

# MICROFILM DIVIDER

OMB/RECORDS MANAGEMENT DIVISION  
SFN 2053 (2/85) 5M



ROLL NUMBER

DESCRIPTION

2330

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Deanna Hall  
Operator's Signature

10/22/03  
Date

2003 SENATE HUMAN SERVICES

SB 2330

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Date

2003 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2330

Senate Human Services Committee

Conference Committee

Hearing Date February 3, 2003

Tape Number	Side A	Side B	Meter #
1	X		2464 - end
			0 - 730
Committee Clerk Signature <i>Donna Kremer</i>			

Minutes:

SENATOR JUDY LEE opened the public hearing for SB 2330 providing for a choice of options for individuals eligible for the aged and disabled medical assistance waiver.

SENATOR TIM MATHERN, from District 11 in Fargo, introduced the bill at the request of the Freedom Resource Center. The bill will create more options of care for persons who use the Medical Assistance program. Gave example of person of needing special care. (Written testimony) (Meter # 2464 - 2840)

CHUCK STEBBINS, with the Freedom Resource Center for Independent Living in Fargo, testified in support SB 2330 .. an implementation of Olmstead decision. State needs to change the way of providing long-term care. (Written testimony provided, copies of letters to Governor Hoeven, and a flyer on home and community based services) ( Meter #2899 - 3931)

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*Donna Kremer*  
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Page 2  
Senate Human Services Committee  
Bill/Resolution Number SB 2330  
Hearing Date February 3, 2003

CAROL HERAUF, who had resided in the Mandan Missouri Slope Lutheran Home and now lives in Mandan with her husband in a house they are buying. She gave testimony in support of the bill. (Written testimony) (Meter # 4050 - 4210)

LINDA WRIGHT, Director of the Aging Services Division, Department of Human Services, testified in favor of the bill. She stated the approval of this bill would allow us to apply for an 1115 Demonstration Waiver which would allow eligible families and individuals to receive a cash allowance to obtain personal assistant services and related supports. In other words, this would provide greater control to the individual client or family. (Written testimony) (Meter #4225 - 4570)

JAMES M. MOENCH, Ex. Director of the North Dakota Disabilities Advocacy Consortium, testified in behalf of the bill. (Written testimony) (Meter # 4642 - 4970)

TERESA LARSEN, Ex. Director of the ND Protection & Advocacy Project, testified in support of the bill. She stated that along with SB 2085 and SB 2194, SB 2330 rounds out the Olmstead package. (Written testimony and Background On Olmstead info) (Meter # 5050 - 5551)

JACK MACDONALD, Lobbyist for the ARC, testified in support of the bill. If this bill is unanimously supported, might think about the emergency clause. Response by Linda Wright - no problem. (Meter # 5584 - 5760)

MURIEL PETERSON, worked for Human Services Aging Division, for 19 years. She stated she was not opposed to Home and Community Based Services, but there were several things that bothered her. Questioned about all costs being considered. Stated vouchers do not solve problem. Discussion with Senator Lee. (Tape 1, Side A, Meter # 5805 - end and Tape 1, Side B, Meter # 0 - 615)

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Page 3  
Senate Human Services Committee  
Bill/Resolution Number SB 2330  
Hearing Date February 3, 2003

LINDA WRIGHT replied that the Olmstead Commission did apply for and receive a Real Choice System Change Grant which now will be implemented by the Department of Human Services. There are a number of pilot projects that will be included in that grant. (Meter 640 - 704)

SENATOR LEE closed the public hearing on SB 2330. (Meter # 730)

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*Deanna D. Hall*  
Operator's Signature

*10/22/03*  
Date

2003 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2330

Senate Human Services Committee

Conference Committee

Hearing Date February 5, 2003

Tape Number	Side A	Side B	Meter #
2		X	3267 - 4193
Committee Clerk Signature <i>Donna Kramer</i>			

Minutes:

SENATOR JUDY LEE opened the committee discussion on SB 2300 providing for a legislative council study of the future role of the state hospital.

LINDA WRIGHT, Director of Aging Services, testified earlier in favor. She talked about the amendments being provided. She had discussed this with Dave Zentner and they see this as enabling legislation which would allow us to pursue some additional options. See no problem.

(Meter # 3270 - 3369)

SENATOR LEE questioned about the client paying? (Meter # 3467)

LINDA WRIGHT: From what she had read, there is the ability to build into this a billing agent or an intermediary that would take care of fringe benefits. (Meter 3496 - 3522)

SENATOR FISCHER made a motion on amendment ... so move.

SENATOR POLOVITZ seconded the motion.

