#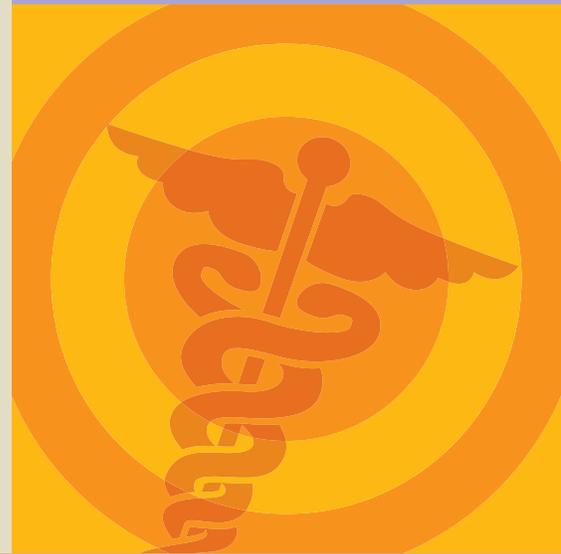 Strengthening *the* Community System of Care *for* Children and Youth with Special Health Care Needs *and* Their Families

Collaboration Between Health Care and Community Service Systems

A W O R K B O O K

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SUMMER 2004

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CHILD AND HUMAN DEVELOPMENT

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Introduction

Building a New Kind of System of Care

Over 15 years ago, frustration with the way families with children and youth with special health care needs (CYSHCN) were served led to a new vision of the systems of care in our nation. Families and service providers were frustrated with the fragmentation of services, the frequent need for families to travel long distances to obtain needed help, and the lack of respect for families' knowledge and needs. The vision that developed was for a system of care that is community based, comprehensive, and coordinated. This system must also recognize that the family is at the center of caring for a child with special needs and must respect the family's culture and viewpoints.

The federal Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) defines children and youth with special health care needs as those who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally. In response to Healthy People 2010, the national health care agenda for the United States of America, the federal MCHB has identified six key outcomes for CYSHCN and their families. These six outcomes have now been incorporated into HRSA's plan for the President's New Freedom Initiative. These outcomes are as follows:

1 Families of CYSHCN will participate in decision making at all levels and will be satisfied with the services they receive;

2 CYSHCN will receive ongoing, comprehensive care within a Medical Home;

3 CYSHCN will have adequate private and/or public insurance to pay for the services they need;

4 Children will be screened early and continuously for special health care needs;

5 Services for CYSHCN and their families will be organized in ways that families can use them easily; and

6 Youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

Although all six outcomes are interdependent, this workbook focuses especially on outcomes 2 and 5. Creating a true Medical Home and making the services in a community easy to use for families require an effective collaboration between the health care system and the broader system of community services and supports. To be effective, this collaborative effort must involve families, service providers, and other civic-minded people from the community where CYSHCN and their families reside.

Meeting the Challenge

For a fully functioning system of care in the community, it is essential that the services and programs outside the traditional health system be connected to and coordinated with health services. Besides the traditional health system, a broad array of educational, social service, mental health, substance abuse, income maintenance, and housing agencies serve children and families. A network of

What Is a Medical Home?

The American Academy of Pediatrics (AAP, 2004), in collaboration with families, other professionals, and public agencies, has developed a model of care called the Medical Home. A Medical Home is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a Medical Home receive the care they need from a well-trained physician who provides primary care and helps to manage and facilitate essentially all aspects of pediatric care. Physicians, families and allied health care professionals act as partners in a Medical Home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential (AAP, 2004). The Medical Home is a model of providing care to patients and families that is:

- accessible,
  - Care is provided in the child's community
  - All insurance, including Medicaid

- continuous,
  - The same primary pediatric health care professionals are available from infancy through adolescence
  - Assistance with transitions (to school, home, and adult services) is provided

- comprehensive,
  - Health care is available 24 hours a day, 7 days a week
  - Preventive, primary, and tertiary care needs are addressed

- family centered,
  - Recognition that the family is the principal caregiver and the center of strength and support for children
  - Unbiased and complete information is shared on an ongoing basis

- coordinated,
  - Families are linked to support, educational, and community-based services
  - Information is centralized

- compassionate, and
  - Concern for the well-being of both child and family is expressed and demonstrated

- culturally effective.
  - Family's cultural background is recognized, valued, and respected

private providers of such services as habilitative therapies (e.g., occupational therapy, physical therapy, and speech/language therapy), mental health services, and alternative/traditional healers also serve children and families. In addition, family supports may include respite services, home health services, crisis services, and peer support. Finally, there may be faith-based organizations and community organizations for particular racial, ethnic, linguistic, or cultural groups that provide services and supports to diverse families. For the purpose of this workbook, we refer to all these services, agencies, and providers collectively as the community service system. Like the health care system, each of these areas has a complex network with a set of rules and regulations, services, providers, and relationships. Yet each of these systems interacts and overlaps with each other and is part of the larger community system of care.

Both the health care system and the community service system are complex and difficult to understand and navigate. Bringing the two systems together presents a particular set of challenges that have prevented better collaboration in the past. Each system has a different view about what has made the collaboration difficult and about who has the responsibility for the failure to connect more effectively. From the perspective of the community service system, the health care system and child health professionals have been particularly difficult to involve in collaborative efforts. The health system is often seen as aloof and unwilling to engage the community service system. From the perspective of the health care system, and individual health practitioners in particular, the morass of community agencies and services, as well as the laws and regulations that govern them, is daunting and requires much time and effort. In addition, child health professionals report that once a family becomes part of a broader community set of services, there is no communication with the Medical Home.

The challenge of collaboration is intensified by the fact that the medical and health systems, the community service systems, and the communities

they serve are undergoing significant changes. Thus, each system is adapting to new ways of supporting children and families as the nature of those families is changing. This challenge, however, is also an important opportunity, because all parts of the community—families, child health care professionals, and community programs and agencies—can meet their goals only through interaction and collaboration. No one person, family, program, or system can effectively ensure appropriate services and supports for CYSHCN.

Changes in the health care system

During the past 30 years, the health profession has changed significantly. In the past, health professionals were educated in the "medical model." This model has provided health professionals with vast amounts of medical knowledge. It is expected, at present, that new knowledge will need to replace medical knowledge every 3 to 5 years to keep the health professional abreast in her field.

New challenges, however, will require an additional set of skills. Because of the complex social realities within communities, health professionals will need to move from a typical medical model of care to a community model of care. In this way, they will truly address the health of children and families. The health professionals of the future will need to be concerned about the whole population of their community. The pediatrician of the future not only will treat the child with an ear infection but also will ask the question, "Does the fact that this child is in child care have an impact on his overall health?" Such concepts as *community pediatrics and community-oriented primary care* (AAP, June 1999) will be the primary care practice of the future. The health professional will move to an expanded definition of medical care, from providing sick care to one of promoting health and preventing illness. This expanded definition will include improved genetic services and prenatal care for the new mother, the availability of safe community playgrounds, and preventive mental health services for children.

Providing this range of medical care will require effective collaboration with the broader community system of services and supports.

