Beginning the Conversation:
A Report of Family Voices' Interviews with Seventeen Managed Care Organizations

FAMILY VOICES

At the Federation for Children
with Special Needs
1135 Tremont Street Suite 420
Boston, MA 02120

May 2000

Comment from a Family Voices Coordinator

"*As managed care organizations and insurance companies provide services for our children it is parents' responsibility to continue to educate them on family issues. Our children rely on us. Therefore it is vital that we develop good working relationships with insurers. How can we do this? We can:*

- *tell them when they are doing a good job*
- *help them include us in the change process as industry standards evolve*
- *share with them our views of areas of need in the future*
- *help them develop relationships with families who can discuss changes needed in areas such as: home care services, durable medical equipment issues, health- education coordination, and specialty referrals."*

Introduction

More than 177 million Americans[1,2] now receive their health care under managed care arrangements, though the number of children with special health needs who do so is unknown. While managed care began in the private sector of health insurance, it is now quite prevalent in the public sector as well. Many state Medicaid programs contract with managed care organizations to include "vulnerable populations," such as children with special health needs, in managed care plans. Accompanying these changes, families, providers and advocates have been concerned about how children with special health needs are faring under these new systems of care.

With these concerns in mind, Family Voices conducted a study in 1997-1998 of 2,220 families about the health care experiences of their children with special health needs. A collaborative project with the Heller School at Brandeis University, the study was based on a survey, entitled *Your Voice Counts!!,* referred to in this report as the *Family Survey*. To collect further information about health care for these children, Family Voices initiated interviews with managed care organizations. Through our network of State Coordinators, who are parents of children with special health needs, Family Voices conducted 17 interviews with managed care organizations in 10 states. The questions from the *Family Survey* informed and enriched these discussions with the managed care organizations. Information collected from these interviews is summarized in this report.

What was the purpose of the family interviews with managed care organizations?

We had three purposes in having Family Voices Coordinators conduct interviews:

- To collect information from plans about policies and practices in areas of special importance to children with special health needs and their families.
- To collect and share information about good ideas, interesting policies, and exemplary programs from these managed care plans – while maintaining confidentiality for participating plans.
- To initiate constructive relationships between managed care plans and Family Voices leaders around the country.

How were the interviews conducted?

- Family Voices Coordinators arranged and conducted the interviews with staff from managed care organizations in their states. Each interview team consisted of two parents, at least one of whom was a Family Voices State Coordinator. Family Voices Coordinators are experienced parents of children with special needs, leaders in children's health care and actively involved with parent and family organizations in their states. They are familiar with issues and resources for children with special health needs and their families. Some work in parent centers, some are paid consultants to state Title V programs, some work from their homes. Most Family Voices Coordinators are volunteers.
- The participating managed care organizations reflected a variety of types of plans, including regular commercial insurance and insurance for self insured groups. All but two plans also had contracts with state Medicaid agencies to provide managed care to Medicaid-eligible individuals and families. One insurer offered care to military personnel and their families.
- Seventeen interviews took place in 10 states, between December 1998 and January 2000; 13 in person and 4 by conference call.
- Family Voices Coordinators most often contacted case management or medical directors at the plans to initiate the interviews. Plans determined how many and which of their staff would attend the interviews. Seven plans involved one staff person from the plan; the other ten plans included two to six staff. Participating staff from managed care organizations included medical directors, case management staff, directors of quality improvement and member services, Medicaid managers, medical resource managers, case managers and in one case a lawyer and in another a plan's chief executive officer.
- The questions asked addressed areas such as: identification of children with special health needs and capacity to serve them; collaboration with families; primary and specialty care assignment and referral; coordination; disagreement between plans and families; and definitions of medical necessity and habilitative care. A full list of questions appears at the end of this report.
- After the interviews, Family Voices Coordinators summarized the discussions and sent them to the plans for their review. At their request, plan names are not included in this report. At a later date Boston staff followed up with the Coordinators to learn of any further activities with the managed care organizations that had occurred as a result of the interviews.
- The information collected from these interviews represents examples of what some plans are doing, but may not be representative of all managed care plans that serve children with special health needs. The plans interviewed were not chosen in a systematic way. The discussions between plan staff and Family Voices Coordinators, although structured by a consistent set of questions, sometimes focused on aspects of a particular product but might not have applied to all of their products. The plans had the opportunity to review written summaries of the interviews, however no effort was made to independently confirm their responses.

