

From Conversations to Connections: A Report on Parent Interviews with Managed Care Plans in Massachusetts about Children with Special Health Care Needs



FAMILY VOICES

© Federation for Children with Special Needs

New England SERVE



October 2001

Acknowledgments

The Massachusetts Family Advisor Initiative was a collaborative effort of Family ♥ Voices, a national network of families speaking on behalf of children with special health care needs, and New England SERVE, a health policy research and planning organization working to promote quality systems of care for children with special health care needs and their families.

Support for the activities described in this report was provided through a series of generous funding partners:

The David and Lucile Packard Foundation, through a grant to Family ♥ Voices,

The Maternal & Child Health Bureau, Health Resources and Services Administration, Department of Health and Human Services, through a grant to New England SERVE for the Shared Responsibilities Project,

The Massachusetts Department of Public Health, Bureau of Family and Community Health, Division of Special Needs, and

The Pediatric Alliance for Coordinated Care, Children's Hospital, Boston, Massachusetts.



Introduction

Over the last decade, managed care has become the predominant way of financing and delivering health care in the United States. Massachusetts has long been at the vanguard of managed care growth, and most people in the state receive their health care through managed care plans. The proportion of children enrolled in managed care arrangements may be even larger than the general population, since virtually every family covered by employer-based health insurance or MassHealth (the Massachusetts Medicaid program) is now required to join some form of managed care.

The exciting news is that there is a growing focus on understanding and improving the experience of children with special health care needs (CSHCN) who receive their care through managed care plans. Policymakers and health care purchasers, both employers and public payers, are beginning to require managed care plans to identify CSHCN and assess the quality of care they receive. In addition, more and more managed care plans are themselves developing new approaches and programs for improving care for these children.

In an effort to learn about managed care practices for children with special health needs, and to establish links between families and managed care organizations, Family ♥ Voices developed a process for parent leaders to interview managed care plans and to discuss plan policies and practices in areas of particular importance to CSHCN. Forty-one interviews with managed care plans have been carried out by family leaders in twelve states since 1998. For more information on the national project, see www.familyvoices.org.



In Massachusetts, Family ♥ Voices collaborated with New England SERVE to establish the Family Advisor Initiative, and expand the purpose of the interviews in this state. Recruitment and training of parents to conduct interviews with managed care plans was seen as the first step in building a network of families who could serve as advocates and policy advisors on quality managed care for CSHCN in the future. This report summarizes the information collected by family advisors who interviewed nine managed care plans operating in Massachusetts in 2001. The report highlights a number of best practices and promising opportunities for further collaboration between parents of CSHCN and managed care plans.

The Context for the Interviews

The growth of managed care has been accompanied by considerable public controversy and concern, particularly about the potential negative effects of managed care on quality of care for vulnerable populations, such as CSHCN. However, there are many ways in which managed care could **enhance** the quality of care for CSHCN, including:

- **Improve access to care:** Through their established relationships with a wide range of health care providers, managed care plans can improve access to care, particularly for Medicaid members, who often experience difficulty finding providers who will accept them as patients.
- **Enhance coordination of care:** Many of the medical management techniques used by managed care plans, such as case management and disease management programs, are designed to help improve coordination of care for members.
- **Avoid unnecessary hospital care:** One of the best-documented successes of managed care is promoting the use of appropriate alternatives to hospitalization.
- **Expand the range of covered benefits:** Most managed care plans provide more comprehensive benefits than traditional health insurance products, particularly for primary and preventive services.
- **Help families navigate the health care system:** As organized financing and care delivery systems, managed care plans can play an important role in helping families understand and use the health care system.
- **Match resources to the needs of children and families:** Managed care plans have the incentive, and the financial flexibility, to pay for services that are not traditionally covered in health insurance plans but which are cost-effective for particular members.
- **Provide supports to physicians and other clinicians:** There are many ways in which managed care plans can help clinicians improve the quality of the care they provide. Health plans can disseminate information on best practices, provide reports on individual clinician practice patterns, sponsor educational sessions, provide additional payment to promote practices such as care coordination and case management.
- **Focus on quality improvement:** As entities that combine financing and responsibility for delivery of care, managed care plans are well situated to assess and improve systems of care for their members. The growth of managed care has helped promote a much greater focus on quality measurement and management, both within managed care plans and across the entire health care system.

