



MEMBERSHIP SURVEY REPORT:

Paying Legally Responsible Relatives of HCBS Waiver Participants

I. Background.

Medicaid is a means-tested program. Consequently, if a child under 18 years of age is unmarried and living at home, all of the countable income and assets of his/her family are attributable to the child. For a child residing in an institution for 30 days or more, however, none of the financial resources of the parents is deemed to be available to the child and the child's financial eligibility to receive Medicaid benefits is based solely on his/her own income/assets (20 CFR 416.1165(g)(4)).

Recognizing that the above policies create financial inducements to place children with severe, chronic disabilities and illnesses in institutions, Congress in the early 1980s enacted exceptions to these "parental deeming" policies aimed at permitting Medicaid-financed home-based care options when it makes both financial and programmatic sense. In enacting the Medicaid home and community-based waiver authority in 1981, Congress authorized the Secretary of Health and Human Services, at the request of a state, to grant a waiver of parental deeming in instances where there is evidence that: (a) the participating children otherwise would require care in a Medicaid-certified

institution; and (b) the aggregate cost to the Medicaid program of caring for such children at home would be no more than the costs of serving them in institutions. Second, in 1982 Congress created a special optional eligibility category for children with severe disabilities who could be served at home at no greater cost than they could be served in a Title XIX-certified institution. This so-called Katie Beckett or TEFRA-134 option, allows states electing to make this special eligibility category part of their state Title XIX plans to treat children living at home who meet the statutory criteria as though they are SSI beneficiaries and, thus, not liable to have their parents' resources taken into account in establishing their Medicaid eligibility.¹

Through the home-based care options outlined above, states have extended Medicaid state plan and HCB waiver services to thousands of children who otherwise would have been prime candidates for institutionalization. Many states also have requested and received approval from the Centers for Medicare and Medicaid Services (CMS) to compensate parent

¹ Section 1902(e)(3) of the Social Security Act, as added by Section 134 of the Tax Equity and Fiscal Accountability Act of 1982 (P.L. 97-248).

caretakers of adults who are living at home and participating in the state's home and community-based waiver program for persons with mental retardation and/or developmental disabilities. But, Medicaid policy still prohibits parents of children, spouses and other legally liable relatives to serve as paid caretakers for their disabled family members, except under the following circumstances. For a number of years, CMS has permitted states, upon request, to pay parents, spouses and other legally liable relatives for providing personal care and related services to HCBS waiver participants who are living in their homes, but only if the caretaker is appropriately credentialed to provide such services (e.g., an RN, an LPN, a respiratory therapist, etc.).

Recently, however, CMS officials announced that they intend to develop new criteria to evaluate state requests for additional latitude in paying legally responsible relatives to furnish personal assistance/care and, possibly, other related services to HCBS waiver participants. As part its analysis of possible optional criteria that might be applied, CMS asked the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the National Association of State Medicaid Directors to conduct separate, informal polls of their respective constituencies to determine: (a) the states' experiences with paying legally liable family members for care-giving services, either as part of an existing HCBS waiver program, a Medicaid state plan service, or through a non-Medicaid-funded program; and (b) the views of state MR/DD and Medicaid officials, respectively, regarding CMS' use of several possible alternative criteria to evaluate state requests for increased flexibility in using HCBS waiver dollars to pay legally liable relatives of waiver participants. This report summarizes

the responses to a membership survey on this subject conducted by the NASDDDS staff during July 2003.

In reviewing the results of this survey, readers should keep in mind that the term legally liable relative has a particular meaning within the context of Medicaid policy. A parent, sibling or other relative may be designated the legal guardian of an adult with a developmental disability and, thus, be recognized before the law as his or her surrogate decision-maker. But, under the terms of the guardianship arrangement, the income and assets of the parent/relative-guardian may not be taken into account in determining the Title XIX eligibility of the same adult and, consequently, the parent/relative-guardian will not be considered a legally liable relative for Medicaid purposes. In most cases, therefore, when we speak of a legally liable relative of an individual with a developmental disability, we will be referring to the parent(s) of a child under 18 years of age with a qualifying disabling conditions. However, there will instances in which someone other than the parents (whether related or un-related to the child) is responsibility for rearing the child and, thus, be properly classified as legally liable for Medicaid purposes.²

II. Survey Methodology.

The survey instrument (see Attachment A) developed by the NASDDDS staff asked respondents:

- Whether legally responsible relatives are eligible to receive payments for furnishing personal assistance/care

² In contract, for frail elders and other persons with disabilities originating in adolescents and adulthood, the legally liable caregiver typically will be the person's spouse.

services to their sons/daughters, brothers/sisters, etc.?