Questions asked and what we learned

Family Voices Coordinators used a semi-structured set of seven questions to collect information on topics of special interest and concern for children with special health needs, developed by Family Voices staff and Coordinators. Some questions were open-ended and included follow up questions. Coordinators also inquired about programs and policies of special benefit to children with special health needs and their families. Below is a summary of responses from the 17 plan interviews, along with a brief explanation of why we thought the topic was important, and relevant findings from the *Family Survey*. Highlights and interesting ideas from the managed care plans are noted in the boxes.

1. Can these plans identify children with special health care needs?

Why
we asked

The capacity to identify children with special health needs is important in order to plan programs, provide specialized services, evaluate satisfaction with care, and track health outcomes.

What
plans said

- While most plans, 15 of the 17, said they could identify some children with special needs, over half qualified their plan's response. One plan said it could not identify such children; and one plan representative simply did not know whether the plan had this capacity.
- A number of plans indicated that their ability to identify children with special needs is required in their contracts either with Medicaid or Title V, but that it only applies to children served under those contracts, and not to children with special needs served under their commercial plans.
- Plans that qualified their answers, nine, said they were only able to identify children with special needs in limited ways, such as: children who are recipients of SSI or through hospital use information, school district information, pharmaceutical use, or other ways.

⊙ *One example of how a plan identifies children with special needs is by sending out a pediatric health risk assessment form to be filled out by all new members.*

⊙ *Another example is a plan that has been actively engaged with Title V and other agencies to develop a system to identify children using the federal Title V definition*[3]*, the International Classification of Diseases Codes (ICD-9)*[4]*, the Questionnaire for Identifying Children with Chronic Conditions (QuICCC)*[5] *and the Questionnaire for Identifying Chronic Conditions - Revised (QuICC-R.) When ready, this plan will enable children to be identified, their physicians notified and given support and financial incentives, and a plan of care developed.*

2. How do these plans ensure their capacity to provide care for children with special health needs?

Why
we asked

Children with special health needs typically require healthcare and related services in kinds and amounts beyond those of other children. Primary care providers and specialists with the skills and experience to meet their needs are very important to their care.

What
plans said

- Many plans described broad networks of health care providers and hospitals. Some plans said they had few or no restrictions for physicians and that any with proper credentials could join. Many said they contracted with most or all major hospitals in the states or areas they serve.
- Some plans mentioned that they followed quality guidelines from organizations such as the American Academy of Pediatrics, the National Council on Quality Assurance[6], and Milliman and Robertson[7].
- Nine plans said they offered some training such as periodic in-service meetings where children with special needs was sometimes a topic. Several plans also mentioned that they sent newsletters to providers that might include articles on topics such as asthma or diabetes management.
- Several plans also mentioned that they had a special treatment focus, typically for conditions like diabetes or asthma, that affect large numbers of children or adults.
- Seven plans said they did not offer any specific or formal training for providers, just individual technical assistance as needed.
- On the other hand, a number of plans highlighted the training they provided for their case management staff, especially those in specialized case management programs, which often serve families of children with special

⊙ *"…There's no restriction for adding providers – [our state] is very rural with limited providers so everything is done to contract with all qualified providers,"* reported one plan.

⊙ *"…We set up educational conferences for providers and have Title V and other community resource groups present. We frequently produce educational programs on how to access and utilize the programs."* reported by a plan

What
families said

In the *Family Survey* most families said their plans provide access to quality hospitals and skilled primary care providers and thought their plans offered skilled specialty doctors. However, families rated less highly their access to other types of specialists such as skilled and experienced physical, occupational and speech therapists, as well as how the plan is doing on approving specialty care, paying for 2nd opinions or paying for out of network services. The more managed the child's plan, the lower the ratings parents gave the plan on all these questions.

3. What is the process for assignment and referral to primary and specialty care for children with special health needs in these plans?

Why
we asked

Under managed care arrangements, the primary care provider usually has a key role in determining the kinds of care children receive, including referrals to specialty care and services. Primary care providers' knowledge and experience with children with special health needs is, therefore, extremely important. With the current emphasis on cost containment, there are concerns that managed care practices may limit access to specialty care and services.

