This theme issue focuses on family-centered practices and policies for service delivery. The first article, "Family-Centered Service Delivery," reports on a study of 130 published sources in education, social work, nursing, psychology, occupational therapy, and related disciplines, which found that the key components of family-centered philosophy and practice were: (1) focusing upon the family as the unit of attention; (2) organizing assistance collaboratively; (3) organizing assistance in accordance with each individual family's wishes; (4) considering family strengths; (5) addressing family needs holistically; (6) individualizing family services; (7) giving families complete information in a supportive manner; (8) normalizing perspectives; and (9) structuring service delivery to ensure accessibility, minimal disruption of family integrity, and routine. Another article, "Measuring Family-Centered Practices," details the findings of a survey of 443 parents of children with disabilities that found the three most desired early intervention staff behaviors were listening to families, treating families with respect, and accepting families as important team members. A third article "Family-Centered Statutory Policy," discusses findings from a study that evaluated family-centered statues in North Carolina and identified 24 quality indicators of exemplary family-centered legislation. The newsletter also describes a Head Start program for Native American children and strategies that staff can use to use it with families. (CR)
Family-Centered Service Delivery

In the former medical way of delivering health care services, professionals looked only at the child, not the family. Then they told the family what to do. End of story. Today, demand for family-centered practices has evolved from the old service delivery style.

Family-centeredness, known also by names such as family-focused, family-oriented, family referenced, and family empowerment, reflects the words of poet Maya Angelou: "At our best level of existence, we are parts of a family, and at our highest level of achievement, we work to keep the family alive."

Family-centered practices and policies are not restricted to the health care or disability fields. Social work, education, psychology, sociology, and occupational therapy also are embracing this form of service provision.

By trying to give families what they want, professionals facilitate families' own power.

Key components. After reviewing 130 published sources in education, social work, nursing, psychology, occupational therapy, and related disciplines, Beach Center researchers found these key components of family-centered philosophy and practice:

- Focusing upon the family as the unit of attention
- Organizing assistance collaboratively (e.g., ensuring mutual respect and teamwork between team workers and clients)
- Organizing assistance in accordance with each individual family's wishes so that the family ultimately directs decision making
- Considering family strengths (versus dwelling on family deficiencies)
- Addressing family needs holistically (rather than focusing on a member with a "problem")
- Individualizing family services
- Giving families complete information in a supportive manner
- Normalizing perspectives (i.e., recognizing that much of what those receiving services are experiencing is typical)
- Structuring service delivery to ensure accessibility, minimal disruption of family integrity and routine

A new definition. Upon completion of the literature review and consultation with families and service agencies across the United States, Beach Center researchers came up with the following definition:

Family-centered service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses upon the strengths and capabilities of these families.

Family-centered care providers acknowledge that each family member influences the family as a whole. To separate one from another is like trying to put together a puzzle without all the pieces. The child's behavior, characteristics, and resources influence other family members and vice versa. As social work educator M. L. Allen said, "For most children in this country, the best investment in their future is an investment in a strong family."
Family-centered service providers try to address all challenges that may influence children who need care. Often that means that the service provider works with other agencies to provide “wrap-around” care, an all-in-one package of assistance.

**Strengths.** Family-centered professionals look hard for the strengths--the talents, resources, attributes, and aspirations--of each family member. Who knows better about a person than his or her family? Family centeredness values parental knowledge and experience. The service provider becomes a consultant who provides families with information that strengthens them to make their own decisions. Family-centered service delivery makes the most of family involvement in decision making. Information is actively shared. Everyone who is significantly involved with the child collaborates in final decisions. Ultimately, the family should make the final decisions.

**History.** Interestingly, the term *family-centered* was coined in the 1950s by the Family-Centered Project of St. Paul, Minnesota, which formed much current thought about working with families facing multiple challenges. Those in the medical field--family practitioners, obstetricians, pediatricians, and nurses--also have done much to increase family-centered services in the last 25 years. Other health professionals have followed their lead.

The consumer movement out of the 1960s, legislation, increased demand for complex chronic illness services, and rising health care costs have pushed the rest of medicine toward family-centered delivery practices.

