

Families as Partners

In Pediatric Health Care

A Guide from the Families as Partners Program



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To the Families as Partners Planning Group: Thank you for your vision, commitment and hard work.

To past and present Families as Partners Coordinators: Thank you for your devotion to promoting families as true partners in health care. It is overwhelming to think of the magnitude of time and heart that you have contributed to the idea and implementation of families as true and essential partners!

Then finally, at the heart are Families – without whom pediatric health care systems cannot function at their best. Families, who despite their personal circumstances tirelessly give their time, ideas and insights in order to improve care for all children and families. Families – each with your own story that when given a chance to be told inspires all of us to be better and do better for all. Thank you!

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INTRODUCTION



Since the late 1980s there has been a growing recognition that family involvement is a necessary component of pediatric health care. This has come to be known as family centered care, which is not only a philosophy but also a practice, built on a foundation of collaboration amongst patients, their families and health care providers. Following in the footsteps of the rest of the industrialized world, health care providers have come to realize that families are in fact consumers and their perspective is invaluable in the development and quality improvement of policies, programs and systems of care. The result is enhancement of health care services appropriate to the child and family's needs and increased consumer satisfaction. This is a win-win situation for everyone when these collaborations are successful.

Despite the obvious benefits of consumer participation, families remain an under utilized resource in pediatric health care. Likewise, Local Public Health Departments, School Districts, Emergency Medical Services and Managed Care Organizations are all entities that come in frequent contact with children/youth with special health care needs and yet often neglect to seek family participation in policy and program development on a routine basis - if at all. Many pediatric hospitals and clinics have recognized this and have taken steps to formally request family advice. We can be proud of these examples of progress, but must work to change the fact that collaboration is still the exception rather than the rule in many pediatric systems of care.

In an effort to address this situation, Children's Hospital of Wisconsin in collaboration with Families and the Southeastern Wisconsin Children and Youth with Special Health Care Needs Regional Center have developed this guide. *Families as Partners in Pediatric Health Care* is for any individual or organization involved with pediatric health care and/or children/youth with special health care needs (CYSHCN) and families who are interested in promoting the practice of utilizing families as advisors. The goals of this guide are the following:

1. To facilitate the delivery of high quality services to children by promoting family-provider partnerships.
2. To educate and support individuals and organizations involved with pediatric health care and/or children/youth with special health care needs.
3. To describe step by step practical approaches and processes for involving families as partners.

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This guide is not designed to be comprehensive of all the practices and approaches currently used to increase family participation. Nor is the intention that this guide be put forth as the only right way to involve families. Rather, it should serve as a guide which may be adapted to best meet the culture and needs of any organization or group seeking to increase and improve the quality of family involvement.

At times it may be challenging and progress may be slow as you work towards involving families as advisors throughout your organization. However, the effort and time taken will make a lasting difference for all children, youth and families. What a worthwhile endeavor! Please review this guide and let us know if and how it has been used within your organization as well as any suggestions you may have.

Thank you for your dedication to practicing and promoting family centered care.

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BACKGROUND



Families are essential partners in the care of their children - partners who come with invaluable expertise and insight. This belief is the foundation of family centered care, a well thought out, systematic approach to delivering health care to children and their families. Family centered care promotes the integrity of the family unit, consequently shaping policy and program development, design of facilities, day to day practice of health care providers (and others) and their interactions with families.

(See Appendix 01 – Components of Family Centered Care)

In order for this to occur, one must first recognize that families are the constant in their child's life while personnel and systems that care for children/youth fluctuate. Practicing family centered care requires genuine respect for the differences in values, beliefs, cultural backgrounds, skills, knowledge and experiences of children and their families. The focus of family centered care is on family strength. The expectation is that the health care system will not only care for the child's medical needs but empower families as caregivers, decision makers and leaders. This places families in the center of the services they consume rather than on the periphery. The result is improved outcomes, more appropriate resource allocation and increased consumer satisfaction.

Family centered care is a term that is increasingly familiar to both families and providers. However, this was not always the case. Until the late 1980's either a systems-centered or child-centered care approach was most often used to deliver pediatric health care. As these terms suggest, systems centered care is driven by the needs of or benefits to the system while child centered care is centered around the strengths and needs of the child. Although there were surely some individual providers, programs or organizations that delivered family centered care, this was the rare exception and most certainly not the expectation. Validation of this approach as best practice came in 1987 with former Surgeon General Koop's federal initiative which called for family-centered, community based, coordinated care for children with special health care needs and their families.

In the years that have followed that 1987 report, the Maternal and Child Health Bureau (MCHB) at the federal level in partnership with state Title V programs, families and public and private organizations have been increasingly vocal about the importance of meaningful family involvement in every aspect of the systems that serve children. This includes family participation in not only practice but also policy and

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program development. *Healthy People 2010*, a comprehensive document designed to achieve family-centered, culturally-competent, comprehensive, and coordinated systems of services for all children and youth with special health needs, in every community, by the year 2010, maintains the value and legitimacy of family centered care. (See Appendix 02 - Healthy People 2010 Goals.) Likewise, the American Academy of Pediatrics has incorporated the concept of family-centered care into some of their policy statements and has devoted a separate policy statement to this practice, titled *Family-Centered Care and the Pediatrician's Role*. (See Appendix 03 Family-Centered Care and the Pediatrician's Role.)

CRITICAL NEED FOR FAMILIES AS PARTNERS



A lot of the progress that has been made in transforming our delivery of services from child or system centered into family centered has been done in the realm of practice – the day to day, individual, patient care that occurs in hospital, home care and clinic settings. Most pediatric hospitals teach their employees about family centered care and they expect their clinical staff to view their patients and families as collaborative partners. Best practice for today's clinical practice involves including families in their child's care and provision of the tools and information that will best support the family's abiding and paramount care-taking role. That is not to say this is successfully accomplished in every situation. Some providers, hospitals and pediatric practices/clinics are more skilled and have more experience practicing family centered care than others. Yet, clearly a lot of time, energy and effort have been spent embracing, teaching, modeling and promoting this approach to health care in the last few decades.

Family centered care, however, is not simply applicable to how we care for children who are hospitalized or who come to the clinic for an outpatient visit. Family centered care is crucial to quality improvement as well as patient satisfaction in all realms of pediatric care delivery. Families experience the health care system from the perspective of a consumer. Therefore, involving families and taking their collective experiences, insights and ideas into account will result in a greater likelihood of developing comprehensive, high quality health care services appropriate to the child and family's needs.

Currently there are many excellent examples of family representation in the practice, programs and policies of pediatric care. State Title V programs and other public and private organizations that serve children have hired parents as paid staff. Family Consultants serve on Family Advisory Councils at many children's hospitals, coordinate parent support services and parent to parent matches, serve as faculty to physicians and other allied health care providers, sit on government task forces, deliver presentations, conduct workshops, review written health teaching material and participate in conference planning.

Despite the obvious benefits of consumer participation, successful examples and even federal guidelines, families are not serving in advisory capacities in adequate numbers in the U.S. A large part of family exclusion from these roles has been due to professional attitudes and expectations. There is not yet a global belief evidenced by actions that family involvement is a necessity. Rather, the culture seems to be

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that inclusion of families can be beneficial with a few hand picked parents but that ultimately the success of an organization does not require parents to be at the table from development to evaluation/evolution of the systems providing care to children. Until we reach a time when *not* having families involved in every phase of health care is unfathomable, pediatric health care will never reach its fullest potential to provide exemplary, efficacious care to children.

In addition, families themselves may be reticent to become involved. Some families may fear that if they speak honestly about their concerns, their child's care will be negatively impacted. Some families do not trust providers and thus are reluctant to be honest about their experiences and ideas. Often, families think they have nothing to contribute or they may be intimidated by those who are perceived to be "important" such as physicians, administrators and other leaders. Still other families presume that lip service is being given to family involvement and that even if they expend time and effort advising a hospital or practice, nothing will change. Thus they choose to remain uninvolved.

Finally there are logistical and practical barriers to family-health care provider collaborations. Successful programs must take into account things like how to compensate parents for their time, child care, missed work and transportation, how to include diverse families, mentoring of both families and staff, continual skill building for families and staff and policy and procedures for family involvement.

SOLUTION



One solution that addresses the critical need to have more families involved in pediatric health care systems is development of a formal family advisor program. The family advisor program's function is to provide a consistent, coordinated and comprehensive approach to family involvement throughout an organization or group. Families are actively recruited and trained to be consultants through such a program. The goal of a family consultant program is to increase family participation and to improve the quality of that participation. The biggest factor in ascertaining success of such a program is an institutional wide commitment to the belief that families have expertise that is absolutely necessary to the systems and programs that provide health care to children. Building successful partnerships requires careful planning and allocation of resources.

Families as Partners in Pediatric Health Care provides some tools that may be used to develop, coordinate and evaluate a family advisor program such as the one described above. It is based on *Families as Partners*, a program developed by Children's Hospital of Wisconsin in collaboration with Families and the Southeastern Wisconsin Children and Youth with Special Health Care Needs Regional Center. Although *Families as Partners* is a program within a large organization, the tools and strategies may be adapted for small entities such as clinics and individual program and practices.

PROGRAM DESIGN



Family Centered Care is neither a destination nor something that one instantly ‘becomes.’ It is a continual pursuit of being responsive to the priorities and choices of families.

Cynthia Bissell

PLANNING GROUP



Once the need for increased family participation is recognized and there is a base of support for development of a system to address this need, it is time to convene a core “work group”. This core group will be responsible for developing the infrastructure of the family consultant program. From the outset, it is essential that the core-planning group consist of an equal number of parents and health care providers.

Suggested group members:

- 3 Parents or caretakers who have one or more children utilizing the services that the organization or group provides. Ideally they should reflect the diversity of the organization’s consumers.
 - 2 of these parents will be paid a stipend for their time.
 - 1 parent is ideally a paid member of the organization’s staff. Suggested minimum time commitment is ten hours/week. This parent will serve as the primary administrator and coordinator of the program.
- 2 staff members who have demonstrated family centered care in their day-to-day practice, have time to devote to the development of this program and have good relationships with a spectrum of families and allied health care providers.

MISSION



Defining the mission of the program is the very first job of the planning group. The mission is crucial. Not only does it state the purpose of the program, but also it should reflect the values of the advisory program and the long-term goal(s), both of which provide direction, clarity and anchorage as the program develops and evolves. Length is not important but clarity is paramount. A sample mission statement for a family advisor program is:

Families as Partners is dedicated to promoting family participation and decision making in Children's Hospital of Wisconsin's committees, programs and services. The goal is to facilitate communication and collaboration among patients, families, caregivers and staff in order to improve the delivery of health care at Children's Hospital of Wisconsin.

GUIDING PRINCIPLES



Guiding principles are exactly what the phrase implies. These principles will lead and direct the program and staff on its course as stated in the mission statement. At the foundation of any family advisor program is family centered care. The guiding principles that naturally flow from that are:

1. ***Families are essential partners:*** Families are indispensable, fundamental, the most basic and necessary partner that health care has, without whom the organization can not fully grow and evolve.
2. ***Meaningful family involvement:*** Family Consultants are not an after thought. Careful consideration is given to the process of matching the skills, expertise and strengths of consumers with the needs, services and values of individual programs and the system as a whole.
3. ***Mutual respect:*** Staff genuinely believes that families are essential to every aspect of pediatric health care and families sincerely esteem staff and their role in delivering care.
4. ***Open Communication:*** Mutual respect yields communication that is uncluttered with rhetoric and insincerity. Both staff and families are receptive to the ideas and perspectives of one another. In this atmosphere, honest, candid discussions take place.
5. ***Collaboration:*** With respect and open communication comes a great gift – learning to see and appreciate the different perspectives each individual and group has. Once these perspectives are brought together and seen as a whole, collaboration toward common goals follows.

RESEARCH



Once the mission is defined and the goals are outlined it is worthwhile to take the time to consult with other individuals or groups who have a program similar to the one that you envision. Requesting a telephone conference with one or more key individuals involved in the program of interest is the most direct method, often yielding useful information not found in the written material. If a conference is scheduled make a list of all the questions your group has ahead of time. This will help focus the conversation and best assure that all of the group's questions are answered. Assign someone to take notes so that the information communicated may be referenced in the future.