-
- **Engage families as active partners in system improvement:** As managed care plans seek to create more integrated systems of care and improve quality, families of CSHCN are wonderful sources of information about what's working well and not so well, and can become important allies in advocating for change.

Yet despite this potential, many families, health care providers and advocates have long been concerned about ensuring that CSHCN enrolled in managed care plans receive high quality care. Some of their **fears** about the potential negative effects of managed care on CSHCN are:

- **CSHCN have health care needs which are different and often greater than other children:** The potential effect of any restrictions or limitations of care have a much greater effect on CSHCN because they differ from the general population in the type, scope and frequency of care they need.
- **Many CSHCN have high medical costs:** As managed care plans seek to moderate medical costs, they may focus their cost containment efforts on CSHCN without sufficient regard to the impact on quality of care.
- **Existing provider relationships and patterns of care may be disrupted:** Requirements to use network providers, changes in the composition of provider networks, and other types of restrictions imposed by managed care plans can force families of CSHCN to abandon long-standing relationships and patterns of care.
- **Physicians and other clinicians will lose their ability to advocate on behalf of patients:** One of the greatest fears of patients, and many providers, is that managed care, through its use of financial incentives and other techniques, may limit the autonomy of providers and thus impede their ability to act as effective advocates for high quality care for their patients.
- **The administrative burden on families will increase:** The time and complexity of complying with requirements for referrals, prior approval, and other restrictions imposed by managed care plans can be particularly hard for families of CSHCN, both because their children often have greater medical needs and because of the additional demands of caring for their children.



The Interview Process

With these possibilities and concerns in mind, the Family Advisor Initiative began to explore the current "state of the art" among Massachusetts managed care plans in creating quality systems of care for CSHCN. A group of 14 parents of CSHCN was identified and recruited to participate in this project in the summer of 2000. These family advisors attended training sessions about managed care and the interview process, and then, working in teams of two, prepared to conduct face-to-face interviews with managed care plans. Nine of the ten managed care plans contacted by the family advisors agreed to participate in the project. These plans were:

- Blue Cross Blue Shield of Massachusetts,
- Boston Medical Center Health Plan (Boston HealthNet),
- Fallon Community Health Plan,
- Harvard Pilgrim Health Care,
- Health New England,
- Neighborhood Health Plan,
- Network Health (part of the Cambridge Health Alliance),
- Tufts Health Plan, and
- United Healthcare of New England.

Family advisors used semi-structured interview questions to collect information from managed care plans (see Appendix A). The interview questions for Massachusetts were developed by the Family Advisor Initiative based on questions created by Family ♥ Voices for use in other states. The interviews were designed to collect information about managed care policies and practices in seven major areas: identification of CSHCN; ensuring capacity to provide appropriate care to CSHCN; primary care and specialty care referrals; care coordination and case management; mental health and behavioral health services for children; methods for resolving disagreements about care; and involvement of families of CSHCN in health plan policy and program activities.

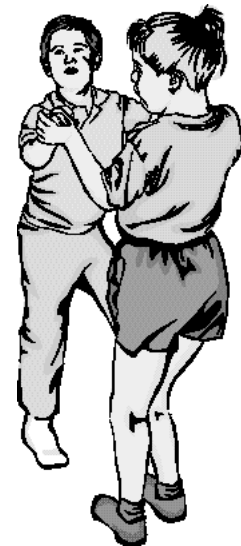
Family advisors also delivered a resource packet containing a range of materials, tools and written resources of potential interest to health plans and their providers. Materials in the resource packet included information on: defining CSHCN, care coordination and case management, family support, physician support, mental health, quality assurance, and financing care, as well as a Massachusetts Resource Directory (see Appendix B). Following the interviews, family advisor teams wrote up their findings, submitted them to the health plans to review for accuracy and then provided them to the Family Advisor Initiative project staff for compilation.

What Was Learned in the Interviews ?

