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TO: **Shirley Patterson York and Jim Varpness**

FROM: **Anne L. Henry, 612-746-3754**

RE: **Comments on the 12/12/03 Consumer-Directed Community Supports (CDCS) Proposed Amendment**

DATE: **January 16, 2004**

The following comments are submitted for consideration by the Department in finalizing the Consumer-Directed Community Supports (CDCS) amendment request to the Centers for Medicare and Medicaid services for Minnesota's Home and Community-Based Waiver programs.

OVERVIEW RESPONSE

The expansion and improvement of the CDCS Option has been long-awaited. As originally imagined, CDCS promised increased flexibility and equity and opportunities for greater self-direction and community integration for persons on all of the state's Medicaid waivers.

The December 2003 proposed CDCS amendment is a serious disappointment to many who have worked to develop more consumer friendly services for persons with disabilities in Minnesota. Although consumers and advocates worked closely with the Department of Human (DHS) staff to establish consumer-directed services as part of Minnesota's home and community-based waiver programs from 1999 through the Fall of 2002, the Department has excluded us from discussions of the provisions contained in the CDCS proposed amendments dated December 12, 2003. Significant changes have been made to the CDCS proposal without public discussion. It should come as no surprise then, that we have many serious concerns and questions about the provisions contained in this draft of the CDCS amendment.

Overall, the budget limitations are so severe that it is difficult to understand why a lengthy list of prohibitions would even be considered. Families of children are subject to a substantial sliding scale fee to participate in the program in the first place. Families of adults who continue to care for them at home are doing so without any legal obligation whatsoever. The fact that the budget methodology limits the comparison group to those living at home or independently rather than including those

living in group homes with agency-provided services reflects a seriously flawed policy favoring providers over individual or family managed care. This and numerous other aspects of the CDCS proposal, directly conflict with the overall philosophy of consumer-directed services and waiver program itself.

POSITIVE ASPECTS

1. **Statewide Availability.**

   Currently, only 34 of Minnesota's 87 counties have chosen to offer CDCS, which is only available to those eligible for the waiver for persons with mental retardation or a related condition (MR/RC). We strongly support the extension of the CDCS Option to persons living in all counties in Minnesota.

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   Currently, only those eligible for the MR/RC waiver can choose consumer-directed services in the 34 counties which offer it. This amendment proposes to extend the consumer-directed option to those eligible for the community alternatives for disabled individuals (CADI), the traumatic brain injury (TBI) waiver, the community alternative care (CAC) for persons who are eligible for a hospital level of care and the elderly waiver (EW). The extension of the CDCS Option to all persons with disabilities receiving home and community waiver services is a positive aspect of the proposed amendment. Our comments cover persons eligible for the MR/RC, CADI, TBI and CAC waivers, not the EW.

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   We strongly support the request to allow parents of minor children and spouses who care for their loved one to be reimbursed up to 40 hours for care provided. The demands of such care often limit the family member's ability to earn a living outside the family home, so this is a welcome policy change.

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   The opportunity to choose a provider for some current case management functions is a positive step in the direction of providing choice of provider for case management services.

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The inclusion of therapies, special diets and behavioral supports not covered as part of the state Medicaid plan as allowable expenses is a positive clarification for consumer-directed community supports in Minnesota. (*See* #5 on page 10).

RECOMMENDATIONS FOR CHANGES

6. Balancing the Needs of Persons Currently Receiving CDCS While Providing a New Option to Others.

The Department faces a daunting challenge in proposing to provide CDCS services as a new option to all eligible persons for all waiver programs in Minnesota under new rules which differ substantially from those governing the current 2,400 CDCS users. It is important to recognize that DHS has significantly different obligations to persons in current service arrangements under CDCS services compared to those now receiving other waiver services in Minnesota who may choose the new CDCS Option in the future. The Department has stated that due to budget concerns, it is necessary to significantly reduce the funds available to nearly 1,000 current MR/RC waiver recipients in order to both fund increases for some current CDCS users and offer a new CDCS option to the rest of the MR/RC recipients living in Minnesota counties where CDCS services have not yet been offered. We believe this is an irresponsible position which will violate the terms of Minnesota's federal waiver agreement by directly threatening the health, safety and welfare of those currently receiving services whose funding will be significantly cut.

The DHS projects that nearly 1,000 current MR/RC waiver participants will have to change their services to traditional provider-based services within less than two years. This proposed amendment fails to recognize that CDCS is not simply one service under a waiver program like home modifications or extended therapies. CDCS services cannot be compared to one or another of the current service options under the home and community waiver program because CDCS is a different way to provide all services needed by a person who requires a 24-hour plan of care.

The change from CDCS services to provider-based services will be an impossible task for such a large number of vulnerable Minnesotans. Persons will lose valuable, trained staff who are unlikely to work for agencies at lower pay. Among those currently using CDCS services are a number of Minnesota's highest need, most vulnerable persons with developmental disabilities. There are individuals who were neglected and abused when receiving institutional care in ICFs/MRs. It is simply irresponsible and dangerous to force persons who have experienced abuse in previous service arrangements and are now receiving appropriate, safe and effective services

to abandon a good situation and return to the inadequacies of a provider system which has failed them in the past. Indeed, the common and widespread problems involved in accessing good quality, reliable services are one of the primary motivations for creating a CDCS Option in the first place.

Besides threatening the health, safety and welfare of a large number of vulnerable MR/RC waiver recipients, the proposed amendment ignores the increased costs that will occur as high-need people seek care from provider agencies. We see no evidence that the increased costs for provider services have been accounted for in the proposed amendment. Instead, it appears that DHS is assuming that families will be able to provide significantly more unpaid care for those who face substantial budget cuts. Putting such added stress on families will be a destructive and destabilizing force which will inevitably lead to crisis placements.

Accordingly, with regard to current CDCS recipients, we urge that DHS continue these individuals under the waiver provisions which allowed their services in the first place. The option can be described as a pilot project or "CDCS I." We understand that DHS is seeking to change the current way CDCS is provided to a new approach. We too strongly support extending a consumer-directed option to all waivers in all counties in Minnesota, but not at the cost of endangering nearly 1,000 vulnerable persons with developmental disabilities on the MR/RC waiver. We believe that DHS can operate the current CDCS or CDCS I, for those now using it and establish a new CDCS option, CDCS II, for those who are not yet using CDCS services. As persons using current CDCS services leave, the numbers under CDCS I will shrink. In addition, some of the guidelines and rules for the new CDCS option could be applied to the existing consumer-directed option. By distinguishing between those using consumer-directed services under the memorandum of understanding process and those who will newly choose CDCS in 2004 or later, DHS avoids violating its waiver agreement with the federal government and prevents significant harm to vulnerable individuals whose well-being is the responsibility of the Department. ***We urge that DHS maintain the current CDCS Option for those using it now and implement a new version of CDCS, with recommended changes, for those using all waivers, in all counties. We would welcome the opportunity to discuss this recommendation in detail with DHS staff.***

7. **Health, Safety, and Welfare Concerns for Persons Terminated from CDCS.**

As stated above, we believe that the budget methodology as it affects persons currently using CDCS services should not be implemented. The risks to health, safety and welfare for current waiver recipients are simply too extreme.

A Termination for 100 persons living in licensed residential settings.

We strongly disagree with the DHS proposal that persons living in licensed residential settings are prohibited from using CDCS services. The flexibility of CDCS services has been very valuable for persons moving from home to a licensed setting. CDCS has provided stability and protection as well as active treatment for individuals living in licensed settings. This opportunity should not be ignored and dismissed so easily, both for those now using CDCS and for those newly offered the option. The health, safety and welfare of at least 100 individuals currently living in licensed residential settings and using CDCS services to meet their needs is at serious risk under this proposal. The provisions about a transition for those whose budgets currently exceed the new limits, Appendix B.1., Attachment B, page 5, provides no guidance for persons living in licensed residential settings terminated from CDCS services. Surely the Department cannot intend to abruptly terminate services currently required in the person's individual service plan to meet their health, safety and welfare. ***We urge that persons living in licensed residential settings be allowed to use CDCS services.***

B Persons using CDCS services projected by DHS to be terminated due to inadequate budgets under the new methodology.

DHS projects that between 850 and 1,100 persons will not be able to continue their current service arrangements because of significant cuts in their budget of 15 percent or more. This figure represents approximately 40 percent of persons using CDCS. As discussed above, this result is simply unacceptable and will violate Minnesota's waiver agreement with the federal government to meet recipient's health, safety and welfare. Any proposal which does so much harm to so many individual vulnerable recipients is irresponsible. The proposed amendment provisions which threaten the well-being of over 1,000 current recipients should be changed in the waiver amendment request. Minnesota does not have the provider capacity; available, trained low-paid work force; or county case management staff to completely change the services for so many people in less than two years. Minnesota has never developed replacement service arrangements for over 1,000 persons in less than two years, even in the most active times of state hospital closures. This proposal is irresponsible and would seriously harm many vulnerable Minnesotans. ***CDCS services cannot be terminated until appropriate alternative services which meet the individual's health, safety and welfare needs are in place.***

8. **Budget Methodology.**

A Equitable versus Rigid.

