Caring Families: Paying Family Caregivers Topic Brief

Introduction

NASDDDS fielded a survey among its members in the spring of 2023. This survey sought to gain information on the practices active among states for paying relatives to deliver supports and services through home and community-based services (HCBS) programs, and which of those practices the states expect to continue beyond the end of the Public Health Emergency (PHE).

As depicted in Figure 1 below, twenty-seven states responded to the survey, most allowing relatives to deliver some supports and services to individuals with intellectual and developmental disabilities (I/DD), including thirteen states that allow legally responsible individuals (LRI), usually parents, to deliver some services as well. The survey also explored the safeguards states use to ensure that the services provided by relatives, including LRI, are delivered in the best interest of the individual, including ensuring choice and fostering community integration opportunities. Additionally, for those states allowing parents of minor children to provide services, the survey asked how the states determine extraordinary care, ensuring that Medicaid is not paying for something that typically would be provided by parents of minor children. Notably, there are wide variations across state policies regarding who and under what circumstances relatives, including LRI, may be paid to deliver supports and services. These variations may include whether the options are available under self-direction or traditional service modalities or both and whether the relative must meet all otherwise applicable provider qualifications. Furthermore, some states require family members to become employed by a Medicaid enrolled provider before they can render any services. It is important to review each specific state policy to understand how that state approaches these flexibilities.

Figure 1: States Responding to NASDDDS’ Survey: April 2023

NOTE: Several more states temporarily allowed payment to LRI during COVID and there are great variations across states regarding the conditions under which LRI can be paid to render services.
In addition to the survey results, NASDDDS conducted a review of approved waivers among non-responding states. NASDDDS notes that most states not participating in the survey allow relatives to provide supports and services, with wide variation and requirements related to situations under which parents of minor children or other LRIs may be paid for service delivery.

The survey also inquired about state practices to engage individuals and families in their process for policy development around these issues. Many states have instituted standing strategies to ensure that individuals and their families have a voice in the approaches used in states to ensure that paid family caregiving flexibilities are available with the appropriate safeguards for the individuals served and the stewardship of public resources.

States recognize that paid family caregiving can be an important tool to address the systemic shortfall of available direct support professionals. States also recognize these options may provide a strategic way to provide culturally and linguistically appropriate services to individuals supported. These opportunities must be balanced by important safeguards to ensure that such strategies do not usurp individual autonomy and do not place individuals at a higher risk for abuse, neglect, or exploitation. NASDDDS members continue to evolve their policies and to make decisions addressing both the drive for flexibility with the essential need for transparent expectations and accountability.

NASDDDS notes that this is a time of transition for states as they return to typical operations post-pandemic. The association will conduct subsequent engagement to better understand those policies that have continued beyond the PHE.

Growing Recognition of the Role of Families in Supporting Individuals with Disabilities

Family caregiving has been evolving as the foundation of Long-Term Services and Supports (LTSS) in the U.S. for many years, stabilizing supports and providing essential care to family members. An estimated 53 million people in the United States supported an adult or child with support needs in 2019.¹ This number, notably high even prior to the pandemic, represented an increase across all “racial/ethnic groups, educational levels, work statuses, genders, and nearly all generations” and represents an estimated $500 billion in unpaid care annually.²

Congress passed the RAISE (Recognize, Assist, Include, Support and Engage) Family Caregivers Act in 2017. This legislation resulted in the formation of a Family Caregiving Advisory Council which submitted a comprehensive report to Congress in 2021. The report offered important recommendations related to engaging and supporting family caregivers and assessing impacts

² ibid
on key Federal programs. In follow up, the Administration for Community Living (ACL) led the development of a National Strategy to Support Family Caregivers in 2022. This strategy includes more than 350 Federal actions to support family caregivers as well as additional tools that can be used at state and local levels.