Some family advisor programs have information about their program online. Additionally, organizations like the *American Academy of Pediatrics* and the *Institute for Family Centered Care* have electronic information or resources that may be accessed and/or ordered. (See Appendix 24 Resources)

There are many benefits to taking the time to do your homework:

1. ***Hindsight is 20/20:*** Experience is a wonderful teacher. Ask individuals representing other programs what went well? What did not go well? What has been sustainable? What do they wish they had done differently?
2. ***No need to reinvent the wheel:*** Family advisor programs are often willing to share their resources and tools. You may ultimately adapt what an organization shares or combine things from several programs but the benefits of not starting from scratch are obvious.
3. ***Enthusiasm is catching:*** It is always a wonderful experience to talk with others who share the same passion that you have. Inspiration comes from listening to others describe a vision that is similar to the one your group has, from hearing how that group started out in a similar place to where your group is now and from recognizing that they are currently where you envision your organization or group will be in the future.
4. ***Networking:*** Through talking with other individuals and groups, connections are built. These veterans are an invaluable resource that your group will be able to seek advice from or collaborate with in future, global, family advisor endeavors.

FUNDING



A sustainable program requires funds specifically dedicated for that purpose. The initial step in securing funding is preparation of a budget. Once the financial needs are outlined, identification of how those needs will be met is the next step.

(See Appendix 04 Sample Budget)

Funding for the program may come from a variety of sources. Some organizations may allocate the resources immediately to the program. Others that are unable to meet all of the program's proposed financial needs may offer some degree of in kind support (room space, computer, copying, mailing, etc.). In this case outside funding will be necessary, which may require submission of a grant proposal to an outside organization. This may be as simple as writing a proposal or it may require the planning group to present the proposal in person to an individual or group. (See Appendix 05 Potential Funding Sources)

FITTING INTO THE ORGANIZATION



Organizational commitment is integral to the success of the program. Establishing a reporting relationship to an established committee or department adds validity to the program. Therefore, this is strongly advised. It is also critical for a key administrator to be actively involved, advocating for the role and benefits of families as advisors. This high level administrator will also be able to assist with identification of funding resources. At Children's Hospital of Wisconsin, *Families as Partners* has a reporting relationship to the Family Advisory Committee and to the Vice President of Patient Care Services. Although the planning committee consisted of three parents, we found it helpful to get the opinions and insight of the entire Family Advisory Committee as we developed the program. On an annual basis a report is submitted to the Family Advisory Committee as well as to key organizational leaders.

PROGRAM DEVELOPMENT



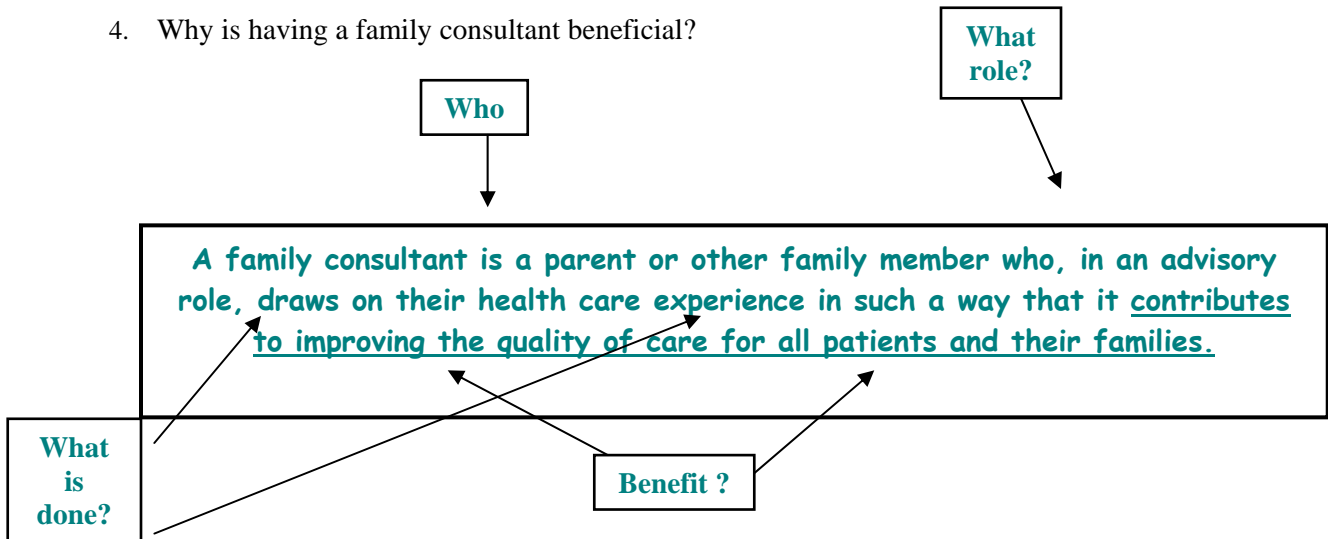
DEFINING THE FAMILY CONSULTANT



At the heart of the program is the Family Consultant, also referred to as Family Advisor, Consumer Representative, Parent Partner and still other terms. The program must be built with and around the Family Consultant. Therefore, it is imperative to define and describe this central role.

There are many definitions for Family Consultant. Some are quite wordy while others are succinct. Some programs borrow a definition from another program or create one that is all their own. Those are just details. The important task in defining “Family Consultant” is to assure that the definition accurately provides an answer to the below questions. These answers will naturally differ depending on the program or organization:

1. Who is a consultant? Is it a parent? A patient? A grandparent?
2. What role will the Family Consultant take?
3. What will the Family Consultant do?
4. Why is having a family consultant beneficial?



Below is another sample definition – this one from the Institute of Family Centered Care.

What is an advisor? Any role or activity that enables families to have direct input and influence on policies, programs or practices affecting care and services for children and families.

DESCRIBING THE FAMILY CONSULTANT



Organizations such as hospitals and health insurers may have broad requirements for Family Consultant. For example they may state the requirements as simply as a family member with any experience interacting with the health care environment. Others may narrow the boundaries to accept only those who have utilized that particular organization's services or products. Still others may further define the advisor as a family member with children with special health care needs or a child who has been hospitalized in the past 12 months or a child that visits a particular clinic. This description will be different for each organization, depending on the needs of the organization, providers and families.

Best practice is to identify diverse families who together create a picture of all of the families who access the organization's services and providers. Diversity can be reflected in life style, ethnicity, socioeconomic status, experiences, culture and perspectives. (See Appendix 06 Life Ways)

In addition to being the parent or caregiver of a patient of the group of organization, Family Consultants will ideally possess all or the majority of the following characteristics:

1. Ability to actively and empathetically listen to others
2. Positive coping skills
3. Ability to effectively and constructively express oneself and one's experiences to individuals and groups
4. Ability to respect privacy and the values of the organization
5. Ability to see the big picture inclusive of all children and families rather than focusing exclusively on one's own situation.
6. Ability to be sensitive to others and to respect diversity
7. Ability to work as an effective team member on a shared agenda and to make decisions by consensus
8. Ability to commit to the project, committee or program for the defined time limit.
9. Ability to display a positive attitude.
10. Understanding of family centered care and commitment to its practice.

At times, a person may not possess all of these abilities but with training and mentoring they may develop the skills and experience required for collaboration.

FAMILY CONSULTANT ACTIVITIES



What types of activities will Family Consultants be involved in? It is helpful to initially brainstorm and write down all of the committees, programs, services and clinics that would benefit from having ongoing consumer advice. This list will likely be extensive. In our experience, after drafting this list we realized that our organization would benefit from having Family Consultants virtually everywhere. Truly, that is how it should be. There should be a place for Family Consultants in every phase of health care from design to development to implementation to evaluation. The concept is really quite simple. If families are involved every step of the way, it is a natural consequence that what evolves will be programs that meet the needs of families and exceed their expectations. That is success. But it must be obtained in steps.

Start small. A list of all of the possible roles for Family Consultants will be helpful both at the time of program development and as the program evolves. However, it is initially more realistic to examine the list with the following in mind:

1. Who in the organization has been supportive to the family's role of decision maker, advocate and leader?
2. Are these individuals involved in committees or programs that would benefit from a Family Consultant?
3. What committees or programs are known for exceptional provision of family centered care?

The answer to those questions will help direct your group to pick a few possibilities where success of the Family Consultant role is likely. Once the activities for the pilot period are identified, schedule meetings with either the entire group or key individuals who represent those activities to explain the program and to ask for their support and participation. (See Appendix 06 Potential Family Advisor Activities).

ACCOUNTABILITY



Requiring some type of time commitment from Family Consultants communicates the value of the role and helps to assure continuity, benefit and success. An expectation of accountability will underscore the esteem that the organization has for the Family Consultant

Accountability, however, should not be at the expense of flexibility and understanding of the changing circumstances for a family. Whenever a Family Consultant is involved, one must know and expect that accommodations will have to be made that allow a certain percentage of “excused absences” and “late assignments.” Flexibility may mean allowing a family member to attend the meeting by phone.

Furthermore, there must be appropriate accommodations in place for low income families. For example, it would be misguided to expect consistent participation from an advisor who does not have access to transportation.

Time commitments must be clearly stated to individuals from the outset so that one may carefully consider whether or not this is a role that fits into one’s current life style. We began by asking families to commit to being included in the data base for one year. This commitment involves attendance at an orientation prior to inclusion in the data base. Advisors included in the data base have given consent to be contacted and asked to participate in an activity that appears to be a good match for that advisor. The family members always retain the right to decline. Additionally, inclusion in the data base does not guarantee placement in an activity. This was especially important to communicate to the Family Consultants during the pilot year of the program, given that there were limited available spots for Family Consultants.

To further assist families in determining whether being a Family Consultant is a role they have time for, the application should provide examples of different activities and a close approximation of the hours that the activity requires. This helps families to identify which activities of interest might fit into their schedule. Before a Family Consultant agrees to a specific assignment, we ascertain we are providing the most accurate approximations of time commitment possible. (See Appendix 08 Sample Application.)

RECRUITMENT OF FAMILY CONSULTANTS



SELF -REFERRALS OR NOT?

It is necessary to develop a plan for identifying potential Family Consultants and subsequent recruitment. Prior to making that plan the group must decide between the following two options:

Any consumer may apply to be a Family Consultant

Vs.

Consumers may apply to be Family Consultants by non self-referral only.

When we began to design Families as Partners we talked with several veteran program coordinators from other organizations. The consistent suggestion was to start small and to utilize the skills of Family Consultants who had been referred by staff. Initially, we felt uncomfortable with this guidance. After all, every family has experiences and strengths that are valuable to the delivery of health care. Solely choosing families who were picked by staff seemed to violate the guiding principles of our program. Our advisees, speaking from experience, recommended that in starting small with parents who were known to work well with others, we would best assure coming away from the pilot period with some good examples of family-provider collaboration. This would help us to succeed in our endeavor to build a program that placed all families in the center of every phase of health care. We decided to follow this counsel, realizing that a successful beginning would provide a foundation on which the program could expand to include any interested family member in the future.

Aside from the guidance offered by veteran program coordinators, another factor that may contribute to the decision of whether or not to solely accept families referred by staff is the culture of the organization. In some organizations the philosophy and practice of family centered care holds an esteemed place and it is actively demonstrated in every phase of that organization's systems. Other organizations may not be as far along with including families. Perhaps staff include families in the day to day care of children but the organization as a whole had not yet embraced the idea of family involvement from the inception of policy development, facilities design, publicity, etc. Finally some institutions may still be delivering child or system centered care with a culture that is resistant to family involvement in any aspect of care. These three types of culture would position an organization to take different steps as they move forward from different starting points.

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As the planning group thinks about and assesses the state of family centered practice within their group or organization, some questions for group discussion are:

1. How are families currently involved?
2. Are there currently any family advisors on the committees and councils of the organization? If so is family advice actively sought before decisions are made or are decisions presented to families as a foregone conclusion?
3. Is there a wide range of activities for families to participate in or only a few choices?
4. Are the current family consultants representative of the diverse population served by the organization?
5. Are there barriers to family participation and if so what is the organization doing to overcome those barriers?
6. Are the policies of the organization family centered?
7. Have families helped to develop the policies?
8. Does care of a child reflect an awareness of the child as one part of a family unit or is care designed to solely meet the needs of the child or the system?
9. Has remodeling or renovating of the building been done with family input before plans are even drafted?
10. Is the general consensus among staff that a family is the agent of the staff or does staff demonstrate an awareness that their role is to serve and support the family?

These answers will contribute to the decisions made about whether or not families can refer themselves to be advisors. An organization that has not only stated but demonstrated a commitment to family centered care may not feel it is necessary to pilot the program solely with families that have been referred by staff. Our institution was certainly committed to providing family centered care and increasing the number of consumers involved in the system but as a whole we had few examples of families involved in non direct patient care activities. Thus, we felt it best to start small with a set of parents/caregivers whose ability to collaborate had been demonstrated to staff over time.