- If payments to legally liable caregivers are permitted by the state, respondents were asked to indicate the type(s) of program(s) to which this option applies (i.e., Medicaid-financed HCBS waiver services; Medicaid state plan services; non-Medicaid funded services; other).
- Respondents in states where relative caregiver payments are authorized were asked to specify the criteria used to determine whether a legally liable caretaker is the most appropriate provider of paid personal care/support services.
- Respondents were asked for their opinion on whether several alternative criteria should apply to permitting legally liable parties to function as paid caregivers for their minor sons and daughters, spouses, wards, etc. They also were given the option of indicating that “my state has decided that legally liable relatives should not be compensated with public dollars for ... [furnishing] personal assistance/care services...” and of adding any written comments they wished to offer.
- If CMS were to decide to use “intensity of support needs” as a criteria, the respondents were asked for their opinion on the threshold level that should be established (i.e., over 10 hours a week; over 20 hours a week; over 30 hours a week; or a specified alternative number of hours a week).
- Finally, the respondents were asked if they wished to suggest any other criteria states (and CMS) should take into account in judging whether legally liable

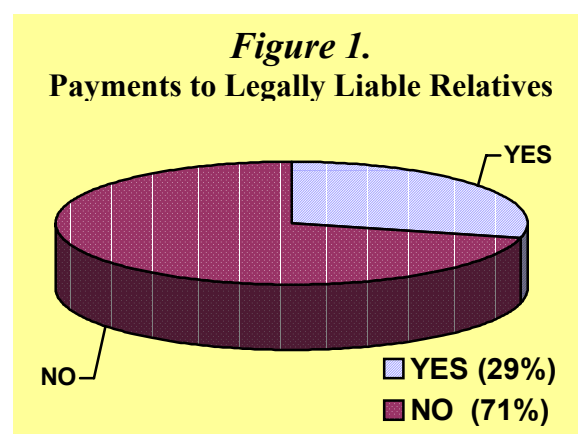
relatives should receive compensation for providing services to HCBS waiver participants.

During the second week of July, the survey questionnaire was distributed via e-mail to state managers of HCBS waiver programs targeted to the MR/DD population in all 50 states and the District of Columbia. State MR/DD waiver managers were asked to return their completed survey questionnaire to the Association by July 30. State MR/DD agency directors received an information copy of the initial transmittal memo and the survey instrument. A follow-up e-mail message was sent to all non-responding states in early August, with a request that completed survey questionnaires be returned as soon as possible.

III. Survey Findings.

A total of thirty-eight (38) member state agencies (including the District of Columbia) responded to the Association’s survey. The overall survey response rate was 74.5 percent.

Current State Practices. Asked about the state’s current policies governing the use of legally liable relatives as paid caregivers, eleven (11) states, or a little over one-quarter (29%) of the respondents, indicated that



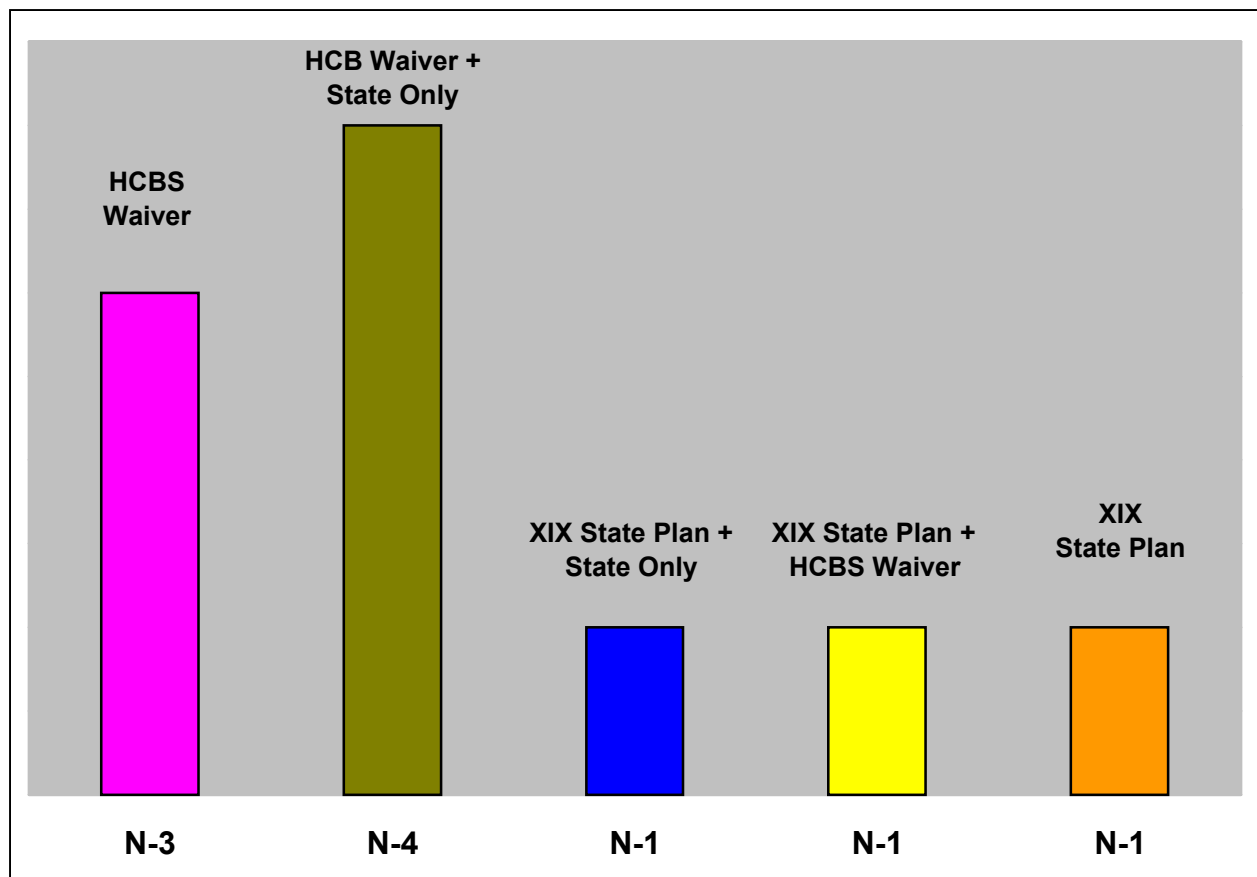
parents and other legally liable relatives are permitted to function as paid providers of personal assistance/care services under certain programs. The remaining twenty-seven (27) states reported that parents/legally liable relatives are not permitted to function as paid caregivers under any circumstances.

