

Caring Families...

Families Giving Care

Using Medicaid to Pay Relatives

Providing Support to Family Members
with Disabilities

National Association of State Directors of Developmental Disabilities Services
NASDDDS

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June 2010

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I. INTRODUCTION

In tandem with the national move from institutional to community-based services over the past three decades, another major change was also taking place, one that only very recently have we have come to recognize and acknowledge. As individuals moved from institutions into the community, most state service systems were oriented toward providing services in licensed or certified out-of-home residential settings such as group homes or adult foster care.

But systems shifted during the mid-1990s from mainly providing services to adults leaving institutions to addressing the needs of children and adults already living in the community seeking supports. This led to a significant change: people continued to live at home with their families rather than enter the residential services system.

According to the most recent data on where individuals with intellectual and developmental disabilities (I/DD) receiving supports and services reside, 57.4% of them live with their families.¹

- ▶ Twenty-five states report that the number of individuals residing with their families is equal to or greater than the total number living in provider-operated residential settings.
- ▶ Seven states (AZ, CA, FL, ID, NJ, SC) report that 70% or more of individuals served live with their families.

While certainly some of this shift is due to expanded services to children, the Medicaid home and community-based services (HCBS) waiver program, the main source of financing for community services nationally, still overwhelmingly serves adults.²

Recent data collected through the National Core Indicators (NCI) project show that nationally, 62% of family caregivers are over 55 years of age. This serves as another indicator that adults with developmental disabilities are continuing to live with their families and not in residential placements.³

The shift to more adults remaining at home with their families is reflected in the general population as well. According to the *New York Times*, using research based on census

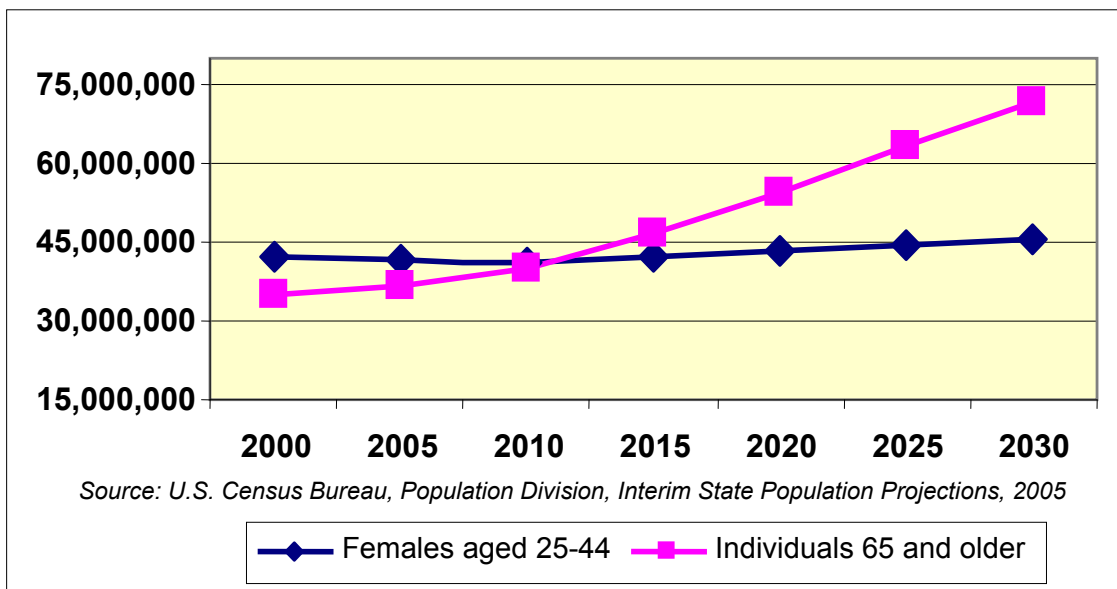
¹ Lakin, et. al, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007*, Research and Training Center on Community Living Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota, August, 2009, p.77.

² 2005 data collected by the Kaiser Family Foundation indicate that about 1.6% of all waiver recipients – across all types of 1915(c) waivers – were children. Data can be found at <http://www.statehealthfacts.org/comparetable.jsp?ind=241&cat=4>.

³ National Core Indicators, *Adult Family Survey: Final Report, 2006-2007 Data*. NASDDDS, April 2008. National Core Indicators, a collaboration between NASDDDS and HSRI, is a set of performance indicators that includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes – outcomes that are important to understanding the overall health of public developmental disabilities agencies. Thirty-one states participate in NCI. (www.nationalcoreindicators.org)

analysis, beginning in 2000, more adults ages 25-39 are living in their parents' homes. In 1980, only 11% of 25-to-34-year-olds were living in multi-generational households, but by 2008, 20% were. Even in 2008, before the effects of the recession were felt, the numbers living at home increased 32% nationally. And in places like Manhattan, the increase of adults living with their parents rose by 40%.⁴

This shift to more individuals served in the community while living at home comes in conjunction with other service system pressures. As is reported regularly, we already have a national shortage of direct support professionals. With the aging of the baby boomer generation, these shortages will become more acute. As the chart below shows, the number of individuals over age 65 is increasing steeply while the number of females aged 25-44 – the main source of direct caregivers – remains flat.



Coupled with a shortage of caregivers are the serious budget issues faced by almost all states. These pressures mean states are both seeking ways to serve individuals and trying to prevent or lessen dependence on costly out-of-home residential services, particularly services provided on a 24-hour/7 days a week (24/7) basis. More than 23 states have divided up their comprehensive home and community-based services waiver programs, creating supports waivers that offer a capped amount of services (typically non-residential) to individuals mainly living in the family home or in their own homes. These waivers, while providing needed supports, are a means to assist individuals to remain in the family home longer, delaying entrance into the out-of-home residential services system.

⁴ Roberts, Sam, "Facing a Financial Pinch, and Moving In With Mom and Dad", *New York Times*, March 21, 2010.

However, services provided in the home also require paid caregivers to provide them. In-home services have been as affected by the shortage of caregivers as have residential services. Services might be authorized in the home, but without available support workers, the service cannot be provided. In these situations, caregiving falls on family members who sometimes have had to quit their jobs or transition to part-time employment because they could not rely on the availability of caregivers. As a result, families suggested that they be paid in lieu of caregivers coming into their home, thus stabilizing supports and clearly providing qualified care to the person. This approach compensates family members for time out of the workforce and still provides a cost-effective alternative to the state.

An unsettling statistic garnered from National Core Indicators is that 48% of family caregivers have an annual income (all wage earners) of less than \$25,000.⁵ Although this data is based on self-reports and does have some statistical limitations, the conclusions are inescapable: significant numbers of people with disabilities receiving publicly financed supports are living with families who are poor. Some states report family members (including immediate family members and other relatives) who are seeking to be paid for care as the employment and income are critical to the financial viability of the family home. Becoming a paid caregiver may, in some instances, be a path to stabilizing the family situation and assuring that an individual *can* remain at home with caring and qualified supports.

Factors such as shortages of direct care staff, families' interest in being compensated for care they provide, and, needing the income in some cases, have challenged states to develop public policy that meets the expectations of individuals with disabilities, their families, and the general public.

Certainly there are positive factors that make paying family members an attractive option. Family homes are a typical setting. Individuals can maintain lifelong community ties and contacts. The National Core Indicators data indicate that individuals who live at home have a high degree of satisfaction with where they live. (Of those living with family, 96% said they liked where they live. For those not living with family, 87% indicated they liked where they live.) A higher proportion of individuals living in congregate settings indicated they were afraid (23.4%), while individuals living with family were least likely to report feeling afraid at home (17%). And individuals living with family were less likely than those living in congregate settings to report feeling lonely *sometimes* or *often*. (In congregate settings, individuals reported feeling lonely *sometimes* 34% of the time and *often* 17%, while those living with family report feeling lonely *sometimes* 34% of the time and 8.9% *often*.)⁶ Family members have knowledge

⁵ NCI, Adult Survey, April, 2008 p.13.

⁶ Lakin, K. C. Doljanac, R., Byun, S. Y., Chiri, G., Stancliffe, R., Taub, S., *Medicaid Home and Community-Based Services for Persons with Intellectual and Developmental Disabilities: Background and Findings from Consumer Interviews and the Medicaid Statistical Information Systems*, Final Report Prepared for the Centers for Medicare & Medicaid Services, submitted by the University of Minnesota Research and Training Center on Community Living, September 2006, p.35.

and understanding about the individual and a commitment to the well-being of the individual that may go beyond that which can be offered by paid staff. Family members can provide stability in caring for individuals in contrast to residential and supported living programs that experience significant turnover. In terms of the “needs” of the services system overall, family members expand the pool of available providers particularly in rural areas. And paying family members may have some positive effects on overall system costs.