The findings of the interviews with Massachusetts managed care plans appear to be consistent with the results of similar interviews in other parts of the country as well as the findings of other efforts in Massachusetts that have examined the policies and practices of managed care plans in caring for CSHCN. Although CSHCN are estimated to comprise 15-20% of the childhood population, these children, as a group, have not been the focus of specific quality improvement activities at health plans in the state. Most health plans have undertaken some initiatives focused on children with specific diseases and conditions or those who use specific costly services. Most commonly, these activities have been related to the national Healthplan Employer Data and Information Set (HEDIS) performance measurement system (e.g., asthma, diabetes, immunizations). Most plans cite examples of specialized policies or programs designed to meet the needs of certain children and their families based on a specific diagnosis or service use.

The plans also reported that they confront a number of **challenges** in ensuring the quality of care and attempting to improve the health plan's capacity for caring for CSHCN including:

- Identifying CSHCN,
- Coordinating care effectively with public agencies,
- Dealing with the fragmentation of care, coverage and financing across multiple payers,
- Finding qualified pediatric providers in certain specialties who are accepting new patients (e.g., child psychiatrists, home nurses),
- Finding qualified physicians who are willing to accept CSHCN ready to transition from pediatric care to adult care,
- Balancing the demands of purchasers for affordable premiums with the needs of many CSHCN and their families. This challenge is most often seen in limitations on certain services, such as custodial care, home nursing, durable medical equipment, and habilitative therapies, and
- Keeping well informed about the full range of resources and supports available to families and children.



Other major findings of the interviews are summarized briefly on the next pages, according to the major areas addressed by the interviews.

Identification of Children with Special Health Care Needs

Why did we ask about this?

The ability of managed care plans to identify CSHCN is an essential first step in monitoring health care needs, providing appropriate services, helping to coordinate care, providing support to providers, assessing satisfaction, and developing quality improvement initiatives.

What did we learn?

- Managed care plans use a variety of methods to identify some CSHCN, including analysis of claims data, notification of a hospital admission or emergency room visit, physician referrals, and inquiries from families. In general, these techniques are based on diagnoses and are used primarily to refer children to case management, disease management programs, or specialized care coordination services, or for referral to special programs outside the managed care plan, such as early intervention.
- The managed care plans that contract with the state Division of Medical Assistance to serve children with MassHealth coverage indicated that they routinely do health risk assessments of all newly enrolled children, as required by their contract with the state, and use this information to refer certain children for case management and other specialized services.
- Only one plan reported that it uses special member satisfaction tools or quality measures to assess care for CSHCN.
- Several plans indicated that they would like to develop more systematic and proactive ways to identify CSHCN.

BEST PRACTICES

One plan reported that it has recently undertaken a systematic effort to identify CSHCN, through the development of an algorithm that can be used to analyze claims and other administrative data. This method is being used to identify a "caseload" of CSHCN, and to begin to develop policies and programs to improve quality of care for these children. Early applications of the algorithm identified 18% of children enrolled in the plan.



Ensuring plan capacity to provide appropriate care to CSHCN

Why did we ask about this?

Children with special needs usually have greater health care needs than other children, and they and their families need access to primary care clinicians, specialists and other providers with the expertise and experience to meet their needs. Managed care plans could play a key role in assisting families to obtain their care from the most appropriate providers, as well as linking families to other supportive services, such as information and training on their children's condition and parent support groups.

What did we learn?

- Managed care plans in Massachusetts report that they have extensive provider networks, including contracts with board certified pediatric sub-specialists and pediatric hospitals and/or other tertiary pediatric care units. Plans use a variety of methods to monitor the overall adequacy of these networks, including credentialing standards, and complaints about access from providers and members.
- However, most plans indicated that they do not have systematic ways to ensure their capacity to provide appropriate care to CSHCN.
- Only two plans use a definition of "medical necessity" that distinguishes between habilitative and rehabilitative services for children.
- Families of children referred for case management or to specific disease management programs (e.g. asthma, diabetes) receive a range of support services and information from most managed care plans. But most families of CSHCN appear to receive virtually no support services or information from the plans. In fact, the plans often indicated that they do not know what kinds of supports or referrals they could potentially provide to these children and their families.
- Only one plan reported that it had policies or programs to promote the transition of adolescents with special needs to adult care and services.

Primary care and specialty care referrals

Why did we ask about this?

Most managed care plans give primary care clinicians a key role in coordinating care, including authorizing referrals for specialty care. The policies and procedures of managed care plans in this area have a crucial effect on the ability of primary care providers to be enablers, or barriers, to appropriate care.