TIME TO RECRUIT

Staff will most likely be a referral source for family consumers who fit the characteristics outlined in the section: *Description of a Family Consultant*. Make your request for referrals known to staff in casual conversations, formal presentations, brochures and letters. This is an effective recruitment method regardless of whether the program requires potential advisors to be referred by staff. Not only is this a wonderful way to find Family Consultants but it also builds support and excitement for the program amongst staff.

If referrals are not necessary, publicity of the program will be both inside and outside of the organization. Recruitment may be done via newspaper articles and ads, flyers, posters, website copy, community bulletin board notices, radio and TV announcements, etc. Local parent-to-parent support groups, community organizations, other families, school and local public health department staff will also be helpful in getting the word out that your organization is looking for Family Consultants.

MENTORS



Organizations have a language and culture that may feel very unfamiliar and even unwelcoming to the Family Consultant when they begin to participate in an advisory role. Although the Program Coordinator will be an available resource for the Family Consultant, a staff member who is involved in the same activity as the Family Consultant should be identified as the advisor's Mentor. The Mentor will introduce the Advisor to the specific activity, be the go to person when the Advisor has questions or concerns about the specific activity the Family Consultant is involved in, introduce the Advisor to others involved and make sure that the Advisor feels welcome and valued. The program coordinator will provide information about parent-provider partnerships, training and support to the Mentor as needed. The most important attribute to look for in identifying Mentors is that the person is actively engaged in family centered care through their own practice.

PROCESS FROM REFERRAL TO INVOLVEMENT



Once the planning group has clearly defined and described the Family Consultant and Mentor Roles, a process needs to be developed that will take an individual from referral to involvement. This will assure that the program provides a consistent, coordinated approach to involving families. If done carefully, it will lay a foundation that will be able to accommodate program growth. Typically the process will include the following steps:

1) Referral 2) Application 3) Interview 4) Orientation and 5) Participation.

This section describes two of those steps – Application and Interview .

APPLICATIONS

The application is useful for quite a few reasons. The most basic purpose is to collect demographic information including email addresses and fax numbers. It should also provide further information which will assist program coordinators to better understand the consumer's experiences within the organization and the community, interest, motivation and diversity. The application should also provide a mechanism for the family to provide feedback. If the organization has a risk management and/or volunteer department their guidance may be helpful as the application is developed. (See Appendix 08 Sample Application.)

When a consumer expresses interest in becoming a Family Consultant an application and pre-addressed, postage paid return envelope should be provided either by hand or mail within a specified time frame. The application may also be sent electronically or by fax, however, this does not allow the return envelope to be sent. Prior to making a referral, the family must grant permission to be contacted by the Program Coordinator. This permission should be documented by both the referral source and the Program Coordinator.

A **cover letter**, included with the application, will serve as an outline of the process involved from application to involvement. (See Appendix 09 Sample Cover Letter to Application)

Once the application is received a **letter of application receipt** should be sent within a specified time frame (for example 72 business hours) letting the consumer know that the application has been received and what will happen next. (See Appendix 10 Sample Letter of Application Receipt)

INTERVIEW

Potential consultants should be interviewed, using an informal format, once the application is received. The decision of whether to conduct the interview by phone or in person should be left up to the family in order to make it as convenient and comfortable as possible for them. The interview allows for clarification of anything on the application that may have been ambiguous to either the provider or the family member. It also gives the consumer a chance to ask any questions they may have and to express anything not included on the application. While it is not possible to fully ascertain during one interview whether a person has the characteristics being sought, one should be able to get a general sense as to whether the parent is able to express themselves constructively, and whether or not they seem able to put aside their own individual agenda in order to do what is right for a larger group of families. (See Appendix 11 Family Consultant Interview)

COMPENSATION



Family Consultants provide a valuable and necessary service to pediatric systems of care. They bring a wealth of expertise, experience and insight to health care. When families participate in advisory roles they additionally expend time and typically incur some degree of expenses. Examples of incurred expenses are child-care, transportation, meals, and loss of income for those employed outside of the home. At minimum the family member should be reimbursed for those expenses. Some organizations give a stipend or gift certificate for the service that the family provides rather than reimbursing each expense item by item. Others offer benefits to the family such as free parking, lunch or transportation in addition to reimbursing expenses or giving a fee for service. However the family is compensated it is important to realize that reimbursing expenses or giving a \$30 stipend for a committee meeting is nominal and a gesture of thanks and appreciation. It is not equal to the competitive market value of expert consultation services.

The Program Coordinator should be responsible for making sure that reimbursement or compensation is provided to the family in a timely manner. This will be easier if a process is developed such as requiring families to submit a *Compensation Form* after each activity is completed. The goal is to assure compensation and reimbursement for all participating advisors; thus the process may need to be adapted for some families. Some families may find it easier to call the Coordinator after an activity and complete the

Families as Partners in Pediatric Health Care

form over the phone. At times the Mentor may take responsibility for completing the compensation form on behalf of the family. The form may also be made available electronically for those families who prefer to submit it via email. (See Appendix 12 Sample Compensation Form.)

Some organizations may require Family Consultants to complete a W-9 form in order to process check requests. Check with your finance department to find out if this is required or if there are other requirements specific to your institution.

COMMUNICATION AND CONFIDENTIALITY



While participating on a committee or serving as an advisor to a particular program, the Family Consultant may hear information that should be treated as confidential. In addition, families in the role of advisor will not only be representing their own family, but also the many families who access the services and providers of the organization. It is crucial that consultants communicate constructively and leave individual agendas at the door. Orientation should focus on the consultant's responsibility to effectively communicate for all families and to protect confidential information. It is also recommended that Family Consultants sign an agreement to abide by these standards before participating in an advisory role. At Children's Hospital of Wisconsin we require Family Consultants to sign a new agreement each year in order to underscore the extreme importance of communication and confidentiality. (See Appendix 13 Sample Communication and Confidentiality Agreement)

POLICY AND PROCEDURE



Some organizations will require the development of a policy and procedure for a comprehensive advisor program. At Children's Hospital of Wisconsin we felt it was reasonable to separate the procedure into four sections: Program Coordinator, Mentor, Family Consultant and Staff/Leadership. Each section will concisely describe roles and responsibilities. This will subsequently serve as an easily accessible reference for everyone involved in the program. (See Appendix 14 Sample Policy and Procedure.)

BROCHURE



A brochure is one of the simplest ways to promote the program to staff and families. Simple, clear information is best. The brochure should include the name of the program, mission, examples of activities, commitment, and program contact information. (See Appendix 15 Sample Brochure.)

KEEPING TRACK



Organization and consistent, timely responses are crucial to the success and longevity of any program. Although the program may start off small enough that the coordinator(s) can remember every advisor, what they are involved in and whether or not compensation has been provided, this will cease to be a reliable, effective method of coordination as the program grows. Therefore, it is best to devise a system for tracking referrals, completion of specific tasks, and other pertinent information.

Once we assure that the parent/caretaker has given permission to be contacted we begin to keep a record to assist with coordination of the program. (See Appendix 16 Sample Progress Note). The progress note is kept in the advisor's cumulative file which can either be electronic or hard copy. In either case, steps must be taken to protect confidentiality. Thus electronic progress notes should be password protected and hard copy records should be stored in a locked file at all times when not actively being used.

A program such as Microsoft Access may also be used. This allows one to sort through the entire pool of family advisors for particular information. The information requested in the application will direct many of the data base fields. For example the application may have a check list of activities that advisors are interested in and another for the departments within a hospital that one has experience with. This data is subsequently put into the Access data base. In the future if a request is made for families interested in serving on a focus group to improve services in a particular clinic or program, the coordinator will be able to quickly identify advisors who would like to participate in a focus group and who have also had experience with the particular clinic/program seeking feedback.

PROGRAM IMPLEMENTATION



PRESENTING THE PROGRAM



Once the program has been developed it will be time to explain and promote the program to providers. Presentations may be informal, given to small groups such as the nurses on a particular unit. At other times, it will be more appropriate to formally present the program to a large group such as the organization's leadership, medical or ambulatory care staff. Regardless of group size, the presentation should be clear, interesting and enthusiastic. This is your chance to "sell" the program to colleagues. (See Appendix 17 Sample Power Point Presentation.)

ORIENTATION AND TRAINING



Successful partnerships require collaboration. For both families and staff this often involves learning new skills. A complete and well thought out orientation to the organization and training in specific skills is essential to effective meaningful, family involvement. It is not acceptable to place a family member in a consultant position without clearly defining what they will do and what they can expect. It is also vital to assure that they have the skills required to participate.

Orientation and training will be different from organization to organization. However, suggested core elements of a family advisor training include:

1. Welcome and ice breaker
2. Organizational structure, mission and goals of the organization
3. Culture of the organization
4. History of the advisor program – when, how and why it started, progress and achievements to date
5. Family-provider collaboration – description, benefits, barriers and strategies for enhancing partnerships.
6. Communication and Confidentiality
7. Compensation

(See Appendix 18 Orientation Summary and Appendix 19 Sample Orientation Evaluation)

Families as Partners in Pediatric Health Care

Once families are matched with a particular activity, information should be more specific. For example a Family Consultant joining a committee or council should know the following before attending the first meeting:

1. The purpose of the committee
2. The members of the committee and their roles within the organization
3. History of the committee
4. Past achievements of the committee
5. Present activities of the committee
6. Past and present challenges of the committee
7. Logistical information about the committee

EVALUATION



Formal and informal, qualitative and quantitative evaluation is critical to the evolution of a meaningful family advisor program. Collecting this information will help to ascertain alignment of the program with the needs of the organization as a whole as well as the providers and families who participate in the delivery of care.

1. *Pre and Post Quantitative Evaluation:* Family Consultants may complete an anonymous evaluation both before they become involved in an advisory role and again six months to twelve months after they become involved in a specific activity. Ideally the same evaluation will be used so as to make pre and post comparisons. (See Appendix 20 Sample Pre Evaluation and Appendix 21 Sample Post Evaluation)
2. *Annual Qualitative Evaluation:* Although the pre and post evaluations provide excellent data to help determine the effectiveness of the program, qualitative data is also needed in order to have a more complete picture of family advisor satisfaction, quality of involvement, suggestions for improvement, etc. Thus an anonymous narrative evaluation can be provided to the family advisors on an annual basis.
3. *Informal evaluations:* Some families may find it easier to simply talk with the program coordinator on a routine basis and this should always be an option offered to families.

4. *Mentor Survey*: Valuable feedback will also be obtained from Mentors. Mentors should be evaluated on a semi-annual basis for the first year and annually after that. (See Appendix 22 Sample Mentor Survey Cover Letter and Appendix 23 Sample Mentor Survey)

ONGOING FAMILY CONSULTANT SUPPORT



The Program Coordinator and the Mentor are responsible for providing any support, training or assistance that the Family Consultant needs. Some ways to provide that support are:

1. Periodic expressions of thanks (in person, email, card, letter, gift)
2. Provide enthusiastic and positive feedback when a Family Consultant provides a remark or insight that is helpful so that they are reminded of the benefit and value that their unique perspective brings.
3. Mentor call or email the Family Consultant before the first meeting to introduce self. Make sure to be present at first meeting and introduce Family Consultant.
4. Periodic “checking in” with the advisor
5. Establishing an email group to provide information and encouragement. (Hard copies should be mailed in a timely manner to those without a computer.)
6. Assistance with paperwork
7. Annual recommitment meeting
8. Matching veteran advisors with new advisors
9. Problem solving with the advisor when they or their mentor report that the advisor is having difficulty with the assignment in order to assure successful participation.

COORDINATION OF THE PROGRAM



A sustainable program needs to be coordinated either by one person or a small group. Coordinators will be responsible for:

1. Receiving and processing all referrals
2. Explaining the program to any interested individual or group
3. Publicizing the program through presentations, meetings, newsletters, etc.
4. Scheduling and conducting interviews after review of application
5. Calling references on the application
6. Conducting Orientation and Training and Annual Recommitment Meetings
7. Processing all check requests for reimbursement or compensation in a timely manner
8. Maintaining a cumulative file for each advisor and assuring all paperwork is up to date and complete
9. Ongoing support of Mentors and Family Consultants
10. Submission of annual report.
11. Setting annual goals
12. Maintaining the data base
13. Disseminating, collecting and compiling evaluations

The above is not all-inclusive but it is extensive enough to show the need for a dedicated staff person who can devote a minimum of ten hours per week to the program. Ideally this Coordinator is also a consumer of the organization's services (parent, caregiver). In addition it is helpful if some members of the planning group continue to be part of the program staff as assistant coordinators. The main responsibility resides with the Program Coordinator but unless the Coordinator can devote 20 or more hours per week to the program, it will be much more manageable if some of the responsibilities can be delegated to the assistant coordinators. At all times there should be family representation in the coordination/administration of the program. If a group is involved in the day-to-day coordination of the program meetings should take place on no less than a monthly basis.