Roll call was read. 5 yeas 0 nays and 1 absent.

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10/22/03  
Date

Page 2  
Senate Human Services Committee  
Bill/Resolution Number SB 2330  
Hearing Date February 5, 2003

Committee Discussion regarding amendments.

SENATOR FISCHER made a motion to Do Pass as amended and rerefer.

SENATOR FAIRFIELD seconded the motion.

Roll call was read. 5 yeas 0 nays and 1 absent.

SENATOR FAIRFIELD to be the carrier. (Meter # 4193)

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10/22/03  
Date

**FISCAL NOTE**  
 Requested by Legislative Council  
 02/10/2003

Amendment to: SB 2330

1A. **State fiscal effect:** Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.

	2001-2003 Biennium		2003-2005 Biennium		2005-2007 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures						
Appropriations						

1B. **County, city, and school district fiscal effect:** Identify the fiscal effect on the appropriate political subdivision.

2001-2003 Biennium			2003-2005 Biennium			2005-2007 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

2. **Narrative:** Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.

This bill provides for a choice of options for individuals eligible for the aged and disabled medical assistance waiver. This bill does not have a fiscal impact.

3. **State fiscal effect detail:** For information shown under state fiscal effect in 1A, please:

A. **Revenues:** Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.

B. **Expenditures:** Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.

C. **Appropriations:** Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.

Name:	Brenda M. Weisz	Agency:	Department of Human Services
Phone Number:	328-2397	Date Prepared:	02/10/2003

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Deanna Stalder 10/22/03  
 Operator's Signature Date

**FISCAL NOTE**  
 Requested by Legislative Council  
 01/28/2003

Bill/Resolution No.: SB 2330

1A. **State fiscal effect:** Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.

	2001-2003 Biennium		2003-2005 Biennium		2005-2007 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures						
Appropriations						

1B. **County, city, and school district fiscal effect:** Identify the fiscal effect on the appropriate political subdivision.

2001-2003 Biennium			2003-2005 Biennium			2005-2007 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

2. **Narrative:** Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.

This bill provides for a choice of options for individuals eligible for the aged and disabled medical assistance waiver. This bill does not have a fiscal impact.

3. **State fiscal effect detail:** For information shown under state fiscal effect in 1A, please:

A. **Revenues:** Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.

B. **Expenditures:** Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.

C. **Appropriations:** Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.

<b>Name:</b>	Brenda M. Welsz	<b>Agency:</b>	Department of Human Services
<b>Phone Number:</b>	328-2397	<b>Date Prepared:</b>	01/31/2003

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Operator's signature: Brenda M. Welsz Date: 01/22/03

30729.0101  
Title.0200

Adopted by the Human Services Committee  
February 5, 2003

903  
2-6-03

PROPOSED AMENDMENTS TO SENATE BILL NO. 2330

Page 1, line 1, replace "the aged and" with "home and community-based services"

Page 1, line 2, remove "disabled" and replace "waiver" with "waivers"

Page 1, line 4, replace "Aged and disabled" with "Home and community-based services"  
and replace "waiver" with "waivers"

Page 1, line 5, replace the first "the" with "a home and community-based service"

Page 1, line 9, replace "waiver" with "waivers and grants" and after "section" insert "under  
existing or future federal legislation"

Renumber accordingly

Page No. 1

30729.0101

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Deanna Waller  
Operator's Signature

10/22/03  
Date



Date: 02-05-03  
Roll Call Vote #: (2)

2003 SENATE STANDING COMMITTEE ROLL CALL VOTES  
BILL/RESOLUTION NO. 2330

Senate Human Services Committee

Check here for Conference Committee

Legislative Council Amendment Number LC: 30729.0101

Action Taken Do Pass as amended and refer

Motion Made By Sen. Fischer Seconded By Sen. Fairfield

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee - Chairman	✓				
Senator Richard Brown - V. Chair.	✓				
Senator Robert S. Erbele					
Senator Tom Fischer	✓				
Senator April Fairfield	✓				
Senator Michael Polovitz	✓				

Total (Yes) 5 No 0

Absent 1 absent

Floor Assignment Senator Fairfield

If the vote is on an amendment, briefly indicate intent:

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Deanna Waller 10/22/03  
Operator's Signature Date

**REPORT OF STANDING COMMITTEE (410)**  
February 6, 2003 4:41 p.m.

Module No: SR-23-1919  
Carrier: Fairfield  
Insert LC: 30729.0101 Title: .0200

**REPORT OF STANDING COMMITTEE**

**SB 2330: Human Services Committee (Sen. J. Lee, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO PASS and BE REREFERRED to the Appropriations Committee (5 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). SB 2330 was placed on the Sixth order on the calendar.**

