

FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Developed by

FAMILY  VOICES[®]

*...keeping families at the center
of children's health care*

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Family Tool

INTRODUCTION

Health care visits for children, youth and their families can be more than getting shots, having ears examined or treating the physical symptoms of an illness. Each visit is an opportunity for families, youth and health care providers to partner to assure quality health care for the child and to support the family's needs in raising their child. This enhanced aspect of the family and health care provider relationship is called family-centered care. The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following:

- **Families and professionals work together in the best interest of the child and the family.**
- **As the child grows, s/he assumes a partnership role.**
- **There is mutual respect for the skills and expertise each partner brings to the relationship.**
- **Trust is fundamental.**
- **Communication and information sharing are open and objective.**
- **Participants make decisions together.**
- **There is a willingness to negotiate.**

Within that framework, ten components of family-centered care have been identified. (National Center for Family-Centered Care (1989); Bishop, Woll and Arango (1993)) Family-centered care accomplishes the following:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

PURPOSE OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Family-centered care is a key aspect of quality in health care for children, youth and their families. This tool is designed to:

1. Increase outpatient health care settings' and families' awareness about the implementation of family-centered care and,
2. Provide an organized way for health care settings to assess current areas of strength and identify areas for growth, plan future efforts and to track progress.

This tool is not designed to provide a score but is meant as an opportunity for reflection and quality improvement activities related to family-centered care within outpatient health care practices. It can also be used by families to assess their own skills and strengths, the care their children and youth receive, and to engage in discussions within health care settings and with policy makers in organizations, health plans and community and state agencies about ways to improve health care services and supports. The tool is intended to assess care for all children and youth and also has some questions that are specific to the needs of children and youth with special health care needs and their families. Questions on the tool address the ten components of family-centered care and the key aspects of family/youth/provider partnerships.

DESCRIPTION OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

The tool is divided into three major sections: 1) Family/Provider Partnership, 2) Care Setting Practices and Policies and 3) Community Systems of Services and Supports. Within each major section, there are several subtopics that address family-centered care.

Sections and Subtopics of the Family-Centered Care Self-Assessment Tool

Family/Provider Partnership

- The decision-making team
- Supporting the family as the constant in the child's life
- Family-to-family and peer support
- Supporting transition to adulthood
- Sharing successes

Care Setting Practices and Policies

- Giving a diagnosis
- Ongoing care and support
- Addressing child/youth development
- Access to records
- Appointment schedules
- Feedback on care setting practices
- Care setting policies to support family-centered care
- Addressing culture and language in care

Community Systems of Services and Supports

- Information and referral and community-based services
- Community systems integration and care coordination

Each section contains a series of questions that ask about concrete actions that reflect family-centered care. Each section is coded with numbers that indicate which of the ten elements of family-centered care it addresses.

DEFINITIONS OF TERMS

Alternative Healing is the use of herbs, aromatherapy, acupuncture, massage and other remedies that are not considered part of conventional (Western) healthcare treatments.

<http://www.aap.org/healthtopics/complementarymedicine.cfm>

Care Setting is the physical location where a family and child/youth receives outpatient health services. These services can be provided by a pediatrician, other physician, physician's assistant, nurse, social worker, care coordinator, or any other staff person at this setting.

Children and Youth with Special Health Care Needs have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by children generally.

McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140, 1998.

Community-based Services are local, non-medical services that help children and families accomplish daily activities. These services can range from school, childcare, after-school activities, family and peer support and advocacy groups, early intervention or Head Start (a program that helps families learn about and promote the development of their young children).

Consent is approval for healthcare decisions. Individual must have legal authority to provide consent. Generally, the parents or legal guardians of minor children (younger than 18 years old) provide consent. For individuals 18 and older who cannot make their own decisions, a legal guardian or proxy can provide consent.

Cultural Competence requires organizations to have a defined set of values and principles and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally. They should:

- Value diversity,
- Conduct self-assessment,
- Manage the dynamics of difference,
- Acquire and institutionalize cultural knowledge and
- Adapt to diversity and the cultural contexts of the communities they serve.

Organizations should incorporate the above in all aspects of policymaking, administration, practice, service delivery and involve systematically consumers, key stakeholders and communities. Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.