Eight (8) of the eleven (11) states reporting that payment of legally liable relatives is permitted indicated that, under specified circumstances such payments are authorized as part of the state’s HCBS waiver program. Two (2) states reported that such payments are permissible under state Medicaid plan services, while seven (7) states said that payments to legally liable relatives are allowed under non-Medicaid funded (state

only) financed services. The distribution, by program type, of states that allow payments to legally liable relatives is displayed in Figure 2.

No attempt was made to gather information on the number of legally responsible relatives who are being compensated with public dollars for furnishing personal assistance/care to persons with developmental disabilities. However, the written comments included by some respondents suggest that paying legally responsible relatives is an infrequently used option even in states where such payments are authorized. For example, one state that allows payments to legally responsible relatives under its HCBS waiver program and through state-only funding reported that

Figure 2. Payments to Legally Liable Relatives by Program Type



guardians are eligible to receive reimbursement of mileage costs incurred in meeting the needs of a waiver participant. But, otherwise legally responsible relatives are not eligible to receive payments for the services/supports they furnish to individuals with disabilities under their care. Another state indicated that blood relatives are eligible to provide family care services, a covered service under its DD waiver program, but the parents of waiver participants are excluded from the definition of an eligible relative (i.e., only siblings, aunts, uncles, etc. are considered eligible to serve as family care providers). Yet another state indicated that spouses and parents may not be paid with Medicaid dollars, but spouses (not parents) are eligible to receive state only payments. Siblings in this same state may be paid for providing supports to a HCBS waiver participant only under the state's self-directed service model.

Existing State Criteria. None of the states permitting payments to parents and other legally liable relatives indicated that they use a written protocol to determine when such parents/relatives should be allowed to function as paid providers. Asked to summarize the criteria used "to determine whether a parent/sibling caretaker is the most appropriate provider of paid personal care/support services," the responding states offered various answers. Easily the most common response from the eleven (11) states that answered this survey question was that the determination was an outgrowth of the individual program planning process (5 states). Two (2) states suggested that the decision to use a legally responsible relative as a paid caregiver rested largely on the preferences of the individual and his/her family. Two (2) states indicated that the inability to locate another appropriate provider or the geographic remoteness of the person's home is used as a primary criterion.

One respondent indicated that state policy prohibits blood relatives from receiving payments for providing respite services if the service is furnished in their own homes, but such relatives may be compensated if the service is provide elsewhere and they are not the spouse, parent, step-parent, foster parent, child or step-child of the recipient or responsible for legal custody of the recipient. Finally, one state that allows legally liable parents/relatives to function as paid caregivers under its HCBS waiver program outlined a two-part test:

1. "The service provided is not a function which a relative would normally provide for the individual without charge as a matter of course in the usual relationship among members of the nuclear family."
2. "The service would otherwise need to be provided by a qualified provider of habilitation services funded under the waiver."

