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ABSTRACT

This report discusses the results of a study that assessed the current system of health care for children with chronic conditions in a staff-model health maintenance organization (HealthPartners) setting. The project interviewed 35 parents of children with chronic conditions, completed a financial analysis of 410 children within eight categories of chronic conditions, and conducted a survey of HealthPartners physicians. The data indicate: (1) most families are satisfied with their child's pediatrician and overall health care; (2) while families appreciate the convenience of having a primary care clinic at the site where most medical care occurs, they report their pediatrician often does not have the time and knowledge to act as coordinator for the child's non-medical needs; (3) case management is often mentioned as a desired service by families and physicians; and (4) the majority of children receive physical therapy, occupational therapy, and speech/language services from school, usually the school pays the costs for these services, and they are neither coordinated with nor reimbursed by HealthPartners. Recommendations are made for developing an integrated service system that promotes the overall health and well-being of children with chronic illness and disability, their families, and their communities. (CR)

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Brave New Partnerships:

**Children With Disabilities
Families &
Managed Care**

Acknowledgments

This report is the outcome of a first time collaboration of HealthPartners, a staff model health maintenance organization (formerly known as Group Health, Inc.), through its supporting research organization, the Group Health Foundation, the Center for Children with Chronic Illness and Disability, a national research and training center based at the University of Minnesota, and PACER Center, a parent training and information center. And while this is an unprecedented collaboration, more importantly, it represents a collaboration of a wide variety of people and disciplines who share a common vision: providing family-centered care for children with disabilities and their families. As such, many new relationships have been built that will promote the care of children with chronic illness and disabilities in Minnesota.

From HealthPartners, we acknowledge and thank Barbara Staub, M.D., the director of this project, for her vision and leadership, W. Brooks Donald, M.D., M.P.H., for his skill in bridging with numerous community agencies, Andy Nelson for his constant support and encouragement, Karen Mason for her commitment to families and young people with disabilities, and Kirsten Hase for her work with the complex financial data.

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We also thank Peggy Mann Rinehart who wrote and designed this report and provided all the photographs, along with Linda Pratt, both from the Center for Children with Chronic Illness and Disability, who prepared and revised drafts and provided production assistance. Thanks to Connie Charipar, too, for her print production assistance.

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Executive Summary



HHealthPartners, the Center for Children with Chronic Illness and Disability at the University of Minnesota, and PACER Center completed a nine month planning grant from The Robert Wood Johnson Foundation to understand the range of needs and costs for the pediatric population with chronic illness and disabilities in a managed care environment. They completed:

- *An in-depth interview with 35 parents of children with chronic conditions.*
- *A financial analysis of 410 children within eight categories of chronic conditions.*
- *A survey of HealthPartners physicians to understand their perspective of providing services to young people with disabilities and chronic illnesses.*

In addition, they convened two community working groups—a Parent Advisory Council and a Community Advisory Council.

The political conflict is clear: If HealthPartners provides a more generous or comprehensive benefit package than its competitors, it will cost more and drive out the healthier population to whom the expanded benefit package is unimportant.

The data indicate that most families are satisfied with their child's pediatrician and overall health care. The families, the physicians and the community members participating in this study value relationships with each other. All agree that when physicians, teachers, social workers and the family communicate, the child benefits.

While families appreciate the convenience of having a primary care clinic at the site where most medical care occurs, they report their pediatrician often does not have the time and knowledge to act as coordinator for the child's non-medical needs.

Case management is often mentioned as a desired service by families, physicians, and the Community Advisory Council. While families indicate that their pediatrician is doing a good job coordinating medical care, they also indicate pediatricians are relatively uninvolved with other issues. Case management should represent and advocate for the needs of the child and family in the areas of education, social and community services, in addition to health care.

