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**ABSTRACT**

This packet was assembled to share the contents of an audio conference sponsored by the National Early Childhood Technical Assistance System (NECTAS) on October 1, 1997. The purpose of the audio conference was to identify strategies for improving communication and working relationships with the health care community, including HMOs, to ensure the early identification and referral of young children with special needs to early intervention and preschool services. Presenters included Ellen Hunt Landry, Corinne Garland, Carl Cooley, and Dan Olsten. Approximately 40 people participated in the call and many submitted questions that helped to shape the content of the conference. The packet includes: (1) an audiotape of the complete conference call; (2) copies of the resource materials submitted by the presenters; (3) a list of the presenters; and (4) a list of participants with contact information. (Author/SG)



# Ensuring the Early Identification of Children With Special Needs:

## Strategies for Working With the Health Care Community



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**Ensuring the Early Identification of Children With Special Needs:  
Strategies for Working With the Health Care Community**

**Resource Packet From the NECTAS  
October 1997 Audio Conference**



National Early Childhood  
Technical Assistance System  
Chapel Hill, North Carolina

The National Early Childhood Technical Assistance System (NECTAS)  
is a collaborative system, coordinated by the  
Frank Porter Graham Child Development Center  
at the  
University of North Carolina at Chapel Hill

with

Federation for Children with Special Needs  
Georgetown University Child Development Center  
Center on Disability Studies, University of Hawai'i at Manoa  
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August 1998

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90 Minute Audiotape of the October, 1997 Audio Conference Entitled "Ensuring the Early  
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## Introduction

This package has been assembled to share the content of an audio conference sponsored by NECTAS on October 1, 1997, entitled "Ensuring the Early Identification of Children With Special Needs: Working With the Health Care Community." The purpose of the audio conference was to identify strategies for improving communication and working relationships with the health care community, including HMOs, to ensure the early identification and referral of young children with special needs to early intervention and preschool services.

The call begins with introductions to the topic and to the presenters, followed by:

- presentations by:
  - Ellen Hunt Landry
  - Corinne Garland
  - Carl Cooley
  - Dan Olsten
- question and answer period

Participants who registered for the audio conference received resource materials that were submitted by each presenter to provide topical background information, as well as brief descriptions of the presenters and the content that each would address during the call. Many participants submitted questions that helped to shape the content of the audio conference. Approximately 40 people participated in the call.

This package was assembled to provide access to the content of the audio conference following the call. The package includes the following materials:

- an audiotape of the complete conference call. Although the tape is not studio quality, it does make available the content of the entire 90-minute call;
- copies of the resource materials submitted by the presenters;
- a list of the presenters; and
- a list of participants

NECTAS is providing access to the information to further the development and implementation of strategies for the early identification of children who would benefit from early intervention services.

**NEC\*TAS NATIONAL CONFERENCE CALL**  
**WORKING WITH THE MEDICAL/HEALTH CARE COMMUNITY**

*Wednesday, October 1, 1997, from 2:00 p.m. to 3:00 p.m. Eastern Time*

**PRESENTERS:**

**(affiliations at the time of the conference call)**

**ELLEN HUNT LANDRY**

Ellen Hunt Landry is a parent of a child with special needs who was part of the statewide training team for Caring for Infants and Toddlers with Disabilities: New Roles for Physicians (C-FIT) in Idaho. Ellen will discuss her experiences with the C-FIT project and provide a family perspective on what is needed to make communication and services between the health care and early intervention/preschool communities work smoothly for children and families.

**CORINNE GARLAND**

Corinne Garland is Co-Director of the EEPD Outreach Project of Caring for Infants and Toddlers with Disabilities: New Roles for Physicians (C-FIT) located at Child Development Resources (CDR) in Norge, Virginia. CDR has just been awarded a new grant, Caring for Infants and Toddlers with Disabilities: New Roles for Nurses (CFIT-N). Corinne will describe the activities of her project and strategies for increasing physician participation in the early intervention system through inservice training.

**CARL COOLEY**

Carl Cooley is with the ADAPT Project, Dartmouth Center for Genetics and Child Development, Dartmouth-Hitchcock Medical Center, in New Hampshire, and is a member of the NECTAS Advisory Board. This project's goal is to enhance the capacity of community-based primary care pediatricians and family practitioners to recognize and respond to the developmental concerns of infants, toddlers, and preschool children and their families and to work collaboratively and effectively with community-based teams providing early intervention and preschool special education services. He will describe the approaches the project has taken to achieve that goal.

**DAN OLSTEN**

Dan Olsten is the Early Intervention Coordinator for Harvard Pilgrim Health Care, a health maintenance organization (HMO) in Massachusetts. Harvard Pilgrim works collaboratively with the state early intervention network to provide health services for children with special needs. Dan will describe Harvard Pilgrim's activities and strategies for early intervention and preschool programs to utilize when working with HMOs.



# STRATEGIES FOR WORKING WITH THE MEDICAL/HEALTH CARE COMMUNITY TO ENSURE EARLY IDENTIFICATION OF CHILDREN WITH SPECIAL NEEDS

OCTOBER 1, 1997

*A NATIONAL CONFERENCE CALL*

*ON TOPICS RELATED TO ASSESSING YOUNG CHILDREN WITH SPECIAL NEEDS*

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# STRATEGIES FOR WORKING WITH THE



OCTOBER 1, 1997

A NATIONAL CONFERENCE CALL

ON TOPICS RELATED TO ASSESSING YOUNG CHILDREN WITH SPECIAL NEEDS

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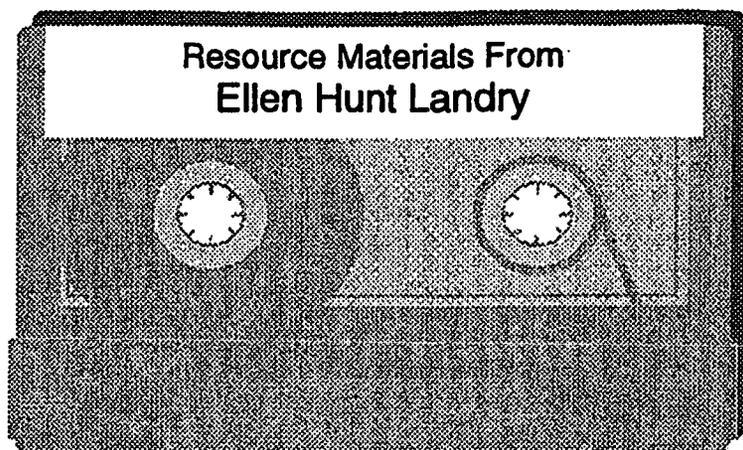
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**Family Voices A National Grassroots Network of Families and Friends  
Speaking on Behalf of Children With Special Health Care Needs  
(English and Spanish)**

**Family Voices Discusses: Managed Care (English and Spanish)**

**Children With Special Health Care Needs in Manged Care: Questions to Ask  
and Answer (English and Spanish)**

**Bibliography on Managed Care and Children With Disabilities**

**The ABC'S of Managed Care Standards and Criteria for Children With  
Special Health Care Needs: A Report From the Egg Harbor Family Summitt**

**Family Voices Alphabet Soup: Health Care Definitions for Children With  
Special Health Care Needs**

## THESE ARE OUR CHILDREN...

Our children with special health needs are, above all, children who want to have a healthy, happy childhood and grow up to be productive adults. Like all children, they live with their families in the towns, cities, and rural areas of the United States, attending school, going to church, and enjoying community events. However, unlike most children, they also have challenging health conditions that usually make their lives and their families' lives more complicated. Some of our children have physical, mental, or emotional disabilities; others live with a chronic illness; many present a brief but life-threatening medical problem. Some of our children need only an accurate diagnosis and routine treatment and monitoring; others will require life-sustaining technology, treatment, and medicines throughout their lives. Children with special health needs tend to receive their health care from a combination of private and public financing and delivery systems. About 10 million children have a chronic health condition of some kind; about four million children have a health condition that limits their school and play activities.▼

## THIS IS WHAT FAMILY VOICES DOES...

Family Voices is a national, grassroots clearing-house for information and education concerning the health care of children with special health needs. We stay on top of public and private sector health care changes that affect our children and families through the collective efforts of our families: a volunteer Coordinator in every state; 10 Regional Coordinators; and a small staff working in several locations around the country. Together, we share the expertise and experiences of families from around the country with state and national policymakers, the media, health professionals, and other families. We work in public and private hospitals, public health programs, in state capitals, in Washington, DC, serving on boards and task forces, working in partnership with health professionals and policymakers, bringing the family perspective to policy discussions and decisions. There are almost 7,000 Family Voices members - families of children with special health needs and friends and professionals who know and love our children.▼

## THE PRINCIPLES OF FAMILY VOICES GUIDE OUR ACTIVITIES...

Above all, Family Voices believes that:

- All children deserve quality health care.▼
- Families with children who have special needs and professionals who work with them have an expert understanding of what works and what doesn't work within current health care systems.▼
- Health systems built upon a set of tested principles and practices that flow from this expertise can improve the health status of all children and families.▼

Therefore, health systems serving children with special health care needs must adhere to the following principles:

1. **Families are the core of any health system.** All families, including those who have children with special health needs, are the primary caregivers and educators for their children. They should be respected and valued for their expertise and commitment to their children.▼
2. **Universal access.** In order for this nation and its children to be healthy, it must guarantee unconditional access to quality primary and specialty health care at a reasonable price - regardless of a family's health, income, employment, location, pre-existing condition, or prior utilization of services.▼
3. **Flexibility.** Whether public or private, a health care system must provide effective, flexible services that are guided by medical and family needs, rather than by the policies of standard medical insurance practices or government bureaucracies.▼
4. **Comprehensive, coordinated, community-based care.** Quality health care means a coordinated system of comprehensive services - prevention, education, screening, diagnosis, primary and specialty care, hospitalization, medication and supplies, equipment, and rehabilitation - all available as close to the family's home as possible.▼
5. **Family-professional partnership.** Outcomes improve when families and professionals make decisions jointly, respecting the expertise, talents, and resources that each brings to the care of the child with special health needs.▼

6. **Cost effectiveness.** By focusing on outcomes, allowing family choice, and strengthening and supporting the role of families in health care systems, costs can be reduced. The elimination of duplicative procedures, unnecessary paperwork, and administrative overhead also reduces costs. As families, we practice cost containment every day!▼

7. **Quality assurance.** Working as partners and remembering these principles, families and health professionals must regularly review and provide feed-back on health care financing and delivery.▼

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## JOIN FAMILY VOICES!

If you want to be part of a grassroots movement to make sure that children with special health care needs receive the health services they need and deserve, please fill out this form and mail it to:

**Family Voices, Box 769,  
Algodones, New Mexico, 87001.**

Although we do not charge membership fees, we do accept donations and promise to put them to good use.

*Note: Our volunteer State Coordinators mail members in their states information from other states and our national office bi-monthly without charge. If you would like to receive the same information directly from Family Voices' national office, please include \$25 for postage and handling. ♥*

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# FAMILY VOICES

P.O. Box 769 • Algodones, NM 87001

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*A national grassroots  
network of families and  
friends speaking on  
behalf of children with  
special health care needs.*

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## FAMILY VOICES

*Una red nacional a nivel de familias y amigos que hablan a favor de los niños  
con necesidades especiales de atención de salud.*

PO Box 769, Algodones, NM 87001 / Td 505/867-2368 / Fax 505/867-6517

**¿Qué es Family Voices?** Family Voices es una red nacional a nivel local de familias y amigos que hablan a favor de los niños con necesidades especiales de atención de salud. Somos familias de todas partes de los Estados Unidos, que tenemos niños con necesidades especiales de atención de salud. También somos cuidadores, profesionales y amigos cuyas vidas han sido tocadas por aquellos niños y sus familias. Somos un grupo diverso, representando una amplia variedad de niños, condiciones de salud, familias y comunidades. Las familias que fundaron Family Voices son padres que desarrollaron redes familiares estatales y nacionales, y organizaciones para mejorar los sistemas de salud y educación que sirven a nuestros niños. Nuestra preocupación por nuestros niños y su necesidad de atención de salud apropiada y accesible, nos ha llevado a juntarnos. *Los niños con necesidades especiales de atención de salud son aquellos que están en o tienen un riesgo elevado de condiciones emocionales, conductuales o de desarrollo y que requieren atención de salud o servicios relacionados de un tipo o una cantidad más allá que la que requieren los niños generalmente (obtenido de Work Group Draft Definition, 1/95).*

**¿Quiénes Son Nuestros Niños?** Nuestros niños con necesidades especiales de atención de salud son primero y sobretodo niños - una de las formas de expresiones de la vida, cada uno con sus propios talentos para dar y necesidades para ser atendidas: niños que tienen el derecho a crecer con sus familias, en sus comunidades, seguros en el conocimiento de que son amados y cuidados incondicionalmente. Nuestros niños requieren las mismas cosas que todos los niños necesitan - una oportunidad para desarrollar y completar la promesa de sus propias vidas. Sin embargo, a diferencia de la mayoría de los niños, nuestros niños también tienen condiciones de salud desafiantes. Algunos tienen discapacidades físicas o mentales; otros viven con una condición de salud crónica; muchos presentan un problema médico breve pero amenazante para la vida. Algunos necesitan solo un diagnóstico preciso y supervisión de rutina; otros necesitan tecnología para mantener la vida, tratamiento y medicinas durante toda la vida. Todos tienen un impacto en sus familias, en las personas que les proporcionan atención de salud, en sus sistemas escolares y en sus comunidades.

**¿Qué hace Family Voices?** Family Voices cree que los niños con necesidades especiales de atención de salud necesitan enfrentar problemas comunes causados por imperfecciones fundamentales en nuestros sistemas de atención de salud. Nuestra meta, es por lo tanto, ayudar a formar políticas de atención de salud locales, estatales y nacionales, y prácticas en los sistemas de atención de salud públicos y privados:

- apoyando a redes de coordinadores voluntarios regionales y estatales que propocionen información precisa y oportuna a familias y creadores de políticas;
- asegurando que los creadores de políticas tengan acceso a información confiable desde las familias que están experimentando las imperfecciones de nuestro sistema de atención de salud diariamente;
- sirviendo como una oficina de compensación que recolecte información desde una amplia variedad de fuentes, y que desarrolle y distribuya documentos de trabajo, boletines y hojas de información para ayudarnos a todos a estar informados sobre los asuntos de atención de salud.
- formando sociedades con profesionales y con otras organizaciones nacionales y estatales, para asegurar que las voces de las familias sean escuchadas y las necesidades de nuestros niños se cumplan;
- utilizando la experiencia de nuestro nivel local - cientos de familias en cada estado - para informar, dialogar y compartir sabiduría a través de los estados.

**¿Qué guía a Family Voices?** Durante los últimos diez años, familias y profesionales han establecido un conjunto de principios que creemos que deberían ser la guía para la realización de políticas que afectan a los niños con necesidades especiales de atención de salud. Estos principios son:

- la atención de salud debe estar centrada en la familia, así las familias pueden criar a sus niños con necesidades especiales de atención de salud en el hogar.
- la atención de salud debe ser basada en la comunidad, global, coordinada y culturalmente sensible.
- la atención de salud debe consistir en una colaboración entre las familias y los profesionales de la atención de salud.
- otros servicios y sistemas que utilizan nuestros niños deben apoyar los principios de estar centrados en la familia.