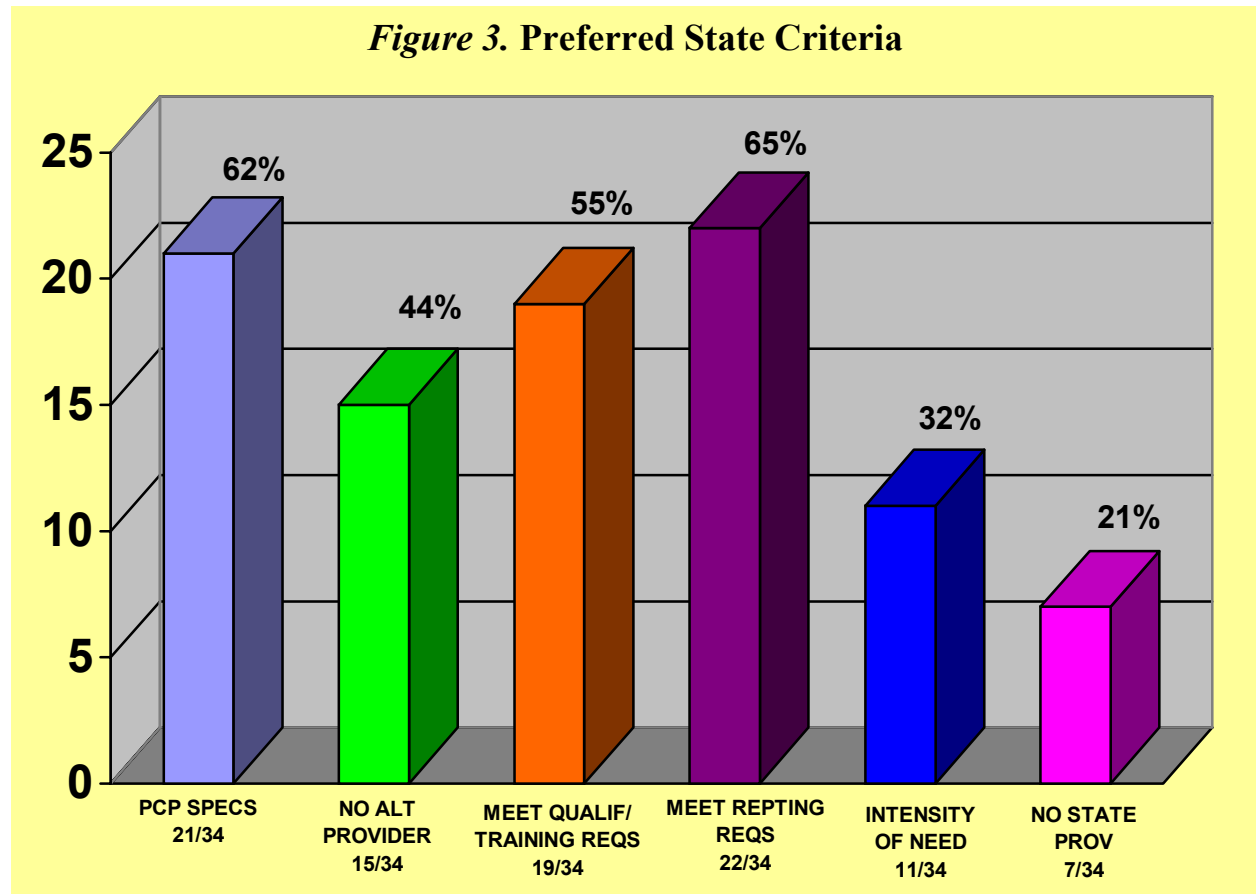
State Views Regarding Proposed Criteria. Respondents were asked to offer their opinions regarding criteria a state might use to determine whether parents and other legally liable relatives should be paid for furnishing personal assistance/care services, assuming CMS decides to alter its existing policies. Five possible criteria were suggested and respondents were instructed to select as many criteria as they felt were applicable. In addition, respondents were given the option of suggesting other alternatives or indicating that state policy prohibits paying legally liable relatives under any circumstances.

Of the five alternatives offered, a majority of the respondents expressed support for tying such payments to the outcome of the person-centered planning process (21 out of 34 respondents; or 62%), meeting the same qualifications/training requirements that are

applicable to all other providers of the same category of service (19 out of 34 respondents; or 55%), meeting the same reporting requirements that are applicable to all other providers of the same category of services (22 out of 34; 65%). In contrast, a minority of the respondents expressed support for using the intensity of the individual’s support needs (11 out of 34; 32%) or the absence of an alternative caregiver (15 out of 34; or 44%) as criteria for determining when legally liable relatives should be compensated for providing personal assistance/care services. Seven (7) respondents reported that their states prohibit payments to legally liable relatives under any circumstances (although three of these respondents also indicated their views regarding appropriate selection criteria from the options discussed above).

Other Suggested Criteria. Survey questions #5 and #7 both offered respondents an opportunity to suggest alternative criteria a state might use to determine whether legally liable relatives should be paid for the services and supports they provide to persons with developmental disabilities. A total of twenty-two (22) states included responses to one or both of these open-ended questions. Due to the similarity of the questions, the responses were considered together in completing the analysis. The comments of some respondents were intended to: (a) offer their views regarding the merits of using one or more of the proposed criteria; or, more broadly (b) comment on whether legally liable relatives should be compensated with public dollars for the services they provide. The latter categories of comments are summarized under “General Comments”

Figure 3. Preferred State Criteria



below. Here, we will examine alternative criteria and other factors to be considered that were raised by the respondents.

Several respondents suggested that age is a factor that needs to be taken into account in determining whether parents and other legally liable relatives should be paid for the services they render. As one respondent put it,

Intensity of need criteria should factor [in] the age of the recipient, as well as [the] quantity and type of support needed. A 3-month [old] child [requires] ... total care with or without a developmental disability. Most non-disabled 17 year olds are far more independent, so age is a critical factor in assessing the support costs of a person reimbursable with waiver funds.

