

DEBORAH DENNING

&

JEFFREY SKWAREK

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PHONE & FAX: 612-789-5167

August 14, 2002

Representative Len Biernat
303 State Office Building
St. Paul, MN 55155

Ref: MR/RC Waivers

Dear Representative Biernat:

It is with great worry that I send you a copy of the letter I am sending to the Department of Human Services (DHS) regarding the Consumer Directed Community Supports/ Mental Retardation Waiver. I am very fearful that some of the decisions currently being made at DHS are going to be very hurtful for my adult son who recently moved home to live with me after 30 years of institutionalization. We really need your involvement in this critical matter.

First, let me refresh your memory about who we are. I'm hoping that you will remember my son and I by our Christmas letter last year, and our meeting with you during the past legislative session. I'm sure you will recall that Jeff used his technology device to speak, telling you about his life challenges as an individual with severe disabilities who had experienced life-long institutionalization. We also shared with you Jeff's system challenges of being developmentally disabled and non-verbal from birth.

At the time, we were so happy and thankful for the CDCS Waiver, and felt a lot of hope for Jeff's future. Now however, less than 9 months later, we're fearful and living with uncertainty in our lives, again.

Because of the need to create statewide consistency (see memo from Senator Ellen Anderson, attached), DHS is preparing a waiver amendment (re-write), to establish new statewide guidelines for submission to the Federal Government. Although many parts of these guidelines seem good and flexible, there are some significant issues that are causing our family great concern. Specifically, I'm hearing that some new "financial formula"

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(that's being created behind closed doors) could even take away dollars from adults like my son in the long run, and I'm concerned that as a parent I am going to be forced to become what they call an "Employer of Record" without option.

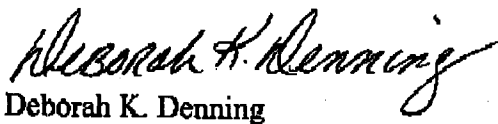
If what I'm hearing is true, adults like my son, with complex disabilities and institutional history to overcome, are going to be hurt. I am also concerned that there will be no real decision making left at the county level where we personally have built strong grass root relationships with people we've grown to trust. Jeff and I happen to live in a very good county that has helped us a great deal over many years, and I don't want to see us lose out now because of the failure of other counties or too stringent state rules.

It is my sincere hope that you can involve yourself right away in this issue, as things are moving very fast at DHS. Many of us were very grateful for Senator Anderson's action on July 18th, and to see Representative Neva Walker and Senator Becky Lourey also in attendance.

Should you be interested in receiving less biased information on my concerns, I am sure that Colleen Wieck (651-296-9964), Executive Director of the Governor's Council on Developmental Disabilities, or Anne Henry (612-334-5785 x254) from the MN Disability Law Center would be very helpful contacts for you to speak to. And, if there is any more information that you need from me, or anything that I can be of help with, please call me at 612-789-5167.

I thank you in advance for your time, interest and any efforts you can make on our behalf.

Sincerely,


Deborah K. Denning

ELLEN R. ANDERSON

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**Senate**

State of Minnesota

MEMO**TO:** Shirley Patterson, Maria Gomez, Mary Kennedy, Steven Larson**FROM:** Senator Ellen Anderson**DATE:** June 26, 2002**RE:** MR/RC Waivers

I have concerns about the CDCS service option of the MR/RC waiver. I have been hearing story after story from parents all over the state about reasonable services they needed to care for their child's special needs being denied by their county. As I understand it, the theory of this option is to be flexible and driven by the specific needs of individual parents and children. The types of disabilities in many of these cases seem to be difficult ones to manage for caregivers, but at the same time in many cases there have been great successes with many of these children when their caregivers have been given the ability to tailor services creatively to meet their individual needs.

The problem as I see it is that many counties are administering the CDCS option inconsistently and contrary to the principle of consumer direction, the statutes and regulations. At the state and county level, I hear many complaints that parents and other consumers' views are not included in developing guidelines for the program.

Parents/consumers are being denied many services that seem necessary and helpful to their children's care. I have a number of examples of this. The appeals process is not providing adequate redress for them. As I understand it, counties have broad authority to deny payment yet referees frequently defer to county judgements. Already overburdened parents cannot be expected to mount court cases against their county and state agencies, and our administration of this program should not be driving parents into litigation as their only recourse.

While DHS has been working on a federal amendment to address the issues that parents have raised, it is months away from implementation and many feel parental input has been disregarded. Instead of moving in ways that could incorporate more flexibility into extremely complex situations, the response has been to take an easier, more strict path of guidelines. Though simpler to implement, such guidelines will not be nearly as effective in relieving families of the additional stress they often face nor be as beneficial in improving the overall health and well-being of families and the individuals struggling to survive and to achieve their full potential.

These are some of the alarming facts I have learned from advocates of disabled children. I look forward to a good discussion at our upcoming meeting and would be happy to provide more details and examples of how disabled children are being denied the help they need to thrive.

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FACSIMILE TRANSMITTAL SHEET

TO:	FROM:
Gene Martinez	Deborah Denning
COMPANY:	DATE:
ARC Hennepin-Carver	AUGUST 14, 2002
FAX NUMBER:	TOTAL NO. OF PAGES INCLUDING COVER:
952-920-1480	6
PHONE NUMBER:	
952-920-0855	
RE:	C.C.
CDCS Waiver Amendment	Jerry Mellum, HCDD

☒ URGENT ☐ FOR REVIEW ☐ PLEASE COMMENT ☐ PLEASE REPLY ☐ PLEASE RECYCLE

Dear Mr. Martinez:

Jerry Mellum told me about the meeting that the Self Determination Advisory Committee is having today, regarding issues and concerns that people are having re: the CDCS Waiver Amendment re-write. I had planned to be there, but unfortunately an unplanned staffing problem has come up which does not allow me to attend. Following are copies of letters that I just sent to Shirley Patterson at DHS, and to my Representative Len Biernat, detailing how very concerned I am about the following sections of the new DHS draft document.

- 1) the "funding formula"
- 2) the mandate that parents become Employers of Record, and
- 3) my fear that our county is no longer going to have any discretion to meet our needs.

Thank you for considering my input into whatever action the Advisory Committee decides to take. And please, don't hesitate to call if you need more information from me, or if there is anything else that you think I can do to be helpful.

Deborah Denning

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FACSIMILE TRANSMITTAL SHEET

TO:	FROM:
Colleen Wieck	Deborah Denning
COMPANY:	DATE:
Governors Council on DD	AUGUST 14, 2002
FAX NUMBER:	TOTAL NO. OF PAGES INCLUDING COVER:
651-297-7200	7
PHONE NUMBER:	
651-296-9964	
RE:	C.C.
CDCS Waiver Amendment	

☒ URGENT ☐ FOR REVIEW ☐ PLEASE COMMENT ☐ PLEASE REPLY ☐ PLEASE RECYCLE

Hi Colleen:

Here is a copy of the advocacy letters that I was finally able to write and that were sent out today. (I still don't know what it should be so emotionally difficult!. It *will* get easier, right?) Please let me know if you have any comments or concerns, or if you think that there are more people that I should write to Thanks! Take care.
