

CLIENT ASSISTANCE PROJECT

LEGAL ADVOCACY FOR PERSONS  
WITH DEVELOPMENTAL DISABILITIES

MENTAL HEALTH LAW PROJECT

PROTECTION AND ADVOCACY FOR  
INDIVIDUAL RIGHTS

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November 8, 1999

Jan Kooistra  
Department of Human Services  
Health Care  
444 Lafayette Road  
St. Paul, MN 55155-3852

RE: Draft Consumer Support Grant Demonstration Project

Dear Ms. Kooistra:

I am writing to comment on the Department of Human Services' draft Consumer Support Demonstration Project § 1115 waiver request. Our office represents persons with disabilities across the State of Minnesota. We were instrumental in drafting and pursuing the state legislative change for the Consumer Support Grant Program during the 1999 legislative session. Our clients needed two changes in the state-funded Consumer Support Grant Program: a) expand eligibility to include families who pay a parental fee for Medical Assistance coverage for their children with significant disabilities and b) provide access to the federal funds used for services which could be "cashed out" under the Consumer Support Grant (CSG) Program. Based upon our involvement in the legislative change and the other statutory provisions, we believe that the Department's draft waiver request is overly restrictive in a number of key areas. On behalf of our clients with disabilities, we urge that the following changes be made to the draft waiver request:

1. Eligible project participants, 3.2, page 7.

We strongly object to limiting the eligibility for this program beyond the limits currently in statute. In particular, adults unable to direct their own care who have another family member, legal representative or other authorized representative who can purchase and arrange supports are eligible for the Consumer Support Grant Program, Minn. Stat. § 256.476, Subd. 3(a)(2). There is no basis on which the Department can limit this group to those who are living with a spouse who will manage their care. This limitation discriminates against adults with cognitive impairment, brain injury and mental illness based on marital status.

The exclusion of unmarried adults who are unable to direct their own care, flies in the face of strong state policy to assist families to care for their disabled members at home as long as possible. If the current eligibility limitations are approved, a family who uses the Consumer Support Grant Demonstration Project to care for their child would have a total disruption of services when that child turns 18 years old. This eligibility limitation does not square with the long waiting list for home and community waived services for those with mental retardation or related conditions, the fact that special education services are provided to age 21 and the fact that Minnesota is experiencing a very serious work force shortage for direct care staff, including personal care assistants. With these factors in mind, we urge that the eligibility criteria be changed to eliminate the requirement of living with a spouse for adults unable to direct and purchase their own care, and instead follow the statutory language for adults unable to direct and purchase their own care.

**2. Persons receiving services through a 1915(c) waiver, 3.21, page 7.**

We disagree that persons receiving home and community-based services through a § 1915(c) waiver should be ineligible for the Consumer Support Grant Demonstration Project. Our state statute governing this program simply prohibits persons from participating in both the home and community-based waiver program and the Consumer Support Grant Demonstration Project concurrently. The waiver request should be clarified to state that persons may "cash-in" their home and community waived services in order to participate in the Consumer Support Grant Demonstration Project.

**3. Managed care programs, 3.22, page 7.**

The description of managed care programs does not include the Demonstration Project for Persons with Disabilities which is scheduled to begin mandatory enrollment in two areas of the state June 1, 2000. Because individuals in these areas will not have a choice of enrolling in managed care, we believe it is unfair to exclude them from participation in the Consumer Support Grant Demonstration Project. While we understand that the demonstration sites hope to offer an array of flexible services, we believe that the Consumer Support Grant Demonstration Project should be an option for persons with disabilities who are required to enroll in managed care under the Demonstration Project for Persons with Disabilities.

4. **People with MA spend downs, 3.23, page 7.**

We disagree that persons eligible for Medical Assistance with a monthly spend down should be excluded from enrollment in the Consumer Support Grant Demonstration Project. It should be possible to calculate the grant amount from services used or projected.

5. **Participating counties, 3.31, page 8.**

We see no statutory justification for limiting the number of counties participating in the Consumer Support Grant Demonstration Project to 24. Given the serious staff shortage across the state, we urge that all counties have the option of participating in the Consumer Support Grant Demonstration Project.

6. **Participating consumers, 3.32, page 8.**

This project should not be limited to 500 consumers, nor should the new and continuing Medicaid recipient limitations remain in the waiver request. This program should be as open and flexible as possible. Given the fact that participation in the state program is so low (34 participants from 8 counties), there is no reason to set an arbitrary limit of consumers. Because the costs in the program will be no greater than would have otherwise been spent and individuals are having a very difficult time obtaining services, the fiscal control on the program is sufficient without limiting the number of participants. This comment assumes that DHS is not seeking to build up the state budget surplus on the backs of persons with disabilities and the frail elderly who are eligible for services, but cannot obtain them due to the extreme direct care staff shortage.

