

## ***Reimbursements for Caregivers & Parents***

### ***Summary***

Under current Federal Medicaid law and within the Division of Services for People with Disabilities (DSPD) rules, reimbursements cannot be made for services performed by “persons who are legally required” to care for the individual. Under Home and Community Based Service Waivers, however, a state may choose to make an “extraordinary care” payment to legally responsible individuals who provide personal care services. If a state includes this option in a waiver, a legally responsible individual can become a service provider.

UDDC seeks to educate lawmakers about the hardship placed upon primary caregivers who are required to care for their family members without the support of Community Based Service Waivers.

### ***Points of Consideration***

Family members and service providers shared the following points and perspectives regarding the proposed changes and toward a change in policy that would allow for these payments to legally responsible caregivers.

### ***System Capacity***

- Caregiver Compensation is not overall cost-neutral, but may provide a cost reduction in hospitalization, mental health services, community resources, and less cost for behavior support. It could also potentially reduce medical costs as parents by keeping families and individuals out of crisis because their care is more stable, regular, and familiar.
  - Could help meet capacity issues that are not currently being met by community service providers.
  - Costs may increase in some areas because individuals were not getting services before and are now getting services. Could result in a reduction in spending over the long term, because funds are spent more efficiently with more people being served.
- Reduces the burden of capacity of our service system. Providers cannot provide services for everyone, and many providers can not provide services to some people with the most severe disabilities, especially those with extreme behavioral challenges.

- Other states follow a model where the compensation is connected to events or activities that a respite or other care professional would provide.

### *Family Choice*

- Families need more options for care. Many parents are unable to place their child in residential and day programs as their children have complex medical and/or behavioral needs.
  - Crisis and institutionalizations are reduced when providers are known or changes between providers are reduced.
  - Family perspective: using a family caregiver prevents abuse and neglect, and provides choices.
- Under the current system, families often feel they have to choose between outside employment and caregiving, although balance can be achieved.
  - Not all families will use this service, and not all providers are available at this time.
  - Having options allows families the chance to be flexible and balanced, and tailor their services specific to their own needs without additional burdens on the system.
  - Many families struggle to maintain employment due to the need to respond to situations, especially if they are in crisis.
  - Allows individuals to get working quarters, in addition to contributing to Utah's income tax revenue and expanding economy.
- Caregiver compensation helps keep the family intact, strengthens parental influence, and empowers family members to take a more direct role in the care of their loved ones.
  - Families would still have choices for providers and caregivers.
  - Allows for greater choice across the lifespan and in end-of-life care.
- Provides continuity of care and prevents changes or behaviors due to providers coming and going. It also reduces administrative burdens from families/parents so that the time is spent more on family care and less on admin work.
  - Positive effects of reduced staff transitions, turnover, and flexibility of care.
  - Legal guardians are prevented from being paid under current guidelines. Some family members, such as siblings, are listed as co-guardians in legal

proceedings, which prevents them from being reimbursed for the care they provide.

- Reduction of crisis and transitions can improve family or time and resources for siblings.
  - Removes some of the burden off siblings who are making up for the gap in services with families.
  - Siblings lack time and resources from parents, and suffer in their well-being. If parents are home and able to be compensated for their time, they can devote their time to these family issues solely, and also receive financial support for the family in general.
  - Caregiver compensation helps families to be able to keep adult children with disabilities living at home with parents if they choose.

### *Programmatic Considerations*

- When is it a paid service and when it is a natural support? Why pay parents to be parents?
  - Basic activities of daily living are not covered, but items included in support plans are reimbursable up to a certain hourly limit.
  - General rules instead of super specific guidelines.
  - Parents need flexibility, including the ability to take a break (respite).
- What are the hour limits and how will the families know what their needs are? How can we ensure money is appropriately spent?
  - Support coordinators and families will need guidance from DSPD about the service.
  - Intent language or policy guidance around the issue of cost neutrality could help prevent budgets from becoming inflated while ensuring needed services.
  - State agencies overseeing these waiver changes will need to define “extraordinary care in such a way as to clearly describe objective program eligibility criteria and service delivery limitations.”<sup>1</sup>
  - Does DSPD budget in the hours unused into their budgets? If all the hours are spent each year, would this actually increase the spending for this service? What is happening with this remaining money, as some families do not always use all their hours or monthly funds?

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<sup>1</sup> <https://le.utah.gov/interim/2020/pdf/00000849.pdf>

- DSPD most likely factors attrition and unused money into their budget based on past years; this additional funding goes into one-time money for accessibility, ramps, assistive tech, etc.
- Existing service codes will need to be clarified as to which ones are permitted for a parent caregiver

### *References and Additional Resources*

Utah Department of Health: "Report on Medicaid Compensation Options for Care Provided by Legally Responsible Caregivers"

<https://le.utah.gov/interim/2020/pdf/00000849.pdf>