FAMILY VOICES®

Defining and Supporting Caregivers

This definition was shaped by caregivers, family members, and individuals with lived experience from across Family Voices' network, including parents, self-advocates, and professionals.

A caregiver is anyone who regularly helps another person with their needs over a period of time. This help is given with the other person's agreement and trust.

Caregiving is often needed because a person has a disability, chronic illness, past trauma, or other challenges. Caregivers help meet needs that the person cannot meet on their own. These needs can be made harder by barriers in systems like health care, schools, or social services.

Caregivers may support:

- Physical needs (like mobility, eating, getting dressed and bathing)
- Emotional needs (like comfort, encouragement, or companionship)
- Mental health needs
- Social needs (like helping someone stay connected to others or manage their schedule)

Choosing the Right Words

We use the word "caregiver," but people have other ways to describe this important role, depending on what feels right to them or what rules and systems they are part of. Other words people use include *carer*, *care partner*, *support ally*, and *support person*, among others.

These words are often combined with other terms, such as family caregiver, young caregiver, or caregiving youth. The words people use can change over time, especially as the person receiving care gets older.

When creating programs or policies, it is important to ask people what language feels right to them and their community.

Who can be a caregiver?

Caregivers can be:

- Parents or guardians
- Grandparents
- Siblings
- Other family members
- Friends or chosen family

Caregivers can support people of any age, including:

- Babies and young children
- Youth and teenagers
- Adults
- Older adults

Caregiving can happen at any stage of life and may last for a short time or many years. Most people will have caregiving responsibilities at some point in their life.

Challenges Faced by Caregivers

Many caregivers do not think of themselves as “caregivers” because they see what they do as part of being a parent, partner, sibling, or friend.

However, caregiving often includes responsibilities that go beyond what most people expect for someone of the same age without a disability or illness. These responsibilities are sometimes called *extraordinary care* because they are essential to keeping a person safe, healthy, and supported at home instead of in an institution.

Caregivers partners often face challenges that can affect their quality of life and how well they are able to support their loved one’s care, including:

- Speaking up for their loved one’s needs in schools, health care, or other systems
- Supporting more than one person in the household who needs care
- Emotional stress, worry, or burnout
- Financial pressure or extra costs
- Difficulty understanding or navigating complicated systems
- Legal responsibilities or paperwork
- Trouble keeping a job or maintaining work hours
- Managing their own physical and mental health

Caregiving across Childhood & Adulthood

For families of children with special health care needs or disabilities, caregiving can last many years.

Caregivers often support their child through:

- Pediatric (children’s) systems
- The transition from youth to adulthood
- Adult health care, education, and support systems

This transition can be especially challenging because adult systems often work very differently from children’s systems.

Finding Solutions That Support Caregivers

Most caregivers are not professionally trained, but they often provide care for people with complex medical needs, disabilities, or serious illnesses.

Over time, caregivers gain important knowledge about:

- Health conditions
- Daily care and support
- How to navigate schools, health care, and community systems

Even though caregivers' experiences are different, many supports can help reduce common challenges, such as:

- Medicaid and health coverage
- In-home services
- Disability and developmental support organizations
- Community-based programs

Learn More

- What is a Caregiver? | Called to Care - Johns Hopkins Bayview
- Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act
- Potential Solution: Family Certified Nursing Assistants | Manatt Health in partnership with Team Select, the Lucile Packard Foundation for Children's Health, Family Voices and Health Leads
- Medicaid as the Payor for Care | Georgetown Center for Children and Families and Family Voices
  - Background
  - Family Perspective

How You Can Support Caregivers

Direct Care and Services

- Listen to caregivers and take their concerns seriously.
- Include caregivers as partners when planning care and making decisions.
- Help connect caregivers to community resources that support their whole lives, such as health care, education, and social services.

Peer Support

- Connect caregivers to peer support, such as Family-to-Family Health Information Centers.
- Include caregivers as leaders and equal partners in advisory councils, focus groups, and committees.
- Support caregivers who are active in community or cultural organizations working to improve care.

Systems Level

- Partner with caregivers to help design and lead policies that improve systems of care.
- Advocate for policies that support caregivers at the organizational, state, and federal levels.
- Work with caregivers to create ways to evaluate programs and improve services over time.

Caregivers are essential partners in care. Supporting caregivers supports families, strengthens communities, and improves systems of care for everyone. For more information about how to engage caregivers, visit familyvoices.org/familyengagement.