The Department has stated that the budget methodology proposed for CDCS services is in response to calls for fairness and equity across the state. While there are significant concerns about the lack of guidelines and supervision by the Department of county implementation of CDCS, the proposed budget methodology is too rigid and attempts to force people with different needs into an inadequate budget category with no exception process. In addition, DHS has not provided enough information about the budget methodology for persons to know how they will be affected.

1) Budget methodology fails to account for significant cost variation.

The waiver program is required to meet individual needs. Minnesota's state laws and service requirements are designed to consider the unique needs of individuals for supports to live in the community rather than institutions. By establishing a statewide budget methodology which only accounts for 60 percent of the cost differences among persons on the MR/RC waiver and 75 percent of the cost differences for the other waiver programs, our state is failing to consider the individual's need for services. Ignoring cost variations amounting to 40 percent for MR/RC waiver and 25 percent for the other waivers will put persons at risk for their health, safety and welfare. **Given the significant costs not accounted for in the proposed budget methodology, DHS must include an exception process to exceed the rigid budget caps (*see* below).**

2) MR/RC Screening Document Inadequate for Budget Determinations.

A second concern about meeting individual's unique needs is the fact that the budget methodology for the MR/RC waiver is based solely upon the screening document which is not a full inquiry into a person's individual needs, but merely a screening as to whether the person is eligible for the ICF/MR level of care. This methodology misapplies a general screening tool and stretches it beyond its original design, intent and capability. The MR/RC screening document is not now used to set budgets to meet individual needs; rather, the individual service planning process examines more detailed

assessments, reviews current circumstances and consults with the legally responsible person in developing needs.

Young children with autism spectrum disorders are especially disadvantaged by the screening document which does not adequately assess these conditions. We are concerned that these children will not qualify for sufficient funds because the CDCS Option is a primary method for obtaining intensive behavior therapy for these young children. There are few, if any, non-CDCS budgets which cover this intensive service. ***Use of the MR/RC screening document fails to account for individuals' unique needs, threatening the well-being of those who would otherwise benefit from CDCS.***

3) Allow Exceptions to Exceed Budget Caps.

We urge that DHS include an exception process for those who would choose CDCS so that when an individual's unique needs cannot be met under the proposed budget methodology, there is an opportunity to increase funding. Given budget constraints, DHS could limit increased funding to the amount that would otherwise be spent for a CDCS person in the waiver program with non-CDCS services, including residential services. This exception process would both protect the basic rights of persons in the community and assure that the spending through this option does not exceed what otherwise would be spent on the individual in services that are likely less effective and possibly even institutional in character. Without an exception process under the CDCS Option, the waiver will be unable to meet *Olmstead (Olmstead v. L.C.*, 119 S. Ct. 2176 (1999)) requirements to prevent unnecessary segregation and provide the most integrated settings for persons with disabilities.

B Failure to include residential placement costs in the budget methodology.

By failing to include out-of-home residential placements costs in the budget methodology, DHS has ignored an important cost driver in our waiver programs. Given the fact that the DHS projects that 950 to 1,100 people will not be able to continue their current service arrangements because of the budget methodology or living in a licensed residence, it is irresponsible from a budget perspective as well as a legal perspective not to account for the inevitable movement to out-of-home, more expensive services as a result of this restrictive methodology. ***Residential services costs should be included***

in the budget methodology and, at a minimum, be used as a comparison when setting any budget limits.

C Budget methodology based on inadequate services.

It is well documented that many persons on the home and community waiver who rely on providers for services in their homes are unable to obtain enough staff to fill the authorized hours of care. The proposed budget methodology enshrines the inadequate service provision now occurring across our state and then cuts that amount by 30 percent. While DHS data show that about half the persons now using CDCS with some similar characteristics to those who would be served within the budget limits or even have access to more funding, it is simply flawed for the Department to assume that the needs of two individuals, matched on some screening document factors, are so much alike that matching their budgets and reducing CDCS funds by 30 percent will meet Minnesota's obligation under the waiver to provide for the health, safety and welfare of each individual being served. This is a dangerous leap without foundation.

In sum, the budget methodology proposed for CDCS services is extremely flawed. For persons who have not yet had the option of choosing CDCS, it may be that in some situations the offer of 30 percent less of an inadequately staffed provider-based system will still be better than their current circumstances. However, for most, CDCS will be a false option because of the budget limit. For 1,000 persons currently living in the community with services through the CDCS Option, the budget methodology proposed will be disastrous. The Department must find a way to offer CDCS statewide on all waiver programs while not sacrificing the health, safety and welfare of many individuals now using CDCS on the MR/RC waiver.

9. <u>Due Process Concerns.</u>

A Notice for those who "exit" the waiver more than once per year.

We are very concerned about how the Department plans to provide adequate notice to persons with disabilities whose services are threatened under the proposed amendment.

First, it is important to note that DHS has stated that persons on all waiver programs will not be removed ("exited") from the waiver when hospitalized

in an acute care hospital. Is this true for persons on the CAC waiver, regardless of the length of their hospitalization?

There are still many unanswered questions about the "exit" provision. When will individuals who "exit" (leave) waiver services more than once per year be notified of the termination of their CDCS services? How many current CDCS recipients on the MR/RC waiver will be affected? How many persons on CADI, CAC and TBI will be excluded from the option because of the "exit" provision? What about a temporary crisis which requires placement in a facility which would require exiting the waiver? For some MR/RC waiver recipients, ICF/MR services are the only respite option. What happens when a person using CDCS is ready to return home after the second respite stay in an ICF/MR? How long is the transition period from CDCS to provider services to assure that health, safety and welfare are met? Will the Department provide advance notice before a person enters a facility in a crisis? To force a vulnerable person in a crisis to dismantle their services in the community after the crisis has passed is unnecessary and inadvisable and will surely result in institutionalization in conflict with the state's obligations under the *Olmstead* decision. ***The provisions on termination from CDCS due to "exiting" CDCS services should be deleted from the amendment.*** Budget concerns can be handled by the monitoring required of county case managers and the DHS waiver management software.

B **Termination of CDCS services "if there are immediate concerns regarding the recipient's health and safety or misuse or abuse of public funds."**

If there are concerns about criminal activity or abuse or neglect, Minnesota has laws and procedures to provide guidance for county or health plan action. Unless there is an immediate abuse or neglect situation under the Vulnerable Adult or Maltreatment of Minor Act, counties and health plans should not be allowed to unilaterally terminate services. Unilateral termination of services puts the waiver recipient at significant immediate risk for their health, safety and welfare. ***This provision should be clarified to apply only to instances in which there is an immediate protection action warranted under the Vulnerable Adults Act or the Maltreatment of Minors Act paired with a requirement that the vulnerable person be provided immediately with appropriate substitute services.*** In all other cases, a corrective action plan coupled with advance notice of termination, when necessary, can be used in cases of financial mismanagement.

We certainly agree that in the case of criminal activity or abuse and neglect swift action should be taken to protect the vulnerable person. However, there have been and will be disputes, differences of opinion and mistaken understandings about the type of service or billing practices which have and will occur between families, guardians, persons with disabilities and their counties. The proposal threatens the due process rights of CDCS recipients by attempting to eliminate the opportunity to seek services pending appeal when a dispute occurs. CDCS services are provided for the eligible vulnerable person and should not be unilaterally terminated by a county except in the case of abuse or neglect. Apart from those very serious circumstances with clear procedures in Minnesota law for county action, it would be a significant violation of due process requirements to terminate CDCS services with no advance notice and opportunity to continue services pending the outcome of a hearing.

10. Licensed Physician Should be Changed to Licensed Health Professional.

The State of Minnesota regulates many types of health care practitioners. Our laws provide for parameters on the scope of practice for these practitioners. It is unreasonable to require that medical doctors prescribe therapies, special diets and behavioral supports not covered in the State Medicaid Plan if Minnesota law allows licensed health practitioners such as chiropractors or psychologists to provide such services.

The amendment documents provided for public comment seem confusing on this issue. The requirement that a medical doctor prescribe "therapies, special diets and behavioral supports not otherwise available through the State Plan" is contained in Appendix B.1., Attachment C (allowable expenditures) and in the Service Description, Appendix B.1. on the top of page 4. However, the section describing Provider Standards, Appendix B.2., page 8 (2) Treatment and Training allows professionally licensed, credentialed or otherwise certified health practitioners to provide supports and services. The regular Medical Assistance program does cover a number of services provided by a licensed health practitioners without requiring the signature of an M.D. ***This requirement is unfair, unnecessary, costly, administratively burdensome and should be deleted.***

11. Community Inclusion Costs.

We urge the Department to change its position regarding the costs of participating in community activities for home and community waiver recipients. Appendix B.1., Attachment C provides that membership dues or costs and tickets to attend sporting

or other recreational events are unallowable expenditures for CDCS. These types of expenses are now allowed in one form or another in all waiver programs for persons receiving services from providers. It is contrary to the purpose of consumer-directed care to remove one of the major methods of community inclusion from coverage for CDCS. To exclude the cost of exercising is also contrary to health maintenance and disease prevention. For many persons with disabilities, use of a fitness facility is part of a specific therapy regime. Obesity is also a major concern for persons with disabilities and results in high health care expenditures. Many persons with disabilities take medications which cause weight gain or need a unique machine or type of equipment to exercise. Given that there will be budget limitations, persons with disabilities and their families or guardians will make the necessary choices on how best to meet needs through the community support plan which is reviewed by the county.

