services and outcomes. Users can look at tables and maps that compare all states at one time. They can also interactively compare any two states or just focus on their own state and easily download charts or tables of results. DRC visitors can download ready-to-hand-out state level reports that present multiple indicators at one time or can select the indicators they are interested in and customize their own state level reports. All indicator results can be compared by state or region, as well as by race/ethnicity, income, insurance, or CSHCN status. This allows data users and child health advocates to demonstrate state variations and disparities in health and system performance.

Both the NS-CSHCN and NSCH are telephone surveys supported by MCHB and conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention. A diverse group of family leaders, pediatric researchers, and health experts comprise the technical expert panel that designs and revise the surveys. In addition to being the source of data for these surveys, families have played a critical role in evolution of the surveys, providing key input on the content and the clarity of the surveys.

The impact of these national data and the DRC can be seen at all levels of child health and health systems performance:

- **At the national level**: Increased attention on children’s health issues has led to more partnerships among DRC staff and federal policymakers. For example, several leading articles on childhood overweight and obesity have been published using data and support through the DRC; these have directly informed policymakers through national, state, and local forums and media articles. With assistance from the DRC, numerous health and system performance indicators from the NS-CSHCN and NSCH have also been used to construct key Healthy People 2010 and emerging 2020 indicators, have been endorsed for use by the National Quality Forum, and reported on in the National Healthcare Disparities Reports published by the federal Agency for Healthcare Research and Quality.
• **At the state level:** The NSCH and NS-CSHCN were developed with State Title V leaders in mind, allowing them to systematically measure their state’s system performance on the MCHB core outcomes, to perform their needs assessments, and to advocate for improved services. North Dakota went even further by working with the DRC to develop a comprehensive report intended to help key stakeholders—policymakers, advocacy groups, community based organizations, and parents—understand the health and well-being of CYSHCN in North Dakota. In November of 2009 the report won an award for excellence in public health communication from the National Public Health Information Coalition.

• **Directly in families’ lives:** Frustrated with fragmented and inadequate health systems for her son Bobby, who was born with Down syndrome, Carrie logged on to the DRC to find information she could add to testimony she was preparing for a legislative budget hearing. With the help of DRC staff, Carrie located the information she needed for her testimony on Massachusetts and national statistics for a budget hearing in 2004 and again in 2005. After the 2005 testimony, flexible funding for support to families with special needs children was increased for the fiscal 2006 budget year. Her testimony was later used by a legislator to confront state government about lack of services for CYSHCN. She continues to work tirelessly to increase medical and support services for families of children with special needs.

The MCHB’s goal of getting this invaluable data into people’s hands through the DRC is being met!

Submitted by
**CHRISTINA BETHELL,**
National Data Resource Center for Child and Adolescent Health,
Portland Oregon

The impact of these national data and the DRC can be seen at all levels of child health and health systems performance.
Transition
The Maternal and Child Health Bureau-funded Healthy & Ready to Work (HRTW) initiative has, since its inception, been committed to enhancing and improving health, education, employment, and community living outcomes for youth with special health care needs. Building on the powerful notion of “nothing about us without us,” the HRTW initiative has worked hard to nurture youth leadership and to ensure that the powerful voices of youth are a central part of the national and state dialogue on transition issues. (cont.)
Through their participation on boards and as members of advocacy groups, youth with special health care needs are showing they can make valuable contributions to the development of public policy. In 2000, Maine was the only state whose Children with Special Health Care Needs (CSHCN) program had a Youth Advisory Committee (YAC). Following Maine’s lead, 22 states now have YACs that provide guidance and advice from the perspective of youth, and eight additional states are planning to add YACs. Youth themselves have been responsible for planning and hosting leadership conferences, preparing and disseminating youth-friendly materials and resources, analyzing and reviewing state policy, and participating in block grant review and needs assessment activities. States have also hired (or contracted with) youth leaders as staff and consultants to their CSHCN programs.

We at the HRTW National Resource Center have learned an immense amount from our work:

- Youth with special health care needs and their families are experts on the intricacies and complexities of their own lives;
- Knowledge gained from youth is vital to understanding how supports should be provided and services organized for them;
- The participation of youth as advisors, staff, and consultants can help change others’ perceptions about those who have been disenfranchised because of their health care needs or disabilities;
- Health care transition outcomes for youth should include adult-focused health care, adequate health insurance, and the knowledge, skills, attitudes, and abilities to use these services and stay healthy;
- It is also critical to encourage the aspirations of youth with special health care needs to pursue college, careers, and involvement in their communities; and
- Health care transition outcomes are enhanced when youth are seen as equal partners with unique strengths and knowledge.

