The Family Voices of California Parent Health Liaison Manual

a guide for providing Parent Health Liaison Services in the community

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California HealthCare Foundation

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Parent Health Liaison Manual

Table of Contents

Forward

In 2002 the California HealthCare Foundation provided funding for the Family Voices of California Council to develop a statewide, user-friendly manual for providing Parent Health Liaison Services. The process included gathering information from a number of sources and coming to consensus about the scope of work and best practices for staff providing Parent Health Liaison services as an integrated service component of a Family Resource Center (FRC).

Purpose Statement

The purpose of the project is to create an easy-to-use guide that addresses family centered care through the provision of Parent Health Liaison services. This manual:

- Identifies a common vision of Parent Health Liaison services
- Sets standards for quality
- Builds consistency/uniformity for staff providing Parent Health Liaison services
- Is a tool for Family Resource Centers and Parent Centers to use in training staff
- Clarifies the role of Parent Health Liaison services for health care agencies

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* For a definition of Family Resource Centers and Parent Centers please see "Attachments."

1. Family Centered Care

Contents:

- Definition of Family
- Definition of Family Centered Care
- Elements of Family Centered Care
- Key Indicators of Family Centered Care
- Principles of Family/Professional Collaboration
- Indicators of Cultural Responsiveness

Use this chapter to:

- Familiarize yourself with Family Centered Care Practices
- Review with potential or recently hired staff who will provide Parent Health Liaison services so they understand their role in facilitating family centered care
- Assess the ability of your program to provide family centered care
- Plan and develop your program
- Work with professionals as a tool to discuss future partnerships

Definition of Family

We all come from families. Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.

Developed and adopted by the New Mexico Legislative Young Children's Continuum and New Mexico Coalition for Children, June 1990.

Definition of Family Centered Care

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 care recognizes the vital role that all families play in ensuring the health and well being of infants, children, adolescents, and family members of all ages. It acknowledges that emotional, social, and developmental supports are integral components of health care.

Family centered care supports family care giving and decision-making; respects family choices; builds on family strengths; and involves families in all aspects of the planning, delivery, and evaluation of health care services.

Adapted from *Egg Harbor Family Summit*, 1996.

Key Elements of Family Centered Care

1. Recognizes that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.
2. Shares unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner while honoring the racial, ethnic, cultural and socioeconomic diversity of families.
3. Recognizes family strengths and individuality and respecting different methods of coping.
4. Encourages and facilitates parent-to-parent support.
5. Facilitates parent/professional collaboration at all levels of health care:
    - care of individual children
    - program development, implementation and evaluation
    - policy formation
6. Assures that the design of health care delivery systems is flexible, accessible and responsive to families.
7. Implements appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
8. Understands and incorporates the developmental needs of infants, children, and adolescents and their families into health care delivery systems.

Adapted from: *National Center for Family-Centered Care* (1990), *What is Family-Centered Care?* (brochure); Bethesda, MD: Association for the Care of Children's Health.

Key Indicators of Family Centered Care

1. Information is written in easy-to-understand language.
2. Interpreters are available if requested by the family.
3. Forms, rights, and benefits can be explained verbally if parents have limited reading ability.
4. Children receive care close to home at flexible hours, including evenings and weekends.
5. Staff are knowledgeable about, and refer to, special education, family support such as family resource centers, respite, community agencies, or other health care providers.
6. All staff are trained in family centered care; families are part of the training.
7. Quality assurance standards are tailored to children with special health care needs and are followed.
8. Families who reflect the culture/language of the community are hired as liaisons to the community.
9. Families receive legible copies of all reports.
10. All services comply with ADA and Section 504 of the Rehabilitation Act.
11. Families can choose from a menu of supports.
12. Decisions regarding treatment, equipment, therapy, and other services are based on input from family and provider teams.
13. Families are involved in the development of policies.
14. Standards of care are developed with the participation of families.
15. Family satisfaction is a major priority and there are mechanisms in place for consumer feedback.

Adapted from: Egg Harbor Family Summit, 1996.

Principles of Family/Professional Collaboration

1. Promote a relationship in which family members and professionals work together to ensure the best services for the child.
2. Recognize and respect the knowledge, skills, and experience that families and professionals bring to the relationship.
3. Acknowledge that the development of trust is an integral part of a collaborative relationship.
4. Facilitate open communication so that families and professionals feel free to express themselves.
5. Create an atmosphere in which the cultural traditions, values and diversity of families are acknowledged and honored.
6. Recognize that negotiation is essential in a collaborative relationship.
7. Bring to the relationship the mutual commitment of families, professionals, and their communities for the purpose of providing services for children with special health care needs and their families.

Adapted from: Department of Social Work, University of Vermont, 4998 Waterman Bldg., Burlington, VT 05405-0160, (802)656-8800.

Indicators of Cultural Responsiveness

Cultural responsiveness honors the racial, cultural, ethnic, religious, sexual orientation and socioeconomic diversity of families by:

1. Recognizing the power and influence of culture in shaping values, beliefs, and experiences.
2. Understanding one's own cultural values, beliefs, and behaviors, and how one responds to individuals whose values and beliefs differ from one's own.
3. Learning about the cultural norms of the communities with which one engages, and about the extent to which individual families share those norms.
4. Approaching each family on its own terms, with no judgments or preconceptions, and enabling each family to define its own needs.
5. Helping families learn how to access and navigate unfamiliar service systems.
6. Acknowledging that families have experienced discrimination that affects future interactions with service providers.
7. Eliminating institutional policies and practices that deliberately or inadvertently exclude families from services because of their race, ethnicity, sexual orientation, beliefs or practices.
8. Building on the strengths and resources of each child, family, neighborhood and community.

Adapted from: National Maternal and Child Health Resource Center on Cultural Competency for Children with Special Health Care Needs and Their Families, Austin, TX.

2. Parent Health Liaison Services

Contents:

Use this chapter to:

- Familiarize yourself with Parent Health Liaison services
- Advertise, screen, and interview potential staff who will provide Parent Health Liaison services
- Assist staff providing Parent Health Liaison services understand their role, how to assist families and work with professionals.
- Evaluate job performance of staff providing Parent Health Liaison services
- Discuss with professionals the role of Parent Health Liaison services
- Provide outreach and public relations

Vision Statement of a Statewide System for Providing Parent Health Liaison Services

Every family of a child with special health care needs will have access to Parent Health Liaison services.

Mission

Family Voices of California promotes the vision of a statewide system of Parent Health Liaison services. This vision can be implemented through health agencies contracting with Family Resource Centers*, who already specialize in information, education, collaboration, and who provide support to families of children with special health care needs. A statewide system will enhance the capacity and ensure the quality of staff providing Parent Health Liaison services to offer culturally/linguistically responsive, community based, family centered health information, education, and parent-to-parent support for families of children with special health care needs. A statewide system for providing Parent Health Liaison services will enhance the ability of families of children with special health care needs and professionals work together to help children reach their potential.

Family Resource Centers:

- Specialize in the support of families of children with special health care needs.
- Normalize the experience of having a child with special health care needs
- Provide community based parent-to-parent support through a network of experienced and skilled peers
- Provide linguistically and culturally responsive support through a network of experienced and skilled peers
- Provide community based up-to-date information and referral

* In this manual a Family Resource Center is defined as those Family Resource Centers and Networks funded through the California Department of Developmental Service's Early Start Program, Family Empowerment Centers funded through the California Department of Education, and the California Parent Training and Information Centers and Community Parent Resource Centers funded through the Federal Office of Special Education & Rehabilitative Services.

- Provide up-to-date resources and personal experience to help bridge support from hospital to home
- Work collaboratively with a multitude of agencies
- Bring together diverse perspectives
- Provide a neutral and safe environment for bringing families and professionals together
- Maintain a statewide system that can provide ongoing training, support, and sharing of resources to ensure the delivery of best practices
- Enhance and support the delivery of Parent Health Liaison services
- Provide supervision and ensure confidentiality

Parent Health Liaison Services:

Through the provision of education, written materials, cultural and linguistic individualized support, parent/professional relationship building activities, and participation on committees and boards staff providing Parent Health Liaison Serivces:

- Assist parents and caretakers to make informed choices for their child's health, coordinate their child's health care, and become more effective advocates for their children
- Assist health care providers and others to better understand family needs and family perspectives and to improve service systems
- Emphasize the need for Family Centered Care and the unique perspective of families of children with special health care needs

In Action with Families

Staff providing Parent Health Liaison services support and serve families in the following ways:

- Connect with families to decrease isolation and normalize the experience of having a child with special health care needs
- Provide parent-to-parent support
- Listen to families' concerns
- Provide culturally and linguistically responsive peer support
- Provide family matches either with specific disabilities and/or similar issues, as determined by the family
- Assist families to identify their strengths, needs, and priorities
- Create open dialog to promote parent professional partnerships
- Encourage confidence and assist family members to identify and articulate their perspective
- Provide accurate up-to-date information and community based resources
- Provide access to support groups
- Provide guidance through multiple systems of service
- Provide information about organizational strategies to assist families in keeping their child's records
- Provide trainings and model successful strategies for parent professional partnerships
- Provide information on acronyms and terminology
- Assist families to identify support resources that will enhance their knowledge of their child's special health care needs
- Follow all confidentiality policies

In Action with Support Groups

Support groups are opportunities for families to be in a safe, semi-structured, yet informal environment that encourages them to seek and offer support. They are not therapy sessions, although they can be therapeutic. Support groups can be facilitated and maintained in or out of a health care agency. Group facilitators may be paid or unpaid, and should have a job description, ongoing supervision and communicate information regarding Family Resource Center activities and events. Before creating a support group, check to see what groups may already exist.

Support Groups:

- May be led by one person or co-led.
- Should be flexible and expand to meet new needs in the community.
- May meet monthly, weekly or on any schedule based on the needs of the members.
- May or may not provide childcare.
- May focus on specific family members, specific language groups, specific special health care needs, a specific age, or an issue.
- Need a location large enough to accommodate members comfortably.

Sample Parent Support Group Facilitator Job Description

Summary:

- Under direct supervision of the ___________, facilitates support groups
- Facilitates support group(s) and maintains contact with parents as appropriate
- Sets and maintains group ground rules for meetings
- Recruits parents for support group(s)
- Provides outreach to agencies to promote group

attendance

- Develops flyers and other outreach materials or strategies to promote the support group
- Coordinates use of facility and may coordinate child care during group meetings
- Responsible for submitting participant attendance sheets and other documentation to the Family Resource Center
- Conducts periodic parent satisfaction surveys and brainstorms with parents to identify new and emerging needs
- Participates in support group staff meetings, trainings and ongoing supervision
- Serves as liaison between parents and ______________ (Family Resource Center)
- Serves as a link and follows through to identify information and support resources
- Performs other related duties as assigned or requested

Sample Qualification/Skills:

- Family member of a child with special needs
- Experience in a support group
- Able to maintain strict confidentiality
- Good listener with training in facilitation skills
- Non-judgemental
- Culturally responsive
- Positive and hopeful about their personal situation
- Understand the key elements of active listening, self-disclosure, problem solving and crisis management
- Knowledge and experience using a Family Resource Center
- Knowledge of services provided by a Family Resource Center and experience using those services

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Adapted from: Exceptional Family Resource Center, Parents Helping Parents of Santa Clara, Support for Families of Children with Disabilities.

Sample Job Description For Staff Providing Parent Health Liaison Services

Summary:

Under direct supervision of the ____________, will provide support to families who have children with special health care needs.

1. Provide families with information, parent-to-parent support and linkages with community services.
2. Provide trainings for families such as Individual Family Service Plan (IFSP), Individual Education Program (IEP), transition services and Section 504.
3. Promote family and professional partnerships.
4. Provide trainings for professionals including but not limited to family centered care.
5. Collaborate and coordinate with community services to promote family centered, timely, community based, coordinated, and culturally responsive services to families as outlined in both Family Centered Care and New Freedom Initiatives.
6. Engage in local and state activities to improve policies and systems of care for children with special health care needs.
7. Responsible for documentation and reporting that is relevant to activities.
8. Participate in ongoing training.
9. Perform other related duties as assigned or requested.
10. Coordinate or represent Family Resource Center in community health related activities.

Adapted from: Support for Families of Children with Disabilities.

Sample Job Description For Staff Providing Parent Health Liaison Services within the California Children Service (CCS) System

Scope of Work

1. Assist in orienting and mentoring families new to the CCS system.
2. Design and implement a program to deliver on-site family-to-family support services at Medical Therapy Program clinics.
3. Link families to the local Family Resource Center to provide multi-lingual consultation and parent-to-parent support to families whose children have special health care needs.
4. Assist in providing outreach to under-served CCS eligible families in (specific county). Collaborate with other Public Health Department programs and health plans to maximize effectiveness.
5. Co-facilitate meetings of the CCS Family Centered Care Committee of (specific county) and facilitate family involvement.
6. Based on input from CCS staff, provide training to CCS staff regarding a variety of family issues including family centered care.
7. Represent the needs and concerns of families whose children have special health care needs at (specific county) CCS designated committees when discussing design and implementation of its programs.
8. Work with CCS staff to evaluate/modify current letters/forms/ brochures into more "family friendly" language.
9. Assist in the translation/printing of letters/forms/brochures into at least two languages.

Adapted from: California Children Services, Alameda County.

Sample Job Announcement

Part-Time Position:	**Staff providing Parent Health Liaison services**
Salary:	**(dependent on experience) + Benefits**
Position Available:	**(date)**
Job Location:	**(Family Resource Center [FRC] Name)**

Position Description:

Staff providing Health Liaison services will engage in (FRC Name) health-related activities in the community. Duties include providing families with information, parent-to-parent support and linkages with community services, participating in health-related committees and meetings, collaborating and coordinating with community services, promoting family and professional partnerships, acting as a resource for community agencies, providing trainings for parents and professionals, and participating in on-going training.

Qualifications:

Requirements include: demonstrated ability to work with diverse entities and people; familiarity with California's health care system for children with special health care needs; personal experience as a family member of a child with special health care needs or demonstrated strong commitment to supporting families of children with special health care needs; proven ability to collaborate and conduct outreach and training, and manage logistics; effective communication skills (both verbal and written) as well as proven organizational skills; ability to work comfortably in a group and independently; competency with word processing in IBM compatible computer systems.

Family members of children with special health care needs are encouraged to apply.