In the alternative, we recommend two less preferred options: (1) set a dollar limit for community inclusion/recreation costs, such as $600 per year, which would annually increase with the CPI; or (2) allow community inclusion/recreation costs for staff accompanying waiver recipients and for adult recipients over 18. It is understood that families normally pay for the recreational costs of their children. However, it is not reasonable to expect families to pay for staff costs for community inclusion activities for their children nor is it reasonable to impose these costs on families of adults who are already contributing enormously to keep their loved one in their family with no legal obligation to do so.

This provision is unnecessarily restrictive and in conflict with the purpose of the waiver programs to promote participation in the broader community for persons with disabilities, not separation and isolation. ***We urge the Department to change the provisions regarding membership dues and costs and other community inclusion recreational costs.***

12. **Add the term "supplements" to the list of environmental modifications and provisions.**

The laundry list of home modifications and provisions is not an exclusive list, however, the importance of supplements in improving the functioning of some individuals with disabilities is clear. ***We urge that the Department include the term "supplements" to assure that these products are available to those using CDCS services.***

13. **Environmental Modifications.**

We understand the CDCS proposed amendment to allow up to $5,000 in environmental modifications to be included in an individual's CDCS annual budget. An individual is permitted to obtain environmental modifications and assistive technology in excess of $5,000 if approved by their county, if funds are available within the county's overall budget allocation. Clearly some environmental modifications are one-time costs which exceed $5,000 and will require county approval to be purchased. We are concerned that there are no standards for county consideration of requests to exceed the $5,000 limit. The budget management by 87 county entities will mean that numerous eligible waiver recipients who need environmental modifications and assistive technology will not be able to obtain these items or services due to the particular county in which they live. The effect of the $5,000 limit will be especially severe on persons with significant physical and sensory limitations. ***We recommend that DHS manage an exception process for individuals whose needs exceed $5,000 and whose counties cannot approve the items because of county budget limitations. A less preferred alternative would be to set statewide guidelines for county consideration of requests to exceed the $5,000 limit for environmental modifications and assistive technology.***

14. **Excessive County Management Activity.**

We are very concerned about the numerous specific county requirements added to this CDCS proposed amendment. We are concerned that the excessive county monitoring required will act as a barrier limiting county staff willingness to inform waiver recipients about the CDCS Option. The excessive county requirements come at a time of serious cuts to county budgets and staff. ***We urge the Department to reexamine county monitoring requirements and eliminate the three-month service authorization requirement and replace it with a twelve-month service authorization time period. Also, we recommend that rather than using the long-term care consultation screening document to distinguish between activities that a parent or spouse would ordinarily perform and activities which exceed normal activity, the Department use the home care assessment instrument which has been used for this purpose successfully by Dakota County.*** The home care assessment is more familiar to consumers and case managers in this area and is far less time consuming and bureaucratic.

15. **Criteria for Allowable Expenditures.**

We urge that DHS change criteria 4.: "for the sole benefit of the individual" contained in Appendix B.1., Attachment C. A number of services are provided specifically to assist the family to care for the individual, and thus benefit others

besides the individual recipient, such as respite care, homemaking services and chore service. Many other services, if they improve the functioning of the recipient, provide an indirect benefit to others, such as services to improve walking, eating, communicating. ***We urge that the term "sole" be deleted.***

16. Consumer Outcomes.

The six consumer outcomes listed in Appendix B.1., Attachment C, should clearly be listed as separate outcomes which can justify goods or services within the CDCS Option. The current language is not clear and could possibly be interpreted to require that all six outcomes must be met for all goods and services purchased under CDCS. Also, use of the term "necessary" is too absolute and subject to interpretation as a standard for all goods and services to meet.

We recommend that DHS make it clear that the consumer outcomes can separately justify services by including the following language in Appendix B.1., Attachment C:

> ***"If all of the above criteria are met, goods and services are appropriate purchases when they are reasonably calculated or designed ~~necessary~~ to meet one or more of the following consumer outcomes:"***

17. Expenses Related to Staff or Family Training.

We urge that expenses related to obtaining training, including travel, lodging or meals, be allowed expenses within the CDCS Option. Because there will be a budget limitation and county authorization for expenses, it is unnecessary to be so restrictive. Many individuals will need specific training in order to appropriately provide services to persons on the various waiver programs who might use the CDCS Option. ***We urge that the Department eliminate the exclusion of expenses for "travel, lodging or meals related to training the individual and his or her representative for paid or unpaid caregivers."*** If necessary, a limit could be placed on this category in the range of $300 - $500 per year.

18. Service Dogs.

The Department has stated that service dogs and all related maintenance costs including vet bills are adequately covered by a variety of non-profits in Minnesota. This is simply not true. Because service dogs are an important service for some persons eligible for the disability waiver programs, it is unreasonable to exclude all costs related to service dogs. There are examples of persons who have been able to

reduce or eliminate staff coverage for periods of time if they have a service dog. Service dogs can provide safety by acting as an alarm system for those with sensory impairments. Service dogs have also been used to reduce symptoms such as anxiety which has allowed a reduction in medication.

Because any costs related to a service dog would have to be included within the budget limits under CDCS and would have to be part of the person's community support plan and approved by the county, we urge that DHS allow costs related to maintaining a service dog to be covered under CDCS.

CONCLUSION

In sum, we urge the Department to consider the recommendations for change in the CDCS amendment. As noted earlier, we are most concerned about the termination of CDCS services to nearly 1,000 individuals now using this option to maintain themselves in the community. We have proposed a method for DHS to avoid service termination for a large number of persons on the MR/RC waiver using CDCS while still moving ahead to offer a consumer-directed option on the other waiver programs and for those on the MR/RC waiver who have not had the opportunity to use CDCS to date.

We appreciate the opportunity to comment on the proposed amendment and hope that ongoing dialogue resumes between DHS staff and various representatives of disability consumer and advocacy groups as soon as possible. We strongly believe that consumer directed services have already been demonstrated to be a cost saving, high quality, innovative service option and welcome the extension of consumer directed services to those who haven't yet been afforded the opportunity.

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RECOMMENDATIONS FOR CHANGES

6. Balancing the Needs of Persons Currently Receiving CDCS While Providing a New Option to Others.

The Department faces a daunting challenge in proposing to provide CDCS services as a new option to all eligible persons for all waiver programs in Minnesota under new rules which differ substantially from those governing the current 2,400 CDCS users. It is important to recognize that DHS has significantly different obligations to persons in current service arrangements under CDCS services compared to those now receiving other waiver services in Minnesota who may choose the new CDCS Option in the future. The Department has stated that due to budget concerns, it is necessary to significantly reduce the funds available to nearly 1,000 current MR/RC waiver recipients in order to both fund increases for some current CDCS users and offer a new CDCS option to the rest of the MR/RC recipients living in Minnesota counties where CDCS services have not yet been offered. We believe this is an irresponsible position which will violate the terms of Minnesota's federal waiver agreement by directly threatening the health, safety and welfare of those currently receiving services whose funding will be significantly cut.

The DHS projects that nearly 1,000 current MR/RC waiver participants will have to change their services to traditional provider-based services within less than two years. This proposed amendment fails to recognize that CDCS is not simply one service under a waiver program like home modifications or extended therapies. CDCS services cannot be compared to one or another of the current service options under the home and community waiver program because CDCS is a different way to provide all services needed by a person who requires a 24-hour plan of care.

The change from CDCS services to provider-based services will be an impossible task for such a large number of vulnerable Minnesotans. Persons will lose valuable, trained staff who are unlikely to work for agencies at lower pay. Among those currently using CDCS services are a number of Minnesota's highest need, most vulnerable persons with developmental disabilities. There are individuals who were neglected and abused when receiving institutional care in ICFs/MRs. It is simply irresponsible and dangerous to force persons who have experienced abuse in previous service arrangements and are now receiving appropriate, safe and effective services

to abandon a good situation and return to the inadequacies of a provider system which has failed them in the past. Indeed, the common and widespread problems involved in accessing good quality, reliable services are one of the primary motivations for creating a CDCS Option in the first place.

Besides threatening the health, safety and welfare of a large number of vulnerable MR/RC waiver recipients, the proposed amendment ignores the increased costs that will occur as high-need people seek care from provider agencies. We see no evidence that the increased costs for provider services have been accounted for in the proposed amendment. Instead, it appears that DHS is assuming that families will be able to provide significantly more unpaid care for those who face substantial budget cuts. Putting such added stress on families will be a destructive and destabilizing force which will inevitably lead to crisis placements.