(Adapted from Cross et al., 1989) <http://www11.georgetown.edu/research/gucchd/nccc/foundations/frameworks.html>

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

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

Family Supports are services that strengthen and support the family's role as caregiver and decision-maker on behalf of their children.

Family-to-Family and Peer Supports are ways to bring together families, youth and others who share similar life situations so they can share their knowledge, concerns, and experiences with each other.

HIPAA (The Health Insurance Portability and Accountability Act). This is a federal law that protects the privacy of personal health information. You must give permission before personal health information can be shared with:

- Health providers,
- Hospitals,
- Insurance companies, state and federal agencies,
- Schools,
- Employers, or
- Anyone else.

You also have the right to read your medical record and make corrections. For more information visit: <http://www.hhs.gov/ocr/hipaa>

Linguistic Competence is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. Linguistic competency requires organizational and provider capacity to respond effectively to the health literacy needs of populations served. The organization must have policy, structures, practices, procedures and dedicated resources to support this capacity.

Goode & Jones (modified 2004). National Center for Cultural Competence, Georgetown University Center for Child & Human Development. <http://www11.georgetown.edu/research/gucchd/nccc/foundations/frameworks.html>.

Provider—in the context of this tool is any person that provides services within the care setting.

Transition to Adulthood—The period of time during which families, youth and providers plan for and develop the process to assure that youth will:

1. Be able to successfully manage all aspects of their healthcare and be prepared to take on adult responsibilities, and ultimately, live as independently as possible and
2. Continue to receive high quality healthcare services.

Directions: Please answer each question by choosing only **one** answer. It may be difficult to rate some items; just answer each question based on your knowledge, experiences and opinions. **There are no right or wrong answers.**

Note: In each question the term “provider” refers to the health care professionals and other staff within your health care setting.

THE FAMILY/PROVIDER PARTNERSHIP

The Decision-Making Team FCC Components: 1, 2, 4, 9

1. Does your provider:

- A. Partner with your family to help you define your role in your child’s care? Never Some of the Time Most of the Time Always
- B. Honor your requests for others (extended family, community elders, faith leaders or traditional healers that are designated by the family) to participate in the process that leads to decisions about care? Never Some of the Time Most of the Time Always
- C. Help you advocate for services and work to improve systems of care, if you so choose? Never Some of the Time Most of the Time Always Does Not Apply
- D. Act to support your family’s chosen role in decision-making? Never Some of the Time Most of the Time Always

2. Do you and your provider:

- A. Work together as partners to make health care decisions? Never Some of the Time Most of the Time Always
- B. Talk about the range of treatment and care choices for your child/youth? Never Some of the Time Most of the Time Always
- C. Discuss which treatment and care choices would be best for your family and child/youth? Never Some of the Time Most of the Time Always
- D. Decide together what the desired outcomes are (e.g., improved health status, better school attendance, less pain, or better involvement with social activities or sports)? Never Some of the Time Most of the Time Always

3. Do choices of diagnostic and treatment approaches take into account:

- A. Family and child/youth preferences for site of care, type of provider (gender, language spoken, etc.)? Never Some of the Time Most of the Time Always
- B. Child/youth’s ability to tolerate the procedure? Never Some of the Time Most of the Time Always
- C. How it will affect the family’s stress level? Never Some of the Time Most of the Time Always
- D. Family insurance status and economic situation? Never Some of the Time Most of the Time Always
- E. Family, child/youth work and school schedules? Never Some of the Time Most of the Time Always

- 4. Does your provider make sure you have the information you need to understand the range of treatment and care choices for your child/youth? Never Some of the Time Most of the Time Always

- 5. Does your provider make sure all your questions about your child/youth’s treatment and care have been answered before you leave the office? Never Some of the Time Most of the Time Always

- 6. Do you feel comfortable letting your provider know if/when you disagree with medical advice and recommendations for treatment and care of your child/youth? Never Some of the Time Most of the Time Always

7. Is there a respectful negotiation process to resolve any disagreements you might have about your child/youth's treatment and care? Never Some of the Time Most of the Time Always