(FRC Name) is an equal opportunity employer.

Adapted from: Support for Families of Children with Disabilities.

Parent Health Liaison Orientation Checklist

Below is a sample checklist that may be used to orient new staff who will be providing Parent Health Liaison services.

OBJECTIVE	**STAFF CONTACT**	**PHONE**	**(✓) NOTES**
A) Review Job Duties; B) Complete Personnel Paperwork; C) Review Benefits; D) Review Time Cards; E) Order Business Cards; F) Sign Terms of Employment; G) Receive Organizational Chart and Staff Phone List			A) B) C) D) E) F)
Review Personnel Policies including			
Tour Building and Review Building Alarm			
Set up Computer Internal/External Email;			
Receive Library Orientation and Website			
Review Parent Liaison Training Manual, other FRC materials, and Standard of			
View Training Videos			
Orientation and Training at Health Care			
Attend Support Groups at (Name)			
Orientation in specific areas of expertise: (unless completed within the last 6 months) • Individual Education Program Training (IEP) • Individual Family Service Plan (IFSP) • Transition Training			IEP IFSP Transition MH
Shadow Staff • Special Education • Early Intervention • Technology Center			SE EI

Adapted from: Parents Helping Parents, Inc., 3041 Olcott St., Santa Clara, CA 95054.

3. Providing Parent Health Liaison Services to Professionals and Health Agencies

Contents:

Use this chapter to:

- Facilitate discussions around expectations, roles and responsibilities with health care agencies

In Action with Professionals and Health Agencies

Family Voices of California promotes the vision that every health care professional and health care agency will have access to Parent Health Liaison services through their local Family Resource Center (FRC). Family Voices of California believes that families and professionals together can create a comprehensive support system to ensure children with special health care needs reach their potential.

Parent Health Liaison services provide a benefit to any program serving children with special health care needs. By linking the family with their local FRC the family has support when needed. Agencies can contract with an FRC for Parent Health Liaison services, collaborate to write grants with an FRC, or the FRC can access funding and write a memorandum of understanding with the agency.

Parent Health Liaison services are useful in a variety of settings:

- Hospitals
- County CCS Programs
- Medical Homes
- Medical Centers
- Clinics
- Private Medical Practices
- Early Intervention Programs
- Schools
- Maternal and Child Health Programs

Following are some examples of Parent Health Liaison services for families and medical professionals.

Parent Health Liaison Services for families may include:

- Providing families with individualized information and parent-to-parent support, linking with the Family Resource Center to ensure more options for language, cultural diversity, and disability matches
- Providing individualized support to assist families navigating systems of service
- Facilitating a support group
- Facilitating a drop-in information time for families, enhancing waiting time at clinics, or while they are in the hospital
- Maintaining a mini-resource area for families, providing materials for families to read while they wait for appointments, or while they are in the hospital
- Maintaining a computer with on-line access
- Assisting in planning, implementing, and evaluating trainings for families including:
    - Medical Home
    - Parent professional collaboration
    - Communication/self-advocacy skills
    - Community resources
    - Individual Education Program (IEP), Individual Family Service Plan (IFSP), Individual Transition Plan (ITP), and Section 504.
- Providing information and invitations to upcoming FRC events
- Distributing information mailings such as the FRC newsletter
- Writing articles for agency newsletters
- Assisting in developing materials, resources and tools for families including: record keeping materials, parent interview tool on child health status, parent need survey, brochures
- Assisting in creating or reviewing materials in different languages
- Providing the Family Resource Center materials such as

resource guides, transition guides (IPP, ITP, IEP, IFSP, etc.), disability packets and other written materials that can be shared

- Attending multi-disciplinary meetings, providing the family perspective and offering FRC services
- Collaborating with community resources

Parent Health Liaison Services for Medical Professionals may include assisting in:

- Planning, implementing and evaluating trainings on:
    - Medical Home
    - Parent professional collaboration
    - Parent perspective
    - Community resources
    - IEP, IFSP, ITP etc.
    - Family centered care

  At in-services, grand rounds, lunches and conferences.
- Developing materials, resources and tools including: record keeping materials, parent interview tool on child health status, parent need survey, brochures.
- Creating and or reviewing materials in different languages.
- Providing the family perspective on advisory, policy and planning committees, and helping to create a family advisory group.
- Planning, implementing, and evaluating outreach for both medical professionals and families.
- The inclusion of families on boards and committees to provide diverse perspectives.

In Action with Committees
"Are You Ready to Serve?"

It is important for Family Resource Centers (FRCs) to promote the participation of staff providing Parent Health Liaison Services on health related committees and boards in the community. Their participation provides the family perspective and brings their FRC's services and expertise to the community. If the staff member can answer "yes" to each of the following questions about committing themselves to a board or committee, then they are ready to serve.

- Can you attend most, if not all, scheduled meetings and give notice when you cannot attend?
- Are you willing to give as much time and energy to the group as other members do?
- Can you get along with others, respecting their opinions and preferences the way you want your opinions and preferences respected?
- Can you think and act as an advocate for other children and families, not just your own child or family? (This means moving beyond your own story and situation and representing other families' experiences.)
- Are you able to resist "bashing" professionals?
- Are you willing to refrain from listening to or repeating gossip?
- Do you understand the art of compromise and negotiation?
- Are you willing to negotiate workable solutions, if it means not sacrificing your basic principles?
- Are your principles and values family centered?
- Can you apply the concepts of family/professional collaboration?
- Is your family willing and able to support your volunteer commitments? (It is best to settle family issues about child care, meals, and homework assistance, etc., before you commit to a board or committee.)

Acknowledgement: Adapted from *The Family Voices Leadership Guide*.

Getting Started

This section is focused on creating linkages with Health Care Agencies to provide Parent Health Liaison services.

Step One: Assessment – Where are Parent Health Liaison Services Needed?

The first step is to conduct an assessment designed to examine where and what Parent Health Liaison services are most needed.

To conduct an assessment, consider sending a survey and/or conducting interviews or focus groups in the community. Each process has unique benefits and challenges. For example, sending surveys is a simple and easy process but may yield limited responses. Individualized interviews are time intensive but may result in more comprehensive information. Focus groups may be harder to schedule, but will stimulate lots of discussion. Make sure to include families and representatives from potential health care agencies in the pool of prospective stakeholders. As time goes on they will become your link. The professionals you invite will depend on the type of health care agency you are considering working with. However, individuals might include: social workers, pediatricians, specialists, nurses, and therapists.

Whatever process or combination of processes you decide to use, be sure to review with stakeholders:

- The purpose of the assessment
- A list of the prospective Parent Health Liaison services

Then ask the following questions:

- How could Parent Health Liaison services have helped your family or the families you serve?
- Where could Parent Health Liaison services be useful in your local area or within the health care agency?
- What services might be most useful?
- Prioritize the list

- What are some possible concerns/challenges about providing Parent Health Liaison services?

Step Two: Working with Partner Agencies

Once you have identified a health care agency and a partner from that agency, schedule an exploratory meeting. The agenda might include:

- Review of input collected from the assessment that reflects community needs
- Discussion of how your agency is currently working with the health care agency
- Discussion of existing challenges
- Explanation of how Parent Health Liaison services might enhance the positive and address challenges
- Review the agenda (see Step 3 below)
- Ask the partner who else should be invited to join an advisory group/committee to help guide the project and to think through how to move forward with the health care agency
- Review the number of meetings you think there will be. (For example, a monthly meeting for 2-3 months to get the project going; then once every 6 months to monitor the project. Offer to meet during the lunch hour.)

Tip:

When making presentations include other sources of information such as *Your Voice Counts** and your County Health Department Report.

Draft a letter to send to the potential committee members and ask the partner to co-sign and/or follow up with a phone call.

Step Three: Meeting with the Partner Agency

Once you have written a draft of who, what/how, where and when, it is time to establish a formal meeting with professionals at the partner agency.

Prepare a presentation that includes:

- Review of your Family Resource Center services/materials
- Review of Parent Health Liaison services

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* See "Attachments"

Tips:
It is helpful to prepare presentation aids using overheads, an easel, or power-point presentation. Prepare a folder of information for each person attending the presentations. Depending on whether this is the first meeting or ongoing, content might include:

- Agenda for meeting
- Results of assessment
- List of services you might provide
- How referrals might work
- Timeline
- Flyer regarding how to access your services
- Referral forms
- Brochures
- Materials such as Newsletters, Resource Guide, sample fact sheets, etc.
- Examples of confidentiality protocols etc.

Always take minutes of the meeting so everyone will remember what was said. Send a letter after the meeting to thank them, and include the minutes of the meeting.

- Review input collected from the assessment that reflects community needs, and ask for their perspective
- Discussion of how your Family Resource Center is working with the health care agency now, and ask for their perspective
- Discussion of the challenges, and ask for their reaction
- Explain how providing Parent Health Liaison services will enhance the positive and address challenges, and ask for their feedback
- What might the activities be?
- What is the timeline for services?
- In those specific places that were identified, who else should be included?
- Review next steps

Next Steps:

- Ongoing meeting schedule
- What might the goal be?
- What are the expected outcomes?
- How will you evaluate and document success?
- What are your resources?
- What might the budget be?
- Drafting scope of work, a proposal, a Memorandum of Understanding (MOU)

Step Four: *Creating a Proposal/MOU*

As soon as you begin to discuss providing services at the facility it is important to review the health care agency's expectations and your expectations.

- What exactly are your services
- What is the timeline
- How will families be referred
- How will outreach for the project be conducted
- How will services be provided
- Where will the services be provided
- How will services be documented and evaluated

The proposal/MOU should include:

- Mission
- Goals
- Approach
- Methods
- Outcomes
- Activities
- Technical support issues: e-mail, database, photocopier, etc.
- Evaluation
- Budget
- Next Steps

(See sample MOU)

Important: You will also want to address and alleviate common concerns (such as, confidentiality, following the health care agencies' protocols, and what to do if there is a problem). You will also want to ensure they understand your agencies' protocols. You should address these in an MOU (see more about this in chapter 4).

Even with a proposal, it may take many meetings to articulate a process to work together. The health care agency may want to start slowly and refer to your agency or have you provide trainings to their staff. Providing data and evaluations over time can demonstrate how Parent Health Liaison services benefit families and professionals. Build on your successes.

Step Five: Outreach for the Project

Once the project is underway, consider who should know about the project and how to get information to them. Things to consider:

- Mini presentations about the project or staff inservices
- Materials such as brochures
- Joint press releases
- Tours and open houses

For all face-to-face in-services, trainings, or open houses have an agenda and offer food.

Step Six: Evaluation

Do not be afraid of evaluation. Evaluation is critical to the success of the Parent Health Liaison services. It is a way to improve services and can help to provide information to funders. It is key to have feedback to see how you are doing and to inform others of your progress.

Types of evaluations may include:

- Family surveys
- Professional surveys
- Training evaluations
- Committee satisfaction surveys

SAMPLE MEMORANDUM OF UNDERSTANDING (MOU) Between (FRC Name) and (Hospital)

WHEREAS, (FRC Name) and Hospital ____ desire a collaboration to replicate the successful national model of family centered care accomplished in a non-profit managed care organization. **WHEREAS** this will involve the establishment of a satellite Parent-Directed Family Resource Center (PDFRC) at ____ which will provide parents of children with special health care needs (CSHCN) with parent-to-parent emotional support, information in lay terms, connection to support and information groups and information about helpful local and national resources and trainings.

WHEREAS, (FRC Name) mission is helping children receive the resources, love, hope, respect, health, education and other services they need to achieve their full potential by providing them with strong families and dedicated professionals to serve them.

WHEREAS, (Hospital Name)'s mission is to recognize that health care services are one of the basic necessities of humankind. (Hospital Name) is committed to creating an institution that brings competent, compassionate care and comfort to the total person – mind, body and spirit. Therefore, (Hospital Name) strives for excellence in the delivery of high quality, cost effective health care to the communities they serve.

WHEREAS, the mission of this project is to ensure quality, state-of-the-art care for children with special health care needs in managed care. Therefore, (FRC Name) and (Hospital Name) are establishing a consumer/provider collaborative working partnership with the following roles and responsibilities:

A. (FRC Name) will be responsible for the following:

Acknowledgement: Adapted from Parents Helping Parents, Santa Clara.

1. to hire, train and supervise staff providing Parent Health Liaison (PHL) Services
2. to provide parent-to-parent support and information for families
3. to provide office supplies, business cards, and office stationery with (FRC Name), hospital and MCHB logos
4. to provide computer and fax equipment
5. to keep accurate records
6. to provide evaluation measures
7. to provide support for parents in their native language whenever feasible
8. to set up the PDFRC using the location and office furnishings provided by Hospital
9. to conduct trainings for physicians in "Better Ways of Breaking Diagnostic News," for nurses and other health care professionals in "The Modern Art of Caring for Families," and for parents and professionals in "P/PACT - Families and Professionals Acting Collaboratively Together"
10. to provide tours of (FRC Name) to any interested professionals affiliated with Hospital

B. Hospital will be responsible for the following:

1. to provide an appropriate location in the hospital
2. to provide suitable office furnishings
3. to provide phone lines for modem, fax and phone
4. to provide signage
5. to allow use of copy service, microwave and refrigerator
6. to provide postage for mailings
7. to pay for monthly fees for modem, fax and phone lines
8. to allow use of group meeting rooms depending on availability
9. to provide training of staff providing PHL Services on available on-site translation assistance
10. to pay for printing of brochure describing the joint project created with input from both partners

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Acknowledgement: Adapted from Parents Helping Parents of Santa Clara.

11. to arrange and co-host an Open House in the PDFRC with (FRC Name)
12. to assist FRC Name in publicizing trainings and locating professional co-trainers

C. Single Point of Contact (SPoC)

1. The Single Point of Contact (SPoC) for (FRC Name) will be_________ Project Director of the Family Centered Managed Care Project, ___________________________ will be the SPoC for the Hospital.
2. The responsibilities of the SPoC shall be:
    a. to organize an Advisory Committee to ensure the smooth implementation of the program
    b. to call quarterly meetings of the Advisory Committee
    c. to develop and design an evaluation tool to monitor and evaluate the program
    d. d. to schedule training activities for the staff

D. (FRC Name) and hospital will put together an Advisory Committee composed of the following:

1. Two parents
2. SPoC from (FRC Name) and (Hospital Name)
3. Social Worker
4. Nurse Practitioner
5. Staff Nurses
6. Community Pediatrician
7. One or two Quality Managers
8. (FRC Name) Program Coordinator and staff providing Parent Health Liaison services

The Advisory Committee will work together to assure the smooth integration of the Parent Directed Family Resource Center into the hospital, and plan ways family centered care principles can be incorporated into day-to-day hospital operations.