Accordingly, with regard to current CDCS recipients, we urge that DHS continue these individuals under the waiver provisions which allowed their services in the first place. The option can be described as a pilot project or "CDCS I." We understand that DHS is seeking to change the current way CDCS is provided to a new approach. We too strongly support extending a consumer-directed option to all waivers in all counties in Minnesota, but not at the cost of endangering nearly 1,000 vulnerable persons with developmental disabilities on the MR/RC waiver. We believe that DHS can operate the current CDCS or CDCS I, for those now using it and establish a new CDCS option, CDCS II, for those who are not yet using CDCS services. As persons using current CDCS services leave, the numbers under CDCS I will shrink. In addition, some of the guidelines and rules for the new CDCS option could be applied to the existing consumer-directed option. By distinguishing between those using consumer-directed services under the memorandum of understanding process and those who will newly choose CDCS in 2004 or later, DHS avoids violating its waiver agreement with the federal government and prevents significant harm to vulnerable individuals whose well-being is the responsibility of the Department. ***We urge that DHS maintain the current CDCS Option for those using it now and implement a new version of CDCS, with recommended changes, for those using all waivers, in all counties. We would welcome the opportunity to discuss this recommendation in detail with DHS staff.***

7. **Health, Safety, and Welfare Concerns for Persons Terminated from CDCS.**

As stated above, we believe that the budget methodology as it affects persons currently using CDCS services should not be implemented. The risks to health, safety and welfare for current waiver recipients are simply too extreme.

A Termination for 100 persons living in licensed residential settings.

We strongly disagree with the DHS proposal that persons living in licensed residential settings are prohibited from using CDCS services. The flexibility of CDCS services has been very valuable for persons moving from home to a licensed setting. CDCS has provided stability and protection as well as active treatment for individuals living in licensed settings. This opportunity should not be ignored and dismissed so easily, both for those now using CDCS and for those newly offered the option. The health, safety and welfare of at least 100 individuals currently living in licensed residential settings and using CDCS services to meet their needs is at serious risk under this proposal. The provisions about a transition for those whose budgets currently exceed the new limits, Appendix B.1., Attachment B, page 5, provides no guidance for persons living in licensed residential settings terminated from CDCS services. Surely the Department cannot intend to abruptly terminate services currently required in the person's individual service plan to meet their health, safety and welfare. ***We urge that persons living in licensed residential settings be allowed to use CDCS services.***

B Persons using CDCS services projected by DHS to be terminated due to inadequate budgets under the new methodology.

DHS projects that between 850 and 1,100 persons will not be able to continue their current service arrangements because of significant cuts in their budget of 15 percent or more. This figure represents approximately 40 percent of persons using CDCS. As discussed above, this result is simply unacceptable and will violate Minnesota's waiver agreement with the federal government to meet recipient's health, safety and welfare. Any proposal which does so much harm to so many individual vulnerable recipients is irresponsible. The proposed amendment provisions which threaten the well-being of over 1,000 current recipients should be changed in the waiver amendment request. Minnesota does not have the provider capacity; available, trained low-paid work force; or county case management staff to completely change the services for so many people in less than two years. Minnesota has never developed replacement service arrangements for over 1,000 persons in less than two years, even in the most active times of state hospital closures. This proposal is irresponsible and would seriously harm many vulnerable Minnesotans. ***CDCS services cannot be terminated until appropriate alternative services which meet the individual's health, safety and welfare needs are in place.***

8. Budget Methodology.

A Equitable versus Rigid.

The Department has stated that the budget methodology proposed for CDCS services is in response to calls for fairness and equity across the state. While there are significant concerns about the lack of guidelines and supervision by the Department of county implementation of CDCS, the proposed budget methodology is too rigid and attempts to force people with different needs into an inadequate budget category with no exception process. In addition, DHS has not provided enough information about the budget methodology for persons to know how they will be affected.

1) Budget methodology fails to account for significant cost variation.

The waiver program is required to meet individual needs. Minnesota's state laws and service requirements are designed to consider the unique needs of individuals for supports to live in the community rather than institutions. By establishing a statewide budget methodology which only accounts for 60 percent of the cost differences among persons on the MR/RC waiver and 75 percent of the cost differences for the other waiver programs, our state is failing to consider the individual's need for services. Ignoring cost variations amounting to 40 percent for MR/RC waiver and 25 percent for the other waivers will put persons at risk for their health, safety and welfare. **Given the significant costs not accounted for in the proposed budget methodology, DHS must include an exception process to exceed the rigid budget caps (*see* below).**

2) MR/RC Screening Document Inadequate for Budget Determinations.

A second concern about meeting individual's unique needs is the fact that the budget methodology for the MR/RC waiver is based solely upon the screening document which is not a full inquiry into a person's individual needs, but merely a screening as to whether the person is eligible for the ICF/MR level of care. This methodology misapplies a general screening tool and stretches it beyond its original design, intent and capability. The MR/RC screening document is not now used to set budgets to meet individual needs; rather, the individual service planning process examines more detailed

assessments, reviews current circumstances and consults with the legally responsible person in developing needs.

Young children with autism spectrum disorders are especially disadvantaged by the screening document which does not adequately assess these conditions. We are concerned that these children will not qualify for sufficient funds because the CDCS Option is a primary method for obtaining intensive behavior therapy for these young children. There are few, if any, non-CDCS budgets which cover this intensive service. ***Use of the MR/RC screening document fails to account for individuals' unique needs, threatening the well-being of those who would otherwise benefit from CDCS.***

3) Allow Exceptions to Exceed Budget Caps.

We urge that DHS include an exception process for those who would choose CDCS so that when an individual's unique needs cannot be met under the proposed budget methodology, there is an opportunity to increase funding. Given budget constraints, DHS could limit increased funding to the amount that would otherwise be spent for a CDCS person in the waiver program with non-CDCS services, including residential services. This exception process would both protect the basic rights of persons in the community and assure that the spending through this option does not exceed what otherwise would be spent on the individual in services that are likely less effective and possibly even institutional in character. Without an exception process under the CDCS Option, the waiver will be unable to meet *Olmstead (Olmstead v. L.C.*, 119 S. Ct. 2176 (1999)) requirements to prevent unnecessary segregation and provide the most integrated settings for persons with disabilities.

B Failure to include residential placement costs in the budget methodology.

By failing to include out-of-home residential placements costs in the budget methodology, DHS has ignored an important cost driver in our waiver programs. Given the fact that the DHS projects that 950 to 1,100 people will not be able to continue their current service arrangements because of the budget methodology or living in a licensed residence, it is irresponsible from a budget perspective as well as a legal perspective not to account for the inevitable movement to out-of-home, more expensive services as a result of this restrictive methodology. ***Residential services costs should be included***

in the budget methodology and, at a minimum, be used as a comparison when setting any budget limits.

C Budget methodology based on inadequate services.

It is well documented that many persons on the home and community waiver who rely on providers for services in their homes are unable to obtain enough staff to fill the authorized hours of care. The proposed budget methodology enshrines the inadequate service provision now occurring across our state and then cuts that amount by 30 percent. While DHS data show that about half the persons now using CDCS with some similar characteristics to those who would be served within the budget limits or even have access to more funding, it is simply flawed for the Department to assume that the needs of two individuals, matched on some screening document factors, are so much alike that matching their budgets and reducing CDCS funds by 30 percent will meet Minnesota's obligation under the waiver to provide for the health, safety and welfare of each individual being served. This is a dangerous leap without foundation.

In sum, the budget methodology proposed for CDCS services is extremely flawed. For persons who have not yet had the option of choosing CDCS, it may be that in some situations the offer of 30 percent less of an inadequately staffed provider-based system will still be better than their current circumstances. However, for most, CDCS will be a false option because of the budget limit. For 1,000 persons currently living in the community with services through the CDCS Option, the budget methodology proposed will be disastrous. The Department must find a way to offer CDCS statewide on all waiver programs while not sacrificing the health, safety and welfare of many individuals now using CDCS on the MR/RC waiver.

9. <u>Due Process Concerns.</u>

A Notice for those who "exit" the waiver more than once per year.

We are very concerned about how the Department plans to provide adequate notice to persons with disabilities whose services are threatened under the proposed amendment.

First, it is important to note that DHS has stated that persons on all waiver programs will not be removed ("exited") from the waiver when hospitalized

in an acute care hospital. Is this true for persons on the CAC waiver, regardless of the length of their hospitalization?

There are still many unanswered questions about the "exit" provision. When will individuals who "exit" (leave) waiver services more than once per year be notified of the termination of their CDCS services? How many current CDCS recipients on the MR/RC waiver will be affected? How many persons on CADI, CAC and TBI will be excluded from the option because of the "exit" provision? What about a temporary crisis which requires placement in a facility which would require exiting the waiver? For some MR/RC waiver recipients, ICF/MR services are the only respite option. What happens when a person using CDCS is ready to return home after the second respite stay in an ICF/MR? How long is the transition period from CDCS to provider services to assure that health, safety and welfare are met? Will the Department provide advance notice before a person enters a facility in a crisis? To force a vulnerable person in a crisis to dismantle their services in the community after the crisis has passed is unnecessary and inadvisable and will surely result in institutionalization in conflict with the state's obligations under the *Olmstead* decision. ***The provisions on termination from CDCS due to "exiting" CDCS services should be deleted from the amendment.*** Budget concerns can be handled by the monitoring required of county case managers and the DHS waiver management software.

B Termination of CDCS services "if there are immediate concerns regarding the recipient's health and safety or misuse or abuse of public funds."

