



INSTITUTE FOR FAMILY-CENTERED CARE

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FAMILY-CENTERED CARE

Family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships between and among consumers and health providers.

Family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them.

Family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.

CORE CONCEPTS

- ❖ Respect
- ❖ Support
- ❖ Strengths
- ❖ Flexibility
- ❖ Choice
- ❖ Collaboration
- ❖ Information
- ❖ Empowerment

In family-centered care:

- ❖ People are treated with dignity and respect.
- ❖ Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
- ❖ Individuals and families build on their strengths by participating in experiences that enhance control and independence.
- ❖ Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

FAMILIES OF CHILDREN WITH SPECIAL NEEDS

Basic assumptions about families:

Each family is unique in their

Composition

Resources

Values

Perception of the world

Anything, which happens to one member of a family, impacts all members

Diagnosis

Treatment plans

Transportation

Financial considerations

Environmental changes

All families, no matter how troubled, have strengths that they can access in order to solve problems; competency mode versus deficit model

Impact of diagnosis

Prenatal diagnosis/diagnosis at birth, example - Down syndrome

Unexpected event at a time of heightened emotional vulnerability

Loss of anticipated 'perfect baby'

Demands of coping with new baby and unexpected life changes at the same time

Later diagnosis, example - autism

Often comes after period of nagging concern

Missed milestones

Loss of skills

Trips to various therapists and doctors

Initial occurrence is followed by years of:

Periodic crisis

Changing demands

Major adjustments for family

Parents remember how the news was delivered to them, often with pain and anger years later

Life cycle issues

Birth of any child

Major adjustment made by couple

Increase in financial obligations

Decrease in personal/couple time

Changes in relationships with friends and extended family

More vulnerable to depression and stress

Special stressors when child has special needs: impacts on multiple levels-

Behavioral (actions)

Affective (feelings)

Physical

Interpersonal

Cognitive

Cumulative effect

Common reactions of parents-

Denial

Anger

Fear

Guilt

Religious interpretation

Confusion

Powerlessness

Rejection

Isolation

Chronic sorrow (Olahansky 1962)

Pervasive psychological reaction marked by periodic occurrences of sadness

Move through stages but unlike bereavement lacks closure

Intensity of sorrow varies across life span

Marked by times of predictable crisis

Not a neurotic manifestation

A natural response to a heartbreaking reality

Roles in families

Help maintain balance in relationships

Insure practical living tasks are accomplished

May result in conflict

Roles in families with special needs children:

Shifting of roles

Addition of new tasks

Specific roles - optimist/pessimist

Parents of a handicapped child

"Teacher" or "expert"

Stability of spousal relationship

Scarcity of research on marital satisfaction

Assumption of negative effects

Marital satisfaction is single best predictor of family's positive coping behavior

What parents need from professionals:

Positive acknowledgment of child

Both layman and medical explanations

Room to express their own ideas or suggestions

Written summaries

Availability

Interventions which parents are able to provide

The positives:

Opportunity to learn to appreciate individual differences

Development of greater compassion, sensitivity, tolerance

Appreciation of the "little things" in life

Recognition of one's own strengths

Love of one's child

PARTNERSHIPS

Requires more than one person
Each partner contributes
Voluntary, conscious joining
Responsibility to partnership
Power, duties, roles understood

HELPING RELATIONSHIPS

Work together
Common aims
Complementary expertise
Mutual respect
Negotiation
Effective communication
Honesty
Flexibility

NEGATIVE EFFECTS WHEN THESE ARE MISSING

1. Undermines "help seekers" sense of competence and control.
2. Fosters dependencies when "help givers" took relative, or in some instances complete control by exercising paternalistic authority.
3. Decreased self esteem by conveying a sense that "help seeker" was inferior incompetent, or inadequate.
4. Fostered a sense of indebtedness or evoked other negative reactions.
5. Help was unsolicited, especially when help was offered by those whom "help seeker" did not know or did not wish advice from.
6. "Help giving" was incongruent with what was sought, or refusal of help was seen as ungrateful.
7. Help was seen as needed by "help giver" but individual perceives no problem and has no identified need.
8. Help was provided non-contingently.