In many ways, the work of the RAISE initiative and the National Strategy are recognition of the important role families play in ensuring that individuals with disabilities have a good life in communities of their choosing. NASDDDS, and our partners at the University of Missouri at Kansas City, have worked since 2011 to identify ways for states to better support individuals within the context of their families. Figure 2 shows that, as of 2023, 22 states have participated in the Supporting Families Community of Practice (CoP) to enhance and drive policy, practice, and system transformation to support people with I/DD within the context of their families and communities. This is especially important given that, according to the most recent data from the Residential Information System Project (RISP) of individuals with I/DD receiving supports and services, 61% (792,030 people) live in the home of a family member. The Direct Support Professional (DSP) workforce shortage and the COVID 19 PHE combined in recent years to increase the pressure on family caregivers of individuals with I/DD, sometimes exacerbating already fragile family economic statuses. The 2021 National Core Indicators-IDD State of the Workforce Survey® reveals a persistently high turnover and vacancy rates (43% and 20%, respectively) among DSPs providing HCBS, making access to needed paid support more difficult for families. Additionally, the 2020-21 NCI IDD Adult Family Survey® reveals that more than a quarter of families supporting loved ones with disabilities earned less than $25,000 in the prior year (2019).

These factors have contributed to a growth in state strategies to pay family caregivers for the support they provide. During the pandemic, states increased the use of flexible strategies to support family caregivers.

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3 Retrieved from: In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2018 (umn.edu)
facilitate paid family caregivers within the Medicaid program nationally, with some states utilizing such flexibilities as temporary measures and others extending the option permanently.

Medicaid and Family Caregivers

In ordinary times, Medicaid policy regarding paid family caregivers is not uniform across all authorities, varying within and across both 1905(a) Medicaid State Plan and HCBS authorities within Section 1915 of the Social Security Act.

For example, Section 1905(a)(24) of the Act expressly prohibits the use of family members as providers of State Plan Personal Care Services. “(P)ersonal care services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the [individuals with intellectual disabilities], or institution for mental disease that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State, (B) provided by an individual who is qualified to provide such services and who is not a member of the individual’s family, and (C) furnished in a home or other location...”

Other 1905(a) services permit the use of family members under the following conditions pursuant to the State Medicaid Manual at section 4442.3(b)(2):

“Medicaid payment may be made to qualified parents of minor children or to spouses for extraordinary services requiring specialized skills (e.g., skilled nursing, physical therapy) which such people are not already legally obligated to provide.” As a result, for example, a state may allow paid family members to render State Plan Home Health Aide services to an individual, which can be similar in nature to State Plan Personal Care.

Under 1915(c) Home and Community Based Services Waiver and 1915(i) State Plan HCBS, states have the option to allow relatives and LRIs to provide an array of services. For 1915(c) personal care provided by LRIs, the provision of those services must be deemed extraordinary care,“ over and above that which the LRI, including parents, would ordinarily provide.

States also may permit the use of paid family caregivers under both 1915(j) Self-Directed Personal Assistance Services and 1915(k) Community First Choice, with some limited variation by authority. Table 1 offers a snapshot of the various Medicaid authorities and their provisions

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6 Section 1905(a)(24) of the Social Security Act.
8 Application for a §1915(c) Home and Community-Based Waiver [Version 3.6], Instructions, Technical Guide and Review Criteria, release Date, January 2019
specific to paid family caregiving. During the PHE and across all Medicaid authorities, states leveraged flexibilities under 1135 of the Act and through 1915(c) Appendix K to increase the availability of paid family caregiving to ensure that necessary supports were available to individuals with disabilities and individuals who are aging at a time when social distancing and infection control were paramount. Some states expanded an existing policy related to family caregiving on a temporary basis, while other states intend to retain the policies set forth during the PHE longer term. CMS described the opportunities available for continuation in a recent All-State Call.⁹