At the same time, the advent of managed care as a reimbursement mechanism for health services has changed the way in which health care professionals can spend their time. Many managed care plans require physicians to increase the number of patients they see daily. In addition, the decrease in reimbursement rates forces many physicians to increase their caseloads to cover office/clinic expenses. Consider the impact that this type of environment has on the care of children with special health care needs. Special needs children require 50 percent more office visits than well children, take 200 to 300 percent more of a physician's time than well children, yet may generate only 150 percent more revenue than children without special needs. The challenge for the health care system is to find the time that effective collaboration takes.

Changes in other community systems

During the same period, many changes and challenges have faced the broader system of community-based services and providers. A variety of programs and entitlements have been developed relating to children's services and, particularly, services for CYSHCN. Although these new initiatives have, to some extent, expanded service opportunities, they have come with particular challenges. First, although federal law mandates many services (e.g., special education services), these mandates often come with inadequate or no funding to be implemented at the community level. For states, and particularly communities, this situation has created an increasing demand for services without adequate funding mechanisms. Second, many programs, whether entitlements or otherwise, have complex eligibility rules. Some rules are based on the family's income or at-risk status; some are based on documented difficulties of the child; some are only for children of certain ages; and still others are based on the potential need for institutionalization of the

child or youth to meet his needs. Thus, communities are faced with the challenge of weaving together a system of services and supports from a fragmented set of programs and funding streams. The enormous complexity of this task makes it difficult to provide a simplified process for families to obtain needed services and has made collaboration among these programs difficult.

Changes in communities/families

Over that same time, communities changed significantly—increasing urbanization and crowding for some communities or losing population and resources for rural areas. The changes evident in communities reflect the many changes occurring in society, in general, and for families and children, in particular. Increased rates of single parenthood, divorce, and childhood poverty; substantial numbers of uninsured individuals; and the impact of violence on communities have a significant impact on health and mental health outcomes for children and their families.

The United States as a whole and many individual communities are experiencing quickly shifting demographic patterns. Such patterns challenge service delivery systems and public agencies to provide culturally and linguistically competent services. On the basis of data from the 2000 Census, approximately one-third of the U.S. population is from racially, ethnically, and culturally diverse groups. From 1990 to 2000, the number of immigrants in this country increased by approximately 50% from 19.8 million to 30 million (U.S. Immigration and Naturalization Service, 2002a & 2002b). Not surprisingly, this influx of diverse populations has led to a multiplicity of languages spoken and to many residents who have limited English proficiency. More than 10.5 million U.S. residents report they speak little or no English. This number is up from 6.5 million in 1990 (U.S. Census Bureau, 2002).

All these events are occurring at a time when society is feeling that "Big" is not necessarily the answer and is looking to the neighborhood and community for the answers and the resources. Thus, it is a challenge to both health care and community service systems to work to address these changing needs. Yet these changes stress both the systems and the individuals within them. Although it may seem difficult to build new relationships and collaborations when coping with change, it is only through collaboration that communities can effectively serve and support children and families, particularly CYSHCN with their multiple needs.

Overcoming the Differences

If community service agencies and providers are going to reach out successfully to the health system and work effectively with it to provide a comprehensive, coordinated community system of care, they must educate themselves about the health system. Physicians and other health care professionals also must prepare themselves to reach out to those other community systems and services if they are to truly support the families with CYSHCN that they serve and create a Medical Home. This process works best when both sides mutually reach out to each other. Do not wait, however, for potential partners to come to you. Although systems may seem formidable, even small changes in behavior within one part of the system can set the stage for larger transformations. In the beginning, efforts to reach out to other community service agencies and providers may be limited to the needs of a specific family. However, this initial contact and later connections around multiple individual families may provide the opportunity for broader systems integration efforts.

How to Use This Workbook
The overview

The workbook is divided into three sections. This introduction constitutes the first section. Section II provides suggestions and exercises designed to help the health care system reach out to the broader system of community services and to help the community services system engage the health system

to build a comprehensive community system of care. Finally, Section III contains a list of other resources related to collaboration.

Originally, the authors considered having two separate sections in the workbook—one for health care professionals and one for other community service providers. Effective collaboration, however, requires a good knowledge of the other partner—how she views the world, what her challenges may be, and what she has to offer. Thus, Section II presents approaches for health care professionals and other community service providers. Read both approaches! This step will begin the process. Then, focus on the content and activities suggested in the section that apply directly to your own efforts.

The five-step process

It takes several steps to arrive at the goal of having the health and other community systems work together to plan, provide, and coordinate services with families who have children with special health care needs. The authors propose five steps that will take you to your goal:

1. **Awareness:** The first step is developing an awareness that the other systems exist and developing a basic understanding of their purposes and perspectives. During this phase, an awareness of common goals and differing approaches, histories, and cultures will help create an understanding of why past attempts may not have been successful and how new efforts can be developed.

2. **Education:** The second step is educating yourself about the specifics of the other system: who they are, where they are, what they do, how their system works, and how to contact them.

3. **Communication:** The third step is making contact, that is, actually talking with people in the other system. Although making contact sounds simple, many attempts to integrate systems into the community get derailed at this step. However, if you plan ahead and proceed with a clear

understanding of your goals and respect for the other system, you can be very successful at initiating and maintaining communication.

4. **Collaboration:** Working together with members of other systems to improve services is the fourth step. Collaboration can take place at several levels. Sharing information or providing services together are less complex levels of collaboration. Some activities, such as sharing space or staff for particular activities, blending or braiding funding, or developing shared administrative, intake, and eligibility procedures, are more complex and will require a longer term set of relationships and a greater degree of commitment and trust.

5. **Shared leadership:** Many people assume that step four is the ultimate goal of systems integration efforts. We believe there is one further step to take to ensure continuity and integration of the changes into both systems. After all, collaboration can take place between two or more systems, providers, or agencies to serve particular families without all systems working together to design system developments and changes. The fifth step involves going beyond practice or agency to provide the energy and leadership needed to make systemic changes.

This workbook addresses Steps One through Three: Awareness, Education, and Communication. The final two steps—Collaboration and Shared Leadership—are extremely complex and are best understood through successful models. Section III of this workbook lists suggested resources that provide an understanding of Steps Four and Five and/or descriptions of best practices and programs that can support communities in those efforts.

Step by Step on the Road to Collaboration

Step One: Awareness

The first step in successful collaboration is increasing awareness of one's own role in the process and of the other parts of the system and how they operate.

Context

Although the health and broader community service systems share the commitment to families and CYSHCN, fundamental differences exist between them. Thus, it is no surprise that they have had difficulty collaborating effectively in the past. The organization and structure of the health system are in some ways very similar to those of most community services and in other ways unique. Both systems are composed of publicly funded programs and private providers, but the health system has relatively few publicly funded programs, such as community public health clinics and maternal and child health systems. In contrast, many services available through the community service system are publicly funded; for example, virtually all child welfare services are publicly funded. Another major difference is that found in the federal and state laws and regulations supporting health and other community services. Unlike many other community services, no mandatory entitlements to health care exist. Finally, the community service system generally is organized around bureaucratic structures including geographic area, level of government, and agency hierarchy. But the medical system is organized around levels of specialization of knowledge and services.