We all have much to continue to learn from one another, but we also have much to celebrate!

Submitted by
DEBBIE GILMER, Healthy and Ready to Work National Resource Center
I was liking summer time, and the living was easy. But, after just a couple of weeks’ rest from my hard work completing Taft College’s TIL (Transition to Independent Living) program immediately after graduating from high school, it was time to start reconnecting with the helping agencies.

The first agency we called was Parents Helping Parents, Inc. (PHP). Mom had learned early in my life that checking in with other parents was one of the best places to start. We would need PHP’s Adult Information Packet and connect with experienced parents.

Next, we called the Regional Center to get me a new case/care manager and reactivate my files, which had been put on the back burner while I was living at Taft. They would help me find and help pay for services I needed to live independently. We called agencies that helped individuals with special needs find and maintain independent housing. Working the net was the name of the game for more success. I made sure that mom and dad put a good computer, printer, and fax machine in my bachelor pad. I already had my trusty cell phone and a pager.

It was fun working with everyone to get me settled on my own, as we all tried to keep an open mind and a positive attitude. I checked in with my doctor at Kaiser Permanente for my annual physical. I was still healthy. And I soon found a great dentist within walking distance of the home that I ended up renting with four other guys through an agency called Greater Opportunities (GO). Each of us has a “worker” from GO, who comes by once or twice a week to check our eating habits, the house upkeep, and stuff like that. We take care of our own cooking, cleaning, clothes washing, and everything. I got my library card, bought my monthly bus pass, and opened a savings and checking account.

We reconnected with the Department of Rehabilitation Services to get assistance with finding, preparing for, and maintaining a job for me. I signed up for a program with Goodwill Industries that prepares people for the workplace. They even showed me how to give a good firm handshake. Community Association for Rehabilitation (CAR) assigned me a job coach and a job developer. In less than a month I was working at a Payless store, stocking shelves. In a few more months, they helped me get a job with more hours and pay as a Sales Associate at a Michaels’ Arts and Craft store. They love my work and include me in social and work functions.

I’m doing just fine. I’ll have breakfast out with mom and dad after church on Sunday. Then, I will ask them about driving me down to see my girlfriend Kim, who lives about four hours away.

Submitted by DEAN POYADUE, San Jose, California
I’m Dean’s very proud mom. We—parents, professionals, service systems, legal entities, and the general public—have all come a long way in the past decade or so in our understanding of the “abilities” of individuals with disabilities.

I believe particular developments not only contributed to our son Dean’s ability to transition to independence, but allowed it to speed along, flourish, thrive, and take root—and to become just an ordinary expectation for him. Aside from his own innate abilities and great, judicious decision making skills, Dean’s transition to independent living has mainly been fueled by changes in these five arenas: parent empowerment, societal attitudes, governmental and disability-related nonprofit organizations, technology, and a community college in California called Taft.

Parent-to-parent programs like Parents Helping Parents (PHP, Inc.) created empowered parents who could be equal collaborating partners at decision making tables. We gave each other the courage to “let our children go”—to face the world. Through Special Olympics, Buddy Walks, Sibshops, Neighborhood Integration, and many other such programs, society’s eyes were more and more opened to truly see the capabilities of all. That fostered not only acceptance, but appreciation, of a wonderful, contributing sector of society many had long neglected getting to know. While much has changed in the last ten years, thanks to the U.S. Government and nonprofits like DREDF (Disability Rights Education Defense Fund), the wheels for this progress started rolling mightily with passage of PL 94-142 in 1975. This law, which was enacted the same year Dean was born, guaranteed our children the right to a free, appropriate education in the least restricted (integrated) environment. And, at former Surgeon General Koop’s conferences we sang about family-centered, community based, culturally competent, coordinated care. For Dean, and I hope many others, it is here.

Technology plays a significant role in almost every aspect of a person’s ability to successfully transition to more independent living (personal care, mobility, transportation, communication, safety, cooking, and other aspects of life too numerous to mention here). Take time to visit a Special Tech Center near you. But the change that had the greatest impact on Dean’s transition success was the creation of a two year, very comprehensive TIL (Transition to Independent Living) program at Taft Community College in California, which included living in dorms on campus. You name it, they taught it there (budgets, housekeeping, specific jobs, travel, relationships, fun, cooking, safety, etc.) We simply must have a Taft program in every county in the USA. Many other Deans are out there waiting and eager to fulfill their true potential!