CHALLENGES



1. Staff forgetting to work through the advisor program when they want family input. Often in their eagerness to include families, the staff simply asks parents to participate in an advisory role without referring them to the program. This defeats the purpose of a centralized advisor program.
2. Difficulty maintaining ongoing communication with Family Consultants, Mentors and the Organization as a whole unless there is at least a 0.25 FTE position dedicated to this program.
3. Staff scheduling committee meetings, focus groups, and other activities at a time that does not fit into the advisor's schedule.
4. Staff not providing enough notice to Program Coordinator when a need for an advisor is identified.
5. Staff not providing enough notice to families of schedule changes.
6. Difficulty overcoming varying levels of receptiveness among staff.
7. Difficulty finding effective advisors who can make a commitment to an ongoing activity.

CONCLUSION



Families are essential partners in the care of their children and as such should be included in every phase of pediatric health care. After all families experience the health care system from the perspective of a consumer. Thus, taking their collective experiences, insights and ideas into account will result in a greater likelihood of developing comprehensive, high quality health care services appropriate to the child and family's needs. Although progress has most certainly been made in increasing the number and scope of families in advisory capacities, there is still a paucity of family advisors in the U.S. Until families are globally involved in every aspect of the health care system, it will never reach its fullest potential to provide exemplary, efficacious care to children. One solution that addresses the critical need to increase the number of families involved as consultants is development of a consistent, coordinated and comprehensive approach to family involvement throughout an organization.

Families as Partners in Pediatric Health Care

We hope that this guide will assist an organization or group in planning to incorporate such an approach throughout their system. Please take this opportunity to assess the family centeredness of your organization and to think about how some of these practical tips and ideas might be used as your organization continues to improve delivery of health care services. Keep in mind that family centered care is not an end but a continual process. Wherever your organization is in that process, consider this: Is it time to raise the bar? Please feel free to contact the Program Coordinator of *Families as Partners* if we can be of assistance to you in developing your own program.



Families as Partners
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APPENDIX



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Components of Family Centered Care

1. Recognition that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuate.

Recognize the family's experience and expertise -listen to their ideas and opinions

2. Sharing of complete and unbiased information with parents about their child's condition on an ongoing basis in a way that the family finds helpful and supportive.

- a. Promote information sharing among patients, families, and providers rather than information "gate keeping" by professionals.
- b. Share information clearly, completely and consistently.
- c. Don't make assumptions about the family's reactions and capacities.

3. Recognition of family strengths and individuality and building on those strengths even in a situation that is challenging

- a. Do not focus on the family's deficits
- b. Be aware of your own values and beliefs and how they help shape your actions and reactions.
- c. Ask families about their opinions and needs.
- d. Emphasize program flexibility rather than rigidity
- e. Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health

4. Honor racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care

Ensure flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family.

5. Facilitation of parent/professional collaboration at all levels of health care—care of an individual child, program development, implementation, and evaluation policy formation.

- a. Emphasize collaboration rather than control
- b. Collaborate with families in the development and evaluation of new and existing programs, policies and facilities.
- c. Build partnerships based on mutual respect and open communication.

6. Assurance that the design of health care delivery systems is flexible, accessible and responsive to families.
 - Implement appropriate policies and programs that provide emotional and financial support to families.

7. Understanding and incorporation of the developmental needs of children and families into health care delivery systems.
 - a. Plan for and support the transition of adolescents into the adult health care setting
 - b. Design facilities to accommodate the developmental needs of children

Family centered care is not an option and it not an approach that can only be used with certain families and certain providers. Although the delivery of family centered care should be tailored to the family, it is quite misguided to decide that certain families do not need or do not have the capacity to receive family centered care.

Unfortunately, this is often the case.

Healthy People 2010 Goals

Broad Public Health Goals for CYSHCN

Read about the these goals at the American Academy of Pediatrics's National Center for Medical Home Initiatives for Children with Special Needs
www.medicalhomeinfo.org/about/hp_2010.html

In [Healthy People 2010](#), the U.S. Department of Health and Human Services, in partnership with States, communities, and many organizations in the public and private sectors, has set out a series of objectives to “bring better health to all people in this country.”

The goals set forth in Healthy People 2010 for children and youth with special health care needs (CYSHCN) are to:

1. Increase the proportion of CYSHCN who have access to a medical home and
2. Increase the proportion of Territories and States that have service systems for children with or at risk for chronic and disabling conditions as required by Public Law 101-239.

www.healthypeople.gov/

Since 1989 the service system agenda has been the foundation for the Washington State Title V Department of Health program for Children with Special Health Care Needs (CSHCN) and all other state Title V programs. Endorsed by more than 70 professional and voluntary organizations, the agenda calls for the development of systems of care for CSHCN that are family-centered, community-based, coordinated and culturally competent. Documenting and measuring systemic changes in terms of meaningful indicators, however, has been challenging.

The long-term outcome of systems development is that all families are able to access health and related services along the continuum of care in a manner that is both affordable and meets their needs; policies and programs are in place to guarantee that children have access to quality health care; providers are adequately trained; financing issues are equitably addressed; and families play a pivotal role in how services are provided to their children.

Six Critical Indicators of Progress for CYSHCN

Medical Home

Once identified, children with special health care needs require a medical home: a source of ongoing routine health care in their community where providers and families work as partners to meet the needs of children and families. The medical home assists in the early identification of special health care needs; provides ongoing primary care; and coordinates with a broad range of other specialty, ancillary, and related services.

Insurance Coverage

Families must have a way to pay for services. The Children's Health Insurance Program (CHIP) has begun to address the issues of children who are uninsured, but the problem of under insurance remains a major concern for CSHCN and their families. In addition the range of wrap-around services needed by families requires the availability of private and/or public health insurance that covers a full range of needed services.

Screening

Infants and children with high risk health conditions must be identified early in order to help assure that they and their families receive the care and assistance to prevent future morbidity and promote optimal development. Advances in brain research, the Human Genome Project, and increased effectiveness of early intervention have expanded our capacity to identify children with special health care needs and offer an opportunity for early intervention.

Organization of Services

In order for services to be of value to CSHCN and their families, the system has to be organized in such a way that needs can be identified, and services provided in accessible and appropriate contexts, and that there is a family-friendly mechanism to pay for them. Thus, effective organization of services is a key indicator of systems development.

Families Roles

Families are the constants in the child's life and are pivotal in making any system work. Family members, including those representative of the culturally diverse communities served, must have a meaningful, enduring, and leading role in the development of systems at all levels of policy, programs, and practice. Family voices must be heard and families should be at each table in which decision making occurs. Thus, the involvement of families is a key indicator of systems development.

Transition to Adulthood

Youth with special health care needs, as adults, must be able to expect good health care, employment with benefits, and independence. Appropriate adult health care options must be available in the community and provided within developmentally appropriate settings. Health care services must not only be delivered in a family-centered manner, but must prepare individuals to take charge of their own health care and to lead a productive life as they choose. The broad definition of children with special health care needs includes those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond that required by children generally.

Critical Indicators for Measuring Success in Achieving the National Agenda

The **National Agenda for Children with Special Health Care Needs** builds on past experiences and success to assure that policies and programs are in place to guarantee that:

- children have access to quality health care services are coordinated
- providers are adequately trained
- financing issues are equitably addressed
- families play a pivotal role in how services are provided to their children and
- children grow up healthy and ready to work.

These changes must occur in ways that will provide optimal outcomes for children with special health care need and their families. As the next step in the implementation of this agenda, six national outcomes have been selected as critical to guide efforts within the Division of Services for Children with Special Health Care Needs.

Core Outcomes to be Achieved

1. All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
2. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
3. All children will be screened early and continuously for special health care needs.
4. Services for children with special health care needs and their families will be organized in ways that families can use them easily.
5. Families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.
6. All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

Information From the US Maternal and Child Health Bureau's
Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs

<http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>

AMERICAN ACADEMY OF PEDIATRICS
Committee on Hospital Care

INSTITUTE FOR FAMILY-CENTERED CARE

POLICY STATEMENT

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

Family-Centered Care and the Pediatrician's Role

ABSTRACT. Drawing on several decades of work with families, pediatricians, other health care professionals, and policy makers, the American Academy of Pediatrics provides a definition of family-centered care. In pediatrics, family-centered care is based on the understanding that the family is the child's primary source of strength and support. Further, this approach to care recognizes that the perspectives and information provided by families, children, and young adults are important in clinical decision making. This policy statement outlines the core principles of family-centered care, summarizes the recent literature linking family-centered care to improved health outcomes, and lists various other benefits to be expected when engaging in family-centered pediatric practice. The statement concludes with specific recommendations for how pediatricians can integrate family-centered care in hospitals, clinics, and community settings as well as in more broad systems of care.

ABBREVIATION. AAP, American Academy of Pediatrics.

INTRODUCTION

Family-centered care is an approach to health care that shapes health care policies, programs, facility design, and day-to-day interactions among patients, families, physicians, and other health care professionals. Health care professionals who practice family-centered care recognize the vital role that families play in ensuring the health and well-being of children* and family members of all ages. These practitioners acknowledge that emotional, social, and developmental support are integral components of health care. They respect each child and family's innate strengths and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Family-centered approaches lead to better health outcomes and wiser allocation of resources as well as greater patient and family satisfaction.

Family-centered care in pediatrics is based on the understanding that the family is the child's primary

source of strength and support and that the child's and family's perspectives and information are important in clinical decision making. Family-centered practitioners are keenly aware that health care experiences can enhance parents' confidence in their roles and, over time, increase the competence of children and young adults to take responsibility for their own health care, particularly in anticipation of the transition to adult service systems.

"During the past decade, family advocates have promoted family-centered care, 'the philosophies, principles and practices that put the family at the heart or center of services; the family is the driving force.'"¹ This is in harmony with but different from *family pediatrics* [*family-oriented care*] as outlined in the report of the American Academy of Pediatrics (AAP) Task Force on the Family, which "... extends the responsibilities of the pediatrician to include screening, assessment, and referral of parents for physical, emotional, or social problems or health risk behaviors that can adversely affect the health and emotional or social well-being of their child."¹ This policy statement specifically defines the expectations of family-centered care.

HISTORY OF FAMILY-CENTERED CARE

Family-centered care emerged as an important concept in health care the second half of the 20th century, at a time of increasing awareness of the importance of meeting the psychosocial and developmental needs of children and of the role of families in promoting the health and well-being of their children.²⁻¹² Family-centered care has long been a characteristic of an effective medical home.¹³ Much of the early work focused on hospitals; for example, as research emerged about the effects of separating hospitalized children from their families, many institutions adopted policies that welcomed family members to be with their child around the clock and also encouraged their presence during medical procedures. Family-centered care was given additional impetus by consumer-led movements of the 1960s and 1970s and by professionals in education, health, and child development. Federal legislation

*In accordance with the policies of the American Academy of Pediatrics, references to "child" and "children" in this document include infants, children, adolescents, and young adults up to age 21.
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of the late 1980s and 1990s,[†] much of it targeted at children with special needs, provided additional validation of the importance of family-centered principles.

Today, momentum for family-centered care continues to build. It is supported by a growing body of research and by prestigious organizations, such as the Institute of Medicine, which in its 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century*, emphasized the need to ensure the involvement of patients in their own health care decisions, to better inform patients of treatment options, and to improve patients' and families' access to information.¹⁴ All these recommendations are intrinsic to family-centered practice. The AAP has incorporated some of the principles of family-centered care into its policy statements "The Medical Home,"¹³ "The Pediatrician's Role in Family Support Programs,"¹⁵ and "Child Life Services."¹⁶ *Guidelines for Perinatal Care*,¹⁷ a manual jointly published by the AAP and the American College of Obstetricians and Gynecologists, also supports the practice of family-centered care.

CORE PRINCIPLES OF FAMILY-CENTERED CARE

Family-centered care is grounded in collaboration among patients, families, physicians, nurses, and other professionals for the planning, delivery, and evaluation of health care as well as in the education of health care professionals. These collaborative relationships are guided by the following principles:

1. Respecting each child and his or her family
2. Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care
3. Recognizing and building on the strengths of each child and family, even in difficult and challenging situations
4. Supporting and facilitating choice for the child and family about approaches to care and support
5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family
6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (eg, family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood

[†]Among the legislation advancing the practice of family-centered are such statutes as: Public Law 99-457, Education of the Handicapped Act Amendments of 1986, Part H—Early Intervention Programs for Handicapped Infants and Toddlers; Maternal and Child Health block grant amendments contained in the Omnibus Budget Reconciliation Act of 1989 (Public Law 101-239); Individuals With Disabilities Education Act of 1990 (Public Law 101-476); the Developmental Disabilities Assistance and Bill of Rights Act of 1990 (Public Law 101-496); Mental Health Amendments of 1990 (Public Law 101-639); and Families of Children With Disabilities Support Act of 1994 (Public Law 103-382).

