

### Considering the Options:

## Paying Parents with Medicaid Home and Community Based Services to Provide Support to Family Members with Developmental Disabilities

Outlined below is the information compiled about paying parents of adults and/or minor children with developmental disabilities with Medicaid funding. It includes a summary of current practice in Vermont and what might be possible if the necessary changes to policy were made. Also outlined are advantages to paying parents, what needs to be considered, what safeguards might be feasible, and other issues for discussion.

### What is current practice in Vermont?

Funding	What <u>is</u> Allowed	What is <u>not</u> Allowed
Global Commitment: Developmental Disabilities Home and Community-Based Services	* Pay other family members (e.g., siblings, grandparents) who are not the legally responsible relative. <i>(1915c DD Waiver Application)</i>	* Pay natural or adoptive parents, spouse or domestic partners, or guardians to provide direct services. <i>(1915c DD Waiver Application)</i>
Choices for Care 1115 Long Term Care Waiver	* Pay parents (“Legally Responsible Relatives”) of adult children for personal care. <i>(1915c Long Term Care Waiver Application)</i>	
State Plan Medicaid		* Pay parents (defined as “Legally Responsible Relatives”) to provide personal care services to their minor children. <i>(Federal regulations 42 CFR §440.167 and Medicaid State Plan Manual Section 4480(D))</i>

## What changes are possible?

Funding	What is Possible	What Would Need to Change
<p>Global Commitment: Developmental Disabilities Home and Community-Based Services</p>	<p>* Pay parents of minor and/or adult children for personal care and any other service under 1915c and 1115 waivers.</p>	<p>* Under Global Commitment –</p> <ul style="list-style-type: none"> <li>- Would need to “modify established state procedures” and possibly the “operational parameters ...defined in the Intergovernmental Agreements between the MCO and [DAIL]” (<i>CMS Special Terms and Conditions letter 12/15/05</i>).</li> <li>- Would need to amend waiver application and have CMS review – need to change who is identified as qualified staff in “waiver services definition”.</li> <li>- For payment to legally responsible individuals, states must 1) provide detailed information on who may be paid to provide services and what those services are; 2) have a process to make “extraordinary care” determination; 3) show how it is in the best interest of the individual; 4) show how to ensure payments are made only for services rendered; 5) 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; and 6) address other foreseeable risks that might attend the provision of services by legally responsible individuals.</li> </ul> <p>(<i>Application for 1915c HCBW Instructions, Technical Guide and Review Criteria</i>)</p>

<p>State Plan Medicaid</p>	<p>* The parent can be paid to provide professional, skilled services (e.g., legally certified or licensed, such as to provide skilled nursing or physical therapy) to their minor child, which they are not already legally obligated to provide. <i>(State Medicaid Manual, Section 4442.3(B)2)</i></p> <p>* The parent of a child aged 18 – 21 can be paid to provide personal care services (or any other service the State permits parents to provide) as they are not, by law, legally responsible to provide care. <i>(State Medicaid Manual, Section 4480(D))</i></p> <p>* Children’s Personal Care Services as currently defined in the State Plan is an EPSDT service, and as such, cannot be restricted only to parents of “severely disabled children” because it would limit the amount or scope of services to individuals entitled to the service.</p>	<p>* The restriction is based on the presumption that a Legally Responsible Relative may not be paid for supports that they are ordinarily obligated to provide, such as personal care to a child. - Situation must meet “extraordinary care” criteria for the state to make an exception to the requirement that parents of a minor child cannot be paid to provide services to the minor child. - Must also be allowed within the confines of the State’s Nurse Practice Act. Would need State and CMS approval. The Pediatric High-Tech Program (up to age 21) allows parents who are Registered Nurses to act as their child’s high-tech nurse and be paid by Medicaid. <i>(VT Nurse Practice Act – Title 26 Ch 28 §1571-1601).</i></p> <p>* We would need to use a waiver or change the State Plan if we want to restrict Children’s Personal Care Services to a specific category of individuals (e.g., “severely disabled children”).</p>
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## **What are the advantages to paying a parent?**

While developmental disabilities services are predicated on the value that individuals be supported to make choices, direct their own lives and be as independent as possible, it is recognized that there are times when it may be the individual's choice and/or in his or her best interest to receive paid supports from family. The following are examples of how paying a parent may result in better outcomes to a minor or adult child living at home.