If there are concerns about criminal activity or abuse or neglect, Minnesota has laws and procedures to provide guidance for county or health plan action. Unless there is an immediate abuse or neglect situation under the Vulnerable Adult or Maltreatment of Minor Act, counties and health plans should not be allowed to unilaterally terminate services. Unilateral termination of services puts the waiver recipient at significant immediate risk for their health, safety and welfare. ***This provision should be clarified to apply only to instances in which there is an immediate protection action warranted under the Vulnerable Adults Act or the Maltreatment of Minors Act paired with a requirement that the vulnerable person be provided immediately with appropriate substitute services.*** In all other cases, a corrective action plan coupled with advance notice of termination, when necessary, can be used in cases of financial mismanagement.

We certainly agree that in the case of criminal activity or abuse and neglect swift action should be taken to protect the vulnerable person. However, there have been and will be disputes, differences of opinion and mistaken understandings about the type of service or billing practices which have and will occur between families, guardians, persons with disabilities and their counties. The proposal threatens the due process rights of CDCS recipients by attempting to eliminate the opportunity to seek services pending appeal when a dispute occurs. CDCS services are provided for the eligible vulnerable person and should not be unilaterally terminated by a county except in the case of abuse or neglect. Apart from those very serious circumstances with clear procedures in Minnesota law for county action, it would be a significant violation of due process requirements to terminate CDCS services with no advance notice and opportunity to continue services pending the outcome of a hearing.

10. Licensed Physician Should be Changed to Licensed Health Professional.

The State of Minnesota regulates many types of health care practitioners. Our laws provide for parameters on the scope of practice for these practitioners. It is unreasonable to require that medical doctors prescribe therapies, special diets and behavioral supports not covered in the State Medicaid Plan if Minnesota law allows licensed health practitioners such as chiropractors or psychologists to provide such services.

The amendment documents provided for public comment seem confusing on this issue. The requirement that a medical doctor prescribe "therapies, special diets and behavioral supports not otherwise available through the State Plan" is contained in Appendix B.1., Attachment C (allowable expenditures) and in the Service Description, Appendix B.1. on the top of page 4. However, the section describing Provider Standards, Appendix B.2., page 8 (2) Treatment and Training allows professionally licensed, credentialed or otherwise certified health practitioners to provide supports and services. The regular Medical Assistance program does cover a number of services provided by a licensed health practitioners without requiring the signature of an M.D. ***This requirement is unfair, unnecessary, costly, administratively burdensome and should be deleted.***

11. Community Inclusion Costs.

We urge the Department to change its position regarding the costs of participating in community activities for home and community waiver recipients. Appendix B.1., Attachment C provides that membership dues or costs and tickets to attend sporting

or other recreational events are unallowable expenditures for CDCS. These types of expenses are now allowed in one form or another in all waiver programs for persons receiving services from providers. It is contrary to the purpose of consumer-directed care to remove one of the major methods of community inclusion from coverage for CDCS. To exclude the cost of exercising is also contrary to health maintenance and disease prevention. For many persons with disabilities, use of a fitness facility is part of a specific therapy regime. Obesity is also a major concern for persons with disabilities and results in high health care expenditures. Many persons with disabilities take medications which cause weight gain or need a unique machine or type of equipment to exercise. Given that there will be budget limitations, persons with disabilities and their families or guardians will make the necessary choices on how best to meet needs through the community support plan which is reviewed by the county.

In the alternative, we recommend two less preferred options: (1) set a dollar limit for community inclusion/recreation costs, such as $600 per year, which would annually increase with the CPI; or (2) allow community inclusion/recreation costs for staff accompanying waiver recipients and for adult recipients over 18. It is understood that families normally pay for the recreational costs of their children. However, it is not reasonable to expect families to pay for staff costs for community inclusion activities for their children nor is it reasonable to impose these costs on families of adults who are already contributing enormously to keep their loved one in their family with no legal obligation to do so.

This provision is unnecessarily restrictive and in conflict with the purpose of the waiver programs to promote participation in the broader community for persons with disabilities, not separation and isolation. ***We urge the Department to change the provisions regarding membership dues and costs and other community inclusion recreational costs.***

12. <u>Add the term "supplements" to the list of environmental modifications and provisions.</u>

The laundry list of home modifications and provisions is not an exclusive list, however, the importance of supplements in improving the functioning of some individuals with disabilities is clear. ***We urge that the Department include the term "supplements" to assure that these products are available to those using CDCS services.***

13. Environmental Modifications.

We understand the CDCS proposed amendment to allow up to $5,000 in environmental modifications to be included in an individual's CDCS annual budget. An individual is permitted to obtain environmental modifications and assistive technology in excess of $5,000 if approved by their county, if funds are available within the county's overall budget allocation. Clearly some environmental modifications are one-time costs which exceed $5,000 and will require county approval to be purchased. We are concerned that there are no standards for county consideration of requests to exceed the $5,000 limit. The budget management by 87 county entities will mean that numerous eligible waiver recipients who need environmental modifications and assistive technology will not be able to obtain these items or services due to the particular county in which they live. The effect of the $5,000 limit will be especially severe on persons with significant physical and sensory limitations. ***We recommend that DHS manage an exception process for individuals whose needs exceed $5,000 and whose counties cannot approve the items because of county budget limitations. A less preferred alternative would be to set statewide guidelines for county consideration of requests to exceed the $5,000 limit for environmental modifications and assistive technology.***

14. Excessive County Management Activity.

We are very concerned about the numerous specific county requirements added to this CDCS proposed amendment. We are concerned that the excessive county monitoring required will act as a barrier limiting county staff willingness to inform waiver recipients about the CDCS Option. The excessive county requirements come at a time of serious cuts to county budgets and staff. ***We urge the Department to reexamine county monitoring requirements and eliminate the three-month service authorization requirement and replace it with a twelve-month service authorization time period. Also, we recommend that rather than using the long-term care consultation screening document to distinguish between activities that a parent or spouse would ordinarily perform and activities which exceed normal activity, the Department use the home care assessment instrument which has been used for this purpose successfully by Dakota County.*** The home care assessment is more familiar to consumers and case managers in this area and is far less time consuming and bureaucratic.

15. Criteria for Allowable Expenditures.

We urge that DHS change criteria 4.: "for the sole benefit of the individual" contained in Appendix B.1., Attachment C. A number of services are provided specifically to assist the family to care for the individual, and thus benefit others

besides the individual recipient, such as respite care, homemaking services and chore service. Many other services, if they improve the functioning of the recipient, provide an indirect benefit to others, such as services to improve walking, eating, communicating. ***We urge that the term "sole" be deleted.***

16. Consumer Outcomes.

The six consumer outcomes listed in Appendix B.1., Attachment C, should clearly be listed as separate outcomes which can justify goods or services within the CDCS Option. The current language is not clear and could possibly be interpreted to require that all six outcomes must be met for all goods and services purchased under CDCS. Also, use of the term "necessary" is too absolute and subject to interpretation as a standard for all goods and services to meet.

We recommend that DHS make it clear that the consumer outcomes can separately justify services by including the following language in Appendix B.1., Attachment C:

> ***"If all of the above criteria are met, goods and services are appropriate purchases when they are reasonably calculated or designed ~~necessary~~ to meet one or more of the following consumer outcomes:"***

17. Expenses Related to Staff or Family Training.

We urge that expenses related to obtaining training, including travel, lodging or meals, be allowed expenses within the CDCS Option. Because there will be a budget limitation and county authorization for expenses, it is unnecessary to be so restrictive. Many individuals will need specific training in order to appropriately provide services to persons on the various waiver programs who might use the CDCS Option. ***We urge that the Department eliminate the exclusion of expenses for "travel, lodging or meals related to training the individual and his or her representative for paid or unpaid caregivers."*** If necessary, a limit could be placed on this category in the range of $300 - $500 per year.

18. Service Dogs.

The Department has stated that service dogs and all related maintenance costs including vet bills are adequately covered by a variety of non-profits in Minnesota. This is simply not true. Because service dogs are an important service for some persons eligible for the disability waiver programs, it is unreasonable to exclude all costs related to service dogs. There are examples of persons who have been able to

reduce or eliminate staff coverage for periods of time if they have a service dog. Service dogs can provide safety by acting as an alarm system for those with sensory impairments. Service dogs have also been used to reduce symptoms such as anxiety which has allowed a reduction in medication.

Because any costs related to a service dog would have to be included within the budget limits under CDCS and would have to be part of the person's community support plan and approved by the county, we urge that DHS allow costs related to maintaining a service dog to be covered under CDCS.

CONCLUSION

In sum, we urge the Department to consider the recommendations for change in the CDCS amendment. As noted earlier, we are most concerned about the termination of CDCS services to nearly 1,000 individuals now using this option to maintain themselves in the community. We have proposed a method for DHS to avoid service termination for a large number of persons on the MR/RC waiver using CDCS while still moving ahead to offer a consumer-directed option on the other waiver programs and for those on the MR/RC waiver who have not had the opportunity to use CDCS to date.

We appreciate the opportunity to comment on the proposed amendment and hope that ongoing dialogue resumes between DHS staff and various representatives of disability consumer and advocacy groups as soon as possible. We strongly believe that consumer directed services have already been demonstrated to be a cost saving, high quality, innovative service option and welcome the extension of consumer directed services to those who haven't yet been afforded the opportunity.

