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## MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

370 Centennial Office Building • 658 Cedar Street • St. Paul, MN 55155  
Telephone: 651-296-4018 • Fax: 651-297-7200 • TTY: 651-296-9962 • Toll Free: 877-348-0505

April 15, 2005

Mr. Kevin Goodno  
Commissioner  
Minnesota Department of Human Services  
444 Lafayette Road North  
St Paul, Minnesota 55155

Dear Commissioner Goodno:

The Governor's Council on Developmental Disabilities met on April 6, 2005 and we discussed at length the Consumer Directed Community Support (CDCS) program. We would like to share with you, in summary, the comments of Council members and then provide you with more detailed information about one individual's experience with this program.

Several of our Council members have benefited from the CDCS program. They are unanimous in their support for an exception process that will enable people with the most significant disabilities to remain in a family home rather than return to traditional waiver services that would result in licensed services in the home or out of home placement.

I want to let you know particularly about Jeff Skwarek. Jeff is a member of our Council and a member of the Department of Human Services Quality Design Commission. He knows first hand the downside of living in out of home placements for 27 years.

Jeff has testified at the State Capitol about his living conditions and living environment during those 27 years. He said that he had no one who communicated with him (he uses augmentative communication); and he suffered abuse, neglect, and injuries. He has lived at home for the past three years and most definitely does not want to return to group living.

Commissioner Goodno/CDCS  
April 15, 2005  
Page 2

The option of receiving licenses services in the home has several drawbacks. Jeff and his family would lose control over who shows up to provide care for him. Dollars that are currently being spent efficiently and used directly for the purchase of services and supports for Jeff, would be redirected into a restrictive, over-regulated, and administratively costly system.

As a result, Jeff would receive fewer hours of services and supports because some of the available dollars would pay for administrative expenses. Jeff's return to a traditional service system model that never adequately served him in 27 years would waste dollars, and threaten his health, safety, and welfare.

I am enclosing a fiscal impact analysis of Jeff based on his current living situation, the proposed CDCS program, and an institutional setting. This comparative analysis is an example of an individual living situation that falls within the parameters of the proposed amendment language and demonstrates the need for an exception process.

I am urging you to support the amendment to S.F. 1837 as proposed by Senator Foley and agreed to by Senator Lourey's Committee on April 7, 2005.

Thank you in advance for your consideration of our comments.

Cordially,

A handwritten signature in cursive script that reads "Colleen Wieck".

Colleen Wieck, Ph.D.  
Executive Director

enclosure

4/14/05

Thoughts to work with for addition to Commissioner Goodno Letter. It's not great, but hope you can do something with it.

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The reality of forcing Jeff off of CDCS due to the current flawed budget methodology & subsequent cuts, only sends him (back) into a different part of the "system" with no cut in dollars, and no savings to the State.

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It is fiscally irresponsible and wrong to force Jeff back into MR/RC "licensed services", whether it be in-home, or, out-of-home placement. To do so takes dollars currently being spent efficiently and directly to the consumer, and re-directs the same if not more dollars into a restrictive, over regulated and administratively costly system, saving the State nothing. To force Jeff back into an old service system model that never adequately served him and that wastes undue dollars, only benefits providers, while limiting and eroding services that will threaten Jeff's health, safety and welfare.

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Hope this helps. Call me at work this afternoon (til 5:00) if you want to discuss.

Deborah

651-641-1376

# J.J. VANDERSON & CO.

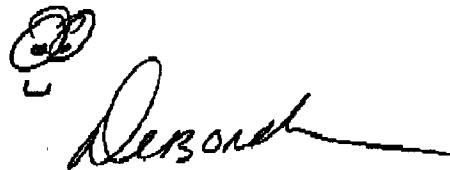
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If all pages are not received, please call 651-641-1376  
Return fax: 651-641-0737

Company: DD Council Date: 4/14/05  
Attn: Mary Jo or Colleen Fax#: 651-297-1200  
Sender: Deb Danning # of Pages: 2

Comments:

Re: Goodns Letter

  
J.J. Vanderson

J.J. Vanderson & Co.  
1214 98th Ave NE  
Blaine, Mn 55434  
651-641-1376



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**Commissioner Goodno/CDCS**