Submitted by
FLORENE POYADUE, founder of Parents Helping Parents, San Jose, California

Many other Deans are out there waiting and eager to fulfill their true potential.
Much has been accomplished in transition during the last decade. But this work was built upon many previous years of work. In 1989, Surgeon General Koop’s last conference was dedicated to Health Care Transition for Youth with Special Health Care Needs.

He “ordered” those of us in attendance to do something, to make change happen soon. I heard him and took this as a mandate “to do,” rather than just “to try.” From 1996 to 2010, I was the Team Lead for a national center on transition funded by HRSA’s Maternal and Child Health Bureau (MCHB) to promote awareness and identify strategies for policy and program change.

In 2000, when MCHB launched its 10 year initiative to build systems of care for children and youth with special health needs, that initiative included a new national performance measure on transition. This new performance measure was a national announcement that youth with special health care needs, like other youth, grow up and deserve to be healthy and productive, to live their lives with a purpose, and to be included in their communities. But they also need extra support. This was a real federal health mandate, not just what I was always being told were the unrealistic expectations of a mother. And it felt great.

At the time of this national launch, my son Glen was 28 and had been recently discharged after a lengthy hospitalization that was life-changing. His progressive disease had attacked his ability to breathe, and he elected to have a tracheostomy and go on life support, a ventilator, full time. His future was uncertain, but it was obvious that his death would come sooner rather than later. And now, the health care transition policy had life and was catching on nationwide. Here I was, working on health policy changes to support the hopes and dreams of youth at a national level, while at the same time preparing for a different kind of life transition for my son.

My son died shortly after he turned 30. He led a full life. He was the catalyst for my work. I have great memories to be proud of and no regrets. Today, every state is reporting progress in preparing children and youth with special health care needs to transition to adulthood. Many are involving youth in health care decisions, as well as developing youth leadership in policy making. Yet we are not there yet. We must continue to raise the expectations of those who provide supports (families as well as providers) and, most important, we must listen to what youth have to say and support their aspirations. I believe that during the next decade Surgeon General Koop’s mandate—health care transition supported by a medical home with transfer to adult systems and services—will become a reality.

Submitted by
PATTI HACKETT,
Natick, MA
Transition to adulthood reminds us of a labyrinth. Of the 500 plus younger patients we have seen since the Center for Youth and Adults with Conditions of Childhood (CYACC) opened in 2007, no two are taking the same path.

Our CYACC team brings a source of illumination for those walking through this labyrinth.

They trek through life accompanied by a variety of diagnoses, from autism, Down syndrome, cerebral palsy, spina bifida, cystic fibrosis, diabetes mellitus, and juvenile arthritis to chronic renal disease and other rare conditions. Each young adult we serve encounters obstacles and the occasional dead end in the path to adult life, sometimes needing to backtrack or redirect at the last fork. Our CYACC team brings a source of illumination for those walking through this labyrinth.

Through service to youth with special health care needs and their families, our transdisciplinary team of social workers, nurses, and physicians has learned many important principles:

- the earlier services are provided, the better;
- encourage new opportunities that stretch youth to reach beyond perceived “limits;”
- avoid the word “can’t;” and
- promote self-advocacy by using questions like “how” and “why not.”

After three years, we now realize that transition to adulthood means so much more than transferring care to an adult physician accompanied by a portable medical summary. We have cultivated a holistic and comprehensive view of transition that includes health, education, employment, living, caregiving, legalities, socialization, and recreation. We use a wealth of formal and informal resources as we collaborate across state agencies, school systems, community organizations, insurers, and local groups, as well as between the pediatric and adult health care systems. Our broad-based advisory board and its youth subcommittee help us discover new routes through the maze. They challenge us when we show signs that we might be veering off a youth- and family-centered path. Our goal remains to help youth reach their highest level of independence and community participation while maintaining their health.
As we worked this past decade to improve the adult lives of our children and youth with special health care needs, in typical fashion, the youth have moved past, around, and over us!

Thanks to the Internet, “smart phones” and other hand-held wireless devices, and social media such as My Space, Facebook, and Twitter, youth are connected to one another and the entire world like never before. Ten years ago kids with hearing loss using TTY may have seemed strange. Now it is commonplace for young people to use texting as their favorite way to communicate. Today, as we use electronic gadgets to remind us, guide us, and entertain us, these same gadgets are also helping people with disabilities live their lives.