Another, related theme that was repeated in several of the comments suggested the use of what might be labeled an excess demand criterion – i.e., evaluating the need to compensate a parent or another legally liable relative in terms of the differential care demands placed on the family, in comparison to a non-disabled age peer. Other respondents stressed that parents and other legally liable relatives should not be compensated for providing “routine” care. If an intensity of support need criteria is used, one state suggested that parents and other legally liable relatives be obligated to provide a base number of hours of care/support per week before being paid with public dollars for rendering additional hours of care/support.

Several respondents suggested that the availability of another qualified care provider should be a prime consideration in deciding whether a parent or another legally liable relative should be compensated for furnishing care/support to an individual with a developmental disability. Generally, these

respondents stressed that, especially in rural areas of their states, often it is difficult to find another qualified provider. Parental income is another important factor to consider, a couple of respondents contended. As one respondent noted, “ If the family needs both parents’ income or if [the individual is living in] a single family home, the need for payment to the family increases.”

Still, other respondents emphasized the complex range of factors that must be taken into account to arrive at a sound decision. One respondent offered this list of factors: age, disability level (level of functioning) of the child, parental income, family size, the presence of another person with a disability in the home, and the availability/access to natural family/community supports. Finally, one respondent suggested that the comparative costs of employing a skilled direct care provider to perform functions that a trained family member otherwise could handle should be taken into account in determining whether to compensate a legally liable relative. She cited the example of a child requiring suctioning that can be preformed by a trained parent but otherwise would have to be delegated to a paid direct care provider. Several other commentators also raised this cost-effectiveness theme.

Use of an Intensity of Need Criterion. Should CMS decide to entertain state requests to use an intensity of need criteria in determining when legally liable relatives should be paid for furnishing care/support services, the survey questionnaire asked respondents to indicate the threshold level that should be established. The choices were 10+ hours a week, 20+ hours a week, 30+ hours a week, or a number of hours per week specified by the respondent. A slim majority of the states (18 out of 34) selected among the specified options or indicated

their own preferred number of hours per week. Those answering this question were almost evenly divided in the preference they expressed (five: 10+ hours; four: 20+ hours; seven: 30+ hours; and four: individual preferences). The individual preferences ranged from a low of 5+ hours a week to a high of 40+ hours per week (two respondents).

In written comments, a number of respondents argued strongly against the use of an intensity of need criterion to determine when a parent or another legally liable relative should be paid for providing services to a family member with a developmental disability. One state warned that “[s]etting a threshold may simply force a person’s team to identify the minimum required in order to reach the goal of a family member providing services.” A respondent from another state made the same point when he noted:

Usually if you create a threshold or barrier, families will figure out how to meet the criteria in order to get what they need. For example, if the criteria (sic) is twenty hours a week and the child could get by with 10 or 15 hours, the family will say, “Looks like he needs twenty.” This could have the unintended consequence of actually increasing the overall cost of the program.

When the fact that only about one-third of the survey respondents rated intensity of need a preferred criterion (see discussion above) is considered in connection with the above (and several other similar) comments, it seems clear that most respondents favor the use of other criteria to decide when legally liable individuals should be compensated for the care/supports they provide.

General Comments. Several survey respondents voiced concerns about

broadening the circumstances under which parents and other legally responsible relatives may function as paid service providers under HCBS waiver programs. One respondent put it this way:

One area of struggle is between those who see this [option] as a stipend or subsidy [to the family] and those who see this [option] as a purchase of services. Stipend folks think that families have been doing the service and know best how to do it anyway. Provider folks think once you pay for a service then the expectations should change.

Another survey respondent indicated that, “[w]hile 99.9% [of paid family caregivers] might be reliable and honest, that .1% kills us with the Legislature... While it is easy to see the benefits of this [approach] for some people,” she added, “it’s opening the door for abuse of the system... and should be the exception, not the rule.”

Other respondents were less concerned about the potential for fraud than they were that, in some instances, waiver participants might be held back from achieving their full potential by overly-protective parents. As one survey respondent put it, “[w]e need to guard against the legally liable relative (LLR) preventing the person from moving [outside the family’s home] – situations we have seen happen when the LLR would lose income because of the SSI being lost or, in this case, waiver reimbursement income and SSI income being lost to the LLR.”

Some respondents indicated flatly that their states were not interested in paying parents and other legally liable relatives to provide HCBS waiver services. One respondent put it this way:

In our conservative state, it is felt that paying parents to take care of their children (regardless of their age) would never be

justified. There is even a current [of] thought to have parents pay a sliding scale fee to have their child/ward receive services from the waiver, regardless of their income or the age of their child/ward.

On the other hand, several respondents pointed out the systemic advantages of using parents and other legally liable relatives as paid caregivers. One state suggested that, if the parents are able to provide the needed supports, they should have the option of acting as paid caregivers as long as the child's support needs exceed the level typical for a child of the same age. "Further restrictions," this state added, "tend to get bureaucratic at times." A few of the survey participants also alluded to the advantages of tapping into a supplementary labor pool at a time when so many traditional community provider agencies are struggling to recruit and train enough direct support workers to maintain existing programs.