But paying family members, like any service option, comes with concerns. States are struggling with creating policies that both permit care by family members but also assure quality and outcomes as well as autonomy for the individual served. As states look to including family members and guardians into the potential pool, many questions arise in crafting public policies:

- ✓ Should states compensate family members for care?
- ✓ Under what conditions should family members be compensated for care?
- ✓ Which family members should be compensated?
- ✓ Should legally responsible relatives be allowed to provide paid care?
- ✓ Should guardians of an individual (either of the person, financial, or both) be reimbursed for providing care? Under what conditions, if any?
- ✓ Should there be limits on the amount of care provided by family members?
- ✓ Should family members have to meet the same qualifications as other provider personnel of similar services?
- ✓ Must family members be hired by an agency in order to provide services?
- ✓ What is the effect on existing “natural” supports?
- ✓ What safeguards should be in place to assure that the individuals with disabilities retain options for choice and control in their own lives when family members, legally responsible individuals, or guardians provide care?
- ✓ How do you assure individual rights for an adult with disabilities living in the family home and receiving paid support from family members?
- ✓ How do you assure service quality and outcomes when family members provide care? Is this different from the “traditional” system?
- ✓ Under what conditions can/should the state say “no” to paying a family member?

We will explore how some states have tackled these issues in hopes that their experiences will offer some guidance as to the positives and pitfalls of paying family members, legally responsible individuals and guardians for care.⁷ The report focuses on the use of Medicaid-funded HCBS services, typically through the use of the 1915(c) waiver program.⁸

⁷ Two recent reports may be of interest: San Antonio, Patricia, et al., “Lessons From the Arkansas Cash and Counseling Program: How the Experiences of Diverse Older Consumers and Their Caregivers Address Family Policy Concerns”, *Journal of Aging & Social Policy*, January 7, 2010, and Simon-Rusinowitz, Lori, et al., “Hiring Relatives as Caregivers in Two States: Developing an Education and Research Agenda for Policy Makers” *Social Work in Public Health*, 25:17-41, 2010.

⁸ A few states including Arizona, Maine, and Vermont provide their HCBS services through a Medicaid 1115 research and demonstration waiver.

II. TERMS

Legally Responsible Individual

“Legally responsible individual” is a very specific term in CMS parlance. The *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria* (heretofore referred to as the “Technical Guide”) defines a legally responsible individual as:

*A person who has a legal obligation under the provisions of state law to care for another person. Legal responsibility is defined by State law, and generally includes the parents (natural or adoptive) of minor children, legally assigned caretaker relatives of minor children, and sometimes spouses.*⁹

As the CMS definition indicates, state regulations come into play as some states may not define spouses as legally responsible. It is our experience that most do, particularly with the advent of spousal impoverishment rules that protect spousal resources for Medicaid-eligible individuals.

The CMS definition means that court-appointed guardians are not considered legally responsible for the purposes of Medicaid, although guardians may have court-assigned responsibilities to act on behalf of an individual. (See below.)

Relatives

Relatives are generally described as individuals related by blood or marriage to the Medicaid beneficiary. This definition may include immediate and/or extended family. Some states make a distinction between immediate family (parents and siblings) and extended family, with differing rules regarding paying these two groups. States have the option to craft their own definition of what group constitutes relatives for the purposes of payments.

Guardians

The legal definition of a guardian is “a person who has been appointed by a judge to take care of a minor child (called a “ward”) or incompetent adult personally and/or manage that person’s affairs.”¹⁰ Guardianship is a legal relationship and must be established through a court proceeding. Many parents of adults with intellectual and developmental disabilities mistakenly assume they are guardians, but unless the individual has been declared incompetent and the parent(s) has petitioned the court for

⁹ *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria*, release Date, January, 2008, p. 300.

¹⁰ Thomson, Gale et al. *West’s Encyclopedia of American Law*, 2nd Edition. Copyright 2008 The Gale Group, Inc.

and been granted guardianship, parents of an adult have no *legal* standing with regard to decision-making for the individual.

As noted above, while court-appointed guardians of adults may have certain responsibilities under the law, they are not, for the purpose of Medicaid regulations, legally responsible individuals. Individual states may choose to define guardians as legally responsible individuals, but federal regulations do not.

III. FEDERAL POLICY ON PAYING RELATIVES

State Plan Services

Under the State Medicaid plan, services generally cannot be provided by a parent of a minor child or a spouse. Anyone providing the service is required to meet the same provider requirements as any other provider – states cannot set different provider standards for family members. Although parents have been prohibited as providers generally, CMS did allow states to make an exception to this requirement in “extraordinary” circumstances. The State Medicaid Manual, section 4442.3 (B)2 reads:

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.

This has allowed Medicaid payment for professional services to legally responsible relatives typically in situations where there is no other provider available. In addition, it is a cost-effective alternative and in the best interests of the beneficiary.

Personal Care. The regulations under the State Plan regarding the provision of personal care is even more explicit. Federal regulations expressly prohibit legally responsible relatives from providing personal care under the State Plan. Federal regulations under 42 CFR §440.167 note that:

- Personal care services [may be],
- (2) Provided by an individual who is qualified to provide such services and who is not a member of the individual's family; and...
 - (b) For purposes of this section, family member means a legally responsible relative.

This prohibition is based on the presumption that legally responsible individuals may not be paid for supports that they are ordinarily obligated to provide, such as personal care to a child or spouse.

HCBS Waiver Services

Over the past decade, federal policy regarding paying relatives has evolved considerably, particularly for services provided under the HCBS waiver. Initially, HCBS waiver policies closely followed the payment and provider policies applied to the State Plan. Although legally responsible relatives could be paid for services *other than personal care* much like under the State Plan, it was not widely known. Very few states used this option. Early on in the history of the HCBS waiver program, West Virginia asked for and received permission to qualify parents of minor children as habilitation providers. Over the next two decades, a few additional states used the option of paying legally responsible individuals for professional services, most notably private duty nursing services in rural areas. One western state found that it was cost-effective and in the best interests of a few children to qualify a parent to provide nursing care rather than move the child to a nursing home or other facility since community-based nursing services were not readily available in very rural areas. Paying the parent allowed the child to remain at home and receive needed care that was more cost-effective than other options and in the best interests of the child.

Although legally responsible relatives could provide services *other than personal care* at state discretion, CMS maintained the prohibition on paying for personal care requiring states to verify in the waiver application that “Payment will not be made for services furnished to a minor by the child's parent (or stepparent), or to an individual by that person's spouse” (Appendix B-1, d.1., 1915(c) waiver template, Version 06-95)

In 2003, CMS changed the HCBS waiver policies to explicitly allow legally responsible relatives to provide personal care. Minnesota led this change requesting that CMS allow legally responsible parents to provide personal care for their children. Minnesota was an early adopter of State Plan personal care services finding this an effective alternative to institutional care. The state had already instituted a protocol by which to make decisions about when children should receive State Plan personal care – based on the developmental stage of the child and what are typical parental responsibilities at each developmental age.¹¹ This laid the groundwork for the change in policy.

CMS continued to clarify their policies and, in the most recent version of the Technical Guide, lays out the requirements for paying legally responsible individuals for personal care, along with guidance on paying relatives and guardians to provide other types of services.

Paying Legally Responsible Relatives for Personal Care

Under the HCBS waiver, CMS makes a critical distinction about paying relatives and guardians versus paying *legally responsible* relatives with regard to the specific type of

¹¹Minnesota uses a screening tool to assess when paying a parent for personal care services is appropriate called, “Determining ADL Dependency in Children 18 and Younger,” found in their *Consumer Directed Community Supports, Lead Agency Operations Manual*, Minnesota Department of Human Services, Appendix E, p. 82

service being provided. When a state elects to pay legally responsible relatives for *personal care or similar services*, CMS requires the state to provide detailed information in the HCBS waiver application. Personal care or similar services are defined as: “(a) personal care (assistance with ADLs or IADLs) whether furnished in the home or the community and however titled by the state in the waiver (e.g., personal assistance, attendant care, etc.) and (b) closely related services such as home health aide, homemaker, chore and companion services.”¹² CMS characterizes paying legally responsible relatives for personal care as, “*extraordinary care payments*” [italics theirs], highlighting that there are special conditions under which CMS permits states to elect this option.