Family centeredness also has long been linked with social work. As one social worker wrote in 1917, “As society is now organized, we can neither doctor people nor educate them, launch them into industry nor rescue them from long dependence, and do these things in a truly social way without taking their families into account.”

Over the last 20 years, family-centered services have developed significantly in special education, early childhood education, and the developmental disabilities fields--largely because of federal legislation encouraging parental involvement in service delivery.

**Benefits of family-centeredness.** Family-centered practices can improve:

- Child functioning
- Parent skills and emotional well-being
- Parents’ view of service effectiveness and sense of control over their child’s care
- Problem solving
- Ability of families to care for their child at home
- Service delivery
- Cost-effectiveness
- Family empowerment

While there are many benefits, however, family-centered service delivery can be challenging to practice. Educators have suggested that obstacles to family centeredness include professionals’ lack of training in counseling and family systems, role clarity, flexible funding, and inclusive services not provided by the school or community. Yet, service providers must meet these challenges if they are to fulfill their professions’ stated values.
When I went to do training on family centeredness, I didn’t go to evaluate programs. I told them what family-centeredness is and how they could look at their own organizations. They then could self-identify how family-centered they were by using the Family-Centered Behavior Scale and knowledge they gained from the training.

Some organizations are doing FC-things, some not. Most programs look at certain parts of their organization and practices, rather than the whole.

One family support program I went to was family-centered in many respects, but the service providers couldn’t get their administration to listen. They wanted me there to speak to them and the administrators, so the administration could hear what they had to say about meeting the needs of children and families better.

My favorite training was with the Oglala Sioux in South Dakota. This particular place I went was a Head Start program. Head Start is a program that has a strong history of family involvement. They just were interested in getting feedback about how well they were doing.

Because families live on a reservation, travel is a real problem. It is a gigantic reservation. People often have to drive over an hour to get to the program facilities from the nearest city or outpost. You drive, then—all of a sudden—here are three buildings: a mental health center, dialysis building, and Head Start.

Because of distance then, they have to deliver services in a specific place and have restraints on hours for people to come. They can’t go to families. But they do provide transportation to their building. Even though these factors make the program center-based, parents, when asked, said they viewed the services as family centered.

Cultural competency is important in family-centered service provision. At the reservation, the majority of social workers are Native Americans who went away to school and came back. They understand their people.

Those who were not Native American had to learn Sioux customs to be really accepted. They had to come to work willing to learn. There was a doctor there who now can speak the language of the Oglala Sioux more fluent than some of the younger Native Americans on the reservation. I also really wanted to know about them. For instance, they had a beautiful quilt on the wall, which I asked about. They told me the star points represented tribes within their tribe and other meaningful elements. They knew I was interested in learning about them.

The Oglala Sioux feel people have to learn their customs to stay there and work. If not, people come in with the idea of change, instead of accepting the way things are on the reservation.

They have people come in who can’t speak their language, can’t communicate, don’t want to learn, and then end up leaving. Families have to start from ground one again. This ruins service continuity.

I didn’t go in there telling them what to do or what they needed to be doing. I also tried to be aware of the difference between my culture and theirs to see how my training materials and presentation would fit. Sometimes you have to change the materials to help families get services delivered to them in the way they want.

On the reservation, I did two trainings on family-centered service delivery. One in the morning, the other in the afternoon for a total of 30 staff members.

In these trainings, I presented the key element of family-centeredness and invited them to discuss their work with families, at both the case and organizational levels. They change things to fit them, which works for them. Evaluations indicated that the training stimulated staff members to view their work in new ways. They were doing an excellent job.
Measuring Family-Centered Practices

**Family-Centered Behavior Scale**

**Who:** 443 parents/caregivers  
**What:** The development of a tool that programs can use to measure their family-centeredness  
**When:** 1994-1995  
**Where:** The Beach Center on Families and Disability  
**Relevant Findings:** The three most desired staff behaviors (according to families) were: listening to families, treating families with respect, and accepting families as important team members for a child.