HealthPartners does not cover all expenses incurred by the family. The costs are currently being underwritten by a

combination of HealthPartners dollars, public program dollars, and the public educational system. The areas where the exact sources of funding are unclear include: case management, physical therapy (PT), occupational therapy (OT), speech and language services, home health/personal care attendant (PCA) services, and to a smaller degree, durable medical equipment and medications.

Most families qualify for, or purchase, supplemental coverage for these services. However, the vast majority of those children receive PT, OT, and speech/language services from school. Usually the school pays the cost for these services and they are neither coordinated with, nor reimbursed, by HealthPartners or medical assistance (MA)/TEFRA* programs.

This underscores the larger public policy issue: Who is responsible for paying for the care of children with special health care needs? If HealthPartners provides a more generous or comprehensive benefit package than its competitors, it will cost more and attract more families with chronically ill children than would normally occur, resulting in a competitive disadvantage.

The data indicate that the school system provides most of the occupational therapy, physical therapy, and speech and language services that this population receives. If the parent survey is representative and schools cover between 60–80% of these services, their annual cost for these 410 children within HealthPartners would be between \$400,000 and \$800,000, two to four times greater than the amount HealthPartners paid for these services over the same period.

HealthPartners, like other health insurance providers, typically bases their benefits on adult, acute, rehabilitative therapies rather than the habilitative needs of children. For adults, PT, OT, and speech/language services are designed to help adults regain function as a result of illness or injury. Since a child often never had the ability, for example, to walk or talk in the first place, they often don't qualify for "rehabilitation." Children with chronic illness or disability

Only two families reported using mental health services, and only two more indicated any problem in accessing needed mental health services.

*TEFRA is a Minnesota program that allows families who have children with chronic conditions to receive Medical Assistance so they can continue to receive care at home. Parents make a monthly contribution based on income.

need habilitation and that needs to be reflected in the benefits language or reflected in the services provided by other community entities.

And, like other insurance providers, HealthPartners has different programs and coverage—different products— for different groups who become HealthPartners members. Defining equality of benefits is illusive.

The parent survey reveals that families' median out-of-pocket expenditures are relatively low, though some families experience high monthly costs. The most significant is a monthly fee for TEFRA services which is based on a sliding fee schedule dependent on service utilization and parental income. There are some co-pays for emergency room visits, medications, durable medical equipment and other areas, but families indicate that these payments are generally assumed by TEFRA or are so small that they don't submit them for reimbursement. A greater impact on family finances comes from non-medical sources such as employment changes, special clothing needs, or changes to the home.

Claims processing also causes concern. Families receive many bills from agencies providing services and there is no easy way for families to determine which bills they have responsibility for, which are covered by HealthPartners, and which need a denial letter from the HMO so that the bill can then be submitted to secondary insurance, Medical Assistance, or TEFRA for payment. In these cases, the public agencies systems and private insurer's systems are often incompatible.

Eighty-eight percent of families say they need help with stress management. Of the families reporting this need, two-thirds report that they have not been able to find needed help. Only two families reported using mental health services, and only two more indicated any problem in accessing needed mental health services. Clearly, mental health support services are needed, and the present system of mental health services is not being accessed to meet that need.

Currently, most non-medical case management occurs through the schools and a common response was that the school case load was far too heavy for careful follow through. Families seemed most satisfied when the case manager knew their child well and was a perceived advocate. Too many case managers and frequent changes in them was a perceived problem. ■

Introduction



Families whose children have chronic illness and disability must interact with at least three huge and often intimidating bureaucracies: the medical system, the human service system, and the educational system. Rarely do these systems share basic information let alone collaborate on behalf of the child.

By the time each family has filled out the forms for each system, established that their child "fits the category" and indeed qualifies for services, the family's and the child's needs are often lost. While maintaining three isolated systems is costly, no one has collected the exact data to understand which systems provide what services and how much they overlap. No one has assessed the costs of the current model of service provision. No one has described current attempts at service coordination nor identified gaps in service delivery from a parent's perspective.