Reading the comments, however, the sense one gets is that, if granted broader authority to use legally liable parents/relatives as paid caregivers, many states would elect to exercise this authority quite judiciously. Several states, for example, indicated that paying parental caregivers is being considered as (or already is) an option under the self-directed component of the state's MR/DD waiver program. But, they gave no indication of plans to expand this option to additional (non-self-directing) waiver participants (and in one case indicated that further use of this option is not likely to occur). A long-time state MR/DD official reported in a separate conversation with the author of this summary report that paying the parents/relatives of minors is a rarely used option even though his state's waiver program has permitted such payments under rather flexible circumstances for a number of years. He attributed the low utilization of paid parent/relative-providers to the

reluctance of county administrators and local provider agency staff to make families aware of this option for fear of raising unrealistic expectations.

IV. Conclusions.

It would be a mistake to draw firm conclusions based on the results of a single brief survey, especially a survey in which one-quarter of the states did not participate. Still, the survey results do seem to suggest that, should CMS decide to afford states greater latitude in using parents, spouses and other legally liable relatives as providers of HCBS waiver services, there are certain criteria states (and, by extension, CMS) should consider employing to determine when a legally liable relative should be compensated for his/her services. These criteria include:

- ✓ The results of the person-centered planning process, when the needs and preferences of the individual and his/her family are taken into account in developing an individual program plan;
- ✓ Requiring parent/relative providers to meet the same minimum qualifications and pre-service/in-service training requirements that apply to any other provider of the same service category; and
- ✓ Requiring parent/relative providers to meet the same reporting requirements that apply to any other provider of the same service category.

In addition to the above criteria, some of the survey respondents stressed the importance of assessing the care-taking/support responsibilities of the primary family caretaker against the responsibilities of family caretakers of a non-disabled child of

a similar age. Still other respondents emphasized the complex web of tangible and intangible factors that need to be taken into account in deciding whether a parent/relative should be permitted to function as a paid caregiver (e.g., family size; the financial resources of the family; the cohesiveness of the nuclear family unit; the presence of another person with disabilities in the household; the availability of natural family/community supports; cost-effectiveness compared to traditional in-home support arrangements; etc.). In general, however, the respondents appeared to be most comfortable with relying on the person-centered planning process to yield sound answers that fit the particular situation, rather than relying on other, externally imposed criteria.

While the attitudes of the survey respondents varied widely, one was left with an overall sense of wariness about relying too heavily on parent/relative providers of HCBS waiver services, at least until the states gain additional experience in employing this alternative service delivery model. A small minority of respondents was categorically opposed to paying parents of minors, spouse and other legally liable relatives, and a few were enthusiastic proponents of the approach. But, most of the survey respondents seemed willing to experiment with using parents and other legally liable parties as providers of waiver services, but wanting to proceed along a slow, deliberate path, rather than employing this option broadly in the near term.

V. Observations.

Given the enormous challenges state/local developmental disabilities service systems face in creating a competent, stable work force both now and in future years, the expanded use of parents, spouses and other

Factors to be Considered: Compensating Legally Liable Parties

- ✓ Outcome of person-centered planning process;
- ✓ Meeting same minimum qualifications and pre-service/in-service training requirements as all other paid service providers;
- ✓ Meeting same reporting/accountability requirements as all other paid service providers;
- ✓ Size of the family;
- ✓ Family's financial resources;
- ✓ Cohesiveness of family unit;
- ✓ Presence of another person with a disability in the household;
- ✓ Availability of natural family/community supports;
- ✓ Cost-effectiveness of employing family member vs. traditional in-home community support provider

legally liable relatives as paid providers would appear to be an attractive option. Not only would the use of relative-providers allow responsible state and local agencies to tap into a new work force pool, but it would help reinforce the concept of individual and family-centered support strategies that is a keystone of current service delivery philosophy. Looking ahead, the competition for hands-on support workers and supervisors within the entire human services arena is going to become even more fierce, given the growing demands fueled by an aging population and a shrinking number of working aged adults. Accessing alternative labor pools will become essential in this type of policy environment.

Still, as the responses to the present survey suggest, there are numerous potential pitfalls

associated with using parents of minors (and other legally liable parties) as providers of Medicaid-funded services. A state can mandate that paid relative-providers meet the same minimum qualifications, training and reporting requirements that apply to any other worker furnishing the same type of service/support (and, as can be seen from the survey results, there is a good deal of backing within state MR/DD agencies for instituting such policies). But, enforcing such policies may be a significantly greater challenge than establishing them. As one observer has put it, “would you want to be the case manager who tells mom that she’s a lousy caregiver and is fired?” And, where precisely should the line be drawn between the sanctity of a family’s home and the responsibility to ensure that public funds are being used effectively and accountably when a legally liable family member is acting as a paid caregiver? There may be acceptable answers to these and other related questions, but it is a policy terrain full of landmines that has to be navigated very carefully.

Whether using parents, spouses, and other legally liable relatives as paid caregiver/support providers is a politically acceptable solution is another question that must be confronted. This option may be justified on fiscal and programmatic grounds. But, at a time when public funding for many social programs are being sliced and desperately poor children and adults are being denied essential services, paying middle class family members to care for their sons and daughters with developmental disabilities may not pass muster within the political arena.