8. Does your partnership with your provider change over time as your experiences, knowledge and skills change? Never Some of the Time Most of the Time Always

Supporting the Family as the Constant in the Child's Life

FCC Components: 1, 2, 4, 10

1. Does your provider ask about:

A. Your family's well-being (adults and other children) and their needs for support? Never Some of the Time Most of the Time Always

B. Your support network and the role of faith/religion or other cultural supports? Never Some of the Time Most of the Time Always

C. Your family's concerns and any stresses or successes you may experience as a caregiver? Never Some of the Time Most of the Time Always

D. Depression, domestic violence, substance abuse, housing or lack of food in your family? Never Some of the Time Most of the Time Always

2. Does your provider offer your family:

A. Information about health and wellness appropriate to child/youth's developmental stage? (This includes information about child development, mental health, healthy weight and nutrition, physical activity, sexual development and sexuality, safety/injury prevention, and oral health.) Never Some of the Time Most of the Time Always

B. Opportunities to become more knowledgeable about promoting your child's healthy development, such as written information, classes, or connect you with other opportunities in your community? Never Some of the Time Most of the Time Always

Family-to-Family and Peer Support

FCC Components: 2, 3, 4, 7, 8, 10

1. Does your provider:

A. Have a process to identify the strengths of families within the practice that they can share with other families? Never Some of the Time Most of the Time Always

B. Actively assist in linking families and youth to other families and youth who share similar life situations, for example, new mothers, children with special health care needs and disabilities, youth in transition, single parent families, grandparents raising grandchildren, etc? Never Some of the Time Most of the Time Always

C. Link families in a way that that reflects the cultural and language preferences of each family? Never Some of the Time Most of the Time Always

D. Help your family/youth make the first connection to support? Never Some of the Time Most of the Time Always

E. Offer opportunities for families/caregivers to learn from each other about how the role of families changes as their children/youth get older? Never Some of the Time Most of the Time Always

F. Offer opportunities for children/youth to learn from other youth or those somewhat older how to be active in decision-making about their own care?

Never Some of the Time Most of the Time Always

Supporting Transition to Adulthood

FCC Components: 1, 3, 4, 6, 7, 8

1. Does your provider:

A. Discuss your family's, child's (from an early age)/youth's vision for the future? (For example, take time to discuss your family and child's hopes and dreams about education, social relationships, meaningful work, development of independent living skills, and health care.)

Never Some of the Time Most of the Time Always

B. Respect your family's cultural beliefs about when a "child" is fully adult?

Never Some of the Time Most of the Time Always

C. Offer opportunities for you and your youth to meet with older youth and young adults who can be successful role models for achieving future goals?

Never Some of the Time Most of the Time Always

2. In preparation for transition, does your provider:

A. Help your youth learn about: managing his/her health, dealing with the logistics of care settings, insurance and decision-making?

Never Some of the Time Most of the Time Always

B. Work with your family to assure that your youth knows about any diagnoses, current treatments and can discuss those with the care provider?

Never Some of the Time Most of the Time Always Does Not Apply

C. Work with you and your youth to develop a formal healthcare transition plan by age 14 that documents provider, family and youth roles?

Never Some of the Time Most of the Time Always Does Not Apply

D. Have a formal mechanism to identify adult health care providers for youth in transition?

Never Some of the Time Most of the Time Always Does Not Apply

E. Have a process to share information with the adult care provider including: transition plans, medical records, key health issues and current family and youth roles in managing care?

Never Some of the Time Most of the Time Always Does Not Apply

F. Help your youth develop a portable medical record to support interactions with providers?

Never Some of the Time Most of the Time Always Does Not Apply

G. Work with the adult provider so that both are involved in your youth's care during transition?

Never Some of the Time Most of the Time Always Does Not Apply

H. Help your family plan for needed legal solutions and supports if child/youth will be unable to independently manage his/her care?