Not surprisingly, these differences between the two systems have led to significantly divergent methods of making decisions and choosing services, breadth and depth of focus, language and terminology, and resource allocation. Awareness of these differences between the health care and broader community systems is the beginning of an awareness that can lead to their successful collaboration.

Contrasts Between Health Care System and Other Community Service Systems

HEALTH CARE SYSTEM	OTHER COMMUNITY SERVICE SYSTEMS

Basis for Decision Making and Choice of Services/Treatment:

In the world of health and medicine, **scientific** inquiry and empirical research serve as the basis of practice. An ever-growing body of literature about the most recent or best designed studies establishes guidelines and choices of treatment. Medical professionals may have a hard time endorsing the application of approaches that are based more on theoretical perspectives, historical experiences within a discipline, or legal/statutory guidelines. However, many medical professionals' practices are also based on these approaches. Still, health care professionals may have concerns about other community providers' efforts because there is no research to support those efforts. Open dialogue can help promote mutual respect for the varied approaches.

Decision making in medicine is based on making an accurate **diagnosis**. For example, a symptom such as a sore throat may have many causes and cannot be treated until the cause is found. Diagnosis guides the specific services and treatments required. When other community systems focus on needs and strengths and not diagnosis, health professionals may feel that their approach is discounted and that other professionals don't understand or value their input. Medical professionals see the diagnosis as imparting important information about medical needs and risks. Because medical research is driven by diagnosis, having an accurate diagnosis may lead to new treatments in the future.

The medical model is very wedded to a **problem-solving** model. Treatment is given to solve a diagnosed problem; is individualized in terms of type, intensity, and duration; and continues until the problem is solved. Thus, health professionals may get very frustrated when other service systems don't provide services in a way that "solves the problem." In recent years, physicians and others in the medical system have had to deal with obstacles and limitations on services they feel are required because of changes in health care financing.

Services provided by other professionals within community systems may have very different traditions. For example, although the field of mental health is moving to a more scientific evidence basis for treatment, individual providers historically have used **theoretical** models to develop and provide services. Other professions have emerged from a more practical background. These providers look to other sources of validation for what they do, such as comparing one's skills to those of a more experienced mentor. When medical professionals question the validity of assessment or treatment procedures, other professionals view this skepticism as showing disrespect for their profession and their skills.

Diagnosis, and its implied perspective of finding the problem and its cause, is often seen by other systems as being too narrow, as not recognizing strengths, as applying labels that can be seen as pejorative in social settings, or as not recognizing the family's needs and perspectives. Assessment in other community service settings often focuses on **identifying strengths** and **addressing needs** that will help the individual or family maintain normal functioning or reach maximum potential. Finding a diagnosis is not seen as essential in facilitating that process. For example, families of children with mobility impairments will need support to make their homes accessible, no matter what the child's diagnosis. At the same time, two families with children with spina bifida will have very differing natural support networks and different levels of need for respite care or transportation.

In addition, in the broader service system, services are delivered based on meeting some legal or bureaucratic set of criteria. For example, within the school setting, only children with a certain level of motor problems may be eligible for physical therapy, or in other agencies, family income level dictates whether services are provided.

In other service areas, the amount or type of treatment or services provided may be based on **legally or bureaucratically determined criteria**, on **level of need**, on **consumer demand**, or on **availability**. Services may be delivered based on the schedule of the provider (school year) or availability (only enough physical therapists to provide services once a week). Service providers may fit children and families into existing services and programs rather than use a highly individualized approach with them (despite legal mandates to the contrary.) Some programs are available only to children and families at a certain income level. Thus, decisions are not driven by diagnosis and solving problems. This complex approach to

Contrasts Between Health Care System and Other Community Service Systems

HEALTH CARE SYSTEM	OTHER COMMUNITY SERVICE SYSTEMS
	determining service provision is frustrating to families and community service systems, but it is shaped by laws, regulations, and funding mechanisms. Health personnel may be seen as lacking an appreciation for the constraints and realities of other services within the community when advocating for services from the medical perspective.
Perspective:	
Primary care health professionals see themselves as interested in many aspects of a person's functioning and development, and how they relate to the many systems and functions of the body. They may view other disciplines as more narrowly focused on only the child's language development, emotional well-being, nutrition, or other facets of functioning. These health professionals sometimes feel frustrated with this more fragmented approach.	The array of professionals within the non-health portion of the community system can bring a more specialized view to the process. Professionals who have a specialty area have a depth of understanding in that area. These more specialized providers may grow impatient with what they see as the health care professional's superficial understanding of their domain. As a result, non-health providers may discount medical professionals' views or may feel frustrated when those they view as generalists make specific treatment recommendations for their specialty services.
Language:	
Medical terminology is highly descriptive, but it includes many technical terms. Commonly used words take on highly specific meanings within the health sector. Thus, communication is difficult unless the parties involved are clear about what each means. There are other differences in language that reflect philosophical differences. Some examples are patient vs. client or consumer; diagnostic work-up vs. functional assessment; and treatment plan vs. service plan.	Each profession has its own language or jargon that makes it hard for others to understand it. Further complicating matters is the fact that some disciplines borrow terminology from the medical world, although sometimes the precise meanings of words and phrases are different. Additionally, the service system itself has its own language of, for example, programs, agencies, criteria, and forms. The alphabet soup of acronyms for such services and programs may be shared by non-health sector people, but may baffle and drive away those from the health system.
Entrepreneur vs. Salaried Status:	
Most health services are provided by the private sector. Funding to pay for those services is based on the number of people treated and the number of services offered. Although sometimes limited by the reimbursement source, almost all families have some choice about where to obtain services. Thus, health care professionals must both find ways to attract "customers" and make decisions about how they use their time based, in part, on making enough money to cover expenses and salaries. In the past, public health clinics, academic medical centers, and special state programs had the luxury of funding sources that did not depend on how many patients were served. However, the advent of managed care, and the shift of publicly spent health care dollars to this type of model, is forcing almost all health providers (clinicians, clinics, specialty centers, and hospitals) to become entrepreneurs.	Many programs and agencies in the non-health sector are publicly funded to provide services to certain groups or populations of families and children. Providers within agencies are typically salaried and are focused on the goal of providing services that are mandated by the system or agency that employs them. The actual service provider is rarely the same person who is charged with funding the program or agency within which services are offered. They also do not have a responsibility for attracting and keeping the families they serve, for they have a ready-made audience. For example, a special education teacher does not have to attract students; they are assigned to the school and classroom by a bureaucratic process. Not surprisingly, decisions about how to use one's time and energies will be very different in this type of system from those in the more entrepreneurial world of health.

Preparing Yourself

The first phase of increasing awareness is becoming more aware of, and better able to articulate, your own system and set of services. Think about the language you use in communicating about family needs, services provided, and assessment approaches. Think about how you can articulate what you do in a way that will be meaningful to counterparts in the other system. Think realistically about the amount of time and commitment you have to give to the collaborative process.

Tips for community service system members

Consider your past personal and professional interactions with the health care system.

• What have been the successful interactions?

• What made the interactions work?

• Which interactions have been less successful? For these, consider the issues identified in the Context section and think about how the differences in systems may have contributed to the difficulties.

• Knowing that time constraints are a major issue in the health care system, identify and prioritize the key ways that the involvement of the health care professionals will substantially improve services and supports for families.