Finally, there is the question of whether the Medicaid program is the appropriate vehicle to compensate spouses, parents of minor children and other legally liable parties for

the services they provide to individuals with severe, chronic disabilities. Unquestionably, a strong case can be made for assisting families that provide essential supports to blood relatives with severe, chronic disabilities within their homes. The dollar value of these informal supports is enormous, and, where public policies can be crafted that relieve the burden on families and, thereby, deflect demand for out-of-home care arrangements, societal investments clearly are justified, particularly when such policies are backed up with empirical cost-benefit data. But, Medicaid, as a vendor payment program that prohibits direct cash assistance, may not be the most appropriate mechanism to accomplish this goal. As the comments of several survey respondents suggest, paying parents, spouses and other legally liable relatives blurs the lines between vendor payments and family subsidies or stipends, raising a variety of tricky trade offs between family privacy and public accountability.

In a number of Western European nations, family allowance programs, which include considerably higher monthly stipends for families caring for relatives with chronic disabilities, have been in operation for decades. Whether this model can be adapted to the needs of the United States is questionable, but it does represent a less problematic approach to aligning public policies with family-centered values.

The cash subsidy programs that some states instituted during the 70s and 80s to assist families caring for children and adults with developmental disabilities (and, in some instances, other populations with severe, chronic disabilities) at home could be viewed as a building block for future policy. States, however, face strong fiscal disincentives under current policy to instituting or expanding such programs,

since the federal government does not match family subsidies.

One approach to removing such disincentives might be to petition Congress to enact legislation authorizing federal dollars to match (at Medicaid FFP rates) state supplements to the federal SSI benefit on behalf of beneficiaries who are living with their families. The Social Security Administration would include this supplemental payment as an enhancement to the basic federal benefit paid to SSI recipients. States would have authority to differentiate the amount of the additional subsidy (including its own matching contributions) according to specified categories of family need, in much the same way as they currently establish SSI supplementation schedules for designated categories of beneficiaries living at home or in various types of non-medical living settings.³ Due to budget implications, these federal matching payments might be limited initially to childhood SSI beneficiaries (thus restricting the potential number eligible for such matching payments to about 920,000 (compared to 6.8 million) persons). Legislation along these general lines would offer states much stronger incentives to invest in family subsidy programs by leveling the playing field between cash assistance and Medicaid vendor payments. It also would avoid the public accountability issues associated with a vendor payment strategy, while recognizing the additional care-giving responsibilities undertaken by families raising a child with severe disabilities.

One distinct drawback to this approach is that it would be limited primarily to low-income families – i.e., families whose

³ As under current law, the actual payment process would depend on whether a state elected to have SSA administer its supplemental payments or administer such payments itself.

income and resources are below SSI eligibility thresholds, since under SSI law (like Medicaid law) a family's resources are deemed to be available to the child. It is possible that a federal-state mechanism could be devised which permitted the deeming of family resources to be waived under selected circumstances; but, such a mechanism would pose difficult design issues and, presumably, would be even harder to administer in a way that avoids "gaming" the system.

An alternative approach would be to amend the existing Child Care Credit under the Internal Revenue Code so that families caring for an individual with severe disabilities at home would be entitled to larger tax credits in recognition of their enhanced care-giving responsibilities. The basic problem with this approach is the higher income families, who are better able to bear the economic burdens of caring for an individual with disabilities, would receive the same benefits as families who are struggling financially. Plus, low-income working families, who pay little or no income taxes, would realize no benefits from an amended Child Care Tax Credit. The effect of these ability to pay factors could be mitigated by: (a) phasing out the enhanced tax credit for higher income taxpayers; and (b) creating a parallel enhancement in the Earned Income Tax Credit for low-income working families that care for an individual with a severe, chronic disability at home.

Still, even with these modifications, there are inherent limitations associated with using the tax code to account for the special care-giving responsibilities of families with a member who has a severe, chronic disability. To begin with, any tax break based on the Child Care Tax Credit would provide no assistance to the millions of

American families caring for frail elders or other adults with severe disabilities at home, thus creating an obvious (and probably politically intolerable) inequity. Furthermore, it would be very difficult to modulate the amount of the tax break received by eligible families. As a result, the revenue loss to the federal treasury would be high and, in the final analysis, the benefit might not be targeted in a way that would significantly influence family decisions regarding the placement of family members with disabilities in out-of-home living arrangements. The net benefits of an expanded tax credit from a public policy perspective, therefore, could be very limited.

Whether one uses the tax code or an income maintenance supplementation strategy, it is clear that legislative changes along the lines

outlined above could entail billions of dollars of additional federal expenditure (or revenue losses). At a time when the federal government is running record deficits and the prospects of future balance budgets appear to be fading, the likelihood of Congressional action on legislation along these general lines appears to be exceedingly slim. The question, therefore, that remains is: should payments to legally liable relatives be shoehorned into existing Medicaid policy, or do we hold out for legislation that rationalizes existing national long-term services policy. Similar questions could have been raised at numerous points during the evolution of federal policy over the past three decades, and probably affords us the best insight into how the existing crazy quilt of LTS policies came into existence.