8. Collaborating with families at all levels of health care, in the care of the individual child and in professional education, policy making, and program development
9. Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health

OUTCOMES OF FAMILY-CENTERED CARE: BRIEF SUMMARY OF RECENT LITERATURE

Family-centered care can improve patient and family outcomes, increase patient and family satisfaction, build on child and family strengths, increase professional satisfaction, decrease health care costs, and lead to more effective use of health care resources, as shown in the following examples from the literature.

Patient and Family Outcomes

- Family presence during health care procedures decreases anxiety for the child and the parents. Research indicates that when parents are prepared, they do not prolong the procedure or make the provider more anxious.¹⁸⁻²¹
- Children whose mothers were involved in their post-tonsillectomy care recovered faster and were discharged earlier than were children whose mothers did not participate in their care.²²
- A series of quality improvement studies found that children who had undergone surgery cried less, were less restless, and required less medication when their parents were present and assisted in pain assessment and management.²³
- Children and parents who received care from child life specialists¹⁶ did significantly better than did control children and parents on measures of emotional distress, coping during procedures, and adjustment during hospitalization, the posthospital period, and recovery, including recovery from surgery.²⁴
- A multisite evaluation of the efficacy of parent-to-parent support found that one-to-one support increased parents' confidence and problem-solving capacity. Interviewees noted that this type of support could not be provided through any other means.^{25,26}
- Family-to-family support can have beneficial effects on the mental health status of mothers of children with chronic illness.²⁷
- Since 1993, family-centered care has been a strategic priority at a children's hospital in Georgia. Families participated in design planning for the new hospital, and they have been involved in program planning, staff education, and other key hospital committees and task forces. In recent years, this children's hospital has consistently received among the highest patient and family satisfaction scores in a nationwide survey of comparable pediatric facilities.²⁸
- In a federally funded medical home project using a quality improvement model, families served by 13 community-based pediatric practices in New Hampshire and Vermont are collaborating with pediatricians and office staff to enhance the prac-

tices' capacity to provide care to children with special needs and to be more responsive to the priorities and needs of these children and their families. These practices have permanently integrated family input into decisions about their processes of care and have demonstrated a 34% improvement on a standardized measure of medical home implementation.²⁹

Staff Satisfaction

- Staff members at a children's hospital in Pennsylvania who participate in education programs with families as teachers believe these experiences to be highly valuable.³⁰
- A Vermont program has shown that a family faculty program, combined with home visits, produces positive changes in medical students' perceptions of children and adolescents with cognitive disabilities.³¹
- When family-centered care is the cornerstone of culture in a pediatric emergency department, staff members have more positive feelings about their work than do staff members in an emergency department that does not emphasize emotional support. This may lead to improved job performance, less staff turnover, and a decrease in costs.³²
- Coordination of prenatal care in a manner consistent with family-centered principles for pregnant women at risk of poor birth outcomes at a medical center in Wisconsin resulted in more prenatal visits, decreased rates of tobacco and alcohol use during pregnancy, higher infant birth weights and gestational ages, and fewer neonatal intensive care unit days. All these factors decrease health care costs and the need for additional services.³³
- After redesigning their transitional care center in a way supportive of families, creating 24-hour open visiting for families, and making a commitment to information sharing, a children's hospital in Ohio experienced a 30% to 50% decrease in the infants' length of hospital stay. Other outcomes included fewer rehospitalizations, decreased use of the emergency department, greater parent satisfaction, and a decrease in maternal anxiety.³⁴
- In Connecticut, a family support service for children with human immunodeficiency virus infection hired family support workers whose backgrounds and life experience were similar to those of families served by the program. This approach resulted in decreases in human immunodeficiency virus-related hospital stays, missed clinic appointments, and foster care placements.³⁵
- King County, Washington, has a children's managed care program based on a family-participation service model. Families decide for themselves how dollars are spent for their children with special mental health needs as long as the services are developed by a collaborative team created by the family. In the 5 years since the program's inception, the proportion of children living in community homes instead of institutions has increased from 24% to 91%; the number of children attending community schools has grown from 48% to 95%; and the average cost of care per child or

family per month has decreased from approximately \$6000 to \$4100.³⁶⁻³⁸

- The risk-management literature indicates that patients and families are significantly less likely to initiate lawsuits, even when mistakes have been made, if there is open and effective communication and there are trusting relationships between the practitioner and patient and family. Communication problems that can lead to malpractice, by contrast, include failing to understand patients' or families' perspectives, delivering information poorly, devaluing patient or family views, and provider unavailability.^{39,40}
- Ongoing research for family-centered care, especially in community-based practices, is needed.

BENEFITS OF FAMILY-CENTERED CARE FOR PEDIATRICIANS

Given the documented benefits, pediatricians who practice family-centered care can expect to experience the following benefits:

- A stronger alliance with the family in promoting each child's health and development
- Improved clinical decision making on the basis of better information and collaborative processes
- Improved follow-through when the plan of care is developed collaboratively with families
- Greater understanding of the family's strengths and caregiving capacities
- More efficient and effective use of professional time and health care resources (eg, more care managed at home, decrease in unnecessary hospitalizations and emergency department visits, more effective use of preventive care)
- Improved communication among members of the health care team
- A more competitive position in the health care marketplace
- An enhanced learning environment for future pediatricians and other professionals in training
- A practice environment that enhances professional satisfaction
- Greater child and family satisfaction with their health care

RECOMMENDATIONS

1. Pediatricians should actively consider how they can ensure that the core concepts of family-centered care are incorporated into all aspects of their professional practice.
2. Pediatricians should unequivocally convey respect for parents' or guardians' unique insight into and understanding of their child's behavior and needs, should actively seek out their observations, and should appropriately incorporate family preferences into the care plan. Decisions on a patient's plan of care should be made only after such consultation has been made. In hospitals, conducting attending physician rounds (ie, patient presentations and rounds discussions) in the patients' rooms with the family present should be standard practice. This will facilitate the exchange of information between the family

- and other members of the child's health care team and encourage the involvement of the family in the decisions that are commonly made during rounds. In teaching hospitals in particular, a lasting impression will be made on students and house staff when they are encouraged in this process by their attending physician.
3. Working with families in decision making and information sharing in all practice settings should always take into account the older child's and young adult's capacity for independent decision making and right to privacy and confidentiality.
 4. Parents and guardians should be offered the option to be present with their child during medical procedures and offered support before, during, and after the procedure.
 5. Pediatricians should promote the active participation of all children in the management and direction of their own health care, beginning at an early age and continuing into adult health care.
 6. In collaboration with families and other health care professionals, pediatricians should examine systems of care, individual interactions with patients and families, and patient flow and should modify these as needed to improve the patient's and family's experience of care.
 7. In every health care encounter, pediatricians should share information with children and families in ways that are useful and affirming. They should also ensure that there are systems in place that facilitate children and families' access to consumer health information and support.
 8. Pediatricians should encourage and facilitate family-to-family support and networking, particularly with families of similar cultural and linguistic backgrounds or families who have children with the same type of medical condition.
 9. In hiring staff, developing job descriptions, and designing performance-appraisal processes, pediatricians should make explicit the expectation of collaboration with patients and families and other family-centered behaviors.
 10. Pediatricians should create a variety of ways for children and families to serve as advisors—as members of child or family advisory councils, committees, and task forces dealing with operational issues in hospitals, clinics, and office-based practices; as participants in quality improvement initiatives; as educators of staff and professionals in training; and as leaders or coleaders of peer support programs.
 11. Health care institutions should design their facilities to promote the philosophy of family-centered care. Pediatricians should advocate for opportunities for children and families to participate in design planning for renovation or construction of hospitals, clinics, and office-based practices.
 12. Education and training in family-centered care should be provided to all trainees, students, and residents as well as staff members.

13. Ongoing research on outcomes and implementation of family-centered care in all venues of care, including community-based pediatrics, is needed.
14. Families should be invited to collaborate in pediatric research programs. They should have a voice at all levels in shaping the research agenda, in determining how children and families participate in research, and in deciding how research findings will be shared with children and families.
15. Health care payment systems should examine their policies to ensure that appropriate reimbursement is provided for family-centered services.

Note: Excerpts of this policy statement have been reprinted from Rationale for Family-Centered Care with permission from the Institute for Family-Centered Care, 2002.

COMMITTEE ON HOSPITAL CARE, 2002–2003

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2001 FAMILIES AS PARTNERS BUDGET

FAMILY STIPENDS AND GIFT CERTIFICATES

CHW Committee Meetings & Consultation (30 advisors x 10 commitments/year x \$30)	\$9000
Parent Speakers (\$40 x 12 sessions)	\$480
Family Advisor Training Sessions	In kind from CHW/ SNFC
Other Speaking Engagements	In kind from CHW/ SNFC
SUBTOTAL	\$9480

STAFFING

Administrator/Parent Coordinator	SNFC/CHW Staff – In kind
Co-coordinator	CHW Staff – in Kind
Parent Co-coordinator (\$30 x 12 meetings)	\$360
SUBTOTAL	\$360

MATERIALS

Family Advisor Packets (30 packets x \$15)	\$450
Recruitment Materials	\$70
SUBTOTAL	\$ 520

TOTAL

\$10,360

- Employees of CHHS who also serve as family advisors will not be paid a stipend or given a gift certificate. CHHS employee time will be included as part of their job or volunteered
- Facilities and equipment usage for training sessions will be donated by CHHS. Other materials used for training will be donated by the Special Needs Family Center (SNFC).
- The Administrator/Parent Coordinator will serve as the administrative representative for the grant funds. We request that grant funds be allocated and distributed through the establishment of a cost center specific to this project.

Potential Funding Sources

1. In kind support such as copying, computer, desk space, telephone, audio-visual help, staff, etc.
2. Corporate donors
3. Private donors
4. Community Groups
5. Granting Foundations
6. Civic Organizations
7. Fraternal Organizations
8. State or Federal Agencies

9. Online Resources

- a. The Foundation Center
<http://fdncenter.org/>
- b. Foundations On Line
<http://www.foundations.org/>
- c. Foundation Directory
<http://library.dialog.com/bluesheets/html/bl0026.html>

What are Life Ways?

Life ways consist of a family's cultural customs, courtesies, beliefs, values, practices, manners of interacting, roles, relationships, language, rituals and expected behaviors.

Life ways may be handed down through generations. They may change as family configuration change such as when two people begin a new family merging their own distant pasts, or when a teenaged child suddenly becomes a parent. They may be the result of a single parent, or grandparent, creating a home.

They may also be, in part, adopted from the community in which the family resides, such as when the family moves to a new neighborhood, town or country.

Most important is that life ways cannot be separated from the family anymore than the family can be separated from them.

*Margarita Luera, State of Washington, Department of Education,
Unpublished manuscript.*

Potential Family Advisor Activities

- Ad Hoc Committee members for any committee requesting short-term family input
- Family Advisory Committee
- Member of other committees and councils (safety committee, patient-family education committee, care coordination, council, etc.)
- Family Advisory groups for clinics and programs and inpatient units
- Facility design workgroups including participation in site visits to other facilities and programs.
- Family Advisor Program coordinators
- Participant on interview team for staff positions
- Rapid cycle improvement initiatives
- Review of policies and procedures related to patient-family care
- Speakers at new employee orientations and in service training
- Special speakers/teachers for staff, including residents and medical students.
- Contributions to organization or group's publications
- Assistance with complaint resolution
- Grants review
- Reviewing teaching sheets
- Reviewing pamphlets and brochures
- Planning committee for educational series for parents
- Co-leaders of diagnosis specific support groups
- Co-hosting of weekly family coffees
- Clinic steering committees
- Feedback and focus groups
- "Secret Shoppers"
- Participation in pre-surgery tours for families
- Fund raising



Families as Partners Application

Today's Date: _____

Name: _____
(Please Print)

Home Address: _____

City: _____ ST: _____ Zip: _____

Home Phone: (____) _____ Cell Phone: (____) _____

Work Phone: (____) _____ Is it ok to call you at work: _____

Email Address: _____

Applicant Birthday (month and day only): _____
(month/day)

Relationship to Child(ren): _____

Children: If you would like to share any other information about your children, please feel free to include it on a separate sheet of paper.

