



*Advocacy and support for people with
developmental disabilities and their families*

www.arcminnesota.com

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Dear Steve,

Thank you for the opportunity to comment once again on the proposed plan amendment regarding Consumer Directed Community Supports. As you know, Arc Minnesota was instrumental in passing the law requiring all Counties to offer this option as part of the MR/RC waived services program. Our experience and understanding of the existing data indicates that when consumers are given a greater voice in service decision making and budgeting for services, they are more satisfied and the service costs are reduced. Indeed, this type of program, when properly implemented, keeps families intact and thoroughly engaged in securing the most appropriate services for their loved ones with disabilities.

When we worked on the legislation, we fully expected that implementation would build upon past success, recognize the existing data and would be consumer driven. Unfortunately, this proposed amendment language, and the guidelines released by some Counties have the exact opposite effect. To continue to call this option Consumer Directed Community Supports is a charade.

We are concerned that DHS and Counties are or will be performing a "bait and switch" with consumers by promising that they will have control over services and then delivering to them more work in the plan development with virtually no control over service delivery or individual budgets.

The draft amendment dated 4/1/02 contains several revisions from the one dated 12/21/01 that address a number of concerns raised by Counties. However, virtually none of the concerns raised by Arc Minnesota and the Disability Law Center in past discussions have been dealt with. This again indicates a disdain for consumer involvement that has been prevalent throughout the implementation process thus far.

We look forward to working with the Department and Counties from now on to ensure that the goals of implementing Consumer Directed Community Supports will be achieved and that consumers will be treated with courtesy and respect and be actively involved in the process.

Our specific comments regarding the draft amendment dated 4/1/02 are as follows:

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**The
Arc**

1). For CAC, CADI, TBI and MR/RC (page 2), *Scope of Services*

Arc is concerned that some guidelines released thus far indicate that certain services covered under the MR/RC waiver are not included in CDCS. We believe that CDCS should encompass all approved waiver services plus additional informal supports. To deal with this issue we recommend changing the sentence as follows:

“CDCS ~~may~~ includes services covered under the waiver, ~~be those~~ similar to other waiver services, or ~~include~~ services not available in the waiver.”

2). To access CDCS, fourth bullet, (page 3), *Identification of Providers*

The following sentence has been added to this paragraph: “This includes identifying who will provide the service, their level of training and qualifications.”

The purpose of the plan as we understand it, is to identify the consumer’s needs for support, and preferred services, along with a discussion of the budget. It is expected that many plans will be developed without knowing specifically who will be providing a particular service at the time of plan development. How can someone identify a provider of services without having a discussion of the service needs and the amount of the budget? This sentence will delay the development of plans until all services have been arranged (thus delaying the delivery of some services) and it places the budget discussion before the service needs discussion. This does not sound like consumer directed supports. We urge you to delete the sentence.

▪ **Tenth bullet, (page 3), *Plan of Care***

This bullet refers to “plan of care”. Is this the same as the CDCS service plan referred to in previous bullets? If not, it needs to be defined. If so, the terminology should be identical.

3). To authorize CDCS, the local agency (or for managed care enrollees, the health plan representative) must assure that CDCS:, third bullet (page 3), *Primary Benefit*

This bullet includes the phrase “primary benefit and use of the recipient”. This phrase is too limiting and is in conflict with the description of CDCS on page 1, dealing with “non-direct support services”. This standard eliminates approved services that are part of the MR/RC waiver such as Caregiver Living Expenses, Caregiver Training and Support, Case Management, Chore Services, Crisis Respite, Homemaker Services, In-Home Family Support, and Respite Care.

Each of these approved waiver services provide benefit to the recipient. One could argue that the recipient is a secondary beneficiary of these services. Is it the intent of the Department to eliminate these approved waiver services from being used under CDCS? If so, the CDCS option is very limited, and this standard is inconsistent with other parts of the draft amendment.

We urge the Department to use the alternative language suggested by the Minnesota Disability Law Center.

- **Fourth Bullet, (page 4), *Reasonable and Customary***

This bullet uses the phrase “reasonable and customary” as a criteria. Arc believes “reasonable” is an appropriate criteria. However, “customary” is in conflict with the use of informal supports described on page 1. It forces Counties to approve the standard lists of services that currently exist in the system and stymies any alternatives or creativity. Is that the Department’s intent with CDCS? We urge it to drop “customary” as a criteria.

4). Administrative Duties:, fifth bullet, (page 4), *Budget Setting*

This bullet replaces one in the previous draft which stated: “Develop individual budgets with the consumer that take into account the person’s preferences and needs along with available resources.”

- **Seventh bullet, (page 4)**

This is a new bullet from the previous draft. While it appears that consumers will be given choices, the new language here and in the fifth bullet raises the question about how the consumer will be involved in developing the individual budget.