Acknowledgment: Adapted from Parents Helping Parents of Santa Clara.

Meetings will be held quarterly to discuss successes as well as issues and concerns that affect the project. The Advisory Committee will be co-directed and co-facilitated by (FRC Name) and (Hospitals Name) Single Points of Contact, namely

This MOU will be reviewed initially by the Advisory Committee with input from the identified SPoC after six (6) months to incorporate any necessary changes or additions.

The parties agree to the terms and conditions of this Memorandum, certify that they are empowered by their respective organizations to legally bind their organizations, and acknowledge receipt of a copy of this Memorandum.
AGREED:

________________________	______________________
Chairman of the Board FRC Name.	Chief Executive Officer Hospital
________________	______________
Date	Date

Acknowledgement: Adapted from Parents Helping Parents of Santa Clara.

4. Protocols for Providing Parent Health Liaison Services

Contents:

Use this chapter to:

- Articulate the role of staff providing Parent Health Liaison services
- Clarify how families may be referred to staff providing Parent Health Liaison services
- Review the confidentiality statement and discuss the health agency's expectations for ensuring the confidentiality of the families served
- Provide a confidentiality protocol if the health agency does not have one
- Review the translation/interpretation protocol regarding the health agency's expectations for ensuring appropriate services for families
- Ensure that the staff providing Parent Health Liaison services can identify, recognize, and respect boundaries

Knowing Boundaries

Once a Parent Health Liaison has begun working with agencies and families, knowing boundaries is essential. It is important to recognize the protocols of the facility you are working with, to explain the protocols of your own agency, to describe the duties of staff providing Parent Health Liaison services and to develop common protocols to implement the Parent Health Liaison program. Following are checklists to help in articulating best practice when thinking about boundaries with agencies and families.

Things To Do and Things Not To Do

Things To Do With Health Care Agencies

- Schedule times to talk or meet with health care agency staff; do not assume any time is okay
- Ask for the health care agency's protocols and review them with a health care agency staff person
- Review the Family Resource Center's written protocols with the health care agency's staff
- Determine who should be notified if there is a problem
- Tell them who should be notified in the Family Resource Center if there is a problem
- Develop specific protocols for the health care agency on what services will be provided, how they will be provided, and the referral process
- Always obtain approval for any joint materials, such as flyers and press releases
- Review the Family Resource Center's confidentiality policy and the health care agency's confidentiality policy – this may include a form that requires a family's signature to release information
- Ask the health care agency staff to provide the Parent Health Liaison with the name, address and phone numbers for the family and the child
- Prepare simple, easy to use guidelines for the health care agency staff illustrating an appropriate referral
- Review what staff providing Parent Health Liaison services can do and cannot do. (Staff providing Parent Health Liaison services can listen to families, staff providing Parent Health Liaison services do not drive families to appointments.)
- Provide health care agency staff with the Family Resource Center's materials, brochures, resource guides
- After a referral, ensure a feedback loop. If health care agency staff have referred a family member, create a simple thank you note and let the health care agency staff know that the family was contacted
- Ensure that health care agency staff understand the value of

parent-to-parent support so that the staff providing Parent Health Liaison services can work with them to better serve families. For example, matching a parent with another parent can normalize the experience of having a child with disabilities

- Staff providing Parent Health Liaison services must follow through on any commitments.
- Staff providing Parent Health Liaison services must follow their agency's policies
- Make sure there is a feedback loop to evaluate your services

Things Not To Do With Health Care Agencies

- Never break confidentiality (for example, staff providing Parent Health Liaison services should not accept or divulge information about a family without the family's permission unless they are certain the family has approved their participation).
- Never make recommendations. Staff providing Parent Health Liaison services are there to provide parent-to-parent support and information. Professionals provide expertise.
- Never break protocols that have been established with a health care agency. If the protocol is not working, then a meeting should be scheduled to consider revising the protocols.

Things To Do With Families and Things Not To Do With Families

Things To Do With Families

Staff providing Parent Health Liaison services should:

- Keep all information confidential.
- If the family would like staff to speak to another person on their behalf, clarify what information is okay to share.
- Identify yourself and your Family Resource Center. At the beginning, families may have many people coming and going and may not remember who you are.
- Explain your role so families understand you are not a therapist, social worker or doctor etc. Be clear that if expertise is needed in one of those areas that you are there to encourage the family to link to the appropriate expertise.
- Let families direct the conversation by encouraging them to express their concerns and questions.
- Be open minded and non-judgmental about a family's perspective.
- Be a good listener and repeat and paraphrase what a family has said to ensure you understand.
- Acknowledge their child when meeting with them, sincerely complimenting the child's attributes (curly hair, great skin, cute smile, robust cry, etc.).
- Remember the whole family is impacted and allow discussion about other family members (spouse or children).
- If appropriate, share similar feelings, fears and apprehensions, remembering that you can never know exactly how someone else feels.
- Tactfully relate positive experiences you or others have encountered and or present alternatives as options, encouraging them to find their own solutions.
- Boost morale and self-image. Sincerely recognize parents for the positive steps they may have already taken.
- Inform them of support services relative to their child's special

health care needs, <u>but don't overload them</u>. Be prepared to repeat information. Remember it takes time to absorb all that is going on.

- Encourage parents to start one file or notebook where they can store all of their child's records and papers.
- Encourage parents to take time for themselves, with a view toward balance in caring for themselves as well as other family members. (Use the example of the instruction on an airplane, "put the oxygen mask on yourself first before helping others".)
- Agree with families that this is an extremely challenging thing that has happened to them and their child (NOT that their "child is a tragedy").
- If you need to talk about a family's situation, consult with your supervisor to access any support you may need.

Things Not To Do With Families

As a staff member providing Parent Health Liaison services:

- Do not discuss families you meet without their permission. Remember how you would feel in their situation. Even if you do not name them, the world is a small place and the slightest detail can inform people of whom you are discussing. Do not break confidentiality, ever. If you have any concerns, speak with your supervisor.
- Do not try to be the "expert." Use your connections to link families with the appropriate resources.
- Do not give medical advice. Encourage families to access the appropriate professionals to answer their questions.
- Do not psychoanalyze. Encourage families to ask the appropriate professional for answers to their questions.
- Do not access the family's medical records.
- Do not give answers or solutions. You may tactfully relate positive experiences you or others have encountered, or present ideas and alternatives. Encourage families to explore solutions that may work for their family.
- Do not criticize or judge, no matter what the issue or your

feelings over it.

- Do not overpower a family.
- Do not criticize professionals or agencies.
- Do not share your problems with families seeking support.
- Do not compare their situation with others saying, “you think you have it bad…”.
- Do not say “everything will be okay.” You cannot predict the future.
- Do not speak for professionals. Encourage families to say what they are thinking and speak directly with the professionals.

Tip:

Some FRCs feel it is important to inform the Health Care Agency about the type of services that were offered to the family. Other FRCs feel it is only important to let the Agency know that contact was made with the family. The FV of CA Council feels what is most important about a referral and sharing information about a family is that it is done with the family's knowledge and consent.

Sample Referral Process Protocol For Health Care Agency and Family Resource Center (FRC) to Sign

Below is a sample of a Referral Process Protocol.

To ensure smooth access to parent-to-parent support (FRC name) and (Agency name) desire to collaborate and will adhere to the following referral protocol. (Agency name) will be given a form to sign to release information to (FRC name) at time of initial intake. Staff at (Agency name) will then provide the Parent Health Liaison from (FRC name) with the name, address and phone number for the family. Once the Parent Health Liaison from (FRC name) has contacted the family they will inform the staff person from (Agency name).

_____________________________ __________

Signature Date

Sample Referral Form

Below is a sample of a referral form that may be used to refer families to Parent Health Liaison services.

Date:_____________

I am interested in accessing information and would like the Parent Health Liaison from (FRC Name) to contact me. I give (Health Agency Name) permission to release the following information:

My Name ____
My Spouse's/Partner's Name____________________________
My Home Telephone # ____________________
My Work Telephone # ____________________
My Child's Name____________________________________
My Child's Birthdate ____________________
My Address____

The best time to reach me is:______________________
Parent Signature________________________________
Date__________

Acknowledgement: Adapted from Parents Helping Parents of Santa Clara.

Tip:

The Family Resource Center's logo and information should be included on the form. The form could be part of a brochure that includes a list of Parent Health Liaison services. The referral form could be a tear out so that the brochure could be kept by the family.

Sample FRC (interagency) Confidentiality Protocols

Below is a sample of a confidentiality protocol.

When hiring new staff the Confidentiality Statement will be reviewed and signed. Families will be given an opportunity to give verbal/written approval to release information at the time of initial inquiry and it will be noted on the intake form. (FRC name) will ensure that its confidentiality protocols are known by any agency that it works with.

Tip:

It is critical when working with agencies to review and discuss the agency's confidentiality protocols as well as the Family Resource Center's confidentiality protocols. The protocol which most protects the confidentiality of the family should be used.

Sample Agency Confidentiality Statement Form

In order to ensure privacy of families (name) will adhere to the following confidentiality statement.

Staff and volunteers at (Family Resource Center [FRC] name) respect the privacy of each family with whom we work and will obtain verbal/written approval to release information* at the time of initial inquiry by noting it on the intake form. Staff members and volunteers will not, under any circumstances, reveal or discuss or otherwise allow to be discovered the identity or any other information of or about an individual or family that (FRC name) has come into contact with, without verbal/written approval to release information. This statement supersedes any and all other policies.

I agree to adhere to this confidentiality statement.

Signed ___________________________________

Name of employee ___________________________

Date______________

♦ Information Example: If someone calls to see if a family has accessed (FRC name) services, unless prior approval has been given the appropriate response from the (FRC name) staff member would be: "Our policy is not to give that type of information without prior approval from the family."

Sample Translation/Interpretation Protocol

Below is an example of a Translation/Interpretation Protocol.

In order to ensure access to appropriate interpreting services for families it is the policy of (FRC name) to encourage families to ask for professional simultaneous interpreting services as opposed to using other family members, the staff of (FRC name) or other individuals who may speak the language but not have simultaneous interpreting expertise. We want to ensure access to appropriate interpreting services and we respect the expertise of professional interpreters just as we respect the expertise of any other professional; therefore, (FRC name) staff does not assume the role of interpreter.

Tips:

Family Resource Centers staff and Parent Health Liaisons must make clear to other agencies that it is not appropriate to use staff providing Parent Health Liaison services as interpreters, even if they speak the language fluently and it is their primary language. You can attend meetings to provide parent-to-parent support, but provision of interpreting is not your area of expertise and should be provided by professional interpreters.

5. Attachments

Family Voices of California

Family Voices of CA is a council of 14 member agencies who seek to improve the lives of children with special health care needs through the following:

1. Improve policies and systems of care for children with special health care needs
2. Provide information and education to families and professionals regarding health care for children with special health care needs
3. Promote family centered, culturally competent, community based coordination, and quality care for children with special health care needs
4. Develop family and professional partnerships

California Department of Developmental Services Family Resource Centers and Networks (FRCs)

California's 54 Early Start Family Resource Centers and Networks are staffed primarily by family members who have children with special needs. They provide information and parent-to-parent support to families of children birth to 36 months. Each FRC is unique. Some operate as independent sites; others are based in Regional Centers for the developmentally disabled, local education agencies, public health facilities, hospitals, or homes. As part of their contracts with the California Department of Developmental Services, FRCs are required to actively collaborate with other agencies serving families of children with disabilities and help families to access early intervention services.

FRC scope of work may include:

- Parent-to-parent and family support.
- Peer counseling and home visits.
- Information and referral.
- Public awareness.

- Parent education.
- Support services in many languages.
- Transition assistance.
- Support services in urban and rural communities.

Parent Centers

Parent Centers – Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) serve families of children and young adults from birth to age 22 with all disabilities. They are funded by the U.S. Department of Education under the Individuals with Disabilities Education Act (IDEA). Each state has at least one parent center; California has 9 PTIs and 3 CPRCs.

The scope of work of PTIs and CPRCs includes:

- Training and informing parents and professionals.
- Helping families obtain appropriate education and services for their children with disabilities.
- Working to improve education results for all children.
- Resolving problems between families and schools or other agencies.
- Connecting children with disabilities to community resources that address their needs.

The President's New Freedom Initiative

Health Resources Services Administration's Maternal and Child Health Bureau will take the lead in developing and implementing a plan to achieve appropriate community-based service systems for children and youth with special health care needs and their families. Components of the plan may include:

1. Development of community-based systems of services that are inclusive of children with special health care needs (CSHCN) and their families, where substantial decision-making authority is devolved from the federal government to the states to the communities.

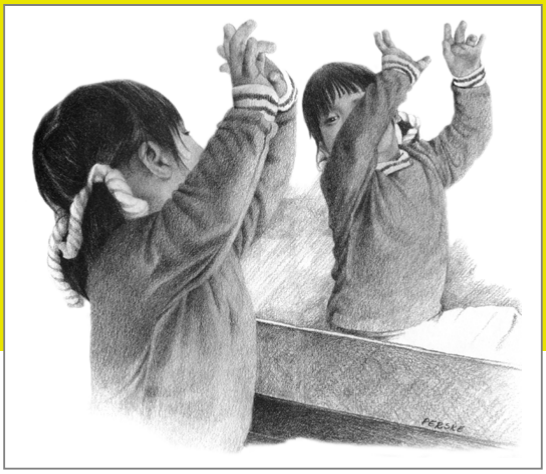
2. Recognition that families are the ultimate decision-makers for their children and encouragement of participation in making informed decisions.

3. Development of standardized elements of the medical home for CSHCNs. In addition, the agency will develop and disseminate models of the medical home, and provide additional training resources to primary care professionals to develop medical homes.

4. Review of the variety of reimbursement mechanisms that impact children with special health care needs.

5. Through the Maternal and Child Health Block grant (Title V of the Social Security Act), and the Newborn Genetics Program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening systems and promote ongoing screening of CSHCN (incorporating EPSDT into the medical home concept).