These families and their children, along with those who depend on Medical Assistance, may be among the first to be enrolled in managed care. If we are to design a managed care system that can effectively and efficiently provide care, we need to know the range of needs and costs for the pediatric population with chronic illness and disabilities.

That's why HealthPartners, the Center for Children with Chronic Illness and Disability, and PACER Center, along with numerous community and advocacy groups, have collaborated to propose a project to establish an integrated service system in an health maintenance organization (HMO) for children with chronic illness and disability.

Objectives & Methods



This planning project assessed the current system of health care for children with chronic conditions in a staff-model HMO setting from the perspectives of the provider, the consumer, and community agencies and organizations.

The focus of the planning phase was on children with a broad spectrum of chronic conditions and their families. The project was divided into five components: Parent Advisory Council, family interviews, analysis of utilization and cost data, physician interviews, and Community Advisory Council.

The Parent Advisory Council

The Parent Advisory Council (PAC) met four times to describe their family's needs, experiences with HealthPartners, and problems encountered with coordination with other agencies. Discussion was facilitated by Ceci Shapland, R.N., from PACER Center.

Twenty-four families were invited to participate in the Parent Advisory Council. Each has a child:

- *who has had the diagnosis of a chronic condition or disability for at least a year; and*
- *who has been a member of HealthPartners for at least a year.*

Brian Ashby and his Dad

Families are at the center of finding and giving care to their children.



Of the 24 families asked, 13 participated. Refusals were primarily based on a family's inability to make the required time commitment.

The Parent Survey

The project team made an intensive study of 35 families having a child with a chronic condition through the administration of an in-home parent questionnaire.

Forty-four families, each with a child meeting the same criteria as the above, were randomly invited to participate. Those serving on the Parent Advisory Council were excluded. Thirty-five families agreed to participate for an overall response rate of 80%. The parent survey group is predominantly mid-upper income, college educated, European American.

Participants in Parent Survey By Condition & Age

<i>Diagnosis</i>	<i>Age 1-4 yrs</i>	<i>Age 5-11 yrs</i>	<i>Age 12-20 yrs</i>
Cystic Fibrosis	2	2	2
Cerebral Palsy	2	2	2
Trisomy 21 (Down syndrome)	2	2	2
Muscular Dystrophy	1	1	1
Juvenile Onset Diabetes Mellitus	1	1	1
Myelomeningocele	2	2	2
Autism	2	1	1
Blind/Deaf		2	
TOTAL:	12	13	11

Parent Survey

Participants involved in the survey were randomly selected. These families had children ranging in age from one year to 20 years old with a variety of conditions.

The diagnosis set of cystic fibrosis, cerebral palsy, muscular dystrophy, juvenile onset diabetes mellitus, congenital heart disease, autism, trisomy 21 (Down syndrome), myelomeningocele, blindness and deafness was chosen to represent the spectrum of chronic illness in childhood.

The Pediatrician

Families say the primary care physician as coordinator promotes a close working relationship with children and families. Dr. Staub has been Brian's pediatrician since 1986.



Utilization & Cost Data

Utilization and cost data on children with representative diagnoses, as well as the most expensive children in the HealthPartners system, was obtained and analyzed. The data represent all the claims to which the HealthPartners information system had access.

The study identified all children (a total number of 410) who had been HealthPartners members continuously from November 1, 1993, and October 31, 1994, who were between the ages of one year and 21 years-of-age and who were identified with the diagnosis of cystic fibrosis, cerebral palsy, muscular dystrophy, juvenile onset diabetes mellitus, congenital heart disease, autism, trisomy 21 (Down syndrome), myelomeningocele and deaf/blind.*

The services provided to these children and their families were grouped into 16 categories: hospitalizations, HealthPartners professional visits, out-of-plan professional visits, mental health HealthPartners visits, emergency room visits, HealthPartners urgent care visits, lab/diagnostic services, pharmacy, durable medical equipment, physical therapy, occupational therapy, speech, home health, and other.