**¿Cuántos Niños Tienen Necesidades Especiales de Atención de Salud?** Mientras la mayoría de los niños con necesidades especiales de atención de salud pueden, con apoyo apropiado, vivir vidas regulares con sus familias en sus comunidades, por lo menos un 6% de los niños Americanos (alrededor de cuatro millones), tienen limitaciones en sus actividades y requieren atención especializada y apoyo. Utilizando la definición provisoria (draft definition, 1/95), es posible que tanto como un tercio de los niños Americanos tengan una necesidad de atención especial de salud en algún momento de sus vidas.

**¿Qué queremos decir por Familia?** Todos provenimos de familias. Las familias son grandes, chicas, extendidas, nucleares, multi generacionales, con un padre, dos padres y abuelos. Vivimos bajo un mismo techo o bajo varios. Una familia puede ser tan temporal como unas pocas semanas, o tan permanente como para siempre. Nos hacemos parte de una familia por nacimiento, adopción, matrimonio o por el deseo de apoyo mutuo. Como miembros de una familia, nos nutrimos, protegemos e influenciamos unos a otros. Las familias tienen fuerza que fluye desde miembros individuales y desde la familia como un todo. Cada familia es una cultura en sí misma, con valores únicos y su propia forma de realizar sueños. Juntas, nuestras familias son la fuente de nuestra rica herencia cultural y diversidad espiritual. Nuestras familias crean vecindarios, comunidades, estados y naciones!

Si Usted desea permanecer en contacto con Family Voices y ser parte de este esfuerzo estatal y nacional, por favor complete ésto y envíelo a: Family Voices, Box 769, Algodones, NM 87001. Gracias!

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 Dirección: \_\_\_\_\_  
 Ciudad: \_\_\_\_\_ Estado \_\_\_\_\_  
 Código Postal (Zip) \_\_\_\_\_ Teléfono \_\_\_\_\_

1 Adaptado de una declaración preparada por New Mexico Coalition for Children, Youth and Families y New Mexico Children's Continuum, 1990



### Family Voices Discusses: MANAGED CARE

Once the words "health reform" were on everyone's lips. Now we hear about "managed care." What is managed care? Is it health reform? Is it good or bad for children with special health care needs? Although "managed care" means different things to different people, Family Voices will try to describe briefly what most people mean by managed care. Please send us your concerns about this topic so that we can provide more information over the next few months.

**What Is Managed Care?** Managed care is a way of providing pre-paid health care within a network that includes a specified group of health care providers and services. The network coordinates and refers patients to its health providers and hospitals, and monitors the amount and patterns of care delivered, the cost of care, and its quality. Managed care differs from traditional "fee for service" plans in which patients choose their doctors and other related services and pay for each service. Managed care plans usually limit which services patients may receive by having physician visits, therapies, home-care, pharmacies, specialists, clinics and hospitals available within their own system, and by using "gatekeepers" to make sure that services considered un-necessary or referrals outside the network are kept to a minimum. Managed care is not "health reform"; it is a way to finance and deliver health care.

**How Does It Work?** Managed care plans are corporations serving large groups of people through a "capitated" system. A business, school system, government body, or membership organization receives a set price from the plan for employees' or members' health coverage, with the employer and employee usually sharing premium costs. There might be a small charge for each service. The physicians and providers in the network work for salaries, not fees for each service. Someone (often a primary care physician or a nurse) is the "gatekeeper," deciding which services will be provided and if referrals out of network can be made. Keep in mind that case management, in which an individual coordinates services for patients, is NOT managed care, although case management can be a part of managed care.

**What Are Some Examples Of Managed Care?** The most common form of managed care is a Health Maintenance Organization (HMO) in which all health services are delivered and paid for through one organization, often under one roof. Preferred Provider Plans (PPOs), offer a group of doctors and hospitals who give a discount on their services to an insurance company or an employer. In a PPO, consumers must choose their primary health provider from an approved list and must pay extra for specialty services received outside the PPO group. Many states have adopted Medicaid managed care plans that restrict Medicaid patients to a specified network of physicians, other health providers and services; states must obtain an "1115 Waiver" to do this.

**Why Is Managed Care Considered So Effective?** As health care costs have risen over the years, policymakers and health economists have looked at managed care as a way to save money. They believe that managed care plans — where everything and everyone is part of a controlled network — can achieve cost containment. Many health professionals and others also believe that a managed care system can provide coordination and quality control. Note: There is little research indicating if managed care is effective for children with special health needs.

**What Happens To Children With Special Health Needs Under Managed Care Plans?** Because many managed care plans are new, there is not much data about its effects on our kids. However, there seem to be good and bad points. Possible positives: Care coordination easier; fewer out-of-pocket expenses; health care needs taken care of in one place; unnecessary procedures unlikely; providers and services closer to home; consumer satisfaction often a priority; continuity of care. Possible negatives: A cost disincentive for making referrals to specialists outside of network for rare disorders or pediatric specialty care; lack of knowledge and experience about some diagnoses by "gatekeepers"; problems obtaining access to specialty equipment, therapies, new medications or treatments; difficulties getting objective second opinions. It is also unclear how patients and policymakers monitor the delivery of care, participate in patient and network decision-making, and lodge complaints in many managed care situations. Note: The expense of providing timely, appropriate and quality care to children with special health care needs may create a dilemma in a system based upon cost-containment.

**What Should You Do If Managed Care Is Offered?** Ask many questions: Who are the gatekeepers and what are their qualifications? Who are the pediatric specialists? Can you choose your own primary physician, pediatrician, specialist, therapist? Does the plan include the therapies, access to specialists, and unusual treatments or medications that your child requires? What will it cost you to go to a specialist or provider outside the plan? Who gives and pays for second opinions? Is there a program or department for children with special health needs? Is there a consumer board and what are its responsibilities and powers? How are doctor-patient decisions made? What are the grievance procedures? What state or federal body monitors the managed care plan and are reports available? Families should insist on the involvement of consumers in the network's policymaking, quality assurance, and grievance procedures.

*Notes: 1. Family Voices thanks Peggy McManus, Betsy Anderson, New England SERVE, the Academy of Pediatrics, and AMCHP for sharing their ideas on managed care with us. 2. Please copy and distribute this paper widely.*

1/96

Family Voices: A Grassroots Network Speaking for Children with Special Needs, Box 769, Algodones, NM 87001 505/867-2368





## FAMILY VOICES

*A national grassroots network of families and friends speaking  
on behalf of children with special health care needs.*

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### **Family Voices Discuta: La Atención Médica Manejada/Managed Care**

Antes se escuchaba mucho sobre el tema de *health reform*/reformas médicas. Y ahora, se escucha mucho sobre *managed care*, es decir, la atención médica manejada por una corporación. ¿Qué quiere decir *managed care*? ¿Es alguna reforma en el sistema de prestar servicios médicos? ¿Estará bueno o malo para para niños con necesidades médicas especiales? Aunque *managed care* no le diga lo mismo a cada uno, *Family Voices* hará el esfuerzo aquí de explicar brevemente este concepto. Por favor, mándenos sus preguntas sobre este tema para que nosotros le sigamos informando en los próximos meses.

¿Qué quiere decir *Managed Care*? Este es un programa para proveer atención médica pre-pagada dentro de un sistema que incluye un grupo de ciertos proveedores de servicios médicos y asistencia médica. Este sistema se encarga de coordinar servicios y designar pacientes a sus proveedores de servicios médicos y hospitales; también se encarga de controlar el tipo de servicios prestados y su frecuencia, los costos de tales servicios, y la calidad de estos. *Managed care* es diferente que los servicios tradicionales *fee for service*/pago por servicios prestados, por medio del cual el paciente escoge su propio médico y el tipo de tratamiento, y paga directamente por los servicios recibidos. Por lo general, en los programas de *managed care*, los servicios que un paciente puede recibir se limitan a los servicios facilitados por el sistema, tales como las visitas de médicos, terapias, *home-care*/cuido en casa, farmacias, especialistas, clínicas y hospitales que forman parte del sistema, que tiene para sí un *gatekeeper*/guardabarreras para asegurar que los servicios prestados por el sistema al cliente sean realmente necesarios, y que las referencias fuera del sistema sean minimales. *Managed care* no es ninguna reforma médica, sino una manera de financiar y entregar servicios médicos.

¿Cómo funciona este sistema? Los planes de *managed care* se originan con corporaciones que sirven a grupos grandes por medio de un sistema "capitado"—basado en un precio calculado por persona. La corporación ofrece a entidades que proveen servicios médicos a sus empleados o socios—algún negocio, un sistema escolar, algún órgano del gobierno, o alguna sociedad—un precio fijo para participar en el plan, un costo que normalmente es compartido por el empleado y su patrón. Es posible que haya un pequeño costo adicional cuando el paciente inscrito en el plan recibe atención médica. Los médicos y otros profesionales dentro del sistema reciben sueldos fijos en vez de pago por cada servicio prestado. Además, hay una persona (en muchos casos un médico o una enfermera) que tiene el papel de *gatekeeper*/"guardabarreras," a quién le toca decidir cuales servicios se le vayan a prestar a un paciente, y si le será permitido buscar tratamiento con profesionales fuera del sistema. No se debe confundir el sistema de "managed care" con un servicio de "case management"/administración del caso, en el cual alguna persona (quizás un trabajador social o algún voluntario) se encarga de coordinar servicios para pacientes. De todos modos, la administración del caso pudiera formar parte del servicio médico prestado bajo el sistema de "managed care."

¿Cuáles son algunos ejemplos de *Managed Care*? La forma mas común de *managed care* es un *Health Maintenance Organization (HMO)*/ Organización de Mantenimiento de Salud por medio del cual todos los servicios médicos son prestados y pagados por una sola organización, muchas veces en un solo sitio. Otro ejemplo es el *Preferred Provider Plan (PPO)*/ Plan de Proveedor Preferido, un sistema que consiste en un grupo de médicos y hospitales que ofrece un descuento por sus servicios a compañías de seguros médicos o a empleadores. En un PPO, el cliente tiene que escoger su proveedor médico primario (*primary health provider*) de una lista aprobada por el plan, y tendrá que pagar extra por servicios especiales recibidas por profesionales fuera del grupo PPO. En muchas partes de los Estados Unidos, los gobiernos estatales se han decidido por planes tipo *Medicaid Managed Care*, es decir que los pacientes de Medicaid (el programa de asistencia médica del gobierno federal) solo pueden recibir servicios médicos a manos de cierto sistema de médicos, profesionales medicales, y servicios de salud; cada estado tiene que obtener del gobierno federal un "1115 Waiver/Permiso especial tipo #1115 que permita este arreglo.

¿Por Qué Se Considera *Managed Care* Tan Efectivo? Dándose cuenta de los incrementos en el costo de servicios medicales en los últimos años, los administradores públicos y economistas especializados en asuntos de salud han dado consideración al sistema de *managed care* como una manera de conservar costos. Ellos creen que los sistemas de *managed care*—en el cual todo y todos forman parte de un sistema controlado—puedan llegar a controlar el costo de los servicios. Muchos otros profesionales y especialistas en asuntos de salud creen que un sistema de *managed care* pueda resultar en la mejor coordinación de servicios y control de su calidad.



**¿Qué Les Pasa A Los Niños Con Necesidades Especiales Bajo un Sistema de *Managed Care*?** Como los planes que ofrecen un sistema de *managed care* son novedosos, no hay mucha información comprobada sobre su afecto en los niños nuestros. Sin embargo, al parecer hay de lo bueno y hay de lo malo. **Los Posibles Afectos Positivos:** Mayor facilidad en la coordinación de casos; menos gastos del bolsillo; la atención médica centralizada en un solo sitio; los procedimientos no necesarios serán mas raros; los proveedores de servicios estarán mas cerca a casa; con mas probabilidad, se tomará en cuenta la satisfacción del cliente; y el cuidado será continuo. **Los Posibles Afectos Negativos:** El costo de referir pacientes a especialistas fuera del sistema en casos de condiciones raras o necesidad de cuidado especializado pediátrico será de poco interés para el sistema; a los "guardabarreras" les pueden faltar conocimiento y experiencia con algunas condiciones médicas;" el cliente puede tener problemas en conseguir acceso a equipo especial, terapias, nuevos medicamentos o nuevas terapias; y puede encontrar dificultades en conseguir segundas opiniones objetivas. Además, no está claro como los pacientes y los administradores públicos vayan a poder supervisar la calidad de los servicios prestados, o participar en las decisiones que afectan tan pacientes como el sistema, o cómo se vayan a levantar quejas en muchas situaciones bajo el sistema de *managed care*. **Nota:** El alto costo de proveer servicios médicos que les sean inmediatos, apropiados, y de alta calidad a los niños con necesidades medicales especiales puede crear dificultades para un sistema basado en la contención de gastos.

**¿Qué Debe Hacer Ud. Si Se Le Ofrece Un Plan de Managed Care?** Ante todo, haga muchas preguntas.

¿Quiénes son los *gatekeepers/guardabarreras* y cuáles son sus calificaciones? ¿Quiénes son los especialistas pediátricos? ¿Tiene uno el derecho de escoger su médico preferido (*primary care physician*), su pediatra, su especialista, su terapeuta? ¿Están incluidos en el plan las terapias, el acceso a especialistas, o los tratamientos no muy comunes o los medicamentos raros que requiera su niño? ¿Cuánto le vaya a costar visitar un especialista o un proveedor de servicios médicos que no esté en el plan? ¿Quién dará segundas opiniones y quién pagará por ellas? ¿Existe algún programa o algún departamento para los niños con necesidades médicas especiales? ¿Cómo se hacen las decisiones entre el paciente y su médico? ¿Cuál es el procedimiento para levantar una queja? ¿Cuáles entidades federales o estatales son encargados de supervisar el plan de *managed care* y cómo se puede conseguir sus reportajes? Las familias deben insistir en la inclusión de consumidores cuando el sistema de *managed care* esté formulando su política general, su garantía de la calidad de los servicios prestados, y sus procedimientos para levantar quejas.

*Notas: 1. Family Voices da sus gracias a Peggy McManus, Betsy Anderson, New England SERVE, el Academy of Pediatrics, y AMCHP por compartir sus ideas sobre managed care con nosotros. 2. Por favor, haga copias y distribuya esta hoja lo mas posible.*

Family Voices: Una Red de Base Hablando por Niños con Necesidades Médicas Especiales. Box 769, Algodones NM 87001. Teléfono 505.867.2368.

## FAMILY VOICES

### Children with Special Health Care Needs In Managed Care: Questions To Ask and Answer

***A Definition:*** Managed Care is a way of delivering health care for a set fee within a network that includes a specific group of providers. A managed care organization refers patients to its own health providers, clinics, and hospitals. Managed care organizations can monitor and coordinate patient care, costs, and quality to provide cost-effective health care.

***About Our Children and Families:*** Like all families, families who have children with special health care needs want the best possible health care for our children so that they can grow up to be healthy, productive, valued members of society. Like all children, our children deserve health care that considers the preventive and developmental aspects of childhood. However, our children must often visit pediatric specialists, other health care providers, and hospitals frequently. They sometimes require specialized medicines and equipment. And many need an array of community supports in order to live at home. As their parents, we have a responsibility to find and use health systems built upon principles of family-centered care with the capacity, flexibility, and commitment to serve our children well. Managed care systems have the capability of providing excellent health care to children with special health needs. As families, we must hold managed care organizations, and those who contract with them, to standards of conduct and service that parallel our own obligations to our children.