1. Parents have knowledge and understanding of their child and may be uniquely qualified to provide supports (e.g., experience, medical knowledge).
2. Parents have a commitment to their child's wellbeing and can build on strong, caring relationships.
3. An individual wants his or her parent to be the caregiver; he or she may prefer the comfort and assurance that can come from receiving care from a familiar and trusted family member.
4. Parents providing consistent and stable supports and may be a viable option when there is a shortage or high turnover of workers.
5. Parents may be more attuned to their child's language and culture; where it may be difficult to find support workers who know the individual's language and culture.
6. It may help stabilize a family situation; for example, it may reduce stress on family when it is difficult to find and/or keep workers.
7. It may mitigate financial concerns when a parent needs to forgo out-of-home employment to stay home to take care of a child; may reduce poverty-induced dependency on other services.
8. An individual may stay at home longer instead of going into a more expensive residential placement, becoming institutionalized, or becoming homeless.

## **What have other states done?**

There are many issues and concerns to be discussed and evaluated around paying parents to provide services to their minor and adult children. The following is a list of some issues and concerns shared by other states that have paid parents.

## **Assessment / Choice**

1. What would the assessment process be to assure that paid supports do not supplant typical parental responsibilities at each developmental age?
2. How to assure respect and support for the choice and control of an adult child in determining where they want to live and from whom they get supports? How to consider potential changes to the relationship between an adult child and his/her parent when the parent is paid to provide the supports?
3. How could an individual be supported to voice an opinion that is different from his or her parents (e.g., personal relationships, desire to move from parent's home; wish to live more independently)?
4. What safeguards can be incorporated to avoid situations where a parent is acting as both the employer of other support workers and an employee providing paid supports?

## **Services / Funding**

5. What supports could a parent be paid to provide to their child? Can a parent be paid to coordinate their child's care?
6. How would payments to a parent be made and by whom? Can a parent receive a tax-exempt difficulty of care payment for providing support to a minor or adult child?
7. Would a parent's income change the parent's eligibility for SSI/SSDI? (See #7 under "Other Issues for Discussion".)
8. Should services be limited when a parent is the paid provider (type of service, number of hours, scope of care)? Would this change how the minor or adult child could request changes in the amount of support?
9. Would a parent be paid the same as other paid workers to do the same work?
10. Would there be considerations regarding whether there would be any cost savings or an increase in costs by paying a parent?
11. Should there be a different expectation of services when a parent is being paid? For example, could it result in less required services for lower cost? Could it shift the expectation to assuring health and safety only (e.g., personal care, supervision, medical oversight) versus the expectation of paid workers to help an individual be as independent as possible through active teaching and facilitating independence?
12. Would there be a different expectation in documentation or reporting responsibilities for a parent?

13. Would a parent need to be hired or contracted by a Designated Agency/Specialized Services Agency (DA/SSA)?

### **Quality Assurance / Safety**

14. What qualifications must a parent meet to be paid? Must parents be trained and/or meet the same competencies as other workers who provide similar services? How would this determination be made?

15. Would a parent be held to the same expectation as agencies for meeting the core values, principles, and outcomes because they are being paid with State funding?

16. How would nursing oversight be assured as required by the Vermont Nurse Practice Act?

17. What safeguards could assure sufficient support for an individual and a parent to mitigate stress and burnout?

18. What safeguards can be put into place that will assure oversight and action if a parent's dependence on income restricts an individual's ability choose to no longer live at home or have someone else be paid to provide the support?

19. How can independent quality oversight be assured when the supports are provided by a parent in the parent's home (e.g., difficulty of an outside entity monitoring supports provided by paid parents, assuring oversight by a Qualified Developmental Disability Professional)?