If a state chooses to permit legally responsible relatives to provide personal care services, the state must provide detailed information in the waiver application covering the following areas: “(a) the legally responsible individuals who may be paid to furnish such services and the services they may provide; (b) State policies that specify the circumstances when payment may be authorized for the provision of **extraordinary care** [emphasis theirs] by a legally responsible individual and how the State ensures that the provision of services by a legally responsible individual is in the best interest of the participant; and, (c) the controls that are employed to ensure that payments are made only for services rendered.”¹³

CMS offers guidance in the Technical Guide as to the issues states should address when considering paying legally responsible relatives. They indicate that their review of a state’s application will look at the “method for determining that the amount of personal care or similar services provided by legally responsible individual is ‘extraordinary care,’ exceeding the ordinary care that would be provided to a person without a disability of the same age.”¹⁴ CMS does not provide any particular protocol nor any specific guidance as to the methods states should use, but the state must have a process to make this determination.

CMS also asks that the state make a determination that paying legally responsible relatives is in the “best interests of the waiver participant.” The guidance goes on to note that 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.”¹⁵

Clearly, CMS is concerned that participant choice and control be preserved when legally responsible relatives are paid for providing care. While again, CMS is not prescriptive, the 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. CMS offers

¹² *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria*, Release Date, January 2008, p. 119

¹³ *Application for a §1915 (c) HCBS Waiver, HCBS Waiver Application Version 3.5*, Appendix C-2:3-d.

¹⁴ *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria*, Release Date, January 2008, CMS Review Criteria, p. 119

¹⁵ *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria*, Release Date, January 2008, p. 119

the following example to illustrate the type of limits a state might impose: “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.” It seems that CMS is “cueing” states to look at what appropriate and reasonable limits they may want to put on the amount of service the state will pay for from legally responsible relatives in order to preserve the amount of unpaid care the family member might typically give. CMS also asks that states address how they will assure that legally responsible relatives are paid only for care they actually render – and how the state has also addressed “other foreseeable risks that might attend the provision of services by legally responsible individuals.”

Again, CMS is does not enumerate what the state must specifically address-but by asking for this type of descriptive materials is apparent that CMS is aware of some of the potential issues that may arise when paying legally responsible relatives.

IV. SURVEY RESULTS

In early 2009, state HCBS waiver managers responded to an online survey titled “Paying Relatives and/or Legally Responsible Relatives.” In addition to factual questions about the size of the program and what category of relatives the state reimbursed, states were asked about any restrictions they have on who may be paid and for what services and if provider qualifications were the same or different for relatives. A copy of the survey can be found in the appendices. Just as a clarification, the survey incorrectly included guardians under the legally responsible category. While some states have regulations regarding the legal responsibilities of guardians, under Medicaid they are not considered legally responsible. Medicaid, as noted above considers only spouses and parents of minor children legally responsible. The collated survey results correct for this, thus only parents of minor children and spouses are counted under the legally responsible category. Overwhelmingly, states have chosen to pay relatives to provide supports. Of the 48 states responding, only 2 do not pay relatives at all, thus fully 96% of the respondents pay relatives to provide supports.

SURVEY RESULTS: Paying Relatives for Care	
Total number states responding N=48	
Type of relative paid	Number of states
None	2
Parent of a minor child	6
Spouse	10
Guardian of child	6
Guardian of adult who is a parent	21
Guardians who are other relatives	23
Guardians who are not relatives	18
Parents who are not legally responsible (parents of adults)	36
Siblings	44
Grandparents	45
Other relatives	46

Paying Legally Responsible Individuals

Of the 48 states (the District of Columbia is included as a state) responding to the question whether they allowed payment to legally responsible relatives, 11 (23%) indicated they pay legally responsible relatives (parents of a minor child or a spouse) for care. Of these 11 states, 10 pay spouses and 6 pay parents of minor children.

Paying Guardians for Care

Many states allow the payment of guardians for care, but there are some nuances regarding which guardians are paid. Six states indicated they would pay a guardian of a child. Twenty-one states noted that they would pay a guardian of an adult who is also a parent of the person, while 23 states indicated they pay guardians of adults who are other relatives. Interestingly, only 18 states agreed they would pay the guardian of an adult who is not a relative.

Paying Other Relatives for Care

Of the 48 responding states, 46 indicate that they do pay other relatives – that is relatives other than a parent or spouse to provide care, while only two states do not pay any relatives at all. Thirty-six states indicate they pay parents who are not legally responsible, that is, parents of an adult. Forty-four states pay siblings, 45 states pay grandparents and as noted above, 46 states pay other relatives to provide care (such as aunts, uncles, nieces, etc.)

Provider Qualifications/Restrictions on Services

As noted earlier, two states do not qualify relatives as paid providers, while 27 states indicated that they restrict what services they will qualify relatives to provide. Ten states indicate that the provider qualifications are different for relatives than for non-related providers, while 38 report that relatives must meet the same provider qualifications as non-related providers. In later sections we discuss some of these limitations as well as the specific types of provider requirements states employ.

V. KEY ISSUES AND STATE POLICIES

Why Compensate Relatives for Providing Care?

As noted in the survey results only 2 of the 48 responding states indicated that they do not have provisions for paying relatives, demonstrating that relatives are widely seen as a viable source for providing needed care. In interviews with state personnel, multiple reasons were offered for why they choose to allow payment of relatives. Certainly workforce issues have driven states to expand the pool of qualified workers to include relatives. As one state official noted, “Without the option, simply finding providers would prove very difficult, especially in the rural areas of our state.”

Relatives provide a pool of knowledgeable care. Many of them brought into the paid workforce know the individual well and have already provided care in the past. Including relatives into the workforce has allowed individuals to remain in the family home while building on strong and caring relationships. For example, Minnesota, one of the six states that pay parents for providing personal care for minor children, notes in their policy, “The intent of this option is to maximize the available personal assistance resources within the home and community-based service system, and to provide consumers with the comfort and assurance of receiving care from familiar and trusted individuals. Generally, consumers rate services from qualified and capable relatives as high quality with a high level of satisfaction.”¹⁶ One state noted that the preferences of the individuals supported were critical in using relatives to provide care. They offered the example of one self-advocate who said, “The person I feel most comfortable with touching me [to provide personal care] is my mom.”

Some states indicate that paying a family member may be a cost-effective alternative to paying someone else to care for an adult individual while the family member goes out to work. As an example, if the potential family caregiver is out working, more hours of paid care may be needed to cover not only work but also travel time to and from work. In addition, the family caregivers may need respite time in order to perform other household responsibilities or care for other family members, all adding to costs.

It is not uncommon for states to cap payment to family members – particularly those that live with the individual – to 40 hours per week. One critical reason that states cap the hours is to comport with wage and hour regulations regarding overtime. Some states use the logic that the family member is paid for a “typical” work week, but continues to provide unpaid care other times during the week. In a sense, the payment for care allows the continuation of unpaid supports, again extending the time the individual can continue to remain in the home with supports and not seek out-of-home placement.

States anecdotally report that in some situations payment of a relative to provide care lengthened the time the individual was able to remain in the family home, relieving pressure to seek out-of-home placement. Providing supports to keep an individual in the family home may also be cost-effective in some situations given the typically higher costs of out-of-home placement. Data found in the 2008 report on residential services and trends by Lakin, et al. offers some indication that keeping individuals in the family home may have an impact on overall costs. For 5 of the 6 states that reported the highest use of family homes (over 70% of individuals served in the family home), the average annual costs ranged from about \$22,956 to \$39,343 against a national average

¹⁶ *Consumer Directed Community Supports*, Lead Agency Operations Manual, Minnesota Department of Human Services, page 79.

annual cost of \$43,464.¹⁷ Only New Jersey's costs exceeded the national average costs per person served in the HCBS waiver.

Unfortunately, there are no national data contrasting the costs of in-home services provided by paid staff members with expenditures related to the provision of comparable services furnished by paid family members. Although the evidence points to lower costs for individuals living at home, we do not know if *paying* family members is directly related to this lower cost.