We all should celebrate the fact that states now place more focus on transition to adulthood and the quality of life for persons with disabilities and special health care needs than they did 10 years ago. Just being alive and living in an institution is no longer acceptable. Living a full life, a life that includes employment, is now the expectation for most youth with special health care needs.

More than 40 states now have a Medicaid Buy-In program, allowing working, disabled individuals the ability to purchase Medicaid coverage. Now people with severe disabilities do not have to choose between having a job and having health insurance. Access to high-quality, appropriate health care seems more likely now because of the passage of national health reform, accomplished at the end of this decade of change.

Having a job remains as a vital part of adult life, and transition planning for youth with disabilities and special health care needs must include employment outcomes. Being healthy is crucial to being ready and able to work. The Social Security Ticket to Work program was introduced and modified during this past decade as a means to help Social Security Disability Insurance and Supplemental Security Income beneficiaries with disabilities get the supports and services necessary to increase self-sufficiency. Employment is the way out of poverty for most people, and clearly youth with special health care needs and disabilities want to be included.

Submitted by
ERIN GLADSTONE AND MARY CICCARELLI,
The Center for Youth and Adults with Conditions of Childhood (CYACC), Indianapolis, Indiana.
What a journey! In the early part of this decade, we were still conceptualizing the process of health care transition and trying to better understand the myriad issues and barriers faced by youth, families, and the health care community in the state of Florida.

A major milestone in the journey was the Consensus Statement on Health Care Transitions, jointly developed in 2002 by pediatricians, family practitioners, and internists, which outlined critical first steps that medical professionals need to undertake to ensure successful transition. Another was the introduction of the National Survey for Children with Special Health Care Needs (NS-CSHCN), which allowed us to start measuring how well we are meeting the Maternal and Child Health Bureau’s (MCHB) core outcome for transition at both the state and national level.

While results from the NS-CSHCN have been somewhat discouraging for advocates in Florida, we are fortunate to have innovative state leaders who responded with a call to action. During Florida’s 2008 legislative session, a bill was passed to establish a statewide Task Force to assess the need for health care transition services, develop strategies to ensure successful transition from pediatric to adult health care, and identify existing and potential funding sources. Under the guidance of Florida’s Title V CSHCN Program, Children’s Medical Services (CMS), with support from the Florida Developmental Disabilities Council, a 35-member Task Force developed a report titled, Ensuring Successful Transition from Pediatric to Adult Health Care. The report outlines 16 recommendations to build a comprehensive system of care for the estimated 500,000 young people with disabilities or chronic health conditions living in Florida.

Since completing the legislative report, the Task Force has continued its work by launching activities in the statewide strategic plan. These include: establishing a State Office of Health Care Transition within CMS that guides regional public/private coalitions in building local systems of care; developing educational programs and materials for youth and their families to help them prepare for health care transition; providing training for health care and education professionals; and creating a website to serve as a clearinghouse of information. We adopted the name FloridaHATS (Health And Transition Services) and are currently piloting the development of regional coalitions and local systems planning in three areas: Tampa-Hillsborough County (HillsboroughHATS), Jacksonville-Duval County (JaxHATS), and the Panhandle area (PanhandleHATS).

We’re excited to help pave the way in developing systems of care where all youth and young adults will receive the services necessary to make a successful transition to every aspect of adult life including health care, work, and independence!

Submitted by the FLORIDAHATS TASK FORCE, Tampa, Florida
For more than 35 years, Hemophilia of Georgia (HoG) has provided a variety of programs and services for people with hemophilia or other bleeding disorders.

Due to the medical advances over the last decade, our young people do not face the complications once associated with having a bleeding disorder. In order to better serve this growing population, we have turned toward preparing our youth to step into the world of work. The Youth Leadership Initiative addresses the transition needs of our young clients. The program has had much success due to community collaboration, a dedicated staff, and, of course, the young people that we are preparing for the “real world.”

The Youth Leadership Initiative provides unique opportunities for our soon-to-be adults. With buy-in from our youth, we integrate educational sessions into our normal activities (such as camp and retreats). We are able to expose our young people to a variety of leadership topics that include cultural diversity, career planning, decision making, how to apply for a scholarship, public speaking, and teamwork. In our life-size “Game of Life,” our youth practice opening bank accounts, buying insurance policies, and choosing career paths. In the evaluations of these sessions, the youth participants always say that they wanted more time in the sessions, liked the team work activities, and felt that their voices were heard.