Because many health professionals look to scientific literature for validation of treatments, it will be extremely helpful for you to be as well versed as possible about research that supports the kinds of treatments or interventions that you deliver or your agency supports/recommends. Increase your awareness about what you do and why you do it. The medical literature includes controlled, empirical studies; however, there is also a role for case studies—reports of a few unusual cases or ones that responded to some new approach to treatment. Often, these cases are the starting point for larger research projects. Work on being able to explain what you do without jargon and in an organized way that links the child's problem, your interventions, and expected outcomes. When you articulate for yourself what you do, you are in a better position to work collaboratively with members of the health services community.

Tips for health care system members

Start by asking yourself the question, "Do I see myself as changing as the needs of my community and society are changing?" If you can answer that question positively, then you are probably already doing some activities that will help you be more responsive to your patients, families, and community. Are you ready to consider reaching out to the broader community systems that serve your patients and their families? Become aware of how much time and energy you are willing and able to expend at this point. Simply engaging in the process to increase your awareness of the other community systems and needs will take time—in addition to your usual practice hours. Although a commitment of time will pay off for the families you serve and for your community, you must be clear about how much time and energy you are prepared to expend. It is better to be realistic and select an activity that you can complete than to choose an intensive approach that you will be unable to complete. If you become overwhelmed or too frustrated at the start, it will be difficult to continue moving toward collaboration with the other community systems.

Take time to review past interactions with the broader community system of services. Identify what led to successful interactions. Also consider what may have led to less than successful interactions. Considering the differences noted between the systems in the Context section, in what ways might you change your approach in the future?

Activities to Increase the Awareness of the Other System

How can community systems become aware of the health care system?

Shared learning

A good way to get a better understanding of the health system and its culture is to become involved in common learning experiences, for example:

- **Grand Rounds.** Most hospitals have conferences called Grand Rounds at which a variety of topics are presented. These conferences generally are open to all interested professionals. Obtain a schedule of your local hospital's conferences and choose some that are relevant to the work you do. Attending such conferences will enable you to become familiar with the language. Listen carefully for comments that give you insight into issues or concerns about the system of care, the financing of health care, or the ways in which people perceive changes in the health system. In this way, you will begin to have a better idea of the way the world looks from inside the health care system.

- **Joint meetings.** Plan a joint meeting of professional societies to educate each other about what each does or to sponsor a special speaker or program that is mutually interesting and beneficial. Again, the goal is to obtain an appreciation for the specific values and history of each approach and to understand the specific issues and challenges each profession faces. Questions for the group may include:

  – What do you consider to be assets in the broader community system of care for the families you serve?

  – What gaps or problems have you or families you serve encountered in the system?

  – What approaches, structures, or activities have facilitated your knowledge of, and connection with, the broader community system of care?

  – What has hindered your knowledge of, and connection with, the broader community system of care?

  – What are the special ways in which you provide care for CYSHCN and their families? What impact does that have on your overall practice?

  – What are the issues facing medicine, in general, and your practice, in particular?

  – What are the ways in which you might participate in the broader community system of care?

Interviews/focus groups

- Talk to individual health care professionals that you know or with whom you may share the care of a family to learn more about the health care system. You could invite a small group of key health care professionals for an early breakfast meeting. You could approach the local medical society, hospital staff, or professional organization or the state chapter of the AAP. You could ask them whether you could have some time during an upcoming meeting to get this feedback. Finally, you might schedule telephone interviews or routinely ask health care professionals for their input about a family you jointly serve.

- Another way to learn more about the health care system is to talk directly to health professionals and to hear their views about why you and they are not working together effectively. It will not be helpful to confront them and demand to know why they are so difficult to engage. Instead, seek the input by asking them how you could approach them more effectively to integrate them into the community's comprehensive, coordinated system of care. Listen without becoming defensive. Ask for concrete suggestions and solutions; don't let the process just become a gripe session.

How can the health care system become aware of community systems?

Informal input from families

- During medical visits, ask families about other services they are getting in the community. Ask about the effectiveness of these services and problems. Find out whether they have specific needs that they are having difficulty meeting. Just as important, ask them for success stories, that is, instances in which they were easily able to get the services and supports they needed. Don't neglect to find out what made those instances particularly successful. Ask whether families with children with special health care needs are finding comprehensive, coordinated, family-centered, and culturally competent services in the community. If so, where? If not, what are the problems? How is local interpretation of federal and state laws affecting these families and children?

Formal input from families

- Focus groups with families can provide key information. Some of the best sources of information about the broader systems in your community are the families that they serve. Aim to have 8 to 10 families whose children have different types of needs attend a 1- to 1½-hour meeting to help you become aware of what is happening in those broader community settings. You will need to schedule this meeting at a convenient time for families. You may have to consider the need for child care arrangements so that families can attend it. Although this should be an informal discussion, you should have a set of questions to ask the families. Such questions will provide you with the information you need to become more aware of what is happening in the non-health systems in your community. Suggested questions might include:

  - What agencies and programs are serving the families? Are they public, private not for profit, or private for profit?

  - What kinds of services do the children and families obtain? How often, at what cost, and at what locations? How many appointments a week do they have? To how many places do they go for services?

  - How have the families found and secured the services they and their children need? Did someone in the system seek them out? Did they have to spend time tracking down services?

  - Is there a person or program that helps families coordinate the services they need?

  - Are there services they need that they are not getting? Why? Lack of money, program eligibility requirements, or no such services exist?

  - What role has insurance/managed care played in helping them obtain or pay for services? What problems with their insurance carrier or managed care company have they experienced?

  - What do the families see as problems in the system?

  - How would families like you to be involved with the broader community systems?

  - How can your office assist families in obtaining the care they need?

Input from office staff

- Staff in the health care professional's office are members of the community and often spend time talking with patients about service issues they encounter. Discuss the types of services and needs of the community at office staff meetings. Ask, "Do we have any unmet needs in our community about which our office should be concerned? Do we have something to contribute to efforts to find solutions?" Other staff members may have obtained information during informal conversations with families and from their own personal experiences. Encourage your staff to become involved in the community—not only to make a difference, but also to be a conduit of information to you about the many sectors of the broader community systems.

Step Two: Education

The second step in building effective relationships between health and other services within the community is for each group to focus on education. Simply being aware of another system and some of its issues is not enough to ensure successful interactions. Each participant in the process must take on two tasks: first to learn as much as possible about the other system (how it operates, how to connect with it to support families, and other information) and second to make active efforts to educate others about her system and how it works. Remember that education is a two-way process: You must educate others about your role and learn about theirs. It is important to gain very specific information about the health care and other community systems in your area. Each agency and every health care practice is different, and if you try to work with each other based only on general impressions, it will be difficult to succeed. Don't forget the invaluable role that families can play in this education process.

Context

With the many changes that are occurring at the community, state, and federal levels, there has been recognition that "one size" does not fit all. Over the past several years, a number of federal laws have recognized the strength of the community in finding the best ways to support and serve CYSHCN and their families. Many of these federal laws provide some funds, typically as part of a block grant to each state. They help communities develop and provide systems to serve these children and families. Some also provide entitlement to services for certain children and families, with shared funding from federal and state agencies.