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Paying Legally Responsible Relatives of HCBS Waiver Participants

An NASDDDS Membership Survey

As many of you are aware, CMS officials are planning to develop criteria to evaluate state requests for additional latitude in paying legally responsible relatives to furnish personal assistance/care and, possibly, other related services to HCBS waiver participants. Under current CMS policy, Medicaid waiver dollars can be used to pay a legally responsible relative only if the relative is an RN, LPN, OT, PT or a similar professional worker, and the subject relative is capable of meeting the waiver participant's service needs as spelled out in his/her individual plan of care. At least one state has requested CMS' permission recently to employ non-professional parents and other legally responsible relatives as providers of HCB waiver services. In considering future requests of this type, CMS is weighing possible criteria that might be applied in determining the circumstances under which it is appropriate to pay parents and other legally responsible relatives for services rendered, and has asked for NASDDDS' assistance in seeking feedback from member state agencies on possible criteria that might be applied in such cases.

Please note that the question at issue is NOT whether states may use parents of adult waiver beneficiaries or other NON-legally liable relatives as paid providers of personal assistance/care services – a practice that many states have embraced as part of their DD home and community-based waiver program for many years. Instead, the focus here is on LEGALLY LIABLE relatives, including the parents of children under 18 years of age who are receiving waiver-financed services.

Would you please take a few minutes to respond to the following questions. In keeping with the Association's usual practice, the results of this brief survey will be summarized in a manner that does not identify individual state responses/respondents in order to maintain state confidentiality.

1. Regardless of the age of the beneficiary or the source of funding (either Medicaid or non-Medicaid), are legally liable relatives of individuals with developmental disabilities in your state eligible to receive payments for the personal assistance/care services they furnish to their sons/daughters, brothers/sisters, etc.? YES ___; NO ___. [If you answered "No" to this question, proceed to Question #5; otherwise, proceed to Question #2.]
2. If you answered "yes" to Question #1, indicate whether the parent/relative payment option applies to (check all that apply):
 - a. ___ Services funded through an approved Medicaid HCBS waiver program.
 - b. ___ Services funded as a Medicaid state plan service.
 - c. ___ Non-Medicaid services financed with state general fund dollars only.
 - d. ___ Other (please specify) _____.

3. If you answered “yes” to Question #1, please summarize the criteria used by your state agency to determine whether a parent/sibling caretaker is the most appropriate provider of paid personal care/support services.
4. Does your state use a written protocol or other formal decision-making process to determine whether a parent/sibling caretaker is the most appropriate provider of paid personal care/support services? ___ YES; ___ NO. If you answered “yes,” would you please share a copy of the written protocol with the Association.
5. Please share your opinion on whether CMS should permit states, upon request, to pay parents and other legally liable relatives as waiver-financed providers of personal care/support services under any of the following circumstances (check all responses that apply):
 - a. ___ Only when it is determined through a person-centered planning process that the parent/relative is the most appropriate available provider of the subject services;
 - b. ___ Only in instance where the state or a designated agent of the state has determined that no practical alternative exists to using the otherwise qualified parent/relative to provide the prescribed services, and, in the absence of such paid services, the individual would be likely to require an out-of-home placement.
 - c. ___ Only if the parent/relative meets all of the certification and training requirements that apply to other providers of the same category of waiver service.
 - d. ___ Only if the parent/relative meets all of the reporting requirements apply to any other provider of the same category of waiver service.
 - e. ___ Only if the individual plan of care specifies that the particular waiver participant’s need for personal assistance/care exceeds a threshold level of intensity of need for in-home and out-of-home personal assistance/care needs established by the state (e.g., more than 10 hours a week; more than 20 hours a week; etc.)
 - f. ___ My state has decided that legally liable relatives should not be compensated with public dollars for the personal assistance/care services they furnish to their sons, daughters, brothers, sisters, wives, husbands, etc.

Comments (on alternative a though e above):

6. Suppose that CMS were to adopt an intensity of need criterion in evaluating state requests to pay parents and other legally liable relatives as personal assistance/care providers

under their HCBS waiver program, what, in your opinion, would be the most appropriate intensity threshold level (circle preferred criteria below):

- a. ten hours or more of in/out of home assistance/care per week
- b. twenty hours or more of in/out of home assistance/care per week
- c. thirty hours or more of in/out of home assistance/care per week
- d. ____ hours (please specify) or more of in/out of home assistance/care per week

Comments:

7. Are there other criteria that you believe states (and CMS) should take into account in judging whether legally liable relatives should receive compensation for providing services to HCBS waiver participants? If so, briefly list such criterion/criteria below:

Should you have any questions concerning this survey, please direct them to Robin Cooper (windfiend@aol.com) or Bob Gettings (rgettings@nasddd.org). **Return your completed questionnaire to Karol Snyder at ksnyder@nasddd.org, on or before the COB on Wednesday, July 30, 2003.**