HoG is very proud and tremendously impressed by the youth that have participated in this program. We constantly receive compliments from outside organizations about how engaged our teens are in these leadership activities. The dedication of our young people is inspiring and motivates us to continue to offer innovative programs with and for them.

Submitted by
SHANNON VERONESI,
Hemophilia of Georgia,
Atlanta, Georgia
Transitioning to adulthood is a challenging process for all young people, but it can be particularly challenging for youth with disabilities and special health care needs.

In 2006, the Title V Program at the Massachusetts Department of Public Health (MDPH) developed a Young Adult Advisory Council (YAAC) to provide a consumer voice and help MDPH address this challenge. We contracted with Partners for Youth with Disabilities (PYD), a Boston-based youth mentoring organization, to help coordinate the YAAC.

To increase geographic diversity, two groups were formed, in the eastern and western parts of the state. Each group had ten members, ranging from ages 16 to 26 at the start. As YAAC member Sarah MacIsaac described:

We come from different backgrounds and locations of Massachusetts and represent a wide array of disabilities, and that is what makes this group unique. For our first few meetings we got to know each other and shared our personal achievements and struggles in health care. We talked about our transitions to adulthood, including what has helped us in our transition, or what could have helped us. We discussed the need for increased education and awareness.

The groups created a video regarding transition for policy makers, health care workers, families, and friends. Over the course of the next 1½ years, YAAC members worked with a videographer to bring their idea to fruition. The final product, *We Are Able: Perspectives of Transitioning Young Adults with Disabilities*, aims to raise awareness of some of the issues faced by young people with disabilities and special health care needs and offer suggestions as to what policy makers and health care professionals can do to help. The messages in the film come from the young people who wrote the script, took the photographs, created the art work, and directed the scenes. While the impetus for the project was a desire to educate health care providers and policy makers and the emphasis is on health care, the film’s messages pertain to all aspects of life for youth with special health care needs.

Several YAAC members have shared some thoughts about their experience:

**YAAC has taught me to respect all people with any type of disability because everyone has something important to offer.** YAAC has also taught me about my own disability and also how important and rewarding it is to give back to the community and others with disabilities. **Olivia Belofsky**

As a member of the YAAC, I have greatly enriched my knowledge of the reasonable accommodations that allow people with various disabilities to participate fully in their transition from childhood to adulthood and in decision making regarding their health care needs. My understanding of how one achieves and maintains health has broadened, as I now realize that wellness demands aspects, such as housing, employment, and accessibility in the community as a whole, that one does not typically associate with health care. **Kate Thurman**

One thing that I enjoyed about being in the YAAC program is self-advocacy and learning there is no shame in asking for help. **Sabrina Thomas**

Submitted by **NICOLE ROOS,**
Massachusetts Department of Public Health,
Boston, Massachusetts

{ YAAC has taught me to respect all people with any type of disability. }
Over the past several years, many states have improved their inclusion of youth and young adults in Maternal and Child Health (MCH) strategic planning, ongoing activities, and medical home training.

For us in Utah, it was the positive experience of including young adults in medical home training that led to our inclusion of young adults on many state committees.

As part of Utah’s Medical Home–Integrated Services Grant funded by the Maternal and Child Health Bureau, a Young Adult Advisory Committee (YAC) was formed to include the youth and young adult perspective in planning medical home training events.

The YAC members provided input on training topics and served as panel members at training events. At one training, a panel of young adults shared with doctors their perspectives about how they could improve their medical home services. A video of the panel was placed on YouTube and incorporated into other training events to supplement young adult speakers or provide their voice when they were unable to attend. YAC members also reviewed and improved outreach materials and the Medical Home Portal web site.

Building on the success of YAC’s involvement, Utah secured a grant from the Administration on Developmental Disabilities. Many of the YAC members transitioned to this grant, known as the Becoming Leaders for Tomorrow Project. In addition to providing input on web sites and outreach materials, the youth leaders shared their young adult perspectives by presenting at university courses and local, state, and national conferences, as well as by participating as equal partners on committees for state agencies. Finally, they participated in the development of the Youth Leadership Toolkit, a guidebook comprised of ideas and discussion topics for trainers and a DVD, with videos directed at medical professionals, educators, disability service providers, parents, and other youth and young adults. The toolkit was disseminated through state Family Voices members and other organizations, and new organizations continue to request it.

