Managed Advocacy in Action

The Families MAP Blueprint
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ABC for Health, Inc.

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About ABC for Health

ABC (Advocacy and Benefits Counseling) for Health, Inc., is a nonprofit public interest law firm that provides free health benefits counseling for families who have children with special health needs and legal services for low-income Wisconsin families having problems paying for health care. ABC gives information on available health care resources, helps families get benefits from private insurance and public financing programs, and helps resolve disputes with insurance companies, health care providers, and government agencies.
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Families Managed Advocacy Project

Negotiating the complex system of health care coverage in this country is truly a bewildering task. Sadly, cost containment measures like prior authorizations, gatekeeper physicians and restricted networks pose great challenges to obtaining needed care for children with special health care needs. And it is not just HMOs that are restricting access to health care coverage. Today, most care is delivered by managed care plans that dominate the health insurance landscape. As a result, new rules and new procedures may needlessly compound the stress and frustration of patients and caregivers. Many families are confused by the cost containment features of managed care and the payment systems that seem contrary to the best interests of medically involved children.

The Families Managed Advocacy Project (Families MAP) was one of thirteen projects funded nationally by the Maternal and Child Health Bureau to examine and detail the impact of managed care services on children with special health needs (CSHN) and develop strategies to improve family satisfaction and involvement in the care received. In this project, partner agencies located in three different parts of Wisconsin—Chippewa, Dane and Milwaukee Counties—worked together to identify and compare differences in the barriers CSHN face in managed care. Strategies were developed for overcoming these coverage and access barriers through partnerships with families, medical providers, policy makers and representatives from managed care organizations.

While many challenges remain in the process of developing a coordinated advocacy system for CSHN, Families MAP is a proven model that has provided parents with education, advocacy, supportive services and, most importantly, a voice in policy development that both helps managed care organizations to better serve children with special health needs and also promote the confidence of families that their children are getting needed and appropriate care.

Families MAP agencies

As the lead agency for this project, and the host of the Dane County pilot site, ABC for Health is a non-profit public interest law firm based in Madison, Wisconsin, which is dedicated to ensuring health care coverage for children and families, particularly children with special health needs. Our partners included Community Advocates, a grass roots advocacy organization working in urban Milwaukee on health care issues, and the Chippewa County Department of Public Health, the home of one of five Regional CSHCN Centers in located in northern Wisconsin. All organizations in the project share a mission of providing information, advocacy tools and support to CSHN. As such, our working relationship was enriched by a common vision of a better system to serve the needs of children and families.

Because of the diversity of our communities and needs, our goals were pursued, not in lockstep, but rather by following different pathways guided by community concerns and priorities. Consequently, we
believe that the Families MAP model can be adapted and fine tuned to serve a variety of communities across this country.

Using this guide

Managed Advocacy in Action reports on the development and operation of our Families MAP project, and also provides a flexible blueprint for the development and growth of managed advocacy programs in other communities. This report gives a brief background on the families, programs and resources around which Families MAP was developed, followed by chapters describing the health benefits counseling model that provides the core philosophy behind the client and committee work making up this project. Much of our work was guided by the critical involvement of parent advocates working with the projects. Input from families began with identification of significant care and coverage barriers. The strategies and action steps developed to address these barriers are described in subsequent chapters.

This project was informed by nearly fifteen years of experience with health benefits counseling and working with families that have children with special health care needs. This managed advocacy model also relies heavily on the elements of the Medical Home model (as defined by the American Association of Pediatrics) and the Maternal and Child Health’s Achieving and Measuring Success: A National Agenda for Children and Youth with Special Health Care Needs and its objectives for ongoing and comprehensive health care for CSHN.

Is the Families MAP program appropriate for your community? Certainly a better-coordinated advocacy infrastructure and supportive services for parents is needed in Wisconsin. Families MAP provides a framework for helping to build capacity within communities, to identify key stakeholders and to provide a forum for issue identification and strategy development to resolve barriers encountered by families. And most importantly, a managed advocacy program can help us achieve our vision of a better health care system that supports partnerships, advocacy and a medical home for children with special health care needs.
The Families Managed Advocacy Project (Families MAP), which involves health benefits counseling, coalition building, community education, and policy reform both inside and outside of managed care organizations, is designed to enable families to access the most reliable and comprehensive health care for their children with special health needs.

These children with special health care needs (CSHCN) range in age from birth to 21 years of age and have a long-term, chronic physical, developmental, behavioral or emotional illness or condition. Their illnesses or conditions:

- are severe enough to restrict growth, development or ability to engage in usual activities;
- have been or are likely to be present or persist for 12 months to lifelong; and
- are of sufficient complexity to require specialized health care, psychological or educational services of a type or amount beyond that required generally by children.

Examples of their illnesses or conditions include cerebral palsy, leukemia, diabetes, autism, attention-deficit hyperactivity disorder and severe asthma.

Based on the above definition used by the Wisconsin Children with Special Health Care Needs Program, it is estimated that about fifteen to eighteen percent, or about 274,000, Wisconsin children have special health care needs.

Their needs are as broad as their numbers. Unlike adults, children are susceptible to a multitude of rare childhood disorders and a smaller set of common ones—there are over two hundred chronic conditions that are specific to children. Each of these conditions brings with it a special set of care requirements and family needs that require a unique response from the medical caregivers.

All children are dependent on adults for protection, guidance and care. Children with special health care needs are no different except that the level of those needs are complex and require far greater time and attention from parents and the rest of the family. The child with special health care needs often requires expansive medical services that cross the line between medical and home care including: primary care, specialty treatment services, mental health services, prescription drugs, durable medical products, nutritional services, community-based services, home nursing services and specialized day care. Clearly, the needs of children with special health care needs are complex and multifaceted, necessitating comprehensive and coordinated health care services.

**Family factors**

There is no doubt that there are many challenges in raising a child with special health needs. From the day of birth or the onset of symptoms, the family has to rely constantly on medical professionals and support personnel to deliver the care their child needs. Like it or not, the family network must be expanded to include skilled and reliable caregivers, knowledgeable case managers, medical and educational personnel. These individuals need to have direct access
to the child and, often, the home of the family. While most families welcome supportive services, family and individual privacy is frequently compromised.

Having a child with special health needs brings many other unique challenges to a family. A child’s siblings might feel frustrated and left out, often longing for the attention that a child with special needs demands. Stress in a household can increase tremendously, buoyed by the extra work, extra financial requirements and extra emotional attention a child with special needs requires. In an ideal world, a child’s medical professionals and health care insurance should support the family and their needs, not become an additional stressor in their lives. The unfortunate reality is that frequently families need to battle to get what their children need.

Additionally, Wisconsin’s geographic characteristics impact the health care and supportive services that children with special needs might receive. Those who live in rural areas often have to drive long distances to an appropriate primary care provider and even longer distances for visits to specialists. Therapeutic interventions might not be available to them at all, or in a reduced capacity, depending on skill and location of needed therapists. Those who live in densely populated urban areas, might be physically close to appropriate providers, but might not have the resources to access those providers. Particularly for families in poverty, lack of transportation options, time availability, lack of child care options, and the sheer number of medical appointments can be overwhelming. For these families, the inclusion of a medical case manager, as in the medical home model, can be a virtual lifesaver for many families managing their child’s health care.

**What coverage programs are Wisconsin families using?**

Most CSHCN in Wisconsin are insured. According to the Maternal and Child Health Title V 2002 Block Grant Application, 77.9 percent of families with children with special health care needs surveyed indicated that they had health insurance. Of that group, 44 percent of families identified Medicaid or BadgerCare as their primary source of health insurance. Just three percent of families receiving care coordination reported no insurance, but there is another nineteen percent for who did not identify any primary insurance.

One of the most frustrating challenges for families was the overwhelming complexity of the coverage choices and of the coverage options within care plans. In addition, many families were dealing with more than one type of coverage or with frequent changes in employer-sponsored plans. In our work with almost 2,000 families to secure coverage and clarify covered services, programs fell into three broad categories: 1) private health insurance plans, 2) public coverage and services including Medicaid/BadgerCare and Birth to 3, and 3) educationally related supports and therapies provided through local school districts.

The families who sought assistance through the Families MAP health benefits counselors were typically two-parent households, most with one or two children and incomes over 200 percent of the poverty level. Those with higher incomes typically had private insurance and many also had Medicaid coverage through the Katie Beckett Program. Families with lower incomes often had SSI eligibility and therefore Medicaid coverage for the child with special needs. Approximately eleven percent had no coverage for the family.

The service needs families most often requested help with were advanced medical care (i.e., surgery, cancer care, hospitalization due to complex care needs), therapies (speech, physical, and occupational), mental health services, and prescription medications. The coverage issues related to these services were typically benefit limitations (such as an insufficient number of therapy sessions covered), benefit exclusions (no coverage for mental health), denials of coverage as not medically necessary, and costs not covered due to copays and deductibles.
Events triggering the requests for assistance were often an application denial, both for Medicaid and private insurance; denial related to a specific treatment need; and loss or imminent loss of coverage due to job changes, divorce, the child’s transition to adulthood, or changes in family circumstances or the child’s health status that threatened eligibility for public programs. A pressing issue for many families stemming from these triggering events was the accumulation of medical debt they didn’t know how to pay, or needing care for their child they couldn’t afford to get. Another issue that rises to the top for many families is quality and coordination of care (see appendix A for a listing of Wisconsin Services and Programs).

Managed care and the special needs child

In the past ten years, most health insurance plans have transitioned from fee-for-service to managed care plans—including Medicaid. Fee-for-service plans, although often more costly, allow you to see any physician, for any service, whenever you choose. You may have to meet a deductible or pay a co-payment for those services, but in general the care you receive is very flexible and therefore suits the needs of children with special health needs well.

Managed care plans are less costly but are also less flexible (see box below on Capitated Rates). Under a managed care organization (MCO), you must get services from a specific group of providers, with authorization by your primary care physician, and must obtain a referral each time you need to see someone outside of the provider group. With Medicaid’s transition from fee-for-service to managed care, coverage for the many families who have children with special health needs has become more complicated.

There are several problems that stand in the way of children with special health needs receiving the optimal care that they and their families can afford. The emphasis on cost-containment creates an environment in which primary and preventative care are emphasized—with a clear economic disincentive against offering complex treatments. This proves particularly troublesome for children with special health needs and their families. These families don’t just take their child to the family practitioner like most parents. They do have a primary health care provider, but many also rely on an intricate web of specialists, therapists, educational-related service providers, social services officers, and a range of other supportive professionals—most of whom remain outside the managed care system. The reality of the child with special needs runs counter to the entire structure of managed care.

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**Capitated Rates**

Managed care organizations pay providers with what’s called a capitated rate. That means a doctor gets a set amount for seeing a set patient—whether she is a healthy 30 year old non-smoker or a 8 year old with spina bifida—and under most cases, the patient will primarily see that doctor and will have to obtain a referral to see any other provider. An MCO does not differentiate between those with intensive needs and those with routine health care needs—all patients are the same when they walk in the door. This makes financial sense, but a side effect is that MCOs have an incentive to either (1) avoid enrolling the disadvantaged and medically complex children who have costly health care needs in order to save money for the extra time children with special health needs require or (2) place onerous restrictions on access to all but the most basic services so that it is difficult for children with special health needs to obtain more expensive services.
Looking toward the future: Incorporating principles of the Medical Home model and Healthy People 2010

As we look beyond the work of Families MAP, we need to take environmental factors into consideration. The Maternal and Child Health Bureau at the United States Department of Health and Human Services and the American Association of Pediatrics have been taking a careful look at the ways in which health care is delivered to and accessed by children with special health care needs. As a result, several concepts are being implemented on a national basis.

The first, the Medical Home model, was developed by the American Academy of Pediatrics, in collaboration with Family Voices, the Maternal and Child Health Bureau, the National Association of Children’s Hospitals and Related Institutions, and Shriners Hospitals for Children. This model focuses on a partnership approach to delivering medical care and is first and foremost family centered. There is a summary of these important principles on the next page.

Healthy People 2010

The Medical Home principles have been incorporated into Healthy People 2010, a joint effort led by the Maternal and Child Health Bureau, the American Academy of Pediatrics, Family Voices, and March of Dimes along with many other organizations in the public and private sectors, to bring better health care to all people in the United States. Achieving Success for All Children and Youth with Special Health Care Needs outlines the 10-year action plan that addresses the objectives in Healthy People 2010 related to the care of children and youth with special health care needs. The six core objectives of Achieving Success are:

- Families of children with special health care needs will partner in decision making at all levels and will be satisfied with the services they receive;
- All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home;
- All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need;
- All children will be screened early and continuously for special health care needs;
- Community-based service systems will be organized so families can use them easily;
- All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. (source: National Center for Medical Home Initiatives)

The Wisconsin Maternal and Child Health Program and its advisory committee is working to make sure that each child in the state has a medical and dental home by 2010. Additionally, this program is working to incorporate the six core outcomes of the 2010 plan in its programs as well.

As we leave Families MAP, we are excited about the opportunities that exist in our state as work continues to provide Wisconsin’s children with special health needs and their families better health insurance coverage and more comprehensive services and care that they require. This blueprint for managed advocacy, when implemented, can provide a great impetus for moving us down that road.
Medical Home Principles

The medical home concept contains seven primary elements. These are described below with a brief explanation of their meaning within the medical home context.

**Accessible:** Accessibility is a multi-pronged component of the medical home:

- **Care in the Child's Community:** In order to be accessible there have to be minimal requirements for obtaining care outside of local community. Additionally, care should be given within a community of other children.

- **Physical Accessibility:** This considers elements such as the geographical location, availability of parking or public transportation and the accessibility of buildings.

- **Time Accessibility:** Increased availability of appointments, reduced waiting times at appointments and coordination of appointments with different providers (for multiple children if necessary) to avoid multiple trips to the facility.

- **Medical Records Accessibility:** All health records must be made available to parents, other health care providers, insurance programs

- **Insurance Accessibility:** Providers must accept all types of insurance private and public, assistance with obtaining eligibility, filing claims and bringing appeals of denials, as well as accommodation as insurance programs change.

**Coordinated:** Care needs to be coordinated among all those involved with the child, including the family, care giver to care giver, institution to institution, between care givers and payors, support, educational and community-based services. Centralized information needs to be available to all of these entities as well.

**Continuous:** The medical home ideal states that care should be continuous between providers, such as the Primary Care Physician, other health care specialists and health care institutions, as well as across the life situations and transitions of the child (Clinical, Home, School, Adulthood).

**Comprehensive:** Comprehensive care includes care that is available at all times, all degrees of intensity (preventive, primary, tertiary) and that insurance coverage is available and accepted for all levels of care.

**Culturally Effective:** A family's cultural background must be recognized, valued and respected, along with the place of the child in these values.

**Family Centered:** The family is always the principal caregiver and the center of strength and support for the child. Providers must support that role and give unbiased and complete information to the family on an ongoing basis.

**Compassionate:** The medical home concept includes expressing and demonstrating concern for the well being of the child and the family by everyone involved in the child’s care.
Managed Advocacy Project

What is managed advocacy? This simple question is more difficult than it sounds due to the fact that managed advocacy is more of a concept and a philosophical approach that can take on a different hue depending on the community where it is implemented. Having said that the definition is hard to pin down and is, in fact, elusive and flexible, there are some basic principles that form the broad outline of the Managed Advocacy concept.

Managed Advocacy Defined

The Managed Advocacy Program is focused on a three-pronged approach:

1) **advocating** directly with families of CSHN to solve their health care access financing problems;

2) **organizing and educating** parents of CSHN, service providers and advocates to become active and involved participants with managed care organizations on a policy level; and

3) **developing** the information and advocacy infrastructure to promote fundamental policy change and ongoing system responsiveness in managed care organizations.

The vision of Families MAP was to improve the system of care for children with special health needs in managed care environments and create a supportive infrastructure where: 1) families fully understand their rights and options and can effectively advocate on behalf of their children, 2) comprehensive and accurate advocacy resources are available to families in a timely manner, 3) systemic problems affecting children with special health needs are documented and addressed in partnership with policy makers and managed care organizations and 4) parents are fully involved and confident in making decisions to place the care of their children in the hands of managed care organizations.

In order for the Families MAP to achieve its vision, five goals would need to be met. Those include: 1) maximizing insurance coverage for children with special health needs and promoting linkages to primary and specialty care, 2) increase the coordination and integration of services among managed care plans and other providers of services to children with special health needs, 3) expand family participation in managed care policy development, 4) develop recommendations to facilitate access to a medical home for children with special health needs and 5) improve family satisfaction in managed care.

