

Consumer Direction

The philosophy and practice of “consumer direction” is an emerging trend in HCBS programs. Consumer direction is not a single method; rather it is a philosophical approach to paying for services or supports. It shifts the locus of decision-making and control from service providers and payers to consumers and families (Benjamin, 2001; Doty, 2004). At one end of the spectrum the consumer has total control over how the care dollar is spent, from hiring a relative to paying for goods. At the other

is traditional service delivery, where the provider or payer decides what is needed and will be covered. In between is a family-centered approach, such as the NFCSP’s “supplemental services” category: giving family caregivers a menu of services from which to choose and taking a flexible approach to approving services. For example, NFCSP funds can pay for a car battery needed for a family member to drive a relative to the doctor’s office.

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The NFCSP, Medicaid HCBS waivers and some state-funded programs permit consumer-directed approaches depending upon each state’s rules and regulations. For example, under the NFCSP, states may make direct payments to family caregivers or provide a voucher or budget for goods and services (e.g., grab bars, respite care) to meet their needs and those of the care receiver. Thus, a state’s NFCSP may give families maximum control as to how, when and to whom respite is provided, or the goods or services to buy directly (Feinberg & Newman, in press). States may also let each individual AAA (the local administering agency) set policy for this option.

States and programs within states differ in the extent to which they offer consumer-directed options to family members. The NFCSP appears to be speeding the adoption of consumer direction in family caregiving programs.

All but two states (Delaware and New York²⁷) report at least one program with a consumer-directed option for family caregivers; 106 programs

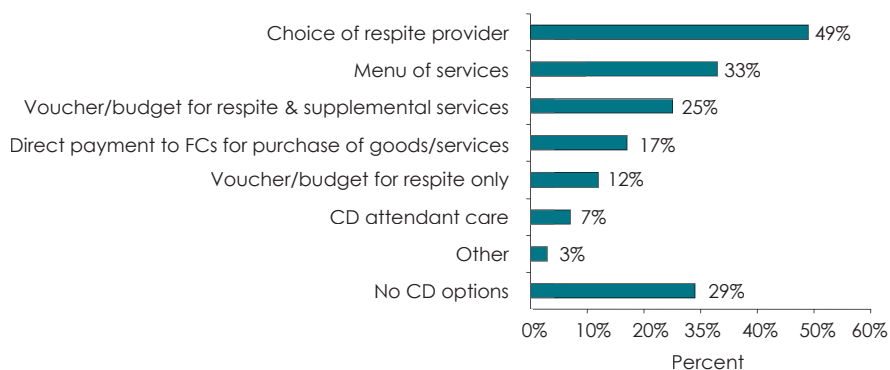
²⁷New York’s Aged/Disabled Medicaid waiver program did not respond to this survey.

nationwide (71% of sample) say they offer consumer direction of some kind. But consumer direction is far from universally available.

- In 43 programs²⁸ (29% of the sample) in 29 states and the District of Columbia, family caregivers have no consumer-directed options.
- The NFCSPs are more likely than the Medicaid waiver or state-funded programs to say they have a consumer-directed option for family caregivers. Just seven NFCSPs (14%) report no consumer directed option in their service package compared to 17 Medicaid waiver (35%) and 19 state-funded (38%) programs.

We asked state program administrators to identify the types of consumer-directed options, if any, their program provides for family caregivers. Direct payments to families to hire, supervise or fire workers, including other family members, or vouchers/budgets for respite and supplemental services give families the most choice and control to select the options that work best for them and their relative. As shown in Figure 16, programs in this survey offer a range of choices.

Figure 16. State Programs Offer a Range of Consumer-Directed Options (N = 149)



Note. CD = consumer-directed; FC = family caregiver

- Most commonly, programs give the family a choice of respite providers, (e.g., between contract agencies such as home care agencies or independent providers), effectively allowing families to hire their own worker. Overall, 73 programs (49%) in 43 states have this option, including two-thirds of the NFCSPs (67%) but less than half of state-funded (42%) or Medicaid waiver (38%) programs.
- One-third of all programs (49 in 35 states, 33%) provide caregivers a menu of services from which to choose those that best fit their needs. Nearly half the NFCSPs (49%) do so, compared to about one-fourth of state-funded and Medicaid waiver programs (26% and 23% respectively).
- Fewer programs (37 in 29 states, 25%) offer a voucher or budget for respite care and supplemental services (e.g., consumable supplies, assistive devices, yard maintenance). Again, NFCSPs lead the way, with more than half (51%) offering supplemental services, one of the five statutory service components under the NFCSP. Relatively few state-funded (16%) or Medicaid waiver (6%) programs provide this option.
- Direct payments to family members to buy goods or services also are more likely from the NFCSPs (31%) than the state-funded (16%) or Medicaid waiver (4%) programs. Overall, 26 programs (17%) in 20 states and the District of Columbia permit such payments to families.

²⁸The South Dakota Medicaid waiver program did not respond to this question.

- ♦ A respite-only voucher or budget appears as an option in 17 programs (12%) in 14 states, more often in state-funded programs (18%) and less frequently in NFCSPs (12%) or Medicaid waiver (4%) programs.

Most states (all but six) pay families to provide care in at least one of their state-administered programs.

We asked state program administrators: "Can family members be paid to provide care in your program?"

- ♦ Over half (57%), or 86 out of 150, in 44 states and the District of Columbia) say they do. Only Alaska, Delaware, Mississippi, Nevada, Pennsylvania and Tennessee do not allow payments to family members.
- ♦ A higher proportion of Medicaid waiver programs (36, 74%) than NFCSPs (59%) or state-funded programs (40%) report they allow payment to family members (other than spouses or parents/guardians of minors).

The practice of paying families to provide care may be perceived by some state administrators as a consumer-directed option for the individual beneficiary or consumer (i.e., the care receiver) without directly aiding the family caregiver. Nine of the Medicaid waivers and five of the state-funded programs reporting no consumer-directed option for family caregivers say they do permit beneficiaries to pay family members to provide care.