To develop a scale that service delivery providers could use to measure their own family-centered practices, Beach Center researchers first reviewed existing literature, then defined family-centeredness based on their findings. This project grew out of an earlier Beach Center scale that focused on early intervention programs [see box]. Two groups, (1) parents who have children with special needs and, (2) professionals who work with these families reviewed and accepted the definition. The project's advisory committee of concerned stakeholders also approved the definition.

The initial 32-item survey (in both English and Spanish) developed by the Beach Center was sent to 1,700 households. Parents and caregivers from 45 states returned the surveys to be analyzed. The survey was sent again to 250 participants to check the instrument's consistency over time. Most survey respondents were women (87%), white (68%), and living in two-parent households (72%). Participants had children with developmental delay (34%), mental retardation (32%), emotional or behavioral disorder (29%), or learning disability (29%).

The three most desired staff behaviors (according to families) were: listening to families, treating families with respect, and accepting families as important team members for a child.

Families appreciated staff who did not judge families because of differences, did not blame parents for their children's behavior, and did not criticize what parents do with their children.

Families, according to the scale, least often received help from service delivery staff accessing support from other families, friends, and community.

On all items, staff members whom participants rated "best" received higher family-centered scores than those rated "worst."

Said Chris Petr, project director, "Judging from the responses, it appears that the Family-Centered Behavior Scale is meeting a real need in the field. The widespread adoption of the Family-Centered Behavior Scale also means that many service agencies are serious about improving family-centeredness. The Family-Centered Behavior Scale is currently being used in statewide evaluations of children's mental health programs in Florida and Kansas, and children's medical services in Arizona. It has also been recommended for adoption in a national evaluation of children's health systems change initiatives."

To obtain the Family-Centered Behavior Scale, contact the Beach Center on Families and Disability, 3111 Haworth, University of Kansas, Lawrence, KS 66045. Cost is $35.00 and includes a camera-ready copy of the Scale in English and Spanish, a manual, and background information on the scale and family-centeredness. All orders must be prepaid.

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The 1991 Family-Centered Program Rating Scale was designed to evaluate early intervention programs. Extensive field testing at 56 early intervention programs in 10 states showed that parents and staff had similar opinions about the importance of program features, including: Flexibility and innovation, providing responsive services, individualizing services, providing practical information, communication style, maintaining comfortable relationships, building collaboration, respecting family's decisions, recognizing family's expertise and strengths, recognizing family need for autonomy, and building positive expectations. Many programs have since used this scale for self-evaluation, and other researchers have incorporated the scale into related studies.

After a cross-disciplinary literature review about family-centered service delivery, Beach Center researchers used their findings to define the concept of family-centered service delivery:

*Family-centered service delivery, across disciplines and settings, views the family as the unit of attention, and organizes assistance in a collaborative fashion and in accordance with each individual family's wishes, strengths, and needs.*

**Key components of family-centered service delivery:**

- Focusing upon the family as the unit of attention
- Organizing assistance collaboratively (e.g., ensuring equal, mutual respect and teamwork between team workers and clients)
- Organizing assistance in accordance with each individual family’s wishes so that the family ultimately directs decision making
- Considering family strengths (versus dwelling on family deficiencies)
- Addressing family needs holistically (rather than focusing on the member with a “presenting problem”)
- Individualizing services for each family
- Giving families complete information in a supportive manner
- Normalizing perspectives (i.e., recognizing that much of what those receiving services are experiencing is normal)
- Structuring service delivery to ensure accessibility, minimal disruption of family integrity and routine

For more information on family-centered service delivery, contact the Beach Center on Families and Disability, 3111 Haworth, University of Kansas, Lawrence, KS 66045, 785-864-7600, Beach@dole.lsi.ukans.edu. Source for this information:


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Professionals who adopt a family-centered vision often must radically shift their thinking. This reorientation may require assessing one’s self and organization, creating support for family participation, providing staff and family training, and expanding program and fiscal flexibility.

As part of this self-assessment, an organization may use a scale, such as the Beach Center Family-Centered Behavior Scale, to measure its level of staff member family centeredness. Organizations and staff members may need to revise their policies so they include family-centered language.