Carl Dunst and Hilton Davis

It's the "Person First" - Then the Disability

Say.....

Child with a disability
Person with cerebral palsy
Person who has
Without speech nonverbal
Emotional disorder, or mental illness
Developmental delay
Deaf or hearing impaired
Uses a wheelchair
Person with retardation
Person with epilepsy
With Down Syndrome
Has a learning disability
Nondisabled
Has a physical disability
Congenital disability
Condition
Seizures
Cleft lip
Mobility impaired
Medically involved, or has
chronic illness
Paralyzed
Has hemiplegia (paralysis of
one side of the body)
Has paraplegia (loss of function
In lower body only)
Of short stature

Instead of.....

disabled or handicapped child
palsied, or C.P., or spastic
afflicted, suffers from, victim
mute, or dumb
crazy or insane
slow
deaf and dumb
confined to a wheelchair
retarded
retarded epileptic
mongoloid
is learning disabled
normal, healthy
crippled
birth defect
disease (unless it is a disease)
fits
hare lip
lame

sickly
invalid or paralytic

hemiplegic

paraplegic
dwarf or midget

Physicians: What Parents Want You to Know About Their Child With Special Needs

The Parent's Point of View

I Like You When You:

- ◆ Recognize my denial, anger, and healthy and natural response to grief.
- ◆ Accept that my child's health care needs are only a part of my family's priorities and that sometimes my family's needs and concerns may take precedence.
- ◆ Value that I'm the expert on my child.
- ◆ Acknowledge that I am a competent partner in health care.

What I Need From You:

- ◆ Help me find the information I need to understand my child's condition. My child's condition is not temporary. I'll be learning about it for a lifetime.
- ◆ Do not withhold or omit any information concerning the severity or extent of my child's condition. Also, do not hesitate to use medical terms when necessary.
- ◆ Help me to understand the range of possibilities. Tell me the worst and best possible prognosis.
- ◆ Acknowledge my sense of urgency by responding quickly to requests for medical information, referrals, etc, so that appropriate services can begin or continue.



- ◆ Remind me of my child's strengths from time to time.
- ◆ Collaborate with other professionals providing care for my child.

If it sometimes seems I expect you to be my social worker, psychiatrist, and omnipotent seer of the future... well I do!

P.S. Thanks for being my competent partner in health care!

The American Academy of Pediatrics (AAP) believes that all infants, children, adolescents, and young adults should have access to a "medical home" that provides comprehensive, coordinated, and family-centered health care.

This goal presents unique challenges for pediatricians offering primary health care to children with special needs within this changing health delivery system. To meet those challenges, the Medical Home Program for Children With Special Needs identifies

and promotes model strategies, training, and technical assistance. By supporting physicians, and other health care professionals, the Medical Home Program for Children With Special Needs seeks to provide better health care for all children.

For more information on how the Medical Home Program for Children With Special Needs can be a resource for you, or if you would like to be added to the mailing list, contact Liz Osterhus, AAP Department of Community Pediatrics, 800/433-9016, ext 7621.

Parent-professional collaboration is an essential component in the provision of medical homes for children with special needs. This document was brought to you by the American Academy of Pediatrics, Medical Home Program for Children With Special Needs with funding provided by the federal Maternal and Child Health Bureau.

This document is a reprint from materials provided by the Hawaii Medical Association's former Medical Home Project.



Parents as Mentors Self-Assessment
Program Year 2005 - 2006

Date _____

Pre/Post Test - circle one

SS# _____

Directions: Read each statement and circle the number on the corresponding scales that reflects your rating of your knowledge, skills and attitudes related to working with families of children with disabilities. This rating should reflect your *current* level of knowledge or skills and your *current* attitudes. Please remember there are no right or wrong responses. We will ask you to respond to these same statements at the end of the trainee-ship to assess your *Parents as Mentors* experience.