#### **Obtaining Good Health Care:**

1. How will children with rare (and not so rare) diagnoses be welcomed and treated?
2. How does a child access pediatric specialists within the managed care organization (MCO), outside the MCO, outside the state? Who decides? Who pays?
3. How difficult will it be to receive related health services, therapies, for example?
4. What equipment is covered by the MCO — power wheelchairs, assistive technology devices, hearing aids? How often can equipment be replaced due to damage or growth?
5. What is the process used to obtain durable and non-durable medical supplies, nursing care and other supports that enable a child to live at home?
6. Do benefits include enabling services: care coordination, transportation, home-care, peer support, counseling, genetic services, experimental procedures, unusual medications or treatments?
7. How close to home are regular clinical services? Specialty services?
8. How is health care provided and paid for if a child requires health services while out of town?
9. Can health care be obtained in alternative settings: home, child care program, school?
10. Do emergency room personnel know how to care for a child with special health care needs? Will a child/family be penalized for emergency room visits? Are there alternatives to using the emergency room for serious episodes outside of office hours?
11. Is there a special department for children with special health care needs?
12. Will the managed care organization arbitrarily assign a primary provider, or can the family be involved in the choice?
13. Is the child's primary provider a pediatrician? Family practitioner? What are his or her qualifications for caring for children with special health care needs?
14. What are the qualifications for specialists who care for children with special health care needs? What

experience do they bring to our children's care? How many of our children do they annually treat?

15. What expertise do other providers (therapists, support staff, home-care agencies) have in caring for our children?
16. How many children with disabilities are covered by the MCO? How many children does the MCO cover who have your child's condition?
17. If a child has a complex condition, can care be obtained in a specialty hospital or other setting with access to equipment and highly trained personnel?

#### **Ensuring Continuity**

1. What assurance is there that pediatricians and specialists who now care for your child will continue to do so?
2. What are the guarantees for continuity of care: primary, specialty, therapeutic, home-care?
3. What happens if a child's provider leaves a managed care network?
4. What happens when an employer chooses another plan? Or when an employer switches to a plan that does not adequately cover your child? Or when a family changes employment?
5. Who sees a child after office hours?
6. How is a plan's financial capacity and longevity guaranteed? What if it goes out of business?

#### **Having Choices:**

1. Can families choose their managed care plan?
2. If the MCO offers more than one plan, can families exercise their preference?
3. Can families choose a child's primary and specialty providers?
4. Can family choose therapists? Home-care providers? Counselors? Vendors?
5. How do vendors and other providers get on managed care organization lists?

#### **Making Decisions:**

1. How does the plan define "medically necessary"?
2. Who makes health care decisions: families, physicians, gatekeepers, others?

3. How long does it take to obtain authorizations for referrals?
4. Who are the gatekeepers? What are their qualifications? Who oversees them?
5. What is the managed care plan's policy on obtaining second opinions? Who pays? How quickly?

#### Addressing Costs of Care:

1. It can be expensive to provide health care to a child with special health care needs: How does the managed care organization address this issue?
2. Are physicians and others expected to ensure access to the array of care — equipment, lab tests, medicines, and referrals outside the MCH — that a child with special health needs often requires?
3. Will physicians and others be encouraged to spend enough time with a child with a complex condition?
4. Is there a cap on the amount of services a child can use in one year? A lifetime?

#### Assuring Quality

1. How is consumer satisfaction measured? How often? How and where are the results distributed?
2. What are the assurances that cost-control and quality health care can co-exist?
3. Must this managed care plan meet certain quality standards? Who sets and monitors them?
4. What can consumers do to make sure that quality standards are met?
5. Who is accountable for quality of care? Are they accessible to ordinary families?
6. Who monitors services for children with special health care needs?
7. What is the oversight — public health, corporate, state, association?

#### Solving Problems:

1. If there are problems with a child's health care, billing procedures, or other matters, how is the matter resolved? By Whom? Are there timelines?
2. Are plans required to have grievance procedures? If so, how family-friendly are they?
3. What public agency monitors problems/grievances, collects grievance information, and publishes it?
4. Can you or your child be represented by an attorney in the grievance process?

#### Controlling Costs:

1. What are the premium costs for a family?
2. What will families pay for each visit?
3. Are there other co-pays, deductibles?
4. Can premiums be raised if the amount of care is considered excessive? How can families know this?
5. If families can find less expensive equipment or other supplies, are they paid for?

#### Finding Information

1. How do families learn about the principles and processes of managed care in general?
2. How do families judge the quality of different managed care plans?
3. How do they determine which plan is best for their child and family?

4. How is information about the plan's quality of services distributed? Are annual ratings published?
5. How is care information fed back to the plan for corporate and state monitoring purposes?
6. How easy is it to get phone numbers and gain access to physicians, administrators?
7. What does the managed care plan do to help its members understand and use their plan?

#### Delivering Family Centered Care:

1. Does the managed care plan know about and use the principles of family-centered care?
2. Is family-centered training offered? To whom?
3. Do plans have family advisory boards? Are there consumers on the MCO's board of directors?
4. Does the managed care organization address the cultural and language characteristics of its patients?

#### Coordinating with Other Caregivers

1. Does the managed care plan coordinate with the state Children with Special Health Care Needs/Title V agency?
2. How are financial and delivery responsibilities for therapies and other services decided between the managed care system and the schools?
3. How does the managed care system coordinate with traditional community providers?
4. Is there a relationship between the managed care system and local or state children's hospitals?
5. Will primary care clinics — especially those in rural or urban areas — be part of managed care systems?
6. If the rest of the family is in a managed care plan and their child with a special health care need is not, how will coordination be addressed?

#### Collecting Data

1. Who is responsible for collecting, analyzing, and distributing data about how children with special health needs are doing under managed care?
2. How will the data affect the delivery of health care to children with special health needs?

#### Systems Planning:

1. Many states are considering enrolling all children served by Medicaid in managed care. If a state's Medicaid agency decides that children with special health care needs will not be served through managed care, is there a plan to ultimately include children with special health care needs in managed care plans? Are families part of that planning process? What are the timelines?
2. If some services (medical, for example) are delivered through a managed care plan and other services (therapies or early intervention) are delivered outside the managed care system, how will services be financed and coordinated? What agency will monitor and report its findings?
3. Are stakeholders, including families, involved in the development of this new way — managed care — to finance and deliver health care?

## FAMILY VOICES

Una red nacional a nivel de familias y amigos que hablan a favor de los niños  
con necesidades especiales de atención de salud.

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### Niños con Necesidades Especiales de Atención de Salud en la Atención de Salud Controlada (Managed Care): Preguntas y Respuestas

**Una Definición:** La Atención de Salud Controlada es una forma de entrega de atención de salud por un honorario establecido dentro de una red de trabajo que incluye un grupo específico de proveedores. Una organización de atención de salud controlada refiere a los pacientes a sus propios proveedores de atención de salud, clínicas y hospitales. Las organizaciones de atención de salud controlada pueden supervisar y coordinar la atención al paciente, los costos y la calidad para proporcionar atención de salud costo-efectiva.

**Sobre Nuestros Niños y Familias:** Como todas las familias, las familias que tienen niños con necesidades especiales de atención de salud, quieren la mejor atención de salud posible para nuestros niños, para que así puedan crecer saludables, productivos, miembros valiosos de la sociedad. Como todos los niños, nuestros niños merecen una atención de salud que considere aspectos preventivos y del desarrollo de la infancia. Sin embargo, nuestros niños a menudo deben visitar especialistas pediátricos, otros proveedores de atención de salud y frecuentemente hospitales. Ellos a veces requieren medicinas y equipo especializado. Y muchos necesitan una gran cantidad de apoyos comunitarios para poder vivir en su hogar. Así como sus padres, nosotros tenemos una responsabilidad para encontrar y utilizar sistemas de salud basados en principios de cuidado centrado en la familia, con capacidad, flexibilidad y compromiso para servir bien a nuestros niños. Los sistemas de atención de salud controlada tienen la capacidad para proporcionar una atención de salud excelente a los niños con necesidades especiales de salud. Como familias, nosotros debemos asegurarnos de que las organizaciones de atención de salud controlada y aquellos quienes hacen contratos con ellos, tengan estándares de conductas y servicios que sean análogos a nuestras propias obligaciones hacia nuestros niños.

#### Obteniendo Una Buena Atención de Salud

1. ¿Cómo serán recibidos y tratados los niños con diagnósticos raros (y no tan raros)?
2. ¿Cómo consigue acceso el niño a especialistas pediátricos dentro de la organización de atención de salud controlada (MCO; Managed Care Organization), fuera de MCO, fuera del estado? ¿Quién lo decide? ¿Quién paga?
3. ¿Cuán difícil le será recibir servicios de salud asociados, terapias, por ejemplo?
4. ¿Cuáles equipos están cubiertos por la MCO – sillas de ruedas eléctricas, dispositivos de tecnología asistida, ayuda para la audición? ¿Con qué frecuencia se pueden reemplazar los equipos debido a daño o crecimiento?
5. ¿Cuál es el proceso que se utiliza para obtener suministros médicos durables y no durables, atención de enfermería y otros apoyos que permiten que el niño viva en su hogar?
6. ¿Los beneficios incluyen servicios de capacitación: coordinación de la atención, transporte, cuidado en la casa, apoyo de pares, consejería, servicios genéticos, procedimientos experimentales, tratamientos o medicamentos poco comunes?
7. ¿Cuán cerca de la casa están los servicios clínicos regulares? ¿Servicios de especialidad?
8. ¿Cómo se proporciona y se paga por la atención de salud si un niño requiere servicios de salud cuando está fuera de la ciudad?
9. ¿Se puede obtener atención de salud en lugares alternativos: hogar, programas de guarderías infantiles, escuela?
10. ¿El personal de la sala de emergencia sabe como atender a un niño con necesidades especiales de atención de salud? ¿Será el niño/familia penalizado por visitas a la sala de emergencia? ¿Hay alternativas para la utilización de la sala de emergencia en episodios serios fuera de horas de oficina?
11. ¿Hay un departamento especial para niños con necesidades especiales de atención de salud?
12. ¿La organización de la atención de salud controlada asignará arbitrariamente un proveedor primario, o la familia puede participar en la elección?
13. ¿El proveedor primario del niño es un pediatra? ¿Un médico de familia? ¿Cuáles son sus calificaciones para

el cuidado de niños con necesidades especiales de atención de salud?

14. ¿Cuáles son las calificaciones para especialistas que se dedican al cuidado de niños con necesidades especiales de atención de salud? ¿Qué experiencia tienen en el cuidado de nuestros niños? ¿A cuántos de nuestros niños tratan anualmente?
15. ¿Cuán expertos son otros proveedores (terapeutas, equipo de apoyo, agencias de cuidado en la casa) en el cuidado de nuestros niños?
16. ¿Cuántos niños con discapacidades están cubiertos por la MCO? ¿Cuántos niños que tienen la condición de su niño están cubiertos por la MCO?
17. Si un niño tiene una condición compleja, ¿se puede obtener la atención en un hospital de especialidades u otro lugar con acceso a equipo y personal altamente entrenado?

#### Asegurando Continuidad

1. ¿Qué seguridad existe de que los pediatras y especialistas que ahora atienden a su niño sigan haciéndolo?
2. ¿Cuáles son las garantías para la continuidad de la atención: primaria, de especialidad, terapéutica y de cuidado en el hogar?
3. ¿Qué pasa si un proveedor del niño deja una red de atención de salud controlada?
4. ¿Qué pasa si un empleador elige otro plan? ¿O cuando un empleador cambia a un plan que no cubre a su niño adecuadamente? ¿O cuando una familia cambia de empleo?
5. ¿Quién ve a un niño después de horas de oficina?
6. ¿Cómo se garantiza la capacidad financiera del plan y la longevidad? ¿Qué pasa si deja de existir?

#### Teniendo alternativas

1. ¿Las familias pueden elegir su plan de atención de salud controlada?
2. Si la MCO ofrece más de un plan, ¿las familias pueden elegir sus preferencias?
3. ¿Las familias pueden elegir los proveedores primarios y de especialidad para un niño?
4. ¿Las familias pueden elegir terapeutas? ¿Proveedores de cuidado en la casa? ¿Consejeros? ¿Vendedores?
5. ¿Cómo se incorporan los vendedores y otros proveedores en las listas de la organización de atención

de salud controlada?

#### Tomando Decisiones

1. ¿Cómo define el plan "medicamente necesario"?
2. ¿Quién toma las decisiones de atención de salud: familias, médicos, controladores, otros?
3. ¿Cuánto tarda obtener autorizaciones para derivaciones?
4. ¿Quiénes son los controladores? ¿Cuáles son sus calificaciones? ¿Quién los supervisa?
5. ¿Cuál es la política del plan de atención de salud controlada para obtener segundas opiniones? ¿Quién paga? ¿Con qué rapidez?

#### Enfrentando los Costos de la Atención

1. Puede ser costoso proporcionar atención de salud a un niño con necesidades especiales de atención de salud: ¿Cómo enfrenta este problema la organización de la atención de salud controlada?
2. ¿Se espera que los médicos y otros aseguren el acceso a la gama de servicios de atención – equipos, exámenes de laboratorio, medicinas y derivaciones fuera de MCH – que un niño con necesidades especiales de atención de salud requiere frecuentemente?
3. ¿Se incentivará a los médicos y otros a dedicar suficiente tiempo a un niño con una condición compleja?
4. ¿Hay un límite en la cantidad de servicios que puede utilizar un niño en un año? ¿Durante su vida?

#### Asegurando Calidad

1. ¿Cómo se mide la satisfacción del consumidor? ¿Con qué frecuencia? ¿Cómo y donde se distribuyen los resultados?
2. ¿Cuáles son las garantías de que una atención de salud de calidad y con un control de costo puedan coexistir?
3. ¿Debe este plan de atención de salud controlada cumplir con ciertos estándares de calidad? ¿Quién los establece y supervisa?
4. ¿Qué pueden hacer los consumidores para asegurar que se cumplan los estándares de calidad?
5. ¿Quién es responsable por la calidad de la atención? ¿Son ellos accesibles a familias comunes?
6. ¿Quién supervisa los servicios para niños con necesidades especiales de atención de salud?
7. ¿Cuál es el organismo supervisor – salud pública, corporativo, estado, asociación?

#### Resolviendo Problemas

1. Si hay problemas con la atención de salud de un niño, procedimientos de cobranza u otras materias, ¿cómo se resuelve el problema? ¿Quién lo resuelve? ¿Hay plazos?
2. ¿Se requieren planes para procedimientos de quejas? Si es así, ¿son amistosos con las familias?
3. ¿Qué agencia pública supervisa los problemas/quejas, recolecta la información de quejas y la publica?
4. ¿Puede usted o su niño ser representado por un abogado en el proceso de queja?

#### Controlando Costos

1. ¿Cuáles son los costos de la prima para una familia?
2. ¿Cuánto pagarán las familias por cada visita?
3. ¿Existen otros co-pagos, deducibles?
4. ¿La prima puede ser elevada si la cantidad de atención de salud es considerada excesiva? ¿Cómo pueden saber ésto las familias?
5. Si las familias pueden encontrar equipos u otros suministros menos costosos, ¿se les paga por ésto?

#### Encontrando Información

1. ¿Cómo se informan las familias acerca de los principios y procesos de la atención de salud controlada en general?
2. ¿Cómo juzgan las familias la calidad de los diferentes planes de la atención de salud controlada?
3. ¿Cómo determinan cual plan es el mejor para sus niños y familias?
4. ¿Cómo se distribuye la información acerca de la

calidad de los planes de servicios? ¿Se publican las evaluaciones anuales?

