

Family-Centered Care Assessment *for Families* (FCCA-F)

User's Guide

June 2014

*For more information or to request permission to use the FCCA, go to <http://www.fv-ncfpp.org/activities/fcca/> or email fcc@familyvoices.org.
The National Center for Family-Professional Partnerships (www.fv-ncfpp.org) is a project of Family Voices to help families of children and youth with
special health care needs partner with professionals to improve care. (Maternal and Child Health Bureau #U40MC00149B0)*

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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 a chance for families, youth, and health care providers to work as a team for good health care for the child and to support the family's needs in raising their child. This part of the family and health care provider relationship is called family-centered care. The heart 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 knowledge each partner brings to the relationship.**
- **Trust is fundamental.**
- **Communication and information sharing are open and objective.**
- **Families and health care providers make decisions together.**
- **There is a willingness to negotiate.**

Family-centered care helps patients, families, and health care providers. Research suggests that family-centered care improves the patient's and family's experience with health care, reduces stress, improves communication, reduces conflict (including lawsuits), and improves the health of children with chronic health conditions^(1,2). Patient- and family-centered care is endorsed by the Institutes of Medicine⁽³⁾, American Academy of Pediatrics⁽¹⁾, and the US Department of Health and Human Services⁽⁴⁾.

Description of the FCCA-F

The FCCA-F is a quality measurement questionnaire developed by Family Voices in its initial stages through an extensive process of in-person meetings, conference calls, and interviews, led by expert family leaders and health care providers. The questions were then revised and tested through a research based validation process that included multiple family focus groups and a national survey of 790 family respondents. The resulting 24 quality measurement questions were found to be psychometrically sound, with documented high reliability and evidence of empirical validity.

BENEFITS OF USING THE TOOL

For families, the FCCA-F offers:

- A health care quality survey developed for families, by families of children with special health care needs.
- A spark for discussions of family-centered care with health care providers or other families.
- A measure of strengths and concerns in a particular child's health care.
- A description of common concerns and expectations that families have of health care.

For health care providers, the FCCA-F provides data for:

- Understanding how families view the family-centeredness of care provided.
- Ongoing assessment and evaluation.

- Informing quality improvement initiatives.

For researchers, the FCCA-F is useful for:

- Establishing correlates of family-centeredness (for example, communication, trust, outcomes, disparities);
- Evaluating the effectiveness of interventions;
- Converting “family-centeredness” from an abstraction to a measurable standard.



Using the FCCA-F in a Health Care Setting

The FCCA-F is validated for use in outpatient care settings, with families of children with special health care needs. It can be used with **all** families

who have an established relationship with the health care provider; it is not appropriate for evaluating a single visit with a provider. Families will answer the questions about a specific health care provider; however, some questions allow for the possibility that the provider partners with other providers (for example, a care coordinator). This section provides guidelines for ensuring the success of the assessment process.

CREATING A SAFE AND SUPPORTIVE ASSESSMENT ENVIRONMENT

Looking at one’s practice or assessing one’s health care provider can sometimes make all concerned feel somewhat vulnerable. It is therefore important to prepare everyone for the process and to create a process that feels safe for providers, staff, families and youth. The assessment process works best if everyone - families, youth, health care providers, staff - understand why and how the assessment will be conducted. Some key considerations in creating a safe and supportive environment for assessment include:

- Talking about the goals of the assessment with all health care providers and staff—emphasize the goal of quality improvement and identifying strengths, not “grading” the practice or individuals in it;
- Creating a process that assures confidentiality—assure families and staff that their feedback on the tool will not be linked to them.
- Families and youth should be given an option to not participate and be assured that this will not affect their care.
- Families may need help completing the FCCA-F; for example, if they are not used to taking written assessments, they may be more comfortable having someone to talk to while they are answering the questions.

Important: We all draw on our own special strengths and resources to solve problems and overcome barriers. The “strengths-based approach” is one of the central ideas in family-centered care; it means being aware of problems while building on strengths. For example, you can think of someone as “a person who can’t read their prescription” or “a person with a great memory”; the first approach treats the person as the problem, while the second recognizes that they have strengths that help solve the problem.

Using a strengths-based approach, toward health care practices, providers and staff as well as toward patients and families, supports a feeling of safety and mutual respect around your use of the FCCA-F.