6. Ensuring that youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including from pediatric to adult health care, from school to employment and to independence.



What Do Families Say About Health Care for Children with Special Health Care Needs in California?

Your Voice Counts!! Family Survey Report to California Participants

May 2000

FAMILY VOICES

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

Background

on the Family Survey in California

In late 1998, Family Voices and Abt Associates Inc. conducted a survey of parents of children with special health care needs in California, extending a national survey conducted in 20 states by Family Voices and Brandeis University. The purpose of the survey was to assess the health care experiences of children with special health care needs and their parents, and to see whether experiences were different for certain children, such as those in managed care plans or those with parents who speak Spanish. The families who responded so generously tell a vivid story of how their child and family are faring in the present health care system. Their answers to our questions are summarized in this report, along with many of their insightful comments.

- The survey, Your Voice Counts!!, was sent out to 7,100 families randomly chosen from California Children's Services (CCS) mailing lists and the membership lists of six California family resource organizations. 954 parents eligible to participate in the survey completed and returned the questionnaire, 153 of which were in Spanish.

- Responses came from Los Angeles, San Diego, Sacramento and Fresno counties and two rural areas in the state[1]. These areas were selected in order to include geographic diversity.

> *"…Everyone deserves the best health care. It's discriminatory that some can't see the doctors they want because they can't afford it….*
> **" Parent of a child with cerebral palsy enrolled in a private managed care plan.**

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[1] The data in this report are weighted to adjust for the different sizes of CCS mailing lists and membership lists of family organizations in each county.

Who

are the children and families?

Children with special health care needs in California whose families answered this survey had a variety of conditions. Most of the children had multiple conditions of a moderate to severe level[2].

- Two-thirds of the children were boys. Three-fourths of the children were between the ages of 1-14. Nearly half were Hispanic, a proportion that roughly mirrors the entire state, as did the 10% of the children who were African American. One-fourth were white and 8% were Asian, a slightly smaller proportion than the state average for those two groups. Five percent identified themselves as multiracial and 1% were Native American.

- Most children were affected by more than one condition: 37% had two or three conditions, 53% had four or more conditions. The most common conditions were developmental delay, cerebral palsy, orthopedic problems, allergies, vision impairment, mental retardation and behavioral problems. Fourteen percent of the children were technology dependent or assisted, needing such things as a feeding tube, shunt, or ventilator, etc.

- Over three-fourths of the children were described by their parents as having a moderate to severe level of disability and two thirds had special health care needs that were not stable.

The children lived in families with diverse income levels in a variety of communities.

- Eighty percent of those filling out the survey were mothers. A quarter of all respondents worked full time and 15% worked part-time. Over half the children (57%) lived in households with incomes below $20,000, while 17% lived in households with an annual income of $50,000 or more.

- Almost three quarters (73%) of the families lived in city/urban communities, 15% in suburban areas and 8% in rural areas. Nearly one-fifth (19%) of the families had another child with special health care needs.

[2] The findings from this survey should be interpreted with caution for several reasons. First, because of the low response rate, the responses may not be representative of all children from the CCS and family organizations in the sample. Second, children from participating organizations may not represent all children with special health care needs in California.

What

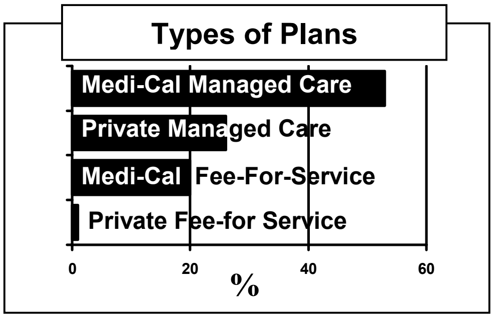
kind of health care coverage do these children have?

Many children in the study had health insurance paid for by employers, families, and/or government programs, such as Medi-Cal and California Children's Services (CCS).

- Among the children in this study only 3% had no health insurance at the time of the survey, but 10% had been without insurance at some point in the past 12 months.
- About two-thirds of the children were enrolled in Medi-Cal. Over one-fifth had health insurance paid for by a parent's employer and 6% had insurance paid for fully by their family.
- About two-thirds of the children had both primary coverage and a secondary source of health coverage, primarily CCS.

Most children were enrolled in health coverage with managed care features.

- Although nearly half (46%) of the families didn't know whether their child was in a managed care plan, most of the children (72%) were in a plan with at least one feature of managed care, such as having a network of doctors or requiring a primary care doctor.
- More than half (53%) of children in the survey were enrolled in Medi-Cal managed care, 26% were in private managed care, 20% were in Medi-Cal fee-for-service and only 1% were in private fee-for-service.



The children in this survey received a range of services from a complicated patchwork of health plans, government programs, and agencies and/or school systems.

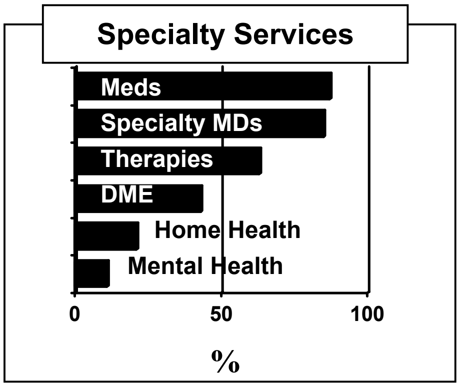
- About two-thirds (68%) of the children in the survey received services from CCS. CCS was the most common payer for all types of therapy, except for speech therapy which was paid for mainly by schools and early intervention programs.
- Only 47% of the children up to the age of three received early intervention services. Over half (56%) of the children over age five received specialized services in school, 42% received services from the California Department of Developmental Services Regional Centers, and 3% received services from the California Department of Mental Health (DMH).
- Over a third (38%) of the children received Supplemental Security Income (SSI).

How often do these children use health care services? What kind of care do they use?

The children in the survey used primary care providers, specialists, and hospitals often in the preceding year, almost twice as often as children without special needs.

- Almost all children had seen a primary care provider at least once. Almost half had seen a primary care provider six or more times in the preceding year.
- Almost all children had seen a specialist at least once. One-fourth had seen a specialist six or more times in the preceding year.
- Half of the children had been hospitalized at least once, but one-tenth had been hospitalized three or more times in the preceding year.
- Half of the children had been treated in the emergency room, while 15% had emergency room treatment three or more times in the preceding year.

Almost all of the children surveyed needed specialty healthcare services in the preceeding 12 months.



- Eighty seven percent of the children needed prescription medications (Meds); 85% of the children needed specialty doctors; 63% needed therapy services (occupational therapy, physical therapy, speech therapy, etc.); 43% needed durable medical equipment (DME) (wheelchairs, ventilators, hearing aids, etc.); 21% needed home health services, and 11% needed mental health services.
- Parents said: 66% of the children needed dental care; 41% of the children needed disposable medical supplies (catheters, diapers, etc.); nearly a third (30%) needed nutritional counseling; and 27% of the families needed respite care.

What kinds of problems are families having getting specialty services?

A large number of parents reported having trouble getting specialty services for their child, particularly mental health services, home health services, and therapy services.

- Children with mental health needs had the most problems (40%) getting the care they needed. Within that group, children with behavior problems and/or Attention Deficit Hyper Activity Disorder (ADHD) had more problems receiving mental health services.

- Two-thirds of the children who received mental health services from the Department of Mental Health reported having problems getting services, compared to 8% of children who received mental health services elsewhere.

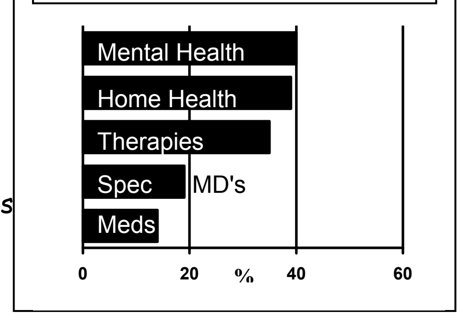
- Of those children needing home health care, 39% reported problems. Of those with problems, half had insurance that wouldn't pay for home health care. Fifty one percent of the families reporting problems had trouble getting payment for enough home health care hours.

- Of children needing therapies, 35% reported problems. The most common problem for children who needed some kind of therapy was that they did not get the therapy they needed. Lack of coverage for occupational therapy and speech therapy was the second most common problem followed by difficulty getting a referral and an adequate number of visits to meet their child's needs.

- Children whose special health care needs were not stable were about twice as likely to have problems getting services, (specifically accessing specialty doctors, medications, and therapy services) as children whose conditions were more stable.

- Of children needing care from specialty doctors, 19% reported problems getting these services. Of children needing prescription medications, 14% reported problems.

Problems Getting Services



> *"...Physical therapy is not, nor will be, covered by Medi-Cal, nor probably by a private plan. I Pay $500-600 per month (myself) for the service for my son-since it would not cause my son `to recover'. The fact that it helps him not to become more impaired is discounted."*
>
> **Parent of a child with cerebral palsy enrolled in a Medi-Cal managed care plan**

How well are children's services coordinated?

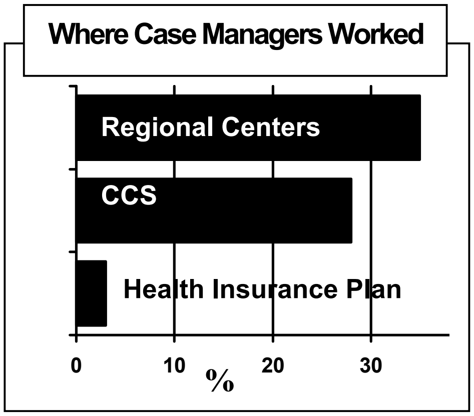
Many parents said they were not aware of any formal coordination of benefits between their child's primary health insurance and their secondary insurance. Several parents expressed frustration with the fragmented system, and the time and skills it takes them to understand and organize everything.

> *"...There is no coordination. They send the bill to each other, back and forth, until I get really angry."*
> Parent of a child enrolled in a Medi-Cal managed care plan and CCS

> *"...They don't coordinate the benefits. I have to call and send information every time."*
> Parent of a child with behavior problems enrolled in a private managed care plan and CCS

> *"...The coordination of benefits is a complex mess. Each agency has its own case managers and budgets, so there is much duplication of effort. Furthermore, each agency has no idea what the other agency is doing. Each agency wants to be the payer of last resort, so having something like a wheelchair approved is a very major hassle for families."*
> Parent of a child with cerebral palsy enrolled in a private managed care plan

Most parents had to coordinate the many systems and payers of health care for their children by themselves, sometimes with great difficulty. Even when parents had case managers, many reported not getting the information and assistance they needed.



- Only about half of the children had a case manager, most of whom were employed by the regional centers (35%) or CCS (28%). Only 3% of the case managers were employed by a health insurance plan

> *"...I mostly do all coordinating between doctors and CCS and Medi-Cal....I experienced the 'run around' with many places who supposedly should be helping me..."*
> Parent of a child with developmental delay enrolled in a Medi-Cal managed care plan

The services that parents received from case managers varied greatly depending on who the case manager worked for.

- Case managers from private plans were better at helping parents understand the benefits of that plan. Case managers who worked for public agencies provided more assistance with coordinating care, identifying other community based programs and resources, and getting SSI.

> *"…For approximately two months, I have [had] a new coordinator for my daughter. She doesn't call or visit with any information. I had to call her so she could connect me with the program that I wanted."*
> Parent of a child with cerebral palsy enrolled in a Medi-Cal managed care plan

When care coordination worked, parents found it very helpful.

> *"…My caseworker is wonderful. She and I chat on the phone whenever I have concerns. She goes to Individual Education Plan (IEP) meetings with me and helps me deal with Medi-Cal, etc."*
> Parent of a child with developmental delay enrolled in a private managed care plan

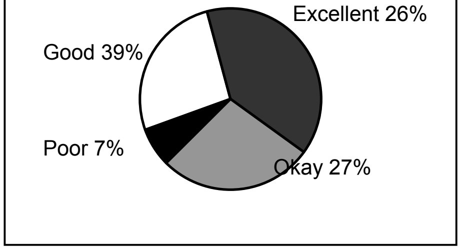
Many parents reported that they found information themselves or through other parents to better coordinate their child's care and identify resources.

> *"..I have done a lot of independent research regarding all my children's needs. I have learned how to coordinate the teams who provide services to this child and my ADHD child. I have had to rely on my own so much I have become able to help others. Some of the school officials that I have worked with have sent others to me for help. (I have a high school education and am a stay at home mom. I've learned a lot on my own to learn the system.)"*
> Parent of a child with asthma enrolled in Medi-cal fee-for-service

How satisfied are parents with their child's primary health insurance plan?

Most parents said they were somewhat or very satisfied with their plan. However, they expressed less satisfaction when asked specific questions about their plan.

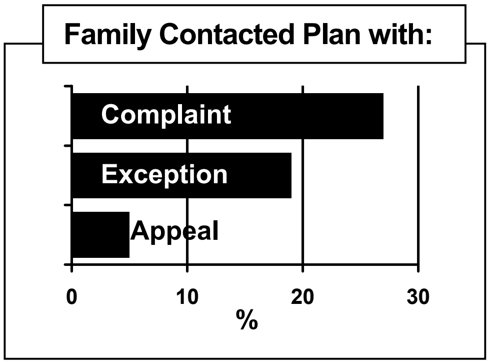
Overall Benefits Meet Child's Needs



- Forty four percent of the families said they were "very satisfied" with their child's primary plan; 42% were "somewhat satisfied", 12% were "somewhat dissatisfied," and 2% were "very dissatisfied."
- When asked if the plan's benefits met their child's health need, only 65% gave the plan a good or excellent rating.
- Families reported that their child's primary plan did a better job of providing access to quality hospitals and doctors than to specialists such as therapists.
- Over half of the parents were dissatisfied with the lack of clear information explaining services covered by the plan. One-fourth gave their plans a poor rating concerning information needed to file a complaint.
- Most parents were dissatisfied with the lack of "family-centeredness" of their primary health plan. Parents were most dissatisfied with the lack of information or newsletters about issues of interest or resources outside of their plan. Many were dissatisfied with or did not know whether their plan offered parent support groups or gave parents an opportunity to give advice to the plan.
- Parents whose child had a primary care doctor were most satisfied, whether it was required by the plan or not.