**April 14, 2005**

**Page 2**

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**Cordially,**



**Colleen Wieck, Ph.D.  
Executive Director**

**enclosure**

**Jeff Skwarek**  
**CDCS Impact Analysis**

3/7/2004

Revenue	CDCS Current	CDCS Proposed	Institution
<u>Funded</u>	<i>per day/per week</i>	<i>per day/per week</i>	<i>per day/per week</i>
Residential	\$362.50	\$250.00	\$362.50
Day Training & Habilitation (DT&H)	\$75.00	<u>eliminated</u>	\$75.00
<b>sub-total</b>	\$437.50	\$250.00	\$437.50
<u>Donated</u>			
Residential (@\$12/hr)	\$168.00	\$60.00	\$0.00
DT&H (@\$35/hr)	\$70.00	\$0.00	\$0.00
<b>sub-total</b>	\$238.00	\$60.00	\$0.00
<b>Total</b>	\$675.62	\$310.00	?
<b>Result:</b>	Gov't dollars enhanced by 54% with donated hours	Gov't dollars enhanced by 24% with donated hours	Gov't dollars <u>not</u> enhanced with donated dollars

	<i>per day</i>	<i>per day</i>	<i>per day</i>
<u>Expenses</u>			
Indirect Dollars (Admin costs)	(\$109.40) 25%	(\$62.50) 25%	(\$175.00) 40%
Community Inclusion (DT&H activities)	(\$1.50) (\$500/yr)	\$ 0 (budget won't allow)	\$ ? (mgmt descretion)
<b>Total</b>	(\$110.90)	(\$62.50)	(\$175.00)

<u>Staff</u>	<i>per day/per week</i>	<i>per day/per week</i>	<i>per day/per week</i>
Ratio	1.5 to 1 (required)	.75 to 1	1 to 4 (or 6)
Hours	37.5	15.5 (?)	24.0
Avg. Pay - PCA	\$ 15.00 (family set pay rates)	\$ 12.00 (?) (DHS imposed rate cap)	\$ ? (agency controlled)
Avg. Pay -Specialists	\$35/hr	0.0	0.0

<u>Servcces</u>	<u>Consumer Centered</u>	<u>Money Centered</u>	<u>Facility Centered</u>
*AAC Specialized:	x	lost	lost
*Personal Attendants	x	decreased	decreased
*Interpreting/Intervention	x	lost	lost
*Health Care Coord.	x	decreased	decreased
*Assistive Tech Support	x	lost	decreased
*Device Programming	x	lost	decreased
*ILS Develop & Training	x	lost	decreased
*Literacy Tutoring	x	lost	lost
*Computer Trailing	x	lost	lost
*Job Coaching/Supports	x	lost	lost
*Diet/Nutritional Services	x	decreased	x
*Respite - Qtrly.	x	lost	not needed
Housekeeping Srvcs.	x	decreased	x
On-Call Lifting Support	x	lost	x
Personal Transport (van)	x	decreased	lost

\*see definition -page 2

**Jeff Skwarek**  
**CDCS Impact Analysis - Page 2**

	<b>CDCS Current</b>	<b>CDCS Proposed</b>	<b>Institution</b>
<b>Result:</b>	Full Service. Needs met. Budget established & designed around unique consumer personal & program needs. Quality, integrated, comprehensive, *AAC customized approach. Defined objectives with measureable outcomes.	Adequate supports <b>cannot</b> be designed around this inadequate budget; eliminates day training and habilitation program & community inclusion support.	Below inadequate. System Centered. Threatens health and safety needs and habilitative requirements. Ignores specialty *AAC accommodations/needs. Wastes administrative dollars.

<b>Financial Impact:</b>	<i>Budget designed around need, plus receives 54% private funds match to gov't dollars. Need for specialty accommodations achieved.</i>	<i>Budget cut by &gt; 50%, and loss of 30% private funds match to gov't dollars. Specialty accommodations greatly diminished.</i>	<i>No budget change but loss of services and loss of specialty accommodations, plus loss of all private funds to match to gov't spending.</i>
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<b>Self Determination Impact:</b>	<b><u>Consumer Coice!</u></b> <b>(+ wiser use of dollars)</b>	<b><u>Consumer at risk.</u></b> <b>Forces institutionalization</b> <b>(Licensed Services)</b>	<b><u>Consumer rejected!</u></b> <b>due to past, life-long</b> <b>instituionalization</b> <b>experience &amp; the loss of</b> <b>necessary specialty</b> <b>supports and services</b> <b>needed to thrive.</b>
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<b>Consumer Profile:</b>           <b>Developmentally Disabled</b>           <b>High Level Needs</b>           <b>(Represents &lt; 1% of MR/RC Waiver Population)</b>	34 years old
	born with cerebral palsy
	institutionalized at 3 1/2
	quadraplegic
	legally blind
	speechless
	mobility impaired
	uses complex alternative symbol language, not device proficient (*AAC communicator)
	weighs 194 pounds
	cannot bear or shift weight
	requires total cares
	requires specialty language interpreter/interveener to direct cares & make needs known
	artifrically retarded due to mis-diagnosis, institutionalization & inadequate support/development services
	making great progress in self-designed school without walls program on CDCS
	Member, Gov. Council on Developmental Disabilities
	Member, DHS Quality Commission