Table 1: Medicaid Authorities at a Glance

<table>
<thead>
<tr>
<th>Medicaid Authorities at a Glance: Paid Family Caregiving Under Regular Authority</th>
<th>Relatives</th>
<th>Legally Responsible Individuals (LRI)</th>
<th>Only in Self-Directed Service Arrangements</th>
<th>Safeguards Required</th>
<th>Extraordinary Care Policies for Personal Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1905(a) Personal Care</td>
<td>No</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>1905(a) Home Health Aide</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1915(c) HCBS Waivers</td>
<td>Yes</td>
<td>Yes</td>
<td>No (available for state election in traditional and self-direction)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1915(i) HCBS State Plan Option</td>
<td>Yes</td>
<td>Yes</td>
<td>No (available for state election in traditional and self-direction)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1915(j) Self-Directed PAS</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (by virtue of authority being entirely self-directed)</td>
<td>N/A</td>
<td>N/A (individuals establish provider qualifications)</td>
</tr>
<tr>
<td>1915(k) Community First Choice</td>
<td>Yes</td>
<td>Yes</td>
<td>No (State can design benefit to allow in both self-directed and agency services)</td>
<td>N/A</td>
<td>N/A (individuals establish provider qualifications)</td>
</tr>
</tbody>
</table>

Results of the NASDDDS Survey

In April 2023, NASDDDS fielded a member survey to ascertain states’ strategies pertaining to paid family caregivers. Twenty-seven states responded. The survey inquired about the nature of the flexibilities in use by states to pay family caregivers, the safeguards they had instituted to ensure choice and well-being of individuals served, and the tools they use, when necessary, to assess whether the care provided is extraordinary. Additionally, the survey asked states to describe their plans beyond the PHE related to paying family caregivers. The survey results

showed that of those states that added flexibilities during the PHE for paying family caregivers, more than 77% intend to continue those flexibilities as permitted in the underlying authority, with more than 25% already adding the flexibilities to their 1915(c) waiver (as of the April 2023 survey field date).

As depicted in Figure 3, of the 27 responding states, an overwhelming number (nearly 90 percent) allow for the payment of non-legally responsible relatives to provide HCBS.

Figure 3: State allowances for relatives (non-legally responsible) to provide paid services

Paying Legally Responsible Individuals – Extraordinary Care

Of the 27 states responding, nearly half indicated they pay legally responsible relatives (parents of a minor child or a spouse) for care and, of those, a majority permit legally responsible relatives to provide personal care or similar services.

As noted above, states and CMS cannot pay for care that otherwise is a typical responsibility of a parent or other legally responsible relative (as stipulated in state law).
A state may elect to make payments for personal care or similar services that are rendered by LRI only when such services are deemed extraordinary care. (See below).

When a legally responsible relative provides such services, the arrangement must be in the best interests of the individual supported, must not contribute to isolation or hamper community integration and must be delivered in accordance with the person-centered service plan, including opportunities for informed choice. States may implement additional safeguards to ensure that the arrangement is truly working for the person supported.

In addition to reviewing the survey results from the 27 responding states, NASDDDS undertook a review of approved waivers among non-responding states. Results showed the patterns of permissible payment practices for relatives and/or LRIs is largely consistent across these additional states, with most states allowing some relatives to provide certain services and a smaller cohort permitting the payment of LRI, including for personal care and similar services.

State Strategies to Determine Extraordinary Care

As noted above, through a HCBS waiver, a state may elect to make payments for personal care or similar services that are rendered by LRI when such services are deemed extraordinary care. Many states elect to utilize this option within their HCBS waivers and have developed a variety of strategies to determine whether the proposed supports meet the test of being extraordinary. Figure 4 provides examples of extraordinary care definitions from six states.

**Figure 4: Samples of state extraordinary care definitions**

**Maryland**

Extraordinary care means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without disability or chronic illness of the same age and which is necessary to assure the health and welfare of the participant and avoid institutionalization.

**Louisiana**

Exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the beneficiary and avoid institutionalization.

**Minnesota**

Extraordinary care is defined as an activity a spouse or parent of a minor would not ordinarily be responsible to perform, e.g., bathing assistance for a 15-year-old child or changing an ostomy bag.

**Pennsylvania**

Support that goes beyond what would be expected to be performed in the usual course of parenting, and when needed support exceeds what is typically required for a child of the same age.

**West Virginia**

The legally responsible adult may only provide services that have been identified as necessary in the Extraordinary Care Assessment which is completed initially and at the annual reevaluation of eligibility.