Denied claims or services received outside of HealthPartners and not billed to HealthPartners (e.g., school,

*The diagnoses of deaf/blind had to be dropped because they could not be correctly identified by the current information system.

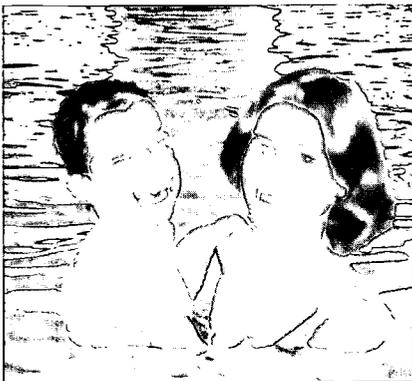
Shriner's Hospital, or claims submitted to another insurance policy) were not represented.

Physician Survey

Physicians from HealthPartners provided their perspectives on the problems and advantages of serving children with chronic conditions in the HMO setting. Twenty-one pediatricians and eight family practitioners from within HealthPartners were randomly selected to complete the written survey. Nineteen pediatricians and two family practice physicians returned the surveys.

The Community Advisory Council

The Community Advisory Council was formed to examine how the system currently functions and to recommend improvements in coordinating services across HealthPartners and other involved agencies, including education and state government agencies. Led by W. Brooks Donald, M.D., M.P.H., 15 representatives from state, advocacy, education, and health organizations were invited and participated in six meetings. In addition, a parent representative, a HealthPartners government programs policy administrator, and three members of the research team attended the meetings. The Community Advisory Council reviewed family needs and interagency barriers within the present system. ■



Recreation

Brian swims every week at Courage Center. Recreation is an important part of maintaining good health for all children, especially those with chronic illnesses or disabilities.

Family Perceptions & Needs



By and large, HealthPartners families are satisfied with their child's pediatrician and overall health care.

They explain that problems arise when services outside HealthPartners must be coordinated. The referral system, in particular, is often cited as troublesome, not so much that it was difficult to obtain access to outside medical specialists, but that the process was cumbersome.

Results from the Parent Advisory Council

The Parent Advisory Council identified two key areas of strength regarding health services.

- *Pediatrician plays a strong central role as medical care coordinator.*
- *Having a primary care clinic where most medical care occurs is convenient.*

They also identified areas that need improvement.

- *Referral process to out-of-plan specialists is cumbersome.*
- *Claims processing is slow and inefficient.*
- *Case management services are lacking.*
- *There is no perceived source for help with behavioral issues or to deal with family stress.*
- *Parents express concern about future health care coverage.*
- *Information about in-plan resources, policies, and benefits is difficult to obtain.*
- *Care coordination among sub-specialists and HealthPartners pharmacies or laboratories is inconvenient.*

Results from the Family Survey

The Family Survey confirmed and expanded on the issues raised by the Parent Advisory Council: Stress is the most significant issue families face. Clearly, mental health support services are needed for families raising a child with a chronic illness or disability. Eighty-eight percent of families report they need help managing stress. Of these, two-thirds report that they have not been able to find needed help. Only two families report using mental health services; only two report problems in accessing mental health services.

Major Child and Family Concerns

Parents Reporting Concerns

	Number	Percentage
Stress Management	31	88.6
Future Planning	20	57.1
Special Education	19	54.3
Entitlement Information	19	54.3
Equipment & Supplies	17	48.6
Finding/Working with Physician	17	48.6
Learning	17	48.6
Social/Recreational Opportunities	17	48.6
Dental	16	45.7
Feeding/Nutrition	16	45.7
Behavior or Emotional	13	37.1
Dealing with Agencies	13	37.1
Finance	13	37.1
After School Care	12	34.3
Communicating	11	31.4
Mobility	10	28.6
House Modifications	9	25.7
Respite Care	9	25.7
Coordinating Appointments	8	22.9
Family Counseling	7	20.0
Parenting	6	17.1

Parents Overall Concerns

The 35 families surveyed report a myriad of concerns. Future planning and special education, in addition to stress management, pose major concerns for parents. Most families report many concerns.