Page 1, line 1, replace "the aged and" with "home and community-based services"

Page 1, line 2, remove "disabled" and replace "waiver" with "waivers"

Page 1, line 4, replace "Aged and disabled" with "Home and community-based services" and replace "waiver" with "waivers"

Page 1, line 5, replace the first "the" with "a home and community-based service"

Page 1, line 9, replace "waiver" with "waivers and grants" and after "section" insert "under existing or future federal legislation"

Renumber accordingly

(2) DESK, (3) COMM

Page No. 1

SR-23-1919

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*Deanna Hall*  
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10/22/03  
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2003 HOUSE HUMAN SERVICES

SB 2330

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*Dennis Waller*  
Operator's Signature

10/22/03

Date

2003 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2330

House Human Services Committee

Conference Committee

Hearing Date March 4, 2003

Tape Number	Side A	Side B	Meter #
1		x	35.8 - end
2	x		0.0 - 1.4
Committee Clerk Signature <i>Sharon Kengrow</i>			

Minutes:

Sen. Mathern appeared as prime sponsor with written testimony and proposed an amendment.

Rep. Porter: What does the amendment do?

Answer: Takes out wording regarding aged and disabled medical assistance waiver. The purpose is to not focus on waiver, the goal is to not disturb what we have going here that's positive.

Rep. Devlin: I see you've directed the Dept. to apply for appropriate waivers and grants, will that affect the fiscal note on the bill?

Answer: that would not affect that, if not granted, we wouldn't have the option. The goal is to take advantage of option made by the Bush Administration.

Chuck Stebbans, Freedom Resource Center for Independent Living, Fargo stating the key language that needs to be stressed is that money follows the individual. As far as any individual who are living in nursing homes or institutions now that the money that it costs for them to stay

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*Deanna Dalko*  
Operator's Signature

10/22/03  
Date

Page 2  
House Human Services Committee  
Bill/Resolution Number SB 2330  
Hearing Date March 4, 2003

there would be able to follow them out of the institution and into the services and options of their choice. The amendments that have been offered is an attempt to clarify or get rid of some conflict between \_\_\_\_\_ and this bill that you just heard.

Susan Helgeland, Chair of the ND Disabilities Advocacy Consortium (NDDAC) appeared in support with written testimony.

Linda Wright, Director of the Aging Services Division, Dept. of Human Services appeared in support if amended with Sen. Mathern's amendments with written testimony.

Rep. Potter: What is a demonstration Medicaid waiver?

Answer: Options to look at available money.

Teresa Larsen, Executive Director of ND Protection & Advocacy Project (P&A) appeared in support with written testimony.

No opposition.

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10/22/03  
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2003 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2330

House Human Services Committee

Conference Committee

Hearing Date March 12, 2003

Tape Number	Side A	Side B	Meter #
2	x		4.5 - 10.7
Committee Clerk Signature <i>Sharon Longfellow</i>			

Minutes: Committee work

Rep. Devlin explained and proposed amendments moved to adopt them along with Sen.

Mathern's amendments, second by Rep. Pollert.

VOTE: 13 - 0 - 0 Amendments passed

Rep. Devlin motioned for DO PASS as Amended, second by Rep. Weisz.

Rep. Uglem: Does this mean if somebody can't get into the SPED Program, but they qualify for a nursing home, they can go into the nursing home and the next month check out, the money will follow them in the SPED Program from the nursing home?

Answer: They have to qualify or meet the requirements for the nursing home before they can be admitted.

VOTE: 13 - 0 - 0 Rep. Devlin will carry the bill.

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*Dennis Wallis*  
Operator's Signature

10/22/03  
Date

**PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2330**

**Page 1, line 7, replace "The" with "To the extent permitted by any applicable waiver, the"**

**Page 1, line 9, after "selects" insert "not to exceed the cost of the service"**

**Renumber accordingly**

By Devlin

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Devin Devlin  
Operator's Signature

10/22/03  
Date

30729.0201  
Title.

Prepared by the Legislative Council staff for  
Senator Mather  
March 3, 2003

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2330

Page 1, line 2, replace "services medical assistance waivers" with "living"

Page 1, line 4, replace "services medical assistance waivers" with "living"

Page 1, line 5, after "Any" insert "aged or disabled", remove "a", and replace "service" with  
"living"

Page 1, line 6, remove "medical assistance waiver for the aged and disabled"

Renumber accordingly

Page No. 1

30729.0201

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Deanna Mather  
Operator's Signature

