FAMILY VOICES®

Well-Being for Families of Children with Complex Health Issues

Family Voices worked with a team of family leaders, clinicians and researchers to learn from families of children, youth or young adults with complex health issues. The team wanted to understand what day-to-day life is like for families, and how the health care system can improve family well-being. Family well-being can be hard to define. Some of the general definitions for family well-being include ideas about families feeling safe, healthy and financially stable, and having educational opportunities. However, when we asked families about how they define well-being, the answers were much more complex.

More than 300 diverse families from across the country responded to the prompt, "My family is doing well when..." The answers families gave fell into distinct areas, with ideas about the family system itself (Family Internal System - FIS), and how the systems outside of the family (Family External System - FES) support their well-being (FIS-FES Interface).

Talking about Family Well-Being

What does well-being mean for you and your family?

- When you look at the themes and statements from other families, what stands out as important to you?
- Share what is important for your family's well-being with your child's care team.

What if your family is not experiencing well-being?

- Talk with your child's care team about what is not working for your family.
- Make a **care map** to see where your family could use more support. Discuss it with your child's care team.

How can you help create changes in the health care system that support family well-being?



Get involved in advisory groups or other community organizations that can connect you to the support you need and help you share your experiences, including your **local Family to Family Health Information Center**.

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How Families Defined Well-Being in Their Family's Internal System

Below are quotes from families about different aspects of their family life that make up well-being for them.

Sleep and Physical Health
Being physically healthy and getting sleep

- "When our child is stable and at home"
- "When our physical health as parents is at its best"
- "When everyone is getting decent sleep"
- "When we have therapy and medication for our mental health needs"

Healthy family relationships
Getting along and relating to one another

- "When I have time and energy for my other children and my spouse"
- "When we feel supported by loved ones"
- "When we are laughing and communication is good"
- "When everyone's needs are met"

Minimal disruptions to routines
Knowing what to expect

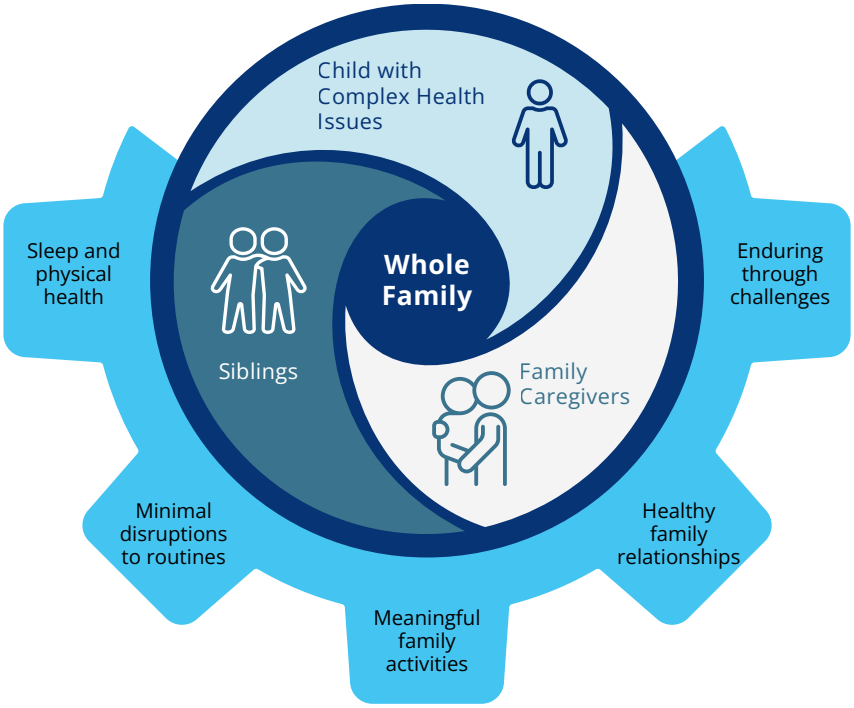
- "When we have a day with no emergencies"
- "When it seems like things are normal, [and] we're able to have a good routine going"
- "When we know what to expect"

Enduring through challenges
Dealing with tough times

- "When we can be together working on whatever comes our way"
- "When we reach a place of acceptance"
- "When our child has a feeling of hope"
- "When we can find joy and laughter in the unspeakably hard"

Meaningful family activities
Doing things together

- "When we have more free time than appointments and therapies in a week"
- When neither parent is totally consumed with the caregiving role"
- "When we are able to enjoy an experience together"



How Families Defined Well-Being in Relation to External Systems

Below are quotes from families about different aspects of their well-being that are influenced by their relationships with the systems that serve them.