What
plans said

- *Selection of primary caregivers*. In nearly all plans interviewed, 16, parents are allowed to select the primary caregiver for their child from a list of approved providers.
- *Who can provide primary care*. All plans, 17, said pediatricians qualify as primary care providers; 13 said specialists also qualify, most often by special request, or only for some children. Four plans specifically said specialists do not qualify as primary care providers under their plans. Most plans also mentioned others who can provide primary care, such as family practice providers or physician's assistants.
- *Standing referrals for specialty care*. Thirteen plans said it is possible, at least for some children, to obtain standing referrals for specialty care. Two plans said it was not possible; one respondent did not know; and one plan does not require referrals for specialty care.

- ⊙ *One plan reported that they had regional management teams that consult with local providers to make clinically appropriate services available.*
- ⊙ *One plan reported that they have developed an electronic - "paperless referral" - system that reduced paperwork, time and money and was easier for the patient.*
- ⊙ *One plan reported that they had a health excellence program to allow access to national experts, out of network, depending on the complexity of the case.*

What
families said

In the *Family Survey*, over three quarters of responding families reported that they chose their child's most important doctor. Forty-five percent of the families said that their child's most important doctor was a specialist. In open ended responses, a number of families spoke of the hassle of needing to continually ask for referrals for specialty care. Among those families who reported problems getting specialty services - access to providers with the needed skill and experience, and access to adequate amounts and kinds of specialty care were among the most frequently reported problems.

4. In these managed care plans, what practices, policies, or activities encourage collaboration with families of children with special needs?

Why
we asked

In many settings families have become active participants, helping to shape care and services for their own and other children. Children's hospitals, Title V programs and other agencies have developed a variety of opportunities and methods to reach out to and involve families in policy and program development. Advisory boards and committees are important vehicles for families to learn about an organization, and often provide opportunities to share family insights, concerns and resources in order to improve services.

What
plans said

- *Advisory boards*. Eight plans said a family of a child with special needs was a member of an advisory board for their plan.
- *Separate advisory board or subgroup for families of children with special needs*. One plan said they had such a group; another said one is planned.
- *Involvement of parents of children with special needs with in-service education for plan staff*. Four plans indicated some family involvement with in-service education; eleven did not; and two did not know.
- *Parents of children with special needs hired for their expertise as parents.* While no plans interviewed said they hired parents, one plan said that parents on their board were paid as consultants for their time.
- Eight plans indicated that they offered "some" or "a little" training for families. Most indicated that training and support were one-on-one activities, and were typically provided by primary care providers or case managers.
- Only a few plans said they offered substantive training or support activities for families. These were usually targeted to conditions such as asthma or diabetes.
- While many plans mentioned efforts to build personal relationships with individual families, such as those developed during the provision of case management, few plans mentioned substantive relationships or roles for families in shaping programs or policies for their plans.
- Most plans did not mention that they had active connections to parent organizations.

⊙ *In one interview, the Family Voices Coordinator noted the willingness of staff in the managed care organization to serve on community advisory committees. In another plan social workers and some nursing staff attended the annual conference run by the state parent to parent organization.*

⊙ *One plan reported that they had met twice, at the request of advocates, with those involved with the care of children with a specific diagnostic condition to discuss family and physician issues related to treatment and coverage.*

⊙ *One plan reported a system to "trade or exchange benefits" in order to get services for a family. Case managers work with the family, allowing a child to receive more of some services instead of others. A letter of understanding acknowledges that these benefits are beyond contracted coverage.*

What families said

In the *Family Survey*, families most often indicated that they had few opportunities to advise plans. Furthermore, most parents gave a low rating to their plan, or did not answer at all, when asked questions about how the plan was doing on offering parent support groups, providing information about resources outside the plan that might be useful, or providing information or newsletters about issues of interest for families.

5. How do these managed care plans coordinate care and services for children with special health care needs and their families?

Why
we asked

Coordination is often a complex area for children with special health care needs, due to the number and kinds of services they require and the number of providers and payers typically involved. For care coordination to work effectively, providers must understand the services and procedures of other service providers and communicate this information to families in ways they can understand and use.

What
plans said

- *Case management or care coordination services for children with special health needs and their families*. Fourteen plans said they offered such services. Many plans highlighted these services, saying that case management offered flexible, creative ways to fill gaps and to individualize care for children and their families.
- *Criteria for case management services*. Most said eligibility for case management services was quite fluid and open. Very few said they had specific criteria.
- Plans said they coordinated with:

  Other insurance plans - Virtually all plans indicated that they work with other insurers or payers to coordinate benefits.