SCORING

To score the FCCA, score each question on a five-point scale, then add together the points for all the questions. For example, if the possible answers range from “Almost always” to “Almost never”, “Almost always” would receive a score of 5, and “Almost never” would receive a score of 1. The total score of all questions added together can range from 24 to 120, with 120 being the best possible score.

If a completed questionnaire is missing answers to five questions or less, adjust the total score by replacing the missing questions with the average score of the answered questions. For example, if 21 of 24 questions were answered, calculate the total score as described above, then divide it by 21 and multiply by 24 ($S_{\text{final}} = 24 \times S/21$). If more than five answers are missing, you can use the individual answers in your analysis, but don’t try to calculate a total score.

The FCCA-F is designed to be challenging, with an average score falling in about the middle of the possible range. Even providers who have done a lot of work with family-centered care should expect to see room for improvement. This is not a checklist that attempts to dictate every step that you should take; you can improve your score by using strategies of your own choosing, and adapt your priorities according to your local context.

USING THE FCCA-F FOR QUALITY IMPROVEMENT

The following are suggested steps to use the FCCA-F to support improvements in family-centered care:

Step 1. Form a project team.

This team should include a project lead, health care providers and clinical staff, front-desk/non-clinical staff, and families/youth served in the health care setting. If the practice has some formal family/youth advisory body, then that group will be a key partner in the process. If no such group exists, the care setting can recruit family/youth partners from within the practice. Families will need supports to participate in the process, which may include stipends for expenses, pay for time and expertise, training and mentoring, and supports related to literacy and language. Family advocacy support organizations within the community and state (such as the Family-to-Family Health Information Centers) can help identify and mentor families for the process. Find the contact information for the Family-to-Family Health Information Center in your state at www.familyvoices.org/projects/f2f.php.

Step 2. Develop a structured plan for how the FCCA-F will be used.

It is important to spend time before using the FCCA-F to define the why and how of the assessment process.

- Define the questions to be answered by the assessment process. Potential questions might include:
 - What strengths do we have that we can build on?
 - What are our areas of greatest challenge?
 - What are areas where we are “almost there” and could quickly have success?

- Do health care providers/staff and families/youth have a similar view of family-centered care in our setting?
- Determine what resources will be needed to successfully complete the assessment. Potential resources include:
 - Time of staff person to coordinate the process;
 - Funds for mailing and time for follow-up phone calls;
 - Supports for families with language and literacy issues to participate; or
 - Time of staff or consultant to tabulate scores and help interpret and report the findings.
- Develop an information sharing plan which includes:
 - When;
 - With whom; and
 - Formats appropriate to each audience; including families with needs for alternate formats. Suggested formats include paper or online versions of the form, Braille, large print, or phone or in-person interviews.

Important: Be respectful of the time and energy it takes families to complete the survey.

- Make sure that you are answering questions that are important to families.
- Collect only as many surveys as you need to answer your questions.
- Act on the data that you collect.

Step 3. Implementing the FCCA-F.

- Prepare health care providers, staff and families for the process—create enthusiasm for the process and emphasize the positive potential outcomes. Talk about how the FCCA-F meshes with the vision, mission, and values of the care setting.
- Inform health care providers, staff and families about the timeline and procedures.
- Disseminate the tool and collect the completed forms.
- Follow-up to assure adequate participation.
- Inform participants about how and when they will receive information about the outcome of the assessment.

Step 4. Analyzing and reporting information.

After you implement the FCCA-F, use the project team to plan the process to analyze the findings. First develop the scores for the FCCA-F by health care provider and then look overall across the practice setting. You may also want to look at the scores on particular items of interest to your quality improvement effort and a second level of analysis—checking for areas where your providers are scoring particularly high or low. You may want to have a staff member or consultant prepare a preliminary report on areas of strengths and areas for growth in the care setting for this group to discuss. Use the information gained from the FCCA-F to answer the questions you developed during the planning phase. Determine goals for change and improvement based on the information you have.

Sharing the information from the FCCA-F with families, youth, health care providers and staff is essential. Create a way to share the information that highlights strengths, indicates areas and priorities for change and does not threaten or blame individuals or groups within the setting. Reports may be: written and verbal; shared via meetings or group sessions; disseminated in care setting brochures, newsletters, websites, etc. Consider alternative formats and languages for reporting so that all families in the care setting have access to the information. Consider holding debriefing sessions or focus groups with families

and health care providers/staff to discuss the findings and gain a deeper understanding of factors that might support change and improvement.

Step 5. Developing a plan for change and improvement.

Using the information from the assessment process, the care setting can then develop priorities, actions and timelines to make the changes and improvements desired based on the initial assessment purpose and goals. In keeping with the concept of family/youth/health care provider/staff partnerships, action plans should include participation from all these groups—all should be involved in defining priorities and defining what successful change will look like.

While a setting may develop a broad plan for improvements with timelines and processes, experience suggests that specific changes occur when made in small, concrete, testable steps. In many states, supported by grants from the federal Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services, partnerships to create a medical home for all children and youth have been undertaken. Within many of these efforts, learning collaboratives have taught care settings how to use a methodology for change called Plan-Do-Study-Act (PDSA)⁽⁵⁾. The FCCA-F can be used in that or other change and improvement processes in several ways including:

- Identifying areas for change;
- Raising questions to be addressed in the change process;
- Providing baseline data to measure change;
- Providing data to measure predicted outcomes of the change process. Individual items or subsections can be used to address very specific changes tested.

Assessment and quality improvement are on-going activities. Action plans should set out timelines for reassessing the care setting and roles and responsibilities for members of the team in supporting change.

Making Health Care More Family-Centered

Family-centered care is a fast-growing area, with new ideas and data coming out all the time. Here are a few ideas to get you started making your health care more family-centered.

TIPS FOR FAMILIES⁽⁶⁾

1. Be confident in the knowledge you have of your child.
2. Organize and keep information up-to-date about your child.
3. Educate yourself about your child's diagnosis and medical treatment.
4. Communicate openly with your child's health care provider.
5. Connect with other families.
6. Be an advocate.
7. Learn more about family-centered care.

TIPS FOR PEDIATRICIANS⁽¹⁾

1. Incorporate collaborative relationships with patients and families into all aspects of professional practice.
2. Respect families' unique understanding of their child's behavior and needs.
3. Allow family caregivers to attend medical procedures.
4. Respect the adolescent's and young adult's capacity for independent decision-making and right to privacy.
5. Modify systems of care, processes of care, and patient flow as needed to improve the patient's and family's experience of care.

6. Share medical information with children and families in ways that are useful, affirming, complete, honest, and unbiased.
7. Encourage and support peer-to-peer support and networking.
8. Provide education and training in patient- and family-centered care to all trainees, students, and residents, as well as staff.

Additional Information

For updated information on the FCCA-F, other FCCA tools, supporting materials on family-centered care and family-led research, and links to outside resources on family-centered care, medical home, and health care quality improvement, go to the FCCA section of the Family Voices website, <http://www.fv-ncfpp.org/activities/fcca/>.

References

1. *Patient- and Family-Centered Care and the Pediatrician's Role*. **American Academy of Pediatrics and the Institute for Patient- and Family-Centered Care**. 2, 2012, *Pediatrics*, Vol. 129, pp. 394-404.
2. *Evidence for Family-Centered Care for Children with Special Health Care Needs: A Systematic Review*. **Kulthau, Karen, et al.** 2, 2011, *Academic Pediatrics*, Vol. 11, pp. 136-43.
3. **Committee on Quality of Health Care in America, Institute of Medicine**. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C. : National Academies Press, 2001.
4. **Department of Health and Human Services**. 2011 Report to Congress: National Strategy for Quality Improvement in Health Care. *Agency for Healthcare Research and Quality*. [Online] March 2011. [Cited: May 29, 2014.] <http://www.ahrq.gov/workingforquality/nqs/nqs2011annlrpt.htm>.
5. **Langley, G., et al.** *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. New York : Jossey-Bass, 1996.
6. **National Center for Family/Professional Partnerships**. Family-Centered Care: From Theory to Practice. *Family Voices*. [Online] 2013. [Cited: May 22, 2014.] <http://www.fv-ncfpp.org/files/7213/6337/0628/FCCforFamilies-r.pdf>.