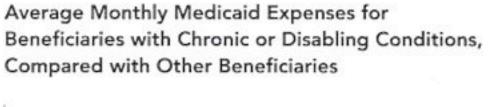
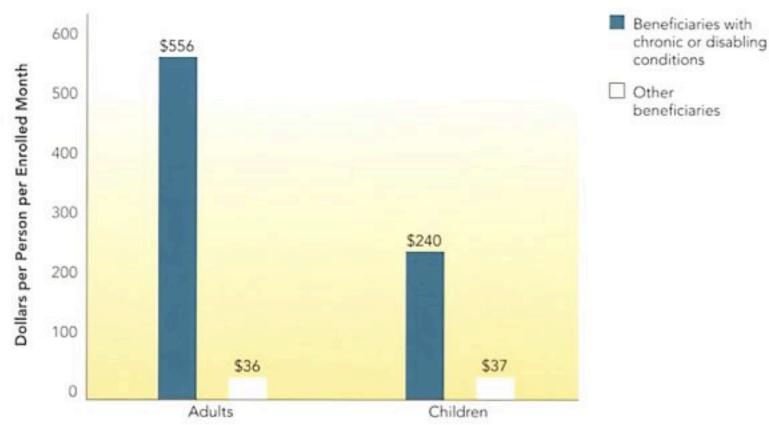


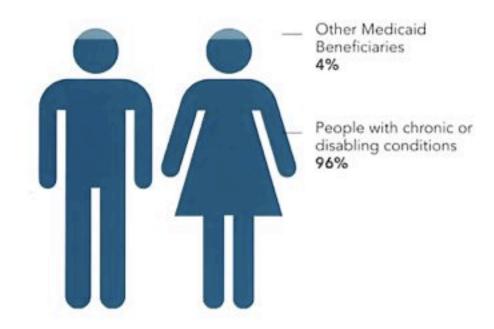
The Complexities of Caring for People with Chronic Illnesses and Disabilities



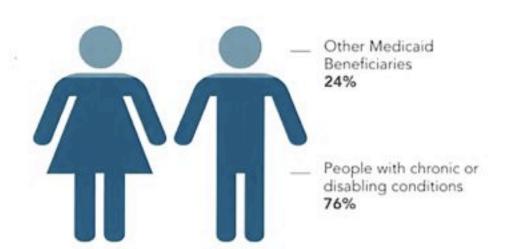


On average, monthly Medicaid costs are much higher for beneficiaries with chronic or disabling conditions.

Percentage of Total Medicaid Expenses Accounted for by Adult Beneficiaries with Chronic or Disabling Conditions



Percentage of Total Medicaid Expenses Accounted for by Child Beneficiaries with Chronic or Disabling Conditions



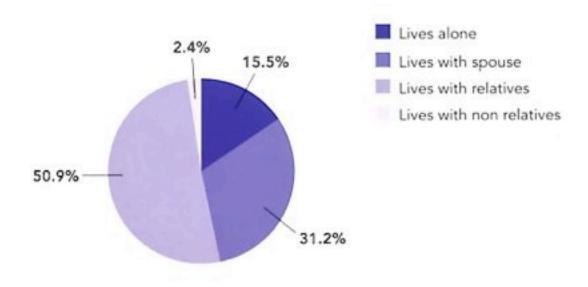
Beneficiaries with chronic or disabling conditions account for all but a small portion of total Medicaid expenses for nonelderly adults.

Beneficiaries with chronic or disabling conditions account for most Medicaid expenditures for children. Policy Issue: States should consider ways to compensate family caregivers and provide them enhanced respite care packages.

A "caregiver" provides assistance to someone with a medical condition. Caregivers can be volunteers or paid and are associated with a service system. However, family members, friends, and others often serve as caregivers as well. As of 1997, there were roughly 25 million family caregivers in the United States, providing about 85 percent of all home care services, at a value of \$300 billion annually.²

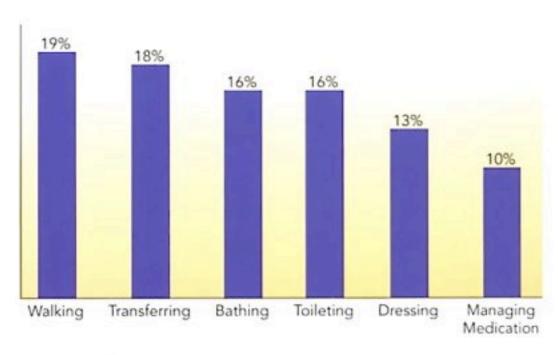
For people with disabilities and chronic illnesses who need assistance with activities of daily living, having a family member provide care is often a welcome alternative. But for the caregiver, who may work a full- or part-time job in addition to caring for their relative, this added responsibility can be quite burdensome.

Community-Based Living Arrangements Among Adults with Chronic Conditions on Medicaid, Ages 18-64



Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

Community-Dwelling Adults with Special Needs on Medicaid with Unmet Need for Help with Personal Care Activities



Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

In order to alleviate part of this burden, some state Medicaid programs, including those in Michigan and California, allow the hiring of family members as formal, paid service providers. Other states, including Maryland and New York, prohibit this practice. The issue remains controversial. Critics claim that paying family caregivers could undermine traditional societal expectations that families provide care informally. Most states currently permit—albeit in varying degrees—family members to be paid providers in at least one public program.³

- 2 Family Caregiver Alliance Newsletter, Summer 1997.
- 3 Doty, P., Kasper, J., and Litvak, S. "Consumer-Directed Models of Personal Care: Lessons from Medicaid." The Milbank Quarterly, 1996: 74(3): 377-409.