



The purpose of this brochure is to provide a rationale and strategies for planning and implementing a *family-centered* approach to services for children with disabilities, chronic illnesses or other special needs.

“Family-centered care” describes a philosophy of service delivery that is driven by the needs and priorities of client families who relate to professionals in a collaborative and mutually respectful way. Basic principles* of family-centered care include:

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.

Where to find more information:

Institute for Family-Centered Care
www.familycenteredcare.org

National Center for Cultural Competence
Georgetown University
www.georgetown.edu/research/gucdc/nccc

National Center of Medical Home
Initiatives for Children with Special Needs
www.medicalhomeinfo.org

National Resource Center for Family
Centered Practice, University of Iowa
(phone: 319-335-4965) nrcplib@uiowa.edu

Who to contact in [name of state]:

[FV state contact info goes here]



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Working with Families as Experts and Consultants



A Guide for Professionals Implementing Family-Centered Care

Families as Partners

Successful implementation of family-centered care requires that outmoded ideas or prejudices about families be replaced by a view that supports the central role of families in care giving and decision-making.

It is a view that assumes families are *partners* with professionals and that decisions involve a team process.

Optimal teamwork requires:

- ↳ Open communication
- ↳ Sincerity
- ↳ Trust
- ↳ Objectivity
- ↳ Empathy
- ↳ Honesty
- ↳ Respect
- ↳ Shared vision and goals

Operationalizing these qualities is easier said than done. For professionals, it means relinquishing some control and operating in a more flexible manner. Family-centered care applies to every level concerned with services for children with special needs: in the care of an individual child, in the way services are organized and delivered at a clinic or hospital, and in the development of policies and programs at the local, state, and national level.



Family-Centered Strategies

There are some very practical strategies that service providers can use to become more family-centered in their approach:

- ↳ Conduct periodic surveys of your client families to ask what things you might change about your services...and then act on the recommended changes and communicate your decisions.
- ↳ Establish an advisory group of families for whom you provide services. Be clear about your expectations and support the group to make decisions about when, where, and how often they meet. Again, act on recommendations from the group.
- ↳ Become familiar with the range of service options that could benefit the children and families you serve. Make available informational brochures about these other services and programs. Ask families if they need other services and then help refer or connect them to resources they need.
- ↳ Group practices or provider groups should have a staff member who understands the service systems potentially needed by client families.

Consider hiring a parent or family member to serve in a direct role assisting families and helping coordinate services.

Outreach to Families

Sometimes the efforts of professionals to involve families in policy planning and committee work fail to get the desired level of involvement by families. Here's a simple checklist that may help address potential barriers to participation:

- ↳ Are meetings set for times and places convenient for families at least some, if not all, of the time?
- ↳ Are there provisions for childcare or stipends to cover costs for sitters or other forms of assistance families need such as transportation, parking, meals, etc.?
- ↳ Are families more than token or isolated members of the group? Is their participation valued in meaningful ways, e.g., leadership roles, paid participation, agendas that address their concerns, etc.?
- ↳ Are there tasks or committee activities families can work on between meetings?
- ↳ If meeting attendance is not practical, can families participate by phone conferencing?



Acknowledgements: Family Voices of TN, *Institute for Family-Centered Care