7. **Services eligible for cash-out, 3.4, page 9.**

The state statute governing this program does not limit cash-out services to home health aide and personal care services. The statute is inclusive in terms of the programs and services which can be "cashed out." The language at Minn. Stat. § 256.476, Subd. 1(1) refers to "alternatives to existing programs and services, such as the Developmental Disability Family Support Program, the Alternative Care Program, the personal care attendant services, home health aide services, and nursing facility services; . . . ." This language is repeated in Subdivision 5 with the same list of programs preceded by the words "such as." The commonly understood meaning of the term "such as" is that it offers examples but is not an exhaustive list. Therefore, we urge that the demonstration project include all home and community-based

services, private duty nursing services and nursing facility and ICF/MR services. There is no statutory basis to restrict the request in the statute, unless the Department can show that allowing nursing facility, ICF/MR or home and community waiver recipients will result in an increased cost to the state, Minn. Stat. § 256.476, Subd. 3(d). It is difficult to see how the cost to the state would be increased by allowing persons to cash-out their facility services or waiver programs, since they are already using a particular amount of funds which can be then transferred over to the Consumer Support Grant Demonstration Project.

8. **Initial grant for enrollees with at least 12 consecutive months of expenditure history, 3.51, and less than 12 consecutive months of expenditure history, 3.52, page 10.**

The reduction by 20 percent of state and federal funds in order to assure budget neutrality is not required by the Consumer Support Grant statute. The statute refers only to 80 percent of non-federal funds, but clearly allows individuals with "exceptional need" to obtain up to 100 percent of the non-federal dollars, Minn. Stat. § 256.476, Subd. 5(f). In addition, Subdivision 7 of the statute requires that all federal funds made available go directly to "the responsible county agencies Consumer Support Grant fund." In other words, the legislation does not provide for a savings of federal funds nor any use of the federal funds for state administration of the program.

9. **Service providers, 3.62, page 12.**

The prohibition against payment of spouses, parents or legally responsible adults for services and supports is contrary to the thrust of the Consumer Support Grant Program. This program is meant to provide consumers with flexibility in arranging for services. For some, their only service options are family members willing to forego other paid employment or activities in order to care for their relative. It is difficult to understand why this state would want to prohibit such provision of services in a time of work force shortage and direct care staff crisis. If the concern is the health and safety of the Consumer Support Grant participant, there are other protections in the program to assure that the needs of the individual are met. The funds can only be used according to a plan, oversight will be provided by the county, many of the individuals using this program will have a case manager. We also suggest that part of an individual's plan include services, activities and contacts with individuals other than paid staff or family members on a regular basis, at least once per week or more if needed. With such oversight and involvement of other agencies and individuals, we believe that it is not necessary to prohibit payment of spouse, parents

or legally responsible adults. If there are neglect or abuse concerns, mandated reporters are currently required under the Vulnerable Adults or Maltreatment of Minors Act to make such reports to the county for investigation.

**10. Budget neutrality, 5.1, page 29.**

The limitation of grants to 80 percent of the projected per person costs is not consistent with the governing statute. As described in number 7 above, the statute allows individuals to get up to 100 percent in the state funds for services "cashed-out" and the language on federal funds requires that all of the federal funds be turned over to the county for the Consumer Support Grant Fund. The amount reserved for administration in the waiver request is excessive. While we understand that there will be some state costs in managing the fiscal data to determine how much money is transferred to the county for this program, we believe that county case management and county Medical Assistance administrative funding should cover the county's costs for administering the program. There is no provision in the statute to cash-out county administrative funds or county case management, which will continue to be available. The only reference to case management in the statute is found in Subdivision 4(g) "reimbursable costs shall not include costs for resources already available, such as special education classes, day training and habilitation, case management, and other services to which the person is entitled, medical costs covered by insurance or other health programs, or other resources usually available at no cost to the person or the person's family." The individual planning, oversight, monitoring and protection activities needed for the Consumer Support Grant Program are similar, if not the same, whether the person is participating in the Consumer Support Grant Program, a home and community waiver program or MA home care services.

We urge the Department to change the waiver request and allow all available federal funds to be used for services for individual participants. One-half the savings of state dollars (up to 20 percent of the non-federal share) can be split between the state and the county to handle any new fiscal tracking, monitoring and protection activities required by this program. Both the county and the state can continue to access Medical Assistance administrative funds for all Medical Assistance eligible participants using the Consumer Support Grant Program. In addition, case management services can be used by the county to individually monitor participants who are eligible for case management services.

The term budget neutrality does not require a savings for the state or federal government. Our state statute does not require a 20 percent savings either. The statutory provision on savings, Minn. Stat. § 256.476, Subd. 5(f), requires that one-

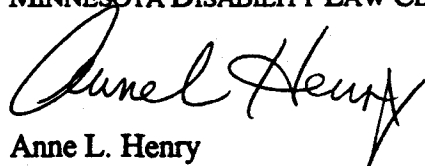
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half of an amount up to 20 percent of the non-federal share be returned. Given that the commissioner has approved of grants above 80 percent of non-federal funds, the savings required by statute is less than 10 percent of the non-federal share of services "cashed out." Given the difficult circumstances for many potential Consumer Support Grant Program participants due to direct care staff shortages, we urge that the Department maximize the service dollars and minimize the administrative costs and savings amount.

Thank you for the opportunity to recommend changes to the draft waiver request.

Sincerely,

MINNESOTA DISABILITY LAW CENTER



Anne L. Henry  
Attorney at Law

ALH:nb

bcc: Colleen Wieck, Ph.D.