Many of these laws require input from health care professionals. In reality, however, the education, child welfare, or other agencies in a state that take the lead in implementing the laws may not effectively integrate the health care system. Unfortunately, the difficulties in integrating health with these other systems has too often meant that families may not benefit from the involvement of health care professionals in developing and obtaining comprehensive services for their children and themselves. On the one hand, health care professionals have not been able to educate these other systems and programs effectively about what they offer. On the other hand, health care professionals often do not know about or understand the myriad of laws, mandates, and programs that serve their patients within the community.

Health care professionals need to learn about programs in general and need to become educated about how public programs are implemented in a particular state and community. Sometimes, local programs take what is best about legal mandates and entitlements to develop outstanding local models. Other times, something is lost in the translation, and families may struggle to access services to which they may be entitled.

Non-health professionals working in the broader service system may have limited knowledge of how to best use input from the health care system. Children and families may then lose the benefits of having medical and health information incorporated into service plans. Attempts to engage the health system that have not been based on a thorough knowledge of its unique culture and values are likely to be unsuccessful. A lack of prior success may lead other community service providers to believe health care professionals "don't care" about the needs of a particular family or only care about being paid. Until professionals from the broader community service system educate themselves about the way health care professionals in their community function, they will continue to have difficulty engaging them.

How to for the Community Service System

Learning about the health system

Key individuals within the broader integrated system need to learn about the health care system, its issues, and the ways in which it works in that particular community. Program directors, policy makers, and care coordinators, at a minimum, need a solid knowledge of the health care system in the community. A variety of approaches to learning about the health care system can be used, including:

- Talk with families you serve to learn about their experiences with the health care system and the health care professionals they consult.

- Join the community/citizen advisory boards of local hospitals or health clinics.

- Join local committees or task forces that are looking at health issues.

- Connect with the local AAP Community Access to Child Health (CATCH) coordinator for your area. This individual has an interest and special skills in addressing child health issues in the community. See Section III for information about how to identify the CATCH coordinator in your area.

- Work with the local medical society, hospital staff, or professional organization or the state chapter of the AAP to learn about local issues. Check these organizations' referral services to learn about health care professionals in your area.

- Follow stories in the national and local press about issues affecting the health care system.

- Talk with your own or your family's health care professionals.

Educating the health system

There are a number of approaches for educating physicians and other health care professionals about the broader set of services and systems in the community. **Key information** should be conveyed in any of these approaches. Be able to clearly articulate the following key information in any educational interaction with health care professionals:

- The name of each program or type of service—both the local name and any state/federal program name, because they are often different. For example, Babies and Families Together may be the local name for the federally mandated early intervention program authorized under the Individuals with Disabilities Education Act (IDEA);

- The federal or state laws that support or mandate the service or program—provide the name of the law and any popular names for the law, as well as a very brief summary;

- The eligibility criteria used to screen who is eligible to receive the services—age, income requirement, type of disability, and other criteria. This information should be presented in a user-friendly manner, such as a grid;

- The process used to determine who can receive services and what types of information are needed to meet those criteria—types of evaluations, diagnoses, functional limitations, time frames, and other data. Make this information easy to use in a format such as a grid or flow chart; and

- The ways in which health care professionals are needed or could be involved with the system or the process. Provide this information in clear and concise bullet points.

Education through shared care of families

- Sometimes, it is too overwhelming to ask a physician or other health care provider to learn about the entire system as a whole. Most adults learn best when the information is practical and relates to current situations they face. Thus, a health care professional can be expected to express great interest in learning about the services a child and family in his care are obtaining within the community.

A child's primary health care provider often receives copies of evaluations or plans developed for a

particular child. However, these documents may do little to educate the health care provider about the broader community service system. Consider inserting the key information about services for a particular child with copies of evaluations into an information packet. In this way, the physician is more likely to learn about one or two parts of the community service system at a time because the information will be tied directly to her patient's welfare.

Families as educators

Families may be willing to make the connection between the broader service system and their health care professionals. They can share key information about programs and services they use in the community. Families can help clarify issues or questions or can suggest that the physician contact the other community service provider for more information.

Written resources for health care professionals

Some adults prefer to learn by reading information. For this purpose, individual agencies or providers, a community collaborative body, a parent advocacy organization, a case management program, or other resource might prepare a set of materials that include the key information on the services and programs available in the community.

Materials, however, are only the start. If these materials are to be effective in educating the health professionals in the community, the manner in which they are disseminated must match the ways that health professionals are likely to use them. It will be important to discover how health professionals in your community prefer to access written information. Some suggestions include:

- Each agency, program, or provider prepares a very brief summary that includes the key information to attach to reports for individual children and their families. When the family is working with a case manager or care coordinator, this individual can keep a centralized copy of the summaries. He also can make the copy available to the family and health care professionals.

- Printed or on-line directories of community services can be useful. Provide each practice with multiple copies and deliver them to key office personnel. Members of the group preparing the materials could stop by individual professionals' offices to deliver the materials personally and to encourage the providers and office staff to review the materials and provide feedback. Simply mailing copies or dropping them off may not be effective. The materials could be lost in the piles of mail and brochures that arrive at a health care professional's office each day. Present information in an organized way that can be reviewed quickly. Include a table or search capability that indicates what services apply to children of specific age ranges or with particular needs. Furthermore, it would be useful to emphasize the ways in which health system providers can interface with the other services and programs. It would also be useful to emphasize the types of input that would be helpful for them to provide.

- Families could be asked to share material with their health care professionals with a request to read them.

- Materials could be mailed/e-mailed or distributed through local professional organizations or hospitals.

- Community service system members could present information at educational or professional meetings. Arranging for this presentation may be as simple as contacting the local medical society or AAP chapters to request the opportunity to present at one of their meetings.

Presentations to health professionals

- Get on the schedule for Grand Rounds at any local hospital in your area. If you can, arrange for Continuing Medical Education (CME) credits for your presentation, you will greatly increase the likelihood of good attendance. To ensure that attendees remember your program or services, prepare descriptive information and distribute a copy of the information in a format that will induce them to keep the material for future reference. Format examples are magnets, laminated

cards that fit into a pocket, or ready-made file folders. A bonus of this type of presentation is meeting many more health care professionals in person. Another bonus is having the opportunity to identify a few contacts who are interested in interacting more effectively with the broad set of systems serving children and families. These contacts provide a good starting point for collaboration.

How to for the Health Care System

Learning about broader community services and supports

Gather written materials

- Most programs and services in the community have some written materials describing their purposes, eligibility requirements, and any rights of families to services. Collect these materials and read them. If reading about programs and policies in the abstract is not your preferred mode of learning, gather the information and keep files. Ask each family you serve who has a CYSHCN which programs and services they use; then, read the information about those programs from your files. Thus, the information you access will be practical and immediately applicable. A number of ways to gather this information include:

  – Create an office project to contact local programs (a staff member could make the contacts) and to request written information.

  – Check the Internet, for even local programs now have World Wide Web sites.

  – Ask families being served in the community to bring you written information about the programs and services they use.

  – Contact family advocacy and support groups. They often have gathered this information or may have developed materials to help families understand the system that will help educate you.

  – Check with the local library—the reference desk or the librarian may keep a special folder about community resources.

Convene an advisory committee

- Develop an ongoing advisory committee of community members, including families you serve, to get input about how your setting is addressing the primary (or specialty) health care needs of the community. You might invite persons from the special education system, the developmental disabilities system, the child welfare system, the child mental health system, the juvenile justice system, or the business community. Quarterly or twice a year, meet to discuss issues facing your community in serving children with special health care needs and their families. Get the committee's perspective on how you and your setting could improve the community system of care. This approach will increase your awareness of the broader systemic issues of other community systems. It also will bring you in contact with others interested in improving community services. They could be potential partners in later collaboration. Consider the need for child care for participants and schedule meetings at a time that will permit maximum participation.

Become involved in committees, boards, and other community groups

- Get involved with the committee of your professional organization that deals with issues related to children with special needs.

- Volunteer for community committees, advisory boards, or commissions convened to study or oversee the functioning of a program that serves children with special health care needs in your community.

- Become involved in local United Way activities. This involvement will give you a good overview of the community service system. It also will provide opportunities to connect with others interested in serving and supporting families in your community.

- Join the advocacy or social concerns committee of your place of worship to learn about community needs and programs. If your time is limited, you may want to start by participating in one or two activities that the committee sponsors. You can later expand your role, as time and interest permit.

Hire parents as professionals

- Hire the parent of a child with special needs to work in the office or clinic as part of your nursing or office staff. This parent could help other families in the practice/clinic negotiate the service system and could be a valuable resource during staff meetings and educational efforts.

Educating others about the health system

In a number of ways, you can help others in the community better understand the importance of health issues and the contribution you can make to supporting and serving children with special health care needs and their families. Some of these ways involve person-to-person contact; others use educational materials you might develop. Any educational effort should convey the following **key information:**

- How medical treatments or medications might have an impact on the child's behavior, capacity to learn in school, or ability to function independently;

- Family support services, patient or family education programs, or case management services within your practice;

- Contact information for your practice—whom to call and the best times to call;

- Best way to communicate with you;

- Availability of you or your staff to participate in meetings or in other ways to develop community service plans; and

- Roles you may take in promoting the broader community system of services.

Educate others through communication about shared care of children and families

- Whenever you are asked for a report about a child's health or are asked to fill out a questionnaire for school or enrollment in another program, you can use the opportunity to educate professionals in other parts of the system. You may want to go beyond the child's diagnosis and treatment needs to include information about your treatment plans and the types of supports that you can offer the child, the family, or other service providers. Include the key information listed above. It is helpful to invite questions or to offer some way for the other system providers to connect with you around your role with this child and family. This informal, patient-by-patient approach will begin to educate others about the importance of considering health issues and about the important roles you play in serving these same children and families.

Develop written educational materials

- A more formal approach to educating other service providers using written communication is to develop a brochure or fact sheet including the key information. You can use these materials in a number of ways: They can be distributed to families so that they understand the importance of linking their health services with any other kinds of services and supports they are receiving. You could attach these materials to reports or questionnaires you complete for other agencies. Brochures and fact sheets also can be sent to case managers or care coordinators for other programs in your community to help them better understand the role of health in serving children and families.

Accompany families who are advocating for services

- The parent/professional partnership is strong and effective. Working with a family to advocate for needed services is also an excellent way to educate others about the health-related needs and about the importance of including the health system in planning with that child and family. Face-to-face

interaction is a powerful way to educate others. You can clarify confusing issues and answer questions immediately. You also will hear the reasoning behind service provision decisions in other systems and will have an opportunity to educate them about health issues that they may have overlooked in their evaluations and intervention plans.

Provide in-service or continuing education programs for non-health professionals

• School systems and other service delivery systems regularly provide continuing education for professionals. They often seek speakers and topics about serving children with special health care needs. Contact the local school system or professional organizations representing non-health professionals to offer your time. Parent requests for training of personnel related to health issues may make the systems more receptive to your suggestions. You also can offer to conduct in-service training at a school attended by one of your patients to help the staff better deal with the child's medical needs. For example, school staff might feel more comfortable including a child with a tracheotomy in a regular classroom if you or a member of your staff takes time to explain its purpose, the type and amount of care needed at school, and the steps school personnel should perform in an emergency.

▌ Step Three: Communication

Context

Having gained a greater awareness of the issues that differ between the two types of systems and knowledge about what the other system has to offer, the next step in connecting is actual communication. The typical difficulties encountered between the two systems center on how communication takes place and on the content of the communication. The "how" relates to differences in the systems noted in Step One—the basis for decision making, perspectives, language, and funding mechanisms. Within the broader community system, communication between professionals and family members about a particular child typically occurs in a face-to-face meeting. In many instances (e.g., early intervention and special education), the law mandates such meetings. They occur during the workday and often during school hours, if the education system is involved. Professionals and family members identify the child's and family's strengths and needs and develop a service plan. Professionals in the health care system can rarely take the time for these meetings, which occur during their own workday. (This issue of the time of meetings is also a problem for some families.) Thus, health care professionals may feel closed out of the process, and community system members may view them as disinterested. The bottom line is that a child's health issues may not be adequately addressed or incorporated into service plans and that various providers may work at cross-purposes. Families are then caught in the middle, trying to sort out the two systems.

Health care professionals often communicate through brief telephone calls, dictated letters, or consult forms. These communications take place at a time and in a manner that fit the busy schedule of the practice or clinic. Communications with families take place primarily during office visits and thus must be concise to fit the time limitations of a schedule. Efficiency is the key to the communication style for many health care professionals.

The essential information to communicate also differs between the health care system and the broader community service system. As previously noted in Section I, the health care system will focus on such information as diagnosis, prognosis, and treatment plans. Other community agencies and providers need to share information about strengths, needs, eligibility, and service plans.

Not surprisingly, communication often becomes a stumbling block to fuller, long-term collaboration. Applying all the knowledge gained in Steps One and Two will allow both health care professionals and members of the broader community system to carefully plan how to initiate communication. Having a plan is key.

HOW TO: Community Systems Communicating With the Health Care System

Successful communication with health care professionals requires a deep understanding about how their practices or clinics work and about how they typically communicate within their own systems. Each office or professional may have different patterns. It is important to get a broad understanding of health system providers, but it is invaluable to know the specifics of how to best communicate with individual professionals. Over time, as relationships develop, more informal modes of communication may develop.

The following set of questions can be used to gain knowledge of a practice or clinic that will help develop a potentially successful approach to communication. Talking to office staff is probably the most effective way to gather this information; however, some physicians may want to participate in the process directly. ASK! Be sure to explain that you are asking these questions to improve the ways in which you communicate with the health care professional. (Some practices will have written information that answers these questions, and they give this information to patients.) Find out a good time to talk with office staff. Consider bringing in food to meet over breakfast or lunch. Be sure to find out about a convenient time for the practice. The key is understanding when the staff are busy and how they prefer to communicate.

Health care professional's office or clinic profile

I. **Scheduling:**

How many patients are scheduled per hour?

How many are actually seen?

What times of day are the most popular for appointments?

You can use information about the scheduling pattern to consider such issues as these: what the impact on the practice might be if a physician attended an hour meeting held 20 minutes across town or why at certain times of day the physician might not be available for meetings or telephone calls.