For instance, staff should ask families how they wish to describe their own ethnicity. If a family prefers “First Nations” to “Native American” or “American Indian,” use “First Nations.” The family might be called “consumer,” “family,” “client,” “user,” or “participant,” depending on family preferences, instead of “patient” or “case.”

Physical space. Staff and families should work together in a welcoming area furnished also for children. Provide reading materials that interest the families served. Accessible service space for a range of consumers, convenient locations, and hours of operation that fit consumers’ needs are also necessary to ensure family centeredness.

Staff training. Initial staff-training needs may be identified through assessing an organization’s family centeredness and cultural competence.

Through professional workshops and literature, staff can begin to think of what it means to create partnerships with the families they serve.

From the start, involve families at all review levels and in planning processes. Include children with special needs and their family members in your team: They are your experts on family centeredness. Seek to enhance the family’s strengths and decision-making capacities.

Staff should listen, point out what the child and family do well, and not blame the family for the child’s problems. Staff should respect family beliefs, customs, and ways of doing things.

Instead of saying “How may I help you?” or “What kind of problems are you having with your child?”—questions that focus on what is wrong and place the professional in the position of expert—ask instead, “What brings you here?” to allow the family to start the story.

Listen to what families wish to share. Acknowledge and validate their experiences. The question “What is going well for you now?,” builds on family strengths and helps identify resources that families already use.

Avoid technical language (e.g., “gross motor skills”) and acronyms (e.g., “LRE,” “IFSP”) that create barriers. Instead, professionals should be alert to using the family’s wording. (Sometimes, a staff member may have to ask families to clarify certain words.)

At meetings, staff should encourage family members to offer opinions, understand their rights, and comment on the service program itself. As part of service provision, staff should help the family get services from other agencies or programs.

Program flexibility. An organization wishing to be more family centered also may want to look into expanding its program and fiscal flexibility.

This flexibility can be achieved in several ways: By freeing existing program funds, reducing commitment to specific programs, tapping new funding sources, and contributing program funds to an interagency funding pool used for children and families whose needs are not met by existing community services.

Building on family strengths helps children with disabilities and families attain their goals and become more competent.
In the last two decades, state governments have enacted statutory policies that have empowered families who have children with disabilities. A recent example of such policies is state family support programs.

The Beach Center created the Family Policy Project to build on these policy developments and encourage states to make all of their statutory policies that serve families and children, whether they are generic or disability-specific, more family-centered.

The Family Policy Project evaluates state policies to determine the extent to which they incorporate family-centered principles. The project's first report, Integrating Family-Centered Policies Into Generic Services: An Evaluation of North Carolina Statutes, was recently published and is available through the Beach Center's publications catalog. The report evaluates North Carolina's laws on the following:

- Mental health, developmental disabilities, and substance abuse services
- Family preservation
- Foster care and adoption assistance
- Guardianship
- Juvenile services
- Early Childhood Initiative

and recommends changes to these policies that would make them more supportive of families, particularly families who have children with disabilities. At the beginning of the project, Beach Center researchers reviewed family-centered literature and developed 22 quality indicators of family-centered legislation. The quality indicators included family-oriented principles, service-oriented principles, eligibility criteria, and a list of specific services families often need.

Next, the researchers analyzed specific laws, identified policies that reflected the quality indicators, and made recommendations for those that did not.

As a final step, the North Carolina Council on Developmental Disabilities and other experts from the North Carolina human services system reviewed project progress and offered comments.

Of the statutes reviewed, North Carolina's Early Childhood Initiative, also known as "Smart Start," was found to incorporate the greatest number of quality indicators for family-centered legislation.

The Initiative is a collaborative program that involves the state, local communities, public and private agencies, schools and families in providing early childhood and developmental services to pre-school children and their families.

Beach Center analysts found that the Initiative's greatest strengths were its provisions encouraging home-based, child- and family-centered services, staff development, family-based decision making, and need-responsive services. The researchers recommended amending the Early Childhood Initiative, however, to require local programs to provide specific services, individualized planning, informal supports, a dispute resolution process, and more consumer participation on local boards.