Never Some of the Time Most of the Time Always Does Not Apply

Sharing Successes of the Family/Provider Partnership

FCC Components: 10

1. Do families, youth, providers and staff take time to share and enjoy successes?

Never Some of the Time Most of the Time Always

CARE SETTING PRACTICES AND POLICIES

Giving a Diagnosis

FCC Components: 1, 2, 6

1. Does your provider:

- A. Fully inform your family about all test results, positive and negative? Never Some of the Time Most of the Time Always
- B. Fully inform your family about any diagnosis in a way that you can understand? Never Some of the Time Most of the Time Always
- C. Help your family name and explain your child's diagnosis to others? Never Some of the Time Most of the Time Always
- D. Work together with your family so you can explain how your child's diagnosis might affect how she will be able to participate in school, social, community and faith-based activities? Never Some of the Time Most of the Time Always Does Not Apply

Ongoing Care and Support

FCC Components: 1, 2, 3, 4, 6

1. Does your provider:

- A. Help you identify your strengths, skills and knowledge related to your child's health care? Never Some of the Time Most of the Time Always
- B. Ask you what is working well? Never Some of the Time Most of the Time Always
- C. Help you identify areas where you may need additional support? Never Some of the Time Most of the Time Always
- D. Ask you about your child's care based on your knowledge about your child's temperament, behavior and reactions, and other current personal and family needs and priorities? Never Some of the Time Most of the Time Always
- E. Ask your family and child/youth to share information, such as changes in daily routine or new stresses that may provide insight into the interpretation of test results or diagnostic procedures? Never Some of the Time Most of the Time Always
- F. Ask your family to initiate consultation appointments or other meetings to discuss changes in your child's care, for example, changes in medications, or other daily procedures? Never Some of the Time Most of the Time Always
- G. Fully inform your family about diagnostic and treatment options in a way you can understand? Never Some of the Time Most of the Time Always
- H. Encourage questions about treatment options and the need for any procedures? Never Some of the Time Most of the Time Always
- I. Offer developmentally appropriate information (for example: stories, workbooks, videos, web-resources, tours) to prepare your child/youth for medical testing and procedures? Never Some of the Time Most of the Time Always

3. Does your provider offer house calls, or other ways that care/treatment can be provided where your child typically spends time?

- Never Some of the Time Most of the Time Always

4. If your family has difficulty traveling to specialty care settings outside of your community, does your provider work with your child's specialists to help you minimize travel? Never Some of the Time Most of the Time Always Does Not Apply

5. If your family uses alternative healing/non-traditional medicine, does your provider work with you to integrate traditional and alternative healing treatments into your child's overall care? Never Some of the Time Most of the Time Always

Addressing Child/Youth Development FCC Components: 3, 4, 6, 8

1. Does your provider:

A. Assess and document the developmental status of your child/youth? Never Some of the Time Most of the Time Always

B. Reassess care approaches at key developmental milestones and transitions? (For example, when your child begins to walk, talk, begins school, enters puberty, and begins middle or high school.) Never Some of the Time Most of the Time Always

C. Offer your child/youth educational opportunities to support self-care? (For example, know how to make appointments, learn about insurance, medications, diet, and other aspects of health care.) Never Some of the Time Most of the Time Always

D. Honor your family's requests about how much you want your child involved in decision-making? Never Some of the Time Most of the Time Always

E. Include your child in making decisions in keeping with age and development? Never Some of the Time Most of the Time Always

F. Explain changes in who can give consent for care as your child gets older? Never Some of the Time Most of the Time Always

Access to Records FCC Component: 9

1. Does your provider:

A. Explain your family's rights and responsibilities under HIPAA (laws about the privacy and sharing of medical information) in a way you can understand? Never Some of the Time Most of the Time Always

B. Have a policy to assure that financial issues, such as copying costs, do not prevent your family from receiving copies of records? Never Some of the Time Most of the Time Always

C. Have a process to assist your family in understanding and interpreting your child's medical record? (For example, provides explanation of medical terms and answers questions about content.) Never Some of the Time Most of the Time Always

D. Allow your family or youth to add information into the medical record? Never Some of the Time Most of the Time Always

E. Inform you of all policies that relate to when and how you can see, add to or get copies of your child's records? Never Some of the Time Most of the Time Always

2. Do all staff that you work with at the care setting give you the same information about policies related to medical records? Never Some of the Time Most of the Time Always