Inclusion and Connection

Feeling connected to community, friends and extended family

- "When 'experienced parents' teach me how to get help, how to appeal insurance denials, how to advocate for my child at IEP meetings, how to navigate social situations and more"
- "When school is meeting my child's needs"
- "When the local community provides adaptive/inclusive classes and events"

Access to Services

Getting the care and services needed to provide care

- "When we can see the providers we need to see in a timely manner"
- "When we get all our supplies each month"
- "When insurance doesn't make any obstacles to coverage"

Patient- and Family-Centered Care

Health care that is focused on the family and acknowledges family expertise

- "When our doctors are working with us as a team to address our child's complex conditions in a prompt and timely manner"
- "When specialists communicate with each other and coordinate care"
- "When we have a medical team that considers the parents an expert on their child"

Financial Stability

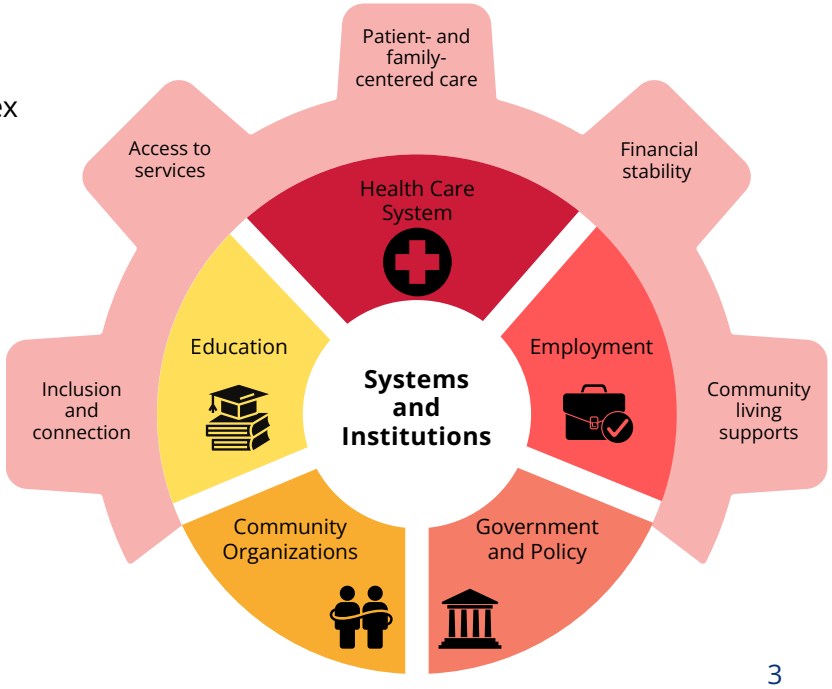
Not having to worry about money or medical bills

- "When the bills are paid and the cupboards are full"
- "When I have a flexible job that allows me to attend doctor's visits"
- "When our family finances are stable and allow us not to worry about expenditures, both budgeted and unexpected"

Community Living Supports

Getting services that help children live at home safely

- "When we have stable, reliable, and appropriately trained private nursing"
- "When we are provided with appropriate respite services to prevent burnout"
- "When staff in every system are well trained and knowledgeable, well paid and not overburdened"



Interface between Internal and External Systems

Below are quotes from families about the conditions that help them experience well-being.