While it makes intuitive sense, and states give anecdotal evidence that paying family members may reduce overall expenditures by delaying entrance into 24/7 out-of-home placement, we do not have any data that directly correlates decreases in out-of-home placements with the payment of relatives to provide services in the family home. For example, one state reported that using family members as host home providers was a cost-effective alternative to residential services for individuals with high medical and behavioral needs. Other states noted that the rates paid for services provided by family members can be significantly lower than those paid to out-of-home residential services providers. And a number of states cap the amount of services they will pay a relative who is residing with the individual in the same home, thus reducing potential service costs for around-the-clock care in an out-of-home residential program. As one state official noted, "There is a savings as the rate we pay for family living is substantially lower than what we pay for supported living."

Conversely, at least one state reports that paying family members may have added to cost as many more families, who previously provided uncompensated care, are coming forward seeking payment for their continued caregiving.

States do express concern about the impact on unpaid care when family members are paid to provide care. Certainly there is an interest in paying family members as a means to assure that individuals can continue to live in a family home and receive needed care – without replacing all the natural supports a family offers.

Many states have policies on the amount of care that can be provided by a family member, limiting the paid hours per week to 40 hours. This limit also assures compliance with wage and hour laws. And states that permit parents of minors to provide care use some type of assessment to assure that the paid support is "above and beyond" what a parent typically would provide for a parent of that age. One state noted that they have worked to preserve unpaid supports by making this topic part of the planning conversation. In this state, support brokers include discussion of how paid supports will help the family continue the unpaid supports the family may already be providing.

¹⁷ Lakin, et al, (2009). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008*, Minneapolis: University of Minnesota, Research and Training Center on Community Living Institute on Community Integration. p.105.

Although it is often unspoken, paying a family member can stabilize the home situation financially, allowing the individual to continue to live in the family home. As noted earlier, just about half of the individuals surveyed who live at home, live in poor families, NCI data shows. The income paid to a family member to provide care may be vital to maintaining the home for the person with a disability and thus is appropriate and in the interests of the individual who wishes to remain in the family home. But this situation can raise concerns about how to assure that the situation is in the best interest of the person and that individuals (most importantly, adults) continue to have choice and control over their own lives.

Another state employee noted, “Beware – the family living model has its traps and can create a system of the recipient being the only source of income for the family, thereby limiting their ability to ever leave the home.” While there are clearly many appropriate and defensible reasons to use family members to provide paid care, the decision to pay relatives comes with the same responsibility to assure individual choice and control as well as the quality and outcomes of the supports provided as with any providers.

State Policies on Paying Relatives

General Policies

Within the broader policy of paying relatives, there are distinctions as to which relatives states choose to pay. As the survey data show, states’ policies differ with respect to paying parents and paying other relatives. As noted above, 45 states pay grandparents, 44 pay siblings, and 46 pay other relatives such as aunts, uncle, nieces, and nephews. As we look at paying parents, the numbers change. Thirty-six states pay parents of adults, but a total of only 11 states pay legally responsible relatives, with 6 states paying the parents of minor children, and 10 states paying spouses.

Missouri. Many states have a general policy with regard to paying family members. Missouri, for example, allows the payment of relatives and family members for personal care and respite services under their comprehensive and community support waivers. It uses a protocol in reviewing the use of relatives that addresses key concerns about some of the knotty issues that arise when paying relatives for care. Missouri’s protocol looks at issues such as whether the individual being supported wants the family member to provide care, if the care is provided to benefit the person – not the family unit, and that the service is cost-effective and does not supplant the care typically provided by family members to each other. Its planning approach directly addresses what can often be contentious concerns. Missouri requires that the person’s individual plan must reflect:

- The individual is not opposed to the family member providing services;
- The services to be provided are solely for the individual and not household tasks expected to be shared with people living in the family unit;
- The planning team determines which family member should be paid to provide the services that best meet the individual’s needs; and,

- A family member cannot be paid over 40 hours per week. Any support provided above this amount would be considered a natural support or unpaid care that a family member would typically provide.

Louisiana provides an extensive “thought protocol” when using family members as paid support workers.¹⁸ Although Louisiana’s protocol is not yet in final rule, individual service planning guidelines give a list of questions and examples that should be taken into consideration. Louisiana’s approach is very centered on the preferences and needs of the individual and openly and frankly looks at possible issues that can compromise the individual’s choice and control. Below, is a sample of some of the questions and issues the planning team considers when using family members to provide supports:

- **Is the use of a family member age and developmentally appropriate?** The team needs to consider the day from the person’s perspective. Sometime having family around may be fine. Other times may not be. Does a 30-year-old generally have his mom accompany him to evenings out with friends? Not usually. Support teams must look at ways of using family as paid direct service workers in situation-appropriate times that are consistent with meeting the person’s support needs. If using family as a paid direct service worker for some times makes sense, then consider including non-family members for shifts involving planned socializing and peer interaction.
- **Will using family members as paid direct service workers enable the person to learn and to adapt to different people and also to form new relationships?** The support team must build in opportunities to meet different people and form relationships, including making choices about selection of different direct support workers.
- **Is the person learning flexibility and skills for increased independence?** The support team and IFS provider must reinforce with the family member that he/she is not in a “caretaking” role, but rather in a supportive role that is intended to encourage autonomy and skills-building for independence in community living. The support team must ensure that the family member providing direct support approaches the job as such and does not present barriers to individual goals and treatment objectives.
- **Is this about the person’s wishes, desires, needs, or about supplementing a family member’s income?** Support teams must consider the motive and level of commitment of a family member requesting to act as a paid direct service worker. Protecting against exploitation is key. In the end, if a family member is only

¹⁸ Excerpts from: "FAMILY MEMBERS AS STAFF, New Opportunities Waiver Rules Regarding Use of Family Members as Paid Direct Support" (*Louisiana Register*, Vol. 30, No. 6, June 20, 2004 §13901. Individualized and Family Support and §13907 Residential Habilitation, Supported Independent Living). [A complete copy of Louisiana’s policies can be found in the Appendices.]

focused on money, the quality of care will be low, and the person will be put at risk.

This type of planning protocol assists the state in assuring that the focus of the services is on the needs and preferences of the individual.

State Policies Specific to Certain Relatives/Guardians

State policy varies widely as to the types and amount of services some or all relatives may provide. Some states choose only to allow relatives to be paid under consumer-directed options, while other open up payment to family members in all their programs. Below we explore some of the states' approaches to family members and some of the issues in using family members as support providers.

Legally Responsible Relatives

CMS policy, as described earlier, requires that if a state is to pay legally responsible relatives for personal care there must be a need for "extraordinary" care. Many states apply some type of "extraordinary care" criteria to the services they permit legally responsible individuals to provide. One of the key concerns in paying legally responsible individuals is the issue of paying for care that otherwise falls within the typical responsibility of that individual. This issue is most salient in paying the parents of minor children for personal care services. States are understandably reluctant to pay for care that otherwise is a typical responsibility of a parent and is appropriate to the age of the child. States have a variety of policies – some exclude personal care while others set protocols to assure that the care given and compensated is related to the child's disability and not typical care for a child of that age.

As an example, **Pennsylvania** allows payment of legally responsible individuals for only certain services, and unlike Minnesota, does NOT include personal care as a service provided by legally responsible individuals. Although Pennsylvania does not include personal care, they still review the request for payment to a legally responsible relative as part of the person-centered planning process, using the criteria below:

"Legally responsible individuals may be paid to provide services funded through the Waivers on a service-by-service basis... These individuals may be paid to provide Waiver services when the following conditions are met:

- The service is considered extraordinary care, which means it is not part of the supports the legally responsible individual is ordinarily obligated to provide;
- The service would otherwise need to be provided by a qualified provider of services funded under the waiver; and

- The service is provided by a legally responsible individual who meets the qualification criteria that are established by ODP [Office of Developmental Programs] in Appendix C-3 of the approved Waivers.”¹⁹

Other states use similar protocols to determine when a legally responsible individual may provide care, particularly with regard to personal care-type services, the one service in particular that CMS policy directly mentions.