> *"...I like Medi-Cal because I can see doctors from different HMOs without a problem, all medication my daughter takes is O.K. I don't like that I work to find doctors for (daughter's) needs. And that they did not cover daughter on therapies."*
>
> Parent of a child with developmental delay enrolled in a Medi-Cal managed care plan

Over a quarter of families had contacted their plan in the past year with a problem.



- Twenty seven percent of the families had called or written their plan with a complaint or problem, of these 26% of the problems had not yet been resolved, one-third were resolved, but not to the family's satisfaction. When parents who reported problems with their child's plan were asked to give more information, about one-third of the comments concerned denials of care, payment or reimbursement.
- Nineteen percent had asked for an "exception to policy." Of these, one-third were not yet resolved and one-third were not resolved to the family's satisfaction.
- Five percent of the families had filed a formal grievance or appeal. Of these, the majority had been resolved to the family's satisfaction.

The more managed the plan, the less satisfaction reported by families.

- Restrictions on coverage and limitation on provider choice appeared to be the leading reasons for dissatisfaction with the child's health plan.

> *"...We wanted coverage with the neurologist she had had for 10 years. But all of a sudden (this neurologist) wasn't on the plan. Our other choice was the neurologist who misdiagnosed her disorder and put her on medication which made her worse."*
> Parent of a child with sensory integration disorder in a private managed care plan

> *"...I want him to see the best – I want to go with the recommendations by those I trust. My son's cerebral palsy is relatively mild at this point and the better the care now, the better his chances are for near or complete resolution. [He] can't see the orthopedist I'd like without changing groups. Second opinion neurologist required letter from pediatrician as well as an authorization letter plus EEG, which requires yet another authorization letter, etc."*
> Parent of a child with cerebral palsy enrolled in a private managed care plan

In general, parents whose children were covered by Medi-Cal managed care plans were more satisfied than parents whose children were in private managed care plans.

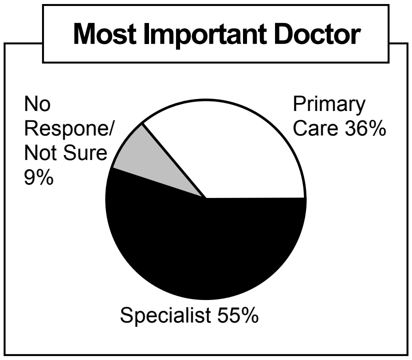
- Parents of children in Medi-Cal managed care plans were more satisfied than parents of children in private managed care plans in a number of areas: benefits that met their child's needs; access to quality hospitals; skilled and experienced primary care doctors and specialists; emergency care and informational materials.

Parents of children in Medi-Cal fee-for-service plans were more satisfied in several areas than parents of children in Medi-Cal managed care plans.

- Parents of children in Medi-Cal managed care were less likely to be satisfied than parents of children in Medi-Cal fee-for-service in two areas: access to skilled/experienced doctors and specialists and making it easy to complete paperwork.

How satisfied are parents with their child's primary care provider and the doctor most important to their child's care?

Most parents gave high ratings to their child's primary care provider and to the doctor they identified as most important to their child's care.



- Eighty percent of families said that their child had a primary care provider and 93% said that this primary care provider had the skill and experience that is needed to care for their child. Eighty seven percent of families rated their child's most important doctor as "good" or "excellent on providing quality care.
- Over half of the parents said that a specialist was the doctor most important to their child's care.
- About a third of the families gave lower ratings when asked about the doctor being available for advice over the phone, being easy to reach in an emergency.
- The majority of parents gave good or excellent ratings to this doctor for his/her ability to show respect for their child, spending enough time with the child, explaining the child's health needs, and including the family in decision making.
- A large portion of parents indicated that "they did not know" about the amount of communication the doctor had with other systems that provide care for their child such as schools or early intervention programs.

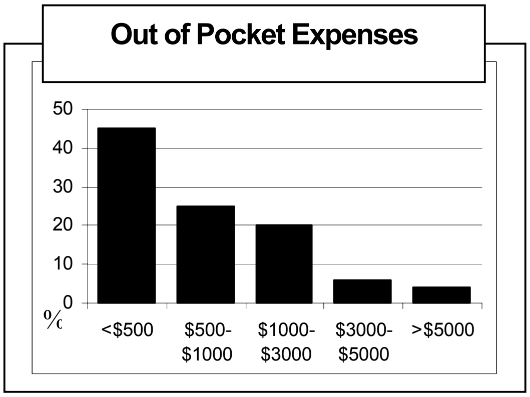
Some parents were more satisfied than others

- Parent's who chose their child's doctor were more likely to be satisfied with that doctor's support, communication, and partnership with the family in decision making than families who did not choose their child's doctor.
- Parents of children with moderate or severe disabilities and unstable special health care needs were less satisfied with care from their most important doctor.
- Parents who responded in Spanish were less satisfied than those who responded in English in the following ways: the overall quality of care from their child's doctor, the doctor's communication with the family, and waiting times. However, parents who responded in Spanish were more satisfied with their doctor's respect for their child and the family than parents who responded in English.
- Parents of children in Medi-Cal managed care plans were more satisfied with their child's doctor's overall quality of care than parents of children in private managed care plans.

What kind of impact does a child with special health care needs have on a family?

For many families, having a child with special health care needs has a significant family impact, affecting their finances, jobs, and time.

- Over half of the parents reported spending some time each week providing health care at home. One-fifth spent 20 or more hours per week providing this care.
- Almost all of the parents spent time each week arranging and coordinating their child's care, with 41% spending five or more hours per week in care coordination activities.
- One-third of the parents reported that their child's health conditions caused financial problems; 28% said they stopped working; and 37% cut down the hours they work.
- Almost half of the parents reported spending between $500 and $3,000 out of their own pocket for the special health care needs of their child in the past year. One-tenth said they spent $3,000 or more.
- Most of the children in this survey had missed more than five days of school in the last 12 months; 25% had missed six to fourteen days; and 15% had missed more than thirty days of school because of their special health care needs.



"Don't give us such a run-around! Find out what our lives are like and be helpful – do not add more stress by making us jump through hoops just to see an appropriate medical professional." **Parent of a child with head injury enrolled in a private managed care plan**

"Allow the family to retain assets that can allow them to be self-supporting while their child's medical needs are met. There is no reason for a family to fall below the poverty line because a child needs special attention."
Parent of a child with one kidney enrolled in Medi-Cal fee-for-service

What advice do families in the survey have for other parents of children with special health care needs?

Parents advised careful examination of health coverage, including asking a lot of questions about the plan.

> *"...Make sure you know you are made aware of exactly what you're financially responsible for in all situations, from office visits to emergencies."*
> Parent of a child with allergies/sinus trouble enrolled in Medi-Cal fee-for-service

> "...*Check all the fine print and if you have any problems regarding benefits – ASK! And if the answers aren't to your understanding, ask again. Don't be afraid to contact insurance companies directly and speak to someone with the knowledge needed to help. Also, speak to the parents of these children if you have any questions before getting a denial for a referral or continued care. We know our children best.*"
> Parent of a child with digestive/gastrointestinal disorder enrolled in a private managed care plan

More than one-fifth of parents who responded in English advised families to make sure the plan they chose allowed for flexibility of choice, especially for choosing doctors and specialists.

> *"...Make sure that you choose a plan, if possible, that has the most flexibility in choosing doctors, specialists and hospitals."*
> Parent of a child enrolled in a private managed care plan

> *"...Make sure they will let you continue with doctors already familiar with your child. Make sure they let you see doctors knowledgeable with your child's medical condition."*
> Parent of a child with autism enrolled in a private managed care plan

Some parents who responded in Spanish advised parents to make wise provider choices based on their ability to provide bilingual services.

> *"...To choose a good medical group, nice, kind and with bilingual staff."*
> Parent of a child with allergies enrolled in Medi- Cal fee-for-service.

> *"..Only choose places where they can speak in their own language about the programs and where they can receive instructions and advice for their patients."*
> Parent of a child with scoliosis enrolled in Medi-Cal fee-for-service.

What

kind of advice do parents have for their child's health plan?

Parents wanted expanded coverage, a choice of doctors and the designation of a specific person who knows how the plan operates that families can contact when they need help.

"...Listen to the parents, we know our kids better than anyone else. Don't be afraid or intimidated by special needs children because they just need a little tender loving care."
Parent of a child with epilepsy/seizure disorder enrolled in a private managed care plan

"... To be able to see the same (one or two) doctors – always! When I need a same day appointment and can't see my primary care doctors it is frustrating to have to explain his whole medical history over and over again."
Parent of a child with seizures and microcephaly enrolled in a private managed care plan

"...Provide a case manager or specific representative that I can contact instead of dealing with a different person each time I call."
Parent of a child with arthrogryposis bulbar palsy enrolled in a private managed care plan

"...Have RNs who are familiar with the disabilities answer a special needs phone line at Medi-Cal. Have someone with the knowledge of what is covered, by which agency and tell you straight out what is needed i.e. referrals, to make sure your child's needs get met."
Parent of a child with Down Syndrome enrolled in a Medi-Cal managed care plan

One-tenth of parents who responded in Spanish requested that the plan hire more bilingual staff and/or providers.

"... To offer sufficient bilingual skilled personnel to communicate and understand well what the users need."
Parent of a child with cerebral palsy enrolled in Medi-Cal fee-for-service

"... To have skilled personnel, and not partially bilingual; a telephone number with a 24 hour service to contact them, because sometimes we can't get in touch with them (during working hours)."
Parent of a child with mental retardation enrolled in Medi-Cal fee-for-service

In conclusion,

what does the family survey tell us?

While some pieces of the health care financing and delivery system are serving these children well, other pieces are not meeting their needs. Many families who have children with special health care needs struggle to navigate a complicated mix of services from health plans, public programs and private agencies.

About Public Policy

- Children with special health care needs are a small but significant part of our nation's population of children. Though not well understood by many health plans, the experiences of these children with special health care needs and their families are reflections of how well health systems in California are performing and should be monitored carefully.
- The comprehensive benefit package of Medi-Cal provides essential services for children with special health care needs and should serve as a model benefit package for all children needing specialized health care services whether publicly or privately funded.
- Medi-Cal administrators should investigate why parents of children with Medi-Cal managed care plans were less satisfied than parents in Medi-Cal fee-for-service plans with the provision of skilled and experienced primary and specialty care.
- For some children whose primary health coverage benefits are limited, secondary health care coverage, like CCS, is essential.

About Health Plans

- Children with special health care needs require flexibility in health care plans such as choice of doctors and specialists, streamlined procedures for accessing specialty care, and care coordination/case management.
- Parents want and need clear information from their health plans about health plan benefits, how to get covered services for their children, where to go with complaints and appeals, and other available resources that will help them meet their child's needs.

About Providers and Quality of Care

- The majority of families of children with special health care needs in this study feel positively about the quality of their doctors, especially if they can choose them.

- Many children who need other specialty providers do not have adequate access to them, particularly to quality mental health providers, experienced therapists and skilled home health providers.

- The needs of parents who responded in Spanish need to be further investigated, particularly around issues of communication with providers and quality of care.

About Coordination of Care

- Families in California face a confusing and fragmented maze of services from health plans, school systems, state agencies and others programs such as regional centers, CCS and DMH. This adds to the complexity of their lives, and their frustration with systems of care meant to serve their children.

- It is presently often left to families to figure out who will provide and pay for therapies such as physical, occupational, speech, and mental health. Payment responsibility among the multiple possible payers must be clarified so that children are not left unserved while agencies and programs negotiate among themselves about payments.

- Case management services, coordination of care and communication among providers are essential for this group of children and must be improved to ensure quality care. Improvements within individual plans, agencies and programs, and across systems that serve children with special health care needs are necessary.

About Children & Families and Information for Families

- Many families provide significant amounts of complicated healthcare for their children at home. They need more support than they now receive. The impacts of a child with special health care needs on a parent's job, finances and time must be recognized and public policies must address these impacts.

- Children with unstable and/or severe health and behavioral needs, are not receiving adequate services from health plans, public programs, and community agencies.

- Families of children with special health care needs require more information and help in their own language in order to ensure a health system that works for their children and families. Parents consistently spoke in the survey about how other families were often their most important source of information, and an established means for parents to learn from other parents needs to be assured.

What
other information is available?

The voices of the families who participated in this study have provided invaluable information to the research and study of families' experiences with health care that will help our understanding of the present and planning for the future for children with special needs.   More information about this study can be found on the Family Voices website: www.familyvoices.org.

Thanks to the family leaders who helped with this study and report including Sherry Torok, Kim Winter, Patricia Herrera, Mara McGrath, Linda Landry, Betsy Katz, Claire Gover, Dee Hayden, Claire Heinzelman, Mary Ellen Peterson, Debbie Sarmento, Randy Lyn Herndon, Stephanie Fox, Pat Mejia and Juno Duenas. Sincere thanks to Dr. Meridee Gregory, Betsy Lyman and Julie Linderman at California Children's Services, and the staff of the participating county CCS programs. A special thank you to all families who filled out the survey.

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

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More information about this study can be found on the Family Voices website: www.familyvoices.org.

Acknowledgements

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ABILITIES, SKILLS & KNOWLEDGE FOR FAMILY RESOURCE STAFF

Goal:

Articulate competencies needed for Early Intervention parent-to-parent support personnel within Family Resource Center/Networks.

Rationale:

Uniformly accepted competencies for early intervention parent-to-parent support staff are either absent or inadequate.

Principles:

In addition to the principles outlined in the Family Support Principles, underlying activities and services of Family Resource Centers and Networks include as priorities the following:

- Peer parents are excellent role models for problem solving, coping and leadership
- Information and support are best met through the model of well trained competent peer parent staff
- Empowered parents transmit confidence and self advocacy to their children giving them a foundation in which to reach their fullest potential

The following recommendations address job functions, hiring criteria, and ongoing professional development for parent-to-parent support.