STATEMENT

KNOWLEDGE AND SKILLS

	1	2	3	4	5
	Strongly disagree		Uncertain		Strongly agree
1. I understand the philosophy and principles of <i>family-centered care</i> .	1	2	3	4	5
2. I can describe family characteristics that influence family resources and coping strategies.	1	2	3	4	5
3. I can explain how my own cultural values might affect my work with families from diverse situations.	1	2	3	4	5
4. I can describe effective help-giving strategies.	1	2	3	4	5
5. I can describe how a child with a disability might impact on all family members.	1	2	3	4	5
6. I am able to listen carefully to how families define their situation and events related to their child with a disability.	1	2	3	4	5
7. I am an empathic and effective listener for families.	1	2	3	4	5

ATTITUDES

8. All families are able to participate as equal partners in the planning of intervention goals and services.	1	2	3	4	5
9. Every family is able to make positive contributions to their child's development.	1	2	3	4	5

	Strongly disagree		Uncertain		Strongly agree	
10. Each family should determine to what level and extent they will participate in intervention services.	1	2	3	4	5	
11. Intervention outcomes generated by or shared by family members are more effective than those developed by professionals.	1	2	3	4	5	
12. All families, regardless of cultural or socioeconomic status have resources to meet their child's needs.	1	2	3	4	5	
13. My personal values and biases will affect my interpretation of family resources and capabilities.	1	2	3	4	5	
14. Parents will make the best decisions for their child with a disability.	1	2	3	4	5	
15. I believe it's OK for a family to take a break from therapy even if I think that the child's progress may suffer.	1	2	3	4	5	
16. Parents are as capable as their interventionists in identifying needs of their child.	1	2	3	4	5	
17. Not using parent input for setting goals might compromise the quality of intervention services.	1	2	3	4	5	
18. Parents are in the best position to decide which discipline should provide services for their child's needs.	1	2	3	4	5	
19. My experience as a family member helps me appreciate how other families function.	1	2	3	4	5	
20. Professionals need families input to be realistic about the abilities of the child with special needs.	1	2	3	4	5	

Comments:



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CONFIDENTIALITY AND PRIVACY OATH

I, _____ promise to hold confidential, verbal and written information received through observation of, direct contact with, or written and verbal material about, families who are recipients of and participants in the ILEND program, 'Parents as Mentors' through University Hospital School. I further promise to uphold, in good faith, ethical obligations concerning privacy, rights, and respect of individuals who are a part of my learning experience, directly or indirectly, including other professionals, family members, student peers and support staff.

Printed Name

Signature and Title

Date

Parent as Mentors Check List

First Semester:

- Confidentiality Statement
- Pre-test Self-Assessment
- Four Family Visits
- Four Reflection Papers
- Final reflection paper
- In person discussion after first and final reflection

Second Semester:

- Identify policy or systems change beneficial to family
- Formulate possible policy or service change
- Identify appropriate individual, agency or policy
- Make Contact/submit documentation of contact & response
- Share contact information with family
- 2-page paper: who, what, where, when, how

First semester work to be completed by mid January

Second semester work to be completed by May 1st

Submit binder with all items on check list

Family Visit: Reflection Guidelines

1. After each family visit, write a brief objective account of the visit/activity in which you have participated. To ensure accuracy do this shortly after the visit.
2. Note your reactions to the family visit from the following perspectives;
 - **Account of visit:** the who, what, where, why, and how of the visit.
 - **Family perspective:** placing yourselves in their shoes. How did you feel the visit went for the family and what was the lesson they had to teach you?
 - **Personal perspective:** your response to the experience e.g., what felt good, what felt sad, what was distressing? Develop a sensitivity to and understanding of the family's circumstances and strengths.
 - **Surprise and/or insights:** What surprised you and your reactions and the insights you gained?
 - **Cultural perspective:** your cultural perspective and the patient's and family's cultural perspective which includes history, traditions, values, and social organization. The goal is to increase your own self-awareness.
 - **Questions that arose from the visit:** what more do you want to know?