Financing

When asked, "Does your child's condition affect your ability to be employed?" just under one-third (28.6%) said "yes." In fact, the greatest impact on family finances comes from non-medical sources such as employment changes. Often, parents who said that their child's condition did not affect employment made comments like the following:

"Because of his condition, I chose not to work."

"No... I stayed out one extra year because of his heart problems..."

"I didn't think anyone in a day care situation would have done the infant stimulation which I did..."

Clearly, decreased employment limits income and therefore limits the amount of money a family has available to meet the family's needs. Additionally, families report decreased employment also increases or is a source of stress.

All families surveyed received their health insurance through their employer but, in addition, nearly one-half (15 families) received additional benefits through state or federal programs such as TEFRA, SSI, Medicaid, Vocational Rehabilitation, WIC, and family subsidies. Pending loss of these programs due to governmental cutbacks is a major source of parental concern.

HealthPartners covers most direct medical expenses. Families report paying from \$10 to \$42 per month in out-of-pocket expenses. However, the vast array of habilitative services are covered by supplemental coverage or are provided in the school setting.

Families, physicians, and the Community



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Trips to Courage Center

While physical therapy is often provided through the schools, Brian receives additional therapy at Courage Center. HealthPartners pays the bill.

Services and Funding Sources

Services	Number Receiving Services	Health Partners	TEFRA	School	Other
Occupational Therapy	19	3	3	16	1
Physical Therapy	15	5	4	10	1
Speech & Language	13	-	4	10	1
Skilled Nursing	3	1	2	1	1
Personal Care Attendant	12	-	7	2	4
Respiratory Therapy	6	3	2	1	-
Mental Health	2	2	-	-	-
Medication	28	24	11		21
Durable Medical Equipment	12	9	6	-	-

Services

A staff model HMO like HealthPartners does not cover all services for children with chronic illness or disability. Physical therapy, occupational therapy, speech and language services are currently being provided by the school with a smaller portion covered by TEFRA or Medical Assistance. Some children receive services at more than one location.

HealthPartners, like other health insurance providers, typically base their benefits on adult, acute, rehabilitative therapies rather than the habilitative needs of children. For adults, PT, OT, and speech/language services are designed to help adults regain function as a result of illness or injury. Since a child often never had the ability, for example, to walk or talk in the first place, they often don't qualify for "rehabilitation." Children with chronic illness or disability need habilitation and that needs to be reflected in the benefits language.

Advisory Council agree that case management services are desirable. However, some parents said they received too much case management. Often, each agency has its own case managers: school, county, health care provider. These case managers can only advocate for a child in one area or concentrate their case management to serve as a gatekeeper for their agency's resources.

Case management should represent and advocate for the needs of the child and family in the areas of education, social and community services, in addition to health care. ■