5. ¿Cómo se entrega la información de la atención al plan, para propósitos de supervisión corporativa y estatal?
6. ¿Cuán fácil es obtener números telefónicos y acceder a médicos, administradores?
7. ¿Qué hace el plan de la atención de salud controlada para ayudar a sus miembros a entender y a utilizar sus planes?

#### Entregando Atención Centrada en la Familia

1. ¿Está el plan de atención de salud controlada informado acerca de y utiliza los principios de atención centrado en la familia?
2. ¿Se ofrece entrenamiento centrado en la familia? ¿A quién?
3. ¿Los planes tienen un consejo asesor de familia? ¿Hay consumidores en el consejo de directores de MCO?
4. ¿La organización de la atención de salud controlada toma en cuenta las características culturales y lenguaje de sus pacientes?

#### Coordinando con Otros Proveedores de Atención de Salud

1. ¿El plan de atención de salud controlada se coordina con la agencia estatal de Niños con Necesidades Especiales de Atención de Salud/Título V (Children with Special Health Care Needs/Title V)?
2. ¿Cómo se deciden las responsabilidades financieras y de entrega de terapias y otros servicios entre el sistema de atención de salud controlada y las escuelas?
3. ¿Cómo se coordina el sistema de atención de salud controlada con proveedores comunitarios tradicionales?
4. ¿Existe una relación entre el sistema de atención de salud controlada y los hospitales de niños estatales o locales?
5. Las clínicas de atención primaria – especialmente aquellas en áreas rurales o urbanas – ¿serán parte de los sistemas de atención de salud controlada?
6. Si el resto de la familia está en un plan de atención de salud controlada y su niño con necesidades especiales de atención de salud no lo está, ¿cómo se puede coordinar ésto?

#### Recolectando Datos

1. ¿Quién es el responsable de la recolección, análisis y distribución de datos acerca del bienestar de los niños con necesidades especiales de atención de salud bajo la atención de salud controlada?
2. ¿Cómo los datos afectarán la entrega de atención de salud a niños con necesidades especiales de atención de salud?

#### Planificación de Sistemas

1. Muchos estados están considerando el enrolar a todos los niños que son atendidos por Medicaid en la atención de salud controlada. Si una agencia de Medicaid del estado decide que ese niño con necesidades especiales de atención de salud no será atendido a través de la atención de salud controlada, ¿existe un plan para incluir finalmente al niño con necesidades especiales de atención de salud en planes de atención de salud controlada? ¿Son las familias parte de este proceso de planificación? ¿Cuáles son los plazos de tiempo?
2. Si algunos servicios (médico, por ejemplo) son entregados a través de un plan de atención de salud controlada y otros servicios (terapias o intervención precoz) son entregados fuera del sistema de atención de salud controlada, ¿cómo se financiarán y coordinarán los servicios? ¿Qué agencia supervisará y reportará sus hallazgos?
3. ¿Están los miembros, incluyendo las familias, involucrados en el desarrollo de esta nueva manera – atención de salud controlada – para financiar y entregar atención de salud?

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**THE ABC'S OF MANAGED CARE**  
***Standards and Criteria for Children with Special  
Health Care Needs***

**A Report from the Egg Harbor  
Family Summit**

**March 1996**

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## The ABC's of Managed Care Standards and Criteria for Children with Special Health Care Needs\*

### A Report from the Egg Harbor Family Summit

In Autumn 1995, about 30 parent leaders from around the country gathered at Egg Harbor, Wisconsin, to discuss health care for children with special health care needs. Based on a universal concern about the unknown effects of managed care on our children, the families agreed to develop a set of family-driven standards for managed care systems that treat children with special health care needs. The criteria from that Egg Harbor meeting are expected to infuse managed care policies, discussions, contracts, and materials.

Like all families, we who are parents of children with special health care needs want the best possible health care for our children. But we also have a unique responsibility. Our children visit health care providers and hospitals frequently, require care from specialists, need specialized medicines and equipment, and must have an array of health related supports to be able to stay at home with us. Therefore, as their parents, we must find health care systems with the capacity, flexibility, and commitment to serve our children. As families we must have access to managed care organizations with systems of services and supports that are built upon the principles of family-centered care.

**Managed care** is a way of financing and delivering care for a set fee using a network of specific providers and services. Managed care differs from traditional fee-for-service health care systems in several ways. A managed care organization can be either a for-profit or a not-for-profit corporation that refers patients to health providers, clinics, and hospitals within its own network. A managed care system can monitor the amount and patterns of care provided, the cost of care, and the quality of care, and can coordinate services within its network. A managed care system also has the responsibility to refer out of its network for those services it cannot provide.

**Family-centered care** is a philosophy and approach to service delivery that shapes policies, programs, and practices. Information sharing and collaboration between families and providers are cornerstones of family-centered care. Family-centered practitioners recognize the vital role that all families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care. With this approach, they support family caregiving and decision making; respect family choices; build on family strengths; and involve families in all aspects of the planning, delivery, and evaluation of health care services.

\***Children with special health care needs** are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond what is required by children generally.

## The Principles Of Managed Care For Children With Special Health Care Needs

### ▼ THE PRINCIPLES

**1. Families are the core of any health care system.** Managed care systems will acknowledge and support the expertise that families bring to their caretaking, decision-making, and care-coordinating roles. Managed care systems will accept and value the richly diverse traditions and languages that families and their children bring to health care settings, and will provide families with the information and resources they require. Services will be delivered in response to needs identified by families and providers. Families will thereby have the supports necessary to make informed decisions.

**2. Family-professional partnership.** Managed care systems will recognize that outcomes for children with special health care needs improve when families and professionals make decisions jointly, each party respecting the expertise, experiences, training, and resources that each brings to the care of the child.

**3. Access.** Managed care systems will provide children with special health care needs unconditional and equitable access to quality primary, preventive, habilitative, and specialty health care, services, and equipment at a reasonable cost to the family. Overriding all considerations and decisions will be the wellness of the child. If gatekeepers are used, they will be well-trained, monitored by families and professionals, and will make their decisions in partnership with the family and other health providers.

**4. Flexibility.** Managed care systems will provide effective, flexible health care and services to children with special health care needs. Medical decisions and referrals will be based on the unique circumstances of the family and the condition of the child.

**5. Comprehensive, coordinated, community-based care.** Managed care systems will assure a coordinated system of comprehensive services to children with special health care needs and their families through direct service provision within the plan and collaboration with public and private community services outside the plan. These services will be delivered as close to the child's home as possible, and include appropriate outreach to underserved families, prevention, education, screening, diagnosis, primary and specialty care, mental health services, wellness management, hospitalization, emergency care, medication, supplies, equipment, habilitation and rehabilitation.

## ▼ APPLYING THE PRINCIPLES

### ACCESS

**In a family-centered managed care system, all children with special health care needs receive primary, acute, and specialty care and services in a manner that is prompt, timely, and free from barriers.**

1. Prior to enrollment, families receive understandable information about the managed care plan, including its practitioners, policies, and descriptions of how decisions are made.
2. Rights and benefits, as well as applications and other information forms, are available and explained to families in their primary language. Interpreters are also available at the request of families.
3. A system is in place to verbally explain forms, rights, and benefits for enrollees who have limited reading abilities.
4. Prior to enrollment, families are encouraged to conduct pre-select interviews with providers. Tools are made available to families to help them select providers.
5. An identified system is in place within the managed care system for children with special health care needs. Special provisions are made for children special health care needs and their families, including at a minimum, screening, health care planning, care coordination, pre-arrangements for access to specialists and emergency care.
6. A screening process is in place that identifies children with special health care needs and refers them appropriately.
7. A comprehensive health care plan is developed with the child and family upon entry into the system or at diagnosis of a special health care need. Existing provider relationships are ascertained and continued if possible.
8. A plan is in place (which all team members understand) for families to use well-child, urgent, and specialty care when they consider it necessary. Information for accessing emergency or urgent care out of state is clearly explained.
9. The health care plan pre-authorizes access to needed specialists, both within and outside the managed care organization.
10. Each child with special health care needs and his/her family are offered care coordination services upon diagnosis or entry into the managed care system.
11. The care coordinator works with the family and other team members to expedite and access needed services, whether in or out of the plan. Referrals for children to pediatric specialists and other providers inside and outside the provider network are made easily and promptly.
12. The care coordinator is knowledgeable about all other service systems, including special education, family support, respite, community programs, public health, and parent-to-parent support, as well as local, state, and federal laws governing these services. The care coordinator

is also responsible for coordinating health-related services provided in the schools with those provided in the managed care organization including access to technology.

13. Children receive their care close to home at flexible hours, including evenings and week-ends.

### **BENEFITS**

**In a family-centered managed care plan, a full range of necessary health care services and supports are provided for children with special health care needs and their families.**

1. Every child with special health care needs has an identified primary care provider.
2. The plan provides for well-child care, prescriptive items and equipment, and habilitative services for children with special health care needs.
3. The term "medically necessary" includes developmental, preventive, habilitative, and diagnostic considerations, and is applied fairly across all diagnoses.
4. The managed care plan is informed about and promotes wellness for children with special health care needs and individualizes prevention services.
5. The plan has access to and provides the latest technology to ensure quality of life for children with special health care needs.
6. Behavioral health services for children with special health care needs and their families are provided by appropriately trained providers, are fully covered, and are equal in scope and application to physical health services.
7. In-home services, long term care, home adaptations, durable medical equipment, and transportation are available for children with special health care needs and their families (on a sliding fee scale, if necessary.)
8. A plan is in place for transition from pediatric to adult health care, for all children including those with special health care needs.
9. Upon reaching the age of independence or with appropriate guardianship arrangements, young people with special health care needs can remain in the plan by paying a reasonable premium.
10. The managed care plan provides coverage from time of application to enrollment.
11. The managed care plan makes referrals for alternative therapies and interventions.
12. The plan makes referrals to alternate resources for items and benefits not covered by the plan.

## **CAPACITY**

**In a family-centered managed care system, qualified personnel and adequately developed policies and systems are in place to serve children with special health care needs and their families.**

1. All staff (from receptionist to physician) receive training by family/professional teams in family-centered care, family issues, and in caring for children with special health care needs. Families and individuals with special health care needs are part of the training teams.
2. Quality assurance standards designed specifically for children, including children with special health care needs, are in place and care is delivered in compliance with them.
3. Physicians, nurses and other health care providers understand the policies and procedures of the managed care plan, and the child's rights within that plan.
4. The managed care organization has the proven financial capacity and administrative infrastructure to fulfill its obligation to its patients, employees, and contractors.
5. The managed care system has a mechanism in place to inform families about the use of emergency and urgent care, including use of after hours care, and the emergency room.
6. Within the managed care plan, there is a family resource center with books, videos, computer access, and a resource and referral process for all children and families, including children with special health care needs.
7. Families who reflect the cultures/languages of the community are hired as staff members in liaison positions and are available at all service delivery sites.
8. Parents and families are a part of the selection process in the hiring of providers.
9. Families receive a copy of all written reports (diagnostic, referrals, etc.) and a tool for organizing the information (e.g., notebook).
10. All health care services provided comply with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

## **DECISION-MAKING**

**In a family-centered managed care system, families are part of the decision making process.**

1. Families can choose from menu of supports - generic and specialized over time.
2. Decisions regarding treatments, equipment, therapies, and other services are based on input from family and provider teams.
3. Each family is provided with a list of benefits covered. A process for negotiating for benefits that are needed and not covered is in place.
4. Case management services and extended benefits are provided based on criteria defined by the family and physician together.

5. Families receive information on the managed care system including services covered, referrals, appealing a decision, the grievance process - in family-friendly language and with telephone numbers. Training sessions are available to families on how to use the managed care system.
6. Families are involved in the development of policies and program implementation through a consumer advisory council which includes families of children with special health care needs.

### **EVALUATION & DATA**

**In a family-centered managed care system, quality assurance standards and patient satisfaction and monitoring mechanisms are developed in partnership with families and are utilized to improve the policies and services provided.**

1. The criteria used to establish standards of care are updated regularly based on current information on pediatric care.
2. Standards are developed with the participation of families.
3. All providers within the managed care organization have adequate information and training on the standards of pediatric care.
4. Information on the effectiveness and appropriateness of given health services is available to providers and is shared with families.
5. Consumer satisfaction with care is a major priority and there are mechanisms for consumer feedback, both on a regular basis and when there are specific issues.
6. Provider satisfaction with the managed care organization and health care delivered, and health status outcomes are part of the quality assurance process.
7. Providers' ability to effectively treat children with special health care needs is part of the evaluation process.
8. The effectiveness of the referral system to pediatric specialists, and the amounts and kinds of specialized care delivered is part of the evaluation process.
9. The effectiveness of the dispute resolution process is part of the evaluation process. A comprehensive list of issues raised and resolutions reached is available for inspection by consumers and providers.
10. Information from quality assurance reviews is available to the public. There is a system in place which indicates how providers performance is improved, or how providers are removed from the plan.
11. Data regarding the demographic make-up of the enrolled population is available including health care utilization broken down by race and by children with special health care needs by specific diagnosis.
12. Annual information about the costs of care, administrative costs, and reports to shareholders (in case of for-profit managed care organizations) is collected and made available to the public.
13. Outcome measures are in place and their results distributed.

**FINANCING**

**In a family-centered managed care system, families and providers work together to maximize impact of dollars spent.**

1. Primary and specialty providers are reimbursed at a level commensurate with their skills and expertise and reflective of increased capitation for children with special health care needs to assure adequate care.
2. The managed care organization acknowledges the extraordinary expenses borne by families who have children with special health care needs by maintaining equipment banks and loan programs, soliciting and supporting contingency funds and developing other cost effective programs with and for families.
3. A review board of consumers, providers, and other public and private entities is established. This board will work in close association with the state board of insurance and is responsible for:
  - reviewing the insurer's definition of non-covered expenses, how they apply deductibles and co-payments, and its effect on family expenses
  - reviewing internal profit sheets and assuring customer access to this information
  - reviewing reasonableness of co-pays, deductibles, and premiums
  - monitoring any grievance filed by a consumer or agency on behalf of a patient
  - reviewing rate setting to assure that access to specialty care is provided to all served by the managed care program.
  - developing a simplified process to explain what has been reimbursed and at what rate.
4. Incentives for wellness programs are included in all managed care programs.

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### ALPHABET SOUP: HEALTH CARE DEFINITIONS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Every family in the United States is finding that their family's health insurance picture is changing. This seems especially true for those of us who have children with special health care needs. We must understand health insurance jargon in order to make good decisions for our children. If, unfortunately, decisions are made for us, it is even more important to know what they will mean for our child. Here's a beginning list of definitions. Please send us those we missed, and we'll update this list. Thanks!

**Access** - Ability to receive services from a health care system or provider.

**Acute Care** - Medical services provided after an accident or for a disease, usually for a short time.

**Adverse Selection** - Occurs when those joining a health plan have higher medical costs than the general population; if too many enrollees have higher than average medical costs, the health plan experiences adverse selection.

**Ambulatory Care** - Outpatient medical services (not provided in a hospital).

**Benefits** - Health and related services guaranteed to be provided in a health plan.

**Capacity** - Ability of a (health) organization to provide necessary health services.

**Capitation** - Way of pre-paying a health plan, provider, or hospital for health services based on a fixed monthly or yearly amount per person, no matter how few or many services a consumer uses.