Appointment Schedules

FCC Components: 6, 9

1. Does your provider:

- A. Recognize your family's schedule and cultural events/holidays as important factors related to scheduling appointments? Never Some of the Time Most of the Time Always
- B. Respond to your concerns about proposed scheduling of appointments and procedures? Never Some of the Time Most of the Time Always
- C. Honor your request for a longer appointment to discuss complex issues? Never Some of the Time Most of the Time Always
- D. Schedule appointments tailored to the needs of your family, and child/youth? (For example, have "no wait" appointments for patients who may have immune system problems or developmental /behavioral issues that make it difficult to sit in the waiting room.) Never Some of the Time Most of the Time Always

Feedback on Care Setting Practices and Policies

FCC Components: 4, 9

1. Are there opportunities for families/youth to provide feedback about care and how the care setting operates? (Examples include surveys, focus groups, and suggestion boxes.) Never Some of the Time Most of the Time Always
2. Does the care setting have a formal advisory committee for family and youth to provide input on policies and practices? Never Some of the Time Most of the Time Always
3. Are families/youth given mentoring, supports and other training to effectively participate on the advisory committee, if they want it? Never Some of the Time Most of the Time Always
4. Does your provider make accommodations for your family and youth to participate in advisory activities? (For example, English or sign language translation, alternate ways to participate, like via conference call or surveys.) Never Some of the Time Most of the Time Always Does Not Apply

Care Setting Policies to Support Family-Centered Care

FCC Components: 4, 9

1. Does your provider share information with families about elements of family-centered care? Never Some of the Time Most of the Time Always
2. Does your provider explain care setting policies? Never Some of the Time Most of the Time Always
3. Does your provider invite families or youth to do presentations for staff to learn about the family perspective? Never Some of the Time Most of the Time Always
4. Does your provider invite families or youth to do presentations for staff to learn how their cultures and values influence health care decision-making? Never Some of the Time Most of the Time Always
5. Does your provider offer stipends for sharing your time and expertise? Never Some of the Time Most of the Time Always

1. Does your provider:

- A. Ask your family about any cultural values, beliefs or practices that might relate to your child/youth’s care? Never Some of the Time Most of the Time Always
- B. Honor your family’s beliefs and practices when developing diagnostic and treatment plans? (This includes respect for diet; customs regarding eating, bathing, dressing; religious rituals related to health; modesty concerns such as gender of the provider, expected roles related to gender or generation.) Never Some of the Time Most of the Time Always
- C. Offer trained interpretation (foreign language or sign)? Never Some of the Time Most of the Time Always
- D. Let other providers know about your need for interpretation services when making referrals? Never Some of the Time Most of the Time Always
- E. Help your family find information and educational materials that you can easily read or that don’t need reading, like videos you can watch? Never Some of the Time Most of the Time Always
- F. Employ staff that reflect who lives in your community? Never Some of the Time Most of the Time Always

COMMUNITY SYSTEMS OF SERVICES AND SUPPORTS

1. Does your provider:

- A. Work with your family to identify needed community-based services? Never Some of the Time Most of the Time Always
- B. Help your family make the first contact with community-based services? Never Some of the Time Most of the Time Always
- C. Follow up to see if your family/child/youth has successfully connected with the service? Never Some of the Time Most of the Time Always
- D. Follow up to see if the service was easy to access? Never Some of the Time Most of the Time Always
- E. Follow up to see if the service was useful? Never Some of the Time Most of the Time Always
- F. Follow up to see if the service was respectful of your family’s culture and values? Never Some of the Time Most of the Time Always

- 2. As your family circumstances change (changing diagnoses, functional level, child transitions, change in family make up, etc.), does your provider work with your family to review current services and help identify new community-based services you may need? Never Some of the Time Most of the Time Always

1. Does your provider:

- A. Include any community-based services your family uses in the medical record? (Examples include early intervention, Head Start, childcare, community recreation programs, vocational rehab, faith-based activities.) Never Some of the Time Most of the Time Always
- B. Have a staff person that helps your family connect with needed services? Never Some of the Time Most of the Time Always

Thank you for taking the time to complete this self-assessment tool. We welcome your feedback. Visit www.familyvoices.org to share your ideas and suggestions for how we might improve future versions.