What did we learn?

- All of the plans require parents to select a primary care provider for their children from the network of contracting clinicians. Half of the plans offer families information about which primary care providers have specific expertise or interest in CSHCN.
- Every plan permits primary care providers to arrange for "standing referrals" for specialty care, generally for up to one year. (This means that families are not required to obtain the primary care provider's approval to seek care from that specialist during the period of the standing referral.)
- Two of the plans have developed policies to pay primary care providers higher rates for providing care to CSHCN, although these payment arrangements are limited in their scope and based on diagnostic criteria. Most of the plans do not use any special payment methods to compensate primary care providers or specialists for caring for CSHCN.



BEST PRACTICES

Five of the plans permit families to make a special request that a pediatric subspecialist be their child's primary care provider.



Care coordination and case management

Why did we ask about this?

CSHCN frequently have multiple and complex needs, which necessitate that care be coordinated across many types of medical care providers, with other systems, such as schools and social services, and often, among multiple payers. For care coordination to work well, providers and families need good information, and support in navigating these many care delivery systems.

What did we learn?

- All of the plans said that they provide care coordination and case management services for CSHCN. The majority of the plans report having a separate pediatric case management unit, staffed by nurses and other clinicians with pediatric expertise. The range of potential case management and coordination support was quite broad, including: assistance with scheduling medical appointments; explanation of health insurance benefits; coordination with other payers, schools, early intervention programs, and state agencies; and in most cases, arranging transportation.
- In some cases care coordination and case management services are provided on a systematic and proactive basis to children who meet certain diagnostic, cost or service use criteria (e.g., to children with specific conditions, such as spina bifida, cystic fibrosis, or severe asthma).
- In general, plans reported that a relatively small number of children had received case management services during the most recent year. Services are provided on a case-by-case basis, based on a review of the individual needs of particular children who are identified to the plans by parents, physicians, or other providers.
- Every plan said that families of CSHCN may request case management and care coordination support. However, surveys have shown that parents of CSHCN often do not know that this support is available from their managed care plans.
- Information about public programs and other services for CSHCN and their families is also generally provided only on a case-by-case basis.
- According to the family advisors, all of the managed care plans were pleased to receive the resource packet prepared by the Family Advisor Initiative and indicated that they would like to receive this type of information on a regular basis.

Mental health and behavioral health services for children

Why did we ask about this?

Ensuring access to appropriate mental health and behavioral health services for children is a challenge in our medical care system. This is an area of particular need and vulnerability for many CSHCN 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 CSHCN with both mental health and other health needs.

What did we learn?

- The managed care plans in Massachusetts cover a wide range of mental and behavioral health services through a mix of carve-out and in-house provider networks.
- A few of the plans reported that they have instituted systematic proactive health risk assessment systems to identify children in need of mental health and behavioral health services.
- However, the majority of the plans rely on primary care clinicians to identify children on a case-by-case basis and refer them for services.

BEST PRACTICES

One managed care plan encourages primary care clinicians, including pediatricians, to screen for mental and behavioral problems by paying an extra fee for these screening and diagnostic services.



Methods for resolving disagreements about care

Why did we ask about this?

Because CSHCN 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.

What did we learn?

- As required by Massachusetts state law, all of the plans have grievance and appeals processes for their members. Written information about the procedures is made available to prospective members and current members in a variety of ways, including member handbooks, special mailings, and member newsletters. All but one of the plans has this written information available in English and Spanish. Written information in other languages is available at several plans.
- The plans report that they notify all members about the dispute resolution and external appeals process available through the new Massachusetts Office of Patient Protection and the Managed Care Consumer Advisory Board Ombudsperson, as required by Massachusetts law.
- Only three of the nine plans report that they have the capability to identify disagreements or appeals concerning children (as opposed to those concerning adults). It is unclear if any of these plans has ever completed a separate analysis of grievances involving children.
- Each plan reported a somewhat different list of the issues that are most often areas of disagreement between the plan and members related to care of CSHCN. Among the specific issues mentioned by at least one plan are: rehabilitative vs. habilitative care; private duty nursing; special therapies; durable medical equipment; home nursing; coverage of weight management services; requests to waive higher co-payments for non-formulary drugs; and requests to waive coinsurance for services received from non-network providers.