ALH:nb

CONSUMER DIRECTED COMMUNITY SUPPORTS (CDCS) SURVEY

INDIVIDUAL COMMENTS

A total of 410 survey respondents provided individual comments in response to the question about what aspect of CDCS most impacted their satisfaction with the program. Respondents often gave more than one answer to the question. Comments were sorted into categories of positive comments and concerns.

Categories of positive comments included:

- Positive comments about the program's flexibility;
- Positive comments about program outcomes;
- Positive comments about staffing.

Categories of concerns included:

- Concerns about staffing;
- Concerns about program guidelines;
- Concerns about the lack of alignment to self determination philosophy;
- Concerns about the inability to fund certain services.

POSITIVE COMMENTS

1. A total of 120 survey respondents offered positive comments about the CDCS program's flexibility and reduction in stress:

- CDCS is a great program; keep it going (49);
- CDCS is responsive to actual needs (30);
- Greater control over resources (21);
- Ability to purchase specific treatments, therapies, equipment, and environmental

modifications (14);

- Able to make changes throughout the year, can move funds between categories, less paperwork (6).

2. A total of 81 survey respondents identified specific positive outcomes:

- An increase in community integration (27);
- Improved family relationships, prevention of out of home placements, and respite care (24);
- An increase in quality of life, freedom, happiness, and self esteem (15);
- An increase in independence, living where I like, getting a job with benefits, and people listening to me (12);
- Better health and fewer behavior issues (3).

3. A total of 72 survey respondents listed positive statements about staffing:

- The ability to hire and retain staff, choice and control in selecting staff who are qualified, reliable, and caring (40);
- Helpful, caring case managers (19);
- Better pay rate is possible so staff feel rewarded and respected (8);
- We do the training (3);
- Work hours of staff match individual needs (2).

CONCERNS

4. A total of 118 survey respondents mentioned concerns with county staff, the amount of effort needed by family members, training, and support staff:

- County staff lack empathy, trust, aren't communicating, have high case loads, inconsistency, and micromanaging (49);
- Training is needed on how CDCS works, what is possible under the program, an orientation to the whole system, accounting, and issues dealing with (29);
- Parents should be paid because of the administrative duties and time spent as a provider of services (14);
- Need help finding staff (PCAs, respite staff (13);
- Need individual help in understanding this program step by step (10);

- Need a housing specialist, staff should be paid on time, need retirement options for in-home staff (3).

5. A total of 115 survey respondents stated problems with guidelines, paperwork, and inconsistency with the program:

- Guidelines are not understood, are inconsistent, have changed and become more restrictive, arbitrary caps are applied, inability to change between categories, inconsistency, don't know how to write a plan that will be approved (54);
- Processes need simplification, too much paperwork, paperwork has increased, too complicated, lack of professional management of the program; all forms could be on the web (34);
- Amount of time this program takes, delays in approval, lack of timeliness of payments (11);
- Monthly fiscal reports aren't understandable or helpful, need better details, reports could be web based, need far better tracking (10);
- Parental fees are too high (3);
- Poor coordination between CDCS and Medicaid (3).

6. A total of 52 survey respondents indicated that implementation of CDCS is not aligned to self determination philosophy:

- Intent of CDCS is not understood and the program is headed toward restrictions, one size fits all, promises aren't kept, no longer flexible, can't make ongoing adjustments, overdocumentation for $5 to $10 purchases (39);
- Funding doesn't match needs (11);
- CDCS doesn't help people without an active family member or advocate (2).

7. A total of 31 survey respondents described the inability to fund certain services or inability to achieve certain outcomes:

- Unable to pay for diets, treatments, alternative approaches (9);
- Unable to pay for community integration activities, ways to connect kids with disabilities in community settings, eating out, a bicycle (11);
- Unable to pay for transit, vans, and equipment maintenance (4;)
- Unable to pay for occupational therapists and music therapists (3);
- Unable to purchase assorted items such as large purchases by setting aside funds over time, fences, and wills and trusts (4).

DAKOTA COUNTY RESPONSE
CDCS Amendments
January 14, 2004

Dakota County Social Services and Public Health submit the following comments regarding the Consumer Directed Community Supports summary dated December 11, 2003.

POSITIVE DEVELOPMENTS:

CDCS will be available statewide, in all counties, through all waivers.

Parents of minors and spouses will be able to be paid to provide care that the state would otherwise pay someone else to do.

Budgets will be set at the state level, and therefore be consistent across counties.

Employee benefits and retention incentives are allowable.

Recipients whose current spending exceeds their new individual budget limit established by this amendment will have up to 12 months from the date of their next annual review to comply with the new budget limit.

Special diets, therapies and behavioral supports otherwise not available through state plan services will be allowed when prescribed by a medical doctor licensed in Minnesota.

DETRIMENTAL EFFECTS:

The parameters of the current version of the CDCS amendment do not support achievement of the consumer outcomes listed under the criteria for allowable expenditures listed in Appendix B1, Attachment C. Rather, this version promotes the opposite:

- Rather than maintain the ability of the individual to remain in the community, it diminishes resources to a point where families of high needs recipients, particular adult recipients, will be unable to care for their family members in their homes. It rewards segregated services and promotes a return to more institutional living arrangements.
- Rather than enhancing community inclusion and family involvement, it restricts access to community environments and pushes families to request placement due to inadequate support resources in the home. While recipients may physically reside in the community, their opportunities to be part of regular community life are diminished.

- Rather than developing or maintaining personal, social, physical, or work related skills, the amendment severely restricts this by disallowing memberships, tickets, and reimbursement for related community training and expenses.
- Rather than decreasing dependency on formal support services, the budget setting methodology provides incentives to remain in or return to formal services.
- Rather than increasing the independence of the individual, it decreases opportunities by disallowing supported opportunities for training in a multitude of community environments.
- Rather than increasing the ability of unpaid family members and friends to receive training and education needed to provide support, it decreases their ability by disallowing reimbursement for travel, lodging and meals related to training. It also disallows costs related to the Internet.

As the following comments will show, overall there is a significant disconnect between two of the stated goals of CDCS and the implementation details:

- Creating a very flexible option that supports the policy of consumer control and tailoring of services to meet individual circumstances.
- Establishing checks and balances, which provide accountability and effective management for public funds.

Restrictions on participation:

Waiver recipients residing in a facility licensed by DHS will not be permitted to use CDCS.

- Dakota County currently has 120 individuals who would automatically be terminated from CDCS. Some of these individuals are original Robert Wood Johnson Foundation Self Determination Grant participants. CDCS has offered an opportunity for a more individualized approach to particular aspects of their service in combination with traditional formal services. Access to CDCS has enhanced their quality of life. To now terminate original grant participants who stepped forward to try a new way of doing things is unconscionable. Many are recipients residing in licensed family foster care. With the added support provided through CDCS they are able to remain in these cost effective living arrangements. Without it, they may not.
- Currently, it is allowable to use CDCS to pay for support in work enclaves in the community. Enclaves are work sites in a business setting supported by a job coach. Several current CDCS recipients use a program that charges a very reasonable rate of around $40 per day. The program has CARF certification but is not a DT&H. Because these individuals live in a licensed setting they will be forced to get support through formal services. That will cost around $80/day. The cost impact of them having to switch to formal DT&H services will be around $80,000 per year.

Waiver recipients who exit the waiver more than once in a service plan year will be ineligible for CDCS for the remainder of that service year.

- The two groups for whom this has the most detrimental affect are recipients with severe and persistent mental illness and those with high medical needs. Because individual budgets will include all services, waiver recipients who have been able to access home care or residential treatment services on a short term basis for resolution of a specific situation will be forced to choose between adequate care in an emergency and continued use of CDCS. Failure to be able to address concerns with short-term intervention strategies outside of waivered services will result in longer term, higher cost interventions when conditions worsen.
- Some current CDCS recipients use ICF/MR respite. They would no longer be able to do so, removing a service option they have accessed for years.

Individual budget setting methodology:

CDCS becomes an all or nothing proposition. One of the goals of the original Self Determination Project was to offer an alternative to forced service choices of all or nothing. This is a step backwards in designing services and support. The budget setting methodology appears to have a goal of driving MR/RC waiver recipients, particularly adults, off of CDCS while maintaining lower cost CDCS child recipients at significantly decreased budget amounts, and of making the option less desirable than formal services in the other waivers. The old adage applies: you can pay now or you can pay later. When recipients do not receive adequate training and support, their conditions tend to intensify or worsen. Their support needs will be more costly in the future. The state does not have the capacity to accommodate all of the recipients who will be requesting placement in entitled settings. The methodology promotes a trend toward institutionalization, not community living.

Individual budgets will not exceed 70% of the statewide average cost of all services for non-CDCS recipients with comparable conditions and service needs.

- A very serious concern is the effect of the proposed budget methodology on those who use CDCS in combination with traditional day programming. Because of the reduction factor, recipients will be forced to choose between adequate day program services and adequate support outside of day program hours if they wish to continue using CDCS. For many adults, CDCS will no longer be a viable option.