  Schools and *Early Intervention Programs* (services for children with special needs, ages birth through age three) – Plans indicated that they coordinate with schools in a number of ways, such as: school health clinics, Individualized Education Plan (IEP) meetings, or with particular staff at schools such as nurses or therapists.

  Title V Programs – Three plans mentioned that regular relationships with Title V programs are written into their Medicaid Managed Care contracts. Other plans mentioned that these relationships with specific health department programs in their states helped them to fill service gaps for children.

⊙ *One plan described its multi-tiered care coordination services. The initial coordinator provides basic information, a second resource person helps educate members about plan benefits and assists them in accessing various educational programs and community resources. On another level, a more specialized nurse is trained to help patients and families find resources in the community and state.*

⊙ *Another plan described their family advocate, a person who can go to the family's home, see the child and family interact and view circumstances firsthand. The advocate can set up a conference call from the child's home and get the case manager to okay services or items over the phone.*

- ⊙ *The case management team at one plan met routinely with schools and early intervention programs. The plan developed policies regarding rehabilitation, PT, and other services. Another plan employed a specific staff person to talk with the neonatalogist about children being discharged from the NICU who needed early intervention services.*
- ⊙ *One plan had a memo of understanding with the Title V, Children with Special Health Care Needs Program that included routine checks on whether children were being served and referred to Title V .*
- ⊙ *In another plan, a new program had been set up in which the plan contacted foundations representing specific diagnoses, such as the American Heart Association or the Epilepsy Foundation and passed on information about support groups and educational opportunities to families.*

What families said

In the *Family Survey,* of the 49% of families who said that they had case management services, only 11% said the case manager they relied on most worked for their health plan. Most said their most important case manager worked for a public agency such as Title V or Early Intervention. While families emphasized how important case management or care coordination was when it worked for them, many families were dissatisfied or critical of the coordination they received, stating they did most of the coordination themselves.

Over half the families gave their plans low ratings on providing clear information about benefits covered by the plan, and information on how to access plan benefits. Many added comments about their frustrations with lack of coordination and information on how to get the services their child needed. They also described significant gaps in communication between providers and other service systems in the community. Many families had more than one payer for a number of special services, adding complications and stress when there were not clear agreements as to who would pay.

6. What procedures are available when these managed care plans and families of children with special needs disagree about care decisions for children?

Why
we asked

Because families of children with special needs are so involved in their children's care and because their children need specialized care and services frequently, questions and complaints are likely to arise more often than for other subscribers in a plan.

What
plans said

- *Written information about grievance procedures*. All 17 plans said written information was available to families, either when a family enrolled or when they requested it. Many plans mentioned that this information was sent when a family filed a complaint.
- *Appeal and grievance procedures*. Nearly all plans, 16, said they had formal appeal procedures; in most cases this is law in their states. (One plan did not know.) Some plans offered patient advocate services. Only two plans, however, said they offered mediation procedures.
- *When asked the 3-4 most frequent areas of disagreement between families of children with special health care needs and plans, plans indicated that they are:*
    - Out of network requests (7)
    - Home nursing, requests for extended home nursing hours (6)
    - Denial or reduction of services (4)
    - Durable medical equipment (4)
    - Other items mentioned were: balance billing, coordination of benefits (who should pay), requests for unproven procedures or alternative medicine, cosmetic surgery, lab services and locations, dental care, therapies, nutritional supplements, maintenance therapies, custodial care, and ER visits.

⊙ *In addition to formal, written complaint procedures, a plan reported that there is also a verbal process, handled differently. The plan will soon have an external review process that will be binding, consistent with NCQA*[6]*.*

⊙ *A plan reported that they have a "problem resolution committee" with external representatives.*

What families said

More than a third of families in the *Family Survey* said they had called or written their plan in the previous year with a problem or complaint and a quarter said they had asked for an exception to policy from their plan. About half were not satisfied with the resolution of their complaint or request. More than half of the families gave their plans low ratings to a question about providing clear information about how to file a complaint.

The areas mentioned by plans as areas of frequent disagreement were very similar to those families reported as problems. Of families receiving home health care, 48% reported problems. Denial and reduction of services and out of network requests were frequently mentioned by parents as problems. Almost half of families whose child needed durable medical equipment said they were dissatisfied or needed but did not get the equipment. Families needing home health, mental health and therapy services reported the most problems in the *Family Survey.*

7. How do these managed care plans determine medical necessity and distinctions between habilitative vs. rehabilitative care?