Name: _____

Birth Date: _____

Has he/she been a patient at Children's Hospital of Wisconsin? ___ Y ___ N

If yes, how many times in the past year:
___ 1-2 ___ 3-5 ___ 6+

Name: _____

Birth Date: _____

Has he/she been a patient at Children's Hospital of Wisconsin? ___ Y ___ N

If yes, how many times in the past year:
___ 1-2 ___ 3-5 ___ 6+

Name: _____

Birth Date: _____

Has he/she been a patient at Children's Hospital of Wisconsin? ___ Y ___ N

If yes, how many times in the past year:
___ 1-2 ___ 3-5 ___ 6+

Name: _____

Birth Date: _____

Has he/she been a patient at Children's Hospital of Wisconsin? ___ Y ___ N

If yes, how many times in the past year:
___ 1-2 ___ 3-5 ___ 6+

Within the past 2 years, have you used any of the following services at Children's Hospital and Health System (CHHS)? (Check all that apply)

- | | | |
|---|--|---|
| <input type="checkbox"/> Emergency Room | <input type="checkbox"/> Inpatient Unit: | <input type="checkbox"/> Outpatient Clinic (please list): |
| <input type="checkbox"/> Day Surgery | ___ HOT ___ 5W | _____ |
| <input type="checkbox"/> Lab | ___ NICU ___ 7W | _____ |
| <input type="checkbox"/> X-ray | ___ PICU ___ 8E | _____ |
| <input type="checkbox"/> Urgent Care | ___ 4W ___ 8W | _____ |

This section is optional. The questions are designed to help us make our committees as diverse as possible:

Ethnicity:

- Hispanic/Latino
 Non Hispanic/Latino

Race:

- American Indian/Alaskan Black
 Asian White
 Other _____

Primary Language Spoken: _____

What other language(s), do you speak (Check all that apply):

- American Sign Language English Hmong
 Spanish Other (specify): _____

Reference:

Please include the name of a Children's Hospital and Health System staff member with whom you have worked (doctor, nurse, social worker, housekeeper, secretary, care partner, physical therapist, etc.)

Name: _____ Department: _____

I give permission to Families as Partners to discuss my application with the above person.

Name (Signature)

Date

The following list reflects the activities that families may be involved in. We do not expect you to have experience. Time commitments are approximate and cannot be guaranteed. Please check the activities below that you have done or would like to do.

Focus Group Participant: One-time family/patient group meeting to give feedback or suggestions on a specific topic.

Time Commitment: 1-2 hours each.

- I have done this
- I am interested in doing this

Children's Hospital Champion: Being interviewed or featured by Children's staff or the media about Children's Hospital services.

Time commitment: Depends on need.

- I have done this
- I am interested in doing this

Committee Member: Ongoing group meetings. As a member you will represent the families who come to Children's Hospital.

Time commitment: 6-12 meetings/year for 1-2 hours each. Committee member for at least 1 year.

- I have done this
- I am interested in doing this

Program and Facility Advisor: Workgroup that works on developing and improving programs.

Time Commitment: short term meetings, 1-2 times/month.

- I have done this
- I am interested in doing this

Conference or Event Planner: Committee that plans a conference, educational series, event, etc.

Time commitment: 1-2 meetings /month for 3-6 months.

- I have done this
- I am interested in doing this

Resident Teaching: Host a pediatric resident in your home to share your experiences as a family with a child with special health needs.

Time commitment: 2-4 times/year for 1½-2 hours in your home.

- I have done this
- I am interested in doing this

Material Reviewer: Review brochures, websites, policies, educational materials from the family/patient perspective. Some materials can be reviewed at home.

Time commitment: 1 or more times/year.

- I have done this
- I am interested in doing this

Formal Presenter:

Participate on a parent panel or give an individual presentation

Time commitment: Depends on need.

- I have done this
- I am interested in doing this

TELL US MORE ABOUT YOURSELF AND YOUR EXPERIENCES

Why would you like to be involved in Families as Partners?

Family Partners should reflect the cultural diversity of families who use hospital services. **Please share anything about your family that you think would add to the diversity of this program.** You might consider your diversity to be ethnic, racial, spiritual, social, economic, educational, geographic, gender, sexual orientation, unique family structure, disability-related, chronic illness, single parent, full-time parent, grandparent, etc.

Is there anything else you would like us to know?

****If you need additional room for any of the questions, please feel free to attach another sheet.****

I understand that completion of this application does not bind the applicant or the program coordinators in any way. FAP reserves the right to choose participants that best meet the needs of the program. Before participating in Families as Partners, you will be asked to sign a confidentiality agreement.

Signature

Date

Thank you for your time and interest. If you have any questions please feel to contact:
Anne Juhlmann phone 414-266-3196; email ajuhlmann@chw.org
Karen Schaefer phone 414 266-3198; email kschaefer@chw.org

Please return forms to: Families as Partners
Special Needs Family Center
Children's Hospital of Wisconsin
PO Box 1997 MS 939
Milwaukee, WI 53201-1997

THIS COVER LETTER IS ON OUR ORGANIZATION'S LETTERHEAD

We are pleased that you are interested in Families as Partners - a program dedicated to promoting family involvement at Children's Hospital of Wisconsin. Below are some things that you might want to know about the process of becoming involved in Families as Partners.

- Participants must be able to make a commitment to serve for one year. The application has further information about types of activities for Families as Partners and the approximate annual time commitment. Before completing an application, please take some time to carefully consider if this is something that will fit into your life at this time. We do not want this to be an additional stress.
- Complete an application and mail it to:
Family Program Coordinator
Special Needs Family Center – MS 939
Children's Hospital of Wisconsin
PO Box 1997
Milwaukee, WI 53201
- Once we receive your completed application, one of our program coordinators will contact you within one month to arrange a time for an interview (either in person or on the phone). These interviews are informal and are designed for us to get to know you better and for you to ask any questions you may have. This will also help us to assure the best fit between you and a hospital activity.
- You will be required to attend an orientation. At that time you will be asked to sign a confidentiality and commitment agreement.
- Based on your availability and the hospital's need, we will make every effort to match family participants with available activities. If we are unable to match you with a current need at the hospital, we will keep your application on file for 12 months.
- If you have any questions about Families as Partners please feel free to call or email:

Thank you once again for your interest in Families as Partners.

Sincerely yours,

Families as Partners Committee:

THIS LETTER IS ON OUR ORGANIZATION'S LETTERHEAD

Name
Address

Date

Dear ,

Thank you very much for your application for Families as Partners. We appreciate your desire to become involved at Children's Hospital of Wisconsin in a family advisor capacity.

In the next month someone will contact you to schedule an interview. In the meantime, if you have any questions please do not hesitate to contact me.

Sincerely,

Family Program Coordinator
Phone number

Family Consultant Interview

Family Consultant Name:

Date:

Interviewer:

1. Follow-up on the profile: summarize, clarify, and respond to questions.
2. What skills have you learned that you could/would like to share with others, like parents, providers, hospital staff, etc. *Prompt: for example, navigating the funding maze, advocating for coverage, school issues, effective communication with providers, etc.*
3. What kind of involvement (per list in profile), especially interests you at this time?
4. What kind of training would help you feel better prepared for this involvement? *Prompt: for example, information, practice, mentoring, computer, run a meeting, write a grant, communicate effectively, public speaking.*
5. What kind of support would make it easier for you to become involved? *Prompt: for example, childcare \$, childcare at meetings, particular time for meetings, car-pooling, mentoring, transportation.*
6. We understand that living with a child with special health care needs can greatly affect the time you have to work as a parent consultant. At this point in time is there anything we need to know about your availability?
7. For you, what stands out as key learnings for you in living with a child with special health needs?

Additional Comments:

Interviewer Comments:

For More Information Contact:

The Center for Children with Special Needs is a program of Children's Hospital and Regional Medical Center. Funding for the Family Consultant Project was provided by the Washington State Department of Health Children with Special Health Care Needs Program and by Children's Hospital and Regional Medical Center in Seattle, Washington. For more information visit: <http://www.cshcn.org>.

Center for Children with Special Needs
A Program of

Children's
Hospital & Regional Medical Center
Seattle, Washington



Families as Partners Compensation Form

Name_____

Date of Service_____

Activity (Committee, Resident teaching, panel presentation, review documents, etc.)

Time spent on activity_____

Address_____

Phone Number_____

I would like to waive the monetary compensation for this activity and donate my time to Children's Hospital and Health System.

Signature_____

Date_____

Please complete and return to:
Families as Partners Coordinator
Special Needs Family Center – MS 939
Children's Hospital of Wisconsin
9000 W Wisconsin Avenue
Milwaukee, WI 53201

If you have any questions please contact:



Communication and Confidentiality Agreement

As a Family Advisor you will be attending committees, participating in focus groups, etc. and will be talking with other families who have children accessing the services at Children’s Hospital and Health System. In this role you will be trusted with confidential, privileged information such as diagnosis, family circumstances, and family experiences with providers and organizations. It is essential that you maintain confidentiality about information shared during these meetings and interactions with families and providers.

Please continue to remember that as you become involved in Children’s Hospital of Wisconsin as a Family Advisor, you will be representing not only yourself, but also all other families of children who come to Children’s Hospital. Professional etiquette including clear introductions of who you are and whom you are representing, (families), friendliness and appreciation for receiving and sharing information is the standard. When you attend meetings, etc. it is essential that you introduce yourself as speaking on behalf of a larger group of parents of children who come to Children’s Hospital, and a representative for the Families as Partners program.

I understand that every patient and family has the right to expect that health records and information will be managed confidentially. It is the responsibility of Children’s Hospital and Health System to protect the confidentiality of such information. In my role as Family Advisor, I agree to be accountable for the protection of all confidential information.

Name (please print):
Signature:
Date:

Children’s Health System, Inc. Administrative Policy and Procedure

This policy applies to the following entity(s):

- | | | |
|--|---|---|
| <input checked="" type="checkbox"/> Children’s Hospital of Wisconsin | <input type="checkbox"/> Children’s Hospital of WI-Kenosha | <input type="checkbox"/> Children’s Hospital of WI-Fox Valley |
| <input type="checkbox"/> Children’s Medical Group | <input type="checkbox"/> Children’s Health Education Center | <input type="checkbox"/> Seeger Health Resources |
| <input type="checkbox"/> Children’s Hospital Foundation | <input type="checkbox"/> Surgicenter of Greater Milwaukee | <input type="checkbox"/> National Outcomes Center |

SUBJECT: Families as Partners Program

POLICY

The Families as Partners Program is dedicated to promoting recommendations of families, and family participation in Children’s Hospital of Wisconsin committees, programs, and services. Its goal is to facilitate communication and collaboration among patients, families, caregivers and staff in order to improve the delivery of health care at Children’s Hospital of Wisconsin. Families as Partners reserves the right to choose participants that best meet the needs of the program.

Family members who participate on any committees will abide by the confidentiality policies of Children’s Hospital of Wisconsin.

PROCEDURE

I. The coordinator or designee for the Families as Partners program will be responsible for outreach to potential participants as well as providing placement and periodic feedback.

1. Identify potential program participants either through direct outreach activities or by making contact with families who have been referred to Families as Partners by alternate sources.
2. Promote diversity among participants and placements.
3. Ensure that the potential participant receives an application for participation in the program.
4. Interview potential participants once application for Families as Partners has been received. The interview process may take place either in person or by telephone. Contact will be made within one month.
5. Place the participant in an existing opportunity if one is available. If no matching opportunity is available at the time of completion of interview, the coordinator will maintain the participant’s information in the database until an appropriate opportunity is identified.
6. Contact potential participants who have not been matched within 12 months to assess continued interest.
7. Schedule a Families as Partners orientation session for new participant.
8. Identify an appropriate staff mentor for the family participant.
9. Contact staff mentor after family participant has completed first project or activity and solicit feedback from the mentor. Feedback will be solicited semi-annually thereafter.
10. Promote feedback to family participant after the first meeting or activity is completed.

Supersedes: None

Effective: 09 2003

Families as Partners Program/CHW/app

11. Serve as a resource for participants in Families as Partners program.
12. Process family participant reimbursement forms and stipends in a timely manner.
13. Maintain a database including:
 - a. Participant name
 - b. Date of application
 - c. Placement
 - d. Interests
 - e. Contact information
 - f. Date of expiration of application
 - g. Completion of training dates
 - h. Other information as necessary
14. Seek continued funding for ongoing support of the Families as Partners program.
15. Report regularly the activities of the Families as Partners program to the Family Advisory Committee.