II. **Office/clerical/billing:**

What is the total number of staff working in the office?

How many and what types of health plans does the office accept?

With this information, you may get a better perspective on the complexity of running a clinic or practice and the expenses that must be covered by the health care professionals' time.

III. **Reasons for visits:**

On a typical day, what proportion of patients visit for:
- routine check-ups?
- relatively minor acute problems?
- serious acute problems?
- chronic problems?
- non-medical issues—developmental, academic, behavioral, mental health, and/or social?

What proportion of children in the practice have special health care needs?

This part of the profile provides you with a sense of the types of services provided by the health care office or practice. It also gives you an idea of how much time is devoted to issues that relate to children with special health care needs. Clinics and practices will differ in their interest in serving this group and in their willingness to devote the extra time needed. Clinics or practices that provide these types of services may be good places to start to develop interaction. In addition, if non-medical issues take a large proportion of the health care professional's time, the professional might appreciate an overture from other community resources to help address those patient and family needs.

IV. **Telephone calls:**

How many telephone calls come in within the day or within a given hour or period?

When does the health care professional take and make calls: To report on progress of treatment? To respond to requests for referrals for other services? To consult with other professionals?

Who is the contact person for billing questions? To request records?

What kinds of calls does the professional prefer to take personally?

By understanding the type, amount, and pattern of telephone calls, you may develop a less critical perspective about the reasons that the physician does not immediately respond to your calls. You may also use this information to identify the best time and method to contact the physician, which issues might be better directed to a nurse or physician's assistant in the office, and to whom you should speak to obtain copies of records, help families with billing issues, or provide information for the physician.

V. **Hours:**

What hours is the office open?

How are after-hour calls handled?

When does the physician conduct hospital rounds?

With information about the office hours and the way that the professional spends the day, you may be able to identify times that might work for meetings or conference calls. You can make educated suggestions about times for interaction that are more likely to result in a positive response.

VI. **Communication with other health professionals:**

How does the professional prefer to seek information from other providers, including specialists, hospitals, and community service providers, about a patient he is treating? Contacting them by telephone, requesting written reports, reading letters, or using another method?

How does the professional share information about patients with other providers? Does he write formal reports, write consult notes, place calls, dictate a brief letter, or type an e-mail message?

Knowing and using the preferred way of communicating increases the probability that the professional will respond to you positively. For example, if a physician prefers to receive information summarized in a quick telephone call, sending lengthy reports and expecting them to be read immediately may not be a successful strategy. On the other hand, some professionals prefer information in written form. Some want the full details, whereas others appreciate a short summary. Busy professionals will respond more quickly to requests for information that are very specific and targeted than to requests for more general information. Some physicians prefer to use questionnaires or checklists, yet others like to dictate a full note. If you understand these preferences, you can make better connections.

Whenever you feel frustrated in your efforts to connect with a particular health professional or clinic, refer to the profile and use the information to develop a more effective strategy.

Formal communication about children and families

Members of the broader community system can use the information gained from the profile and other interactions that have built their awareness and knowledge about the health care system. They can then strategize about how to communicate effectively to ensure input from the health system for children and families. Strategies may include:

• Work with health care professionals to develop forms, fax sheets, and checklists that allow for a quick communication of the types of information that are needed for a particular community program or process (e.g., eligibility, service plan development, and other data). These could be developed for communication both to and from the health care provider. Longer reports could be added for completeness of the record, but might not facilitate timely communication.

• Choose more accessible meeting times and places for the times when face-to-face input is crucial. An occasional lunch-time meeting at the physician's office, where she can pop in for a short period of time, might be considered.

• Arrange for participation by conference call in a meeting. Be prepared to quickly summarize the issues and the type of input needed from the health care provider. This information might be provided before the call, so that the health care provider can give the crucial information in a very short time.

Communication to build relationships

Developing the relationships needed to build effective collaboration over time requires some face-to-face interaction. It is good to be in communication about broader issues in the community, as well as about specific children and families. Thus, a number of informal approaches to communicating with the health care system are useful, including:

• Take a physician, nurse, or member of the office or clinic staff to lunch. Sometimes, it may work best to take lunch to the office.

• Ask a family you serve to let you accompany them on an office visit to the health care professional. It will be a chance to meet the person within the context of a mutual interest and to answer any questions about the child's or family's services and needs in the broader community.

• Offer to do an in-service training session for the health care professional and the office staff about some program or set of services in the community. This approach may be appreciated, because it saves office staff from having to take the time to seek out the information and helps them understand how the system works for families they serve.

HOW TO: Health Care System Communicating With The Broader Community Systems

Understanding the information needed by community programs and systems and the way in which they typically communicate will enhance the ability of health care professionals to communicate effectively and **efficiently** with those systems. The following questions will inform your approaches. You can gather this information by talking directly to programs, by reviewing their written materials, by having your staff research information about the other services in the community, or by asking patients or members of a family advisory committee to share their knowledge.

Community systems/program communication profile

1. Who is the contact person for the overall program? For particular families?

2. How does the intake process work? Is there one community point of entry to all services? Can providers or families call in? Is there particular paperwork? Is there any way to ascertain whether a family is eligible for a service before referring them?

3. What is the best way to contact the program? Regarding a specific family? About program services and requirements?

4. What is the preferred mode of communication? Written? At required meetings? Are there confidentiality issues?

5. What kinds of input do they need?

6. What kinds of information will they send back to the health system? Evaluation reports? Service plans?

With the information developed in the profile, health care professionals can use a variety of approaches to increase communications with the broader community systems.

Formal communication

Community systems need information from the health system to assist in determining eligibility for services. These systems also need such information to ensure that an appropriate service plan for a child and family is developed that takes into account health issues. As noted, this information exchange often takes place in team or staffing meetings. Because attendance at those meetings is not always feasible for health care professionals, it is important to develop a formal way to include your input in the planning process to ensure that families and children get the best care. A number of approaches can be used, including:

• Learn what types of information are needed and in what format. Then develop a process that works for you, for example, checklists, fax sheets, and report shells—one that provides timely information in a useful form for the family and the community systems.

• Consider having a member of the office or clinic staff accompany families to meetings when there is a significant health issue to be addressed. When health issues are complex, families need support to ensure that both systems coordinate their efforts.

• Consider hosting team or staffing meetings in your office at times when you can participate.

• Develop a process in your office to help educate families about how to share the health information effectively at team meetings.

Informal communication

It is often difficult for health care professionals to take time outside the office to talk directly with representatives of other programs and services. However, time invested in this way can quickly move the process forward. These types of activities can be one-time efforts that take a lunch hour to complete, or they can involve a considerable commitment of your time and effort. These approaches include:

• Take a superintendent, principal, or director of a community program out to lunch. You may worry that he may be too busy to take time to meet with you, but he may be very impressed that you are taking your time to connect with the non-health leaders of the system. Whom you invite and in what types of activities you engage will depend somewhat on the size of the community you serve. In smaller communities, you may go right to the top. In large communities, you may want to connect with the people who serve the same area or segment of the community as you do.

• Offer to provide in-service training about health issues as a way to visit an agency or community service organization and to increase your own knowledge about their services and procedures.