Managed Advocacy by Design

Experience has shown that managed care systems generate both worry and frustration for children with special health needs and their families. The context within which these families care for their children is sensitive and complicated. It includes not only their primary health care providers, but an intricate web of specialists, therapists, educationally-related services, social services, and other family support systems – most of which remain outside the managed care system. The transition to managed care for
these families can disrupt carefully nurtured networks of care and support, and exacerbate the difficulties of navigating multiple systems of care and financing. Moreover, the managed care system, organized around the axes of cost containment and primary preventative medicine, is not very adept at responding to the needs of children with chronic illnesses and disabilities. It is not uncommon for children with complex needs to require many different types of services, by multiple providers, who may or may not be familiar with the child’s condition(s). The role of the health care advocate, which falls to the family or family support case manager, becomes a frustrating, but essential task.

Families MAP was developed at a time when managed care was developing rapidly across the state of Wisconsin. Of course the expansion of a system of care that did not necessarily fit well within the care needs of people with special needs, particularly children, caused great concern for advocates, parents and providers. Indeed, it was the notion of “direct cost containment” that stimulated parents and advocates to action. These efforts have led to the development of strategies to create systems that are supportive to families that need to navigate the complicated world of managed care.

The Families MAP Project was an important opportunity to develop and test models of managed advocacy for families and children with special health needs. As the dominant delivery system for health care in Wisconsin, managed care presents severe challenges to many families and their children. Our challenge was to design a system that would both support the family and honor the central role they play in a child’s life, but at the same time respond to an evolving health care system that was reacting to escalating costs through restrictions in choice and limitations in service. As health care has become more sophisticated and integrated, the advocacy systems that were developed to help families through that system have not kept pace. Families MAP, as demonstrated in Wisconsin, offers the potential to ensure that families have access to accurate and timely information and appropriate resources; to peer-to-peer parent support and, most importantly, to skilled and knowledgeable advocates and lawyers who understand the system and who can help families negotiate those systems.
A Blueprint for Helping Families with Health Care Coverage

Chapter Three

The design of Families MAP is based on several simple principles. Yet as in any good plan, simple principles choreographed in harmony can create a model of enduring quality and durability. Like a well-built home, Families MAP stands on a solid foundation of health benefits counseling and legal services, the cornerstone is the active participation and the contributions of life experience from parents. The sturdy walls are held together by a strong collaborative network of key stakeholders working together to solve difficult system and public policy issues related to coverage and access to care for families.

In order for the Families MAP model to fully function the three major components of advocacy must be in place. Additionally, parent participation and key stakeholder collaboration should work together to promote positive change both for individual families and the larger systems of care and coverage for CSHN.

The Foundation

Direct services to clients are the essential element of the Families MAP model. Although service providers abound in the spectrum of needs that families and CSHN require, very few programs integrate community-based advocacy and legal resources on behalf of clients. Health benefits counselors are problem solvers in the area of health care payments. They are responsible for being familiar with as many health care payment options as they can, ranging from Medicaid to the local Lion’s Club. What they don’t know about, they are responsible for having the investigative tools to find out. And when they know something of a program, but not in enough detail to answer their client’s questions, they are responsible for having the persistence to get the answers or support their clients in getting the answers. Persistence, investigative skills, and comprehensive detailed knowledge are the hallmarks of a health benefits counselor, whether that counselor is a parent consultant, a benefits specialist in the health care facility, or a benefits counselor in a community-based advocacy organization.

The services provided by benefits counselors are broad, ranging from brief information and referral to intensive formal advocacy. Some examples of activities counselors may engage in are:

- explaining the application process for Medicaid;
- assisting with preparation of a Katie Beckett Program application;
- providing counseling and intervention in asset valuation for SSI applications;
- representing clients at HMO grievance hearings, Medicaid fair hearings, and SSI appeals hearings;
- locating financing resources for obscure or unusual health needs;
- negotiating with health care providers and collectors over medical debt payment problems;
- researching health insurance policy language to challenge inappropriate claim denials.
The Cornerstone: Parent involvement

To say the direct and active involvement of parents in the planning, development and implementation of Families MAP was crucial is an understatement. Parent leadership provided not only the passion and the link to real world experiences but also helped to craft the vision and build the structure of a new system of advocacy that merged with the established concepts of care embedded in the Medical Home philosophy.

Families MAP endeavored to help families advocate for themselves by giving them the tools, information and advocacy advice to resolve difficult issues. Families MAP also honored the family’s role to decide their own priorities and approach to solving a given problem in the context of the needs of the entire family. Thus even if a parent asks a MAP counselor for help regarding only one child with special needs, the coverage needs of other children and the parents will be examined. Throughout the process, families were not alone. Rather, in the background was a structure of support from other parents and a link to accurate and timely information that was buttressed by the force of advocacy and the law.

Parents and families had a direct link to other parents. The parent advocates who worked as staff to the project and pilots provided an important linchpin in bridging the gaps between Families MAP and other groups serving families. Parents engaged with a variety of advocacy and grassroots organizations and were vocal members of committees and boards engaged in policy discussions. More importantly they were well connected to parent support groups and leadership training programs. Their dedication and credibility gained through experiential kinship with other families was critical for the successful implementation of Families MAP. Through frequent contacts at HealthWatch meetings with others involved in helping families, parent advocates helped everyone reach a philosophic higher ground that was based on a mutual respect and a willingness to help meet a common goal: creating a better system for families and children with special health needs.

The Walls: Key stakeholder collaboration

The ability to build contacts and support in the community of colleagues and bureaucrats (who may also be potential competitors and adversaries) is vital to the development of a Families MAP model. ABC for Health has approached this need in a variety of ways. We have worked with other advocacy groups in our state by inviting members of various advocacy groups to join our statewide stakeholders committee; communicating with advocacy groups through our training programs, newsletters and publications; participating in and supporting other organizations by serving as speakers and participants; making appropriate referrals to their agencies—and we have participated actively in local HealthWatch committees.

We have also learned through daily contacts with others involved in helping families in the health care system that there is an etiquette for dealing with high level bureaucrats and lower level staff, both on individual cases and on broader policy reform issues, and that that etiquette must be based on a basic respect for their willingness to help and recognition of the validity and reasonableness of their perspective.

Collaboration in implementing a Families MAP model works best when a clearly outlined and detailed plan of collaboration is developed; where job responsibilities were well-defined and the respective responsibilities of each agency were understood from the beginning. Good will and trust is decreased if careful communication is lacking about such important issues as the role of the health benefits counselor; the participation of parents within the network; the nature of the relationship between the partner agencies and the training and backup agency; the financing of positions; the responsibilities for funding the position; payment for associated costs and ongoing training. It is critically important to ensure that there is a commitment of time and money to both develop and maintain the key components of the Families MAP. Health care coverage is a rapidly
changing field, and without continual updating, the value and reliability of the counselor’s advice can deteriorate rapidly, and soon a credibility gap emerges as program staff lose their expertise on the current health care coverage landscape.

Community education

Spreading the word. ABC for Health has found that a critical component of the Families MAP program is a variety of training and public education efforts. These activities are effective means of outreach, and provide an efficient way to extend the information and experience developed by the counselor and other project staff to a broader audience. Moreover, the necessity of communicating knowledge and strategies to an audience solidifies and hones the program’s expertise and health care financing knowledge. The project has provided intensive and ongoing workshops and trainings for parents and advocates as well as health care provider staff and health professionals. Public education projects have included consumer-friendly resource manuals and informational brochures as well as web site information and other online materials. Project staff has also been invited into university classrooms and health policy forums to discuss the concept of health benefits counseling and provide input on the future of the health care system. All of these activities build visibility in the community, while also providing significant, practical help for families and service providers.

Policy reform

Making micro macro. A great strength of the health benefits counseling component of Families MAP is its ability to encompass both individual casework and policy level reform. The detailed and grounded knowledge gained through working with families as they struggle with the system makes for a much richer and well thought out critique of the policies guiding that system. One of the benefits of having a varied and community-based approach to health benefits counseling is the keen insight into system failures that counselors develop. The legal backup component, working in concert with counselors, then provides the expertise to translate individual case histories into an advocacy strategy, whether through HealthWatch committee work or policy positions or individuals engaging in community organizing, or advocacy within an administrative agency.
Identifying Barriers in Managed Care

What problems do parents experience with managed care?

One of the first activities of the project was to identify barriers to health coverage and care faced by families. First we began by analyzing our experience as health benefits counselors and attorneys in representing clients. ABC for Health developed health benefits counseling as a service to families that helped us to identify, solve and organize around the health care financing and access issues negatively affecting families. Our direct knowledge gained in representing families provided an important glimpse into the struggles and barriers they encountered. Advocating for others often begins with identifying their problems and concerns about getting needed services for their children and searching for ways to address them. Moreover, many of the complications that families have when trying to navigate the health care system relate to figuring out how to pay for and access needed services. Offering services to assist families in identifying their problems, sharing them and working together to solve them is the key ingredient of “advocacy” in managed advocacy program.

Next we assembled the key stakeholders involved in the care and treatment of CSHN. These included the parents, providers, managed care representatives, school health providers, as well as legislators and the media. By working with these stakeholders we assembled an important cross section of issues that affected CSHN from a variety of perspectives. Our first efforts were at HealthWatch, which were monthly meetings of the stakeholders described above to discuss systemic issues and strategies for change. Subcommittees took action on the needs and strategies identified at the HealthWatch meetings. More ideas came from participants in training activities and events. The barriers faced by parents in an attempt to secure services or coverage for their CSHN are innumerable. The following are the major issues heard from families, clients and service providers who participated in HealthWatch coalition meetings or attended community education events.

Accurate and timely information on care and coverage options for CSHN is difficult to obtain

Many families struggle finding services and funding after their child is born. Parents are overwhelmed by the care needs of their child and are often confused about referrals or fail to get the right information about appropriate services at either the state or local level. In general, providers at all levels appear to lack formal mechanisms to link services so families can benefit maximally from money spent for their child’s care. Many health care providers, education staff, and social service agencies in the community remain unaware of the full array of current services available to families.

The eligibility and application process for public health coverage programs is complicated and confusing

The eligibility and application process for Medicaid/BadgerCare is often confusing and misleading for families. CSHN may fall into one or several different categories of recipients eligible for Medicaid, but these categories are not self-explanatory in and of
themselves. In many cases, families self deny before they see the income eligibility guidelines and assume they are not eligible. In fact, at least some members of their family may be eligible for coverage. Even when families fill out and submit the application, they are often unable to determine from the long, complicated notices whether they are enrolled or have been denied.

**Choosing a Medicaid HMO is confusing**

On top of the challenges that all families face during the application process for Medicaid, families with CSHN often must, if approved, make a decision about their provider network without adequate knowledge about which network would best serve the needs of their child. This can happen because the choice of managed care organizations (MCO) offered to families is based on those that have not reached their Medicaid enrollments caps. Often only one MCO is available to those that are eligible and if there is actually a choice between MCOs, families do not receive adequate information about which services they provide or what specialists are available.

**Families struggle to obtain needed HMO plan information about services and processes**

Families may face obstacles obtaining and understanding HMO plan information. Again, families need accurate, timely and helpful information about items such as notification requirements after emergency care, the correct procedure for obtaining referrals, what providers are in their network, and what to do when network participants change. Families of CSHN may need information about how HMOs treat a particular condition or whether a specific drug is on their HMOs formulary. Obtaining such information is often challenging and families are often faced with long waiting periods on the phone and vague and contradictory information when they contact their MCO for assistance.

**Services are provided by a fragmented system of providers and specialty practices**

Parents of children with special health needs are frustrated by fragmented services and poor access to specialty practices necessary to meet their child’s needs. Fragmentation occurs when there is no coordination between programs, providers, and community resources. This lack of coordination of necessary services is broader than just in the child’s specific medical provider in a clinic or hospital setting. It also occurs when parents work with social workers and discharge planners, expecting information and referral sources to resources that will help their child.

The following were identified by parents as barriers that affect providers and agencies and kept them from working together effectively:

- Lack of communication between agencies and providers;
- Differing priorities and attitudes among agencies and providers;
- Difficulty in updating information regarding other services of agencies;
- Lack of coordination between specialists or services within the same agency
- General administrative demands, e.g., changes in policies and large caseloads;
- Inadequate funding and staffing;
- Competition for funding; and
- Confidentiality requirements

**Funding sources are fragmented and this leads to confusion about coverage**

For a parent of a child with special health needs, paying for the myriad of medical care needs, therapies, and durable medical equipment can be an overwhelming financial hardship. The complexity of navigating these systems increases dramatically
when parents must deal with coordinating benefits between different insurance plans as well as public benefits program rules and regulations.

Therefore, many parents purchase a private insurance plan and supplement the private insurance with Medicaid coverage, usually through eligibility for either Supplemental Security Income (SSI) disability eligibility, or through eligibility for the Katie Beckett Medicaid program. In some circumstances, if both parents are working, there are coordination issues between two private insurance plans and Medicaid. Each coverage plan is complicated in and of itself. Parents and children often end up being caught in the middle between two or three entities all pointing fingers at the other in an attempt to get someone else to pay the bill, while in the meantime, the bills mount or the child is not getting needed services.

**Access to other services and specialists is controlled by a primary care physician who often does not have an expertise in needs of the child**

Managed care plans frequently require that a child have a primary care physician (PCP) that makes referrals to other services and specialists. Whatever type of practitioner the PCP is, the reality is that the PCP manages both the care and the benefits, and essentially becomes a gatekeeper responsible for deciding, in compliance with HMO financial formulas, whether or not a referral to a specialist is appropriate.

Parents are concerned that general practitioners and pediatricians do not have specialized knowledge to recognize and care for needs of their child; and because of that, are afraid of a missed diagnosis.

In addition, HMOs set seemingly arbitrary rules (as opposed to set standards), and financial limitations (as opposed to health-care needs). The result is that patients — and especially children with special health needs — do not receive needed or appropriate treatment. An HMO’s referral system affects not only the access to care by untimely decisions or inappropriately denied referrals, but also the quality of care if standards for referrals are made too restrictive.

**Lack of diagnosis-specific medical information and resources for parents**

Parents are frustrated by their lack of knowledge about the complex medical diagnoses of their children. They are anxious to know everything they can about their child’s conditions, treatments and learn coping strategies that will help them and their child manage symptoms, monitor progress, be alert to significant changes, and have the latest possible information on treatments and care that will help their children. They look to their primary care physicians for this type of support and information, but often find that these doctors do not have the time to inform themselves on the complex, diagnosis-specific information parents are looking for. This leaves parents to spend endless hours doing their own research.

**Access to needed services for CSHN, particularly therapy services, is challenging.**

In an effort to curb inappropriate utilization, and thereby control costs, health plans may establish complex prior approval procedures for many needed services. This system of hoops and hurdles must be negotiated before access to necessary care will be granted. However, the process of receiving a prior authorization for care, or appealing a denial of care to a grievance committee can seriously delay needed services, sometimes irreparably. However, many chronic conditions CSHN have require ongoing specialty care. Despite this, the use of standing referrals still is not available in most MCOs.

**Lack of clarity about medically necessary services leads to frequent denials**

The term medically necessary services is sometimes used in both public and private coverage to deny services, equipment and treatment for CSHN.
Oftentimes the definition used in state or private plans is ill suited to meet the ongoing needs of CSHN. Services may be considered experimental in nature simply because the third party payer does not have access to available documentation or research outcomes that could justify a medical need. Consequently, obtaining referrals and approval for services is extremely challenging for families with CSHN. In addition, understanding the grievance procedure, coupled with gathering the needed proof to challenge a denial based on medical necessity is both challenging and complicated for families.

**There is usually no health benefits counselor working for the family to assist with fragmented services and funding**

Many families struggle while trying to negotiate a variety of services and programs, each with their own set of rules. Families benefit from a health benefits counselor who advocates only for the family and child and who would be helpful in negotiating these complex systems. Coordination problems are also exacerbated for families who deal not only with multiple agencies, but also with multiple systems that can include long-term support programs, public school programs, health care specialists, child protective services, and others. Parents also report that when dealing with multiple medical specialists, therapists, and billing departments, they sometimes run into providers who do not understand the complexity of families’ needs.

**Loss or changes in coverage because of changes in plan or provider**

Continuity of health coverage is a common problem for families who have insurance through their employer, where the employer-sponsored coverage may change from one plan to another every year. At any point during a person’s enrollment in an MCO the employer may terminate the contract. This means that at any point a family with a CSHN may be forced to switch providers and thus disrupt their child’s continuity of care.

**Finding qualified providers and paying for them**

For families in many parts of the state the shortage of dental and mental health providers who accept Medicaid and understand the needs of CSHN has reached a crisis level. Other services that provide support to families, such as respite, day care and in-home nursing services can be anywhere from difficult to impossible to find. In addition, in a true medical home, the variety of services a child with special needs requires will be offered in a minimal number of settings. When services are fragmented, parents are often forced to go to many different providers in a variety of locations to access care. This may include accessing services such as therapies, specialty care, assessments and evaluations, or specialized durable medical equipment.

And when they can be located, parents still ran into difficulty finding a means to pay for them.

**Grievance procedures are limited and difficult to pursue**

Families often feel at a disadvantage when pursuing a grievance. Facing a managed care grievance team that includes legal staff, claims administrators as well as medical consultants is intimidating. Without help from a lawyer or advocate, families may also not be fully aware of their rights. Since attorney
fees are mostly nonexistent when challenging an MCO and fees to families may quickly exceed the cost of care, many families go it alone.

**Using the MAP Blueprint**

The next three chapters describe the activities used in Families MAP to create solutions to these challenges for the families in our project. First, health benefits counseling services were offered to any family of a child with special health needs with a health care financing problem—getting coverage, paying bills, or getting prior authorizations for services. Once contacted, benefits counselors worked directly with individual families to address the immediate health care or coverage need the family was facing.

These families and others contacted through networking with community agencies and providers were invited to work with a group of interested parents, service providers and advocates in locally formed HealthWatch committees. HealthWatch committees identified local needs and goals that guided the development of each program. Activities included networking to solve locally based problems and strengthen community resources; policy action; and community training and educational resources.

There were successes and some frustrating disappoints that emerged when trying to address so many complex issues in a continually changing environment. The impact of parent involvement in this project was enormous, and yet, the challenges to parent participation remained a constant concern whether planning work schedules, meetings or community workshops.
Families in crisis due to a health care coverage or access issue need a source of accurate and timely information; they also need a reassuring voice and a steady hand to help guide them through an often emotional process of challenging an inappropriate coverage denial or termination of benefits. For the families participating in the Families MAP pilots the health benefits counselor served the role of advocate, friend and a link to legal resources and a vast array of supportive resources.

Health benefits counseling provided the foundation of the individual advocacy piece of Families MAP. Our counselors, parent advocates and attorneys worked with parents of children with special health needs to identify and resolve many problems with health care coverage or access issues, including: connecting to information on public and private health care financing programs and supportive services, gaining an understanding of their coverage options that empowered them to make their own decisions; receiving application assistance for Medicaid programs and advocacy assistance with grievances and appeals, and taking actions that improved health care and avoided depletion of family resources.

Frequently families contact a health benefits counselor during a crisis. Something has gone wrong or is simply too confusing or stressful to deal with or understand. The counselor’s role is to work with families to resolve immediate problems as they also evaluate the health coverage needs of the whole family. By taking a proactive approach to working with a family, counselors can help prevent future coverage issues while at the same time empowering the family with information tools and resources. The counselor will also follow-up on unresolved issues to ensure a potentially successful coverage strategy does not fail because of a missed deadline or incomplete form. On occasion, advocacy efforts rise to the level of legal intervention after administrative appeals, or internal grievance procedures have been exhausted. Access to legal services by an attorney can provide the critical leverage needed to nudge a recalcitrant third party payor into action. Sometimes the mere shadow of the law can effect positive change for families struggling with benefit denials or terminations. Other times a lawyer may have to intervene by filing suit.

Health benefits counselors gain an important ground-level view of the problems encountered by families with children with special health care needs in their communities. Moreover casework leads to the identification of system-wide barriers, specific managed care plan policies, or geographic barriers that affect families in their daily lives. For example, in Families MAP, one such issue was funding stream coordination between the Medicaid program, the public schools and private insurance providers. A state representative who became active in Families MAP attended several lis-

**Health Benefits Counseling Services**

Direct client services include: health benefits counseling to inform families of possible eligibility for programs or services; consultation about patient’s rights and obligations under their managed care plan; assistance with filing grievances and appeals; legal assistance with filing hearings, and connections to support groups or other relevant organizations.
tening sessions with parents. Based on their concerns, he launched an initiative to help develop a better process to coordinate funding for families and children with special health care needs. This initiative also led to a workgroup on coordinated funding to carry on this policy initiative.

Health Benefits Counseling: The process

Perhaps the most powerful and most compelling way to describe the process of health benefits counseling and Families MAP is through the stories of brave children and families served by the project. Yet the detailed systems and structures developed as a part of the health benefits counseling process merit a discussion and description to fully understand the process to get quickly to the details of the issues challenging a family. Consequently the nitty gritty process of health Benefits counseling that follows will also be enlivened by examples that represent the casework of the health benefits counselors and attorneys.

Family Needs

In a perfect world, benefits counseling would be available to all families 24/7. In our Families MAP reality, this was not possible. What we could do was strive to create systems that help families and CSHN at critical times when parents feel they need counseling help the most: at the birth of a baby, when a family first learns of a diagnosis from a provider, or when a family finds that their health coverage or access to coverage has been terminated. No matter the circumstance, a first priority for a health benefits counselor is getting connected to families when and where the counseling services can be of the greatest benefit. This in turn decreases stress on families caused by worry about medical expenses, and starting or delaying needed treatment and the real or long-term damage for children caused by these missed opportunities.

Everything begins with getting the message to parents that they are not alone in trying to find assistance and answers to their questions. Health benefits counseling begins with quickly connecting families with advocacy to find the care and coverage solutions they seek. Connecting families to benefits counseling quickly is also important due to the limited application time frames of public health coverage programs. Sadly, missed time lines mean missed coverage opportunities for families. The vigilance of the counselor working with the family can save not only dollars for the family but also the heartbreak of massive bills and possible disruptions in relationships with providers. In the end family stress is reduced and more care and attention can be focused on the child.

Reaching out to parents

Word of mouth from parent to parent may be the most effective strategy for health benefits counselors to connect to parents. Word will spread quickly if high quality services that get results are delivered. Through parent-to-parent support groups or other parent-related associations, parent advocates are very effective in talking with other families and sharing resources and valuable firsthand experience. Outreach to parent support groups can be achieved by sending written information describing services or attending meetings to talk to parents about health benefits counseling services.

In addition to parent groups, the counselor should be well-networked with health care providers, community agencies and advocates who work closely with families and CSHN. Indeed an important strategy that health benefits counselors use to get connected to families is integrating with the service provider community. For example following up on an initial contact by a medical provider who may call on behalf of the family or may contact the benefits counselor to see if a referral is appropriate. These technical assistance calls build relationships between agencies and provide an ongoing informa-
tion network that expands the effectiveness of any benefits counseling efforts done by a single organization.

All of these ways of forming connections involve doing community outreach. Brochures, newspaper articles, presentations to community groups, presenting information at workshops and conferences all build connections and get the word out. If a counselor can’t do all of these things, the most important place to put effort is on building a strong connection to the professional network in the community. The other things will come.

The First Step: Intake interview

Most often, the first contact with a parent is a phone call in which the benefits counselor collects information, first to analyze the coverage problem and determine if the issue falls within the scope of the counselor’s services, or make a referral to other community resources. Once the caller is determined to falls within the health benefits counselors scope of services, an intake form is completed (see a sample intake form in appendix B). The intake interview collects information that serves a number of purposes. It will be used to:

- determine the urgency of the problem—there is no way to overstate the importance of a timely response when offering financial counseling services and the need to identify immediate sources of care and coverage pending the review of a denial.
- determine what the caller is asking - in a family crisis, the caller may not always be able to clearly say what they want. They may simply state that they have no health insurance for their CSHCN, or cannot pay for a needed service.
- determine if the family has private or public health care coverage
- determine financial and non-financial eligibility for either purchasing a private insurance plan or applying for public programs (as illustrated in the case study below)

Case Study—Financial and non-financial eligibility

Angela and Kevin are married and have one child with special health care needs due to a genetically inherited condition. Angela is now 5 months pregnant with their second child, and the pregnancy is considered high risk due to the genetic factors that affected her first child. Kevin was recently laid off from his job of five years, but fortunately was only out of work for a month before finding a new job. Kevin signed up for insurance at his new job, but was told that there was no coverage for Angela’s pregnancy because it was pre-existing condition. Angela then checked into Medicaid Healthy Start as a coverage option, but found out that Kevin’s income was too high for her to qualify without first paying a several thousand dollar deductible.
Angela knows Rose, the parent consultant in Chippewa Falls, because she attends Health-Watch meetings and a parent group in her area to help her and Kevin find support and resources in coping with their son’s disabilities. Angela talks to Rose at one of the meetings about her concern in finding health insurance to pay for her prenatal care and the birth of her baby. Rose tells Angela that she will look into some options for her. Later that day, Rose makes a call to the Health Benefits Counselor she works with to discuss Angela’s concerns.

The first thing that Rose is told is that there is a federal law called the Health Insurance Portability and Accountability Act (HIPAA) that protects people from being rejected coverage due to a pre-existing condition under these circumstances (this law does not allow pregnancy to be considered a pre-existing condition). HIPAA applied to Angela because she was moving from one group insurance plan to another without a 63-day gap in coverage. The Health Benefits Counselor did an intake with Angela and referred this case to the supervising attorney to address with Kevin’s employer.

- determine if a grievance or appeal needs to be filed and the deadline for doing so
- determine what documentation needs to be collected from the caller to proceed with evaluating the case – for example, if the caller has received a denial for a requested service, ask for a copy of that denial
- determine if other parties need to be contacted and a release of information needs to be signed
- explain what a health benefits counselor can and cannot do – define the scope of assistance and do not raise expectations above what can be offered

**Gather documentation and evaluate issue**

After completing the intake the counselor will gather relevant documentation to evaluate and assess the identified case issue. There are times when, after initial investigation, the issue might look somewhat different from what the family initially described. For example. A family calls and tells the counselor that they have a denial of services and an unpaid bill as a result. They may be calling looking for representation in the grievance process or to find out if other funding sources might cover those costs. Upon reviewing the insurance policy, the counselor identifies that the service is clearly not covered and that the family may end up being financially responsible for service their child has already received. Although this may not be the answer the parents were initially looking for, once the confusion is cleared up, many times parents are happy to have a better understanding of their coverage options.

**Medicaid notices**

Notices a family receives after applying for Medicaid coverage should be reviewed by a health benefits counselor both for accuracy and to make sure the family or child receives the most beneficial coverage available to them. If a family receives a denial of eligibility, that denial should be assessed to determine the reason for the denial and to make sure all information used in the calculation of eligibility was correct. For example, if a family is denied eligibility for Medicaid due to excess income, the notice should be checked to make sure a Medicaid Deductible was calculated as in the case example below.

**Case Study—Medicaid Deductible**

Katie and Sam are married and have two children, Emma age 6 and Josh age 2. Josh is a child with special health care needs. They have insurance through Sam’s employer, but there is a $500 calendar year deductible per family member and co-payments ranging from $15.00
to $50.00 for all medical services. The out-of-pocket costs, especially for Josh, are running in the thousands each year. Katie and Sam are looking for some help with these costs. Sam makes $35,000 per year and the income guidelines for Medicaid eligibility for Josh to get coverage under the Healthy Start Medicaid program is $33,485 (year 2002), so Katie and Sam assumed there were no coverage options available to them.

While talking to a Health Benefits Counselor about their medical costs, Katie is told about “wrap around coverage” and the Medicaid Deductible feature. This is when a family enrolls in Medicaid as a way to help meet out-of-pocket medical costs even though the family already has a private insurance plan. This is especially helpful for a family with a CSHCN where there generally are more doctor appointments, therapy visits, and prescriptions to buy. The Medicaid Deductible feature allows the family to use the outstanding medical debt and health insurance premiums they currently pay to offset their income that is above the Medicaid income guidelines. With a Medicaid deductible met, Josh can have Medicaid Healthy Start pay for all of his medical care that is not covered by Sam’s private health plan.

After assessing the case with the family and usually after consulting a supervising attorney, the health benefits counselor should appeal a denial that appears incorrect. The same process will also hold true for other types of denials, such as denial of coverage under a private insurance plan, a request for prior authorization for a type of medical treatment, durable medical equipment such as a wheelchair or walker, or for therapy services.

Key Counseling Elements

**Health benefits counselors (HBC)**

The benefits counseling process has many twists and turns, with new directions to be explored all the time. Counselors work with families to handle problems from identification through to a legal referral. In broad strokes their responsibilities include:

- Conducting outreach to identify families of CSHN
- Provides counseling and assistance to children with special needs who are not covered and have inadequate coverage.
- Investigate terminations and denials of coverage for services and equipment
- Provides counseling and assistance families dissatisfied with their treatment by a managed care organization, assists with problem resolution including filing of complaints and grievance procedures.
- Serves as an independent advocate on behalf of enrollees in the resolution of disputes. Monitors and enforces compliance with contracts and regulations at both an individual case level and systemic level.
- Disseminates information and provides counseling regarding state managed care and insurance laws
- Collect information from HMOs as well as maintains detailed and categorized records of the services it provides. Include client demographics, number and types of problems and requests for assistance, source of referrals to the program, success of advocacy work, time spent on specific programs or inquiries, and program costs.
Parent advocates

Families MAP was enriched by having a parent advocate working in each of the pilot projects. These settings gave the project experience with the differences in challenges faced by rural and urban families. Projects were set up in a Public Health Department housing the Regional CSHN Center and in two community-based organizations—a large consumer advocacy organization and in a nonprofit law firm. Counseling, training and technical support services were provided to parents by an experienced health benefits counselor and attorney located in the nonprofit law firm.

Parent advocates combined the real life experience of raising a child with special health care needs with the experiential kinship that is offered to parents they assist. Many parent advocates have experienced the hard knocks of problems accessing and paying for expensive and ongoing care for their children. They have experienced hassles with insurance companies and denials for requests for services. These are parents of CSHCN who want to use their life experience to help other parents avoid their frustrations and disappointments, and who want to improve the system for their own child and parents and children coming down the road. Parent advocates are also in a critical pipeline of new information and can learn new skills to help them in their own personal situation.

In this project, parent advocates worked part time in the community in which they live and access services for their own children. A flexible, part-time schedule allows a parent of a child with special needs the ability to take care of the many needs their demanding personal life requires, yet allows them to network and grow in knowledge and abilities as a parent in the CSHN community. Parent advocates report that they felt rewarded in their ability to help other parents and a renewed optimism in dealing with their own life stressors.

Parent advocates played an important roll in the Families MAP project in accomplishing some of the goals mentioned in the health benefits counseling section. These key players in the project were in their communities doing outreach to other parents and connecting those parents to services on a daily basis. The parent advocate ran local support groups, arranged local training events and brought in speakers for other parents who were having difficulty accessing or financing health care services for their CSHCN. The parent advocate also worked closely one-on-one with each parent they came in contact with to provide individual counseling and referral to other needed resources. Counseling services provided by parent coordinators included counseling families on their coverage options from a variety of financing resources, helping them with eligibility strategies and the application process, helping to resolve coordination of benefits problems between private HMO coverage and Medicaid, and dealing with denials of referral and therapy requests.

Technical support on complicated case issues and questions was provided to the parent advocates by the health benefits counselor and the project attorney. The parent advocate was able to call with questions and get guidance on how to proceed with a case, or if it was appropriate to refer the case to the counselor for staffing with an attorney if it looked like a representation or legal issue faced the family the parent advocate was working with. Some cases remained with the parent advocate, and some cases were moved to other resources for case resolution.

Legal services

The importance of a link to legal services for a health benefits counselor or a parent advocate should not be underestimated. The law has the potential to be the great equalizer between the enormous power and leverage possessed by large insurers or government agencies. More importantly the mere presence of lawyers working with your program is not an indication that all interactions with other organizations will be adversarial and confrontational. What it will mean is that the discussions, negotiations and strategies developed will be done within the shadow of the law. Indeed the presence of a lawyer can have a stabilizing effect on the process of resolving
a payment or eligibility dispute for a family. In fact most disputes (over 99%) for families were resolved without going to court.