Why
we asked

Medical necessity is a term used by many health plans to determine which services they will cover for an individual. While plans nearly always have guidelines for the rehabilitative services they cover, some may not define or cover habilitative care. (Rehabilitation generally refers to care and services that assist an individual to regain skills they previously had, perhaps prior to an illness or injury. The term habilitation is used to define similar services, especially those needed by children, to develop and maintain skills.)

What
plans said

Medical Necessity

Even with definitions and procedures, plans commonly mentioned that they face gray areas in making decisions about medical necessity. Several mentioned that ultimate decisions rest with the plan's medical director.

- A number of managed care plans mentioned that they follow state laws or procedures spelled out in their contracts with Medicaid. (It should be noted that Medicaid definitions of medical necessity vary from state to state. Also, as previously mentioned, managed care plans covering those eligible for Medicaid typically also provide coverage for other children and families and may use different standards of care for each category.)
- Many plans referred to their own definitions and standards for medical necessity, including written policies.
- Some plans also referred to other national standards for medical necessity.
- One plan said it no longer uses a definition of medical necessity, but relies instead on the benefits listed in their certificate of coverage.

Habilitative/Rehabilitative Care

- A small number of plans indicated that there are no restrictions regarding habilitative care
- Two said they follow EPSDT (the Medicaid term for Early and Periodic Screening, Diagnostic, and Treatment Services for enrolled children), which is generally interpreted to cover habilitative care.
- Other plans mentioned some of the complexities in determining coverage for these services.
  - There must be "significant improvement" or the need must meet medical necessity guidelines.
  - One plan said it defines "habilitative" as maintenance care, which they do not cover.

- ⊙ *A written definition of "medical necessity" appears in one plan's member handbook.*

- ⊙ *One plan respondent described some of the issues with terms and definitions:*
  - *the custodial care definition can limit some services*
  - *problems come up when defining developmental disabilities*
  - *there are limitations on the number of sessions covered, for instance for OT, PT, speech*
  - *many habilitative services are not covered*

- ⊙ *"We are always looking for the smallest gains we can possibly eke out of a case. The slightest things, smallest gain in function, and consider those to be huge progress. Same is true for rehabilitation, looking for maintenance. The fact that you are maintaining is a gain in and of itself."*

Comment from a managed care plan respondent

What families said

In the *Family Survey,* families mentioned numerous issues with habilitative and rehabilitative services. About a quarter of the families receiving therapies identified problems getting occupational, physical and speech as well as other therapies. For most of these therapies, families reported a number of payers, including health plans, schools and families themselves, and many expressed frustration with the complexity of getting these numerous payers to coordinate and agree on who would pay what portion of the costs. In open ended comments, some families made specific comments about children being denied services because of insufficient progress, or belief that the child would not progress.

In Conclusion

Many participating family leaders and staff from managed care plans indicated that these interviews provided a very helpful opportunity to meet and discuss issues for children with special needs. Over the years families of children with special health needs have learned that establishing partnerships with professionals who work with their children is a key strategy for improving care and services. While there have been notably few collaborative activities between families and health insurance programs, opportunities to increase such collaboration should be actively supported to improve care. Based on information collected in these interviews and from the *Family Survey,* Family Voices makes the following suggestions for ways to improve services for children with special health needs in managed care plans.

1. All plans should have a way to identify children with special health needs in order to adequately serve these children and monitor their care.

2. Managed care plans should use standardized definitions and tested and recognized tools to identify children with special health needs in order to ensure comparable, quality information, across plans.

3. Standards required through state Medicaid contracts should be widely known and used. Many contracts provide examples of important safeguards to ensure quality care for children with special health needs.

4. To ensure equity, similar guidelines and practices for both Medicaid and non-Medicaid eligible children should be used whenever possible, for all children served by a plan.

5. Plans should extend their systems of outreach, tracking and treatment developed for those with high incidence conditions, such as diabetes and asthma, to those with low incidence conditions, since children's special needs are typically low incidence.

6. As national standards of care and quality measurement tools become widely used, they should contain specific standards for children with special health needs.

7. All those providing care for children with special needs, including those who staff managed care plans, should be knowledgeable about community and local agency resources.

8. Providers must have the time, knowledge and resources to communicate with other service providers and systems in order to serve children with special health needs effectively.

9. Training for plan staff who work with children with special health needs, especially for case managers, should be linked with training provided by Title V, Children with Special Health Care Needs Programs, as well as other agencies and service systems, in order to improve the coordination of care for these children.