JOB FUNCTIONS:

Staff providing any level of direct parent-to-parent support should exhibit competencies in the following:

Assist families in identifying family strengths, needs and priorities
Provide culturally responsive support and materials in their native language
Perform intake and maintain records
Follow all confidentiality policies
Provide accurate information and referral
Communicate the intricacies of the systems and services involved in the care of their child
Connect families with intra-agency resources
Connect families with other agency and community resources
Connect families with peers, (on-line, support groups, etc.)
Engage in outreach activities
Network and collaborate with community agencies
Provide feeling focused support
Participate in staff development activities

HIRING CRITERIA:

When hiring the following criteria are essential for competence of parent-to-parent support staff:

Demonstrated commitment to mission, goals and purpose of the FRC/N empowerment model
Personal knowledge and experience of disabilities and the impact on families

Ability to effectively engage in joint problem solving, negotiating and team building
Competent in use of active listening skills
Ability to communicate effectively with families, respecting each family's culture, values and circumstances
Ability to be resourceful in accessing current information
Demonstrate knowledge as a consumer with one or more of the following services or systems such as early intervention, family resource center, regional center, education, managed care, mental health, medical service delivery system.

ONGOING TRAINING AND SUPPORT NEEDS

Ongoing training is essential for parent-to-parent support staff to stay current and be efficient. The training we are encouraging is the minimum for parent-to-parent support regarding early intervention and does not preclude other training such as child abuse. The following training and support needs are excerpted from Family Support Guidelines for Effective Practice of California's Early Start Programs:

Effective communication skills
Coping skills, grief response, "Feeling-focused support"
Decision making and problem solving
Enhancing natural support systems
Helping families assess their strengths and values
Respecting families cultural values and ensure they get materials in their native language
Parent-professional collaboration
Community resources, both generic and specialized
Accessing community resources, what is the eligibility, and appeals and due process procedures
Recognizing situations which require referral to others and respecting limits/boundaries
Increasing families self-advocacy/empowerment
General knowledge regarding accessing information on disabilities
Self care strategies
Knowledge of IDEA Part C and Part B
Knowledge of Early Start State Statute and regulations
Knowledge of the Lanterman Act
Knowledge of Medi-Cal Managed Care
Education requirements

QUALIFICATIONS FOR PARENT-TO-PARENT SUPPORT PERSONNEL

Personnel Category	Job Duties	Education or Equivalent	Classes/ Training	Experience	Professiona l Growth*
Executive Director / Program Director	May include: Fiscal Planning and Management, Fund Development, Personnel Management, Program Planning and Development	Leadership, human resources, personnel management, facilities management, data collection, budgeting, financial planning, financial operations, fund development, the operational framework for a 501 (c)(3), program planning, strategic planning, early intervention system and services, confidentiality, parent-to-parent support, family centered support, local generic resources, parent professional collaboration, work with board of directors or advisory board, interagency collaboration working with families and professionals in behalf of children	Training regarding job duties	1 year administrative experience and 3 years in disability and family related services	24 hours annually
Supervisory Personnel	May include: Supervision, mentoring, training, evaluation of staff	Personnel management, supervision, mentoring, training, early intervention system and services, confidentiality, parent-to-parent support, family centered support, local generic resources, parent professional collaboration, working with families and professionals in behalf of children	Supervision for 1 year	2 years experience in disability and family related services	24 hours annually
Direct Service Personnel	Listening and talking, meeting with families and professionals, speaking in behalf of families	Early intervention system and services, confidentiality, parent-to-parent support, family centered support, local generic resources, parent professional collaboration, working with families and professionals in behalf of children	Orientation and ongoing supervision	2+ years personal experience with service delivery system	Access to 48 hours training / Weekly mentorship / supervision
Community Outreach Personnel	Speaking in public, training, community committee participation	Public speaking, trends/ systemic issues vs. personal experience, early intervention system and services, confidentiality, parent-to-parent support, family centered support, local generic resources, parent professional collaboration, working with families and professionals in behalf of children	Orientation and ongoing supervision	Personal experience with service delivery system	Access to 16 hours training / weekly mentorship / supervision
Interpreters	Interpreting at meetings and workshops	Rules of conduct for interpreters, Early Intervention terms and vocabulary, family centered support, confidentiality	Orientation in Family Centered Services and Support and 6 hours of training's		Access to 16 hours training / weekly mentorship / supervision
Receptionist	Answering phones, greeting families at drop-in center	Family centered support, confidentiality	Orientation in Family Centered Services and Support		

PARENT-TO-PARENT VOLUNTEERS should have opportunities for training, supervision and evaluation.
PROFESSIONAL GROWTH: Hours are based on full time employees, i.e. they should be pro-rated for part time staff.

DEFINITIONS FOR QUALIFICATIONS FOR PARENT-TO-PARENT SUPPORT PERSONNEL

DIRECT SERVICE PERSONNEL: Provision of direct service to families might include phone line, office and home visits and accompanying families to medical, educational meetings, etc. Provision of direct service to the community might include outreach; training, working with professionals in behalf of families and promoting parent professional partnership. [It is not necessary for front line staff to have a high school diploma, etc., As long as they can fulfill the job requirements. This will allow us the opportunity to hire teen parents.]

INSERVICE: On the job training

MENTORING: Discussion and modeling of best practices for family support, individualized support to utilize training

OTHER PERSONNEL: Includes any staff, which may have direct contact with families, such as interpreter, clerical support, and receptionist.

PRE-SERVICE: Training that occurs before being hired

PROGRAM DIRECTOR: Direct overall operations of the organization which might include: administrative, fiscal management, program development, fund development, supervision of staff, public relations, data and progress reports, Board liaison

SUPERVISION: Regularly scheduled observation with opportunities for feedback, discussion of effective strategies, professional evaluation

TRAINING, CLASSES, WORKSHOPS AND CONFERENCES: Any knowledge based skill development activity, on a topic directly related to meet the requirements of their job

IT’S THE LAW!

Selected Federal laws and regulations that mandate linguistic competence:

■ Title VI of the Civil Rights Act of 1964

"No person in the United States shall, on ground of race, color or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Guidance issued by the Office of Civil rights further clarifies Title VI as it relates to persons with limited English Proficiency. Specifically, providers should establish and implement policies and procedures to fulfill their Title VI equal opportunity responsibilities including reasonable steps to provide services and information in appropriate languages other than English to ensure that persons with limited English proficiency are effectively informed and can effectively participate in any benefit. Nearly every health care provider is bound by Title VI, because Federal funding of health care is almost universal.

■ The Hill-Burton Act

Enacted by Congress in 1946, the Hill-Burton Act encouraged the construction and modernization of public and nonprofit community hospitals and health centers. In return for receiving these funds, recipients agreed to comply with a "community service obligation", one of which is a general principle of non-discrimination in the delivery of services. The Office of Civil Rights has consistently interpreted this as an obligation to provide language assistance to those in need of such services.

■ Medicaid

Medicaid, a Federal-state cooperative program of medical assistance, provides health insurance to adolescents, children and families who are poor, and people with disabilities and those who are indigent and elderly. Medicaid regulations require Medicaid providers and participating agencies, including long-term care facilities, to render culturally and linguistically appropriate services. The Health Care Financing Administration, the Federal agency that oversees Medicaid, requires that states communicate both orally and in writing "in a language understood by the beneficiary" and provide interpretation services at Medicaid hearings.

■ Medicare

Medicare, the Federal program that provides insurance to people 65 years of age or older, with certain disabilities who are under 65 years of age, and of any age with permanent kidney failure. Medicare addresses linguistic access in its reimbursement and outreach education policies. Medicare "providers are encouraged to make bilingual services available to patients wherever the services are necessary to adequately serve a multilingual population". Medicare reimburses hospitals for the cost of the provision of bilingual services to patients.

■ Emergency Medical Treatment and Active Labor Act (EMTALA)

This Act requires hospitals that participate in the Medicare program that have emergency departments to treat all patients (including women in labor) in an emergency without regard to their ability to pay. The EMTALA Act was passed to reduce the practice of "dumping" patients who lacked the financial ability to incur hospital costs. EMTALA stipulates a hospital’s responsibilities to the patient which include the diagnosis, treatment, informed consent, and notification of condition and intent to transfer to another facility. Hospitals that fail to provide language assistance to persons of limited English proficiency are potentially liable to federal authorities for civil penalties, as well as relief to the extent deemed appropriate by a court.

Linguistic Competence: Policy Making Implication for Primary Health Care Organizations and Programs

Health care organizations have been slow to develop and implement policies and structures to guide the provision of interpretation and translation services. In the absence of policy, structures and fiscal resources, the burden of such services remain at the practitioner and consumer level. The following checklist is designed to assist primary health care organizations in developing policies, structures, practices and procedures that support linguistic competence.

Checklist to Facilitate the Development of Linguistic Competence within Primary Health Care Organizations

Does the primary health care organization or program have:

__ A mission statement that articulates its principles, rationale and values for providing linguistically and culturally competent health care services?

__ Policies and procedures that support staff recruitment, hiring and retention to achieve the goal of a diverse and linguistically competent staff?

__ Position description and personnel/performance measures that include skill sets related to linguistic competence?

__ Policies and resources to support ongoing professional development and inservice training (at all levels) related to linguistic competence?

__ Policies, procedures and fiscal planning to insure for the provision of translation and interpretation services?

__ Policies and procedures regarding the translation of patient consent forms, educational materials and other information in formats that meet the literacy needs of patients?

__ Policies and procedures to evaluate the quality and appropriateness of linguistic services?

__ Policies and procedures to periodically evaluate consumer and personnel satisfaction with interpretation and translation services that are provided?

__ Policies and resources that support community outreach initiatives to persons with limited English proficiency?

__ Policies for and procedures to review periodically the current and emergent demographic trends for the geographic area served in order to determine thresholds for the provision of interpretation and translation services?

GLOSSARY

HEALTH CARE DEFINITIONS

These definitions have been adapted from the following sources:

- PASSPORT: Knowing the Language (produced by "Families as Participants: Working Within a Managed Care System", a project funded by the US Maternal and Child Health Bureau)
- "Alphabet Soup: Health Care Definitions for Children with Special Health Needs" and other information sheets by Family Voices
- “The ABCs of Managed Care”, a report from the Egg Harbor Family Summit
- “Managed Care for Children with Special Health Care Needs: Physician Case Management Model” by Subcommittee on the Managed Care Initiative of Children’s Special Health Care Services Advisory Committee.
- “Understanding Medi-Cal: The Basics”, published by the Medi-Cal Policy Institute

ACCESS:
Ability to receive services from a health care system or provider.

ACCOUNTABLE:
There is a mechanism to provide information concerning the performance and utilization of the system of services.

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 that the general population; if too many enrollees have higher than average medical costs, the health plan experiences adverse selection.

ALLOWABLE EXPENSES:
The necessary, customary and reasonable expenses that an insurer will cover.

AMBULATORY CARE:
Medical care provided on an out-patient (non-hospital) basis.

ANNIVERSARY DATE:
The date on which a health plan or insurer contract with an employer or an individual subscriber is renewed each year. It is the date when premium costs and benefits are most likely to change. It may be preceded by an "open enrollment period," when employees have the option to switch health plans.

ANNUAL MAXIMUM LIMITS OR CAPS:
The limit an insurance plan sets on a given service. It may be a certain number of visits or a dollar amount. If a person needs more of a given service than is allowed y the limits in a plan, one will need to request an exception.

APPEAL:
To formally request a health plan to change a decision.

ASSISTIVE TECHNOLOGY DEVICE:
Under IDEA, any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability.

ASSISTIVE TECHNOLOGY SERVICE:
Under IDEA, any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device.

AVERAGE LENGTH OF STAY:
Measure used by hospitals to determine the average number of days patients spend in their facilities. A managed care firm will often assign a length of stay based on standards of care to patients when they enter a hospital and will monitor them to see that they don't exceed it.

BAD FAITH:
Unreasonable refusal by a health plan or insurer to pay a valid claim which can be remedied in a civil suit.

BALANCE BILLING:
The practice of billing a patient for any portion of health care charges that are not "covered" (paid for) by health insurance. The circumstances under which balance billing is allowed are usually spelled out in providers' contracts with plans.

BASIC BENEFITS:
A set of "basic health services" specified in your member handbook and those services required under applicable federal and state laws and regulations.

BEHAVIORAL HEALTH CARE FIRM:
Specialized managed care organizations, focusing on mental health and substance abuse benefits, which they term "behavioral health care." These firms offer employers and public agencies a managed mental health and substance abuse benefit. Almost none existed 10 years ago, but they are now a large industry.

BENEFICIARY:
The patient (your child) or family who receives the "benefits" or services from health insurance.

BENEFITS or BENEFIT PACKAGE:
The health care services covered by a health plan or health insurance company, under the terms of its member contract.

CAPACITY:
Ability of a (health) organization to provide necessary health services.

CAPITATION:
Method of payment for health services in which the insurer pays providers fixed amounts for each person served regardless of the type and number of services used. Some HMOs pay monthly capitation fees to doctors, often referred to as a per member per month amount.

CARE COORDINATION:
Process of having all care needs coordinated by one person with an emphasis on maximizing a family's capabilities to manage their child's needs and provide quality care without duplication or inappropriate usage.

CASE MANAGEMENT PROGRAM:
Special programs now offered by many insurance companies, particularly for individuals who require high-cost care or have a chronic condition. Under such a program, a case manager is assigned to oversee a given member's health needs. Case managers may arrange alternative benefits within or outside the plan. Contact your plan to find out if you are eligible and how it works.

CATEGORICAL:
Designates persons eligible for assistance because they fall into certain welfare groups or categories (Aged, Blind, Disabled).

CERTIFICATE OF INSURANCE:
A description of health benefits included in a health plan, usually given to insured members by the employer or group.

CHILD WITH A DISABILITY:
Under IDEA, a child with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities who needs special education and related services.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS:
Those children who have or 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.

CLAIM:
The documentation of a medical service that was provided to a covered patient by a doctor, hospital, laboratory, diagnostic service or other medical professional. In managed care, claims are not necessary (See Capitation and Co-payment definitions.)

CLINICIAN:
A term that is often used to describe all types of medical professionals who care for patients--doctor, nurse, physicians' assistant, therapist, etc.

CLINICAL STANDARDS:
The care guide used by health plans and providers in making decisions about medical necessity.

CO-PAYMENT (or CO-INSURANCE):
The portion of charges paid by the patient for medical and hospital services, after any deductible has been paid. Indemnity plans typically require a co-payment to be a percent of the charge for the service (for example, 20%). The amount may vary based on the type of service, when the service is received (for example, within a certain number of days of an emergency), or where the service is received (out-

patient versus in-patient). In managed care plans, the co-payment is usually a small fixed amount regardless of the cost of the service.