The link to legal services that are part of a Managed Advocacy Program must be affordable for families. Many families are too poor to hire private counsel, but even if they could afford it, they would have a hard time finding a private lawyer willing to take a case involving a health insurance claim dispute or medical debt. We typically found that families with medical debt can find counsel to assist in bankruptcy proceedings more easily than they can locate an attorney to provide the legal counsel and representation on health care coverage issues that MAP provided. Consumer health care coverage law is a specialization rarely practiced by attorneys working in consumer bankruptcy or poverty law, perhaps because the interface of state and federal rules governing eligibility and billing of public programs is complex, and because many cases involve relatively small sums of money and statutory attorney fees are not generally available. Additionally, those who qualify financially for a Legal Services Corporation attorney might not obtain assistance for a case involving private health coverage because few if any Legal Services or Volunteer Lawyer programs offer counsel in private pay or mixed private and public coverage program disputes.

As a part of Families MAP legal services were provided for Families and CSHN on the following issues: private health insurance disputes and denials of coverage based on preexisting condition clauses, medical necessity, and usual and customary costs, in both state regulated and federally regulated ERISA plans; COBRA continuation and conversion; denials of service from HMOs in both private and MA/HMO plans; health insurance marketing; eligibility for or access to services under childhood disability programs such as SSI and the Katie Beckett Program; and multiple private and public health financing streams for a single insured.

- consultation and advice by telephone or in person;
- case investigation (fact finding and gathering financial, medical or insurance information or documents);
- referrals to the private bar, pro bono attorneys, and other agencies;
- negotiations with insurance companies, HMOs, collection agencies and health care providers;
- filing complaints with the Commissioner of Insurance and monitoring actions taken by the Commissioner to ensure proper redress for clients;
- representation at administrative hearings, before the State Claims Board, in state and federal court; and
- appellate review.

Families are also less able to withstand the medical debt that arises when insurance claims or Medicaid benefits are denied. The target populations for ABC’s legal services have ongoing medical bills that rapidly become credit (and legal) problems. Chronic illness, very expensive health insurance and medical expenses not covered by their policies are all obstacles to needed health care. Families are especially vulnerable to serious credit problems associated with catastrophic illness. Furthermore, many families already struggling with the psychosocial needs of a seriously ill family member may accumulate unnecessary medical debt due to coordination of benefit problems. They are frequently harassed for payment by unscrupulous collection agencies that violate state and federal law.

Using Casework to Create Change in Families MAP

Providing legal services allowed the lawyers with Families MAP to identify and frame many of the larger issues and frustration faced by families in a legal context. Not only did the attorneys use the law and the experience of past court battles and decision to
help assert the rights of families, they also kept an eye to the future to the new legal and advocacy pathways that needed to be created to address emerging health care coverage and access concern for families. As with health benefits counseling, the individual casework conducted by lawyers was an important vehicle for education and system change.

**Case Study—Home care denial**

Sally Smith, a single parent, has a 6-year-old medically involved daughter named Emma. Emma has a neurological disorder that requires private duty nursing services 24 hours a day. Sally has two other children, an older son, John, who is 14 and starting his first year of high school and Tim, a 3-year-old who recently was diagnosed with Attention Deficit Disorder. Sally has taken care of Emma at home since she was released from the Neonatal Intensive Care Unit when she was about three months old. Recently, Sally received a notice from the state that private duty nursing hours would be reduced from 24 hours a day to 16 hours a day. The rationale for the reduction in nursing hours was that Sally, as a parent, is required to provide certain cares to her child and is available to provide cares. Sally has learned many of the procedures and services required by Emma, since there are times when there may be a shortage of nurses or a nurse fails to show up for a shift. Although Sally is capable of providing the services, she is not comfortable since she is not trained as a nurse, nor does she have the time to take over a nursing shift since she needs to work full-time as well as meet the needs of her other children. Sally contacted the attorney at an advocacy organization who intervened and filed a suit in court claiming that the State had developed no criteria to identify situations where parents should be required to provide these types of care for their children, nor did the State define circumstance in which the other care needs of family members as well as needs of the mother are taken into consideration. The court reversed the State’s decision and the judge indicated that the State was, in essence, punishing the mother for being a good mother and learning to provide the cares, but then expecting her to take over the role of a trained nurse. Twenty-four hour care was reinstated for Emma.

This example demonstrates how active and involved parents can get caught and penalized by the State’s drive for cost containment. The state is interested in curbing redundant or not medically necessary expenses. As they examine costs to cut, high-ticket items like private duty nursing are closely scrutinized. Here the state crossed the line when they failed to look at the situation from a family centered perspective. By failing to account for the mother’s other activities and other children, the state put forward an argument that was seemingly grounded in common sense. Parents have a responsibility to care for the needs if their children. But the state failed to look at the circumstances of this family and this mother to make an appropriate and legal determination of the care need of a medically fragile child. The law helped to play a correcting influence on over zealous state determinations and this decision was useful to advocates and families across the state.

Private insurers are also very interested in cutting unnecessary and what they consider to be experimental or duplicative costs. The drive to cut costs from private insurance can border on fraud or bad faith, particularly when some unscrupulous companies use an illegitimate contract term to deny benefits. Phantom clauses can be inserted into policies that have little or no meaning. Like a scarecrow in the field, what might look scary at first blush, is actually harmless.
Case Study—Phantom clause

Tom and Rita Jorgenson have a 15-year-old son named Isaac. Isaac was recently diagnosed with a brainstem tumor that could not be operated on. The family sought the care of a specialist who had developed an innovative therapy to treat brainstem tumors. The treatments had undergone Food and Drug Administration trials. The insurance company, however, denied care for Isaac as not being covered due to it being experimental. The policy contained a clause that indicated any treatment or service that was not medically approved by the American Medical Association would not be covered under the terms of the policy. The family contacted an attorney to review the denial, contacted the AMA, and discovered that the AMA is not in the position to approve or disprove certain types of therapy—experimental or non-experimental treatments. The attorney received an affidavit from the general counsel at the AMA confirming the position of the AMA and forwarded it to the insurance company to challenge the denial. After alerting the insurance company of the fraudulent nature of the clause in their policy, the matter was settled and the treatments were paid for by the insurance company.

The important lesson from the above example is that sometimes there may be language in an insurance policy that is meaningless or makes no sense. In situations like this, a family should carefully review the policy and contact an attorney if they find language that they don’t understand or that may be placed in the policy only to deceive or confuse the policyholder.

Combining the ingredients

Benefits counseling combines the work of the health benefits counselor, parent advocate, and staff attorney. The common element of all three positions is advocacy on behalf of families. They are all advocates, each with a unique set of skills or life experience that when combined becomes a powerful force for families seeking health care coverage or access.

A benefits counseling program can find a home in many different places. Anyone who is interested in advocating for others, specifically in the area of health care financing and navigation can provide client services that serve to address these issues.

In a provider organization, it could be a senior staff member of a financial services department, a social worker, a discharge planner, or the person who manages the charity care program. In a nonprofit, it could be anyone willing to become an expert on health care financing and access issues.

Good locations certainly include clinics and hospitals, public health departments, nonprofit advocacy agencies serving health and social needs, and public interest law firms.

Getting started

Whether you are one person or there are a group of people that have identified the health care access and financing problems facing families that have children with special needs, you or that group of people have the capacity to do something about it. It may mean taking time out of your day to work on those issues with families, it may mean trying to integrate this type of advocacy into your job description.

Turn a problem into an advocacy issue. Develop an issue that is important to you. Find others with similar concerns and learn everything you can.

Share hard-to-find information with other parents and/or professionals. Some information related to CSHN is hard to find or difficult to locate. The first step in becoming an effective advocate can be putting together or learning about existing resource lists. Developing personal relationships with CSHN staff, county agency, etc., will lay the groundwork for an organizational meeting to discuss shared goals.

Becoming a skilled health advocate largely depends on practice. It requires the willingness to learn as you go by taking on new cases and searching for
solutions, and eventually becoming skilled and knowledgeable about health care coverage, access, policy and advocacy.

There are many tools and resources a Health advocate will use to increase his or her ability to serve clients. In Wisconsin, HBC’s attended trainings specific to health care financing programs sponsored by the State Department of Health and Family Services. Federally funded legal service offices also put on trainings once a year on a variety of topics, including childhood disability programs under the Social Security Administration. Training programs from other statewide and local community organizations on related health care coverage or health care related programs were attended whenever the opportunity presented itself.

Key tools for the advocate to have on hand are program and policy manuals and handbooks that describe program rules and state regulations that apply to health coverage and eligibility rules. In Wisconsin a HBC has a subscription to the Medicaid Handbook and receives the periodic updates that keep the handbook current with program rules. Wisconsin also puts out regular Operations Memos with updates, clarifications, and changes to program rules. It is a valuable tool to keep current on upcoming MA Handbook and policy changes. Other valuable resources every HBC has include the Wisconsin Administrative Code and Wisconsin State Statutes. Internet access is very important to be able to search websites for information about government programs, community based programs and state resources, and other electronic manuals for specific program information and rules related to CSHCN (e.g. Katie Beckett program, Healthcheck (EPSDT) program, Birth to 3, Medicaid Provider Handbook). Developing a resource with frequently used contacts and resources is an invaluable tool for any benefits counselor to have (see appendix for a list of Health Care Financing Resources).

The Final Steps

After you have identified your community needs and assembled the key components of a health benefits counseling program you may want the answer to the threshold question of how to fund a program. Clearly health benefits counseling programs should be funded as a necessary service for families by the state or Federal government. A similar program for seniors is funded statewide in Wisconsin through State funds and Federal Older American Act funds. For Families, The Family Opportunity act holds promise for advocacy resources. Other resources to tap into include Medicaid administrative resources or outreach dollars. Other funding may include case management or care coordination benefits available through EPSDT in your state. Finally, providers who have a vested interest in getting medical services paid for may be willing to institute a program of health benefits counseling at their facility. That said the service can be shown to more than pay for itself in a provider setting. Our work has shown that a $10 investment has the capacity to generate over $100 in third party reimbursement after the first encounter when health benefits counseling is provided to a MCH population. This service has also been shown to be a great customer service as well as contributing to better provider staff morale.

Our work in developing a families MAP program documents the compelling need to help families through the blizzard of red tape they encounter as they seek care and service for their children. Health benefits counseling programs can provide just the help that a family needs. Now is the time for policy makers and agency leaders to step up to the plate to support the deliver of comprehensive health benefits counseling services that include support for both parent advocates and links to legal services.
Working with HealthWatch Committees

Concept of Health Watch

Everyday, in communities across Wisconsin, caring people strive to offer guidance, support and services to families who have children with special health needs who are struggling with the challenges of multiple service needs and coverage programs. Parents, Birth to 3 coordinators, public health nurses, economic support workers, health care providers, school nurses and counselors, advocates, lawyers, and clergy – all are important stakeholders who help families wind their way through the health care coverage and financing maze.

However, many of the challenges that confront families and their children with special health needs cannot be resolved by individuals working in isolation or even within a single agency or provider organization. Only by coming together to identify problems and community resources can we really address system based barriers. Working together, people in communities across the state are able to create change. One way of pursuing systems change is the development of HealthWatch committees.

The greatest strength of these coalitions is their diversity of voices and the ability of group members to identify problems in their day-to-day interactions with families. Coalitions such as these are a testament to the power of local associations to find creative solutions for local and statewide problems.

HealthWatch is an organizational effort intended to stimulate development of sustainable local committees focused on health care access and financing issues for children with special health needs. A HealthWatch committee works to:

- Create a local forum for networking to resolve local service issues and problems
- Identify systemic issues for policy change
- Provide community education events and resources

The HealthWatch concept first had its start in 1989 when a diverse group of health care providers, representatives of community based organizations and government policy makers met in Milwaukee to discuss local, systemic issues that they encountered through their work. In response to these local concerns, they organized a HealthWatch coalition. The HealthWatch concept evolved as these individuals learned that by meeting regularly to advocate for families in need of care, with a particular emphasis on Medicaid managed care problems, they could effectively work together to resolve many of these issues. The Milwaukee committee proved to be such a successful model for collaborative issue spotting and problem solving that ABC for Health created a similar committee in Dane County in 1996.

HealthWatch and Families MAP

Through Families MAP, ABC for Health worked to create CSHN focused HealthWatch subcommittees in Milwaukee, Dane County and rural Chippewa County in 1998. Each of these pilot sites focused
their discussions on the specific barriers that families who have children with special health needs face in managed care. In Chippewa County, where no formal HealthWatch committee had existed previously, a new committee was organized which had a specific focus on children with special health needs.

During the years of 1999 through 2001, Wisconsin’s Title V Maternal and Child Health program and local public health departments conducted a variety of surveys of families who have children with special health needs. These surveys further supported the compelling issues that were being discussed in the HealthWatch committees. Two enormous barriers facing families were access to care and adequate information about services and resources. Parents specifically identified a need for a more coordinated system of identifying health resources and supports for their children and their families. And, as families’ needs were identified, it was recognized that there was no formal mechanism to document and capture these needs statewide. Additionally, a systematic way of developing strategies and action plans to address these identified concerns needed to be formulated.

Each of the pilot sites was charged with forming a committee that would focus on identifying problems and strategize solutions regarding health care coverage and access for families of CSHN. Pilots had wide latitude in the development of these committees. Due to the unique demographics and other factors in each of the pilot locations, each HealthWatch committee developed quite differently from one another and faced distinct challenges.

What follows is a synopsis of the HealthWatch development in each pilot site. Their unique characteristics are highlighted and reflect the fact that HealthWatch committees adapt well to the particular characteristics of their communities. You will learn more about how these committees were formed, what the singular factors were in each location, the varying evolutions of these committees and the lessons that were learned at each site.

Experience by location

Milwaukee

According to 2000 census data, Milwaukee is a city of nearly a million people. Twenty five percent are identified as African American and 8.8 percent as Latino. Children are numbered at 27,626 and an estimated 20,426 families with children in the household are living beneath the poverty level.

Community Advocates (CA) was the home for the Milwaukee pilot project. CA is a 25-year-old community-based organization whose mission is to work with low income and destitute persons and families to gain and ensure access to programs and services. This mission is accomplished by staff and volunteers providing self-advocacy, representation, gap-filling, and system advocacy services to all persons in need. CA also specializes in coalition building. Employees work out in the community with many other agencies and understand the needs of families. CA is conveniently located in the middle of Milwaukee where over the last 25 years they have earned a widespread reputation for helping families get what they need. A parent advocate was identified to staff the CSHN HealthWatch subcommittee.

Getting started

Since Milwaukee County had an existing, broad-based HealthWatch committee before Families MAP, the Milwaukee parent advocate called upon about 60 current HealthWatch members to participate in the CSHN subcommittee. These participants included representatives from four major Medicaid HMOs, parents/grandparents of CSHN, representatives of the Latino Health Organization, Hmong American Friendship society, the Black Health Coalition, W2 Job Centers, the Medicaid enrollment contractor, specialty hospitals and rehabilitation facilities serving CSHCN, Milwaukee Public Schools, child care providers, assembly and state senate representatives, and other health care advocates.
Of the seventeen major ideas generated by the initial meeting, the top three were the fragmented nature of state services, insufficient provision of health care for families of children with disabilities and a need for more advocacy for families with special needs children with all levels of government. Of those three, fragmentation of services was prioritized as the most profound problem: families—even those eminently eligible for services—were unsure of who to talk to and where to go. Even when they did get to the right place, there were often waiting lists for receiving benefits. Compounding matters were the large number of low-income families in Milwaukee coupled with county workers not fully understanding eligibility criteria for families applying for state and federal health coverage programs.

Building capacity

The process of building the local HealthWatch subcommittee in a large urban county like Milwaukee was fraught at times with fits and starts. The issues the subcommittee addressed at times strayed from the core issues of health care coverage and access in managed care for CSHN. At times, attempts to refocus the mission of the committee caused drops in participation and continuity of membership. At other times, Milwaukee encountered difficulty in maintaining the initial committee participants due to “turf” issues between the numerous provider agencies, and an atmosphere of protectiveness over clients and families. This lead to a lack of information sharing and few referrals for benefits counseling early in the project. Ultimately a core group of subcommittee members emerged to refocus the agenda and make significant contributions in the form of unique trainings and models of consumer participation on managed care organization committees.

Activities

Milwaukee provided trainings on a variety of programs, including Medicaid and BadgerCare, Katie Beckett eligibility, SSI, prior authorizations, community resources, prescription drugs, the Medical Home model, a training on managed care and CSHN from a provider/parent, and a parent panel sensitivity training for W2 workers. They were also involved in an orientation for committee members on the rules and laws pertaining to their rights within certain programs and how to navigate through the system.

There were also opportunities for HealthWatch groups to collaborate on advocacy issues. In fact, during a time period when budget cuts threatened health coverage programs in Wisconsin, Dane and Milwaukee counties sent a joint letter to the Governor supporting a proposal to allocate more funding to BadgerCare. Later, during intense budget debates, the governor took Medicaid “off the table.”