• Attend a school board meeting—let power brokers know about your interest in special education.

• Attend an eligibility meeting for special education, early intervention services, or other special programs in the community to understand how the process works.

• Get involved with the committee of your professional organization that deals with issues related to children with special needs.

• Volunteer for community committees, advisory boards, or commissions convened to study or oversee the functioning of a program in your community that serves children with special health care needs.

• Become involved in local United Way activities. Doing so will give you a good overview of the community service system and will provide opportunities to connect with others interested in serving and supporting families in your community.

Conclusion

Taking the first three key steps toward collaboration—awareness, education, and communication—will greatly enhance the services and supports for CYSHCN and their families in your community. Progress in developing collaborative relationships takes time and may not run in a smooth, straight line. There may be great successes and then some setbacks. If potential partners are willing to deal with their challenges and to go back and reassess the reasons for roadblocks encountered, then families will benefit. Families have a key role in keeping the process on track. They must remind members of both systems that the ultimate goal is to serve children and families more effectively.

Once a community has negotiated these first steps, then families, health care system providers, and community system members can work toward establishing structures and practices. Such structures and practices ensure integrated services, plan for new and changing needs in the community, and address the cultural and linguistic needs of diverse populations in the community. Section III of this workbook lists resources that both amplify the information here and provide information and examples of the next steps for collaboration and shared leadership.

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Resources

This section provides a list of resources to help guide health care professionals and members of the broader community service system along the path to effective collaboration for CYSHCN and their families. Some resources address the three steps—awareness, education, and communication—discussed in this workbook. Others provide information about the fourth and fifth steps—collaboration and shared leadership—that are needed to create a truly integrated and easy-to-use system of services and supports for CYSHCN and their families at the community level.

The National Center of Medical Home Initiatives for Children with Special Needs is housed in the American Academy of Pediatrics. This Center provides access to information and advocacy materials that address barriers to the Medical Home. Their Website at http://www.medicalhomeinfo.org provides information on best practices, useful tools, and training materials about how to create a Medical Home. A key piece of that process is connecting effectively with the broader community service system. The Website also provides information about these systems and training approaches to bring the health care and broader community service system together. It contains a wealth of information including the definition of the Medical Home, information about training initiatives, links to key resources, successful models, and state partners. One noteworthy example is a section on the Utah Medical Home Project's guide for physicians on interacting with the educational system. For additional information:

> National Center of Medical Home Initiatives
> 141 Northwest Point Boulevard
> Elk Grove Village, IL 60007
> PHONE: (847) 434-4000
> FAX: (847) 228-7035
> E-MAIL: medical_home@aap.org

Communities Can! is a national network of communities dedicated to providing integrated, family-centered, culturally competent, and comprehensive services and supports to their families, including those with or at risk for special needs. It is coordinated by the Georgetown University Center for Child and Human Development. For the past 5 years, with the sponsorship of the Federal Interagency Coordinating Council and its member federal agencies, Communities Can! has recognized communities who do an exceptional job of bringing together the many programs and funding streams to coordinate and integrate services for young children and families effectively. At the Website http://gucchd.georgetown.edu/commcan.html, a series of monographs that describe the effective approaches of these communities are available in a section, "Community Recognition." The monographs provide information about how these communities started their efforts and examples of implementation of the last two steps in the process, collaboration and shared leadership, described in this workbook. Communities Can! can also connect anyone interested with those communities to learn more directly how they have accomplished effective collaboration. An additional resource through Communities Can! is *Building Blocks of Community Based Systems of Care*, which shares principles of

collaboration and community system building and more effective approaches. This publication is available from Communities Can!

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Community Access to Children's Health (CATCH).

The CATCH Program of the American Academy of Pediatrics is based on the concept that local child health problems can be solved locally, often using local resources. To that end, the CATCH Program provides training and technical assistance in the key skills necessary to develop and implement a community-based child health initiative, including needs assessment, community asset mapping, developing resources, motivating colleagues and community, coalition building, and program evaluation. In addition to the training and technical assistance available through CATCH program staff, each AAP Chapter in the United States has designated at least one member to serve as a Chapter CATCH Facilitator. These individuals support community-based programs at the local level by providing their fellow pediatricians with guidance and encouragement. To find a Chapter CATCH Facilitator in your state please check the Roster of Chapter Facilitators on the CATCH Website www.aap.org/catch/.

> Please contact the CATCH Program office at:
> CATCH Planning Funds Program
> Division of Community-based Initiatives
> Department of Community Pediatrics
> American Academy of Pediatrics
> 141 Northwest Point Blvd
> Elk Grove Village, IL 60007
> PHONE: 847/434-7085
> E-MAIL: catch@aap.org

Policy Statements from the American Academy of Pediatrics

provide both insight into the issues within the pediatric health care system and valuable information about how to address specific issues in caring for CYSHCN and their families. These statements are available at the AAP Website at http://www.aap.org. Click on Policy Statements on the home page, and it will take you to this section of the Website. Recommended Policy Statements relating to this topic include the following:

• The Medical Home;

• The Pediatrician's Role in Community Pediatrics;

• Family-Centered Care and the Pediatrician's Role;

• Culturally Effective Care and the Pediatrician's Role;

• Role of the Pediatrician in Family-Centered Early Intervention Services;

• The Pediatrician's Role in Family Support Programs;

• Care Coordination: Integrating Health and Related Systems of Care for Children with Special Health Care Needs;

• The Pediatrician's Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP);

• The Pediatrician's Role in Family Support Programs;

• Provision of Educationally-Related Services for Children and Adolescents with Chronic Diseases and Disabling Conditions;

• The Continued Importance of Supplemental Social Security Income (SSI) for Children and Adolescents with Disabilities;

• Guidelines for Home Care of Infants, Children and Adolescents with Chronic Disease;

• Assessment of Maltreatment of Children with Disabilities;

• Counseling Families Who Choose Complementary and Alternative Medicine for Their Children with Chronic Illness or Disability;

• Emergency Preparedness for Children with Special Health Care Needs; and

• The Role of Home-Visitation Programs in Improving Health Outcomes for Children and Families.

The **Community Tool Box** is a Website (http://ctb.ku.edu) that provides over 6,000 pages of practical skill-building information to promote community health and development. This Website includes step-by-step instructions, examples, and checklists to help community members build relationships and develop strategies to enhance community services and supports.

The **Federal Interagency Coordinating Council (FICC)** is part of the Individuals with Disabilities Education Act (IDEA). It brings together representatives of federal agencies with responsibilities related to young children (under age 8) and families, family members, and states. The FICC member agencies work to improve services in communities for young children with or at risk for disabilities. The FICC meets quarterly to address general issues and to learn about key issues. The FICC Website at http://www.fed-icc.org provides information about IDEA and related programs, as well other services and programs for families with young children with disabilities.

Family Voices is an organization that partners with professionals and families to advocate for health care services that are family centered, community based, comprehensive, coordinated, and culturally competent. The Website http://familyvoices.org has publications, resources, and links with information to support community collaboration.

The **Institute for Family-Centered Care** offers resources and publications to support partnerships among families and professionals to promote dialogue and problem solving. The Website http://familycenteredcare.org has information about many useful publications and resources.

Bibliographic Resources

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