II. Mentor will provide support and feedback to Families as Partners participant for the duration of participant involvement in opportunity

1. Orient family member to committee or activity for the participant.
2. Communicate meeting times, agendas and other logistics to participating family members.
3. Provide feedback to coordinator after participant's first activity or meeting. Feedback will be provided to coordinator semi-annually or as needed thereafter.

III. Families as Partners participants will become involved in appropriate activities in order to increase collaboration and communication between patients, families, and caregivers

1. Complete application and mail it to the coordinator at the Special Needs Family Center.
2. Participate in an informal interview to identify appropriate placement based on participant interests.
3. Attend orientation prior to beginning service in the Families as Partners program.
4. Read and sign a confidentiality and commitment agreement. One year program participation is requested.
5. Participate in activities including but not limited to:
 - a. Participation on committees.
 - b. Participate in groups that provide feedback and suggest solutions.
 - c. Review policies and procedures.
 - d. Review educational materials.
 - e. Give presentations to hospital staff from the family perspective.
 - f. Share family experiences with pediatricians in training.
 - g. Promote Children's Hospital of Wisconsin in the media.
6. Agree to be contacted at a later time within the following 12 months if an appropriate placement is not identified at the time of application and interview.
7. Reply to the annual written renewal in order to remain an active participant in the program.
8. Provide feedback regarding experience as a participant in the program.
9. Complete reimbursement request forms when applicable and mail to coordinator.

IV. Staff and leadership will identify appropriate family participants and/or opportunities for the Families as Partners program.

1. Identify appropriate activities for the Families as Partners program participants.
2. Contact coordinator about existing areas of need for participants.
3. Identify families or caregivers who are interested in participating.
4. Refer family members to coordinator or obtain permission from the potential participant to give contact information to the coordinator.

REFERENCES:

- Children's Hospital of Wisconsin: The Special Needs Family Center 8/11/2003
- Diversity Committee
- Family Advisory Committee

Approved by the Family Advisory Committee 08/2003

Cynthia S. Christensen, Executive Vice President
Children's Hospital of Wisconsin (CHW)

Children's Hospital and Health System (CHHS) does not make any representation with respect to any sort of industry recognized standard of care for the particular subject matter of this/these document(s). Additionally, CHHS form documents are subject to change, revision, alteration, and/or revocation without notice.

Families as Partners



Children's Hospital
of Wisconsin®

A member of Children's Hospital and Health System.

Children's Hospital of Wisconsin

Families as Partners

(414) 266-3196

PO Box 1997

Milwaukee, WI 53201

www.chw.org



Children's Hospital
of Wisconsin®

A member of Children's Hospital and Health System.

Families as Partners



Mission

Families as Partners is dedicated to promoting family participation in Children's Hospital of Wisconsin committees, programs and services. The goal is to gain family input and recommendations in order to improve services.

Training and resources

As a participant, you will receive a formal training session and materials. Children's Hospital staff will support, guide and help you.

Ways family members can be involved

As a participant in Families as Partners, you may be asked to:

- Participate on committees.
- Review policies and procedures.
- Review educational materials.
- Participate in groups that provide feedback and suggest solutions.
- Give presentations to hospital staff from the family perspective.
- Share family experiences with pediatricians in training.
- Promote Children's Hospital in the media.

Time commitment

Children's Hospital values all family participation and respects your time limitations. We will try and find an activity that fits into your family schedule.

Application

Thank you for your interest. If you have questions or would like an application, contact Anne Juhlmann at (414) 266-3196 or ajuhlmann@chw.org

Families as Partners Progress Note

Name:

Address:

Phone:

Email:

Contacted Date __/__/____

Gave application + brochure Date __/__/____

Received application Date __/__/____

Acknowledged application Date __/__/____

Contacted for interview Date __/__/____

Interviewed Date __/__/____

Orientation/Training Date __/__/____

Confidentiality Agreement signed Date __/__/____

Pre Placement evaluation Date __/__/____

Placement Date __/__/____

6-12 month post evaluation Date __/__/____

Mentor Name

Mentor Pre evaluation Date __/__/____

Mentor Post evaluation Date __/__/____

Mentor information packet Date __/__/____

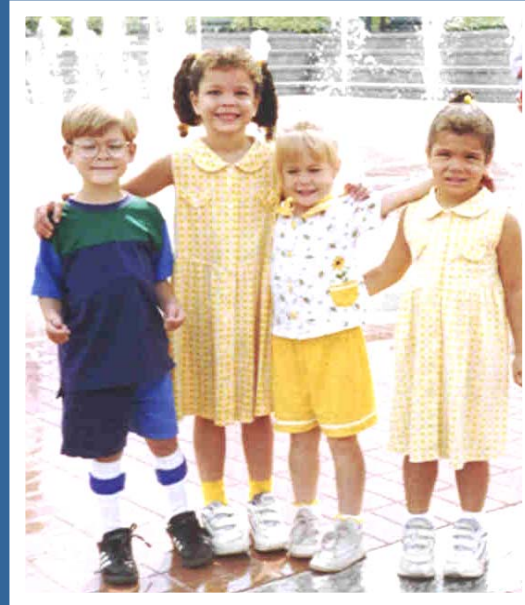
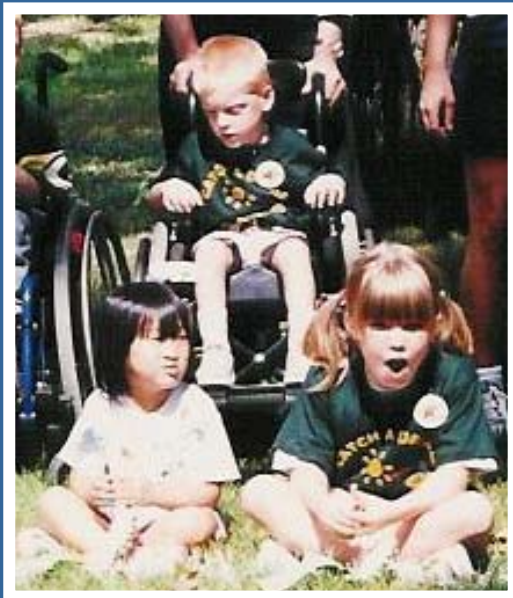
Notes:

Compensation

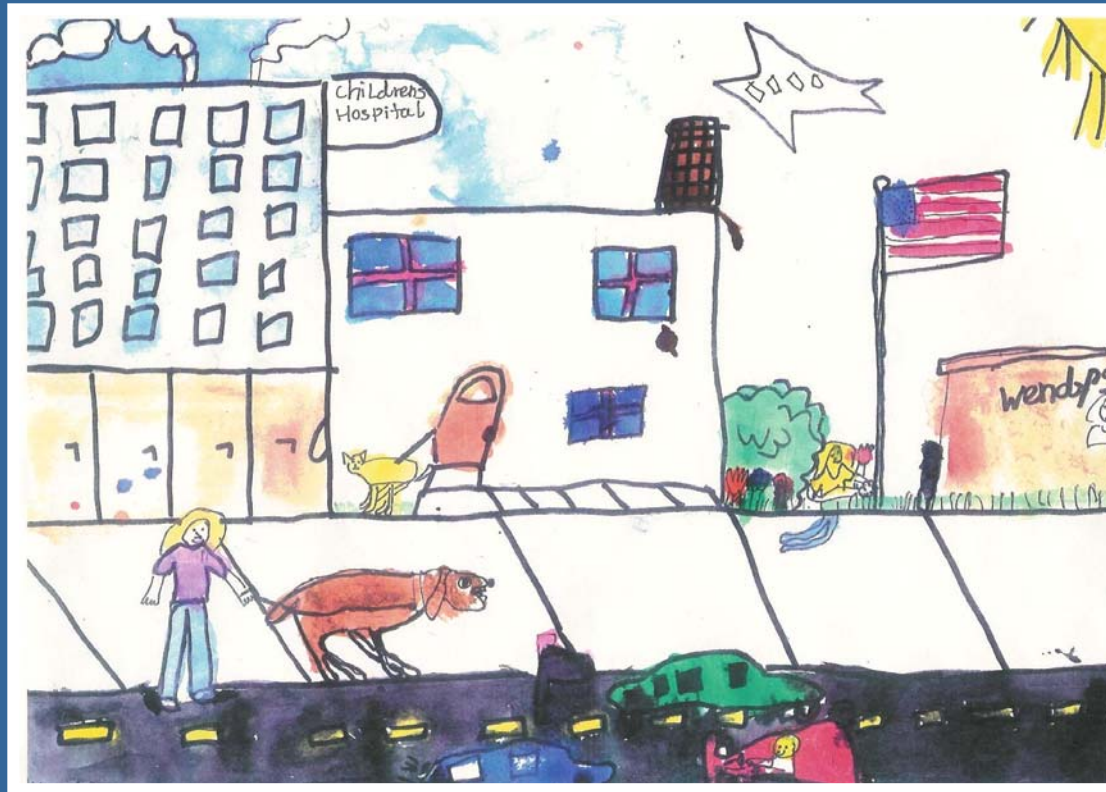
Date	Activity	Date comp form received	Date check request made	Date stipend sent

Families as Partners

A program dedicated to promoting family involvement at Children's Hospital of Wisconsin



Families as Partners



Family participation and decision making in programs and services at CHW, in order to improve pediatric health care

Families as Partners



Guiding Principals

- Families are essential partners
- Meaningful family involvement
- Mutual respect
- Collaboration
- Communication

Families as Partners

We continue to raise the bar

Growing realization
that families are
the best resource
that a hospital has
in the care of
children.

**Families as partners in
all that we do**

Families are our best resource

**Family centered care is
a core competency**

**Family centered care committee
1 parent, the rest staff**

**Families should be seen
and not heard**

Families as Partners

Planned and developed collaboratively by staff and family.

Name

Phone

Name

Phone

Name

Phone

Name

Phone

Name

Phone

Families as Partners

WANTED

**Diverse families who create a picture,
representative of all families at
Children's Hospital**



Families as Partners

Family Consultant

A parent, or other family member who, in an advisory role, draws on their health care experience in such a way that it contributes to improving the quality of care for all patients and their families.

Institute for Family Centered Care

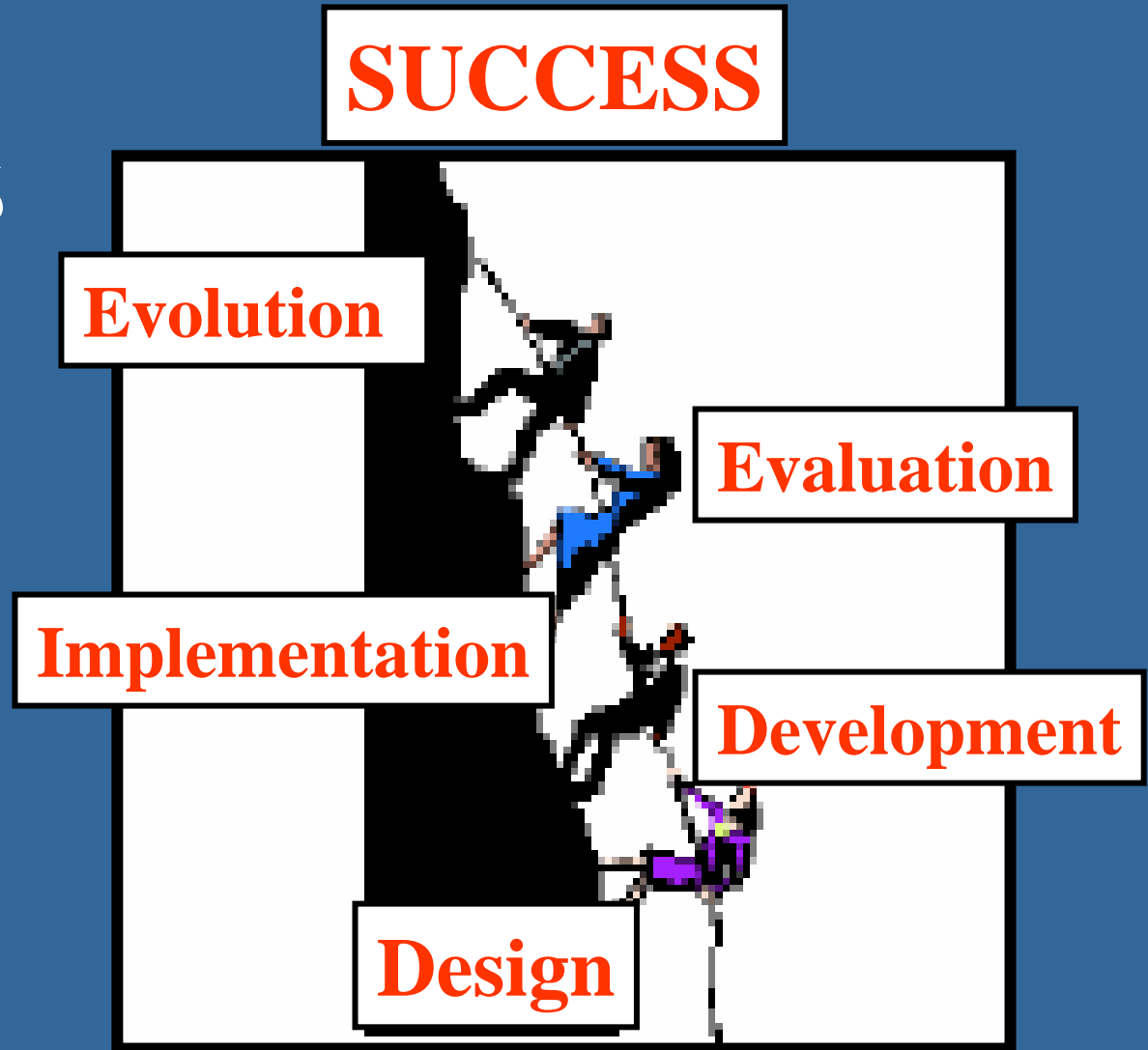
Families as Partners

We want families involved

- On committees and on feedback groups
- To review policies and procedures.
- To review educational materials
- As “Family Teachers” for Pediatric Residents and Medical Students
- As special speakers for hospital staff
- **In every phase of health care**