20. Are there times when the State can or should be able to say no to a parent being paid and, if so, what would be the criteria and process?

### **What safeguards are feasible?**

Based on the experience of other states, the following safeguards may address some of the considerations noted above when parents are paid to provide supports to their minor and/or adult children. These ideas are for consideration and discussion and are not meant to address all issues.

1. Outline clear criteria on how paying parents would work. Give specific examples. Be clear about concerns and criteria designed to address those concerns.
2. Expect parents to follow the same State rules, policies, and guidelines as other paid workers (e.g., DAIL Background Check policy, Quality Review Process).

3. Arrange for an independent entity /service coordinator to facilitate a person-centered planning process and assure individuals have opportunity to express their wishes and desires and assure those wishes and desires are incorporated into the individual support agreement. All paid supports must be agreed to in the individual support agreement.
4. Assure individuals have a strong circle of support and/or an effective advocate who does not live with the individual and is not paid to provide direct supports.
5. Develop a prior-approval process to determine that parent-paid services are an individual's choice and are in the individual's best interest. If allowable, identify who makes this decision if a parent who is paid is the individual's Legally Responsible Relative.
6. Set restrictions about paying guardians / Legally Responsible Relative (e.g., disallow a guardian of an adult child to be paid to provide supports to that individual; disallow a guardian from living with an adult child when a parent is being paid to provide supports; disallow a family member from being a guardian when a parent is being paid to provide supports).
7. Develop a process to determine the "extraordinary care" criteria (e.g., the paid supports are not ordinarily performed by a parent or the responsibility of a parent; services would otherwise need to be provided by an agency; qualified staff are consistently not available; services are paid at a rate that does not exceed what would otherwise be paid to a provider; amount and scope of services cannot exceed what is allowed).
8. Build in mandatory respite that is separate from payment to parent for providing direct support.
9. Develop a process to evaluate whether paying the parent is in the best interest of the individual and a process for ending the arrangement for paying a parent, when needed. Consider the role of an Ombudsman or a process similar to a Guardian ad Litem.
10. Develop a process for determining that a parent meets the criteria to be paid.
11. Assure someone other than another household member(s) checks in on a regular basis to see how things are going. Require oversight from an independent Qualified Developmental Disability Professional.
12. Develop a process that provides programmatic and fiscal oversight; including verifying payments are only made for services provided and services provided reflect those approved in the support plan.

## Other Issues for Discussion

1. Consider how to define what children meet the criteria for receiving services and what services they are eligible to receive.
2. How would the System of Care Plan need to change if we allowed parents to be paid? Consider the intent of the System of Care Plan and the contrast between wanting to keep families together and expecting families to provide unpaid support to their minor or adult child for as long as possible. How would funding need to be prioritized to help make this happen?
3. Consider the use of a Specialized Service Agency or a “Transition II” type entity to provide supports to parents who are paid.
4. Verify if a tax-exempt difficulty of care payment can be paid to a parent of a minor or adult child (IRS Code 131: determine how “foster care” is defined – Section 131(c) defines a difficulty of care payment as compensation to a foster care provider for the additional care required because the qualified foster individual has a physical, mental, or emotional handicap.)
5. Review how the Social Security Administration (SSA) rules may affect SSI, SSDI and Social Security retirement benefits when a parent is paid a wage to support their child. Review how SSA rules may affect the parent of a minor (e.g., being paid a wage that is used in the deeming process which results in a decrease of the child’s SSI).
6. Consider whether paying a parent will be less expensive, cost neutral or more expensive given the expectation that State resources be used in the most effective way possible.  
More Costly: parents previously uncompensated now want payment; must pay hourly wages if parents are not eligible for difficulty of care payments.  
Cost Neutral: pay parents same amount as other workers.  
Less Costly: pay parents less for providing lower level of supports than what would be provided by other workers; lengthen time an individual can remain in the parent’s home relieving pressure on out-of-home placements (presuming higher cost for out-of-home placement).