

CLIENT ASSISTANCE PROJECT

LEGAL ADVOCACY FOR PERSONS  
WITH DEVELOPMENTAL DISABILITIES

MENTAL HEALTH LAW PROJECT

PROTECTION AND ADVOCACY FOR  
INDIVIDUAL RIGHTS

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**TO:** Interested Persons

**FROM:** Anne L. Henry 

**RE:** Options for Family, Guardian Reimbursement for Services Provided to Persons with Disabilities

**DATE:** March 31, 2000

Because of the significant workforce shortage and a growing desire to make individual choices about services, there has been a lot of interest in payment of family members and guardians for services provided to persons with disabilities. The issues in this area are somewhat convoluted and have been creating confusion as to whether Minnesota is using options available in other states or not. The following information is provided to clarify which opportunities Minnesota has or is in the process of developing:

1. Consumer Support Grant (CSG)
  - A. State-Funded Consumer Support Grant.

The current Consumer Support Grant program allows families to use the state share of Medical Assistance funded home care services in a flexible and individualized manner. The problems with the current CSG program include:

- 1) The amount of money available is less than half the amount paid by Medical Assistance for home care and waiver services. The statute allows persons to use the state share of Medical Assistance (48.5% in 2000), but also allows a 20% deduction for administrative costs by the state and county. DHS has stated that any county which asks for the full 48.5% of Medical Assistance state share is given authority to use the full 48.5% without any deductions for administrative costs. There are currently no restrictions on use of state CSG funds to reimburse parents of minors or adults or spouses for services provided.

- 2) Participation in the CSG program is a county option. About 24 of 87 counties have agreed to allow the CGS program as of early 2000, with about 50 individuals participating in those counties.
- 3) If a person is screened and waiting for home and community waiver services eligibility, the parent of a minor child or legal guardian cannot both be paid for services, and participate as a member of the waiver screening team. Persons who cannot make informed decisions among service options for themselves must have a legal representative (defined as parent of a minor or legal guardian of an adult) participate in the screening process.

**B. Consumer Support Grant (CSG) Federal Demonstration Waiver (Section 1115).**

Legislation adopted during the 1999 session requires the Commissioner of Human Services to apply for federal permission to add federal funds to the state funds already available in the current Consumer Support Grant program. The Department of Human Services has decided to use the Federal 1115 Section Demonstration Waiver process. Minnesota's 1115 Demonstration Project waiver request will be submitted in May, 2000 to the federal Health Care Financing Administration (HCFA). A draft distributed in October generated a multitude of comments citing many significant problems.

DHS is pursuing the CSG 1115 Demonstration Project as a Home Care Services Project, not including waived services. If HCFA approves Minnesota's 1115 Demonstration Project request to add federal money to our Consumer Support Grant program, this program offers the option of flexible use of service dollars under a plan developed at the county level. It is likely, if approved, that the service dollars would be placed in a joint account with the county or other fiscal agent rather than direct cash payments to families. There are federal restrictions on the payment of parents of minors and spouses with federal Medicaid funds.

**2. Personal Care Assistant Program.**

**A. Payment Of Family Members.**

Federal Medicaid regulations prohibit payment of a member of an individual's family acting as a PCA. Federal regulations further define "family member" as a legally responsible relative. This means that under federal law, Minnesota cannot reimburse the parent of a minor or a spouse for provision of PCA services. However, any other

family member, including siblings, aunts, uncles, stepparents and grandparents can be paid. Parents of adults who are not the legal guardian can clearly be reimbursed for PCA services under federal regulations, but not under state law. Parents who are the legal guardians ought to be able to be reimbursed under federal regulations because the term "legally responsible" means financially responsible. Minnesota's private guardianship law is clear that parents of adults who are guardians are no longer financially responsible for their adult son or daughter, but have taken on the obligations of exercising their son's or daughter's legal rights. The Legislature is considering an amendment this session to allow legal guardians of adults to provide PCA services as long as a responsible party lives with the recipient.