**Co-payment** - What a consumer pays for each health visit or service received, usually under \$10.

**Coverage** - Agreed upon set of health services that a plan will pay for and/or provide.

**Deductible** - Annual amount that consumer agrees to pay for health services before insurance plan pays.

**Dual-Eligibles** - People who are eligible for both Medicaid and Medicare.

**DME/Durable Medical Equipment** - Necessary medical equipment that is not disposable; for example, wheelchairs, walkers, ventilators, commodes.

**Enrollee** - Person (consumer) who is covered under a health insurance plan, whether fee-for-service or managed care.

**EPSDT/Early and Periodic Screening, Diagnosis and Treatment Program** - Mandatory Medicaid benefits and

services for Medicaid-eligible children and adolescents under age 21; designed to ensure children's access to early and comprehensive preventive health care and treatment. State Medicaid programs must provide EPSDT benefits.

**ERISA/Employee Retirement Insurance Security Act** - Federal act that allows businesses to develop self-funded health insurance programs. Such programs can limit benefits packages because they are not under the jurisdiction of state insurance regulations.

**Fee for Service** - Traditional health insurance, allowing consumer to choose providers and services, often with a deductible and co-payment. Also known as indemnity coverage.

**Formulary** - List of approved prescription medications which health plan pays for; medicines not listed in the formulary will not be covered.

**Gatekeeper** - Person, usually a primary care physician, designated by health plan to decide what services will be provided and paid for; approves all referrals, sometimes coordinates care.

**Grievance Procedure** - Defined process in a health plan for consumers or providers to use when there is disagreement about a plan's services, billings, or general procedures.

**HCFA/Health Care Financing Administration** - The federal agency responsible for Medicaid and Medicare; part of the U.S. Department of Health and Human Services/HHS.

**HMO/Health Maintenance Organization** - Health plan that requires its enrollees to use only certain health providers and hospitals, usually those within its own network.

**HEDIS** - System for determining the quality of a health plan's services and outcomes, based on certain data. HEDIS data, information, and guidance about children are limited.

**High Risk Insurance Pools** - State programs that enable people with health problems to join together to purchase health insurance; even with subsidies, premium rates are high because pool members are high risk.

**IPA/Individual (or Independent) Practice Association** - Association of physicians and other providers, including

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hospitals, who contract with an HMO to provide services to enrollees, but usually still see non-HMO patients and patients from other HMOs.

**Long-term Care** - Health maintenance and health services, including respite, home and personal care, for people with chronic conditions, disabilities, or mental illness. Can be provided in an institution or in the community. Term was designed with adults in mind. *Family Voices seeks a term better suited for our children and families... any ideas?*

**Mandatory Enrollment** - Requirement that certain groups of people must enroll in a program, Medicaid managed care, for example.

**Managed Care** - Way of financing and delivering health care for a set fee using a network of specific providers and services.

**MCO/Managed Care Organization** - Health organization, whether for-profit or not-for-profit, that finances and delivers health care using a specific provider network and specific services and products.

**Medicaid** - Federal program (Title XIX of the Social Security Act) that pays for health services for certain categories of people who are poor, elderly, blind, disabled, or who are enrolled in certain programs, including Medicaid Waivers. Includes children whose families receive assistance. Is financed with federal and state funds, amount varying by state.

**Medicare** - Title XX of the Social Security Act which pays for health care for the elderly and adults who are disabled.

**Medical Necessity** - Legal term used to determine eligibility for health benefits and services. It describes services that are consistent with a diagnosis, meet standards of good medical practice, and are not primarily for convenience of the patient.

**PCCM/Primary Care Case Management** - System that pays primary care providers a monthly fee to coordinate medical services. Especially used by Medicaid.

**PHO/Physician Hospital Organization** - Organization that includes hospitals and physicians contracting with one or more HMOs, insurance plans, or directly with employers to provide medical services.

**PHP/Prepaid Health Plan** - Health organization that receives prepaid capitation payments for a select set of benefits; for example, physician services or lab tests.

**POS/Point of Service Plan** - Health plan whose members can choose their services when they need them, either in the HMO or from a provider outside the HMO at some cost to the

member. Or a plan in which the primary provider directs services and referrals.

**PPO/Preferred Provider Organization** - Managed care organization (MCO) that contracts with a network of providers who deliver services for set fees, usually at a discount to the MCO. PPOs usually sell to insurers and employers and do not assume insurance risk.

**Quality Assurance** - Monitoring and improving health care, either an individual plan or broad health systems review, in a consistent and organized way.

**Reinsurance** - Insurance purchased by a health plan to protect against extremely high medical costs, either for specific groups or individuals.

**Risk** - Refers to the chance that a health plan or a provider takes when they agree to deliver health services to a group of people for a certain payment rate, even if costs for the services exceed the payments.

**Risk Adjustment** - The higher capitation rate paid to providers or health plans for services to a group of enrollees whose medical care is known to be more costly than average.

**Risk-sharing** - Occurs when two parties, usually Medicaid and an MCO, agree through a formula to share any losses that result when medical costs exceed payments.

**SNF/Skilled Nursing Facility** - An institution providing skilled nursing and related services to residents; a nursing home.

**Spend-down** - The process of using up all income and assets on medical care in order to qualify for Medicaid.

**Stop-loss** - A form of health insurance that provides protection for medical expenses above a certain limit.

**SSI/Supplemental Security Income** - Monthly cash assistance for people, including children, who have low incomes, and who meet certain age or disability guidelines. In most states, SSI also includes access to Medicaid.

**Utilization Review** - A series of processes that assure that medically necessary acute inpatient and outpatient care has been provided in the most appropriate and cost-effective settings.

**Waivers** - The result of a process that allows state Medicaid agencies to apply for and receive permission from HCFA to provide services not otherwise covered by Medicaid and/or to do so in ways not described by the Social Security Act. Most Medicaid managed care programs require Waivers. The Waivers, which can differ greatly, are known by their numbers (1115, 1119), or as home-and community-based, or as Katie Beckett Waivers.

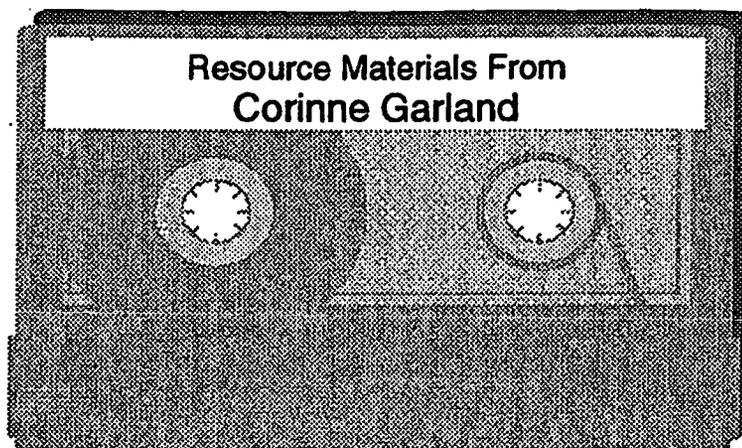
**Legislative Advocacy Tip Series #2**

## Medicaid Managed Care: 20 Questions to Ask Your State

1. What type of managed care waiver is the state seeking?
2. How do I find out about the state's plans?
3. What population groups will be included in the system?
4. How will beneficiaries' choice of providers be limited?
5. What types of quality measures will be used?
6. Do the waiver and contracts spell out the scope of benefits?
7. Is consumer involvement anticipated?
8. What types of monitoring and enforcement are envisioned?
9. Is the state ready for this program?
10. Does the program address cultural and linguistic needs?
11. Is the state seeking a waiver that requires beneficiaries to enroll in managed care?  
*The trend is definitely toward mandatory enrollment.*
12. What types of providers are being included?  
*Is the plan limited to prepaid health plans that meet the requirements of 42 U.S.C. 1396b(m)? Are there special provisions/protections for safety-net providers, such as community health clinics, public health departments, and school-based health clinics?*
13. How will providers be paid?  
*Is the state going to use fee-for-service reimbursement with a case management fee (such as \$3.00 per month per enrollee) or will providers receive pre-set, capitated payments? The trend is decidedly toward latter.*
14. What type of solvency/financial risk arrangements are being used?  
*Is the state adhering to the federal agency's "Medicaid Solvency Guide for Risk-Based Managed Care Plans"?*
15. How does the state assure adequate access to primary and speciality care providers?  
*What is the actual source of the data supporting the state's claims of adequate provider participa:*
16. Are there standards for accessibility, coverage and appointment scheduling?
17. How does the state define an "emergency"?  
*Has the state used the federal Medicare anti-dumping provision definition of an emergency (42 U.S.C. 1395dd) or is the definition more restrictive?*
18. What is the process for marketing and education about the program?
19. Will the program be coordinated with other programs that serve Medicaid beneficiaries?
20. How will grievances and fair hearings be handled?  
*Is the in-plan and out-of-plan grievance process explained clearly?*

This Advocacy Tip lists 20 questions to ask as your state develops Medicaid managed health care. It assumes familiarity with managed care and the Medicaid law. It is excerpted with permission from a 4-page memo available from the National Health Law Program (NHL) which provides further background and additional, more detailed questions for each of the 20 questions. For background discussion, you can use these National Health Law Program manuals: *Section 1115 Medicaid Waivers: An Advocates's Primer (Oct. 1994)*; *An Advocates's Guide to Medi-Cal Managed Care (1994)*; *An Advocates's Guide to Medicaid Case Management Systems (D1988)*; *Toward a Health future - Early and Periodic Screening, Diagnosis and Treatment for Poor Children (April 1995)*.

Jane Perkins and Lourdes Rivera, National Health Law Program, 202-887-5310



**CFIT Abstract: Caring for Infants and Toddlers With Disabilities: New Roles for Physicians Outreach Project**

**CFIT Model CFIT Course Sequence Introductory Seminar**

**Sample 1: Talking to Your Child's Doctor**

**Sample 2: Family-Centered Care Suggestions for Early Intervention Providers Parents Want You To Know**

**Sample 3: Things You Can Do To Help Your Family Cope**

**References and Readings**

**The following additional materials can be requested directly from Corinne Garland or Andrea Quigley at Child Development Resources, Inc. P.O. Box 280, Norge, VA 23127. (757) 566-3300.**

- **Growing Successful Partnerships (August 1996, rev. August 1997)**
- **Communication and Collaboration (August 1996, rev. August 1997)**
- **Three Steps to Improving Your Communication Skills (August 1996, rev. August 1997)**
- **Your Child's Doctor by T. Berry Brazelton, M.D. Excerpted from "Allies in Development," in *Touchpoints: The Essential Reference*, 1992. (Excerpted by CDR August 1996, rev. August 1997)**
- **Building a Good Relationship (August 1996 rev. August 1997)**
- **If Things Are Not Working With Your Pediatrician by Brazelton, T.B. (1992). *Touchpoints: The Essential Reference*. Reading, MA: Addison-Wesley Publishing Co. (pp. 451-455) (Excerpted by CDR August 1996 rev. August 1997)**
- **Trust Differences Partnerships "Building Relationships" by Child Development Resources, Inc. (August 1996, rev. August 1997)**

## Caring for Infants and Toddlers with Disabilities: New Roles for Physicians Outreach Project

Caring for Infants and Toddlers with Disabilities: New Roles for Physicians Outreach Project (CFIT Outreach) is designed to increase physician participation in the early intervention system through replication of a proven model of inservice training. The CFIT model addresses two important needs: the need of families of children with disabilities to ensure the involvement of their physicians in community early intervention systems and the need of physicians to acquire new information and skills in order to be full participants in community-based early intervention teams.

The CFIT model was developed by Child Development Resources working in collaboration with the Virginia Academies of Pediatrics and Family Physicians and colleagues at the University of Virginia School of Medicine. Evaluation data provide evidence of the efficacy of the model in increasing both pediatricians' and family physicians' knowledge and competency as members of early intervention teams. Physicians throughout the country are asking for continuing education to prepare them for new roles in caring for young children with disabilities.

The CFIT model includes three replicable components: State Planning, Introductory Seminars, and Independent Study. The Introductory Seminars and the Independent Study have been approved for continuing medical education credits.

- **State Planning:** CFIT Outreach staff will work with state leadership planning groups composed of Part H representatives, physicians representing state chapters of the American Academies of Pediatrics and Family Physicians, parents, and other key stakeholders to plan the replication process in each state. Using a train-the-trainer approach, interdisciplinary teams will be trained to conduct Introductory Seminars.
- **Introductory Seminars:** Regional seminars introduce physicians to the concepts of a community-based, interdisciplinary, interagency early intervention approach to family-centered services and to the Independent Study.
- **Independent Study:** An independent study manual and accompanying audiotapes provide a knowledge base in four competency areas: child find, developmental evaluation and assessment, IFSP, and transition.

CFIT Outreach, funded by a grant from the Early Education Program for Children with Disabilities (EEPCD), Office of Special Education Programs, U.S. Department of Education, is a program of Child Development Resources, Inc. (CDR). For more information, please contact Andrea C. Quigley, Coordinator or Barbara A. Kniest, Co-Director.

**CFIT MODEL**

**CFIT COURSE SEQUENCE**

**INTRODUCTORY SEMINAR**

**OUTCOME:** An understanding of the need for competency-based training based on the change in physicians' roles as a result of Part H of IDEA and increased commitment to participate in the Independent Study Program.

PURPOSE	METHOD	INSTRUCTIONAL TECHNIQUE	INSTRUMENTATION	TIME
To provide an overview of the changing roles of physicians as a result of Part H of IDEA with regard to: <ul style="list-style-type: none"> <li>▸ Child Find</li> <li>▸ Assessment</li> <li>▸ IFSP</li> <li>▸ Transition</li> </ul>	Group Training	<ul style="list-style-type: none"> <li>▸ Interdisciplinary Panel (Physician, Parent, and Early Intervention Service Provider)</li> <li>▸ Group Discussion</li> <li>▸ Handouts</li> </ul>	<ul style="list-style-type: none"> <li>▸ Introductory Seminar Evaluation</li> </ul>	3 Hours

**INDEPENDENT STUDY AND TECHNICAL SUPPORT**

**OUTCOME:** A strong knowledge base in each of the four competencies.

PURPOSE	METHOD	INSTRUCTIONAL TECHNIQUE	INSTRUMENTATION	TIME
To provide detailed information for each of the four areas of competencies (Child Find, Assessment, IFSP, and Transition)	Individual Learning	<ul style="list-style-type: none"> <li>▸ Written Materials</li> <li>▸ Audiotapes</li> <li>▸ Technical Support</li> </ul>	<ul style="list-style-type: none"> <li>▸ Physician Knowledge Pre/Post Measure</li> <li>▸ Physician Competency Pre/Post Measure</li> <li>▸ Independent Study Manual and Audiotapes Evaluation</li> </ul>	6 Weeks

## REFERENCES AND READINGS

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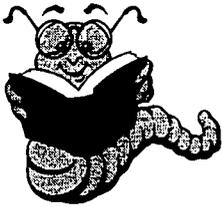
Winton, P.J. (1988a). Effective communication between parents and professionals. In D.B. Bailey and R.J. Simeonsson (Eds.), *Family assessment in early intervention*. Columbus, OH: Merrill Publishing Co, 207-228.

SAMPLE 1

# TALKING TO YOUR CHILD'S DOCTOR

## Suggestions from Families

- **Prepare questions or concerns before your visit.**



Be informed, do homework, and analyze your questions and concerns.