Another issue involved the widespread practice of balance billing Medicaid recipients for services. The coalitions sent a letter alerting the Attorney General and the Medicaid program about the widespread practice of illegal billing of Medicaid recipients. The Division of Health Care Financing later adopted new procedures to alert recipients of their rights. These examples helped to demonstrate the power of a collective and amplified voice of the HealthWatch model.

Lessons learned

People identified—even to the point of getting somewhat off-track—everything that they felt negatively affected children with disabilities. With the numerous barriers that existed for Milwaukee’s low-income population, often single parent families; it was difficult to reign in discussion to only those problems related to managed care.

As mentioned earlier, many of the families that worked with Community Advocates had more than one major challenge to address. Not only did these families have children with special needs to get health care for, but they were also dealing with employment, childcare, transportation and other issues. The combination of these challenges made it difficult to keep some families at the table. The Milwaukee com-
Working with HealthWatch Committees

managed advocacy in action

committee also realized firsthand how working with parents comes second to their taking care of their children when they become seriously ill.

For more information on the Milwaukee HealthWatch, contact Ken Germanson at Community Advocates, (414) 449-4767 or at comadvo@execpc.com.

Dane County

Dane County is home to Madison, the state’s capitol city. The entire county has little less than half the population of Milwaukee, at 410,719, and 51 percent of the population of the county resides in Madison. 106,531 of the total county population are children. Four percent of the residents are identified as African American, with 3.5 percent Asian and 3.4 percent Latino. An estimated 3,611 families with children were under the poverty level.

Getting Started

Dane County’s HealthWatch has been in existence since 1996. Like Milwaukee, their focus is broader than just children with special needs (see appendix D for the mission statement for the South Central Wisconsin HealthWatch). However, also like Milwaukee, the children with special needs subcommittee was formed with participation of HealthWatch members.

An initial kickoff event was organized, at which participants (ranging from state senate representatives to parents to HMO representatives to Department of Health and Family Service staff members) brainstormed a laundry list of issues they saw as barriers facing families of CSHN in managed care. From this list, five basic task forces were formed—Internal Communication and Supportive Services, Uncovered Benefits, Prior Authorization and Referrals, Network of Providers, and Funding Stream Coordination

Building Capacity

In the beginning, meetings were held after work hours to discuss the issues identified and brainstorm solutions to them. It didn’t take long to realize that even though committee members cared about the issues, parents especially are very busy people, and many were not able to participate regularly after work and school hours.

It also soon became apparent that when meetings were coupled with a training on a topic that could actually assist parents and advocates in their day-to-day lives or work, participants were much more likely to attend. Over time, meetings to discuss issues became less frequent and trainings on issues committee members identified took more prominence. These trainings became an integral part of the Families MAP community education program.

Activities

As was just mentioned, Dane County provided several training events for local committee members. These topics included:

- Social Security and Disability
- Advocating with Your Provider
- Mental Health Laws
- Managed Care Contracts
- HMO Panel on Grievance Procedures and Services for CSHCN
- Prior Authorization Forum
- Getting Therapies Approved
- Managed Care Rights and Responsibilities
- Review of the Medicaid Contract
- Health Insurance Checkup
- Alternative Therapies
- Cultural Competency

In addition, a quarterly newsletter was sent statewide, and included topics such as:

- Transitions
- Prior Authorization Basics (see Prior Authorization insert, appendix E)
- Parent Advocacy
- Methods for getting things covered
· Mental Health
· Medical Home
· Consumer Health Care Financing Updates
· State budget and local issues

Lessons learned

It was difficult for this committee to take a countywide focus. Since Madison is the geographic hub of the county, and since state legislators and other officials have offices in Madison, there always seemed to be an overrepresentation of Madisonians at Dane County events. We found, however, that taking good meeting minutes, and posting these and agendas on our web site, as well as highlighting training information in a newsletter which was distributed widely, were good techniques for informing those who were not able to attend meetings (see appendix F for a digest of some HealthWatch minutes). And hosting meetings over an extended lunch hour seemed to increase regular participation of committee members.

For more information on the Dane County HealthWatch Committee, contact Bobby Peterson, ABC for Health, 608-261-6939 or email at bobbyp@safetyweb.org

Chippewa

Chippewa County is located in rural northwestern Wisconsin, about 90 miles east of St. Paul, Minnesota. It has approximately 1/17 the population size of Milwaukee county, and 1/8 that of Dane, with 55,195 people, 16,000 of which are children. Two percent of the residents identified as African American, 9% as Asian and 5% as Latino.

Getting Started

Unlike Milwaukee and Dane counties, Chippewa County did not have an existing HealthWatch committee from which to form a CSHN-focused sub-committee. Due to their more rural location and smaller number of potential committee members, they determined it was best to have one HealthWatch committee with an emphasis on CSHN.

At one of the first meetings, the sub-groups each identified four main issues to work on. Finding the issues in common, they found speakers for each of the issues.

They were initially unsure whom to invite to the meetings. Getting all of the agencies together (including parents of CSHN, nurses, county social services and Medicaid enrollment staff, HMO representatives, private health care providers and vendors, school parent facilitators, Head Start and Katie Beckett Program staff, health care access advocates, and members of the faith community) was much needed in that community. After the initial meeting, a series of smaller forums were held which attracted many of these people.

Building Capacity

The Chippewa committee determined that having only professional speakers wasn’t the best idea. At meetings, they would ask participants to voice any issues that they were concerned about and who they wanted to hear from at particular meetings. They began to incorporate parent stories as well. The Committee became very participant driven, as opposed to chairperson driven.

Activities

Being in a more rural location, the Chippewa committee found that mental health access issues were the biggest barrier. Responding to this, the Chippewa committee formed a special sub committee to focus attention on the issue and develop community strategies to address the identified problems. They held a public forum on mental health issues, a seminar on the role of the HMO advocate, and a training on BadgerCare. Prior authorizations, SSI basics and application process, Social Security determination process were other training topics addressed.
Lessons learned

Members of the committee worked hard to form positive relationships with other agencies, particularly those workers in economic support.

The committee invited people from various churches to participate, although only one representative responded. Other organizations heard about HealthWatch from committee members. HMOs in particular were very receptive. For them it was dual purpose, they could both and give sort of “inside” information about the workings of a managed care plan. One benefit was that these representatives could often be approached right after the meeting by a number of concerned people. This informal networking and problem solving can be one of the most valuable aspects of a HealthWatch committee.

For more information about the Chippewa County HealthWatch, contact Rose Marsh at Chippewa County Department of Public Health at 715-726-7908.

Funding Resources for HealthWatch Committees

One of the biggest challenges in developing any new program is identifying a funding source. Developing a HealthWatch committee is no different. Although we can point to less family stress, greater access to care, better coordination of services and links to a medical home that offers less expensive care in the long-run, it may be difficult to quantify short-term savings to a healthcare system that is chronically short of resources. Nevertheless, there are opportunities to help initiate a HealthWatch committee in your community with some resourcefulness, some cooperative community stakeholders, and support from the state and federal Medicaid programs (see the CSHN HealthWatch Toolkit on this Families MAP Publications CD for resources on starting a local HealthWatch).

Funding may be available from the state, Title V program or from your county Medicaid office. In addition, you may have a local community foundation that is interested in supporting collaborative activities to help build local infrastructure and supportive services. The HealthWatch committee of Families MAP fits this criterion nicely. Another opportunity may be to use local dollars as match to help secure federal Medicaid reimbursement. These resources may come from outreach or part of the administrative dollars that go to support Medicaid programs. By fostering local communication, problem solving and strategies, this system can be improved to help the cost effective delivery of healthcare and supportive services that are embedded in the managed advocacy concept.

Local health departments have a very important role in assuring the health care access needs of their respective communities. There may be existing meetings that a managed advocacy program agenda could be added onto to help focus on the needs of families and children with special health needs. A good place to start may be by contacting your local county health department director or even a member of your local county board to see if they can help get a local HealthWatch coalition started. Forming the local coalition may be the important starting point to get the other attendant services developed.

As you establish a HealthWatch committee in your community, be sure to identify the high priority areas that families need assistance with. These high profile issues will help not only gather momentum and enthusiasm for your work, but will also gain the attention of funders as community priorities that are in need of local support. Keep building and strengthening your local coalition to help ensure that you have the broadest range of support and allies. Get letters of support and help communicate the needs of your community to make sure that your managed advocacy program is well funded and serving the needs of your community.
HealthWatch Committees and Systemic Policy Change Activities

The goals of the HealthWatch committees was not only to educate parents, advocates and providers, but to facilitate communication among groups affected by managed care programs, identify areas of concern regarding access to health care services, participate in problem solving strategies and offer policy changes to make the managed care system more responsive to the needs of families of CSHN. The Committees worked to identify problems and attempt to collaborate with coalition members to solve problems on a local level. The HealthWatch committees that were developed during Families MAP planted the seeds for a larger movement on a statewide basis.

One of the strong points of the HealthWatch committees is that problems and issues were identified from real life experiences. The committee members were able to participate in developing specific policy recommendations. Partnerships were developed as parents and advocates worked along with policy makers as equal members on the HealthWatch committees. And, committee members were informed of existing mechanisms for officially proposing policy changes and were connected to other related statewide advocacy initiatives.

A major activity the HealthWatch committees got involved in was drafting proposed changes to the Medicaid contract between the state and MCOs. For a complete description of how to influence the managed care contract in your state see appendix G, HMO/Medicaid Contract.

Hosting Events for Policymakers

An important outcome of the HealthWatch committees is to influence public policy. Therefore, local coalitions should identify strategies to engage public policy leaders. There are a variety of ways to help educate public policy leaders. For example, busy legislators may not have time to attend specific HealthWatch meetings or events, but a staff representative from their office could become a regular participant and important liaison to the legislator. One strategy to involve political leaders is to give them an opportunity to speak at your meeting or on a topic that is important to them. As part of the process, there could be questions and answers that will provide an opportunity for issues and concerns of the HealthWatch committee to be introduced and debated.

There are several important logistical considerations that need to be taken into account when planning to host a public policy event. For example, it may be a good idea to conduct an event near or even at the State Capitol. This way, busy legislators can avoid losing precious time in travel. Another possibility is to find when the legislators are in the home district and schedule an event around their visit. Many legislators want to hear what the issues are from local constituents and this can provide a good opportunity to provide important dialogue on issues of concern that the committee has identified.

Identifying the correct legislator to involve in your work is also an important consideration. Obviously, working with Families with Children with Special Health Care needs members of the Health or Children and Families committee may be appropriate legislators to target. If your HealthWatch committee is planning a broader town hall agenda for a group of legislators and policymakers, make sure that your panel gets good information ahead of time about types of issues that will be addressed, how the question and answer format will be developed. For example, at some forums the questions from the audience were submitted in advance to a moderator to avoid the chance that legislators might be embarrassed or sidetracked on other issues that were not germane to the issues and concerns of the HealthWatch committee. Setting up an appropriate structure that gives the legislator a chance to air their issues as well as to field important questions can help to establish credibility and trust with your HealthWatch coalition.

Remember, legislators are not the only policymakers. Your coalition should also work to engage representatives from key agencies like the
State Medicaid Bureau, the Children with Special Health Care Needs Program, Public Health offices, as well as major stakeholder from the provider and special education community. In summary, hosting public policy events can be a major way for advancing the agenda developed by HealthWatch committees. Only through open debate and dialogue and engaging the key decision makers will meaningful change occur in your community. By developing strategic links to key policymakers, your HealthWatch group will not only grow stronger, but you will attract more members as you advance an agenda for children with special health care needs in your community.

HealthWatch Committees and Community Education

A critical component of Families MAP was creating a variety of training and public education opportunities. Such activities are effective means of outreach, networking and providing an efficient way to extend the information and case experience of health benefits counselors to a broader audience.

There are many ways to share your message. This depends on available resources and those of the HealthWatch committee. Some effective means for sharing information with other professionals and families that Families MAP used are:

- Public events
- Trainings and public forums
- Presentations at local community meetings, professional meetings, workshops, and exhibits at health fairs.
- Information resources, including brochures, newsletters, publications, resource lists and agency website.

Public Events

Families MAP pilots created a variety of information and training events for parents and providers based on locally identified priorities. Topics offered included training for health care provider staff and health professionals, parents and staff from community agencies who work with CSHN families. In addition, presentations at conferences and workshops were done for families and the general public.

Topics were chosen as parents, providers and advocates in the community identified barriers families were facing in getting health care. Speakers were found with knowledge and expertise in those specific topic areas. For example, parents said that they had difficulty in communicating with their child’s physician. The project was fortunate to find a physician in the community who was also a parent of a child with special needs. This parent/doctor did a presentation on his perspective of being both a parent trying to communicate with his child’s doctor, and being the doctor on the other side with his patient and trying to effectively communicate with the families he worked with.

Another topic that Families MAP held training sessions on was the prior authorization process for therapies. Again, a therapist who works with CSHN was identified and agreed to make multiple presentations to both parent groups and other therapists on better ways to address their frustrations and concerns with the prior authorization process. At one training, the prior authorization review staff from the State of Wisconsin did a joint presentation with this therapist on what helped prior authorization requests be approved and move through the evaluation process more quickly.

In relation to funding stream coordination, a forum was held in which a legislator came to hear what parents, providers, and school staff had to tell him in regards to the difficulty of getting the Medicaid program to pay for therapies outside of the school environment. This topic ended up being addressed at an additional training session as the legislator re-
quested the opportunity to learn more about this problem and how it could be remedied on a system-wide basis.

Once topics were chosen, and speakers had been secured, it was necessary to publicize the events and reach as large an audience as possible. Parents were not always able to attend events, so topics were often covered in meetings and with follow-up fact sheets, website minutes and in newsletters.

**Publications**

To reach a larger audience, public education projects such as consumer-friendly resource manuals and booklets and informational brochures were used. All of these activities built visibility in the community while also providing significant, practical help for families.

The website made a number of the resources more widely available, including the *MAP Report*, the project newsletter, and a series of fact sheets on financing resources for families. A larger publication, *The Health Insurance Guidebook*, was published as a pdf included on this Families MAP CD, which made linking to numerous other web resources a possibility. A limited number of copies were also printed for families who did not have easy computer access.

All community education projects tied back to the health benefits counseling and policy efforts of Families MAP.

**Conclusion**

HealthWatch coalitions are a vital part of an overall strategy of managed advocacy. The coalitions not only help to zero in on the public policy concerns relating to coverage for CSHN and families but they also work to greatly amplify the issues. More importantly community collaborations can result in strategic alliances that help inform the public and policymakers about health issues concerning kids and families. Finally, the friendships you make as part of a community coalition like HealthWatch are endearing. Don't be surprised if the representative of a managed care organization or a county worker that you once viewed with suspicion or even anger soon becomes an important colleague…and maybe even a friend.
Managed advocacy was conceived during a time of rapid change in the health care delivery systems in Wisconsin. Those changes continue today and will continue tomorrow as we as a society grapple with skyrocketing costs and the implications of restricting individual choices about health care services. As such Managed Advocacy and the processes described in this monograph are continuing to evolve. In response to the changing environment of health care delivery, new structures of advocacy and supportive services for parents will need to continually be developed and fine-tuned. However, we believe, the framework of Managed advocacy in Action will provide a flexible blueprint for years to come as our systems of care and coverage for CSHCN evolve.

Now that you have reviewed the process and seen the blueprint of a Managed Advocacy Plan in Action you might be ready to take the next steps toward building a program in your community. What are the next steps? Begin to ask the questions in your community to see if the mood is right for the establishment of Managed Advocacy. Remember that the model is designed to be collaborative and not adversarial. There will be pitfalls along the way and you may be greeted with suspicion and looks of puzzlement. Broken fences may need to be mended as you assemble key stakeholders and parents. The inclusion of advocates and lawyers working with parents was not meant to be provocative, but rather was an attempt to level the playing field between families and the large bureaucracies and institutions serving them. On an equal plateau, families, advocates and providers all working toward a common goal: improving the systems of care and coverage for Children with special health care needs.

The development of a managed advocacy program is not a simple proposition. In fact assembling the pieces to build a program will take hard work, creativity and most of all passion. However once you begin the process it may be impossible to turn back the clock. Moreover, the combination of advocacy, parent involvement and links to key community stakeholders can have a catalytic effect in your community to promote significant and lasting change to the attitudes and philosophy of the providers and the bureaucracies that are established to help and support families and CSHN.
**Wisconsin Services and Programs**

**Wisconsin Public Coverage and Services**

**Wisconsin Medicaid Programs**

Wisconsin families eligible for Medicaid coverage must, whenever possible, enroll in one of the Medicaid HMOs currently serving the state. Enrollment options vary with zip code, ranging from a single HMO in an area up to three from which to choose. Exemptions allow those children with an SSI disability determination to opt out of an HMO, and choose fee-for-service coverage.