  EXAMPLE: Recipients A and B have similar characteristics. Both have severe retardation, are in their mid twenties, living at home. They attend the same day program. The only difference is that Recipient A has all formal services and Recipient B has CDCS for support services outside of day program. The following table illustrates the effect of the new budget setting methodology on CDCS recipients vs. non-CDCS recipients. If the day program costs remain constant, Recipients B would have to make

cuts the support costs outside of day program, drop CDCS, or make cuts in day program. This methodology has serious drawbacks for CDCS recipients. It comprises their health, safety and/or community inclusion, all stated goals of the waiver program.

Non-CDCS and CDCS Recipient Comparison

	Recipient A (non-CDCS)	Recipient B (CDCS)	Recipient A (non-CDCS)	Recipient B (CDCS)
	FY2002 Expend.	FY2002 Expend.	New CDCS amendment	New CDCS methodology 70% of av. FY2002 non-CDCS Expend.
Day Program	$60/day	$60/day	$60/day	**$60/day**
Other Support	$60/day	$60/day	$60/day	**$24/day**
TOTAL	$120/day	$120/day	$120/day	**$84/day**

The proposed budget setting method also does not take into consideration the effect of individualizing DT&H rates to reflect the needs of the recipient. A new law allows counties and providers to individualize the rates. Historically DT&H service recipients, regardless of need, have been charged a single rate at a particular DT&H. With individual rate setting, higher needs recipients will be charged more and lower need recipients less. Because the CDCS budgets are based on historical non-CDCS expenses, lower needs recipients will have an advantage over higher need recipients in their budget allocations. These next tables show that the moderately and higher need recipient will again experience a greater cut in their support costs if the DT&H rates are individualized while the non-CDCS recipient will not experience any change in service, and the lower need CDCS recipient may actually realize a gain. This is not an equitable method of resource allocation.

Higher Needs Recipients Comparison

	Recipient A non-CDCS	Recipient B CDCS	Recipient A non-CDCS	Recipient B CDCS
	FY2002	FY2002	Individual DT&H rate structure	New CDCS methodology (70% av. FY 2002 non-CDCS Expend.)
DT&H	$60/day	$60/day	$80/day	**$80/day**
Other Support	$60/day	$60/day	$60/day	**$4/day**
TOTAL	$120/day	$120/day	$140/day	**$84/day**

Lower Needs Recipients Comparison

	Recipient C non-CDCS	Recipient D CDCS	Recipient C non-CDCS	Recipient D CDCS
	FY2002	FY2002	Individual DT&H rate structure-no change in services	New CDCS methodology (70% av. FY 2002 non-CDCS Expend.)
DT&H	$60/day	$60/day	$30/day	**$30/day**
Support	$30/day	$30/day	$30/day	**$33/day**
TOTAL	$90/day	$90/day	$60/day	**$63/day**

- Waiver recipients enrolled in MnDHO and MnSHO are not subject to the state's budget setting methodology. Waiver recipients with the same needs and conditions will have different methodologies applied to determine their individual budgets. This does not promote statewide equity in resource allocation, a stated goal of the amendment.
- High-needs CDCS recipients whose needs cannot be met within their new allocation of under $200/day have an increased risk of institutionalization in ICFs/MR, nursing homes and hospitals. One of the primary reasons current high-needs CDCS recipients chose this service option was because they were unable to get their support needs met safely and consistently through the formal service system. This methodology threatens their health, safety and general well being. It increases overall Medical Assistance costs for the state if they go into higher cost entitlement services. This is in direct conflict with the states goals of decreasing ICF/MR and nursing home placements. It takes recipients out of their families and out of their communities.
- Recipients with mandated day program services who wish to continue using unlicensed support will have to give up their waiver in order to

access PCA Choice or the Consumer Support Grant. Consequently, they will not have waiver funding to pay for day program. Due to budget cuts, counties do not have adequate resources to provide funding for day program for those who leave the waiver. Recipients are faced with an unacceptable choice: forgo day program or forgo support outside of day program.

Administrative burden:

Numerous things in the amendment increase the administration of CDCS, ultimately making it a more costly service.

- The delineation of duties between required case management and flexible case management, and the inclusion of flexible case management in the individual budget means that recipients will need to clearly understand the difference. They will need to know what they can expect from Dakota County as part of required case management. Currently, Dakota County recipients rely heavily on their social workers for ongoing assistance in developing and implementing their Community Support Plan. The likely result is one of the following, or both: recipients will not ask for the help they need or social workers will not bill for the services they provide. This compromises effective case management services for all waiver recipients. Additionally, when families choose the IIIP process, the county is a required participant. Based on our understanding of the delineation of required and flexible case management, Dakota County would have to charge against a recipient's individual budget for time spent developing the IIIP, even though county participation is mandated. Practically speaking, the tracking of required time vs. flexible time, and the separate billings is unnecessarily burdensome.
- Service authorizations limited to 3 months at a time across 4 separate service lines will necessitate numerous adjustments across a recipient's budget year. Recipients spend unevenly across a year. Even if the 3-month amounts can vary, expenditures do not always occur in the time frame estimated. Each adjustment means additional communication between fiscal entities and counties. Setting up all of these lines in MMIS is 16 times the work currently required. Additional adjustments will require even more time. The result can be recipients restricted to time frames and categories for purchasing because counties do not have the capacity to make the required adjustments on an ongoing basis. This does not support the stated goal of "a very flexible service option that supports the policy of consumer control and tailoring of services to meet individual circumstances". Three-month service authorizations do not contain costs. The individual budget setting contains cost. In fact, 3-month authorizations in four separate service lines, and the required work and communication surrounding them will likely drive up the cost of the fiscal entity services.

- The category of "Self Direction Support Activities" requires recipients, fiscal entities and counties to unnecessarily separate expenses directly related to wages for billing purposes, specifically, workers compensation and payroll expenses and benefits from wages. These things are required by law and/or tied directly to wages paid any employee in Minnesota. They are not administrative expenses directly related to CDCS. Their delineation will require administrative work beyond what is currently done, again driving up costs and making CDCS unnecessarily complicated for recipients to manage. The more complicated the management, the more likely recipients will require additional assistance in this category, decreasing the amount of funds available for use in the other three categories.
- Separating payment for background studies from the individual budget means separate service authorizations will have to be set up for an item that is currently provided by and covered in the fiscal entity fees. It creates another layer of administration contributing to more costly service.
- Requiring billing for services through one fiscal entity unnecessarily inflates the cost of services CDCS recipients choose to purchase through licensed agencies who already have the ability to bill MMIS directly. It requires an additional layer of involvement that is unnecessary and costs money. Agency 1 must submit billings to Agency 2 who will then bill MMIS and remit payment to Agency 1. A transaction currently done between two parties (Agency 1 and MMIS) would involve three parties. Every party incurs costs to process these transactions. This increases administrative costs and decreases funds available for direct support services for recipients.

Unallowable Expenditures:

Based on the number and type of disallowed expenses, it could be said that the title *Community* Support Plan is a misnomer. MA funds paid to licensed service providers can be used to purchase many of the things disallowed for CDCS recipients. Other disallowed expenditures under CDCS are specifically allowed for non-CDCS recipients through other waivered services. At the very least, CDCS recipients must be able to purchase the same supports and services as non-CDCS recipients. It appears that the goal of the proposed CDCS amendment is to advantage the formal, more expensive service system and to discourage participation in CDCS by putting more restrictions on use of funds.

These beneficial expenditures for current CDCS recipients will not be allowed:

- *Membership dues or costs.*
  Many current CDCS recipients have purchased a membership to the YMCA or similar facilities. They find that the outcomes are more beneficial using regular community environments rather than segregated therapeutic service environments. Not only do recipients gain from the physical activity. They gain in social skills by sharing regular community places doing regular community activities. A Y membership is less costly

by far than a year's worth of physical, behavioral or occupational therapy. Provider agencies have no restrictions about purchasing memberships for recipient use.

Many caregivers benefit from memberships in organizations specific to the disability of their family member. They gain valuable information and connections that assist them in providing care. Provider agencies can purchase memberships that their support their work.

- *Expenses for travel, lodging or meals related to training the individual or his/her representative or paid or unpaid caregivers.*
  Training is an important component of services. This amendment requires that the Community Support Plan designate provider qualifications and required training. The service category of Treatment and Training includes "Training and education to paid or unpaid caregivers and .....to recipients to increase their ability to manage CDCS". Is the expectation that expenses be paid by caregivers and recipients with personal funds? Are state employees who are required to attend conferences and training required to pay their own expenses? Are provider agency staff required to pay their own expenses for state required training under the consolidated rule? This exclusion discriminates against CDCS recipients. These are allowable expenses under the MR/RC waiver's Consumer Training and Education and Caregiver Training and Education services. It doesn't make sense that it can be done there and not with CDCS.

- *Vacation expenses other than the cost of direct services.*
  If travel costs cannot be covered for support staff, those who need that level of assistance will not be able have a vacation, a regular part of community life. They are essentially trapped in their hometowns unless they happen to be fortunate enough to have families who have sufficient resources to private pay. Additionally, vacations can be excellent relationship building respite experiences for families. They get a break from the daily routine and a chance rejuvenate through a shared enjoyable experience.