BEST PRACTICES

- One plan has an on-staff Ombudsperson who is responsible for ensuring that members' rights are upheld, including appeals and grievance rights. The Ombudsperson chairs grievance panels, as well as a plan-wide member advisory council.
- Another plan has a patient advocate on staff who assists members in pursuing complaints or grievances.



Involvement of families of CSHCN in policy and program activities

Why did we ask about this?

Families of CSHCN 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 CSHCN.

What did we learn?

- Most plans have no formal mechanisms and very limited experience involving their members in policy or program planning activities.
- Consumer involvement is most developed in the area of appeals and grievance committees. Three plans have voting consumer members on these committees.
- Only one plan has begun to actively engage parents of CSHCN as partners in its efforts to improve quality of care for CSHCN.
- Most plans do not appear to have significant relationships with families or parent organizations.

BEST PRACTICES

- One managed care plan has a member council that meets four to six times throughout the year. Part of the council's role is to help guide changes in the plan's policies and programs.
- Another plan has convened an Advisory Group on CSHCN, which includes several parents, providers, and representatives from key external organizations such as the Department of Public Health, Department of Mental Health, and Division of Medical Assistance. The group meets on a regular basis to advise the plan on its initiatives to improve care for its CSHCN. This plan has also recently hired a parent of a child with special health care needs to serve as an advisor to the plan and as a resource for member families who have children with special health care needs.



Opportunities for Quality Improvement

Both the family advisors and the managed care plans report that the interviews provided a wonderful opportunity for parents to learn more about managed care, and for managed care plans to learn more about issues, and potential resources, for CSHCN.

The results of these interviews suggest a number of potential opportunities to build on the relationships established between parents of CSHCN and health plans in Massachusetts. Through this activity, families have demonstrated a strong interest and capacity to work with health plans to improve the care received by CSHCN; managed care plans have welcomed family advisors and found their resources and expertise valuable in addressing the needs of a vulnerable population. These initial conversations between the family advisors and health plans identify a number of specific opportunities for partnerships, including:

1. Focusing Attention on CSHCN:

As further efforts emerge at both the state and national level to improve care for CSHCN, managed care plans will need to broaden and deepen their understanding about this population of children. Partnerships between plans and family leaders in their own communities can assist health plans with information about the service delivery system, opportunities for family supports, and linkages to statewide parent networks.

2. Increasing Visibility of Case Management & Care Coordination:

Managed care plans can develop more proactive approaches for identifying CSHCN who could benefit from case management and care coordination. Managed care plans can also involve families of CSHCN in improving member understanding of the range of care coordination and case management supports that may be available from their managed care plans.

3. Enhancing Supports for PCPs:

Health plans can develop and implement policies to provide additional support to primary care providers and other clinicians who care for CSHCN, including provider education on CSHCN and appropriate payment for risk assessment, care coordination and case management.

4. Working Together to Address System Needs:

Addressing system-wide challenges or gaps in services for CSHCN will require collaborative advocacy efforts by key stakeholders, including families, providers, managed care plans, and relevant state agencies. Three issues identified by all plans as a common concern at this time in Massachusetts are:

- The shortage of child psychiatrists,
- The shortage of pediatric home nurses,
- Providing better support to CSHCN, their families, and providers as children transition from pediatric care to adult care.

Potential Areas for Family Involvement

A common denominator in all four areas identified above is the need to share existing information among systems and key stakeholders and, in some cases, the need to create new channels of communication and coordination across systems of care. Because of their acquired knowledge, and their interest and capacity to work with health plans, as demonstrated in the Family Advisor Initiative, parents can serve as willing and capable allies in enhancing the quality of systems of care for children with special needs. Family leaders can work with health plans to identify effective mechanisms for family participation.