Keep a set of all your medical records in one place (notebook, folder, etc.).

Take records with you for appointments in case they are not sent ahead from sending sources.

Bring articles, information, or ideas in written form to help you tell the physician about the directions or goals you have for your child and family.

Be clear with yourself about what answers you need.

Use a Questions & Concerns worksheet (see sample)

Bring a written list, write down pertinent information about your child.

Go over your list with physician.

Ask the most important questions first, and, if time is limited, ask the physician to respond to the other questions later.

Ask the physician what he knows of your child's story and fill the gaps.

Ask specifically what the doctor knows and correct any misinformation.

Although repetition can be frustrating, have a brief summary ready to tell physicians, to highlight specific medical or health information for the visit.

Learn some professional language (words doctors use) so that you can talk in a way that they can understand.

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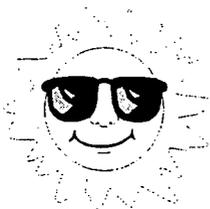
**Prepare the physician.**

Call before hand. Let the physician know that you have many questions and that you need an extended visit.

Send relevant information or share your questions before the visit.  
*Physicians generally respond well to any efforts to share helpful information ahead of the appointment time or during the appointment.*

Establish your credibility with the physician early in your relationship.  
*Let her know what you want for your child and that you want her help in knowing how to provide care and treatment.*

- **Recognize the positive.**



Let the physician know what you like and appreciate about his attention to your child.

"Icky" but effective...flatter, praise, and show appreciation.

Celebrate successes.

Share pictures of child or her accomplishments.

Keep the physician informed of your child's new skills and accomplishments.

Share your view of the situation.

- **Express personal, cultural, or religious beliefs.**

Beliefs that will affect your response to the physician's suggestions are important for her to know.



Find a physician who will work as you like and with whom you will feel comfortable.

- **Take notes.**

Review notes with physician.

Be sure you both understand the same thing.



- **Bring reinforcements.**

A spouse, friend, relative. Anyone who will help you with the visit.  
*Help listen. Help remember. Help care for your children.*

Identify your patient advocate, a valuable resource and support,  
especially when working with many physicians.

- **Give your physician the handout "What Parents Want You to Know..." (Sample attached)**



List characteristics of you or your family that you want your physician to know when you work together.

*Adapted from:*

Moore, D. and Ramsey, L. "Forging Family/Professional Partnerships in New Ways," FAST! (Families Are Special, Too!) Conference, April 1996,

The PARTners Plus Project, U.S. Department of Education, Early Education Program for Children with Disabilities, Grant Number HO24B40032, Child Development Resources, Inc., Norge, VA.

**TAKING CHARGE: A PARENTS' GUIDE TO HEALTH CARE FOR CHILDREN WITH SPECIAL NEEDS.** The Parent Education Advocacy Training Center & The ARC of Northern Virginia, 1993.

SAMPLE 2

**Family-Centered Care  
Suggestions for Early Intervention Providers**

**PARENTS WANT YOU TO KNOW...**

- The more I know, the less fearful I am about my child's condition - I can then be able to explain my child's condition to family/friends.
- Give me information that will help me understand and prepare for future meetings (IFSP/IEP) concerning my child and our family. Give information to me in written form as well as verbally. Having information in a booklet helps me to make good decisions.
- Please allow time for explanations/demonstrations. Dealing so intensely with so many professionals is very overwhelming. (Use a video or other audio/visual techniques to enhance understanding.)
- Explain "alphabet" terms and abbreviations. Answer my questions in terms that I can understand. Be willing to say "I don't know but I will try to find that information out for you" - and I will respect you for your integrity.
- I may not be a professional but I can understand the information if it is explained in easily understood language. Although I may be a professional, do not assume I have all of the needed information.
- Don't expect me to understand all of the information you have provided at one time. Remember that with time, I will understand and remember more.
- Listen to my ideas/concerns. I have observed my child and know her better than anyone else. Don't feel threatened if I question your knowledge or authority - I'm just trying to provide my child with the best care.
- Treat my child as a person instead of a diagnosis or label. Hold or touch my baby lovingly.
- Try to communicate with other professionals who work with my child. It is too frustrating and confusing to be getting conflicting ideas on positioning, feeding techniques, etc.

- Help me meet other parents who have children with specific needs. I may welcome the support and recommendations concerning the ifsp process from someone who has already experienced it.
- Understand that if I am having difficulty focusing on my child's developmental needs, there may be other important matters such as the needs of other family members, financial concerns, or health issues that require my attention.
- Talk to me - not at me. I want to be an equal partner with you in providing the best services for my child.
- Feel that you can voice your concerns/ideas, but don't expect me to agree with your judgements about my child or my family.
- Realize that although my child has a disability, she is part of a family who enjoys outside interests and activities. Help me to incorporate your suggestions into our family's life.
- Remember that our family is unique. We are different from other families - with different needs, abilities, styles, personalities and values.

***TAKEN/ADAPTED FROM PARENT PROFESSIONAL PARTNERSHIP***

**The Parent Professional Partnership is funded by the  
Developmental Disabilities Planning Council  
of the Commonwealth of Pennsylvania  
Children's Hospital of Pittsburgh, September, 1991**

SAMPLE 3

# THINGS YOU CAN DO TO HELP YOUR FAMILY COPE

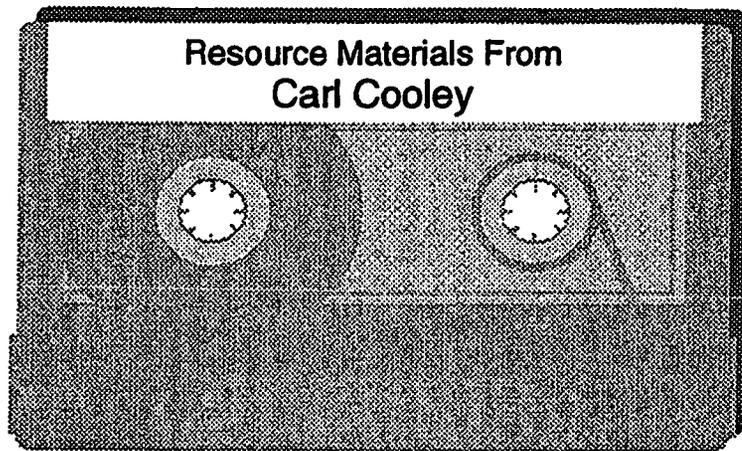
## FACTORS THAT CONTRIBUTE TO FAMILY RESILIENCE

- **Balance special needs with family needs**
- **Develop communication competence**
  - Understand new terms and language
  - Express feelings openly
  - Do not blame
  - Express anger and fear
  - Resolve conflicts
  - Share positive feelings of caring & commitment
- **Attribute positive meanings to situations**
- **Make a commitment to your family**
- **Engage in active coping efforts**
  - Face problems directly
  - Learn about your child's condition and find services
  - Balance & decide which family needs are most important
- **Maintain social contacts**
- **Collaborate with professionals**
  - Share information
  - Decide together
  - Take risks together
  - Respect differences between each other

*Adapted from:*

Patterson, J. (1991). Family Resilience to the Challenge of a Child's Disability. *Pediatric Annals*, Vol. 20, No.9, September 1991

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**Accessing Developmental and Psychological Training Project (ADaPT):  
Blending Community-Based, Family-Centered Consultation to Early Care and  
Education Professionals With a Traineeship for Primary Care Physicians**

**Accessing Developmental and Psychological Training Project (ADaPT):  
Blending Community-Based, Family-Centered Consultation to Early Care and  
Education Professionals With a Traineeship for Primary Care Physicians**

**Programs Benefit Doctors, Kids, and Communities**

**The Pediatric Leadership Conference Newsletter Improving Community-  
Based Services For Families of Children With Special Health Care Needs**

**Reference List**

Accessing Developmental and Psychological Training Project  
(ADaPT): Blending Community-Based, Family-Centered  
Consultation to Early Care and Education Professionals With a  
Traineeship for Primary Care Physicians

**ABSTRACT**

The primary goal of the ADaPT Project is to significantly enhance the capacities of community-based primary care pediatricians and family practitioners to recognize and respond to the developmental concerns of infants, toddlers, and preschool children and their families and to work collaboratively and effectively with community-based teams providing early intervention and preschool special education services. This goal is realized by 1) providing an innovative, effective training opportunity for primary care physicians in areas relevant to best practices in developmental pediatrics, and 2) providing specific consultative and technical assistance support to early intervention and preschool special education programs.

Physician trainees complete a year long, short-term course in developmental pediatrics consisting of 12 (once a month) full-day, mentored, community-based clinical experiences, a curriculum of readings and seminar discussions, and a role as a pediatric consultant during the training year to the community's early intervention and preschool special education professionals. Each monthly training day consists of a morning spent with the local early intervention program(s), a noon conference open to community professionals and parents, which is presented by the project's teachers/mentors or other invited speakers, and an afternoon session spent with the local preschool special education program. Observations/consultations provide the focus for the morning and afternoon case-based training sessions. The teachers/mentors are drawn from the staff of the Hood Center for Family Support and Dartmouth Center for Genetics and Child Development at the Children's Hospital at Dartmouth.

The ADaPT Project also convenes an annual fall leadership conference for the physician trainees as well as selected parents and early intervention and preschool professionals from the participating communities. The conference has a theme of national significance and features a visiting consultant/facilitator who is nationally recognized as an authority on the chosen topic. Participants meet with families, state agency policy-makers, and project faculty to identify and prioritize needs and to develop an "action agenda" regarding systems change.

The ADaPT Management Team consists of representatives from the state agencies collaboratively funding the project, a parent, a primary care pediatrician, the Project Director and the Project Manager. The Management Team meets quarterly to review the project's accomplishments and refine plans for future stages of the project.

Funding for ADaPT is provided at the federal level by the Maternal and Child Health Bureau. State collaborative funding is provided by the NH Infants and Toddlers Program, the NH Division of Mental Health and Developmental Services, the NH Department of Education, the NH Bureau of Special Medical Services, the NH Division of Children, Youth, and Families, and the NH Developmental Disabilities Council.

For further information please contact either the Project Director, W. Carl Cooley, MD or the Project Manager, Nancee E. Tracy, Ed.M. at:

Hood Center for Family Support  
Children's Hospital at Dartmouth  
One Medical Center Drive  
Lebanon, New Hampshire 03756  
(603) 650-4419

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*Accessing Developmental and Psychological Training Project (ADAPT): BLENDING  
COMMUNITY-BASED, FAMILY-CENTERED CONSULTATION TO EARLY CARE  
AND EDUCATION PROFESSIONALS WITH A TRAINEESHIP FOR PRIMARY  
CARE PHYSICIANS*

**GOAL:**

The aim of the ADaPT Project is to significantly enhance the capacity of early childhood professionals providing early intervention, education, and primary health care services to:

- recognize and respond to developmental concerns of young children
- support and collaborate with families
- work more closely and effectively across disciplines and agencies in community-based settings

**PHILOSOPHY:**

- Community-Based
- Family-Centered
- Training and Technical Assistance Process

**ELEMENTS:**

- Monthly Training Days
- Mentored Traineeship for Local Physicians
- Technical Assistance and Support to Community Providers
- Annual Conference

**TRAINING DAYS:**

- Consultation and technical assistance to early intervention and preschool
- Noon conferences
- MD seminars

**TECHNICAL ASSISTANCE AVAILABLE:**

- Observation/Consultation
  - \* Home Visit
  - \* Preschool Site Visit
  - \* Child Care Site Visit
- Case Reviews
- Case-Based Discussion
- Topical Discussion

**MENTORED TRAINEESHIP:**

- Local Primary Care Physician
- 12 Month Commitment
- Participate in All Training Days in Community
- Complete Twelve Module Curriculum
- Orientation to state MCH/Title V programs and personnel
- Provide Developmental Pediatric Support in Community/Training Year
- Attend Annual Conference
- CME Credit (70 Category 1 credits) and Stipend (\$4800/year)

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**ANNUAL CONFERENCE:**

- Two day meeting
- National Speaker
- Community-Based Teams Including Parents
- Problem Solving Format
  - \* Presentations
  - \* Facilitated Discussions
- Collaborative Action Plan To Implement
- Topics:
  - \* Year 1: Community Collaboration and Partnerships
  - \* Year 2: PDD/Autism
  - \* Year 3: Emotional Health/Behavioral Challenges

**NOON CONFERENCE TOPICS:**

- Overview of Developmental Disabilities
- Down Syndrome
- Prematurity and Developmental Outcomes
- The Quality of Interactions Between Parents & Children
- PDD: Pervasive Developmental Disorder
- Pediatric HIV
- Neurologically Based Behavior Syndromes
- ADHD: Attention Deficit/Hyperactivity Disorder
- The Stanley Greenspan Approach to Developmental Assessments and Interventions
- Failure to Thrive
- The Undiagnosed Child

**CURRICULUM MODULES:**

- Overview of Developmental Disabilities: Prevalence, Definitions, and the Biopsychosocial Model
- Family Support, Family Centered Care, and the Influence of Cultural Diversity
- Developmental Screening and Assessment
- Cerebral Palsy and Other Neuromotor Disorders
- Mental Retardation
- Language Disorders
- PDD/Autism and Infant/Toddler Mental Health
- Prenatally Determined Conditions Affecting Development: The Role of Genetics and Prenatal Exposure to Teratogens
- Developmental Outcomes of Low Birth Weight and Prematurity
- Attention Deficit / Hyperactivity Disorder
- Developmental / Educational Interventions
- Health Care for the Child with a Disability: Primary Care Roles and Financing Issues

**OUTCOME:**

The interaction of primary care physicians, parents and early care and education professionals through the ADaPT continuing education process has enhanced services to families, fostered new community relationships and alliances, and created a collaborative environment for community action.

## VITAL SIGNS

### Programs benefit doctors, kids, and communities

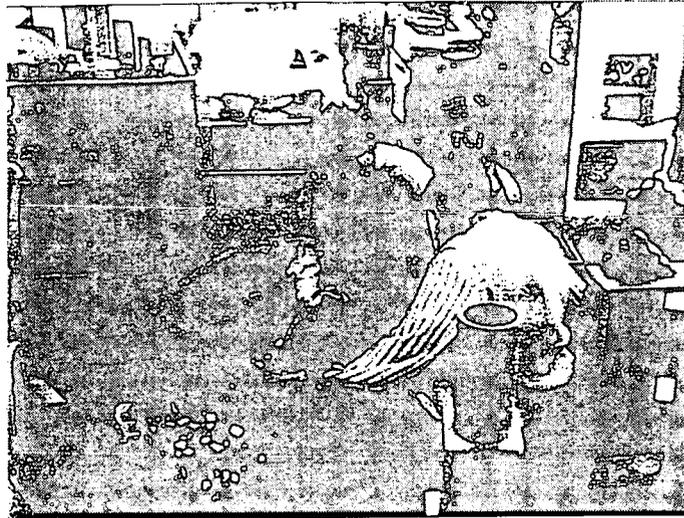
Jim McGuire, M.D., a pediatrician at the Hitchcock Clinic in Keene, N.H., had treated a local child with muscular dystrophy quite often. But it wasn't until he began spending time at the child's preschool, as part of a new program organized by DMS's Hood Center for Family Support, that McGuire heard about other obstacles the child faced: a learning disability, family difficulties, and housing problems.