The largest section of the report is devoted to the North Carolina Mental Health, Developmental Disability, and Substance Abuse Act. The recommendations regarding these policies were numerous, including:

- Commitment to residential facilities should be defined as the most restrictive environment and statutory preference should be given to maintaining children in their homes with provision of appropriate services and supports.
- Child- and family-centered planning should be required to address the needs of the child with a disability and family.
- Incentives and training on the use of informal supports should be provided to families of children with disabilities.
- Area authorities (cities and counties that are responsible for coordinating public services in specific geographic areas) should be required to provide a basic level of home- and community-based services.
- The North Carolina Department of Human Resources should be required to provide training and technical assistance to area authorities. Current education and training programs should be more widely available and used not only at the pre-service level, but as in-service training.

(continued on p. 9)
After a literature review on family-centered policy, Beach Center researchers identified 24 quality indicators of family-centered legislation. If legislation authorizes and mandates the service delivery system to be family centered and need responsive, families can become more empowered. To increase family empowerment, state policies should include the following:

**Family-Centered Principles**
- Prevent out-of-home placement of persons with disabilities and provide home- and community-based care
- Merge formal and informal (e.g., friends, neighbors, extended family) family supports
- Promote family-based decision making and treat parents as collaborators
- Provide outreach to families, integrate families into communities, and reduce the negative impact of disability on people with disabilities, their families, and the community

**Service-Oriented Principles**
- Respond to family needs and individualize services
- Deliver services in the least restrictive environment
- Include home- and community-based services and encourage formal and informal family supports
- Coordinate services on state and local levels
- Be culturally sensitive and competent
- Provide current education, training, and technical assistance to staff, service providers, and service agencies.
- Be legally accountable to consumers of service
- Provide services and supports to families in a way that is cost-efficient and prevents the commitment of people with disabilities to care facilities

**Service Eligibility**
- All families with children with disabilities (at home or in a facility) under age 18 (and between ages 18-21 if living at home) should be eligible for state programs
- State programs should be available for all families with children who have disabilities with priority in eligibility for children with severe disabilities
- Eligibility requirements based on socioeconomic status should use broad criteria, because even in average-income families the economic and psychological stresses of caring for a child with a disability can limit typical family goals and activities

**Specific Services**
- States should provide alternative care arrangements (e.g., family respite, child care, sitter services, attendant care, homemaker services, camps, recreation services)
- States should provide services to support and educate families (e.g., family counseling, family support groups, parent training and support groups, sibling training and support
groups, futures planning, transition to adulthood planning, supported employment training, crisis intervention, case management and service coordination, information and referral, advocacy

- States should provide specialized technology, equipment, or modifications (e.g., telecommunication devices, adaptive equipment, home and vehicle modifications, transportation costs to service providers, utility costs to care for the child at home)
- States should provide health-related services and equipment (e.g. special diets, behavior management, speech therapy, nursing care, skills training, dental services, home health service, evaluations and assessments)
- States should provide financial assistance (e.g., rent assistance, health insurance premiums, cash subsidies for items or services)

Advisory Councils
- Create advisory councils of parents and professionals to advise or monitor state fund expenditures for services to families and children with disabilities

People-First Language
- Use “people-first” language that refers to the person before the disability (e.g., boy with autism, rather than autistic boy) in all communication

This information is derived from work done by Beach Center researchers analyzing the degree to which state legislation authorizes family-centered services to families of children with disabilities. For more information on this research, please contact the Beach Center on Families and Disability, 3111 Haworth, The University of Kansas, Lawrence, KS 66045, 785-864-7600, Beach@dole.isi.ukans.edu.

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(continued from p. 7)

The Project has already had a positive influence in North Carolina. In July, Rud Turnbull, co-director of the Beach Center, spoke to a group of North Carolina parents, agency staff, and policy makers regarding strategies for implementing the Project’s recommendations.