A fee-for-service Medicaid card allows more flexibility in seeking care from a wide range of physicians and providers, as long as those providers accept Medicaid. This flexibility is especially important for CSHCN who may need to see a variety of specialists to treat their specific diagnosis.

Wisconsin provides comprehensive coverage for all but one of its Medicaid programs (Healthy Start Presumptive Eligibility for pregnant women). The state has also chosen to allow families and children to become Medicaid eligible through optional Medicaid programs such as the Medical Assistance Deductible program and the Family Fiscal Unit (FFU). These two strategies were very helpful to CSHCN who had large medical expenses or were seeking coverage for one specific person in the household. *The Medicaid deductible allows families with excess income to use their outstanding medical debt to offset their income that is above the eligibility guidelines for Medicaid. The FFU allow the calculation of individual eligibility if a person in the applicant family meets specific program criteria.*

**BadgerCare:** This is Wisconsin’s SCHIP program. It provides low-cost or free family Medicaid coverage to low- to moderate-income families with children under age nineteen who do not have access to, or coverage by, a private health insurance plan. The income guidelines are 185% FPL. BadgerCare covers children under the age of nineteen and the natural, adoptive, or step-parent(s) who reside with them. It does not cover non-legally responsible relative caregivers such as grandparents, aunts and uncles, etc.

**Healthy Start:** Pregnant women, infants, and children under the age of six are eligible for Healthy Start. An applicant’s family income must be under 185% of the federal poverty level (FPL).

**Healthy Start OBRA:** For children ages six to nineteen the income eligibility guidelines are 100% FPL, much lower than for Healthy Start or BadgerCare.

**Katie Beckett:** Allows certain children with long term disabilities or complex medical needs, living at home with their families, to receive a Wisconsin Medicaid card. Children under age nineteen who are not eligible for other Medicaid programs because the income or assets of their parents are too high, may be eligible for Medicaid through the Katie Beckett Program if they are determined to be disabled by Social Security standards; require a level of care at home that is typically provided in a hospital or nursing facility; can be provided safe and appropriate care in the family home; as an individual, do not have
Income that exceeds program guidelines, or assets in excess of $2000; do not incur a cost of care at home to the Medicaid Program that exceeds the cost MA would pay if the child were in an institution.

**CIP IA/CIP IB/CIP II/COP W:** To enable persons who might enter nursing homes, intermediate care facilities, or the state centers for the developmentally disabled to live at home or in a variety of community settings such as group homes.

**Community Options Program (COP):** This program enables persons who live at home or in any community setting, such as a group home, ready access to generic community resources. Flexible funding to meet a variety of needs such as respite, adaptive home modifications, vehicle transportation modifications, etc.

**CSHCN Program (MCH Title V Block Grant program):** Manages five regional centers and Wisconsin First Step Hotline. The regional centers were launched in 2000 to provide information, referral and follow-up services to families that have children with chronic illnesses or physical disabilities. They promote parent-to-parent support networks and local provider networking for service coordination.

**Birth to 3:** For parents with a child under three years of age who are concerned about the way their baby is developing, this program offers early intervention services; information and referral; development of a plan of services; assistance to find funding for services. This program coordinates developmental, health, and social services within the local community in a comprehensive fashion that recognizes the importance of parents, family and friends in a young child’s life. Families transition out of Birth to 3 when their child turns four and becomes eligible for evaluation for school district services.

**Family Support Program:** To provide support to the family to enable the family to care for a severely disabled child at home. Support includes the services of a Family Support Program Coordinator who can help families identify and obtain needed services and resources and link families together, and funding (up to $3,000 per year) to purchase goods and services not available through other programs.

**Health Insurance Risk Sharing Plan:** State sponsored pool that provides insurance coverage to high-risk persons with chronic or disabling conditions who do not qualify for Medical Assistance or Social Security disability, and who cannot purchase coverage through any other alternative insurance plan.

**Supplement Security Income (SSI):** A cash assistance program that is run by the Social Security Administration for children who are disabled and for whom their household income is low enough to qualify for the monthly cash benefit. A child who receives an SSI check, automatically is eligible for Medical Assistance coverage.

**Managed Care Plans in Wisconsin**

There are 21 health maintenance organizations operating in Wisconsin, thirteen of which provide managed care services through Medicaid HMO contracts with the state. See appendix G for information on participating in a review of the state Medicaid HMO contract.

**Local School Districts Services**

School districts offer a variety of services for CSHCN. However, the number and type of service varies depending on the size of the school district. Examples of some services available through the school are comprehensive education needs assessment (IEP), physical therapy, occupational therapy, speech therapy, and tutoring. These services are bases on educational needs and goal, not community needs.
Appendix B  Intake Form

Date of Referral____________________________________
Referring Person ___________________________________
Agency_____________________________________________ Phone ( _____ ) ________________________________________

Client Contact Information

Name_____________________________________________ Spouse/Partner’s Name____________________________________
Address ___________________________________________________________________________________________________
City ___________________________ Zip ___________________________ County _______________________________________________
Work/Daytime Phone ( _____ ) ___________________________ Evening Phone ( _____ ) ___________________________ □ No Phone
Best Time to Contact ______________________________________ Is it okay to call you at work? __yes __no

Medicaid Eligibility Screening Questions

Have you or anyone in your family applied for Medicaid or BadgerCare? __yes __no

Do you have a Forward card? __yes __no

If yes, call 1-800-362-3002 to verify if coverage is current
If no, continue to use this form to screen for potential Medicaid eligibility.

Please draw a sociogram of the family and the relationships in this family (for example, step-child, step-parent)

Please tell us more about your background and family situation

What is your marital status? ___married ___divorced ___separated ___widowed ___never married
What is your race or ethnicity? ___white ___american indian ___asian ___black ___hispanic ___multiracial

Please list all persons currently living in your home (please check the box for a stepchild and note each person’s health insurance coverage status)

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Date of Birth</th>
<th>Sex</th>
<th>Relationship to you</th>
<th>Stepchild? Current Coverage (circle all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>M / F</td>
<td></td>
<td>Private Insurance / Medicaid / None</td>
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<td>Private Insurance / Medicaid / None</td>
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<td>Private Insurance / Medicaid / None</td>
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<td>M / F</td>
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<td>Private Insurance / Medicaid / None</td>
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<td>M / F</td>
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<td>Private Insurance / Medicaid / None</td>
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<tr>
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<td>M / F</td>
<td></td>
<td>Private Insurance / Medicaid / None</td>
</tr>
</tbody>
</table>

-- over --
Continuation of Intake Form for ___________________________________ referred on_______________________
client name screening/referral date

Please tell us more about your employment situation

What is your current employment status? (check as many as currently apply)
___employed full-time ___employed part-time ___seasonal employment ___self-employed ___unemployed

What is the employment status of your spouse/partner? (check as many as currently apply)
___employed full-time ___employed part-time ___seasonal employment ___self-employed ___unemployed

Please provide some information on your family’s health status

Is any female in your household pregnant? ___yes ___no if so, what if her due date? _________________________________________
(for more information on coverage options, see Healthy Start and Presumptive Eligibility fact sheets)

Do any people in your household have current or ongoing medical needs that are not being met or are difficult to meet?
If yes, who are they and what are their needs? _________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

If you would like us to review your eligibility, please provide us with the following financial information

Does anyone in your household have any past or present unpaid medical bills (including dental, eye care, insurance premiums, etc)?
___yes ___no if yes, what is your estimate of your total medical debt? ________________________________________________________
(for more information on using medical debt to offset income for eligibility, see the Medicaid Deductible fact sheet)

Does anyone in your household pay child support?
___yes ___no if yes, how much is paid out on a monthly basis? _________________________________________________________________

Income Information (please list the sources and gross amounts of all household monthly income)

Income from
Employment ______________________________
(or hourly wage and # of hours)
Child Support ______________________________
Spousal Support ______________________________
Unemployment ______________________________
Workers Comp ______________________________
Unemployment ______________________________
Unearned Income ______________________________
(e.g., disability benefits, interest income)

Asset Information (for purposes of calculating unearned income, enter amount of monthly interest earned)

CD ______________________________
Savings Account ______________________________
Stocks/Bonds ______________________________
Other ______________________________

Thank you for completing this form!

Outcome Information ...

client chose not to pursue eligibility ❑
gave brief information and referral ❑
lost contact with client ❑
completed simplified application ❑
provided follow-up / monitoring on application progress ❑
client gained Medicaid / BadgerCare eligibility ❑
client did not gain eligibility ❑
referred case to backup person or other agency (ABC for Health) ❑

Outcome Notes ______________________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
Health Care Financing Resources

**ABC for Health**
*Description:* statewide benefits counseling and legal services for families with children who are having problems financing health care
*Contact Info:* 1-800-585-4222 or 608-261-6939 or info@safetyweb.org
*Web Address:* [http://www.abcforhealth.org](http://www.abcforhealth.org)

**Adoption Assistance**
*Description:* financial support and health insurance for pre-adopted children with special needs
*Contact Info:* adoption agency or 608-266-0690

**AIDS/HIV+ Drug Reimbursement Program**
*Description:* pharmaceuticals for people with AIDS
*Contact Info:* 1-800-991-5532
rogerka@dhfs.state.wi.us

**AIDS/HIV+ Health Insurance Assistance**
*Description:* health insurance premiums paid for people with AIDS
*Contact Info:* 1-800-991-5532 or lipsejm@dhfs.state.wi.us
*Web Address:* [http://www.dhfs.state.wi.us/aids-hiv/Overviews/AIDS_HIV_hlth_ins.htm](http://www.dhfs.state.wi.us/aids-hiv/Overviews/AIDS_HIV_hlth_ins.htm)

**Air Life Line**
*Description:* air transport in private planes
*Contact Info:* 1-877-AIRLIFE
staff@airlifeline.org
*Web Address:* [http://www.airlifeline.org](http://www.airlifeline.org)

**American Legion Temporary Financial Assistance**
*Description:* financial funding for healthcare, rent, and any other of children of legion members needs
*Contact Info:* 1-800-322-0838; 608-745-1090
vsovmill@vba.va.gov
*Web Address:* [http://www.legion.org/membership/memdisc2.htm](http://www.legion.org/membership/memdisc2.htm)

**BadgerCare**
*Description:* state sponsored low cost health insurance for families with children
*Contact Info:* county social services/recipient services: 1-800-362-3002
*Web Address:* [http://www.dhfs.state.wi.us/badgercare/index.htm](http://www.dhfs.state.wi.us/badgercare/index.htm)

**Betaseron Foundation**
*Description:* makes betaseron available to MS patients
*Contact Info:* 1-800-948-5777
*Web Address:* [http://www.betaseronfoundation.org](http://www.betaseronfoundation.org)

**Birth to 3**
*Description:* a variety of services for children with special health care needs under age 3
*Contact Info:* 608-266-8276
grbbbb@dhfs.state.wi.us
*Web Address:* [http://www.dhfs.state.wi.us/bdds/b3.htm](http://www.dhfs.state.wi.us/bdds/b3.htm)

**Birth to Three Directory**
*Description:* directory of county contacts
*Web Address:* [http://www.dhfs.state.wi.us/bdds/b3dir/b3dir.htm](http://www.dhfs.state.wi.us/bdds/b3dir/b3dir.htm)
Bureau for the Blind
Description: independent living services
Contact Info: 1-888-879-0017 or 608-266-3109
Web Address: http://www.dhfs.state.wi.us/aboutDHFS/DSL/Guide/DSLbureaus.htm

Bureau for the Deaf and Hard of Hearing
Description: independent living services
Contact Info: 1-800-947-6644
Web Address: http://www.dhfs.state.wi.us/aboutDHFS/DSL/Guide/DSLbureaus.htm

Car Insurance - Medical
Description: auto insurance policy

Center for Independent Living
Description: adaptive aids and equipment
Contact Info: 1-800-690-6665

Child Care Payment Assistance
Description: payment of child care for low-income working parents
Contact Info: county social services

Children's Craniofacial Association
Description: travel costs associated with surgery; adults included
Contact Info: 1-800-535-3643
Web Address: http://www.ccakids.com

Children's Miracle Network
Description: assistive devices on a case-by-case basis
Contact Info: 1-800-428-5000
Web Address: http://www.cmwnwi.org

Chronic Disease Program
Description: financial funding for kidney disease, cystic fibrosis, and hemophilia needs
Contact Info: 608-221-3701

Church Funds
Contact Info: your church

College Health Insurance
Contact Info: your college

Community Action Agency
Description: limited housing modernization and rent assistance
Contact Info: 608-244-4422

Community Health Centers Directory
Description: medical services on a sliding fee scale
Contact Info: 608-277-7477
Web Address: http://www.bphc.hrsa.gov/databases/fqhc
http://www.wphca.org/org.html
http://www.wphca.org/affiliate.html

Community Options Program (COP)
Description: a variety of services for persons with disabilities
Contact Info: check statewide directories
Web Address: http://www.dhfs.state.wi.us/LTC_COP/cop.htm

Community Options Program Directory
Description: directory of county and tribal contacts
Web Address: http://www.dhfs.state.wi.us/LTC_COP/contacts.htm

Comparison Shop for Health Care Costs
Description: substantial cost differences do exist
Contact Info: provider's office

County Social / Human Services
Description: directory of county social / human services offices
Contact Info: county social services
Web Address: http://www.dhfs.state.wi.us/Medicaid1/contacts/medcontact2.htm

Crime Victims Compensation Program
Description: payment of crime-related required services not covered by insurance
Contact Info: 1-800-446-6564
wisaq@doj.state.wi.us
Web Address: http://www.doj.state.wi.us/cvs/programs/cvc.asp

Cystic Fibrosis Center
Description: general information and referral to local health care centers for care and financing
Contact Info: 1-800-344-4823; 608-263-8555
<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Contact Info</th>
<th>Web Address</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disabled Children's Relief Fund</strong></td>
<td>provides grants for assistive devices and</td>
<td>516-377-1605</td>
<td><a href="http://www.dcrf.com">http://www.dcrf.com</a></td>
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<td></td>
<td>rehabilitative services</td>
<td></td>
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<tr>
<td><strong>Division of Supportive Living</strong></td>
<td>a variety of independent living services</td>
<td>608-266-5383</td>
<td><a href="http://www.dhfs.state.wi.us/aboutDHFS/DSL/dsl.htm">http://www.dhfs.state.wi.us/aboutDHFS/DSL/dsl.htm</a></td>
</tr>
<tr>
<td><strong>Division of Vocational Rehabilitation</strong></td>
<td>a variety of employment-related health services</td>
<td>608-243-5600</td>
<td><a href="http://www.dwd.state.wi.us/dvr">http://www.dwd.state.wi.us/dvr</a></td>
</tr>
<tr>
<td><strong>Early Intervention (Birth to Three)</strong></td>
<td>a variety of services for children with special</td>
<td>608-266-8276</td>
<td></td>
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<tr>
<td></td>
<td>needs under age 3</td>
<td><a href="mailto:gribb@dhfs.state.wi.us">gribb@dhfs.state.wi.us</a></td>
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<tr>
<td><strong>Earned Income Tax Credit</strong></td>
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<td>608-266-8100 or tax preparer</td>
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<td></td>
<td>Elder Law Center</td>
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<td></td>
<td>benefits counseling and legal assistance for</td>
<td>608-224-0660 or 1-800-366-2990</td>
<td><a href="http://www.dhfs.state.wi.us/bdds/b3.htm">http://www.dhfs.state.wi.us/bdds/b3.htm</a></td>
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<td>the elderly on a broad range of issues, including</td>
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<td>health care</td>
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<tr>
<td><strong>Energy Assistance</strong></td>
<td>cash toward heating bills</td>
<td>608-224-0660 or 1-800-366-2990</td>
<td><a href="http://www.dhfs.state.wi.us/bdds/b3.htm">http://www.dhfs.state.wi.us/bdds/b3.htm</a></td>
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<tr>
<td></td>
<td>county social services</td>
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<tr>
<td><strong>Family Health Center Insurance Plan</strong></td>
<td>sliding fee scale health insurance through</td>
<td>1-800-942-5420</td>
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<td>Marshfield Clinic for residents of certain</td>
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<td></td>
<td>counties in Central Wisconsin</td>
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<tr>
<td><strong>Family Support Program</strong></td>
<td>a variety of services for children with special</td>
<td>county social service</td>
<td><a href="http://www.dhfs.state.wi.us/bdds/fsp.htm">http://www.dhfs.state.wi.us/bdds/fsp.htm</a></td>
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<tr>
<td></td>
<td>needs</td>
<td></td>
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<tr>
<td><strong>First Star Bank</strong></td>
<td>a variety of items</td>
<td>608-257-3764; 1-800-538-0838</td>
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<tr>
<td><strong>Food Stamps</strong></td>
<td>vouchers for groceries</td>
<td>county social services</td>
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<tr>
<td><strong>Foster Children</strong></td>
<td>health insurance for children in foster care</td>
<td>county social services</td>
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<tr>
<td><strong>General assistance or General Relief-Medical</strong></td>
<td>limited medical care and other services</td>
<td>county social services</td>
<td></td>
</tr>
<tr>
<td><strong>Health Insurance Risk Sharing Plan (HIRSP)</strong></td>
<td>high risk health insurance</td>
<td>1-800-828-4777; 608-221-4551</td>
<td><a href="http://www.dhfs.state.wi.us/hirsp">http://www.dhfs.state.wi.us/hirsp</a></td>
</tr>
<tr>
<td><strong>HealthCheck</strong></td>
<td>sealants and orthodontia services</td>
<td>local clinic / public health; 1-800-722-2295</td>
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<tr>
<td><strong>HealthCheck Other Services</strong></td>
<td>Medicaid non-covered services</td>
<td>local clinic / public health</td>
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<tr>
<td><strong>Healthy Start</strong></td>
<td>health insurance for pregnant women and children</td>
<td>county social services; 1-800-722-2295</td>
<td><a href="http://www.dhfs.state.wi.us/medicaid1/recpubs/factsheets/healthy_start.htm">http://www.dhfs.state.wi.us/medicaid1/recpubs/factsheets/healthy_start.htm</a></td>
</tr>
<tr>
<td><strong>Hear Now</strong></td>
<td>hearing aids and cochlear implants</td>
<td>1-800-648-HEAR</td>
<td></td>
</tr>
</tbody>
</table>
HIKE
Description: hearing needs for children and schools
Contact Info: 608-847-4194; 262-896-0643