"Usually the child is in the clinic for a specific problem," McGuire says. "It was nice to have the time to spend talking to people about the other issues."

Called ADaPT — Accessing Development and Psychological Training — the program works to bring together doctors with preschools and early intervention programs. This match, program organizers hope, will make doctors more sensitive to the needs of developmentally disabled children and their families.

**Nonmedical issues:** "I think that they saw that they needed to organize their time a little differently for kids with complicated problems," says Carl Cooley, M.D., the interim director of the Hood Center. "I think they recognized that there are nonmedical issues to talk about during those visits: How's the family adapting? What's the financial situation? Do they need a time away from the demands of their child?"

At the same time, Cooley adds, the pediatricians have something



When physicians Nancy Van Vranken, right, and Carl Cooley sit down to "play," it's serious business — part of a program to aid children with disabilities.

to offer special education programs. Such programs need regular pediatric advice, from interpreting medical diagnoses to knowing how soon they can visit a child with chicken pox. —

The \$150,000 program is funded by state and federal grants. Last year, three community doctors completed the program. Two more, including Nancy Van Vranken, M.D., a pediatrician at the Lahey Hitchcock Clinic in Concord, began in January.

"It's wonderful to be able to really sit down and spend time and not feel the pressure of another patient in the waiting room and a stack of files on your desk and another phone call you have to make," Van Vranken says.

Among physicians, interest in ADaPT has been far greater than the space available. When the project began, Cooley sent an informational letter to the state's 120 pediatricians; within 48 hours, he had heard from nearly 40.

Doctors in the program spend a day a month with a mentor, visiting local preschools and early intervention programs. At noon-

time, mentors host a conference, open to the community, on a related topic — for instance, Down syndrome or autism. Doctors also receive a list of readings about developmental disabilities.

**Coping:** "I'm hoping physicians will feel more sensitive to the point of view of families who are coping with meeting the needs of a child with a disability," Cooley says of the program's intended effect. "And that they'll see the need to collaborate in the care of kids, that it really requires a team. The communities have teams, but they don't tend to work together as effectively as they could."

McGuire's stint in the project ended in December. But he found the work so useful that he is continuing monthly meetings at the preschool and plans to organize more noon conferences.

"He sort of represents the extreme of a successful outcome," Cooley says. "He's identified himself in the community as somebody who is willing to work with the nonmedical people and be a resource to them."

The ADaPT project is one way

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# The Pediatric Leadership Conference

Improving Community-based Services  
For Families Of Children  
With Special Health Care Needs

What are the best ways to meet the primary health care needs of children with disabilities and their families?

A unique gathering of New Hampshire pediatricians, parents and professionals met in March of 1992 to try to answer this question. This was the first Pediatric Leadership Conference ever held.

The purpose of this Conference was to galvanize a small group of primary care physicians around improving community-based services for families of children with special health care needs.

The Pediatric Leadership Conference was designed to develop a positive approach and promote a sustained impact. Discussions included how the relationship between a physician and a family may lead to a valuable partnership in the pursuit of health.

Declared a success by all the participants, the programs resulting from the Conference continue to improve community-based services for children with special health care needs and their families in New Hampshire.

*No one in Medical School  
ever taught us the little things  
that are important.*

—Greg Prazar, MD



Greg Prazar, MD, with Peter Roginski and his mother

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# Making A Difference

## For Families With Children With Disabilities

A source of accessible, primary health care in their own community is a crucial support element for families of children with disabilities.

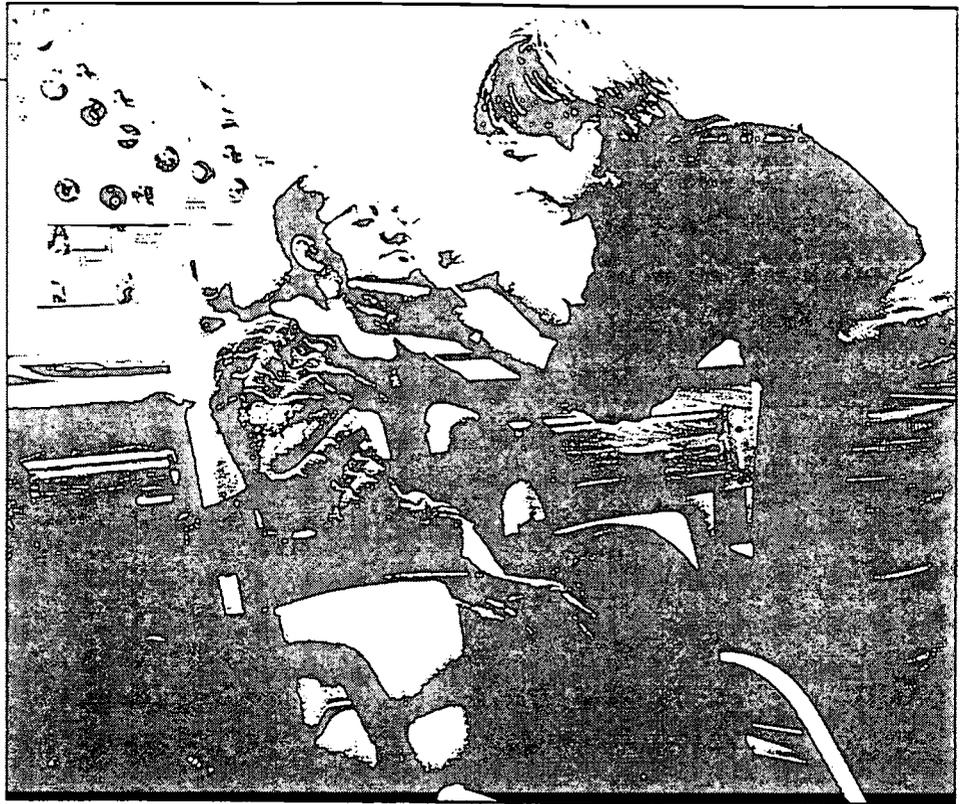
The Surgeon General's Report of June 1987 described family-centered, community-based, coordinated care. That description has provided a measure for the evaluation of present services and future needs. Similarly, Part H of the Individuals with Disabilities Education Act acknowledges the importance of community-based health care services and the role of primary physicians on the local interagency team.

Policy and legislation at the federal and state levels have encouraged moving the health services for children with special needs away from specialized, tertiary care clinics and back to the community while also examining ways of enhancing the resources of communities to provide the best possible care.

It is known that families play a central role in the identification of needs and the assessment of services.

Community-based service providers have been encouraged to collaborate and communicate with one another.

The meaningful involvement of private primary health care providers in this process has been a challenging element of every model project and technical assistance effort.



Nancy Van Vranken, MD, with patient

### A Positive Approach

To examine and enhance the role of primary care physicians caring for children with special needs and their families, the Dartmouth Center for Genetics and Child Development (a part of the New Hampshire University Affiliated Program) and the New

Hampshire Pediatric Society received funding for a pilot project from the New Hampshire Infant and Toddler Project (New Hampshire's federally funded planning project for Part H of the Individuals with Disabilities

Education Act).

Many efforts aimed at primary physicians in other states have involved large-scale, continuing education conferences or programs with equal participation by physicians, families and early intervention professionals. Some of these efforts served only to highlight differences among the perspectives, needs and goals of the participants. Often the focus became frankly critical of health care providers and health care services.

In order to develop a more positive approach and in the hope of promoting a sustained impact (rather than a single event or conference), a leadership training model was developed.

*Let's be helpful and  
inventive.*

*—Participating Physician  
NH Pediatric Leadership  
Conference*

## Participants

The primary participants were community-based pediatricians and family practitioners from the communities served. In New Hampshire, 24 community-based pediatricians and family practitioners were selected, two from each of the twelve developmental services regions of the state.

The secondary participants included parents, intervention professionals, key state-level administrators, and a knowledgeable and

capable group facilitator. The secondary participants for the New Hampshire Pediatric Leadership Conference included four parents and two early intervention professionals. The state-level administrators included the Commissioner of Health and Human Services. Margo Peter, M. Ed., Project Manager of the Hawaii Medical Home Project, acted as the group facilitator.

The primary and secondary participants formed the core faculty for the conference.

*I was overwhelmed, surprised and honored by the invitation (to join the Leadership Conference). It made me decide I wanted to stay in clinical practice. It had a profound effect on my life.*

—Dixon Turner, MD



## Selecting Participants

In order to bring together a group of physicians with established interest or commitment to the task at hand, a nomination process was used.

Families receiving early intervention or family support services in the area served were asked to nominate their own pediatrician or family physician if they felt that they had received particularly special care and attention. Nomination forms were circulated to families requesting their reasons for nominating their physician and asking for some anecdotal examples of the special care they had received.

Primary participants were selected from the recommendations of the returned nomination forms. In New Hampshire, about 60 nomination forms were returned recommending 40 different physicians. Based on the number of nominations received and the compelling qualities of the anecdotes, 24 physicians were identified and invited to the conference.

Invitations were in the form of a congratulatory letter to the physicians for having been recognized by families utilizing their practices. All but one of the physicians

responded enthusiastically in New Hampshire, and 18 were able to attend the conference. Several were obviously moved emotionally by this acknowledgment of their efforts to provide high quality care.

### Promoting A Sustained Impact

The Conference format combined background and content presentations by the core faculty with two periods of facilitated discussion by the group as a whole. The family perspective was the subject of both a keynote address and an after dinner panel discussion by parents. The facilitated discussion

*I began to feel more comfortable looking at care from a broader sense than strictly medical needs.*

—Nancy Van Vranken, MD

sessions were intended to provide the primary participants (the physicians) with a sense of investment in the issues raised.

The first discussion at the New Hampshire Pediatric Leadership Conference focused on identifying best practices and the obstacles to best practice in the provision of primary health care to children with special health care needs. The second session asked the participants to identify action steps and commit themselves to a process of addressing those steps.

The conference concluded with the identification of areas of need and the development of action plans to identify and pursue possible, achievable goals.

### The NH Success Story

The New Hampshire Pediatric Leadership Conference was held on March 12 and 13, 1992, as an overnight retreat at a rustic

Adirondack lodge on the shores of Squam Lake in Holderness, NH.

The agenda mixed the format described above with opportunities

for informal discussion and mutual support. The entire proceeding was recorded on video tape.

The process and outcome were deemed a success by all of those involved.

Considering that the assembled group of physicians represented "best practice" in the eyes of families, their knowledge of the community and state-wide systems of support for families was extremely limited. (Only 2 of the 18 physicians knew in which developmental services region they practice; only 1 physician knew about the state's regionalized system of family support services and how to access it.)

### Conference Conclusions

The conference concluded with the physicians identifying three areas of need:

- 1) Information (about services, about families, about disabilities; about conveying information to their colleagues);
- 2) Support (among themselves around the challenges to

the provision of good care in today's communities); and

- 3) Action (as a group and as individuals to have an impact on services in their communities and

in the state).

The conference participants wished to establish themselves as a group and to continue to meet over the next year. They planned

to identify and pursue concrete, achievable goals and hoped to meet at a follow-up retreat after a year.

*There was a hand-shake on mutual grounds. A partnership was forged.*

—Kathy Mandeville  
Parent

### The Results

The Dartmouth Center for Genetics and Child Development, the NH University Affiliated Program and the New Hampshire Pediatric Society planned for the continued support of these pediatric leaders around the areas identified at the conference. Quarterly meetings of the group have continued combining a format of continuing education in areas such as family support, reimbursement for services, inclusion, and life-span perspectives with an agenda of action and involvement for the group.

The video tape footage of the Squam Lake meeting was edited into an educational tool for use at community hospital pediatric staff meetings, for teaching residents and medical students, and for review by policy makers.

A second two-day retreat was held in September 1995.

The New Hampshire University Affiliated Program pioneered and continues to use this leadership training format to develop leadership skills among parents, educators, school administrators and day care providers.

The Pediatric Leadership Conference participants now constitute the Committee on Children with Disabilities of the NH Pediatric Society.

*Families know their children better than specialists. Families often have the answers.*

—Greg Prazar, MD

# The ADaPT Project

“Accessing Developmental and Psychological Training”

*A Direct Result Of The NH Pediatric Leadership Conference*

The primary goals are:

- 1) to significantly enhance the abilities of community-based primary care pediatricians and family practitioners to recognize and respond to the developmental concerns of infants, toddlers and preschool children and their families, and
- 2) to work collaboratively and effectively with community-based teams providing early intervention and preschool special education services.

These goals will be realized by:

- 1) providing an innovative, effective training opportunity for primary care physicians in areas relevant to best practices in developmental pediatrics, and
- 2) providing specific consultative and technical assistance support to early intervention and preschool special education programs.

## The Training

Physician trainees complete a year long, short-term course in developmental pediatrics consisting of twelve full-day, mentored, community-based clinical experiences, a curriculum of readings and seminar discussions, as well as a role as a pediatric consultant to the community's early intervention and preschool special education professionals.

Each monthly training day consists of three sessions. The morning is spent with the local early intervention program(s). The noon conference, open to community professionals and parents, is presented by the project's teachers/mentors or other invited speakers. The afternoon session is spent with the local preschool special education program.

Evaluations of consultations about children enrolled in the early intervention and preschool programs provide the focus for the morning and afternoon case-based training sessions.

The teachers/mentors are chosen from the staff of the Dartmouth Center for Genetics and Development at the



Dartmouth-Hitchcock Medical Center.

## The Annual Conference

The ADaPT Project also convenes an annual fall leadership conference for the physician trainees and selected early intervention and preschool professionals from the participating communities. The annual conferences each have a nationally significant theme and feature a visiting consultant and facilitator who is nationally recognized as an authority on the chosen topic. Participants meet with families, state agency policy-makers and project faculty to identify and prioritize needs, and to develop an “action agenda” regarding systems change.

## The Management Team

The ADaPT Management Team consists of representatives from the state agencies collaboratively funding the project, a parent and a primary care pediatrician, the Project Director and Project Manager. The Management Team meets quarterly to review the project's accomplishments and refine future plans of the project.

## Funding

Funding for ADaPT is provided at the federal level by the Maternal and Child Health Bureau. State collaborative funding is provided by the NH Infants and Toddlers Program; the NH Division of Mental Health and Developmental Services; the NH Department of Education; the NH Bureau of Special Medical Services; the NH Division of Children, Youth and Families; and the NH Developmental Disabilities Council.

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NH University Affiliated Program  
Dartmouth-Hitchcock Medical Center  
One Medical Center Drive  
Lebanon, NH 03756



The Pediatric Leadership Conference  
is sponsored by the  
Hood Center for Family Support,  
a component of the  
New Hampshire University Affiliated Program.