10. Care coordination services provided by managed care plans should be linked to other care coordination programs such as those from Title V or Early Intervention programs, so that families really do receive coordinated care. Plans and other service systems should involve families in planning, developing and evaluating coordination services.

11. Plans should provide families of children with special health needs clear information about: plan benefits; how to access covered services; complaint and appeal procedures; and special features intended for or likely to be needed by children with special health needs or their families.

12. Plans should permit specialists to be primary care providers and should allow standing referrals to specialists when needed for children with special health needs, since specialty care is of great importance to these children.

13. Plans should monitor what families know about special features of a plan that are important to children with special health needs, such as referrals to specialists, case management programs, or others. Plans should also monitor how easily families can follow plan procedures.

14. Plans should monitor the most frequent problem areas families of children with special needs experience. They should ensure that families are given clear information about how plans make decisions about such services. Plans should work with other agencies and service systems to address problem areas, whether through the plan itself or through other community resources.

15. Opportunities for families of children with special needs to advise plans and help shape programs and policies that directly affect families should be part of every plan.

Appendix: Interview Questions

1. Does your plan have a way to identify children with special health care needs?

a. If Yes: What definition is used?

b. If Yes: Who/What method does your plan use to identify children with special health care needs?

c. If Yes: How is such an identification used? For example what administrative or other procedures does such an identification trigger?

Optional Question: What happens when a child already covered by the plan becomes a child of special needs (through illness or accident)?

Optional Question: What is your policy on pre-existing conditions, i.e., when a family with a child with special health care needs joins a plan?

2.How does your plan ensure its capacity to treat children with special health care needs? *Please expand on the following points:*

a. Staffing or provider network *(i.e., tell us here about how you determine the numbers and kinds of pediatric providers, including the specialty doctors and therapists, and the numbers and kinds of specialists offered by your plan)*

b. Hospital Network *(Tell us about the network of children's hospital providers associated with the plan and how it is determined.)*

c. Do you have guidelines for how and when the plan may change their provider networks and/or location of services?

Optional Question: What happens when providers leave your network? Do you provide opportunities for families to stay with a provider (who is now out of the network) to ensure continuity?

d. Does your plan provide specific training about children with special health care needs and their families?

e. Does your plan provide support services or consultation for staff and for families of children with special health care needs?

3. How are children with special health care needs assigned to primary care providers?

a. Who can be a primary care provider?

b. Beyond primary care, what are the roles and responsibilities of a primary care provider in your plan?

c. Is it possible for a child with special needs to get standing referrals to specialists or other simplified method for access to specialists?

d. If Yes: *Please tell us about how this works.*

Optional Question: Can a child's primary care provider change as the child's needs change (i.e., can a child transition from a pediatrician as a primary care provider to a specialist as a primary care provider if their needs change)?

4. Are there any particular practices, activities, or policies of your plan that encourage family/staff collaboration or other innovative ways to involve families, particularly families of children with special health care needs?

a. Does the plan: (Please check all that apply and add comments in the space provided.)

☐ Have an advisory board that includes families of children with special health care needs?

☐ Have a separate group or subgroup of parents of children with special health care needs?

☐ Involve parents in in-service trainings: for example, as participants or as presenters?

☐ Hire parents for their expertise as parents of children with special health care needs?

5. Does your plan have a system to coordinate care and services for children with special health care needs and their families?

a. If Yes: Who coordinates the care for children with special health care needs?

b. Does your plan have case management services for children with special health care needs and their families?

c. If Yes: How does a child get referred for case management?

d. If Yes: Are there eligibility criteria to receive case management?

e. If Yes: What kinds of services does case management provide?

f. Does the plan coordinate with other providers or payers of a child's care outside the plan (such as another health insurance plan, public health programs, schools, etc.)?

g. If Yes: How does the plan coordinate with other providers with different payment source(s)?

6.What specific procedures does your plan offer when families disagree about care decisions for their child?

a. Is written information about these procedures and processes on disagreements available?

b. If Yes: How is this written information on disagreements made available to families?

c. What are the 3-4 most frequent issues of disagreement, particularly as related to children with special health care needs?

7. How is "medical necessity" determined by your plan?

a. Does you plan have any special ways to ensure that "medical necessity" determinations are responsive to children with special health care needs?

b. Do you have specific definitions and/or restrictions on habilitative versus rehabilitative services?