**\*AAC=Augmentative & Alternative Communication**  
*(specialized communication)*





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January 26, 2005

The Honorable Linda Berglin  
Minnesota State Senator  
309 Capitol Building  
75 Rev. Dr. Martin Luther King, Jr. Boulevard  
St. Paul, Minnesota 55155-1606

Dear Senator Berglin:

The Governor's Council on Developmental Disabilities was created 33 years ago and is charged with implementing the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). Our annual federal allocation is used to increase the independence, productivity, self determination, integration and inclusion of people with developmental disabilities and their families in the community. These are the primary results defined in the DD Act.

Between 1986 and 1989, our Council funded an experimental voucher program in Dakota County to determine if consumer control of funds was a workable and worthwhile approach. The results of the experimental program demonstrated that families could buy more services at less cost with higher satisfaction levels.

Since that time our Council has carefully followed the design, development, implementation, and evaluation of the Consumer Directed Community Supports (CDCS) option within the Home and Community Based Waiver.

The purpose of this letter is twofold:

1. To express our strong support of the continued movement of the service delivery system to individualized budgets and consumer direction; and

2. To highlight the current problems with the CDCS option.

First and foremost, we are very pleased that the CDCS option will now be extended from 30 counties to all 87 counties and to all current waivers. At the same time, we are also very concerned about the current budget allocation methodology that is causing many individuals and families who have chosen this option to file appeals.

The Minnesota Disability Law Center has carefully documented several problems with the budget methodology. These problems include fundamental flaws due to invalid and unreliable variables used in the funding formula.

We support the Arc of Minnesota and the Minnesota Disability Law Center in their conclusions and the following recommendations:

1. Current budgets need to remain in place until a more valid budget methodology can be implemented;
2. The Department of Human Services needs to exert special efforts to creating a fair budget methodology that involves a range of stakeholders.

Thank you in advance for considering our comments about the CDCS option. We look forward to working on needed improvements that will help this program to better serve individuals and families.

Respectfully,

A handwritten signature in cursive script that reads "Colleen Wieck".

Colleen Wieck, Ph.D.  
Executive Director



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Minnesota State Representative  
563 State Office Building  
100 Rev. Dr. Martin Luther King, Jr. Boulevard  
St. Paul, Minnesota 55155-1606

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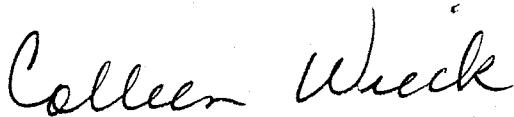
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Colleen Wieck, Ph.D.  
Executive Director



MAY 12 2005

Minnesota Department of **Human Services**

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May 5, 2005

Colleen Wieck, Ph. D.  
GCDD  
370 Centennial Office Building  
658 Cedar Street  
St. Paul, MN 55155

Dear Ms. ~~Wieck~~:

*Colleen*

Thank you for your letter regarding the Consumer Directed Community Support (CDCS) service. I appreciate hearing your thoughts and concerns.

The Legislature is currently considering CDCS "exception" language that is budget neutral. We are not, however, optimistic that the Center for Medicaid Services (CMS) will approve such an exception process based on the comparability requirements of the waiver program. The Department of Human Services (DHS) does not support exceptions as a general rule, as they do not assure comparability for people in the same program. Neither the DHS nor the legislature will support exception language with fiscal implications. Enhanced funding for this program and the purpose of the exception competes with other spending requests at the department.