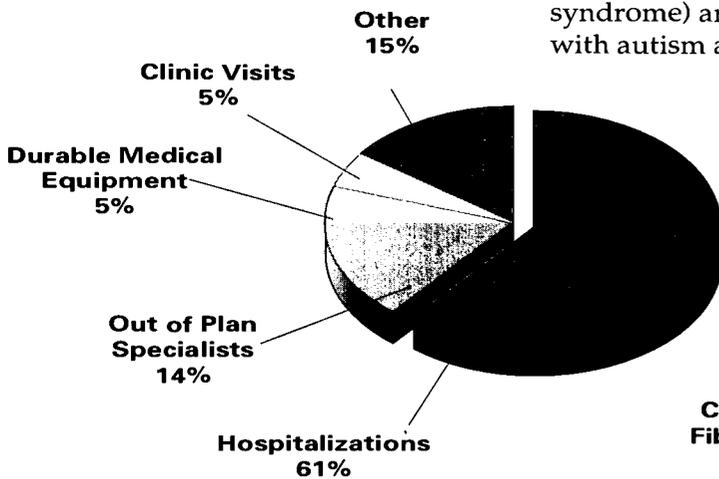
Cost & Utilization Analysis



The annual cost of HealthPartners care to the 410 children meeting the study criteria was just over \$6.2 million. This is an average of \$15,122 per child. Almost two-thirds, or \$4.15 million, was spent on hospitalization. Further analysis shows that the 25 “most expensive” children accrued hospital costs ranging from \$15,633 to \$770,060. Clearly, hospitalization is the single most expensive service provided to children and their families.

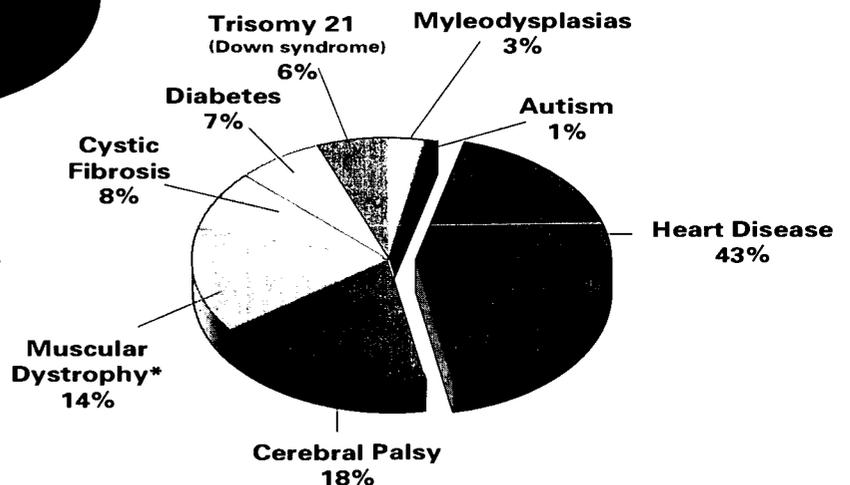
Cost by Expense Category

Clearly, hospitalization is a major reason children and youth with chronic illness and disability are costly. Occupational therapy, physical therapy, medication, outpatient diagnostic or lab work, emergency room visits, speech and language services, those included in the “other” category, represent a lesser expense.



Some disabilities and chronic illnesses like cystic fibrosis, heart disease and, in this study, muscular dystrophy* have a high rate of hospitalization. They are the most expensive conditions for HealthPartners to manage.

Other conditions such as autism and trisomy 21 (Down syndrome) are less expensive for HealthPartners. Children with autism and trisomy 21 require specialized school services and more in-home support. Likewise, there is a range of expenditures among conditions. Children and youth with cystic fibrosis, for example, have no expenses for physical, occupational, and speech therapies. ■



Cost By Disease Category

Conditions associated with a high rate of hospitalizations were associated with a disproportionately high expense.

*One patient with muscular dystrophy was responsible for \$889,861 of the \$961,440 total cost for that condition. If that patient were excluded, muscular dystrophy would fall to the fifth most expensive of the eight diagnoses studied.

Physician Survey



Most physicians in the study say they follow fewer than 20 children with complex medical conditions or physical disabilities. However, they also state that six to 20 percent of their time is devoted to caring for these young people.

Most say they enjoy caring for the child's medical needs. They believe HealthPartners provides a broad benefit package to these children and offers care coordination which is superior to other health care systems. As primary care providers, they feel informed and able to coordinate and guide appropriate care.

Still, the majority believe coordination with other providers, agencies, and schools is time consuming and difficult. The majority say they do not know for sure how equipment, supplies or special services will be paid for, if not by HealthPartners. They also say it is often difficult to locate needed services. Many physicians feel they do not have enough time to spend with complex patients to review sub-specialists' reports, to evaluate medications, and to coordinate care. ■



Physical Therapy

Therapy helps Brian to function at the best level he can. Unlike those children and adults who sustain a physical disability because of illness or accident, Brian was born with cerebral palsy. He has no function to regain.