- *Tickets to attend sporting or other recreational events.*
  The ability to attend events enhances community inclusion. It allows recipients to develop and maintain their skills in real environments. Because tickets for support staff will not be allowed, recipients will miss opportunities for participation in regular events of community life. Provider agencies are allowed to reimburse staff for these costs when accompanying recipients.

- *Costs related to Internet access.*
  Not only is travel for training or vacation disallowed. But this mechanism for accessing information and sights unseen will also be lost. For those

unable to attend training, they can access information through the Internet, including DHS training and information websites. If recipients can't travel, at least they could use the Internet to gain information. They could see places others go, and have some ability to socially relate. They could use email to communicate with others, increasing their skills at the same time. Provider agencies provide are able to provide Internet access to recipients and staff.

The Internet also plays an administrative support role in the management of CDCS. Some fiscal entities are beginning to offer online time reporting for payroll and reports to recipients via email. Dakota County checkbook users can receive notification of deposits into their accounts by email.

In addition, the Internet often allows CDCS recipients to purchase goods at reduced costs.

The amendment identifies Treatment and Training, and Self Direction Support Activities as service categories. The above uses of the Internet meet those service descriptions. The amendment needs to allow CDCS recipients to operate in the 21st century.

- *Services, goods or supports provided to or benefiting persons other than the individual.*
  How will this be defined in relation to the stated outcomes? The ability to support caregivers maintains the ability of the individual to remain in the community and decreases dependency on formal services. Currently Chore Services is an allowable waivered service, and apparently will be permissible under CDCS. Yet it can be said that this service benefits others.

  There are many circumstances in which there may be indirect benefit to others, but the expenditure would not be made if not for the disability of the individual. If the expenditure is not made, the health and safety of the recipient would be compromised. A couple of examples include: replacement of carpeting with flooring due to incontinence and projectile vomiting; installation of air conditioning due to inability to regulate body temperature.

ALTERNATE PROPOSALS

Allow combinations of licensed services and CDCS. Separate formal service costs from CDCS. Determine the average cost of similar non-CDCS recipients. When someone chooses to use CDCS in combination with formal services, determine the cost of any desired formal day or residential services. Apply the 70% factor only to those dollars remaining after the cost of formal services has

been deducted. For example: Typical cost of non-CDCS recipient is $100/day. CDCS recipient with similar needs wishes to use a day program costing $55/day. The $55/day is subtracted from the $100, leaving $45/day. The 70% factor is applied to the $45/day to get $31.50 per day. The CDCS recipient's budget would be $86.50 per day, rather than $70/day under the current method. This would not incur any greater cost than if the recipient decided to stay in the formal system and not use CDCS at all.

When a CDCS recipient chooses their county to provide flexible case management services, allow that amount to be subtracted from the individual budget and combined with the amount for required case management into one service authorization with one billing code.

Rather than disallowing community activity expenditures, set a parameter, such as $1200 per year as a maximum.

Allow service authorizations to be set up for one year with one billing code.

A number of counties have significant experience setting budgets. A committee made up of stakeholders, including counties with this experience, has made repeated offers to work with DHS to determine an equitable method that maintains cost effectiveness but does not penalize CDCS recipients. Take advantage of the offer and the experience to create a viable CDCS option.

SUMMARY

Overall, Dakota County is incredibly disappointed in the proposal as it stands because it:

- Takes away flexibility
- Decreases consumer choice
- Decreases community involvement
- Forces recipients into the formal system
- Adds administrative burden to recipients, counties and fiscal entities.

The proposal is a giant step backwards from the initial goals of Self Determination, and a giant step toward institutional living and segregated care.

The ultimate result of this proposal is that fewer individuals will receive waivered services. Increased administrative costs and propelling of recipients into the formal system will mean more costly services. Counties are locked into aggregate budgets that cannot be expanded. CDCS recipients will be forced to use all formal services at higher cost. A county's only choice to manage these costs will be will be to stop providing waivers to individuals currently waiting. When recipients leave the waiver, their resources will need to be used to cover

the increased costs of those who had to leave CDCS for formal services because CDCS is no longer a viable option.

This is a sad development in a service that has been shown to provide 150% more service per dollar spent than the formal system. A goal of the amendment is to provide this option across all waivers in all 87 counties. According to figures provided by DHS, of the 2,438 current CDCS recipients, approximately 1,000 are expected to leave the service. Eight hundred new CDCS recipients across the other waivers and in other counties are expected to begin. This does not sound like an expansion of the option. Fewer recipients will access CDCS than do today. Making something available but not viable is a slap in the face to the thousands of waiver recipients in Minnesota who are using or have anxiously awaited the opportunity to use this service. This sounds like a march to kill the most successful service option waiver recipients have experienced.

Thank you for the opportunity to review and comment on the proposal.

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COMPARISION—CURRENT AND PROPOSED CDCS SERVICE WITHIN THE MR/RC WAIVER

- The chart is a comparison of current Hennepin County guidelines for CDCS under the MR/RC waiver. It compares current guidelines to the proposed changes.
- This information is based on the Amendment memorandum from DHS that you received in the mail. We used materials developed by Dakota County, ARC of MN and Disability Law Center in this comparison chart when they applied to the Hennepin County guidelines.
- There are currently 2400 CDCS recipients in Minnesota; 1400 receive services through Hennepin County. We have learned that we provide more Consumer Directed services then any other county in the country. It is very important that your experiences and your feedback be heard by the MN Department of Human Services, as you have the most direct information regarding how to use this funding effectively to make a difference in the lives of your family members!

CURRENT	***PROPOSED***
CDCS is available only in the MR/RC waiver, and only in 34 counties.	CDCS will be available in all counties in all waivers: MR/RC, CAC, CADI, TBI and Elderly Waiver.
Parents of minors cannot be paid to provide care.	Parents of minors will be able to be paid to provide care above and beyond normal parenting within parameters. (Appendix B1, p. 11-12)
Each county sets the individual budget amount.	Budgets will be set by the state and be consistent county to county.
Hennepin County uses its own criteria to set individual budgets.	Budgets will be set using the screening document and will be based on 70% of the statewide average ***cost*** of non-CDCS recipients with comparable conditions and service needs. (Appendix B1, p.4)
Budgets are set based on the individual needs of the person. There is no predetermined minimum or maximum amount.	The individual budget minimum will be $20/day or $7,300 per year. The maximum will be $200 per day or $73,000 per year.
A waiver recipient may use CDCS for part of their services and use traditional day program services. Day program costs are outside the individual budget.	The individual budget will include ***all*** goods and services to be purchased through the waiver, except required case management and background studies, with a 70% reduction factor. (Appendix B1, p. 3)
CDCS services can be blended with licensed services.	Clients residing in a facility licensed by DHS (SLS, foster care) will not be permitted to use CDCS. (Appendix B1, p.2. & Attachment C)
Case Managers provide required county services to consumers as well as assist with CDCS programming, or direct support services. See lists of "required county functions" and "direct support functions" on Attachment B	Case managers will continue to provide required services. The flexible case management services, or "direct support functions" listed in Attachment B will be funded through your CDCS budget. You may choose to have a case manager from the county provide any of the flexible services or a support coordinator.
Most environmental modifications are paid for outside of the person's budget.	The first $5,000 of the modifications must be paid for within the budget. The person can seek additional funds from the county.
Plans are developed based on the needs of the	Plans are completed and billed in four

individual and authorized based on "Principles of Decision Making".	categories: Personal Assistance; Treatment and Training; Environmental modifications and provisions; and Self-direction support activities. (Appendix B1, Attachment A)
Service authorizations are set up for the entire budget year.	Service authorizations will be limited to 3-month periods. (Appendix B1, p. 4)
Therapies are not allowed.	A Medical Doctor licensed in MN, must prescribe therapies, specialized diets, and behavioral support. (Appendix B1, Attachment C)
Goods and services that are not of specific benefit to the person with a disability have not been allowed.	Services, good or supports provided to or benefiting persons other than the person with the disability are not allowed, chore services are still allowed. Clarification has been requested. (Appendix B1, Attachment C)
Expenses for travel, lodging and meals while attending conferences and training are covered.	It is unclear as to whether any training expenses, including conference and training registrations will be covered. (Appendix B1, Attachment C)
Staff expenses including mileage reimbursement, food is covered.	It is unclear as to whether these expenses will be covered especially as it relates to transportation, food, lodging for staff training. Clarification has been requested.
Memberships to the Y, Science Museum, Zoo, Arc. etc. are allowed as approved within the person's plan.	No membership dues or costs will be allowed. (Appendix B1, Attachment C)
Vacation expenses (transportation, portion of lodging, food, other related expenses) for support staff are allowed.	No vacation expenses other than the cost of direct services will be allowed. (Appendix B1, Attachment C)
Tickets to movies, sporting events and other community activities are allowed within a $600 guideline as part of an approved plan.	No tickets are allowed, even for support staff. (Appendix B1, Attachment C)
Internet service is allowed up to $20 a month under caregiver training and education.	No internet service is allowed. (Appendix B1, Attachment C)
Rates for staff is based on the skills, training, education and training the staff has. Range for reimbursement is $8 to $14 per hour but can be more based on skills and training.	The current rate for PCA services is $14.92/hour. This is the rate families would receive. Employment expenses would come out of this rate.