Marian Hartman, a planner, evaluator, and legislative liaison on developmental disabilities, stated that Turnbull’s remarks were well-received. “Rud did an excellent job of stimulating a discussion about how to move the state to a more family-friendly system of services and supports. The group was excited about continuing this effort and will be meeting again to discuss specific strategies for delivering change,” she said.

The Family Policy Project is currently evaluating Kansas policies to determine the extent to which they are family-centered. The results of this analysis should be published in fall 1997.
Family-Centered Practices in Early Intervention: Literature Review. Summarizes information concerning family-centered practices in early intervention programs and literature related to validation of family-centeredness. Also describes family-centered issues. 1995. $6.75. (12F)

Family-Centered Program Rating Scale. Evaluates family-centeredness of early intervention programs to families. Consists of 59 statements about program features and staff member services with respondents rating each feature’s importance and the program’s performance on each. One scale is for providers, one for parents (in English or Spanish). (The User’s Manual is strongly recommended for optimal Scale benefits.)

Provider Scale. 1991. $1.30. (4F)
Parent Scale (English). 1991. $1.30. (5F)
Parent Scale (Spanish). 1991. $1.30. (6F)

Family-Centered Program Rating Scale: User’s Manual. Details information about Rating Scale, including rationale, instrument development, administration, scoring, interpreting, uses, and research study information. 1991. $5.65. (3F)


Research Brief: Family-Centered Behavior Scale. Summarizes research on Scale development (see 15F). 1996. $.50. (16F)


Family-Centered Service Delivery: A Cross-Disciplinary Literature Review and Conceptualization. Reviews 120 articles in education, health care, sociology, and social work and presents a consensus definition of “family centeredness” and its characteristics. Includes practice, policy, and research implications. 1995. $6.25. (10F). This approach to service delivery, though theoretically simple, is a challenging one for professionals to implement, for it demands that we redefine many aspects of practice and shift the locus of control to the consumers of our services. It is important that we rise to this challenge if we are to fulfill the professional values that we espouse. (p. 57)

Send prepaid orders to the Beach Center on Families and Disability, 3111 Haworth, University of Kansas, Lawrence, KS 66045. Price includes postage.
Doctoral Program. The U.S. Department of Education recently awarded the Beach Center 5-year funding for its doctoral program. The funds will support one post-doctoral fellow and provide stipends for three additional doctoral students (the program currently has nine doctoral students) to study at the center. Maya Kalyanpur, assistant professor of special education at Towson State College, MD, will be the Beach Center's first postdoctoral fellow beginning in the fall 1997 semester. Her research and writing focus on maximizing cultural responsiveness within special education settings.

Sibshop News. The Beach Center co-sponsored the Kansas statewide training for Sibshops (workshops for siblings of children with special needs) May 9-10 at Emporia State University. Nine new facilitators in Kansas received training to conduct Sibshop workshops. Ann Guthrie, Beach Center researcher, helped coordinate the training.

Parent to Parent. Betsy Santelli, Parent to Parent coordinator, will continue working for the Beach Center in Minnesota researching Parent to Parent. Contact Betsy at: 2415 Brookridge Ave., Golden Valley, MN 55422, 612-525-0509, Betsy@pclink.com

Congratulations. Gardner Umbarger, Beach Center medical technology researcher, was selected the Student Governor to the Mental Retardation/Developmental Disability Division of the Council of Exceptional Children. Also, Rud Turnbull, Beach Center co-director, received the American Association on Mental Retardation 1997 Leadership Award in May.

Home Page Additions. If you haven't looked lately, the Beach Center web page has lots of information you can use. Recent additions include: Significance of 1997 Amendments to IDEA and IDEA and Recent Case Law That Has Impacted It. http://wwwlsi.ukans.edu/beach/beachhp.htm

BEACH PUBLICATIONS


Check It Out!

Surf the 'Net to Find the Beach

That is, the Beach Center on Families and Disability at the University of Kansas. Once on-line, you can check out our fact sheets, research reports, doctoral program, and info-packed newsletters. You also can hook into Parent to Parent (research gives P2P a big "thumbs up"), link to other recommended WWW sites, and learn more about who we are and what we do!

http://www.lsi.ukans.edu/beach/beachhp.htm

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