Families as Partners

Families
+ Staff
Success



Families as Partners



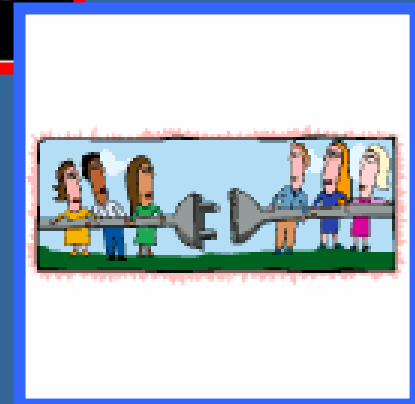
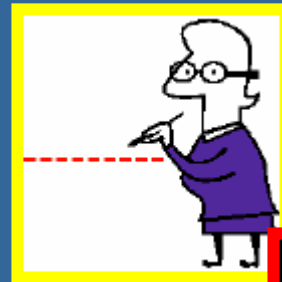
Staff Wanted

- To identify opportunities for family involvement
- To refer families
- To mentor families

Families as Partners

What is the process?

- Referral
- Application
- Interview
- Orientation
- Involvement
- Evaluation



Families as Partners

Benefits to Families

- Provide meaning to experiences
- Meet other families
- Improved satisfaction with services.
- Improved delivery of care to all children and their families



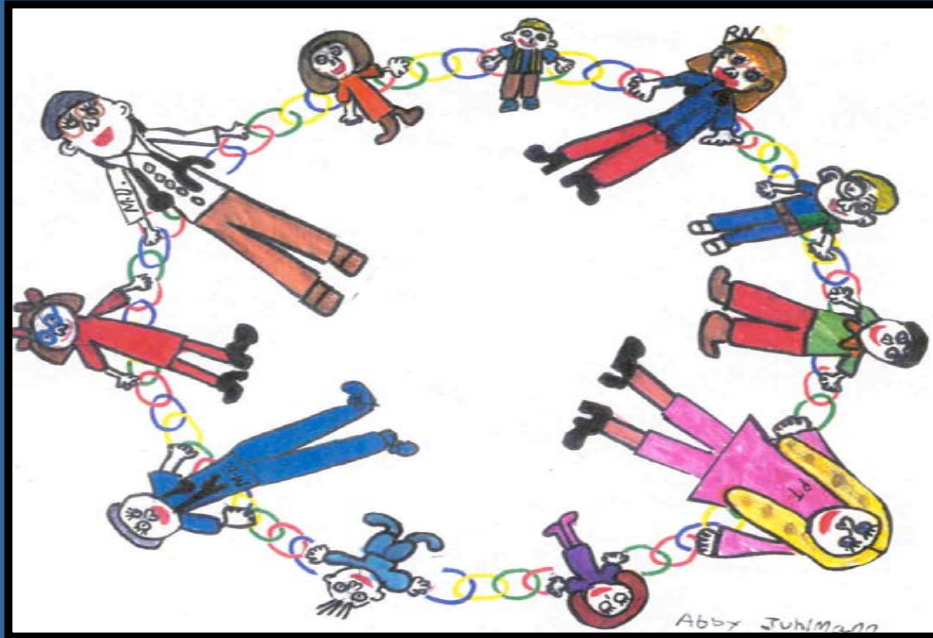
Families as Partners

Benefits to Staff

- Increased understanding of both the philosophy and the practice of family centered care.
- Programs that best meet the needs of families.
- Satisfied customers
- Improved delivery of care to all children and their families



The partnership between parents and professionals is based on the realization



*that everyone's role is important,
that what we do together is greater than
what any one of us can do separately!*

From the Institute of Family Centered Care

Families as Partners

Alone we can do so little.
Together we can do so much.

Helen Keller



Copyright 2003
Anne Juhlmann RN BSN
Waukesha, Wisconsin

Summary of Family Responses

Families as Partners Orientation

We started the orientation with an icebreaker. Each participant introduced themselves and told us what they like about Children's Hospital of Wisconsin and what they would like to see changed/improved at Children's Hospital.

FAP Orientation Objectives:

1. Overview of Families as Partners – mission and the program
2. Overview of CHHS Mission
3. Explore the elements of partnership
4. Explore the benefits of involvement
5. Explore the barriers to family involvement
6. Communication and Confidentiality
7. Responsibilities

Discussion of the Elements of Partnership – family responses

- Collaboration – families and staff working together and sharing ideas.
- Respect – value other points of view
- Trust
- Confidentiality
- Honesty – share all information
- Communication - honesty and feelings and needs of both staff and families
- Always keep an open mind
- Internalize/empathize
- Value the importance of everyone's role/position/frame of reference

Benefits of Involvement for Families -family responses

- Increases worldwide knowledge
- Gives families a chance to "give back"
- Gives families an opportunity to use their experiences to help someone else
- Empower ones own family and other families
- Educating other parents and physicians
- Fosters change - helps the hospital staff become aware of what works at other hospitals since families often have experiences at other pediatric hospitals in the US.
- Provides perspective for families and for staff
- Gives staff and families a better understanding of one another
- Sharing ones story and experiences is in and of itself a benefit.

Potential Benefits of Involvement for Staff – family responses

- Quality improvement
- Process improvement
- Translation and facilitation of quality ideas moving out of the room to become better systems and processes.
- Breaks down the hierarchy
- Improved customer service

- Staff gains advice from those who know best – families (customers).
- Improved public relations
- Increased respect – parents respect the hospital more if they know that the staff is making efforts to involve families at all levels.
- Improved care to children – improved care for even one child is a benefit.

Potential Barriers to family involvement – family responses

Items marked with * are viewed as the biggest barriers according to the families at FAP Orientation. Pre-conceived ideas of staff about families and families about staff was voted as the hardest challenge to overcome.

Not all listed items are barriers for every family.

- *Pre-conceived ideas of both families and staff
- *Isolation (culture, language)
- *Leadership commitment
- *Training and educational level of parents
- *Economic issues with involvement – family advisor must take off work, pay for child care, transportation, etc.
- Childcare
- Emotions
- Proximity
- Organizational culture
- Space to meet
- Commitment of the family advisor's significant other/spouse
- Sleep deprivation
- Hospital staff will need to live up to increased expectations
- Commitment of both families and staff
- Accountability of everyone
- Attitude
- Accessibility to the appropriate people
- Family feelings of powerlessness.
- Time
- Energy
- Transportation
- Intimidation
- Training and education of staff

Strategies for overcoming pre-conceived ideas (biggest potential barrier according to the families)

- Getting staff and families to the table - together
- Stay in learning mindset
- Positive communication skills
- State things "from my perspective" and not as if it is a fact
- Empower staff
- Staff buy in to the idea of family involvement

Evaluation

Families as Partners Orientation

What went well

What could have been better

Do you feel that you have a better understanding of the role that families can play as partners with their providers?

And additional comments

FAMILIES AS PARTNERS

PRE-SURVEY

Please answer questions the following questions. They will be collected at the end of orientation.

Scale Definition: 1= Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree

	1	2	3	4
I have been involved in decision making at Children’s Hospital of Wisconsin in the care of my child.				
I have been involved in decision making at Children’s Hospital of Wisconsin as a consumer in systems related to care delivery,				
I am valued by Children’s Hospital of Wisconsin as a parent.				
I am valued by Children’s Hospital of Wisconsin as a consumer of services.				
There are roles at Children’s Hospital of Wisconsin for parents as consultants.				
I am very satisfied with the care my child receives at Children’s Hospital of Wisconsin.				

Please list the ways that you would like to participate as a member of Families as Partners.

Is there anything else that you would like to comment on?

FAMILIES AS PARTNERS

POST-SURVEY

Please answer questions the following questions. They will be collected at the end of orientation.

Scale Definition: 1= Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree

	1	2	3	4
I have been involved in decision making at Children’s Hospital of Wisconsin in the care of my child.				
I have been involved in decision making at Children’s Hospital of Wisconsin as a consumer in systems related to care delivery,				
I am valued by Children’s Hospital of Wisconsin as a parent.				
I am valued by Children’s Hospital of Wisconsin as a consumer of services.				
There are roles at Children’s Hospital of Wisconsin for parents as consultants.				
I am very satisfied with the care my child receives at Children’s Hospital of Wisconsin.				

Please list the ways that you would like to continue to participate as a member of Families as Partners.

Please provide us with any suggestions or comments you may have about Families as Partners.

THIS LETTER IS ON OUR ORGANIZATION'S LETTERHEAD

To: Families as Partners' Staff Mentors

From:

Date:

Re: Staff Survey

Enclosed you will find a "Mentor Survey". Please fill this out and mail back to **Families as Partner in the Special Needs Family Center, MS 939**. We greatly appreciate any feedback you offer.

Thank you for your participation and willingness to have family representatives on the various committees and initiatives that you are involved in.

If you have any questions about the survey or Families as Partners please do not hesitate to call _____ (phone) or _____ (Phone).

FAMILIES AS PARTNERS PROGRAM

MENTOR SURVEY

1. Were you adequately prepared for the role of parent participation on your committee?

Yes ___ No ___ Somewhat ___
Suggestions for improvement:

2. Has parent participation positively impacted on the activities of your committee?

Yes ___ No ___ Somewhat ___
Comments:

3. Are staff members comfortable with parent involvement on the committee?

Yes ___ No ___ Somewhat ___
Comments:

4. Does it appear that the parent is comfortable and interactive on the committee:

Yes ___ No ___ Somewhat ___
Comments:

Resources

The Center for Children with Special Needs
Children's Hospital and Regional Medical Center
<http://www.cshcn.org>

Institute for Family-Centered Care
7900 Wisconsin Avenue, Suite 405
Bethesda, MD 20814301-652-0281
www.familycenteredcare.org

Family Voices, Inc.
2340 Alamo SE, Ste. 102
Albuquerque, NM 87107
(505) 872-4774 or (888) 835-5669
Fax: (505) 872-4780
<http://www.familyvoices.org/>
Email: kidshealth@familyvoices.org

Title V Toolbox for Family Participation
<http://www.familyvoices.org/toolbox/>

The National Center for Medical Home Initiatives for Children with Special Needs
http://www.medicalhomeinfo.org/about/hp_2010.html

The American Academy of Pediatrics
<http://www.aap.org/>

Rules for the Road
http://www.marchofdimes.com/14756_14762.asp

Blough, Joan, Patt Brown, Sharon Dietrich, and L. Bryn Fortune. The Parent Leadership Program. Bethesda: Institute for Family Centered Care, 1996.

Jeppson, Elizabeth, and Josie Thomas. Essential Allies - Families as Advisors. Bethesda: Institute for Family Centered Care, 1999.

Koop, C. E. (1987). *Surgeon general's report: Children with special health care needs*. Rockville, MD: U.S. Department of Health & Human Services.

Stewart, Elizabeth A., and Chandice Covington. "Parent Consultants In The Health-Care System: A New Approach In The Care Of Children With Special Needs." Issues in Comprehensive Nursing 15 (1992): 123-139.

United States. Maternal and Child Health Bureau. Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs. 1 Sept. 2005
<<http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>>