



FAMILIES OF CHILDREN/YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN) play a critical role in partnering with their child's provider. Families observe and monitor their child's health. They learn more about their child's condition. They share their knowledge. They provide health care services themselves—as directed by doctors. They often coordinate their child's health care among several providers. Through these experiences, a family member becomes a key partner. They learn what works and doesn't work with services and policies.

Health plans can benefit from learning more about CYSHCN from families who have been there, done that. Look for opportunities to share your experiences with your health plan through Family Advisory Councils or other committees. Join with other families to share information. Help others learn about cultural differences so that they do not become barriers to good care. Use the following questions to begin a dialogue with your child's health care plan. Help them examine and improve their programs, policies and resources for CYSHCN.

IDENTIFYING CYSHCN

The Maternal Child Health Bureau estimates that over 15 million U.S. children have special health care needs*. Health plans need to be able to identify CYSHCN. It helps them provide services, plan programs, and evaluate outcomes. Health care plans may have designed their own methods for identifying CYSHCN. They use claims analysis, outreach surveys, etc.

Does the health plan have a systematic way to identify CYSHCN?

- What is the definition?
- What method is used?
- Is it in place for all plan products?
- What kinds of special needs are identified?
- Does the method of identification allow the plan to identify children and youth at the time of enrollment?
- After enrollment?

How is the identification used?

- Referral to case management or care coordination services within the plan?
- Referral to special programs within the plan?
- Referral to programs or services in the community (Early Intervention, Title V, etc.)?
- Use of satisfaction tools or quality measures?



* National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 01-08-2014 from www.childhealthdata.org.

ENSURING APPROPRIATE CARE

Children and youth with special health care needs require more health care than other children. They often need a variety of providers to meet their needs. Health care plans are key. They assist families to get care from the most appropriate providers. They help them find other supportive services, such as information and training about their child's condition and referrals to parent support groups and community services.

- How does the plan ensure that it has an adequate network of providers with pediatric training including primary care providers, specialty care doctors, nurses, mental health providers, ot/pt/speech therapists, home health providers, etc.?**
- Does the plan have a policy of using board certified pediatric sub-specialists?**
- Does the plan provide opportunities when needed for a CYSHCN to stay with a provider who leaves the network to ensure continuity of care?**
- Are all or most hospitals with pediatric services in the state or area served by the plan included in the network?**
- Does the network include a pediatric hospital or unit in a hospital that provides tertiary pediatric care?**
- Does the plan have a definition of "medical necessity" that is appropriate for children and distinguishes between habilitative and rehabilitative services? Do providers with knowledge of CYSHCN make these decisions?**

Does the plan offer in-service training for staff and providers including:

- Training on pediatric issues and transition?
- Training about CYSHCN or specific conditions?
- Training for the case management staff about CYSHCN?
- Information on support services/consultation for staff/providers about CYSHCN?
- Training on working with families from diverse populations?

Does the plan offer the following services for families of CYSHCN:

- A knowledgeable person to answer family questions?
 - Clear information on plan benefits and programs?
 - Training (on such topics as how to access community services, manage home care, etc.)?
 - Support services such as special funds for high cost care?
 - Parent support groups for members?
 - Referral to parent groups or disability organizations outside the plan?
- Does the plan have policies or programs that promote the transition of adolescents with special needs to adult care and services?**
 - Does the plan use consumer satisfaction tools with the capacity to measure quality of care for CYSHCN? How does the plan report the results to members?**
 - Does the plan contact with other providers of health care, i.e. the Indian Health Service, Rural health clinics, or Federally Qualified Health Centers who provide services in rural areas?**



PRIMARY CARE AND SPECIALTY CARE REFERRALS

Most health plans give primary care doctors an important role in coordinating care. They are the ones who can authorize referrals for specialty care. The policies and procedures of plans are important. They can help doctors make sure your child gets appropriate care. Or they can be barriers to appropriate care.

- Does the plan allow parents to select their child's primary care provider?
- Does the plan offer families information about primary care providers' specific expertise or special interest in CYSHCN?
- Can pediatricians, family practitioners, and general practice physicians serve as primary care providers for a child?
- Can a family request that their child's pediatric specialist be the primary care provider?
- Does the plan use different reimbursement rates or other special incentives for primary care providers when they provide care for CYSHCN?
- Can CYSHCN receive standing referrals to specialists or other simplified methods for access to specialists or special services?



MENTAL HEALTH AND BEHAVIORAL HEALTH SERVICES

It is hard to get appropriate mental health and behavioral health services. It is even harder to coordinate that care with other healthcare services.

- Does the plan identify and respond to the mental or behavioral health needs through periodic behavioral screening of children and youth?

Are mental health/behavioral health services coordinated with other healthcare when

- Mental health/behavioral health services are provided within a specific network of providers?
- Mental health/behavioral health services are provided through a separate contract/network of providers? (i.e. "carved out.")

Are the following services provided?

- Assessments?
- Outpatient counseling (individual/family)?
- Wraparound services to help a family maintain a child at home or to be involved in a child's treatment?
- Family support?
- Case management?
- Respite?
- Crisis intervention?
- Inpatient hospital care?
- Pharmacological services?
- Residential including therapeutic foster care, etc.?
- Aftercare treatment plans that are in place prior to hospital discharge?