References

References

1. PPO Market Report:1999 Edition. Medical Benefits. Vol. 17, No. 4, February 29,2000.
2. The Interstudy. Competitive Edge 9.1, Part II: HMO Industry Report. Bloomington, MN, 1999.
3. United States Maternal and Child Health Bureau - Division of Services for Children with Special Health Care Needs. Broad definition of children with special health care needs. 1999.
4. 1996 ICD-9-CM, International Classification of Diseases, 9th Revision, Vol. 1-2. Inc Context Software System / Hardcover / Published 1995.
5. Stein RE, Westbrook LE, Bauman LJ. A questionnaire for identifying children with chronic conditions, based on a non-categorical approach. Pediatrics 1997 99:513-21. A shorter version is known as the QuICC-R.
6. National Council for Quality Assurance (NCQA) works to improve the quality of health care by assessing and reporting on managed care through collaborative efforts with states, the federal government, employer and consumer groups, corporations and business coalitions. They are located at 2000 L Street, NW, Suite 500, Washington, DC 20036.
7. Milliman and Robertson, Inc. provides information and analysis on health care plans and practices. They are located at 1301 Fifth Ave, Suite 3800, Seattle, Washington 98101.

For More Information

FAMILY VOICES is a national grassroots organization of families, professionals and friends who care for and about children with special health care needs. Family leaders from around the country organized Family Voices in December, 1992, to ensure that our children's health is addressed as public and private health care systems undergo change in communities, states and the nation. Currently there are over 30,000 Family Voices members throughout the country.

Reports and fact sheets from the Family Survey, *Your Voice Counts!!*, are available from the Family Voices website: www.familyvoices.org.

For further information about the managed care interviews, contact:

Family Voices
PO Box 769
Algodones, NM 87001
Tel: (505) 867-2368
Fax: (505) 867-6517
Email: kidshealth@familyvoices.org
www.familyvoices.org

OR

Betsy Anderson
Family Voices at the Federation for Children with Special Needs
1135 Tremont Street Suite 420
Boston, MA 02120
Tel: (617) 236-7210 X 121
Fax: (617) 572-2094
Email: betsyand@fcsn.org

For more information about Medicaid Managed Care

Since the mid- nineties many state Medicaid programs have encouraged or even required recipients with disabilities and special health needs to join managed care plans. By 1999, 32 states had included children eligible for Supplemental Security Income (SSI) in managed care programs.*

Medicaid agencies in each state determine their own contracts with insurors. In some states, Title V is part of a contract with Medicaid, to help assure quality or care coordination standards. Insurers contracting with Medicaid typically also offer a variety of commercial plans to other individuals or groups.

For further information about Medicaid Managed Care:

*US Government Accounting Office Health Education and Human Services (GAO/HEHS - 00-37), Report Mar, 2000. US GAO Office. PO Box 37050, Washington, DC 20013.

- *Medicaid Managed Care: Challenges in Implementing Safeguards for Children with Special Needs*

Center for Health Services Research and Policy (CHSRP), George Washington University School of Public Health and Health Services, www.gwu.edu/~chsrp:

- *Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts - 3rd Edition,* published in June, 1999.
- CHRSP Purchasing Specifications Project. A series of specifications available or in development for: Pediatrics, Medicaid Services, SCHIP Services, Children with Special Health Care Needs, Child Development, Children with Mental Illness and Addiction, Disorders, Children in Foster Care

Special Thanks
We want to thank staff from the 17 managed care organizations who participated in the interviews with us.

Our thanks to Family Voices Coordinators and their parent partners:
Juno Duenas and Judy Janec, Kim Winter and Reva Guimont, Beth MacDonald and Sheila Donnelly, Carolyn Allshouse and Debbie Harris, Lauren Agoratus and Louise McIntosh, Ruth Walden and Mavis Thompson, Kathy Bachmann and Robyn Kyman, Lyn Thoreson and Megan Oehlke, Becky Adelmann and Lauren Bridge, Dara Howe and Donna Guyton, Maureen Mitchell and Cathy Cook.

Funding Source
The interviews with managed care organizations are funded by the David and Lucile Packard Foundation of California, through a grant to Family Voices, Inc.

Suggested citation for this report:
Anderson, B., Wells, N. Martin, L. (2000). Beginning the Conversation: A Report of Family Voices' Interviews with Seveteen Managed Care Organizations. Unpublished manuscript. Boston, MA: Family Voices at the Federation for Children with Special Needs.