*The role of the primary care physician  
has been broadened as the concept of managed care  
has taken root. That role, particularly in the case of children  
with any significant kind of special health care needs  
and/or disability, has not yet been supported by  
medical education. The Leadership Conference aims to improve  
their comfort and develop models for their involvement.*

—W. Carl Cooley, MD

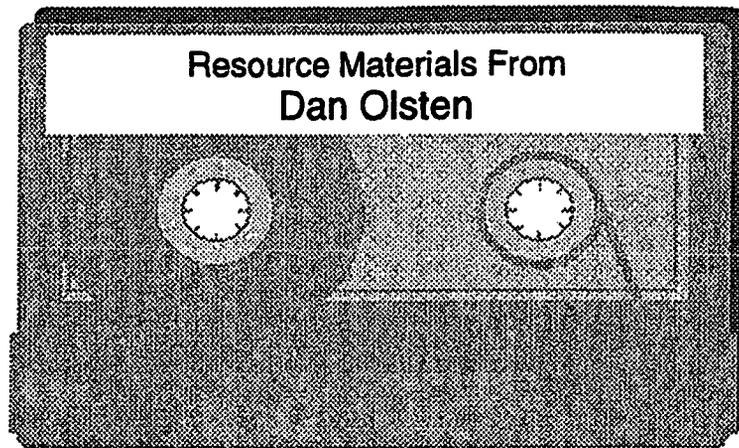
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*We have to be advocates to  
help families break through  
artificial barriers.*  
—Participating Physician  
NH Pediatric Leadership Conference

**It's the little things  
that count.**



**Overview of Harvard Pilgrim Health Care**

**Collaboration Between Early Intervention and Harvard Pilgrim Health Care**

**Developmental Consultation Services (Coordinating Services With an HMO)**

## *Successful Strategies for Working with the Medical / Health Care Communities to Ensure Early Identification of Children with Special Needs*

*A National Conference Call  
Wednesday October 1, 1997*

- ➔ *Overview of Harvard Pilgrim Health Care*
- ➔ *Collaboration between Early Intervention and  
Harvard Pilgrim Health Care*
- ➔ *Developmental Consultation Services  
(Coordinating services within an HMO)*

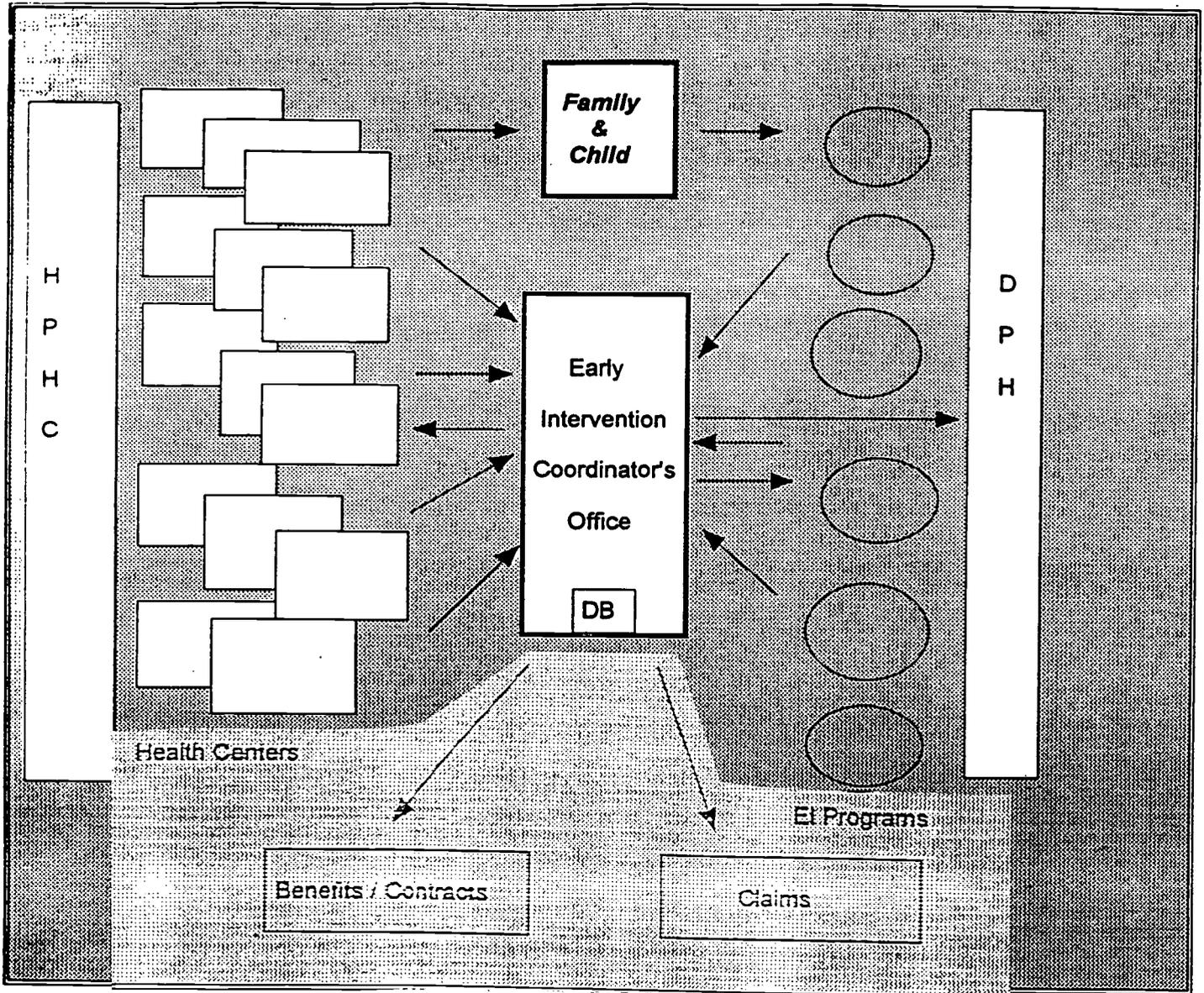
*Dan Olsten  
Harvard Pilgrim Health Care*

## *Harvard Pilgrim Health Care - Overview*

- ◆ Largest provider of Managed Care in New England
- ◆ 8,000+ employers offer HPHC to their employees
- ◆ Provides coverage to 1.1 million members in New England
- ◆ Fully accredited by NCQA
- ◆ Network includes 19,000 doctors and 110 hospitals <sup>62</sup>

## *Harvard Pilgrim Health Care - Overview*

- ◆ Physician practice in many settings:
  - ◆ - Multi-Specialty Health Centers
  - ◆ - Group Practices
  - ◆ - Community Health Centers
  - ◆ - Local Private Practices
  
- ◆ HPHC Foundation
  
- ◆ 8,000 employees
  
- ◆ Combined revenues of \$2.04 billion



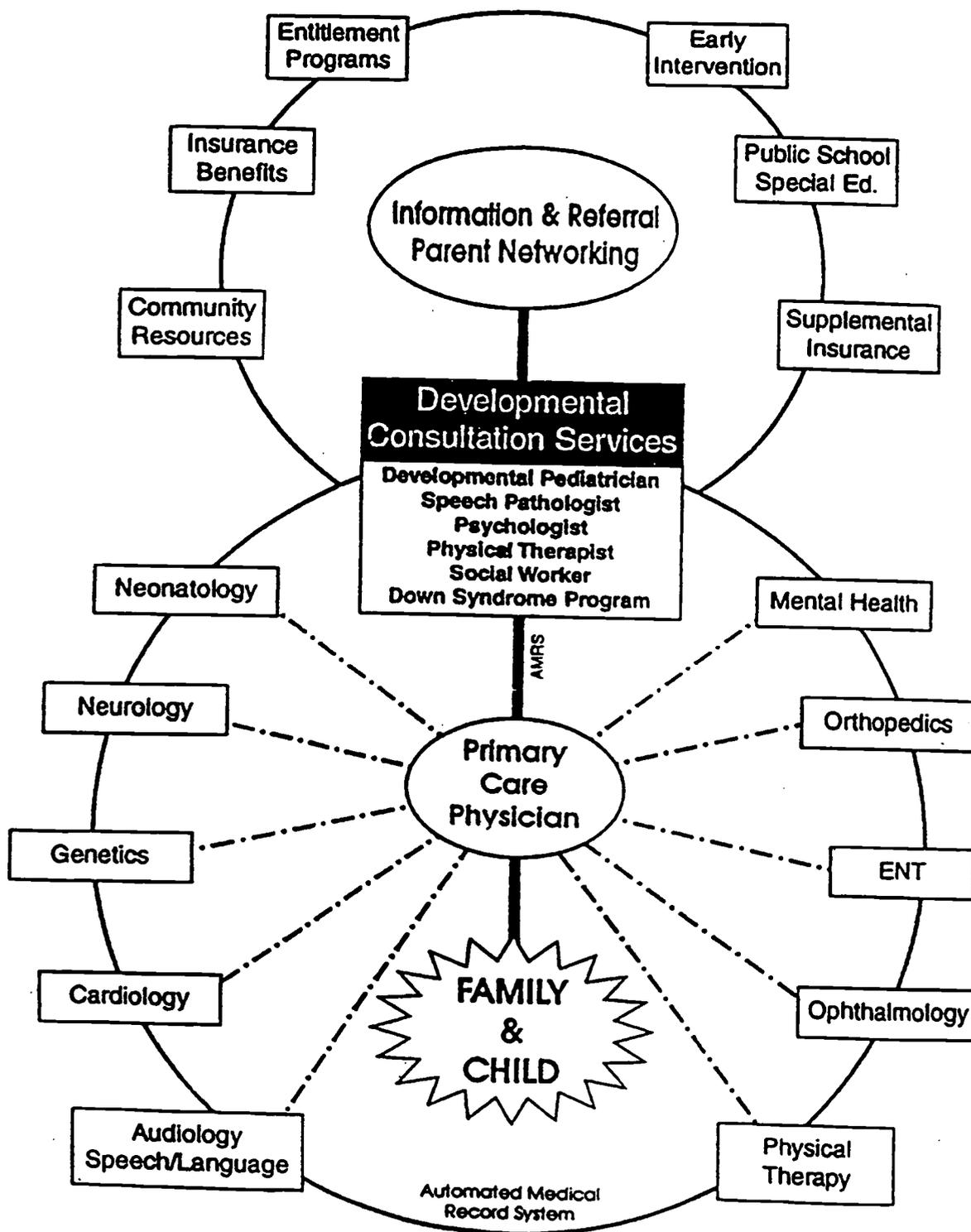
### Single Point of Entry

### HCD Early Intervention Coordinator's role

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Program	Last Name	HCHP ID#	First Name	DOB	Ref Start	Ref End	Referred For
Middlesex				/96	7/10/97	7/10/98	Treatment
Middlesex				/96	10/28/96	10/28/97	Treatment
Middlesex				'95	9/27/97	2/07/98	Treatment
Middlesex				1/96	9/15/97	9/15/98	Treatment
Middlesex				1/95	1/09/97	1/09/98	Treatment
Middlesex				1/95	7/01/97	3/09/98	Treatment
Middlesex				1/96	6/18/97	6/18/98	Treatment
Middlesex				/94	10/31/96	10/31/97	Treatment
Middlesex				/94	10/03/96	3/30/97	Treatment
Middlesex				/96	6/10/97	8/10/97	Screen/Assessment
Middlesex				/95	7/14/97	9/14/97	Screen/Assessment
Middlesex				/94	1/17/97	8/31/97	Treatment
Middlesex				/95	7/28/97	5/19/98	Treatment
Middlesex				/95	7/10/97	9/10/97	Screen/Assessment
Middlesex				/97	9/01/97	9/01/98	Treatment
Middlesex				/97	9/01/97	9/01/98	Treatment
Middlesex				/97	4/07/97	6/07/97	Screen/Assessment
Minute Man				/94	6/23/96	6/23/97	Treatment
Minute Man				/94	8/14/96	8/14/97	Treatment
Minute Man				/95	8/11/97	10/11/97	Screen/Assessment
Minute Man				/96	6/29/97	6/29/98	Treatment
Parents with Toddlers				/94	1/31/97	3/10/97	Treatment
Parents with Toddlers				/97	5/09/97	5/09/98	Treatment
Parents with Toddlers				/95	7/02/97	9/02/97	Screen/Assessment
Parents with Toddlers				/95	8/10/97	2/03/98	Treatment
Parents with Toddlers				/95	6/24/97	6/24/98	Treatment
Parents with Toddlers				/95	6/24/97	6/24/98	Treatment
Parents with Toddlers				/95	4/26/97	4/26/98	Treatment
Parents with Toddlers				/96	6/12/97	6/12/98	Treatment
Parents with Toddlers				1/95	6/16/95	12/31/95	Treatment
Parents with Toddlers				1/94	4/01/96	1/03/97	Treatment
Pentucket Area							





**Holistic Approach to  
Caring for a Child  
with  
Special Health Care Needs**

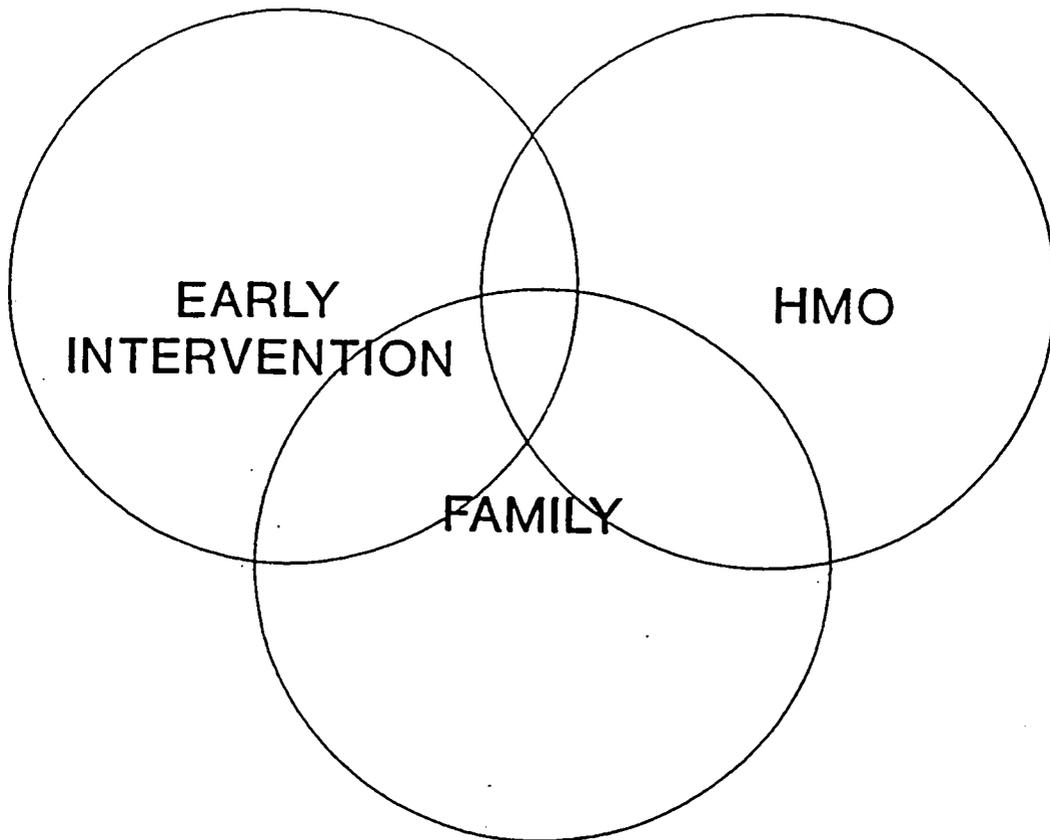
## DEVELOPMENTAL CONSULTATION SERVICES

### OUR MISSION

The Developmental Consultation Services is an interdisciplinary team dedicated to promoting the health, abilities, and achievement of children with, or at risk for, chronic physical and/or developmental concerns.

Through periodic consultation and ongoing care coordination, we assist and support families and health care providers in advocating effectively for children whose needs often extend beyond the health care system into the home and community.

**EFFECTIVE COLLABORATION INVOLVES A  
FINELY TUNED, FLEXIBLE AND ONGOING  
INTERSECTION OF THESE SYSTEMS.**





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