It now appears that Local Agencies will set a budget that will be given to the consumer who will then have some choices, if the budget is sufficient. The consumer is taken out of the loop in setting the budget. How is this consumer directed if the consumer is not included in making the very first decision about resources available?

- **Deleted bullet, (page 4), *Federal Requirements***

The previous draft contained a bullet with this language: “Follow all prescribed policies and regulations regarding consumer’s informed consent, freedom of choice and appeal rights.”

Will it now be optional for Local Agencies to abide by standards that are contained in the MR/RC waiver program, as it relates to CDCS? Since CDCS is an approved service within the MR/RC waiver program, one must question the legality of dropping these requirements. Arc Minnesota encourages the Department to re-insert this language.

5). Service Requirements: Second bullet, (page 5), *Financial Fraud*

This is a new bullet. What is the expected process for determining whether consumers have a documented history of financial fraud? Will Local Agencies conduct background checks of prospective consumers? Will consumers need to prove that they haven’t such a history? Will all requests to participate in CDCS be forwarded to a County Sheriff or County Attorney for a

review? Or, will it be assumed that all prospective consumers are honest, law-abiding citizens who have the best interest of their loved ones at heart, unless through participation in CDCS, they prove otherwise? Arc Minnesota recommends the last approach.

- **Fifth bullet, (page 5), *Governed Payment Rates***

What are the services where payment rates are established and governed by Minnesota Statutes? Does this mean that if an approved rate is published in the state register or DHS bulletin annually, that CDCS participants cannot pay more than that rate for a similar service?

It is not uncommon for families using this option to pay more for a service, like personal care assistance, than the approved state reimbursement rate for that service. The trade off is that they may get less service, but that they attract better staff, turnover rates aren't as high and family stress levels are reduced. This bullet seems to mean that such a practice will not be allowed and any flexibility presumably available in CDCS does not apply.

Arc Minnesota is opposed to the phrase "and services where payment rates are established and governed by Minnesota Statute," being included. The Department simply needs to ensure that the overall cost of using this option "is a cost effective alternative to what would otherwise have been purchased through the waiver."

- **Sixth bullet, (page 5), *Accepted Practices***

It is not uncommon for professional fields to have internal disagreements about accepted practices, experimental practices or therapeutic treatments. The use of ABA therapy for children with autism is one example. Does this language mean that if a DHS representative or a Local Agency representative disagrees about whether this practice is accepted, that the consumer will not be able to use CDCS to obtain this therapy?

Does it expect that Department program staff or County case managers will have complete and total knowledge about all possible experimental practices or that they will have the time and inclination to research them? If the FDA does not have oversight authority for a particular practice or therapy does this mean the practice will not be paid for? What about situations where people are participating in clinical trials approved by the FDA?

We understand the problem and goal here, but Arc Minnesota believes that the Department is proposing overly restrictive criteria that will produce unintended consequences potentially damaging to the consumer with a disability.

- **Eighth bullet, (page 6), *Spending Limits***

Arc Minnesota is opposed to the arbitrary limit of \$600 annually being available to achieving outcomes in the community and identified in the service plan. There is nothing about this limit that is consumer driven. This number is to make it easier for Local Agencies to deny certain activities without having a discussion about how the community services relate to addressing

the consumer's needs. This ought to be an individual determination. We urge you to remove this arbitrary limit.

6). Budgets: (page 8), *Service History*

The term "(if available)" should be inserted after "service history" rather than "person's assessed needs". That was the placement in the previous draft.

7). Provider Qualifications, 4th Paragraph (page 9), *CDCS Employer*

This paragraph refers to "CDCS employer". That term is new and is not defined anywhere. Is the intent for it to be "CDCS counselor"?

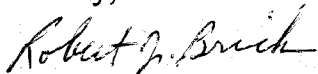
▪ **6th Paragraph (page 10), *Prohibition of Family Members as Counselors***

A sentence states "Consumers and family members cannot be CDCS counselors". What if a family member owns or manages a business that meets the other criteria and will perform the functions for a much lower fee (or for free) than is typically being charged currently by Fiscal Agents, Employers of Record (now CDCS counselors)? Shouldn't the consumer be allowed to use this service instead? Arc thinks this sentence is too restrictive and should be deleted.

We also urge the Department to take this opportunity to ask the Federal Government for the authority to pay parents of minor children to provide services to their disabled children. We know there is another workgroup trying to deal with this in the context of the Home Care Demonstration Project. It would seem that if the Department really wants this to happen, it would take every possible opportunity to promote and advance the issue. We urge it to demonstrate its support for this concept by including it in this application as well.

Thank you for the opportunity to comment. We are looking forward to working with you and others to address these and the other issues that are causing concerns for families and preventing CDCS from being consumer-directed.

Sincerely,



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