Community Advisory Council



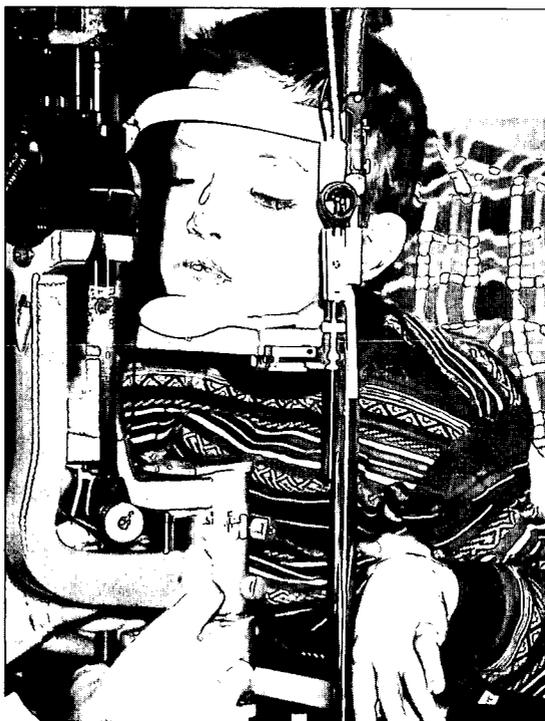
The Community Advisory Council identified problems within the community in order to describe barriers families face. Interestingly, the recommendations from the Community Advisory Council for changes within the HealthPartners system echoed those made by families and physicians.

Case management is important. However, the Community Advisory Council agrees that current case management focuses on management of costs and utilization for the specific agency. Rarely does one work as an advocate for the child and the family. There is poor communication between systems.

The notion of "health care reform" creates anxiety. Agencies protect their "turf," fear budget cuts, and therefore fear collaboration. Families, in turn, are anxious about changing restrictions and eligibility requirements. They fear the loss of programs like TEFRA that have funded critical, often expensive, services. ■

In-Plan Specialists

Brian visits the pediatric ophthalmologist regularly. These visits are part of the HealthPartners benefit package.



Discussion and Recommendations



The families, the physicians, and the community members participating in this study value relationships with each other that are based on mutual respect and trust. All agree that when physicians, teachers, and social workers

communicate, the child benefits.

All agree that:

- *families and providers need to make placement and treatment decisions that support and empower families rather than safeguard agency ideology or funding.*
- *caring for a child with a chronic condition within the context of the family and the community is more successful than simply treating a disease.*

Families report that their greatest stress comes from arranging for multiple services through multiple agencies for their children with chronic conditions. The present study underscores this finding: there is little collaboration among the medical, social service and education communities.

Part of the lack of coordination is due to fragmented funding. While HealthPartners covers most direct medical expenses, there is still debate about who should fund certain health-related services such as durable medical equipment, occupational, physical and speech therapies, home care services—ranging from respite care and personal care attendant services to respiratory care and nursing care. Is this the responsibility of the federal government? The state government? The school system? And we still don't know if the various therapies and family services reduce the overall costs of these expensive children.

Finally, this present study points out that managing the stress that comes with caring for a child with a chronic or disabling condition is the number one concern for most families. Of the eighty-eight percent of families who say they need help managing stress, two-thirds have been unable to find the help they need.

What Can HealthPartners Do?

The Community Advisory Council, the Parent Advisory Council, along with the families interviewed and physicians surveyed, agreed that staff model HMOs like HealthPartners need to develop strategies that promote the overall health and well-being of children with chronic illness and disability and their families. They make the following recommendations to HealthPartners:

1. Expand case management and care coordination so that:

- A care coordinator works with a physician to improve the care the family is receiving;
- A care coordinator investigates resources that are unfamiliar to the physician and the family, and identifies those resources that are most beneficial; and
- A care coordinator links families with community services.