Minnesota's state PCA statute allows the following relatives to provide PCA services under a hardship waiver: 1) Parents who are not the guardian of adult recipients (18 years or older); 2) Adult children of recipients; and 3) Siblings who are at least 16 years old. Other relatives such as stepparents, grandparents, aunts or uncles, can be paid as a PCA without a hardship waiver. It is important to remember, however, that our state law requires that recipients who cannot direct their own care have a responsible party who can be a paid PCA living with them in order to receive PCA services.

#### **B. Fiscal Agent Option.**

Changes made by the 1999 Legislature require DHS to offer the "**fiscal agent option**" for PCA recipients. DHS expects to have this fiscal agent option in place by July 1, 2000. Federal approval for this change has been obtained. The fiscal agent option will allow a recipient or responsible party to hire and terminate the PCA, recruit and hire professional supervision (RN or mental health professional), supervise and evaluate the PCA in areas that do not require professional supervision, and flexibly use funds currently used by provider organizations for administrative functions. The fiscal agent option should allow recipients or their families to modestly increase PCA pay, but will not change the rules on which family members can be paid as PCA's. DHS Bulletins are available on their web site.

In October 1999, the Health Care Financing Administration (HCFA) made revisions to requirements for the PCA program. These new revisions clarify that a person who cannot direct their own care could still participate in Minnesota's fiscal agent option (called Consumer Directed Services at the federal level) if another family member acted to direct the services. Minnesota already has in place a surrogate for those who cannot direct their own care, termed "the responsible party" in our state PCA law.

The recent HCFA revisions offer no change in the prohibition against paying spouses and parents of minors.

**3. Home and Community Waiver for Persons with Mental Retardation or a Related Condition (MR/RC Waiver).**

**A. Residential Habilitation Option Under The MR/RC Waiver.**

DHS issued a bulletin (98-56-15) dated October 21, 1998, which announced changes in our MR/RC waiver plan regarding immediate family members providing residential habilitation services. Family members, with the exception of parents/stepparents of minor children and spouses of adult recipients, who meet provider qualifications may provide residential habilitation services. In other words, family members, such as parents of adult children, may be employed by an agency and provide residential habilitation services. Parents who are legal guardians of adult children should be able to work for a waived services provider and be paid for residential services as soon as DHS has amended the Home and Community Waiver plan.

**B. Consumer-Directed Community Supports Under The MR/RC Waiver.**

Minnesota received approval from HCFA at the end of 1997 to add Consumer Directed Community Supports to the MR/RC waiver. Consumer Directed Community Supports are offered in counties (only four as of 1/00) which enter into a memorandum of understanding (MOU) with the state regarding protections and quality assurance for persons using Consumer Directed Community Supports. Services can be individually designed, using either formal or informal providers. At this time, spouses, parents of minor children, and legal guardians of adult children cannot be reimbursed for any services provided through Consumer Directed Community Supports. However, language adopted as part of the 1999 DD waiting list bill requires DHS to amend the MR/RC waiver plan to allow legal guardians of adults to be reimbursed for services provided because there is no federal rule against paying those not financially responsible. DHS expects to request the waiver amendment in early 2000.

DHS has committed to extending the Consumer-Directed Community Supports to all the other waiver programs by January 2001.

Minnesota's Consumer-Directed Community Supports is much like a similar option in Wisconsin's home and community waiver. Wisconsin patterned their request after Minnesota's and received approval for this option about six months after Minnesota.

4. 1999 DP Waiting List Legislation.

Two provisions in the DD waiting list legislation adopted during the 1999 legislative session require DHS to work on changes regarding family members reimbursement for services provided.