We have generated a defensible budget methodology for CDCS recipients which does allocate the available resources based upon a common set of factors that have significant relationship to the costs of providing services. Dollars have been enhanced based upon age groups to recognize transition periods, including transition from school.

DHS continues to evaluate numerous aspects of CDCS and the more traditional services within the waiver program. We are specifically evaluating the overall service flexibility within traditional waiver services and challenges that have been identified in designing service packages to complement and assist families of minors with their responsibilities to their children, assuring health, safety and welfare of adults regardless of living arrangement, as well as greater flexibility and ease of use of services that prevent institutional alternatives. DHS agrees that Minnesota has been over dependent on more expensive, corporate models as a result of our deinstitutionalization efforts. These models continue to be replicated for persons who may not need this level of support, rather than

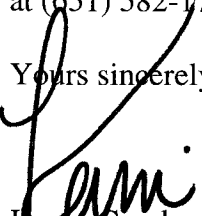
Colleen Wieck, Ph. D.  
May 5, 2005  
Page 2

creative expansion and development of less costly and more flexible services that rely less on licensure and more on supports to people within their family and within their community.

I know you and your organization will continue to provide feedback regarding the use of waiver services. We have the collective responsibility to assure our most vulnerable citizens have choices and opportunities to live full and productive lives.

For further questions, please contact Kathleen Kelly, a member of the Department staff, at (651) 582-1759.

Yours sincerely,

  
Kevin Goodno  
Commissioner

*Thanks for contacting  
me with your concerns!*

1 Senator ..... moves to amend S.F. No. 1837 as follows:

2 Page 20, after line 12, insert:

3 "Sec. 28. [CONSUMER-DIRECTED COMMUNITY SUPPORTS  
4 METHODOLOGY.]

5 For persons using the home and community-based waiver for  
6 persons with developmental disabilities whose Consumer-Directed  
7 Community Supports budgets were reduced by the October, 2004,  
8 state-set budget methodology, the commissioner of human services  
9 must allow exceptions to exceed the state-set budget formula up  
10 to the amount being spent by the person as of September 30,  
11 2004, when the individual's county of financial responsibility  
12 determines that:

13 (1) necessary alternative services will cost the same or  
14 more than the person's current budget; and

15 (2) administrative expenses or provider rates will result  
16 in less hours of needed staffing for the person than under the  
17 Consumer-Directed Community Supports option. Any exceptions the  
18 county grants must be within the county's allowable aggregate  
19 amount for the home and community-based waiver for persons with  
20 developmental disabilities.

21 Sec. 29. [COSTS ASSOCIATED WITH PHYSICAL ACTIVITIES.]

22 The expenses allowed for adults under the Consumer-Directed  
23 Community Supports option shall include costs, including  
24 transportation, associated with physical exercise or other  
25 physical activities to maintain or improve the person's health  
26 and functioning.

27 Sec. 30. [WAIVER AMENDMENT.]

28 The commissioner of human services shall submit an  
29 amendment to the Centers for Medicare and Medicaid Services  
30 consistent with sections 28 and 29 by August 1, 2005.

31        Sec. 31. [INDEPENDENT EVALUATION AND REVIEW OF UNALLOWABLE  
32 ITEMS.]

33        The commissioner of human services shall include in the  
34 independent evaluation of the Consumer-Directed Community  
35 Supports option provided through the home and community-based  
36 services waivers for persons with disabilities under 65 years of



1 age:

2 (1) provision for ongoing, regular participation by  
3 stakeholder representatives through June 30, 2007;

4 (2) recommendations on whether changes to the unallowable  
5 items should be made to meet the health, safety, or welfare  
6 needs of participants in the Consumer-Directed Community  
7 Supports option within the allowed budget amounts. The  
8 recommendations on allowable items shall be provided to the  
9 senate and house of representatives committees with jurisdiction  
10 over human services policy and finance issues by January 15,  
11 2006; and

12 (3) a review of the statewide caseload changes for the  
13 disability waiver programs for persons under 65 years of age  
14 that occurred since the state-set budget methodology  
15 implementation on October 1, 2004, and recommendations on the  
16 fiscal impact of the budget methodology on use of the  
17 Consumer-Directed Community Supports option.

18 Sec. 32. [EFFECTIVE DATE.]

19 Sections 28 and 29 are effective upon federal approval of  
20 the waiver amendment in section 30. Sections 30 and 31 are  
21 effective the day following final enactment. "