

From Dialogue to Action:

Strategies for Family Involvement with Managed Care Plans

Meaningful dialogue is an important first step in building successful partnerships between families and health care professionals. Viable and effective partnerships can be strengthened from ongoing collaboration. Family Voices parent leaders, many of whom have years of experience in working with managed care plans, have documented the following strategies to help families and managed care plans develop strong partnerships focused on improving care for children with special health care needs. Frequently, these strategies are implemented through hiring families as paid staff or consultants or through a contract with a family organization. To learn more about family involvement in program and policy, please visit the Family Voices website - FiPPs project.

Parents as Advisors on Program and Policy

- ♥ Parents serving on Health Plan Advisory and Grievance Boards,
- ♥ Parents providing on-going review of plan written materials,
- ♥ Parents consulting to plans on policy and program design, and
- ♥ Parents participating with health plans and other key stakeholders in forums, workgroups, and discussions of systems level changes to improve care for CSHCN

Parents as Providers of Resources and Information

- ♥ Parents providing education and training for plan staff about family perspectives, resources, and specific disability issues,
- ♥ Parents acting as liaisons between plans and parent support groups to locate, organize, and plan trainings and resource sharing,
- ♥ Parents working with plans to provide parent support and referral to family resources for plan members with CSHCN
- ♥ Parents linking plans with parent advocacy activities, and
- ♥ Parents contributing to plan materials, including family-friendly newsletter articles, web content, or interactive web activities

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PARENTS PARTNERING WITH MANAGED CARE PLANS:

A Discussion Guide on Services for
Children and Youth with
Special Health Care Needs



Family Voices is a national grassroots organization with a network of families and friends in every state speaking on behalf of children and youth with special health care needs. Family Voices believes that strong family-professional partnerships improve decision-making, enhance outcomes, and help to ensure quality health care for children with special needs.

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Families and health care professionals are important partners in providing care for Children and Youth with Special Health Care Needs (CYSHCN). Successful partnerships are based on shared knowledge and trust, and so a first step in building this partnership between families and managed care plans is to engage in meaningful discussions about CYSHCN. The following questions were developed by Family Voices parent leaders to help focus these discussions on programs, and policies and resources. Through dialogue, and then through collaboration, families and managed care plans can work together to improve services for children and youth with special health care needs.

I. Identifying Children and Youth with Special Health Care Needs

The ability of health plans to identify CYSHCN is an essential part of providing services, planning programs, and evaluating outcomes. The Maternal Child Health Bureau estimates that up to 9 million children in the United States have special health care needs. Current national initiatives include the development of identification tools, and many managed care plans are increasingly designing their own methods of identification, through 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 this 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 outside the plan (EI, Title V, etc)?
- Use of satisfaction tools or quality measures?

Family Voices, Inc.
2340 Alamo SE, Suite 102, Albuquerque, NM 87106
Tel: (505) 872-4774 Fax: (505) 872-4780
www.familyvoices.org

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VI. Resolving Disagreements about Care

Because CYSHCN generally use more medical care and often have highly specialized needs, their families are more likely to have questions and complaints than other plan members. Clearly identified and communicated procedures 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 resolving disagreements easily available to families? Does the plan have written information available about these procedures in multiple languages?

Does the plan collect information about disagreements or appeals concerning children? Can the plan identify the most frequent areas of disagreement?

VII. Involving Families of CYSHCN 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 managed care plans in helping to improve plan policies, procedures and programs, and important allies in more general 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?

Does the plan involve families in reviewing materials for families about plan benefits and services?

Are families included in advisory or planning roles in the following ways?

- 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?

V. Mental Health and Behavioral Health Services

Ensuring access to appropriate mental health and behavioral health services for children and youth is a challenge in our medical care system. This is an area of particular need and vulnerability for many CYSHCN and their families, which is heightened by the difficulties of coordinating behavioral health care with the broader scope and amount of medical care services used by most CSHCN.

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 health care 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 mental health/behavioral health 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?



Artwork is reprinted courtesy of the artist, Martha Perske, from Circles of Friends and Hope for the Families by Robert Perske, Nashville: Abingdon Press.

II. Ensuring Appropriate Care

Children and youth with special health care needs require more health care than other children and often need access to a variety of providers to meet their needs. Managed care plans are key in assisting families to obtain care from the most appropriate providers, as well as helping 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 its capacity to serve CYSHCN through an adequate network of providers with pediatric training including primary care providers, specialty care physicians, 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:

- General in-service training on pediatric issues and transition?
- Specific training about particular CYSHCN or all CYSHCN?
- Specific training for the case management staff about CYSHCN?
- Support services or consultation for staff and providers about CYSHCN?

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 accessing community resources, managing home care, etc.)?
- Support services such as special funds for extraordinary expenditures?
- 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? Does the plan report the results to members?

III. Primary Care and Specialty Care Referrals

Most managed care plans give primary care clinicians an important role in coordinating care, including authorizing referrals for specialty care. The policies and procedures of plans have a critical effect on the ability of primary care providers to be enablers, or 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?



IV. Care Coordination and Case Management

Children and youth with special health care needs often require care coordinated across many types of providers, and systems, such as schools and social services, and often multiple payers. For care coordination to be effective, all providers, systems, payers, and families need accurate information and clearly identified channels of communication.

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 by the plan?