2. Advocate for an industry-wide acceptance of benefits based on the needs of children so that:

- The development of children with disabilities is not stymied by a benefits package based on adult needs;
- Benefits are flexible and allow for individual family and child needs; and
- Benefits are presented clearly and applied consistently across disease groups.

3. Increase the coordination of care within HealthPartners so that:

- Referrals are streamlined for the special needs population;
- Referrals are designated for a specific period of time;

- Claims and billing information are simplified; and
 - At least one member of the claims department is trained to answer questions specifically regarding children and youth with disabilities.
-

4. Provide a special orientation of HealthPartners for families with children and youth with disabilities so that:

- Families understand resources available through the system and how to access them, including continuing care, mental health services, social work services, and case management;
 - Families learn how to appeal the system; and
 - Families feel they are heard.
-

5. Promote the use of mental health services so that:

- Outside consultation is available to families working through the issue of having a child with a chronic condition; and
 - Pediatric health psychologists are available and familiar with the needs and stresses of families.
-

6. Expand the hours of service to help meet working family's needs and minimize loss of school time for the children.

What Can Communities Do?

It really does take an entire community to nurture, care for, and raise our children—especially those with chronic illness or disability. Many of the recommended changes in health care systems and clinical care can be addressed without government or agency edict. Often, all that is required is for professionals, aware of the issue, to make the changes.

The following recommendations address issues that are “external” to specific health care delivery systems and clinics yet are considered essential for a community if children with chronic illness or disabilities and their families are to thrive.

1. Separate agency-focused case management from independent family-centered care coordination.

Families should have access to independent care coordination and family advocacy, that is family-centered, community-based and culturally sensitive.

2. Develop easy access to information, support, referral and advocacy for both families and providers.

- Develop a telephone information service.
- Develop a computer-based information system.

3. Improve communication between agencies and health systems.

- Educate practitioners to plan for and respond to families’ anxiety as systems change.
- Allow for thoughtful and seamless transition when shifting between public and private funding systems.

4. Understand that health care is a market driven enterprise.

- Establish incentives for individual health care systems that reward creative methods of serving children with chronic illness or disabilities.

- Advocate for a safety net of expanded benefits and limitation of cost sharing co-payments for families.

5. Avoid cost shifting.

- Monitor short- and long-term outcomes and costs to all aspects of the system, including the family.
- Encourage creative financial models or pilots that involve more community and family-controlled decision-making.
- Create a health care financing system that encourages competition for serving children with chronic illness or disabilities.

Conclusion

There is agreement that further research is needed in order to develop and test criteria needed to assess the quality of children's health in general and those elements that will result in quality care for children with chronic conditions within managed care environments. Proponents argue that managed care is the optimal setting in which to develop integrated, coordinated, community-based and family-centered services.

Currently, at HealthPartners the medical needs of children and youth with chronic illness and disability are being met with good primary care at the child's home clinic and specialty care covered by the plan.

Some bemoan the pitfalls of applying managed care models to children with chronic conditions; however, this is the first study that takes a hard look at how families with children who have chronic illness and disability and their families are faring. The news is mixed. Families are doing well; HealthPartners clearly provides more coordinated services than a fee for service basis. Still, families are relying on a hodgepodge of financing that may be dramatically reduced in the near future. They are surviving, but families really need access to more information, more interagency coordination, and more preventive mental health services if they are to thrive.

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The **Group Health Foundation** was established in 1990 to conduct public domain research to help improve health care for HealthPartners members and for the community.



The **Center for Children with Chronic Illness and Disability** was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of the psychological and social well-being of children with chronic conditions and their families.

The **National Center for Youth with Disabilities** has the mission of improving the health and social functioning of youth with disabilities through technical assistance and consultation, disseminating information, and increasing services between the health care system and others.





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