COBRA (Consolidated Omnibus Budget Reconciliation Act) PL.99-272:
A federal law that provides the opportunity for individuals to continue the same insurance coverage for 18-36 months after they lose their jobs or for covered dependents to continue coverage after the death of the insured. The individual is responsible for paying the full insurance premium. There may also be language in the policy on provisions for continuing the same coverage. The Insurance Commissioner in your state or your employer may offer information on your rights for continuation.

COLLABORATIVE CARE:
The role of families as primary decision makers and caregivers is acknowledged and supported when the health financing system pays for services that support this role. Family participation in the allocation of health resources is achieved when the parent is recognized as primary decision maker in the development of individualized plans of care.

COMMUNITY-BASED:
The system of care responds to the needs identified by the community and draws from the community to address needs. Services are provided in or near the home community to the extent possible.

COMMUNITY RATING:
An insurance practice of pooling people within a geographic area and charging everyone a set premium for a set benefit package without considering their individual health status.

CONCURRENT REVIEW:
A managed care technique in which a representative of a managed care firm continuously reviews the charts of hospitalized patients to determine whether they are staying too long and if the course of treatment is appropriate.

CONTINUITY OF CARE:
The degree to which the care of a patient from the onset of illness until its completion is continuous; that is, without interruption.

CONTINUUM OF CARE:
A range of medical, nursing treatments, and social services in a variety of settings that provides services most appropriate to the level of care required. For example, a hospital may offer services ranging from nursery to a hospice.

COORDINATION OF BENEFITS:
The process for how benefits will be applied if you have more than one health plan. Regulations on coordination of benefits may exist within your state or your insurance plan may describe how such coordination should happen. Usually one plan is designated to pay all claims first and the residual bills are the responsibility of the secondary carrier. These provisions are to prevent individuals from collecting more than once for the same medical charge.

CO-PAYMENT:
A cost-sharing arrangement in which the member pays, to the provider, a specified amount for a specific service.

COST SHIFTING:
A phenomenon occurring in the US health care system in which providers, hospitals or health care centers are less than adequately reimbursed for their costs and subsequently raise their prices to other payers in an effort to recover costs. Low reimbursement rates from government health care programs often cause providers to raise prices for medical care to private insurance carriers.

COST CONTAINMENT:
An attempt to reduce the high costs surrounding the allocation and consumption of health care. These costs may from inappropriately used services and from care that can be provided in less costly settings without harming the patient.

COVERAGE:
Agreed upon set of health services that a plan will pay for and/or provide.

CREDENTIALING:
The process of verifying a physician’s (or other provider’s) credentials to participate as a provider in a health care plan. Criteria for credentialing vary from plan to plan, but examples of typical credentialing requirements for physicians include state licensure and admitting privileges at plan hospitals, and may include other accreditation or certification requirements.

CROSSOVER:
Refers to a claim that has been processed and paid in part by Medicare and then processed by Medi-Cal for those with dual eligibility.

CURRENT PROCEDURAL TECHNOLOGY (CPT):
A set of codes developed by the American Medical Association that describes medical procedures for

billing. Each item submitted by your provider to an insurance company for payment must be listed by code on the bill.

CUSTODIAL CARE:
Care provided primarily to assist a patient in meeting the activities of daily living, but not care requiring skilled nursing services.

CUSTOMARY AND REASONABLE:
Refers to a fee that falls within a common range of community fees.

DEDUCTIBLE:
The amount that you must pay out-of-pocket for covered medical care before the benefits of the coverage begin. Check what this amount is per family member. There may also be a total family limit. Deductible amounts vary a great deal from policy to policy. Deductibles are usually set as an annual amount.

DIAGNOSIS-RELATED GROUPS (DRGs):
Method of reimbursing providers based on the medical diagnosis for each patient. Hospitals receive a set amount determined in advance based on length of time patients with a given diagnosis are likely to stay in the hospital. Also called prospective payment system.

DOCUMENTATION:
Written records relating to your family's medical care and insurance. You may need detailed records to support your case if you disagree with your insurer.

DUAL-ELIGIBLES:
People who are eligible for both Medicaid (called Medi-Cal in California) and Medicare. In such cases, payments for any services covered by Medicare are made before any payments are made by the Medicaid program.

DURABLE MEDICAL EQUIPMENT (DME):
Necessary medical equipment that is not disposable: for example, wheelchairs, walkers, ventilators, commodes.

EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT PROGRAM (EPSDT):
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.

EFFECTIVE DATE:
The date on which coverage under a health plan or insurance contract begins.

EMERGENCY CARE:
The immediate care that is necessary when a child has a condition, illness, or injury that is life-threatening or would significantly impair his/her health.

EMPLOYEE RETIREMENT INCOME SECURITY ACT (ERISA):
A federal law that establishes uniform standards for employer-sponsored benefit plans. Because of court decision, the law effectively prohibits states from experimenting with alternative health-financing arrangements without waivers from Congress.

EMPLOYER CONTRIBUTION:
The amount of money an employer pays toward the health benefit plans of its employees usually through a payroll deduction. The employer may pay the same fixed number of dollars toward every plan it offers to its employees ("an equal-dollar contribution"); it may pay a fixed percentage of the premium for every plan offered ("equal-percentage"); or it may adjust its contribution in other ways.

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

ENROLLMENT AREA:
The geographical area within which a health plan member must reside in order to be eligible for coverage. Most HMOs place a limit on the length of time members (except students) can live outside the enrollment area each year and still be covered.

ERISA (Employee Retirement Income Security Act of 1974:
Administered by the U.S. Department of Labor, ERISA regulates employer-sponsored pension and insurance plans for employees.

EVIDENCE OF COVERAGE:
The written document provided by a health plan to an enrollee that describes exactly what services are covered and under what conditions. Providing such a document is required by law, and the document describes the obligations of the plan toward the member and the member’s responsibilities as an enrollee.

EXCEPTION TO POLICY:
A plan (public or private) can choose a different method of treatment, usually after agreement among the patient, care coordinator, and/or primary provider.

EXPLANATION OF BENEFITS:
The statement from your insurance plan that itemizes the actions taken on claims that have been submitted.

EXCLUSION:
A treatment or service that is not covered by a policy.

EXPERIENCE RATING:
An insurance practice of setting premiums based on previous use of health services and health status. An employer whose employees have a high use of services will pay higher rates. This practice generally discriminates against people with disabilities or chronic illness.

EXPERIMENTAL TREATMENT:
Medical treatment not usually covered by insurance companies or public programs because its efficacy is considered unproven. Insurance companies or public programs may reject claims when they decide that the treatment is experimental. Insurers may rely on an internal medical review, consultation with outside experts, or a combination of these and other means. Articles in the current medical literature may influence decision. Individuals have won claims by proving that other insurance companies have paid for the treatment in question or that the treatment has been beneficial in other ways.

FAMILY CENTERED CARE:
Health care delivery and systems that are based on the concerns, priorities and resources of the family, recognizing that the family is the constant in the child's life and the child's best advocate. Parent-professional partnerships are facilitated in family centered practices.

FEDERALLY QUALIFIED:
An HMO that has met certain federal standards regarding financial soundness, quality assurance, member services, marketing and provider contracts can be federally qualified. HMOs that are not federally qualified are still subject to federal and state regulations and requirements intended to protect consumers and providers and ensure quality of care.

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.

FIRST-DOLLAR COVERAGE:
A health insurance policy with no required deductible.

FORMULARY:
A list of prescription drugs and their recommended doses that have been selected by a health plan, insurer or group of doctors as the best choices in terms of effectiveness and value, among the many possible options for a given condition. Formulary drugs may be recommended or required as a condition of HMO prescription drug coverage (unless individual circumstances make a different drug a more appropriate choice for the patient). Formularies are frequently changed based on cost and availability.

GATEKEEPER:
A term given to a primary care provider in a managed care organization network who controls patient access to medical specialists, services and equipment.

GENERIC MEDICINES:
Medications that do not carry a brand name, but contain the same ingredients. Usually less expensive.

GRACE PERIOD:
A specified period immediately following a premium due date, during which payment can be made to continue the policy in force without interruption. States may have laws requiring health insurance policies to allow a set number of days of "grace."

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.

GROUP PRACTICE:
The provision of health care services by a group of physicians formally organized in a business entity that shares equipment, records and personnel in the provision of patient care and in business management.

GUARANTEE RENEWABLE:
An insurance contract that an insurer cannot terminate, providing the insured pays the required premiums in a timely manner. With these contracts, insurers have the right to raise premiums but only for an entire class of policyholders.

GUARANTEED ISSUE:
An insurance contract that is issued regardless of prior medical history. Small employers (between 3-50 employees) cannot be refused coverage because of the medical history of one or more employees. Some

individual plans are available on a Guaranteed Issue basis, although premiums are higher.

HEALTH CARE FINANCING ADMINISTRATION (HCFA):
Federal agency that oversees all aspects of financing for Medicare and also oversees the Federal Office of Prepaid Health Care Operations and Oversight.

HEALTH INSURANCE PURCHASING COOPERATIVE (HIPC):
A group of employers and individuals functioning as an insurance broker to purchase health coverage, certify health plans, manage premiums and enrollment and provide consumers with buying information. The larger group may be able to negotiate for lower premiums and/or more comprehensive benefits than smaller companies or individuals. Also called health insurance purchasing group, health plan purchasing cooperative or health insurance purchasing corporation (See Managed Competition definition.)

HEALTH MAINTENANCE ORGANIZATION (HMO):
An organized health care system responsible for financing and delivering health care to an enrolled population.

HEALTH SCREENING:
A method used by some insurers and health plans to determine whether applicants are likely to create high medical costs, either because they are already sick or because they are likely to have a costly illness in the future. Health screening is used to detect pre-existing medical conditions and to determine whether the applicant is at risk for illness because of factors like excessive weight, smoking or a past history drug abuse.

HEALTHY FAMILIES:
California's State Children's Health Insurance Program to fund health coverage for uninsured children who are not eligible for Medi-Cal.

HEALTH PLAN EMPLOYER DATA AND INFORMATION SET (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.

HOME AND COMMUNITY-BASED WAIVERS:
Medicaid waiver that allows states to offer an alternative health care package for people who would otherwise require nursing home or hospital care.

HOSPICE SERVICES:
Services to provide care to the terminally ill and their families.

HOSPITAL DAY:
A term to describe any 24-hour period commencing at 12:00 am or 12:00 pm, whichever is used by a hospital to determine a hospital day, during which a patient receives hospital services at the hospital.

ICP-9:
A numerical system for medical conditions and procedures that is used for billing, research and statistical purposes. For example, a specific diagnosis like cleft lip and palate has a unique code.

INDEMNITY HEALTH INSURANCE:
Usually a fee-for-service health plan that reimburses physicians and other providers for health services furnished to plan enrollees.

INDIVIDUAL (or INDEPENDENT) PRACTICE ASSOCIATION (IPA):
Association of physicians and other providers, including hospitals, who contract with an HMO to provide services to enrollees, but usually still see non-HMO patients and patients from other HMOs.

INDIVIDUALIZED EDUCATION PROGRAM (IEP):
Under IDEA, a written education plan for a school-aged child that is the student's primary education document and is developed by a team including the child's parents.

INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP):
Under IDEA, the planning document used for children under three years of age, and their families.

INDIVIDUAL PROGRAM PLAN (IPP):
Under the Lanterman Act, the program plan developed by the responsible regional center, the developmentally disabled person, and the person's parents, legal guardian, or conservator.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA):
The federal law pertaining to students with special needs within the education system.

INPATIENT CARE:
Medical care that requires the patient be admitted to and treated in a hospital. Most hospital care is inpatient care; a patient can also receive "outpatient" care in a hospital's emergency room or ambulatory care center.

INTERAGENCY COORDINATING COUNCIL (ICC):
A state council composed of families and professionals to set policy and monitor Part H/C, the federal early childhood special education law.

LANTERMAN ACT:
California state law guaranteeing certain rights to persons with developmental disabilities, including a right to treatment and habilitation services, humane care, prompt medical care and treatment, and to be free from harm and hazardous procedures.

LIFETIME MAXIMUM:
The total amount that an insurance policy will pay out for medical care during the lifetime of the insured person. In the case of a chronic condition, one should check into options for enrolling in another group plan during an open enrollment period well before approaching a lifetime maximum.

LIMITATIONS:
Conditions or circumstances for which benefits are not payable or are limited. It is important to read the limitations, exclusions and reductions clause in your policy or certificate or insurance to determine which expenses are not covered.

LOCK-IN:
The requirement that members of an HMO or other managed care plan must have all of their covered services provided, arranged or authorized by the plan or its doctors, except in life-threatening emergencies or when members are temporarily "out of area." This contrasts with a "point-of-service" plan, which allows patients to receive covered services without prior authorization but at a higher cost outside a plan's network.

LONG-TERM CARE:
A continuum of maintenance, custodial and health services for people with chronic illness, disability or mental retardation.

MANAGED CARE:
The integration of health care delivery and financing. It includes arrangements with providers to supply health care services to members, criteria for the selection of health care providers, significant incentives for members to use providers in the plan and formal programs to monitor the amount of care and quality of services.

MANAGED CARE ORGANIZATION (MCO):
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.

MANAGED COMPETITION:
A method for controlling health care costs by organizing employers, individuals and other buyers of health care into large cooperatives that will purchase coverage for their members. Insurance companies and managed care organizations will compete to supply coverage for the lowest cost. (See Health Insurance Purchasing Cooperative definition.)

MANDATED BENEFITS:
Specific benefits that insurers are required to offer by state law. Each state has its own legislation on mandated benefits.

MANDATORY ENROLLMENT:
Requirement that certain groups of people must enroll in a program. Medicaid managed care, for example.

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 received assistance. Is financed with federal and state funds, amount varying by state.

MEDICAL HOME:
A concept wherein health care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent. In a “medical home,” physicians and parents share responsibility for ensuring that children and their families have access to all the medical and non-medical services needed to help them achieve their maximum potential.

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.

MEDICALLY NECESSARY SERVICES:
A clause in a health insurance policy that states that the policy covers only services needed to maintain a certain level of health. The clause also defines--often in general terms--what those services are. One should find out exactly what an insurer means by this term in order to present a request in the most appropriate way. Interpretations of the term "medically necessary" vary widely.