Necessary knowledge to support child within systems

Knowing where to go to get what they need

- "When my family seeks out resources and information to empower ourselves"
- "When we are well prepared for any medical emergencies"

Ability to navigate and advocate within systems

Knowing how to get what they need

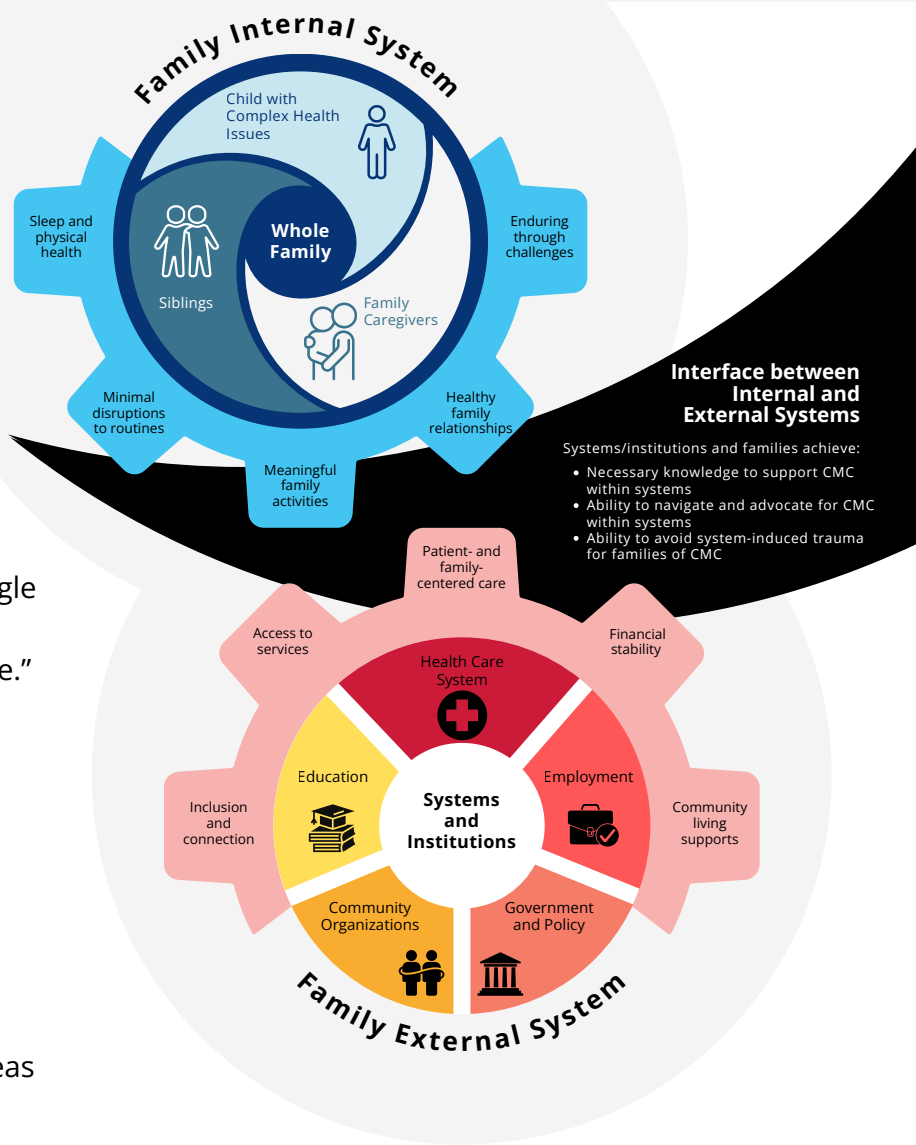
- "When our family easily navigates all the health systems"
- "When we advocate effectively for our child's needs"

Able to avoid system-induced trauma

Working with systems that don't make it harder to get what they need

- "It often feels like we have to fight, struggle with even those who are supposedly on our team and are invisible in our struggle."
- "When our daughter's therapies, medications, and equipment needs are met without having to make daily phone calls to doctors, insurance companies, therapist offices, medical equipment companies, nurse agencies, and pharmacies"
- "When we have to fight and prove ourselves worthy of resources, other areas fall by the wayside, which means we are always in a perpetual cycle of trying to make everyone 'good' so we can rest, but that rest never comes."

What Determines Family Well-Being for Families of Children with Medical Complexity (CMC)



Dive deeper through our online module