Minnesota sets criteria which must be met in order for a spouse or parent of a minor child be permitted to provide personal care services. Their policies require certain criteria be met including that the parent or spouse meet all provider qualifications and that the service is not an activity that a parent or spouse would normally provide, such as transportation of children or household maintenance.²⁰

Minnesota policy with regard to children under 18 further indicates that, “A parent is legally responsible to meet the needs of a minor child, including the need for assistance and supervision typically required for children at various stages of growth and development. A parent can, however, receive payment for Personal Assistance Service when this support 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.”²¹ For the parent of a minor child to be paid to provide personal assistance services to their child, the case manager must complete an assessment that identifies that the child is “dependent beyond typical age-related dependencies.” This assessment, the [Long Term Care Consultation Services Form: Supplemental Form for Assessment of Children under 18 \(DHS-3428C\)](#), is used to determine what care may be compensated and what is typical care for a child (at that age).²² The assessment is used as the basis for determining whether or not the legally responsible relative will be paid for care. A similar process is used when a spouse is paid for care with the case manager completing an adult assessment of ADL skills.

West Virginia allows the payment of natural and adoptive parents and legal representatives of children (and adults) for some services, including respite and community residential habilitation. In these instances, West Virginia requires an “Extraordinary Care Assessment” using a scored instrument that assesses the amount of assistance an individual needs with various adaptive living skills in the context of age. The instrument also looks at motor skills, maladaptive behavior and communications skills as well. The assessment identifies those areas where the individual needs assistance and is used to substantiate the need for care by natural and/or adoptive

¹⁹ Appendix C-2.d, Pennsylvanian Application for a 1915(c) HCBS Waiver # 0147.R04.01, July 1, 2009, p.97

²⁰ A complete list of these criteria can be found in the *Consumer Directed Community Supports (CDCS) Lead Agency Operations Manual*, Section 13, Paying Parent or Spouse under CDCS, 13.3, Determination of ADL Dependency, p. 79-81.

²¹ *CDCS Manual*, Section 13, Paying Parent or Spouse under CDCS, 13.3, Determination of ADL Dependency, p. 80

²² *Ibid.*

parents as well as legal representatives. Family members providing respite are prohibited from living with the individual receiving the respite service.²³

Non-Legally Responsible Relatives and Other Family Members

Parents of Adults. As noted above, 36 of the 48 states responding indicate that they pay the parents of adults to provide services. Most state policies do not make any specific distinction between the parents of adults and other relatives. Parents of adults are treated under state policy in the same way any relative is treated.

For example, **Montana** allows the payment of parents of adults (along with other relatives) for most of their services as long as the parent is employed by a qualified provider agency or becomes a qualified provider under contract to the state.

Some states, such as **West Virginia**, allow the payment of parents for specific services such as respite, adult companion services and community residential habilitation, but require that the parent (or any other family member) NOT reside with the individual being provided the service.

Louisiana allows the payment of a parent for Individual and Family Support services as long as the parent does not reside with the individual and is not the legal guardian of the individual being supported.

Other Family Members or Relatives. There is considerable variation in state policy with regard to paying family members. Some states treat family members in the same way they would any provider and make no special limitations or requirements around the provision of services by family members. Others limit payment to family members or relatives to certain services.

In **Louisiana**, family members who are not legally responsible relatives (defined in state statutes as the parent of a minor child, foster parent, curator, tutor, legal guardian, or the recipient's spouse) may be providers of supported living services if they meet the same qualifications as any other worker. For another service called Substitute Family Care (SFC) – akin to foster home or host home services, immediate family members (mother, father, brother, and/or sister) are not permitted to be providers to their own family member.

Other states have a wide variety of policies that apply only to family members. For example, some states limit the number of hours a family member can be paid to 40 hours per week. Others explicitly state that family members cannot be paid overtime. These policies serve to limit the ways family members can be compensated for care

²³ Extra-ordinary Care Instrument, Attachment DD-25, CHAPTER 513 MR/DD WAIVER SERVICES, NOVEMBER 1, 2007, found at http://www.wvdhhr.org/bms/Manuals/Common_Chapters/bms_manuals_Chapter_500_MRDD.pdf

and reflect state policy aims such as expanding the provider pool or assuring that families continue to provide uncompensated care when possible.

Paying Legal Guardians

As noted earlier in the survey data, about half of the 48 states responding to the survey pay guardians. Only 6 states pay the guardians of children, but 23 will pay the parent of an adult child for whom they are the guardian. Twenty-three states pay guardians who are another relative, while 18 indicated they will pay guardians who are not related.

Some states that do allow guardians to be paid providers add in safeguards to assure that the individual is supported in making decisions. Although federal policy does not consider legal guardians “legally responsible,” some states such as **West Virginia** treat legal guardians as they would parents of minor children, requiring an “Extra-ordinary Care Assessment” when legal guardians provide certain types of paid supports.²⁴

In **Virginia**, the family must have someone not living in the home as an “authorized representative” to assure that the preferences and decisions of an individual being supported are honored.

New Mexico allows only legal guardians who are related by blood or adoption to provide care while according to state regulations other guardians may not act as providers.

Missouri does not permit any family member who is a guardian to provide services, but does not extend this prohibition to non-family members.

Minnesota makes a distinction regarding paying guardians of minors and does not permit the legal guardians and conservators of minors who are not related by blood, marriage, or adoption, to be paid to provide waiver services with the exception of consumer-directed services (described in more detail in the following section).

In **Washington**, when a provider is also a guardian, case managers are instructed to find a third party to monitor that services are being provided as a means to assure the safety and outcomes for the individual being supported.

As is evident, there is little uniformity in state policy for paying guardians. Each state has crafted their policies in accordance with state policy aims or other state regulations. It is noteworthy that some states have taken steps to assure that the voice of the individual being supported is heard.

Virginia’s requirement for an authorized representative is one means to preserve choice and control for an individual when family members or guardians provide care.

²⁴ *Extra-ordinary Care Instrument*, Attachment DD-25, CHAPTER 513 MR/DD WAIVER SERVICES, November 1, 2007. A copy is found in the Appendices to this paper.

The requirement for a representative helps mitigate the issue when a guardian is both a paid service provider and the individual who usually signs off on the individual support plan.

VI. PAYING RELATIVES AND CONSUMER DIRECTED SERVICES

Many states permit the use of family as providers under consumer-directed options. This situation can present some unique challenges. For example, if the guardian is the paid employee, defining who is the employer of record becomes problematic. Even if the person is able to direct their own services, firing a relative (particularly a parent) could become challenging – particularly if the individual resides with the caregiver. As noted earlier, some states do not permit the paid related caregiver to live with the individual – at least mitigating the concern that “firing” could compromise the living arrangement.

Issues of choice and control, as well as competence to direct services can potentially be exacerbated when family members are paid. **Missouri** directly addresses this by a policy whereby if the person employs his/her own workers using an approved fiscal intermediary, the family member serving as a paid personal assistant cannot be the employer of record. Another representative must act on behalf of the person as the employer of record. (Missouri also does not permit legal guardians to act as personal assistants.) This arrangement at least assures separation of these roles, giving some assurance to the individual that they can terminate the employment of the family member if needed.

In **Hawai'i's** consumer-directed program, if an adult has a guardian it is expected that the guardian will take on the role of the person's designated representative. Guardians (who are the representative) cannot hire themselves to provide services. Hawai'i does allow a guardian to be a paid provider when a parent is not the sole guardian of the adult child. One of the guardians can be designated as the representative and hire the other parent/guardian to provide services.

Minnesota approaches this concern by placing some limits on the roles a parent or spouse can be paid to perform. A parent or spouse who is paid for care is able to function in other roles such as those performed by a fiscal management service or a managing employer but may not be compensated for those activities.

VII. QUALITY ASSURANCE AND PAYING FAMILY, RELATIVES, AND GUARDIANS

States all perform a variety of quality compliance and quality assurance activities whether or not immediate family members, other relatives, or guardians are allowed to become paid providers. Routine reviews of individual support plans, monitoring by case managers and support brokers, oversight and monitoring reviews by state staff, data

collection on quality through incident management systems, and other systems such as the National Core Indicators or Council on Quality and Leadership are routine parts of every state's quality management approach. But states engage in some quality management activities that specifically relate to assuring good outcomes when employing family members, relatives, and guardians.

Provider Qualifications for Relatives

All states require all individuals, regardless of their relationship to the person supported, to meet provider standards. Some states, as an added quality assurance measure, only permit immediate family members and relatives to be paid as employees of an established, qualified provider agency. A few states permit more flexibility in provider standards (than for traditional providers), but require that the planning team document how the person is qualified and establish any additional training requirements that the individual must fulfill before being paid as a provider.

There is some variation among states in setting provider standards for relatives in contrast to other non-related service providers. Ten of the 48 states responding to the survey indicated that there are different standards for relatives as compared to other providers.