MEDICARE:
Title XX of the Social Security Act, which pays for health care for the elderly, and adults who are disabled.

MEDICALLY UNNECESSARY DAYS:
A term used to describe that part of a stay in a facility, as determined by a case manager, as excessive to diagnose and treat a medical condition in accordance with the standards of good medical practice and the medical community. Excessive may be because stay was too long or was in a more costly or less efficient setting.

NATIONAL ASSOCIATION OF INSURANCE COMMISSIONERS (NAIC):
An organization of state insurance commissioners that writes model laws and regulations governing the insurance industry.

NATIONAL COMMITTEE ON QUALITY ASSURANCE (NCQA):
An independent, not-for-profit organization that reviews and accredits managed care plans, including HMOs. NCQA also developed a set of tools called Health Plan Employer Data and Information Set (HEDIS) which provides standardized performance measures for reporting on health plans they review.

OMBUDSMAN:
Person designated by a health plan or Medicaid to solve problems and answer questions from consumers in an objective way.

OPEN ENROLLMENT PERIOD:
A period when employees may sign up for a health plan without waiting periods or consideration for preexisting conditions. Many employers offer these periods yearly and when employment begins.

OPT-OUT:
An option available through some managed care plans, such as point-of-service HMOs and Preferred Provider Organizations, to choose or receive covered care from providers outside the plan's network at a higher cost.

OUT OF AREA:
Beyond or outside the geographical area served by an HMO or other managed network plan. When HMO members are inside their plan's service area, they must have their care provided, arranged or authorized by their HMO or HMO doctor in order to get full coverage; when they are temporarily out of area, different coverage rules apply.

OUT-OF-PLAN SERVICES:
Services furnished to patients by providers who are not members of a patient's managed care network.

OUT-OF-POCKET COSTS:
All the health expenses that you must pay, including deductibles, co-payments and charges not covered by any health plan.

OUTCOMES MEASURE:
A tool to assess the impact of health services in terms of improved quality and/or longevity of life and functioning.

OUTPATIENT BENEFITS OR COVERAGE:
Treatment or services received in a setting such as a clinic or doctor's office and not as an admitted patient in a hospital. In the case of a chronic condition, one should carefully check the out-patient benefits in any plan because most services will take place on an out-patient basis.

PARENT TRAINING AND INFORMATION CENTER (PTI):
Every state has a parent-run organization funded by the U.S. Department of Education to provide information and training to families around education issues for their children with special needs.

PART C:
Early Start - the early childhood component of IDEA which used to be called Part H. Regional Centers and Special Education departments are responsible for Early Start services for children birth to three years of age who are developmentally delayed or who are at risk of delay.

PARTICIPATING PROVIDERS:
A physician who signs a contract with a PPO or HMO plan and agrees to accept the plan's allowable charges.

PER DIEM COST:
Cost per day; hospital or other institutional cost for a day of care.

PHYSICIAN HOSPITAL ORGANIZATION (PHO):
Organization that includes hospitals and physicians contracting with one or more HMOs, insurance plans or directly with employers to provide medical services.

POINT-OF-SERVICE:
A term that applies to certain health maintenance organizations and preferred provider organizations. Members in a point-of-service HMO or PPO can go outside the network for care, but their reimbursement will be less than if they had remained inside.

PRACTICE GUIDELINES OR PROTOCOL:
Description of a course of treatment or established practice pattern. Managed care entities develop and distribute these to providers in their network to guide clinical treatment decisions. (See also Standard of Care definition.)

PRE-AUTHORIZATION:
Approval from an insurance plan or a designated primary care provider is obtained before specialty services are provided or the service will not be reimbursed.

PRE-EXISTING CONDITIONS:
A physical or mental health condition that has been treated or would normally have been treated before enrollment in an insurance plan. Policies may exclude coverage for such conditions for a specified period of time. In some cases, pre-existing conditions exclude a person completely from buying health insurance. An insurance company may decide to charge higher premiums or offer the insurance but refuse to cover any treatment relating to the specific condition. Some states have laws limiting exclusions for pre-existing conditions.

PREFERRED PROVIDER ORGANIZATION (PPO):
A form of managed care plan in which a group of providers contract with an insurer and agree to provide services at pre-negotiated fees. Members must have a primary care provider who is a member of the PPO. Members are given incentives to use providers within the organization, but may use providers outside the plan for greater out-of-pocket costs.

PREMIUM:
The charge paid to the insurer for health coverage. This may be paid weekly, monthly, quarterly or annually.

PREPAID HEALTH CARE ACT:
A federal law passed in 1973 that sets standards for federally qualified health maintenance organizations. Among the standards are minimum benefits and formal grievance procedures.

PREPAID HEALTH PLAN (PHP):
Health organization that receives prepaid capitation payments for a select set of benefits; for example, physician services or lab tests.

PREPAID PLANS:
A health insurance plan where you pay a fixed premium to cover much of the care you receive. Prepaid plans include HMOs and PPOs.

PREVENTIVE CARE:
Medical services that try to reduce the chances of illness, injury or other conditions. This contrasts with acute care, which is given after the condition has occurred.

PRIMARY CARE:
Routine medical care, usually provided in a doctor's office.

PRIMARY CARE CASE MANAGEMENT:
System that pays primary care providers a monthly fee to coordinate medical services. Especially used by Medicaid.

PRIOR APPROVAL:
Permission needed from a Primary Care Provider or the health plan before a service can be delivered or paid for.

PROFESSIONAL REVIEW ORGANIZATION (PRO):
An organization that determines whether care and services provided are medically necessary and meet professional standards under Medicare and Medicaid.

PROLONGED ILLNESS CLAUSE or EXTENDED BENEFITS:
A possible option in insurance coverage for 100 percent reimbursement (instead of partial) for all

services relating to a condition. This option may also add to the lifetime maximum.

PROSPECTIVE REVIEW:
The process in which a plan reviews a planned hospital admission prior to the admission date in order to evaluate whether the admission is medically necessary. A component of utilization management.

PROVIDER:
A hospital, skilled nursing facility, outpatient surgical facility, physician, practitioner or other individual or organization which is licensed to provide medical or surgical services, therapy, treatment and accommodations.

QUALITY ASSURANCE:
A term that describes attempts by health care organizations to measure and monitor the quality of care delivered.

QUALITY MANAGEMENT:
A formal set of activities to assure the quality of services provided. Quality management includes quality assessment and corrective actions taken to remedy any deficiencies identified through the assessment process.

RATIONING:
The allocation of medical care by cost or availability of services.

REFERRAL:
A formal process by which a patient is authorized to receive care from a specialist, therapist or hospital. Most managed care organizations (MCO's) usually require a referral from the member's primary care provider in order for specialty care to be covered.

REFERRAL PHYSICIAN:
A physician who has a patient referred to him by another source for examination, surgery, or to have specific procedures performed on the patient, usually because the referring source is not prepared or qualified to provide the needed service.

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

RENEWAL:
The clause in an insurance plan that describes how one might renegotiate the contract after the term is finished. Guaranteed renewability of an insurance policy protects from loss of coverage, although an insurer may still raise premiums.

REPORT CARD:
A published report for consumers on the premium costs for a plan and overall quality of a health plan or provider. Report card generally measure a plan's delivery of appropriate services, patient outcomes, patient satisfaction and cost structure.

RIDER:
A legal document added to an insurance plan that either restricts or adds to coverage. States may have regulations about riders.

RISK:
An insurance term related to financial responsibility for medical care. A "high-risk" individual is someone who has a high likelihood of having a serious illness, because of past medical history, family history or health-related behavior, such as smoking or alcohol abuse. "At risk" or "risk-bearing" means being responsible for the cost of care for a group of people. For instance, if an HMO pays a hospital a fixed amount of money per member to provide all of the care he or she needs, the hospital is "at risk" for that member. "Risk adjustment" is an extra payment made by a medical insurance company to a health provider or medical group if its members are, on average, sicker and more expensive to care for.

RISK POOLS:
Arrangements by states to provide health insurance to the unhealthy uninsured who have been rejected for coverage by insurance carriers.

RISK SHARING:
A situation in which a managed care entity or a provider assumes responsibility for services for a specific group but in which it is protected against unexpectedly high costs by a pre-arranged agreement. The Managed Care Organization (MCO) or provider may receive higher payment for those individuals who need significantly more costly services. Usually Medicaid and an MCO, agree through a formula to share any losses that result when medical costs exceed payments.

SCHIP:
The State Children's Health Insurance Program recently passed by Congress to fund health coverage for America's 10 million uninsured children. SCHIP sends millions of dollars to every state over the next 10 years for states to design and plan their own programs. Also known as Title XXI. [California's proposed SCHIP is called "Healthy Families."]

SECOND OPINION REVIEW:
A managed care technique in which a second physician is consulted regarding diagnosis or course of treatment.

SECONDARY CARE:
A level of medical care between primary care and tertiary care, usually provided by medical specialists and usually requiring a referral from an HMO member's primary care provider.

SELF-INSURED:
An arrangement in which an employer writes its own plan to cover health care costs for employees. Benefits and costs are determined by the employer. These plans may be administered by an insurance company or involve an insurance broker.

SELF-REFERRAL:
A patient's ability to refer himself or herself, under certain circumstances, for specialty care, without receiving a formal referral or prior authorization from the patient's MCO or primary care provider.

SERVICE AREA:
The geographical area within which an HMO or other managed care plan provides and arranges medical care for its members. This area is sometimes the same as the plan's enrollment area, but not always.

SERVICE LIMITS:
Certain number of times you may use a health service and a certain time period when you may use a service.

SINGLE-PAYER SYSTEM:
A health care financing arrangement in which money, usually from a variety of taxes, is funneled to a single government entity which then pays the medical bills for all covered members. Canada and England are single-payer health systems.

SINGLE POINT OF ENTRY:
An individual can gain access to services only through a primary care provider who decides what services are needed. (See Gatekeeper definition.)

SKILLED NURSING FACILITY (SNF):
An institution providing skilled nursing and related services to residents; a nursing home.

SOCIALIZED MEDICINE:
A health care financing and delivery system in which doctors work for the government and receive a salary for their services.

SOLE-SOURCE OPTION:
An employer chooses a single insurer or health plan to cover all of its employees. If the sole-source option is an HMO, it will usually offer both a standard lock-in plan and a point-of-service plan that allows members to choose to get care outside the HMO network at a higher cost.

SPEND-DOWN:
The process of using up all income and assets on medical care in order to qualify for Medicaid.

STAFF-MODEL HMO:
An HMO that directly employs on a salaried basis the doctors and other providers who furnish care.

STANDARD OF CARE:
Written practice guidelines based on medical diagnosis that physicians and managed care organizations may use to guide treatment and service choices. See also “Practice Guildelines or Protocol.”

STATE INSURANCE REGULATIONS:
The laws and regulations that govern insurance companies operating within a given state. There is also a state process for filing complaints and appeals. A state Commission of Insurance and associated departments or division provide information and assistance. [In California, the Insurance Commissioner is Chuck Quackenbush. Consumer Information and Assistance Line is 1-800-027-4357]

STOP-LOSS:
A clause that limits liability to a specified amount on medical expenses covered by a policy. After expenses reach that amount, the insurance company pays all remaining covered medical expenses for the year including deductibles and co-payments.

SUPPLEMENTAL SECURITY INCOME (SSI):
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.

SUPPLEMENTARY AIDS AND SERVICES:
Under IDEA, the developmental, corrective, or supportive services required to assist a child with a disability to benefit from special education. Includes, transportation, speech-language pathology, audiology, psychological services, physical and occupational therapy, recreation, social work services, counseling, orientation and mobility, medical services for diagnostic and evaluation purposes.

TARGETED CASE MANAGEMENT:
A Medicaid term for case management services covered under Title XIX of the Social Security Act (as of November 1995). Federal law defines Targeted Case Management as services that will assist individuals eligible under the state Medicaid plan in gaining access to needed medical, social, educational and other services.

TAX EQUITY AND FISCAL RESPONSIBILITY ACT OF 1988 (TEFRA):
Federal program allowing a child with extensive health needs to receive medical assistance, even if the family's income is higher than allowed under regular medical assistance guidelines.

TERTIARY CARE:
The upper level of medical care and services, usually provided in hospitals by highly trained "sub-specialists" using the most advanced medical technology.

THIRD PARTY PAYMENT:
The payment for health care by a party other than the beneficiary.

TITLE V/CSHCN:
The state agency that uses state and federal funds to provide services, programs and systems of care for Children with Special Health Care Needs (CSHCN). The federal version (Division for Children with Special Health Care Needs/DCSHCN) is located in the federal Maternal and Child Health Bureau (MCHB).

UNCOMPENSATED CARE:
The care provided by doctors and hospitals for which no reimbursement or payment is made; also known as charity care.

UNDERWRITING:
An insurance company practice of assessing risks of illness and costs and setting premiums based on the assessments. Similar to experience rating.

URGENT CARE:
Occurs when a patient has an illness that is not life-threatening but that requires immediate attention.

USUAL, CUSTOMARY AND REASONABLE (UCR):
A fee controlling system to determine the lowest value of physician reimbursement based on: (1) the physician's usual charge for a given procedure; (2) the amount customarily charged for the service by other physicians in the area; and (3) the reasonable cost of services for a given patient after medical review of the case. If charges are higher than what the carrier considers normal. The carrier will not pay the full amount charged and the balance is your responsibility.

UTILIZATION:
The amount of medical services used by a given population, usually over a specific period of time or as an average related to the number of people in the population. For instance, an HMO's utilization rate for office visits might be five visits per member per year. Hospital utilization is often reported as the number of days in the hospital, on average, for each 1000 members of the group being measured (days/1000). In the interest of reducing costs, health plans and insurers try to reduce unnecessary or inappropriate utilization through "utilization management" or "utilization review."

UTILIZATION REVIEW:
A process that assures that medically necessary acute inpatient and outpatient care has been provided in the most appropriate and cost-effective settings.

WAITING PERIODS:
The period of time required by an insurance company after a person is covered by a policy before specific health services are covered by the plan. This time can vary from a number of months to a number of years.

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.

WRAP-AROUND:
A supplementary insurance plan designed to pay for additional health benefits not covered by another plan. A wrap-around policy can provide more comprehensive benefits for a person with extensive needs.

Notes: