

**Recommendations: Strategies**  
Parent comments clearly described areas for improvement within each patient/family-centered category. The QI team used these comments to identify interpersonal, expertise, and environmental strategies for improving communication related to clinical service delivery within the first three patient/family-centered core concepts. These strategies are described below:

- Dignity & Respect**
- Establish a personal connection through warm welcoming gestures, a supportive attitude and words that reflect a nonjudgmental understanding of their experiences
  - Address family’s concerns and accommodate their lifestyle and choices
  - Create a physical environment that is accessible, age-appropriate, has a friendly décor, and conveys warmth

*“It’s the personal connection that you feel”  
-parent of a child*

- Information Sharing**
- Provide open, accurate and multi-modal communication about everything from what to expect during their clinic visit to their child’s diagnosis and prognosis, and the next steps in care
  - Include multiple perspectives, practical recommendations with modeling, and clear explanations during the appointment and in the written report
  - Provide timely and efficient care, with minimal wait time during the visit, minimal number of times families are asked the same questions; more choices for appointment times; and better after-visit access to staff

*“My time is valuable”  
-parent of a child*

**References**

<sup>1</sup> Koop CE. Surgeon General’s Report: Children with Special Health Care Needs Campaign ’87. Washington: U.S. Dept of Health and Human Services Public Health Services; 1987: 3-40.

<sup>2</sup> Institute of Medicine, Committee on Quality Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press; 2001.

<sup>3</sup> Steering Committee on Quality Improvement and Management and Committee on Practice and Ambulatory Medicine. Principles for the Development and Use of Quality Measures. Pediatrics. 2008; 121(2): 411-418. doi: 10.1542/peds.2007-3281.

<sup>4</sup> The Joint Commission. Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals. Oakbrook Terrace, IL: The Joint Commission; 2010.

<sup>5</sup> Johnson BH, Abraham MR. Partnering with patients, residents, and families: A resource for leaders of hospitals, ambulatory care settings, and long-term care communities Bethesda (MD): Institute for Patient- and Family-Centered Care; 2012.

- Participation**
- Take time to learn and honor the family’s preferences, goals and learning style and offer opportunities that build their connection with staff (e.g., outreach, training, educational events)
  - Recognize that family participation evolves over time and that staff can help empower families to share their expertise, gather and discern information from a variety of sources, voice their preferences, and make informed decisions
  - Explain all clinic procedures from the pre-visit planning to the summary report; offer notetaking materials and access to a support person during the visit; and provide a single point of contact after the visit

*“Information is power”  
-parent of a child*



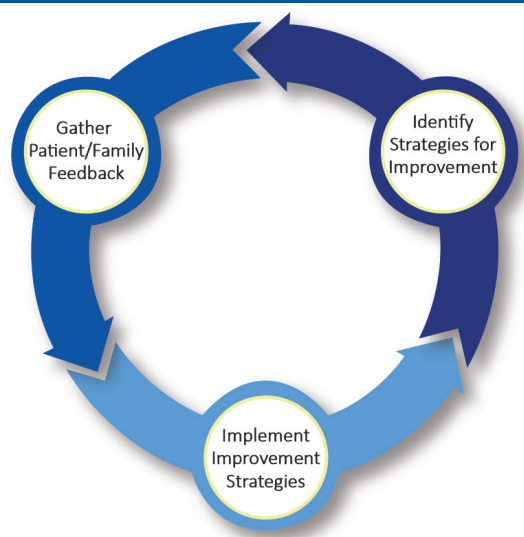
**Conclusion: Family Feedback in QI**  
This QI project demonstrates that directly gathering patient/family feedback from parents of children receiving interdisciplinary care in a pediatric specialty clinic setting captures perspectives and preferences not typically gathered through standardized, provider-based satisfaction surveys. The resulting improvement strategies are tailored to users of these clinics. The collaborative Patient/Family-Centered Continuous Quality Improvement Cycle allows the clinics to be responsive to patient/family feedback.



In 2016-2017, the Waisman Center Developmental Disabilities and Genetics Clinics conducted a quality improvement (QI) project to gather feedback about the communication individuals and families experience before, during, and after their clinic visits. This issue brief describes the project, shares its findings, and identifies strategies for improving clinical practice based on this feedback.

This work could not have been completed without the generous, thoughtful, and constructive feedback provided by the families who participated in this QI project. We thank them for their time and willingness to share their perspectives and experiences. The Waisman Center Clinics, in partnership with UW Health, Maternal Child Health Title V, and other key partners, provide comprehensive clinical care and support for children, youth, and adults with developmental disabilities and genetic conditions and their families. Trainees from the Leadership Education in Neurodevelopmental Disabilities and Related Disabilities (LEND) program at the University Center for Excellence in Developmental Disabilities were integral to this project and dissemination of the work.

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Patient/Family-Centered Continuous Quality Improvement Cycle

**Issue Statement**  
Engaging patients and their families in health care quality improvement (QI) is critical to the process of measuring quality and ultimately improving health outcomes because it ensures that improvement strategies reflect the perspectives and preferences of those receiving care. Through the Waisman Center Clinic partnership with UW Health (a large healthcare system in Wisconsin), clinic patients/families receive standardized, provider-based satisfaction surveys. These surveys are not specifically designed to capture patients and families’ perspectives on clinics with two or more clinicians. The Waisman Center Clinics aimed to address this gap by directly gathering patient/family satisfaction data specific to these interdisciplinary clinics to identify strategies for improving clinical practice.

**Background**  
For more than thirty years, leading health and family-based organizations and associations have promoted partnerships with patients and families as a critical component of quality clinical care. In 1987, Surgeon General C. Everett Koop, physician and parent, articulated the elements of family-centered care.<sup>1</sup> These elements laid the foundation for the Maternal Child Health, Children with Special Health Care Needs infrastructure. In 2001, the Institute of Medicine’s *Crossing the Quality Chasm* outlined six domains for quality improvement, including patient/family-centeredness.<sup>2</sup> In 2008, the American Academy of Pediatrics issued a policy statement,

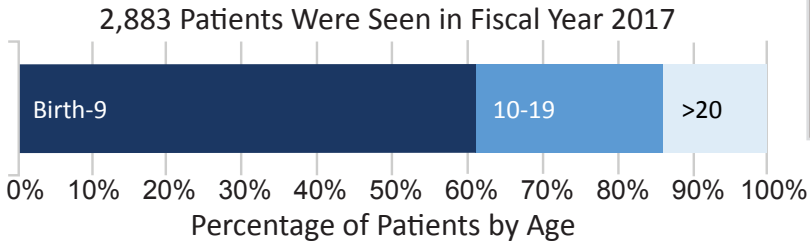


Background continues...

*Principles for the Development and Use of Quality Measures*, emphasizing the importance of partnerships with families in quality improvement efforts.<sup>3</sup> In 2010, the Joint Commission began work to advance patient/family-centered care in hospitals.<sup>4</sup> And in 2012, the Institute on Patient-and Family-Centered Care articulated core concepts that advance patient/family-centered care in all settings.<sup>5</sup>

The Waisman Center Clinics are committed to providing patient/family-centered comprehensive diagnostic, treatment and follow-up care and support to individuals with developmental disabilities and genetic conditions and their families. Care is provided by an interdisciplinary (ID) team of professionals who use a collaborative team approach to optimize outcomes of services and supports with meaningful inclusion of families, individuals and professionals. The ID team may include two or more of the following disciplines: developmental pediatrics, psychology, behavior analysis, speech-language pathology, occupational therapy, genetic counseling, genetics, physical therapy, psychiatry, audiology, nutrition, nursing, and social work. Given that the majority of patients in these clinics are children, families are integral to visits and follow-up. Therefore, it is crucial that clinic staff effectively communicate with the patients and their families and that satisfaction data gathered adequately capture parents’ perspectives on this interdisciplinary care.

Majority of Waisman Clinic Patients are Under Age 20



The Waisman Center Clinics implemented a quality improvement (QI) project to gather feedback about the communication that patients/families experienced before, during, and after their visit. The project QI team included the clinics program manager and four trainees in the Wisconsin Leadership Education in Neurodevelopmental and Related Disabilities Program. The results were intended to: (1) provide a summary report of family feedback and recommendations to staff, clinicians, and leaders; (2) encourage clinic teams to consider the family feedback in assessing current functioning and potential changes in clinical service delivery; and (3) inform the development of an ongoing method for gathering patient/family satisfaction data.

Methods: Gather Feedback

The QI team conducted three focus groups and four phone interviews with parents whose children had been to the Cerebral Palsy, Genetics, and Autism & Developmental Disabilities Clinics within the past two years. The QI team asked the same questions (see below) in both formats. The focus groups were audiotaped and then transcribed; detailed notes were taken by a team member during the interviews. The QI team provided a summary of participant comments and invited participants to offer additions or corrections before ending the focus group or interview.

Focus Group and Phone Interview Questions

- Before the clinic appointment**
- Think back to your appointments here. How well did we prepare you for what to expect during the visit?
- During the appointment**
- To what extent was your main concern/question answered during the appointment?
  - How did you feel about the length of your appointment?
  - To what extent did you leave the appointment feeling like you were respected, supported, listened to and understood?
- After the appointment**
- What did you find helpful about the written report?
  - How were the recommendations useful?
  - Is there anything important that has not yet been mentioned or that you want to add that might be valuable to us for understanding families’ experiences and satisfaction with the clinic?
- Wrap-up**
- What is one thing that we could improve on?
  - What is one thing that we did well?

A total of 10 parents, all mothers, participated in the focus groups and interviews. Their education ranged from a vocational degree to a graduate degree. The children represented by these parents had a current age ranging from 2 to 20 years (average = 10.6). The participant race and ethnicity were consistent with the broader clinic patient profile (88% white and 91% non-Hispanic). Some children of parents in the Cerebral Palsy and Genetics Clinics focus groups were also seen in two or more clinics.

After gathering family feedback, the QI team members reviewed and categorized parent comments using the Institute for Patient and Family Centered Care’s (IPFCC) Core Concepts.<sup>5</sup>

Core Concepts of Patient- and Family-Centered Care

- Dignity and Respect. Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- Information Sharing. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.
- Participation. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- Collaboration.<sup>\*</sup> Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation; in research; in facility design; and in professional education, as well as in the delivery of care.

*<sup>\*</sup>This category was not seen in the parents’ comments; the project was about clinic communication not collaborative planning.*  
Institute for Patient and Family Centered Care (IPFCC; Johnson & Abraham, 2012)

Findings: Family Feedback

The majority of parent comments were positive and appreciative of the Waisman Center Clinics. Most parents felt that they were seen by experts who understood and supported their family, received high quality clinical care, and were encouraged to participate in the manner they chose. Within the first three IPFCC categories, the parent comments addressed the importance of the interpersonal attitude and skill of clinic staff; the expertise of clinic staff and family members; and the clinic environment and logistics. Their comments are summarized below:

- Staff interpersonal skills, the quality of clinical care, and the physical space and logistics of the clinic experienced by families contributed to families feeling like they were treated with **dignity and respect**
- The quality of interpersonal communication between the parent and staff, information they received from staff, and the physical and logistical attributes of the clinic visit that allowed for efficient and helpful sharing contributed to families perceptions of the **information shared**
- Staff interpersonal skills, parents’ use of the expertise and knowledge they gained about their child’s condition and treatments through a variety of sources, and clinic procedures impacted how parents **participated** in their child’s appointment and care

