Alliance for the Betterment of Citizens with Disabilities

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ABCD Policy Synthesis: Supporting Family Caregiving Via the Federal Waiver

(This policy synthesis is derived from Supporting Informal Caregiving, a chapter in *Understanding Medicaid Home and Community Services: A Primer*, produced by the U.S. Department of Health and Human Services, October 2000)

This synthesis is intended to give all stakeholders information on how the Home and Community Based Services Waiver (Community Care Waiver) can be used to support family caregiving.

In New Jersey, 40% of individuals served by the Division of Developmental Disabilities (DDD) are under age 22 and living at home, with the expectation that by the end of the decade that 50% of individuals served will be under age 22.

Despite this fact, less than 7% of funding in DDD (approximately $21-$24 million) is spent on family support services. These funds are all state money, although the federal government allows some family support services to be part of the Community Care Waiver and receive federal matching funds for most services.

Federal Medicaid Policy and Informal Caregiving

Home and community services can be furnished to individuals who live with their families or in their own home just as readily as to individuals who are served in formal living arrangements, such as groups homes or assisted living.

- States have wide latitude in configuring their eligibility policies to expand access to home and community services for people who live with their families.

- Federal policies present no *substantial* barriers to states in utilizing Medicaid dollars to support people with disabilities who live with their families.

  There are no Federal limitations on the provisions of the Home and Community Based Services (HCBS) waiver based on living arrangement other than the person *cannot* reside in an institutional setting. The same is true with respect to personal assistance and other services furnished under the state Medicaid plan.

- Services must address the beneficiary's needs to be considered Medicaid reimbursable either under the HCBS waiver program or under the Medicaid State Plan. In other words, services cannot be furnished if they principally benefit the "family unit."

- Services and supports that strengthen informal caregiving include:

  Personal care/personal assistance
  Respite
  Home/Vehicle Modifications and other assistive devices
  Caregiver training and education
  Day Care
  Family-Directed Services

Availability of informal care in determining services

- There is no Federal requirement that family members provide some minimum amount of care as a condition of service eligibility. Yet, states can and do take into account the amount of informal care available to an individual when determining service provision.

  If a person needs 40 hours of support per week and informal caregivers are available, able, and willing to provide 20 hours, then only 20 hours of paid supports will be authorized.

- Assessment of the need for paid supports may focus on specific tasks that an informal caregiver who lives with and is regularly available to assist the beneficiary is unable to perform.

- A State may consider the kinds of household tasks family members expect to share or do for one another when they live in the same household, such as household maintenance-as opposed to intimate personal care tasks that individuals normally do for themselves.

Payment of Services

- Federal Medicaid law and policy does not enable cash payments to be made to or on behalf of beneficiaries. Since cash subsidy programs can not be financed through a waiver, the State must fully fund this part of family support

- Federal Medicaid law permits family members to become paid caregivers, unless considered legally responsible for the care of an individual (i.e., spouses and parents/guardians of minor children).

- States maintain the option of paying these family members under certain exceptional circumstances, such as payment for providing skilled nursing services for which there is no presumption that the service would normally be provided free.

- States have the option to choose to pay any family members to provide personal care services to a variety of relatives, including adult children of an elderly parent, parents of adult children,

siblings, and grandparents. Friends and neighbors may also be compensated for providing services that would otherwise require purchasing.

Payment of Services (continued)

- If a state chooses to make personal care payments to family members, they are permitted to establish provider qualifications that differ from the qualifications for agencies or individual contractors who furnish similar services.

- Approximately, half the states have elected to make payments to family members who provide personal care services under HCBS waivers for people with developmental disabilities.

- For non-personal care services, the Centers for Medicare and Medicaid Services (CMS) has affirmed that payment to family members, especially when services are difficult to obtain from other sources, may be the most practical method.

- The rules for payment to relatives of non-personal care services are similar to those for obtaining services from another source: the relative must meet whatever provider qualifications established by the state and charge no more than any other provider of that service.

  CMS expects the state to limit payments to certain types of relatives and requires a demonstration that the service is not otherwise available, that it may not be obtained as economically and/or that there is a clear benefit to the individual from the relative providing the service.

Operating Distinct Waiver Programs

- Some states have introduced distinct HCBS waiver programs intended mainly to underwrite services and supports for individuals who live with their families or on their own with informal caregiving available to them.

  States that make services and supports more readily available to people with developmental disabilities who live with their families experience lower demand for group home and similar services.

- These programs typically operate under stricter cost caps than the State's parallel HCBS waiver program for the same population. However, these programs give individuals and families considerable flexibility in selecting a mixture of services and supports that best meet their needs and preferences.

  Availability of Medicaid funds allows the states to offer more robust services and support to families than typically provided under family support programs.

- Oklahoma has two distinct waiver programs to children and adults who live within their families. The program for children operates under a $10,000 cost ceiling, with more limited services than the program for adults, which operates under a $15,000 cost ceiling.

- The stricter cost caps help the state avoid imposing service-by service restrictions on utilization in order to maintain program cost-effectiveness.

- A clear advantage to operating a distinct waiver program is that state officials and other stakeholders are often more disposed to consider new approaches to furnishing home and community services when they are creating a program instead of modifying a current one.

- The main disadvantage appears to be the administrative burdens associated with operating multiple HCBS waiver programs for the same general target population.

Examples of States that target benefits for Families within a HCBS Waiver

- States can achieve the same purposes of a distinct waiver program by specially targeting benefits within a single HCBS waiver program.

Utah

- In its single HCBS waiver program for people with developmental disabilities, Utah offers assistance and support services intended to enable family members with a disability to remain and receive supports in their family homes. The intent is to prevent or delay unwanted out-of-home placement.

- Services and supports can be provided either in or out of the home and may include provisions to assist the individual with a disability to obtain community supports; include instructions, supervision and training to the family/caregiver/individual in all areas of daily living; and/or other activities identified in the individual's support plan as necessary for continued skill development .

- Services can be obtained through state-contracted providers. Families may also choose another model where the family hires and trains individuals to provide the supports. The family may use individuals age 16 and older as direct providers of support.

Illinois

- This waiver program for people with developmental disabilities includes a supported living option intended for people who live with their family or on their own. Service plans under this option are subject to a yearly cost cap of $18,000.

- The supported living option is a distinct benefit nestled in the state's HCBS waiver program. This enables states to identify distinct benefits especially geared to individuals who live with their families.

- Under the cap, individuals and families may choose from (a) distinct services available only to individuals who select the supported living option (intensive case management, personal care, skilled nursing, respite, and transportation) and (b) certain services available to other program participants as well (day habilitation, behavioral services, and therapy services).

Conclusion

- The Division of Developmental Disabilities is beginning to explore the possibility of including family support in the Community Care Waiver or to develop a separate waiver for family support services.

- New Jersey has considerable flexibility to support individuals who wish to live with their families by including much of its current family support program into the Community Care Waiver.

- The *New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Families* lays out a vision to provide more services and supports to a larger number of individuals and families. In order to fulfill this vision when funds are limited, it is important to explore leveraging State with federal funds.

- Inclusion of family support services into the Community Care Waiver, or into a separate waiver, will mean that for the State to receive federal dollars, the individuals served will need to be eligible for Medicaid waiver services.

    New Jersey's current eligibility criteria for waiver services include all individuals with income levels equal to 300% of the SSI federal benefit rate (approximately $1,635 a month). Individuals must maintain their resources (assets) below $2,000.

Discussion among all stakeholders must take place about whether to incorporate services these services into the current waiver, establish a new waiver and the service needs of individuals and their families who may not be eligible for waiver services because of income and resources.

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