EXAMPLE OF REFLECTIONS

Account of Visit:

I came to the S's home late Saturday afternoon. Amy S. the mother greeted me at the door and requested that I accompany her and Jimmy (her son) to the grocery store. She relayed that these trips were always difficult to manage because of Jimmy's challenging behaviors. While at the store, Jimmy began to run through the food aisles knocking several items down in his path. Amy ran after him promising treats if he would sit in the supermarket cart. For the remainder of the errand Jimmy sat in the cart asking for particular snacks crying, yelling and grasping his mom's clothing if she refused. Amy occasionally allowed Jimmy some of these purchase requests and opened a few packages for him to snack. This would quiet him for a brief period. The shopping trip lasted for ninety minutes and all of us were exhausted on the drive back. When we arrived I assisted Amy in bringing in the grocery bags. Jimmy had fallen asleep on the way home in his car seat. Amy thanked me several times for my help and expressed how overworked she often felt, parenting Jimmy alone and with little support. After assisting in putting the groceries away and making another date to visit, I left to go home.

Family Perspective:

I felt overwhelmed and exhausted even trying to imagine how Amy copes with Jimmy's behaviors in their daily routine. She seems very alone and without much help. Her ability to get up every day and face these challenges is remarkable.

Personal Perspective:

I must admit that I couldn't wait to leave this visit. I was very embarrassed and felt helpless at Jimmy's public display. I couldn't help but wonder if Amy was just reinforcing his negative behavior with snacks and bribes. I wondered if all outings were this complicated. I wasn't sure how to assist Amy when Jimmy acted out and she offered another cookie.

PARENTS AS MENTORS FAMILY VISIT ASSIGNMENT

The ILEND trainee will be paired with a volunteer family who has a child with a chronic medical illness or special needs early in the fall semester. The trainee will contact the family and make arrangements for the initial visit. Throughout the semesters, at least **four** visits should occur, hopefully in a variety of environments (i.e., home, park, shopping, IEP meeting, doctor's appointment, therapy, etc.)

When you do your home visits, you may find it helpful to consider yourself a "participant observer." Participant observation is a research tool developed by anthropologists and adopted by researchers in other fields, including sociologists, educators and medical researchers. A participant observer enters a setting such as a community, a classroom, a neighborhood, or a family to learn from the people who live there. A participant observer aims to **become a participant** with the people in the setting rather than being an observer. On a home visit, you enter a family culture seeking to become a participant in that family culture, and observe from the perspective of a family member. Participant observation provides a powerful tool for building an understanding of the ways people in different settings experience life. Building an understanding of the clients and families you support will enhance your ability to meet their needs in a collaborative and empowering way.

EXPECTED OUTCOMES

The purpose of this assignment is:

1. To give the ILEND trainee an opportunity to see beyond an individual's illness or diagnosis. The trainee will experience the individual at home and in the community from the family's perspective and the trainee's personal perspective.
2. To help ILEND trainees recognize and acknowledge his/her own biases, beliefs, and privilege and how these biases, beliefs and privilege, can affect the client/family-clinician relationship.
3. To provide an opportunity for the trainee to view families/consumers as teachers from whom health professionals can learn rather than viewing families/consumers as something to be assessed.

Sample Questions for Self-Reflection Regarding Family-Centered Practice

Do I ...

- during interactions demonstrate respect for families as experts on their children?
- help families from diverse backgrounds feel comfortable?
- introduce myself to families and explain my role and function?
- assure that families receive clear, useful, and comprehensive information?
- learn about families' unanswered questions and concerns?
- consistently ask families about their insights concerning their children?
- involve parents as partners in all aspects of the delivery of care for their children?
- honor parents' primary role in making decisions about their child's care?
- assure that parents' priorities and choices guide treatment and care?
- offer choices for parents for participation in care?
- feel comfortable sharing responsibility with families'?
- encourage parents to read their child's chart?
- help families connect with other families for mutual support?
- ask about families' satisfaction with and perceptions of care?
- offer a variety of ways for families to request changes?
- help staff and families find common ground when disagreements occur?
- analyze, with families, problems that occur to see what we can learn to improve communication and care?
- support the involvement of families as advisors about programs and policies?

Note: Adapted from *Conveying respect for families: A tool for self-reflection*. In J.L. Hanson, E.S. Jeppson, B.H. Johnson, & J. Thomas, *Family-centered care: Changing practice, changing attitudes*, Bethesda, MD: Institute for FCC