- A. The Department is required to request a Federal Demonstration Waiver to allow recipients or their families to use 95% of the funds which would have been spent to provide formal or informal supports. This provision is very much like the currently available Consumer Directed Community Supports in that funds that would have been allocated to an individual can be used for the purchase of services to meet long-term needs. The purchase of these services would be directed by the person or their guardian.
- B. DHS is required to develop criteria to allow legal representatives (guardians) to be reimbursed for providing specific services under both the Consumer Support Grant program (*see #1B*) and the MR/RC waiver Consumer-Directed Community Supports Option (*see #3B*). This provision was necessary because Minnesota's case management statute contains a provision which prohibits anyone with a service provider interest from participating on the screening team. An individual who cannot make informed choices must have a guardian or conservator to participate in the screening process. An individual must have a current screening in order to receive home and community waiver services or to be able to use the home and community waiver services amount for a Consumer Support Grant. Therefore, it was necessary to require the Commissioner to submit an amendment to the MR/RC home and community waiver to allow legal representatives to provide supports and receive reimbursement under the waiver plan despite our screening statute prohibition.
- C. DHS was required to report to the legislature by January 15, 2000 on recommendations to allow parents of minors to be reimbursed consistent with federal requirements and health and safety assurances. This report has not been issued as of March 10, 2000, but much work has been done, which verifies that federal policy must change in order to pay parents of minors.

5. Federal Issues Regarding Reimbursement For Parents Of Minors And Spouses For Services.

Federal Medicaid has had a long-standing rule against allowing spouses or parents of minor children to be reimbursed for services which "would normally be provided without charge as a matter of course in the usual relationships among members of a nuclear family." This

position has been interpreted by the federal government to mean that exceptions could be made for "extraordinary services requiring specialized skills such as skilled nursing or physical therapy." Parents and spouses who are nurses or therapists (but not PCAs) could be reimbursed with no federal law problem.

Given the severe workforce shortage and the fact that some family members are foregoing other employment or limiting their activities in order to care for their child, federal policy should be changed to allow payment to parents of minors and spouses who act as PCAs. It appears that West Virginia may have gotten just such a policy change for parents of minors when an extreme hardship due to lack of a qualified provider under the home and community waiver exists. However, West Virginia's option would not apply to the PC A program which has specific federal regulations as a barrier to parents of minors being reimbursed for services. Until federal law changes, DHS ought to pursue the option of allowing parents of minors to provide services under the home and community waiver and Section 1115 Demonstration Waivers with safeguards and monitoring.

Efforts are underway to pass federal changes to allow parents of minors to be reimbursed. The federal law which may deal with this issue is the Grassly, Kennedy Family Opportunity Act.

## **SUMMARY**

### **I. CURRENT LAW ALLOWS THE FOLLOWING OPTIONS:**

**A. All family members**, including the parent of a minor, legal guardian or a spouse can be reimbursed through the Consumer Support Grant program with state funds only (limited to 48.5 percent of M.A. home care expenditures), provided; 1) the county participates in the program; 2) the county approves a plan for such reimbursement; and 3) there is another parent or legal guardian to participate on the screening team for home and community waiver services since Minnesota's case management statute prohibits anyone paid to provide services from participating as a member of the screening team.

B. Family members other than parents of minors, a legal guardian of a child or adult and a spouse, can be reimbursed for services through the 1) the Residential Habilitation Option as staff of a provider agency under the MR/RC waiver or 2) a hardship waiver for PCA services.

II.. COMING SOON FOR LEGAL GUARDIANS:

- A. DHS is in the process of amending the MR/RC waiver plan to allow legal guardians to be reimbursed under the waiver Consumer-Directed Community Supports option. HCFA has 90 days to respond after the amendment is submitted, so hopefully, this option will be available by July 2000, but only in counties which opt to participate.
- B. Legislation allowing legal guardians for adults to be paid as PCA's is currently under consideration in S.F. 2841 and H.F. 3409 and likely to pass.

III. COMING SOON FOR PCA RECIPIENTS:

- A. The fiscal agent option should offer some relief by allowing a modest increase in PCA hourly wages and flexibility in hiring, training, scheduling and supervision. This option should be available by July 2000.

ALH:pjc/nb