Hill Burton Hospitals
Description: hospitalization
Contact Info: 1-800-638-0742

Homestead Tax Credit
Description: low income singles and families renters and homeowners tax refund
Contact Info: 608-266-8641
Web Address: http://www.dor.state.wi.us/ra/hmst02.html

Hospital Charity Care
Description: hospitalization
Contact Info: Local hospital

Indigent Drug Programs
Description: certain drugs free through pharmaceutical companies
Contact Info: 1-800-PMA-INFO
Web Address: http://www.edhayes.com/indigent.html

Judicare
Description: legal services agency for Northern Wisconsin
Contact Info: 1-800-472-1638 or 715-842-1681
info@judicare.org
Web Address: http://www.judicare.org

Katie Beckett Program
Description: health insurance for disabled children under age 19 living at home
Contact Info: 608-266-3236
Web Address: http://www.dhfs.state.wi.us/bdds/kbp.htm

Knights of Columbus
Description: offers long-term insurance for nursing homes and home healthcare for Knights of Columbus members
Contact Info: local Catholic church
Web Address: http://www.kofc.org

Knights Templar Eye Foundation
Description: vision needs
Contact Info: 773-205-3838
ktef@knightstemplar.org
Web Address: http://www.knightstemplar.org/ktef

Knights Templar Hearing Foundation
Description: hearing needs
Contact Info: 414-965-2200; 1-800-242-2307

Legal Action of Wisconsin
Description: legal services agency with offices in Kenosha, Madison and Milwaukee
Contact Info: 1-800-362-3904
law@legalaction.org
Web Address: http://www.legalaction.org

Legal Services of Northeastern Wisconsin
Description: legal services agency with offices in Green Bay, Oshkosh and Sheboygan
Contact Info: 920-432-4645 or 1-800-236-1127
Web Address: http://www.lsnew.org

Lion’s Club
Description: vision and hearing needs
Contact Info: local club
Web Address: http://www.lionsclub.org

Local service groups
Description: assistance on case by case basis
Contact Info: local community

Locks of Love
Description: free wigs for children
Contact Info: 1-888-896-1588
info@locksoflove.org
Web Address: http://www.locksoflove.com

Low Income Rental Housing
Contact Info: 1-800-334-6873 or 608-267-9077

Lutheran Bishops Fund
Description: assistance on case by case basis
Contact Info: local Lutheran pastor

Lutheran Social Services
Description: counseling on a sliding fee scale
**Managed Advocacy in Action**

**Health Care Financing Resources**

**Features:**
- Managed Advocacy in Action
- Health Care Financing Resources

**Contact Info:**
- **414-281-4400**
- **http://www.nsswis.org**

**Magic Foundation**
*Description:* funding for growth hormones, education
*Contact Info:* 1-800-362-4423; 708-383-0808
*mary@magicfoundation.org*
*Web Address:* http://www.magicfoundation.org

**Medicaid**
*Description:* health insurance for low-income families with children
*Contact Info:* 1-800-362-3002
*Web Address:* http://www.dhfs.state.wi.us/medicaid/index.htm

**Medically Needy**
*Description:* health insurance for disabled or blind children and adults, adults over age 65 or for children age 6 to 19
*Contact Info:* County social services

**Medicare**
*Description:* federally sponsored health insurance for blind or disabled adults over 18, or adults over age 65
*Contact Info:* Social Security office or 1-800-MEDICARE
*Web Address:* http://www.medicare.gov

**Miracle Ear Children’s Foundation**
*Description:* hearing aids for school-age children
*Contact Info:* 1-800-234-5422
*Web Address:* http://www.miracle-ear.com/services/children_request.asp

**Miracle Flights for Kids**
*Description:* volunteer pilots fly children to hospitals
*Contact Info:* 1-800-359-1711; 702-261-0490
*dbedell@miracleflights.com*
*Web Address:* http://www.miracleflights.com

**Muscular Dystrophy Association**
*Description:* services related to muscular dystrophy
*Contact Info:* 414-453-7600
*Web Address:* http://www.mdausa.org

**National Children’s Cancer Society**
*Description:* transportation, housing, and assistance on a case-by-case basis
*Contact Info:* 1-800-532-6459
*Web Address:* http://www.children-cancer.org

**National Easter Seal Society**
*Description:* camps, equipment, etc.
*Contact Info:* 608-277-8288; 1800-422-2324
*franmk@wi-easterseals.org*
*Web Address:* http://www.wi-easterseals.org

**National Eye Care Project**
*Description:* eye care for people age 65+ (eyeglasses not included)
*Contact Info:* 1-800-222-3937

**National Patient Air Transport Helpline**
*Description:* free or reduced rates for air travel
*Contact Info:* 1-800-296-1217
*Web Address:* http://www.patienttravel.org

**New Eyes for the Needy**
*Description:* eyeglasses only
*Contact Info:* 973-376-4903

**Office for the Blind**
*Description:* independent living services
*Contact Info:* 608-243-5656

**Office of the Deaf and Hard of Hearing**
*Description:* independent living services
*Contact Info:* 608-243-5625

**Parent’s Health Insurance for Post-Secondary Students**
*Contact Info:* parent’s policy

**Patient Advocate Foundation**
*Description:* advocacy and legal referral
*Contact Info:* 1-800-532-5274

**Planned Parenthood**
*Description:* male and female reproductive health services, education, sliding fee scale
*Contact Info:* 1-800-230-7526
*ppw-info@execpc.com*
Web Address: http://www.plannedparenthood.com

**Presumptive Eligibility**
*Description:* immediate health insurance for pregnant women
*Contact Info:* local public health agency

**Public Health Agency**
*Description:* home health care, mammograms, pap smears, immunizations, birth control, STD testing
*Contact Info:* Local Public Health Department
*Web Address:* http://www.dhfs.state.wi.us/DPH_Ops/LHDL.HTM

**Qualified Medicare Beneficiary Program**
*Description:* Medicaid coverage for Medicare premiums and copays
*Contact Info:* county social service

**Red Cross**
*Description:* services for hemophilia and other bleeding disorders and disaster relief
*Contact Info:* 1-800-261-4182 or local chapter
*pmoen@arcbadger.org*
*Web Address:* http://www.redcross.org

**Ronald McDonald House**
*Description:* housing for parents of hospitalized children with serious illnesses
*Contact Info:* 608-232-4660; 630-623-7048
*Web Address:* http://www.rmhc.com

**Salvation Army**
*Description:* assistance on case by case basis
*Contact Info:* 1-800-378-7272 or local chapter; 608-256-2321
*Web Address:* http://www.salvationarmy.org

**School System**
*Description:* therapy and educational necessities for students with special needs
*Contact Info:* Local school system

**See America**
*Description:* provides assistance for eye surgeries and exams
*Contact Info:* 1-800-208-6733

**Short Term Disability Insurance**
*Description:* private insurance/policy through employer

**Shriners Hospitals**
*Description:* medical services for children with orthopedic problems, burn injuries, or cleft palate
*Contact Info:* 1-888-293-2832
*Web Address:* http://www.shrinershq.org/Hospitals

**Sister Kinney Institute**
*Description:* rehabilitative services and therapy
*Contact Info:* 612-863-4457

**Social Security Disability Income**
*Description:* monthly income for disabled adults
*Contact Info:* Social Security office
*Web Address:* http://www.ssa.gov/disability/

**Supplemental Security Income**
*Description:* health insurance and cash payment for disabled or blind children and adults, or adults over 65
*Contact Info:* Social Security office; 1-800-772-1213
*luedtka@dhfs.state.wi.us*
*Web Address:* http://www.dhfs.state.wi.us/ssi/

**Starkey Hearing Foundation**
*Description:* hearing aids
*Contact Info:* 1-800-328-8602
*Web Address:* http://www.starkey.com/about/about5_foundation.html

**Telecommunications Equipment Purchase Program (TEPP)**
*Description:* specialized telephone access equipment
*Contact Info:* 608-231-3305

**Tribal Health Centers**
*Description:* available services dependent on each tribe
*Contact Info:* tribal health center
*Web Address:* http://www.dhfs.state.wi.us/dph_ops/lhdl.htm#Tribal
Unified Services Board  
*Description:* services related to mental health, developmental disabilities, and substance abuse  
*Contact Info:* county social services

United Cerebral Palsy of West Central Wisconsin  
*Description:* lending library of equipment used in physical therapy, neuro-developmental clinic, and financial assistance  
*Contact Info:* 1-888-845-5775; 715-832-1782  
*ucpwcw@aol.com*  
*Web Address:* [http://www.ucpa.org/main.cfm/156](http://www.ucpa.org/main.cfm/156)

Veterans Health Benefits  
*Description:* various health care programs for veterans and their families  
*Contact Info:* local county veterans service office or 608-266-1311; 1-800-947-8387  
*Web Address:* [http://dva.state.wi.us/benefits.asp](http://dva.state.wi.us/benefits.asp)

Viatical Settlements  
*Description:* sale of life insurance policy for cash, call the Office of the Commissioner of Insurance to get names of companies licensed to do business in Wisconsin  
*Contact Info:* 1-800-236-8517

Vision USA (available in limited months)  
*Description:* eye exam and glasses  
*Contact Info:* 1-800-678-5357  

Waisman Center Genetics Clinic  
*Description:* genetics-related services  
*Contact Info:* 608-263-5776  
*webmaster@waisman.wisc.edu*  
*Web Address:* [http://www.waisman.wisc.edu](http://www.waisman.wisc.edu)

Western Wisconsin Legal Services  
*Description:* legal services agency  
*Contact Info:* 608-785-2809 or 1-800-873-0927  
*wwlslxo@execpc.com*

WIC Program  
*Description:* food and infant formula  
*Contact Info:* 1-800-722-2295  
*herriph@dhfs.state.wi.us*  
*Web Address:* [http://www.dhfs.state.wi.us/wic](http://www.dhfs.state.wi.us/wic)

Wisconscare  
*Description:* low cost health insurance in certain counties  
*Contact Info:* 608-221-3815  

Wisconsin Coalition for Advocacy  
*Description:* protection and advocacy for persons with developmental or physical disabilities and people with mental illness  
*Contact Info:* 1-800-928-8778  
*Web Address:* [http://www.w-c-a.org](http://www.w-c-a.org)

Wisconsin Coalition of Independent Living Centers  
*Description:* adaptive aids and equipment  
*Contact Info:* 1-800-690-6665 or 608-251-9151  
*wcilc@gdinet.com*

Wisconsin Council for the Blind  
*Description:* rehabilitation, canes, and loans  
*Contact Info:* 1-800-783-5213 or 608-255-1166  
*dick@wcblind.org*  
*Web Address:* [http://www.wcblind.org](http://www.wcblind.org)

Wisconsin Women’s Cancer Control Project  
*Description:* mammograms, pap smears, exams, and tests  
*Contact Info:* 1-800-422-6237

Wisconsin’s Well-Woman Health Screening Program  
*Description:* breast and cervical cancer, diabetes, depression, heart disease, osteoporosis, etc.  
*Contact Info:* 1-800-397-7094  
WisTECH
Description: assistive technology for daily living
Contact Info: 608-266-9303
Web Address: http://www.wistechstate.wi.us

Worker's Compensation Bureau
Description: work-related injuries
Contact Info: 608-267-1365
Web Address: http://www.dwd.state.wi.us/wc

World Life Foundation
Description: air travel
Contact Info: 1-800-289-5433
HealthWatch Mission for South Central Wisconsin

Description of HW in Dane county

The HealthWatch committee was developed to advocate for and with low-income families in Wisconsin on issues relating to access and quality of health care services with a particular emphasis on Medicaid managed care.

Although the mission has been revised since it was first created, HealthWatch Dane County’s mission is to advocate for underserved populations on issues relating to access and quality of health care services and coverage, with particular emphasis on people enrolled in Medicaid and BadgerCare.

The goal is to improve the delivery of quality health care services to people with low incomes. To accomplish this goal, HealthWatch will facilitate communication among groups affected by managed care programs, identify areas of concern regarding access to health care services, and participate in problem solving strategies and offer policy changes.

Goals and objectives of the group include:

1. Advocate on health care issues to state, county and local agencies and managed care organizations.
   " Develop contract recommendations to the State. (Managed care, and enrollment.
   " Analyze and interpret information from the State and HMOs, regarding utilization data, audits, contract evaluations, reimbursement figures and health goals.

2. Monitor, analyze and respond to ongoing policies and practices of HMOs, certified Medicaid and other providers.
   " Monitor, analyze and respond to ongoing state initiatives involving health care.

2. Monitor, develop and promote strategies to resolve issues arising from the impact of welfare reform upon the access to quality health care coverage for low-income families, with specific attention to the following:
   " Eligibility and access.
   " Expansion of safety net programs to cover those who will become uninsured.
   " Support the development of a monitoring or evaluation system to assess the impact of welfare reform.
   " Support the development of a statewide network of advocacy for access to quality health care for low-income families.
   " Provide input to the State administrative rule-making process on health care issues.
   " Link with other HealthWatch groups around the state for a more unified voice on shared issues.

3. Increase membership, participation and involvement of interested organizations, including Family Medicaid/BadgerCare enrollees in HealthWatch, specifically to:
   " Develop additional resources to achieve HealthWatch goals.
HealthWatch Mission for South Central Wisconsin

1. Managed Advocacy in Action

- Conduct outreach to culturally diverse populations and organizations.
- Conduct outreach to FAMILY MEDICAID/BADGERCARE enrollees and organizations that serve such persons.
- Promote opportunities for consumer involvement in HealthWatch actions and decision-making.
- Build partnerships with other committees and organizations that share the HealthWatch mission.

4. Support innovative strategies to provide advocacy and services to FAMILY MEDICAID/BADGERCARE enrollees toward a goal of "benefits management" through health benefits counseling.

5. Promote the education of health care professionals about health care reforms taking place at both the state and federal levels.

HealthWatch activities include, but are not limited to, advocacy with the managed care industry, recipient and provider education, supporting and promoting the role of local health departments in monitoring and assuring access to care for people and influencing the development of policy. The goal is to improve the delivery of health care services to low-income families and individuals. HealthWatch will facilitate communication among groups affected by Medicaid managed care programs, identify areas of concern regarding access to health care services, and participate in problem solving strategies and offer policy changes.