During many of the interviews, plans mentioned potential areas where parent involvement is needed, and parents, themselves, offered suggestions for new partnership models. Some of these examples are:

- Parents of CSHCN participating in policy/practice discussions on Advisory Boards,
- Parents of CSHCN participating on Grievance Boards,
- Parents providing training to case management and other staff as well as providers on specific issues for CSHCN,
- Parents acting as liaisons between plans and parent support organizations,
- Parents providing in-house or out-of-house consulting on program and policy design,
- Parents staffing or contributing to health plan Family Resource Centers,
- Parents contributing family-friendly newsletter columns or web-based information,
- Parents providing review of health plan consumer materials,
- Parents contributing to policy discussions through health plan foundation grants,
- Parent advocacy groups informing and connecting with plans to share information, and
- Parents participating in policy discussions and initiatives for CSHCN at the state or regional level, such as The Massachusetts Consortium for Children with Special Needs,

Conclusion

As health plans in Massachusetts continue to identify CSHCN enrolled in their plans, and participate in the national and state initiatives designed to assess and improve the care received by this population, families can play an important role in these quality improvement efforts.

Family Advisor Initiative: Interview Tool



1.0 Identification of Children with Special Health Care Needs (CSHCN)

- 1.1 Does your health plan have a systematic way to identify CSHCN?
- 1.2 If Yes, do you use this method to identify CSHCN enrolled in all or only some of your health plan's products or lines of business?
- 1.3 If Yes, do you identify CSHCN because of a contractual requirement or inter-agency agreement? With Medicaid?
- 1.4 What definition and method do you use to identify CSHCN? For example, what kinds of children are identified?
- 1.5 Does this method allow you to identify CSHCN only at the time of enrollment, or also after enrollment?
- 1.6 How does your health plan use the information once you identify CSHCN?

2.0 Ensuring Capacity to Provide Appropriate Care for CSHCN

- 2.1 How does your plan make sure CSHCN get the services they need?
- 2.2 Tell us about the network of pediatric providers associated with the plan and how it is determined - primary care providers, specialty care physicians, nurses, mental health providers, OT/PT/Speech therapists, etc.
- 2.3 Does your plan have a policy of using board certified pediatric sub-specialists?
- 2.4 Are all or most hospitals in the state (or area) served by the plan included in the network?
- 2.5 Does the network include a pediatric hospital or unit in a hospital that provides tertiary pediatric care?
- 2.6 What type of in-service training does your plan offer for staff and/or providers? 1) General in-service training about pediatric issues, 2) Specific training about CSHCN or about particular conditions, 3) Specific training for the plan's case management staff about CSHCN
- 2.7 How does your plan define "medical necessity?"
- 2.8 Does your plan's definition of "medical necessity" distinguish between habilitative and rehabilitative services for children?
- 2.9 Does your plan offer any of the following services for families of CSHCN? If so, are these services offered for all/many families or only families of children with specific conditions (if specific condition(s), please identify)? 1) Training, 2) Information, 3) Support services, 4) Parent support groups provided by the plan, 5) Referral to parent groups or disability organizations outside the plan
- 2.10 Does your plan have policies or programs that promote the transition of adolescents with special needs to adult care and services?

3.0 Involvement of Families of CSHCN in Policy and Program Activities

- 3.1 Does your plan encourage consumer or member involvement in policy level activities or committees (e.g. activities designed to assist the plan, its staff, or other members)?
- 3.2 Does your plan include members in any of the following types of advisory or planning roles?
 - 1) General member advisory board (if Yes, does this include families of CSHCN?),
 - 2) Separate advisory group for families of CSHCN,
 - 3) Planning or reviewing quality assurance activities,
 - 4) Appeals or grievance committee,
 - 5) In-service training for plan personnel

4.0 CSHCN: Primary Care & Specialty Care Referrals

- 4.1 Do parents select their child's primary care provider? If No, how providers are assigned?
- 4.2 Does the plan offer families information about primary care providers' specific expertise or special interest in CSHCN?
- 4.3 We assume that pediatricians, family practitioners and general practitioners can be primary care providers for a child. Is this correct?
- 4.4 Can a family request that their child's pediatric subspecialist be their child's primary care provider? If Yes, does this require special arrangements?
- 4.5 Does your plan use any special or different reimbursement rates or incentives for primary care providers when they provide care for CSHCN?
- 4.6 Is it possible for a CSHCN to receive standing referrals to specialists? Or are there other simplified methods for access to specialists or special services?