West Virginia is among the states that set a different standard for relatives who are permitted to be providers of Adult Companion Services and Respite. Agency providers are required to have a high school diploma or GED, while family staff has no graduation requirement.

In **Arizona**, family providers of attendant care are exempt from the fingerprint clearance required of other providers. (Arizona does allow immediate family members to provide attendant care with the exception of spouses.) Family attendant care providers must be trained in First Aid and CPR, but the planning team has the authority to identify other training requirements.

Washington has a similar exclusion for parent providers of personal care services. It waives criminal background checks and modifies some of the training requirements as well. But overwhelmingly, states require the same qualifications for family and relatives as they do of other non-related providers. And in many states, family members must also be employed by a provider agency as would any other non-related individual.

Conflict of Interest, Choice, and Control

While assuring that providers are qualified is, of course, a basic requirement of the HCBS waiver program, some of the most troubling and complex concerns about quality are not around the basic, "up-front" qualifications of family members and relatives. Of more concern, are potential conflicts of interest, assuring consumer choice and control, and evaluating the quality and outcomes of the service. In reviewing multiple state

systems, there are a variety of policies and practices that can contribute to assuring quality when relatives are providing support.

A strong person-centered focus in the initial planning process is critical to assuring that the care provided by relatives and family is in the best interests of the individual. As described earlier in this report, **Louisiana** developed a very comprehensive and robust approach to planning that keeps the attention on the needs and preferences of the individual.

Other states such as **Minnesota** and **Missouri** include specific sets of questions intended to assure that care by a family member or relative preserves individual choice and control and reflects the wishes of the person supported.

Connecticut requires a review by a Prior Approval Committee to assure that provision of services by a family member is in the best interests of the individual and also comports with their policies regarding the use of relatives as providers.

Frank and open discussion about the use of family members and honest assessment about whose interest is at the heart of employing family members can lay the groundwork in assuring that the individual's opportunities for independence and exercising choice and control over his or her own life are preserved. Specific attention in the planning process to "delicate" questions – such as those about financial relationships, firing family members, or assuring adults can exercise rights – are a means to head off problems that otherwise may only come to light once services have been initiated.

Case managers and support brokers need training in family dynamics as well as guidance in keeping the focus on the person supported, even in the face of potential pressures from families to become paid providers. Establishing clear guidance for those engaged in the services planning – and support to the individual to be clearly heard – are critical to assuring individual choice and control. For individual consumers, the opportunity to develop self-advocacy skills and the opportunity to speak with service planners in confidence can help assure the use of family members is the preferred path.

We have mentioned a number of tactics states take to mitigate conflicts of interest and assure direct consumer choice and control when family members are paid as providers. The myriad of approaches reflects the "local" nature of state policies and the particular policy aims of each state. But to recap, a few specific policy examples of how states mitigate conflicts of interest and assure choice and control are:

- ✓ The individual has a separate representative if a family member provides care under a self-directed option;
- ✓ If the provider is a guardian, the individual has a third party representative;
- ✓ Restrict guardians from being paid providers;
- ✓ The employed family member may not live with the individual;

- ✓ The paid relative or guardian may not be the employer of record (in consumer-directed options);
- ✓ Required use of an independent broker to monitor services;
- ✓ Counseling by brokers (or case managers) regarding conflict of interest.

Specific attention to the potential conflicts of interest – and support to individuals to exercise choice and control – are essential to assuring that the supports provided by relatives are in the best interest of the individual and uphold key system values.

VIII. PARTING THOUGHTS...

Bringing relatives and guardians into the paid workforce is now a routine approach to providing support to individuals with intellectual and developmental disabilities. There clearly are sound reasons for paying relatives and guardians. Relatives provide a cadre of caring and invested individuals to the provider pool. In rural areas, the use of family members can be essential due to workforce shortages. Paying a relative can stabilize the situation and permit the person to remain in the family home – delaying out-of-home placement. Individuals with disabilities themselves may prefer care from a family member who knows them well.

But bringing these relatives into the paid workforce raises concerns that states must actively address. Issues of choice, control, and conflict of interest must be clearly and openly attended to in the individual planning process as well as in state policies and regulations. Engaging in frank and open conversation with paid family members – and providing individuals with disabilities avenues to make certain their voices are heard – are critical to assuring that paying family is in the best interest of the individual.

Including stakeholders in the policymaking process is also essential to success. This may mean responding to concerns from the provider community about the impact of paid family caregivers on their business or responding to concerns voiced by self-advocates who want assurances that they can exercise choice and control in situations where family members are paid for care.

Based on the information states offered, a few critical themes and promising practices emerge that are worth recapping. Overall, clarity about state policies – when you pay family members, who you pay, what qualifications, and the process by which to decide if a family member will be paid – is critical to the success of using family members to provide paid care. As we have tried to point out, there are many excellent reasons to turn to families to provide paid care – but that doing so comes with matters worth addressing.

To recap, some recommendations:

- Clearly establish your policy aims when paying family members. This means being explicit as to under what conditions you compensate family members. For example,

- Based on your policy aims, decide which family members you compensate and for what specific services;
- Develop a written planning protocol to use in your person-centered planning process for making decisions as to if and when family members should be paid for providing supports;
- Establish clear guidelines as to how many hours per week you will pay an individual family member and how many family members you pay who reside in the same home with the individual;
- Carefully consider potential conflicts of interest when paying the parents of adults, guardians, or individuals who also act as a representative in both traditional and self-directed options;
- If compensating legally responsible individuals such as parents of minors, a clear, objective assessment that helps ascertain what care you will pay for is helpful in order not to replace age-appropriate natural care giving;
- Assure that the issues of choice and control are directly addressed in the person-centered plan for adults being supported by family members through such actions as providing opportunities for self-advocacy, developing competent circles of support, and/or the use of a non-related representative or advocate in the planning process; and
- Develop quality compliance and quality assurance processes that specifically address the unique concerns in that arise when paying family members and guardians.

Without doubt, states overwhelmingly support the use of family members and relatives to provide paid supports. There are benefits to individuals, to families, and to the overall services system in permitting family members to be paid as providers. And, as we have seen, there are concerns that are worth addressing to assure this practice is in the best interests of the individuals served. Addressing these unique issues that arise when paying family members helps assure that individuals continue to receive high quality supports that reflect their personal outcomes and preferences.

APPENDICES

NASDDDS Survey
Paying Relatives and/or Legally
Responsible Individuals for Service
Under the HCBS Waiver

We receive many questions from members regarding federal and state policies on paying relatives – and particularly parents – for providing services to their own children, including adults. We are in the process of preparing a new monograph on state practices regarding the payment of relatives and/or legally responsible individuals for services provided under the HCBS waiver. We are interested to know if your state pays relatives, what relatives, and additionally if your state pays relatives who are legally responsible including parents of children or guardians of adults.

This very brief survey is just to get some ideas from you as to what your state permits. We will be following up with some states for more in-depth information through brief interviews. Please just go with your first reaction to the questions – we realize there are a lot of nuances and iterations of which relatives can be paid and for what services. This is just a scan to get a general picture of state practices.

1. Please complete the following.

First Name

Last Name

Title

State

Email Address

Phone Number

2. Does your state pay relatives of the person receiving supports to provide them with services under your HCBS waiver?*

Yes

No

3. Does your state pay legally responsible relatives or other legally responsible individuals?*

Yes

No

Which legally responsible individuals does your state pay? Check all that apply:

Parents of child

Court-appointed guardian of a child

- Court-appointed guardian of an adult who is a parent
- Court appointed guardian of an adult who is another type of relative
- Court-appointed guardian of an adult who is not a relative

4. Does your state pay other relatives? *

- Yes
- No

Which other relatives does your state pay? Check all that apply:

- Parent of adults who are not legally responsible
- Sibling
- Grandparent
- Spouse
- Other relatives related by blood or marriage (aunt, uncle, cousins)

5. Do you have any restrictions on what services these relatives can provide to the individual? (For example, parents of adults may only provide in-home supports, such as personal care, but not habilitation services such as employment supports or skills training)

- Yes
- No

6. Do you have any restrictions on which relatives can provide services?

- Yes
- No

7. Are provider qualifications for relatives (or some relatives) different from other types of providers offering the same type of service?