HealthWatch provides an important forum for consumers and advocates to vocalize their concerns related to managed care and more importantly advocate for positive change.
Prior Authorization Basics

Problems with PAs

As many families and advocates have discovered, the Prior Authorization (PA) process for getting medically necessary therapies approved is both cumbersome and complicated. This is particularly difficult for parents working with school- and community-based services, private insurance and Medicaid.

While a child has a right to receive both school therapies and medically necessary community therapies, there is often a conflict over who should pay. Problems can be avoided by creating a PA request that is carefully coordinated with the Individualized Education Program (IEP). A child can be functional in school and not in a home environment. As a result, the IEP team should clearly explain that the requested PA service is medically necessary for non-education needs.

Putting a PA Together

PA requests are prepared by the provider offering the services. Each request includes two attachments that are reviewed by EDS consultants: the Prior Authorization Therapy Attachment (PA/TA) and a copy of the Individualized Education Plan (IEP) for school-aged children or the Individualized Family Support Plan (IFSP) for children not yet in school.

The PA/TA and IEP/IFSP are used together to review the recipient's medical and therapy histories to determine if the requested PA is appropriate. If the recipient is receiving other services (such as home health services, in-home autism program services or has access to or uses adaptive equipment), information about those services should be included in the PA request.

PA Therapy Attachment

The PA/TA contains information such as the total number of sessions required and number of times per day/week. The PA/TA also includes pertinent medical and personal history, including the recipient's diagnosis and date of onset of the diagnosis, the recipient's occupational and education status, living situation, durable medical equipment used, and recent changes in his/her condition.

The TA also is used to report the recipient's therapy history, which includes current therapies, previous therapies, and the objectives of the therapy. It further describes the progress of previous therapies in measurable and functional terms since treatment was initiated or last authorized.

PA/TA vs. IEP

A PA may be denied if the requested therapy is also listed in the IEP/IFSP as it may be considered duplicative. The TA is the place where supplementary and related information can be described to strengthen the recipient's case for the equipment or services. IEPs often don't provide specific information that could be compared to what is requested in the PA. Providers need to describe why the requested therapy is medically necessary and how it will result in a functional outcome different from that of the school therapy.

New PA/TA Form

Wisconsin Medicaid has introduced a revised PA/TA that providers have been required to use since January 2002. Revisions to the form were made to help providers identify required elements and give suggestions about the clinical details needed in the request. For more information and copies of the new form, see the shaded box.

If Your Prior Authorization Is Denied

If the PA is denied, the recipient or the recipient's family or legal guardian will receive a form letter stating the services requested, the action taken and codes for any modified or denied services. The letter also contains an explanation of how to initiate the appeal process, which is overseen by the Division of Hearing and Appeals (DHA). The appeal must be filed within 45 days or families will lose their right to appeal. Families who wish to have assistance in preparing for the hearing, may request a postponement of their first hearing date, while they are seeking counsel.

Reduction or Modification

If a PA request is approved with a reduction in the duration of the request, it is considered an approved PA. If the frequency of the service is reduced (i.e., therapy was requested for 3x/week but changed by the reviewing consultant to 1x/week), it is considered a modification. The recipient or the recipient's family will be notified of their right to appeal modified and denied PA decisions.
Improvements to the Process

PAs for things such as medications, orthopedic shoes, etc., can now be done over the phone. Also providers have been able to fax PAs since November 2000. When submitted, the entire PA will be reviewed for any clerical errors and then returned for corrections, so that providers need to make only one set of clerical revisions. When the PA is resubmitted, if the necessary clerical information has been corrected, the PA will be forwarded to the clinical consultant for review. If the clinical documentation is incomplete, all additional clinical information needed will be identified before being returned to the provider.

All documentation needs to be clear and detailed to provide reviewers with ample information that services are appropriate and necessary. Many cases are made more difficult because of inadequate documentation of progress made by CSHN. Certainly this type of “front end” effort can help avoid many difficulties and problems later on down the road. Even with good documentation there are still several areas that can cause frustration for parents.

Role of the Parents

In a March 2002 presentation, Lynn Steffes, a pediatric physical therapist, explained that in the PA process, the therapist tries to capture functional and measurable information. It is critical that families consider themselves partners in therapy, both in assisting children at home and in initiating the PA. Parents can begin, by making sure their child is diagnosed early. Parents are sometimes reluctant to label their child with a diagnosis, but getting an accurate diagnosis may help to get services covered. (For more about working successfully with a therapist, contact Lynn at stefbiz.wi.rr.com.)

Most children receive therapy only a few times a week. Therefore, therapists work with parents on maintaining the skills at home. However, a line needs to be drawn between reinforcing therapy lessons at home and asking the parents to be a therapist. The therapist should find out from the family what outcomes they desire for their child, as they will most likely be more apt to work with their child on attaining those goals at home. Also if a family member cannot assist with therapy homework due to things such as caring for other children in the home or work reasons, this can be noted in the PA to potentially insure the therapy hours outside of the home.

Role of the Therapist

The role of the therapist is to listen and interpret the challenges the family is having and educate them to help them navigate the system. Historically, providers have tried to assist and even insulate families from the process by telling them that they would take care of the prior authorization and follow-up. Rather, providers, families, members, advocates and the doctor must all be empowered and involved. Therapists need to try and optimize care, not maximize it.

More Is Not Always Better

Therapists should look at any treatment plan to determine whether or not the child actually needs a specific service. Providers should also look at past reports before evaluating a child. There are cases where the length of treatment may be too long for the child to handle or where more therapy will not yield additional benefits, but will keep the child from going about their life for another three or more hours a week.

Reduction of Requested Services

On the other hand, when EDS or DHCF reduces the frequency or duration of therapy, the therapist may not be able to accomplish the original goals in the shorter time period. When PAs are returned it takes some weeks to catchup, leaving the therapist and child with very few weeks of approved therapy. If a subsequent PA is then requested, it may be denied because no progress had been shown from the previous PA.

This insert can be used as a tool to help parents better understand how to write and effective PA. However, it only scratches the surface of the information available for parents about the PA process. For additional information about PAs, refer to the shaded box below.

ADDITIONAL RESOURCES

DAWN Resources on Prior Authorization
dawninfo.org/advocacy/issues/medicaid.cfm

Medicaid Therapy Services
www.dhfs.state.wi.us/medicaid1/recpubs/child_index.htm

New Prior Authorization Therapy Attachment Form and Instructions
www.dhfs.state.wi.us/medicaid/updates/2001/2001-37.htm

Department of Public Instruction
Parent Page: www.dpi.state.wi.us/dpi/dlse/een/hmparents.html
IEP: www.dpi.state.wi.us/dpi/dlse/een/sbiep.html
A sample digest of selected HealthWatch reports from the minutes of the Dane County HealthWatch Committee

**Inappropriate Billing of Medicaid Recipients**

Bobby is concerned that when Medicaid recipients are told it’s illegal for a recipient to be billed by a provider, they throw the bills away without notifying anyone. This can create serious problems if the matter if referred to collections or judgment is entered against family. These third party billing issues are easier to untangle if they can be dealt with right away. Bobby would like to see families facing this issue referred to Amy Jones at the Justice Department (200.3444), Mullin Williams at the US Attorneys Office (608.264.2222) or ABC for Health. Pam suggested that people working with Medicaid recipients remind the consumer to immediately contact someone if a provider bills them.

**Families MAP and the HMO Contract**

The next Families MAP meeting on July 17th will focus looking at contract issues and how it affects children with special health care needs. Because FMAP is working to promote a partnership between MCOs, parents and advocates, recommendations at that meeting will need to be made on a consensus basis. The southern forum is July 11th and will also focus on the HMO contract. ABC will let the FMAP participants know so they can participate.

**Job Losses**

It’s important to keep families facing a lay-off connected to health care coverage. Matt Olson at ABC included a list of the plant closings announced by DWD in the Weekly Update. ABC is considering sending letters to plant personnel around the state to inform them about BadgerCare eligibility.

**COBRA**

Jim, from Dane County Economic Support, added that it is important for people to realize that COBRA is not the only health insurance option for people leaving or losing a job. People have 60 days to decide whether or not to opt for COBRA. Paul also pointed out that confusion over when insurance from a previous job ends can result in families losing BadgerCare.

**HMO Panel**

The HMO panel discussion on 8/3, sponsored by Families MAP was a forum to bring the HMOs and consumers together to get questions answered and create some understanding, and was a success. ABC may suggest that the Statewide Coalition and the pilots use a similar format and hold other forums. Minutes are being put together and will be sent out shortly.

**CSHCN Report**
Barbara reported about the prior authorization forum concerning the denial of therapy services for CSHCN. The forum included Rep. Mark Miller who is interested in learning more about the subject in hopes of bringing it to the legislature for a solution. The forum was timed in conjunction with the legislative audit bureau.

Bobby reported that ABC would like to have a smaller meeting with Miller to discuss some of the strategies that have been developed by the stakeholders. Barbara also reported that the State legislature has a special committee on developmental disabilities that is looking at the waiting list issues.

**Outreach**

Barbara explained that she is working on outreach for FMAP. She is working to get more parents of CSHCN informed about the work of FMAP and hook them up with our agency and the committee. She is also learning about managed health care issues that families are dealing with. If anyone is working with a parent organization or parent of a CSHCN that has any managed health care issues please refer them to Barbara.

**Regional CSHCN Centers**

There was a discussion concerning the regional health care centers. The state has funded 5 regional centers to work directly with the counties (probably local and county health departments) to coordinate services for CSHCN and to provide supportive services to the county. The Waisman Center is the regional center for the southern region (including Dane County). A list of the CSHCN centers will be posted on the ABC website at [www.abcforhealth.org](http://www.abcforhealth.org). If you would like a copy, contact Michele at 261-6939 ext. 200. Barbara will contact Amy from Waisman to give a presentation on the services that are available in this region.
Each state has a contract between the single state Medicaid agency and the health maintenance organizations (HMOs) that serve the state’s Medicaid population. The contract is an important document because it governs how Medicaid clients are treated, who will pay, what services the clients will receive, what rights the clients have and how those rights are enforced.

In addition to being a valuable advocacy tool, your state’s HMO/Medicaid contract is a vehicle for making changes to the system. The contract must be renewed periodically (typically every two years). This is a great time to bring issues to the attention of state administrators and collectively develop recommendations to resolve problems in the state’s Medicaid managed care system. The procedure for renewing the contract will vary from state to state. Federal regulators look for evidence that the state solicited community level input into the state contract. Some states may actively solicit public participation in the process; others may attempt to do things behind closed doors. However the state chooses to go about revising the terms of its contract, keep in mind that the process is a matter of public record and that your advocacy network is entitled to access. If you feel you being shut out of the process you may want to contact your regional CMS administrator to complain. Or if you find that the state does not openly solicit public commentary on the contract renewal, remember that other avenues—the media, friendly legislators, or letter campaigns, for example—are available to make your voice heard.

Getting input from your network

Your advocacy network’s input into the contract process is especially important for at least two reasons. First, two parties, the state and the HMOs, leaving the Medicaid population out of the loop, sign the HMO/Medicaid contract. Your advocacy group can speak as and on behalf of Medicaid clients, thus injecting a missing piece into the contract renewal. Second, if your advocacy group is composed of representatives of all sectors of the medical world—patients, providers, advocates, etc.—you have at your disposal a powerful pool of knowledge about the realities of the health care system. Together, you can possess both an intimate understanding of what works and what doesn’t work as well as the perspectives needed to come up with innovative solutions. If, additionally, you can reach consensus on recommendations for changes to the contract, the suggestions you submit will have the added clout of a group of people who use and work in the system. Moreover the state may actually appreciate your advocacy efforts as it provides an important counterweight in often difficult negotiations with politically powerful managed care entities.

With respect to the contract renewal cycle specifically, your network will need to find out when the current state HMO/Medicaid contract expires and whether and how public input on the upcoming contract will be taken. To get this information, your group should contact the single state Medicaid agency. I specific? Once you know when and how to make your recommendations, you can begin planning a strategy for compiling the suggestions.
Establishing procedures

It is also important for your group to think about and come to agreement in advance on what the group’s procedure will be for submitting contract change suggestions. This will help to avoid headaches and surprises down the line.

As your advocacy group may well find, however, the contract on paper often differs substantially from how HMOs, providers and Medicaid clients interact on a day-to-day basis. An essential part of your contract review, therefore, should be an effort to draw on the practical experiences of people using, working in, or operating the Medicaid managed care system. Finally, there are some national resources that can be very helpful to your group’s analysis of your existing contract. The Center for Health Services Research and Policy at George Washington University publishes a periodic comparative review of state Medicaid managed care contracts. The same Center has also published “Sample Purchasing Specifications”—essentially a model contract—for state Medicaid managed care programs. These two documents can help you to identify some of the strengths and weaknesses of your contract and give you ideas about alternative contract provisions. Both publications are available via the Center’s website at: Center’s website at:).

Additionally, new federal legislation may have impacts on state Medicaid managed care contracts. The best source for this information is FamiliesUSA, which can be contacted via the web at: http://www.familiesusa.org. Select “Managed Care” from the Issues sidebar.

Out of this review, you should be able to gather a rather substantial set of comments, ideas and suggestions for changes. For organizational purposes, it may be useful to you to divide the feedback you have received into four groups:

- Eligibility and enrollment issues. Including: Outreach, mandatory enrollment, reenrollment, disenrollment, assignment of primary care physicians, continuity of care, barriers to client comprehension, etc.
- Benefits, coverage, services and access issues. Including: Emergency and urgent care, special health care needs including CSHCN, provider incentives, ‘medical necessity’ determinations, discrimination against Medicaid clients, etc.
- Payment and billing issues. Including: Avoiding billing Medicaid clients, third party liability, addressing low Medicaid cap rate, etc.
- Grievances and appeals issues. Including: Internal and external Medicaid patient advocates, notice of right to appeal, sanctions, etc.

The next step is to convert the comments, ideas and suggestions you have gathered into a viable contract change suggestions. If your state has a specific system for receiving public input, be sure at this point that the recommendations you are drafting fit whatever format the state requires. In some cases, submitting a comment alone may be sufficient. In other cases, you may have to include specific citations from the existing contract. This is a tricky step that you may want to delegate to a lone individual or try to tackle in groups.

If, your state does not have an established procedure for submitting recommendations for contract changes, you will still need to synthesize your groups’ thoughts and ideas on the existing contract into a format (bullet points or a talking paper, for example) that can serve as the platform for your public relations campaign.

Building consensus

Once your group has a set of draft contract change suggestions, your next task is to build consensus around them. A clear explanatory statement detail-
ing the group’s procedure for making comments should accompany drafts. The same individual or groups that wrote the drafts of your group’s contract change suggestions will then need to incorporate the comments received from the group to produce a finalized set of contract change suggestions.

Distribute the finalized versions to all members of your group. At this point, your group will need a system by which each member can indicate that they either approve or reject the individual contract change suggestions. The two most obvious ways to do this are either by inclusion or by default. Using the inclusion method, members respond to the finalized suggestions by indicating whether or not they will sign on. Under the default method, the group secretary or chair can indicate that she intends to submit the finalized contract change suggestions by a specified date unless any member of the group indicates their objection.

**Submitting your results**

As the next to last step, you must submit your suggestions to the state. If there is a formal process for this, then making your submission should be relatively straightforward, however, depending on how important the changes are to your group, you might want to consider some kind of public relations event to coincide with the submission in order to draw extra attention to your idea and put additional pressure on the state to accept it. If your state has no formal process for public input in the contract renewal process, you will need to be more creative about your method for submission. It’s possible that you can piggyback off of a sympathetic legislator or otherwise make your suggestions known through the media and lobbying. You might also wish to consider a campaign to open the Medicaid managed care contract renewal process to greater public input and access.

Finally, your group will need to follow-up and monitor the contract renewal process. This is especially important whether your group decides to submit contract change suggestions or not. Even if nobody else weighs in on the new contract, the state and the HMOs will since they are the contracting parties. Both the HMOs and the state have incentives to reduce costs and they may use the contract renewal to pursue these interests in ways that are detrimental to the provision of quality service to Medicaid clients.

Your advocacy network is in an excellent position to evaluate any changes that either the state or the HMOs propose. To do so, however, your group must keep a close watch on the development of the new contract. You should be able to obtain drafts of the new contract before it is signed, appealing to public records laws if necessary. In the event that your analysis reveals major and detrimental changes to the contract, you may want to prepare some form of response, through lobbying or public relations strategies, to prevent the offending piece of the new contract draft from being incorporated into the final version.

This last piece of the process should not be looked upon as an afterthought. Your advocacy network should consider defending the strengths of the current contract just as important as the effort to find remedies for the contract’s weaknesses.