5.0 Care Coordination & Case Management

- 5.1 This question is about how the plan coordinates care for its members with other providers and programs outside the health plan. Does the plan assist families in coordinating their child's care with: hospitals, community-based health care providers, schools or early intervention programs, state agencies (such as DMH, DPH, DSS)? Is this assistance provided systematically or on a case-by-case basis? Can you offer any examples of your plan's care coordination efforts, including successes or barriers?
- 5.2 Does your plan make information about public programs and services for CSHCN and their families (e.g., SSI, DPH, DMH, etc.) available to families? Would you like to receive this kind of information to share with families?
- 5.3 Does your plan offer case management services for CSHCN and their families? Do you have any written information that describes your plan's case management services?
- 5.4 Which of the following specific case management services does your plan provide?
 - Explanation of health insurance benefits, including eligibility for specific plan services
 - Assistance scheduling medical appointments
 - Arranging transportation to health services
 - Help coordinating Primary Care and Specialty Care, including Mental Health Services
 - Help coordinating health services in school with other medical and health services
 - Accompanying families to school or other meetings
 - Information and assistance in obtaining community services or programs outside the plan
 - Help coordinating care received through the plan with services received from state agencies
- 5.5 Is your plan's case management system for children separate from that for adults?
- 5.6 How many children were served by your plan's case management program last year?
- 5.7 What is the background (or training) of case managers serving children and their families?
- 5.8 Are there specific eligibility criteria to receive care coordination or case management services?
- 5.9 Can a parent request case management services for their child with special needs?

Appendix A

6.0 Mental Health & Behavioral Health Services for Children

- 6.1 How does your plan identify and respond to the mental health or behavioral health needs of children?
- Periodic screening of all children for behavioral health needs is plan policy?
 - Mental Health/Behavioral Health Services are not included in the benefits?
- 6.2 What arrangements are made to provide Mental Health /Behavioral Health Services? Are services provided within a specific network of providers? Are services provided through a separate contract/network of providers?
- 6.3 What specific Mental Health/Behavioral Health services are provided?
- Outpatient Counseling (individual and family),
 - Case management
 - Inpatient hospital care
 - Residential (IRTP - Intensive Residential Treatment Program, therapeutic foster care, other)
 - Family support
 - Crisis intervention
 - Aftercare treatment plan in place prior to discharge
 - Respite
 - Assessments
 - Pharmacological services
 - Wraparound services

7.0 Disagreements About Care

- 7.1 What specific procedures does your plan offer to families when they disagree about care decisions for their child?
- 7.2 Do you have written information available for members and their families that describes these procedures?
- 7.3 In what language(s) is this information available?
- 7.4 How is the written information on resolving disagreements made available to members and families?
- 7.5 Is your plan able to collect information about disagreements or appeals concerning children (as opposed to those concerning adults)?
- 7.6 What are the 3-4 most frequent issues of disagreement related to care of CSHCN?
- 7.7 Do you have a way to notify your members about the new Massachusetts Office of Patient Protection or the Managed Care Consumer Advisory Board Ombudsman and their dispute resolution processes?

8.0 Summary

- 8.1 Finally, what are the 3-4 biggest challenges confronting your health plan in serving CSHCN and their families?

Family Advisor Initiative: Contents of Resource Packet



General Information on CSHCN

- *Definition of Children with Special Health Care Needs (CSHCN).*
A definition of CSHCN endorsed by the federal Maternal and Child Health Bureau

Family Voices

- *Family Voices Brochure.*
Information about Family Voices, a national, grassroots clearinghouse for information and education concerning the health care of CSHCN. **For additional information about Family Voices, call 617-236-7210.
- *Beginning the Conversation, Family Voices*
This document is a report of Family Voices' interviews with seventeen managed care organizations in ten states that took place in 1998-1999. **For additional copies, call 617-236-7210.
- *What Do Families Say about Health Care for Children with Special Health Care Needs? Your Voice Counts!! The Family Partners Project Report to Families, Family Voices, Federation for Children with Special Needs & Brandeis University.*
Family Partners, a collaborative project between Family Voices and Brandeis University, conducted a national survey seeking information about the health care experiences of CSHCN and their families. This document summarizes themes identified in the 2,220 family surveys that were completed between March 1998-April 1999. For additional copies, call 617-236-7210.