- Yes
- No

**Excerpt From Minnesota's Developmental Disabilities
HCBS Waiver Application:
Appendix C-2 (e), pages 6-7: Other State Policies
Concerning Payment for Waiver Services Furnished
by Relatives / Legal Guardians**

Appendix C-2 (e), pages 6-7: Other State Policies Concerning Payment for Waiver Services Furnished by Relatives / Legal Guardians

The State makes payment to relatives/legal guardians under ***specific circumstances*** and only when the relative/guardian is qualified to furnish services. Specify the specific circumstances under which payment is made, the types of relatives/legal guardians to whom payment may be made, and the services for which payment may be made. Specify the controls that are employed to ensure that payments are made only for services rendered. *Also, specify in Appendix C-3 each waiver service for which payment may be made to relatives/legal guardians.*

For purposes of the waiver, relatives are defined as parents (biological and adoptive) of minors and spouses.

Providers of waiver services and professional guardians and conservators shall not be paid to provide waiver services. This does not preclude guardians and conservators who meet the criteria in this section from being paid to provide waiver services.

Consumer-directed service provided to adults and minors

Relatives, and legal guardians or conservators who are related by blood, marriage or adoption may be paid to provide services to adults and children through the consumer directed consumer supports (CDCS) service under the category of personal assistance. Refer to the CDCS service description and provider specifications for the criteria used to determine whether legally responsible individuals may be authorized for this service.

Waiver services, other than CDCS, provided to adults

Only legal guardians and conservators who meet all of the following criteria may be paid to provide waiver services to adults. The service must be included in the enrollee's care plan and the guardian or conservator must:

- Be related by blood, marriage, or adoption, or if not related by blood, marriage, or adoption, are only the guardian or conservator for one enrollee or enrollees who are siblings;
- Not be otherwise responsible to provide the care or service;
- Not be an enrolled MA provider for the service being rendered;
- Be qualified to provide the service;
- Be employed by a provider to provide the service.

Waiver services, other than CDCS, provided to minors

Legal guardians and conservators of minors who are not related by blood, marriage, or adoption, shall not be paid to provide waiver services, with the exception of parents providing CDCS as described above.

This information is not repeated in each service description in Appendix C-3.

Appendix C-3, pages 45-46: Service Specifications for CDCS Services

Services and supports provided by a legally responsible individual.

CDCS may be used to pay parents (including biological and adoptive parents) of minor enrollees under age 18) or spouses of enrollees. The only service covered is personal assistance services provided as defined in Attachment A. Parents of minors and spouses must meet the provider qualifications for this service.

For an enrollee's spouse or parent of a minor enrollee to be paid under CDCS, the service or support must meet all of the following authorization criteria and monitoring provisions. The service must:

- Meet the definition of a personal assistance services as outlined in the federal waiver plan and the criteria for allowable expenditures under the CDCS definition;
- be specified in the individual plan of care (community support plan);
- be provided by a parent or spouse who meets the qualifications and training standards identified as necessary in the enrollees community support plan;
- be paid at a rate that does not exceed that which would otherwise be paid to a provider of a similar service and does not exceed what is allowed by the department for the payment of personal care assistance (PCA) services;
- NOT be an activity that the family would ordinarily perform or is responsible to perform;
- be necessary to meet at least one identified dependency in activities of daily living as assessed using the Long Term Care Consultation (LTCC) Screening Document.*

*The LTCC screening will be used to provide a means to identify activities in which the enrollee is dependent, to distinguish between activities that a parent or family member would ordinarily perform and those activities that go beyond what is normally expected to be performed, and to identify areas in which the level of assistance or supervision required exceeds what is typically required of a person of the same age. The LTCC screening will be used to determine whether extraordinary care is required and may be provided by a spouse. To determine if extraordinary care is required and may be provided by a parent, the LTCC screening for age appropriateness is completed.

In addition to the above:

- a parent, or parents in combination, or a spouse, may not provide more than 40 hours of services in a seven day period. For parents, 40 hours is the total amount regardless of the number of children who receive services under CDCS;
- the parents and spouses must maintain and submit time sheets and other required documentation for hours paid;
- married enrollees must be offered a choice of providers. If they choose a spouse as their care provider, it must be documented in the community support plan.

Monitoring Requirements:

Theses additional requirements apply to enrollees electing to use legally responsible individuals as paid service providers:

- monthly reviews by the fiscal agent of hours billed for family provided care and the total amounts billed for all goods and services during the month;

- planned work schedules must be available two weeks in advance, and variations to the schedule must be noted and supplied to the fiscal agent when billing;
- at least quarterly reviews by the county on the expenditures and the health and safety status of the individual enrollee;
- face-to-face visits with the enrollee by the county on at least a semi-annual basis.

**Minnesota Assessment for Determining
ADL Dependency**

Appendix E : Determining ADL Dependency in Children Age 18 and Under

Dressing	Assessor's Score	Transfers	Assessor's Score
• Independent	00	• Independent	00
• Intermittent supervision or reminders. May need physical assistance with fasteners, shoes or laying out clothes	01	• Needs intermittent supervision or reminders, i.e. cuing or guidance only.	01
• Constant supervision, but no physical assistance. (N/A 0-48 months)	*02	• Needs physical assistance, but child is able to participate. Excludes carseat, highchair, crib for toddler age child. (N/A 0-30 months)	*02
• Physical assistance or presence of another at all times, but child is able to physically participate. (N/A 0-36 months)	*03	• Needs total assistance of another, and child is physically unable to participate. (N/A 0-18 months)	*03
• Totally dependent on another for all dressing. Child is unable to physically participate. (N/A 0-12 months)	*04	• Must be transferred using a mechanical device, i.e. Hoyer lift.	*04
Grooming		Mobility (walking)	
• Independent	00	• Independent. Ambulatory without device.	00
• Intermittent supervision or reminders	01	• Can mobilize with the assist of a device, but does not need personal assistance.	01
• Help of another to complete task, but child is physically able to participate. (N/A 0-48 months)	*02	• Intermittent physical assistance of another. (N/A 0-24 months) (This does not include supervision for safety of a child under age 5.)	*02
• Totally dependent on another for all grooming needs. Child is physically unable to participate. (N/A 0-24 months)	*03	• Needs constant physical assistance of another. Includes child who remains bedfast. (N/A 0-12 months)	*03
Bathing		Positioning (bed mobility)	
• Independent	00	• Independent. Ambulatory without device.	00
• Intermittent supervision or reminders	01	• Needs occasional assistance from another person or device to change position less than daily.	01
• Needs help in and out of tub	02	• Needs intermittent assistance of another on a daily basis to change position. Child is physically able to participate.	*02
• Constant supervision, but child does not need physical assistance. (N/A 0-60 months)	*03	• Needs total assistance in turning and positioning. Child is unable to participate. (N/A 0-9 months)	*03
• Physical assistance of another, but child is physically able to participate. (N/A 0-48 months)	*04		
• Totally dependent on another for all bathing. Child is physically unable to participate. (N/A 0-12 months)	*05	Toileting	
Eating		• Independent	00
• Independent	00	• Intermittent supervision, cuing or minor physical assistance such as clothes adjustment or hygiene. No incontinence. (N/A 0-60 months)	*01
• Intermittent supervision or reminders	01	• Usually continent of bowel and bladder, but has occasional accidents requiring physical assistance. (N/A 0-60 months)	*02
• Needs constant supervision and/or assistance in setting up meals, i.e. cutting meat, pouring fluids. (N/A 0-60 months)	02	• Usually continent of bowel and bladder, but needs physical assistance or constant supervision for all parts of the task. (N/A 0-60 months)	*03
• Needs physical assistance. Child can partially feed self. (N/A 0-24 months)	*03	• Incontinent of bowel and bladder. Diapered. (N/A 0-48 months)	*04
• Needs and receives total oral feeding from another. Child is physically unable to participate. (N/A 0-12 months)	*04	• Needs assistance with bowel and bladder programs, or appliances (i.e. ostomies or urinary catheters).	*05
• Receives tube feeding.* Child has documented incidents of choking or reflux on a weekly basis or more that is related to diagnosis or disability.	*05		

* "Dependency" is signalled by a score asterisked and bolded.

**Louisiana Office for Citizens with Developmental
Disabilities**

**Policies for Paying Family Members as Staff under the
New Opportunities HCBS Waiver**

FAMILY MEMBERS AS STAFF

A. New Opportunities Waiver Rules Regarding Use of Family Members as Paid Direct Support (Louisiana Register, Vol. 30, No. 6, June 20, 2004 §13901 Individualized and Family Support and §13907 Residential Habilitation – Supported Independent Living)

1. For Individual & Family Support (IFS) services - Reimbursement will not be paid for direct support services furnished by a legally responsible relative. A legally responsible relative is defined as the parent of a minor child, foster parent, curator, tutor, legal guardian, or the recipient's spouse.