**Wyoming**

Extraordinary care cases shall meet the following criteria: 1. The participant's Adaptive Behavior Quotient is 0.35 or lower on the Inventory for Client and Agency Planning (ICAP) assessment; and 2. The participant needs assistance with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs) exceeding the range of expected activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the beneficiary and avoid institutionalization.
According to the HCBS Technical Guide, “[b]y extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the individual and avoid institutionalization.”

States have used varying metrics to ascertain whether care is extraordinary.

Safeguards and Quality Improvement Strategies: Ensuring that Family Caregiving is in the Best Interest of Individuals Supported

When a state permits relatives to provide services in HCBS, the state must have strategies to ensure that the provision of services is in the best interest of the individual supported. The state should consider approaches to enable the individual to speak freely about his/her/their choices and whether they agree with the provision of the support by a relative or family member. When parents of minors are providing services, the state must devise strategies for ensuring that the provision of services is truly in the best interest of the child and that the arrangement does not hinder the child’s ability to engage in meaningful community activities.

While CMS is not prescriptive, the HCBS Technical Guide indicates that the state should note if there are any limits on the amount of care for which legally responsible relatives will be compensated and notes that “[s]tate policies should include additional safeguards such as:

- Determining that the provision of personal care or similar services by a legally responsible individual is in the best interests of the waiver participant, a state should consider establishing safeguards when the legally responsible individual has decision-making authority over the selection of providers of waiver services to guard against self-referral.
- Limiting the amount of services that a legally responsible individual may furnish. For example, a state may decide to limit the amount to no more than 40 hours in a week and thereby take into account the amount of care that a legally responsible individual ordinarily would provide.

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10 Application for a §1915(c) Home and Community-Based Waiver [Version 3.6], Instructions, Technical Guide and Review Criteria, release Date, January 2019

11 Information in Figure 3 excerpted from survey response data and/or publicly available information on state websites.
• Implementing payment review procedures to ensure that the services for which payment is made have been rendered in accordance with the service plan and the conditions that the state has placed on the provision of such services.
• Addressing other foreseeable risks that might attend the provision of services by legally responsible individuals.” 12

States have instituted a variety of safeguards in consonance with this guidance, as depicted in Figure 5. Though there is wide variation across states on the strategies in use, several states limit the specific services that a family member can provide and/or limit the number of hours per week that a family member, including a LRI, can provide. Several states responding to the survey noted that they limit the number of hours to 40 that a LRI may provide.

Continuous Engagement with Individuals, Families, and other System Partners: A Key to Ongoing Success

Understanding the needs of individuals within the context of their families requires a strong, ongoing engagement process. As states expanded their policies during the pandemic, they were informed by the real-life experiences of individuals and their loved ones. States established ongoing opportunities for dialogue so that families could inform policies and so that states could explain the rationale for different decisions about family caregiver payment. These conduits for communication must continue to ensure transparency both about the flexibilities and the responsibilities among family members who provide services and to ensure that the state has mechanisms to learn about the needs in their communities and the impacts of policy decisions.

Ongoing engagement can be an important source of information as states seek to improve access equally to all communities served within HCBS and to identify potential providers of supports who can meet the needs of individuals in a culturally and linguistically appropriate manner. These great opportunities must be balanced with sensible protections to ensure the health, welfare, autonomy, and choice of individuals supported.

Conclusion

While paid family caregiving has been an option in HCBS waivers for years, the COVID-19 PHE exponentially increased and expanded the use of paid family caregivers nationally. As the country unwinds from the PHE and as states determine which flexibilities utilized during the PHE will continue, it is clear that paid family caregiving will likely retain a more prominent role in the service delivery systems supporting individuals with I/DD. States are working now to balance the benefits and flexibilities afforded by paid family caregiving with the necessary safeguards related to health and welfare and fiscal stewardship.

12 Application for a §1915(c) Home and Community-Based Waiver [Version 3.6], Instructions, Technical Guide and Review Criteria, release Date, January 2019, page 120-122.
APPENDICES

- NASDDDS Survey: Paying Relatives and/or Legally Responsible Individuals for services under the HCBS Waiver: [LINK]
- Synopsis of Extraordinary Care Strategies Across States: [LINK]

About NASDDDS

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) represents the nation’s agencies in 50 states, Puerto Rico, and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families.

www.nasddds.org