CARE COORDINATION AND CASE MANAGEMENT

Children and youth with special health care needs use many types of providers. They are served by many systems, such as schools and social services. Their services are paid for by multiple payers. This makes care coordination difficult. Providers, payers, and families need accurate information. They need clear channels to communicate. This is the only way to get effective care coordination.

Does the plan coordinate care with other providers and programs including

- Hospitals and/or community-based health care providers?
- Schools or early intervention programs?
- State agencies such as Departments of Mental Health, Public Health, or other social services?

Does the plan offer case management services for CYSHCN and their families?

Does the plan have specific case management staff with skill and experience in serving CYSHCN?

Does the plan have a clear referral process for a child to receive care coordination or case management services? Does the plan have family-friendly written information about such services within the plan?

Can a parent request case management services for their own child?

What case management services does the plan provide?

- A clear explanation of health insurance benefits and eligibility for specific plan services?
- Assistance scheduling medical appointments?
- Help coordinating primary and specialty care, including mental health services?
- Help coordinating health services in school with other medical and health services?
- Help coordinating care from the plan with care from state agency services such as public health and mental health or other payers?
- Accompaniment for families to meetings with schools or other agencies?
- Information and assistance in obtaining community services and public programs and services available to families (such as SSI, public health programs, etc.)?
- Information on medical research, other resources, or web sites that are helpful to families?
- Help arranging transportation to health services?
- Help finding payment sources for needed services not covered or limited by the plan, such as eye glasses, hearing aids, or hearing aid batteries?



RESOLVING DISAGREEMENTS ABOUT CARE

CYSHCN generally use more medical care than other children. They often have highly specialized needs. Their families are more likely to have questions and complaints than other plan members. Clearly identified and communicated procedures are important. They can help ease the burden on staff and families in resolving disputes.

Does the plan offer specific procedures when families disagree about care decisions for their child including

- A patient/member advocate?
 - A mediation process?
 - An appeal/grievance procedure?
- Is information on how to resolve a disagreement easily available to families? Does the plan have written information available in multiple languages?**
- Does the plan collect information about disagreements or appeals concerning children? Can the plan identify the most frequent areas of disagreement?**



INVOLVING FAMILIES IN POLICY AND PROGRAM ACTIVITIES

Families of CYSHCN are among the most knowledgeable people about what is working well and not so well in the health care system. They can be essential sources of information and support to health care plans. Their input can help improve plan policies, procedures and programs. They can be important allies in efforts to create better systems of services and care for CYSHCN.

Does the plan involve families for their expertise as parents of CYSHCN in policy level activities or committees?

- Are families included in advisory or planning roles with the plan?
 - In a general member advisory board?
 - In a separate advisory group for parents of CYSHCN?
 - In planning or reviewing quality assurance efforts?
 - In an appeal or grievance committee?
 - In in-service training for plan personnel as participants or as presenters?
- Does the plan pay parents for their involvement in these activities?**
- Does the plan ask parents for feedback on their experiences with the plan?**



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READY TO BE A FAMILY LEADER? - QUESTIONS FOR YOU

First and foremost you are your child's most important advocate. You may also find that you have become inspired to work with other families and professionals as a family leader to improve care at a systems level. As a family leader, you can use your family experiences and skills to urge systems to be more family-centered. Your feedback can help professionals to learn how to be more responsive to family needs, more flexible, comprehensive and coordinated. You can connect providers to community based services and help them become more culturally competent. This impacts systems in ways that benefit your own child as well as many other families of CYSHCN.

Some systems, programs and professionals reach out to include families. They welcome and encourage family involvement as systems advocates and change agents. Others need help to understand the value of family participation.

Ask other families as well as providers and administrators about any opportunities to participate on committees or groups dedicated to improving health care. Tell them about your interest and special abilities and offer to help. As you consider opportunities to join a committee or group, ask yourself these questions:

- Can you attend most, if not all, meetings requested and give notice when you cannot attend?**
- Are you willing to give as much time and energy to the group as the other members do?**
- Are you willing to listen to others' views and to seek a win-win in a situation?**
- Can you get along with others, respecting their opinions and preferences the way you want your opinions and preferences respected?**
- Can you think and act as an advocate for other children/youth and families, not just for your own child/youth or family? (This means moving beyond your own story and situation and representing other families with other experiences.)**
- Do you understand the art of compromise and negotiation?**
- Are you willing to negotiate workable solutions if it means not sacrificing your basic principles?**
- Are your principles and values family-centered?**
- Can you apply the concepts of family/professional collaboration?**
- Will you encourage, help, or mentor other families in the future who may want to get involved?**

OUT OF NECESSITY COMES ADVOCACY



I became an advocate for children with special health care needs out of necessity. When my infant daughter came home from the hospital with 24-hour nursing, on a ventilator, and with a gastrostomy tube, I found that fighting for appropriate medical care and educational services became a part of my everyday agenda.

Through the years, Lizzy has developed into a healthy child who also happens to have special health care needs. My life has been enriched by my daughter and the many parents, legislators, Medicaid staff and policy makers we have come to know as friends. I can certainly say my daughter's life has had a positive impact on the quality of care that children with special health care needs receive in Delaware.

From speaking before our joint legislative finance committee, to attending state and national conferences and presenting on health care issues, helping form new parent groups in our state, and sitting with the Governor as he signs the permanent reauthorization of Delaware's birth-to-three program, I have been thrown into the role of advocate—like so many other parents—out of necessity. We stay there, however, because we love it...and we love our children.

- Beth MacDonald, Delaware