It is interesting to look back and see how new ideas and grant requirements have impacted daily practices at local, state, and national levels. While new ideas may seem startling and grant requirements may seem daunting, professionals and families often work together to create exciting changes that improve the lives of children and youth with special health care needs.

Submitted by
BARBARA WARD,
Children with Special Health Care Needs, Utah Department of Public Health, Salt Lake City, Utah
During the past decade families, providers, local, state, and federal agencies, and other organizations have joined forces not only to improve systems of services for children and youth with special health care needs (CYSHCN), but to ensure that those systems are responsive to the needs of all families.

This has meant incorporating the principles, policies, structures, and practices of cultural and linguistic competence into every aspect of their work.

Cultural competence and linguistic competence are widely recognized as fundamental components of quality health care and as essential strategies for reducing disparities and improving health care access, utilization, quality, and outcomes. In reviewing the efforts of the past decade, we have learned five major lessons about what supports progress in advancing and sustaining cultural and linguistic competence.

• **Leadership.** Strong and informed leadership is essential to spur the necessary changes within systems, organizations, policies, and practices. Leadership must be cultivated at all levels of an organization, system, or community.

• **Shared ownership.** Cultural competence and linguistic competence cannot be owned by any particular group. Staff, families, community partners, providers, and other key stakeholders need to share a vision and understanding of the conceptual frameworks and benefits of cultural and linguistic competence.

• **The “isms”: confronting the undercurrents.** Addressing racial and ethnic disparities and inequities in care demand an intentional focus on conscious and/or unconscious bias, prejudice, stereotyping, discrimination, racism, and other “isms.”

• **Keeping it real.** People need to see cultural and linguistic competence as relevant to their day-to-day work and/or life experiences. It is essential to create a work environment that values, encourages, and prioritizes continuous learning.

• **Weaving it into the fabric of the organization.** Leadership must make concerted efforts to eliminate the common perception that cultural and linguistic competency is an “add-on.”

During the last ten years, there was a significant increase in the importance given to cultural and linguistic competence in health policy, research, clinical care, health professions training, and legislation, including those concerned with children and youth with special health care needs and their families. Much of this can be attributed to: increased racial, ethnic, cultural, and linguistic diversity in the U.S.; enactment of P.L. 106-525, which established the Center for Minority Health and Health Disparities within the National Institutes of Health; the groundbreaking Institute of Medicine Report published in 2002, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*; the promulgation of the National Standards on Culturally and Linguistically Appropriate Services (CLAS) in Health Care; the growing body of evidence on the efficacy of cultural and linguistic competence in health and mental health care; federal legislative and regulatory mandates; and the changing requirements of health care accreditation organizations. In addition, a number of states launched their own initiatives and created plans...
or enacted legislation to address racial and ethnic health disparities and to advance cultural and linguistic competence in health care and health professions training.

The Maternal and Child Health Bureau (MCHB), spearheaded by the Division of Services for Children with Special Health Needs, brought focused leadership to these broad public policy initiatives by implementing requirements and guidelines for cultural and linguistic competence within the programs that it funds. MCHB’s strategic plan objectives related to services, research, and training address cultural and linguistic competence, health disparities, and barriers to health care access. MCHB also requires that all its grantees demonstrate cultural competency and address health disparities (i.e., racial, ethnic, linguistic, geographic, and economic).

There has been notable progress in state Title V CSHCN programs in the past decade as well. States are taking different pathways to address cultural and linguistic competence, including:

- partnerships and collaboration;
- strategies to increase access to care and adaptation to services;
- an array of language access services (interpretation and translation for individuals who are English language learners or monolingual);
- training and personnel development;
- organizational assessment and strategic planning processes;
- changes in organizational policy and procedures; and
- developing Block Grant needs/strengths assessment strategies, as well as goals and objectives, that advance and sustain cultural and linguistic competence.

Systems and organizations are at various stages of awareness, knowledge, and skills related to cultural and linguistic competence. During this past decade, however, the journey to achieve cultural and linguistic competence in systems serving children and youth with special health care needs and their families has moved forward significantly.

Submitted by the
NATIONAL CENTER FOR CULTURAL COMPETENCE
Let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider that each decision either affirms or denies a child’s most basic human right.
–Polly Arango
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design: kor group, Boston MA

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