Family Support: Massachusetts Resources

- *Information about the Federation for Children with Special Needs.*
The Federation for Children with Special Needs is an independent advocacy organization committed to quality education, healthcare for all, and protecting the rights of all children, in particular children with special needs. A brochure and web site information is presented here. **For additional information about the Federation, call 617-236-7210
- *Resources for Families of Children with Special Needs, Family TIES.*
Family TIES (Together in Enhancing Support) is a statewide information and support network for families of children with special needs in Massachusetts. This is the 3rd edition of the Family TIES resource manual for families caring for a child with special health care needs. **For additional copies, please call 1-800-905-TIES (8437).

Family Support: Financing Care

- *Paying the Bills, New England SERVE.*
This document, written by parents of children with special needs, offers tips for families on financing health care for children with special needs. The parent authors have tapped their own experiences, as well as those of other families and professionals, in order to share information and techniques for getting payment for children's health care. **For an additional free single copy, call 1-888-434-4634. For additional multiple copies, call 617-574-9493.

Appendix B

Physician Supports

■ *Practicing Comprehensive Care, Pediatric Alliance for Coordinated Care.*

The Pediatric Alliance for Coordinated Care, PACC, a medical home demonstration project in Boston, was developed to better equip pediatric practices with the support they need to care for CSHCN in the community. This document is a "Physician's Operations Manual for Implementing a Medical Home for CSHCN." **For additional copies, call 617-355-4678.

Defining and Measuring Quality Care

■ *Quality Measurement Projects, National Policy Center for CSHCN.*

This document prepared in May 2000 lists contact information for eighteen (18) projects that are involved with defining and measuring quality care for CSHCN. **For additional copies, call 410-614-5553.

■ *Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs, New England SERVE.*

This document identifies key elements contributing to quality health care for children with chronic illness or disability and their families. **For additional copies at \$10 per copy, call New England SERVE at 617-574-9493.

■ *Quality Health Care Systems & Policies for Children with Special Health Care Needs, Family Voices.*

In this document Family Voices outlines six principles that the organization identified as the foundation for quality health care for children with special health care needs.

Care Coordination & Case Management: Massachusetts Resources

■ *Public Case Management & Care Coordination Programs for Children with Special Health Care Needs in the Commonwealth of Massachusetts: Results of a State Agency Survey, Massachusetts Consortium for Children with Special Health Care Needs & New England SERVE.*

This document summarizes the results of a survey conducted during the winter of 1999-2000 of Massachusetts state agencies offering case management or care coordination services to CSHCN. The goal of the survey was to understand case management and care coordination programs directly run by or overseen by state agencies. A downloadable .pdf version is available on the New England SERVE website at www.neserve.org.

Mental Health

■ *Information from PAL: The Parent/Professional Advocacy League.*

PAL is a statewide network of parents and professionals in Massachusetts who advocate on behalf of children and adolescents with mental, emotional or behavioral needs. Included here is a PAL brochure, a list of related web sites, a sample PAL newsletter, and a list of parent support groups throughout the state.

Family Advisor Initiative

■ *Question and Answer Sheet about the Family Advisor Initiative*

Special Thanks

To the staff from the nine managed care plans who participated in the interviews.

To the family advisors who conducted the interviews: Kathleen Barrett-Lewis, Christine Binkunski, Naomi Chedd, Peggy Curran, Barbara Donati, Beth Fleahman, Linda Freeman, Lavinia Frazier, Lisa Martin, Mary Ann Orlando, Remetrious Pena, Beth Pond, Donna Rocco, and Donna Welles.

To Kathleen Bennett, MD, Medical Director of Boston Medical Center Health Plan, and Deborah Allen, Sc.D., Director, Division of Special Health Needs, Massachusetts Department of Public Health, who participated in a training session for the family advisors.

To the Massachusetts Consortium for Children with Special Needs for their encouragement and support for the critical role of families in assessing the quality of care for CSHCN.

To project staff Betsy Anderson, Peggy Curran and Nora Wells of Family ♥ Voices and Margaret Driscoll, Susan Epstein, Alexa Halberg, and Nancy Turnbull of New England SERVE.

Other information about this project and project reports can be obtained by contacting:

Nora Wells
Family ♥ Voices
@ Federation for Children with Special Needs
1135 Tremont Street, Suite 420
Boston, MA 02120
nwells@fcsn.org
www.familyvoices.org

Alexa Halberg
New England SERVE
101 Tremont Street, Suite 812
Boston, MA 02108
ahalberg@neserve.org
www.neserve.org