2. For Supported Living (SL) services - Family members who are not legally responsible relatives as defined in §13901.D.1, can be SL workers provided they meet the same qualifications as any other SL worker. Legally responsible relatives may not be SL providers. Payment for SL does not include payments made directly or indirectly to members of the individual's immediate family. Minors living in their guardian's home are presumed not to need SL services. If SL services are needed, they must be requested with justification.

3. For Substitute Family Care (SFC) services - Immediate family members (mother, father, brother and/or sister) cannot be substitute family care parents.

B. Act No. 333 (2008) and Limitations on Family Members as Paid Direct Support

1. In the Regular Session, 2008, of the Louisiana Legislature, Act No. 333 was passed. This act requires the state Department of Health & Hospitals (DHH) to develop criteria regarding any parent, stepparent, grandparent, son, daughter, brother, sister, aunt, or uncle of a participant serving as a direct support worker. Act No. 333 (2008) Online document link:
<http://legis.state.la.us/billdata/streamdocument.asp?did=499966>

2. The Act asserts that general state policy is to not allow family to serve as a paid direct service worker unless the relative meets the criteria established by the rule and has received a waiver issued by the secretary of DHH or his designee. The waiver must state that the relative is the best available appropriate direct service worker for the person using services. Family members who have acted as paid direct service workers prior to July 1, 2008 are grandfathered in and allowed to continue working as paid direct service workers.

3. As of March 2010, Act No. 333 is not yet in effect. DHH is still working on developing the criteria for family members as direct support and the process to apply for and get a waiver. Before these changes can be enacted, they must be posted in rule format, according to state regulations, and also receive approval at the federal level from the Centers for Medicare & Medicaid Services.

C. Support Team Discussion of Using Family Members as Paid Direct Support

1. Support teams should anticipate implementation of Act No. 333 by regularly discussing any use of family as paid direct service workers and by actively considering alternatives. In accordance with the act requirements, DHH will

establish regulations for requests of waivers to enable family members to act as paid direct service workers. The following provides guidance for team discussion and consideration in preparation for a waiver request:

a. Is the use of a family member age and developmentally appropriate?

i. The team needs to consider the day from the person's perspective. Sometime having family around may be fine. Other times may not be. Does a 30 year-old generally have his mom accompany him to evenings out with friends? Not usually. Support teams must look at ways of using family as paid direct service workers in situationally appropriate times that are consistent with meeting the person's support needs.

ii. If using family as a paid direct service worker for some times makes sense, then consider including non-family members for shifts involving planned socializing and peer interaction.

b. Will using family members as paid direct service workers enable the person to learn and to adapt to different people and also to form new relationships?

i. The support team must build in opportunities to meet different people and form relationships, including making choices about selection of different direct support workers.

ii. The support team must discuss any barriers to increased community integration or friendship development presented by use of family as paid direct service workers and how to address these barriers.

c. Is the person learning flexibility and skills for increased independence?

i. The support team and IFS provider must reinforce with the family

member that he/she is not in a "caretaking" role, but rather in a supportive role that is intended to encourage autonomy and skills building for independence in community living. The support team must ensure that the family member providing direct support approaches the job as such and does not present barriers to individual goals and treatment objectives.

a. Support teams should approach with considerable caution use of family as paid direct support for persons with significant behavioral challenges due to requirements of treatment plans and treatment objectives.

d. What happens when the family caregiver is gone? Who else is prepared to step in and provide support?

e. Is this in the best interest of the person in the long-term?

i. Is this something that is sustainable for the long-term? Continuity of care in provision of direct services is an important aspect of achieving personal outcomes, including goals, wellness, and progression of skills.

f. Is this about the person's wishes, desires, needs, or about supplementing a family member's income?

i. Support teams must consider the motive and level of commitment of a family member requesting to act as a paid direct service worker. Protecting against exploitation is key. In the end, if a family member is only focused on money, the quality of care will be low, and the person will be put at risk.

2. Support teams should consider paying a family member in the following situations:

a. Staff supports are required at difficult times of the day to get or schedule employees;

b. The participant lives in a rural or isolated area;

c. The family member may work on a temporary basis while other staffing options are explored;

d. When having a family member as staff:

i. Truly reflects the person's wishes and desires,

ii. Increases the person's quality of life in measurable ways,

iii. Increases the person's level of independence,

iv. Increases the person's choices, and

v. Increases access to the amount of service hours for needed supports;

3. Holding regular team discussions and considering all of the above factors will assist in the preparation of waiver requests once Act No. 333 goes into effect.

West Virginia DD- 25: Extra-ordinary Care Instrument

PERSONAL CARE SKILLS	Not-Applicable	Independent	Semi-Independent	Minimal Assistance	Moderate Assistance	Total Assistance	AVERAG SCORE
	Not - applicable is not included in the average	Completes without assistance	Sometimes needs verbal prompt to complete task	Verbal prompt required to complete task	Physical prompt and/or repeated instructions required to complete task	Unable to complete without constant physical assistance of another person	
	N/A	0	1	2	3	4	
Dressing (n/a 0-48 months of a,ge)							
Grooming (hair) (n/a 0 48 months of age)							
Bathing (n/a 0- 48 months of age)							
Oral hygiene (n/a 0 48 months of age)							
Eating with utensils (n/a 0 36 months of age) -----							
Simple Meal Preparation (n/a 0 -120 months of age)							
Household Skills (adult only)							
Toileting (n/a 0- 36 months of age)							
TOTAL PERSONAL CARE SKILLS Average of 3.0 and above is "extraordinary"							

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INSTRUMENT March 3 1, 2006
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COMMUNICATION SKILLS	Not-Applicable	Independent	Semi-independent	Minimal Assistance	Moderate Assistance	Total Assistance	AVERAG SCORE
	Not - applicable is not included in the average	Completes without assistance	Sometimes needs verbal prompt or assistance to complete	Verbal prompt or assistance required to complete task	Physical prompt and/or repeated instructions required to complete task	Unable to complete without constant physical assistance of another	
	N/A	0	1	2	3	4	
Ability to communicate basic wants and needs (n/a 0-36 months)							
Ability to understand simple directives, instructions (n/a 0-48 months)							
Ability to initiate age appropriate social contacts with peers in own neighborhood (n/a 0-84 months)							
Ability to understand very basic reading and writing (i.e. ability to recognize basic signs and written communication) (n/a 0-84 months)							
TOTAL COMMUNICATION SKILLS Average of 3.0 and above is "extraordinary"							

MALADAPTIVE ISSUES (will require a formal guideline, protocol or plan)	Not - applicable is not included in the average	This is not a problem -	Mild	Moderate	Serious	Extreme	AVERAG E SCORE
	N/A	0	1	2	3	4	
Participates in Self - Injurious Behaviors							
Participates in destruction of property							
Participates in behavior physically hurtful to others							
Participates in behaviors that interferes with activities of others							
Demonstrates unusual or repetitive habits							
Participates in behavior that is offensive to others							
Demonstrates verbal aggression							
TOTAL MALADAPTIVE ISSUES 2.0 or above on any item would be reason to evaluate for a guideline or protocol or plan - Has to be linked to ICAP assessment. (Follow the Protocol for ICAP for guidelines, protocols or BSP)							

	Not-Applicable	Independent	Semi-independent	Minimal Assistance	Moderate Assistance	Total Assistance	AVERAG SCORE
SPECIALIZED PHYSICAL MEDICAL AND THERAPEUTIC NEEDS	Not - applicable is not included in the average	Completes without assistance	Sometimes needs verbal prompt to complete task	Verbal prompt required to complete task	Physical prompt and/ or repeated instructions required to complete task	Unable to complete without constant physical and/or verbal assistance of another	
	N/A	0	1	2	3	4	
	Ability to carry out specific therapeutic exercises (Le. Physical, Occupational, Speech- Hearing - Language Plans)						
Ability to manage own medication (adults only 18 years of age and above)							
TOTAL SPECIALIZED Score of 3.0 on either item							

Payments will not be made for the routine care and supervision which would be expected to be provided by the care taker, or for activities or supervision for which payment is made by source other than Medicaid. Medicaid does not cover these components.

Services that are provided by legally responsible relatives will not cost more than equivalent services from customary providers.