10/22/03  
Date

Date: March <sup>12</sup>, 2003  
Roll Call Vote #: 1

2003 HOUSE STANDING COMMITTEE ROLL CALL VOTES  
BILL/RESOLUTION NO. SB 2330

House HUMAN SERVICES Committee

Check here for Conference Committee

Legislative Council Amendment Number \_\_\_\_\_

Action Taken Do Pass as Amended

Motion Made By Rep Devlin Seconded By Rep Weisz

Representatives	Yes	No	Representatives	Yes	No
Rep. Clara Sue Price - Chair	✓		Rep. Sally Sandvig	✓	
Rep. Bill Devlin, Vice-Chair	✓		Rep. Bill Amerman	✓	
Rep. Robin Weisz	✓		Rep. Carol Niemeier	✓	
Rep. Vonnie Pietsch	✓		Rep. Louise Potter	✓	
Rep. Gerald Uglem	✓				
Rep. Chet Pollert	✓				
Rep. Todd Porter	✓				
Rep. Gary Kreidt	✓				
Rep. Alon Wieland	✓				

Total (Yes) 13 No 0

Absent 0

Floor Assignment Rep Devlin

If the vote is on an amendment, briefly indicate intent:

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Deanna Ballantyne Operator's Signature 10/22/03 Date

**REPORT OF STANDING COMMITTEE (410)**  
March 13, 2003 9:06 a.m.

Module No: HR-45-4641  
Carrier: Devlin  
Insert LC: 30729.0202 Title: .0300

**REPORT OF STANDING COMMITTEE**

SB 2330, as engrossed: Human Services Committee (Rep. Price, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (13 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2330 was placed on the Fourteenth order on the calendar.

Page 1, line 2, replace "services medical assistance waivers" with "living"

Page 1, line 4, replace "services medical assistance waivers" with "living"

Page 1, line 5, after "Any" insert "aged or disabled", remove "a", and replace "service" with "living"

Page 1, line 6, remove "medical assistance waiver for the aged and disabled"

Page 1, line 7, replace "The" with "To the extent permitted by any applicable waiver, the"

Page 1, line 9, after "selects" insert ", not to exceed the cost of the service"

Renumber accordingly

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10/22/03

Date

2003 TESTIMONY

SB 2330

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Deanna Halliwell  
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10/22/03  
Date

**PRESIDENT WILL PROPOSE \$1.75 BILLION PROGRAM  
TO HELP TRANSITION AMERICANS WITH DISABILITIES  
FROM INSTITUTIONS TO COMMUNITY LIVING**

**Questions and Answers  
(January 22, 2003)**

**"Money Follows the Individual" Rebalancing Demonstration**

***Q1. What do you mean by "money following the individual"?***

**A1.** When "money follows the individual" in the long term care system, services and supports move with the person to the most appropriate and preferred setting and can change as his or her needs change. It is a market-based approach that gives individuals free choice over the location and type of service they receive. By making the individual the focus of decision-making and funding, people are able to make more cost-effective decisions, including substituting more effective or less costly services in lieu of traditional or overly medicalized services.

***Q2. What is the goal of the "Money follows the Individual Rebalancing Demonstration"?***

**A2.** The goal of the "Rebalancing Demonstration" is to assist states in developing and implementing a strategy to "level the playing field" and create more cost effective choices between institutional and community options.

***Q3. What types of programs could a state fund through this demonstration?***

**A3.** States will be encouraged to develop and adopt a coherent strategy for reducing reliance on institutions.

◆ Developing a coherent package of state plan and home and community-based waiver where funding is available to "follow the person" to the most appropriate and preferred setting.

◆ Funding services for individuals who transition from an institution to the community including enrollment in a home and community based waiver program.

◆ Providing individuals a single point of access for long-term support including good, free information about options.

***Q4. Have any States implemented successful models?***

**A4.** Yes. Wisconsin set aside approximately \$3.2 million of state only and Medicaid funds over two years to target nursing facility residents who would like to live in the community. State staff report that 153 people left Wisconsin nursing facilities

1

in 2001 due to the targeted funding. In another example, the Texas legislature included a rider in the state's appropriations act in 2001 to promote independence and community integration. This rider allows any interested Medicaid nursing facility resident to apply for transition into the community and have the money follow them when they leave the nursing facility. This has helped over 950 people transition into the community since the law became effective September 2001.

### **New Freedom Initiative Demonstrations**

**Q5** *What are the New Freedom Initiative Demonstrations announced in the President's 2004 Budget?*

**A5** Two of the proposed demonstrations will provide assistance to families and informal caregivers by providing them temporary relief from care giving, thus enabling individuals with a disability or long-term illness to remain in the community. One of these demonstrations is focused on caregivers of adults who have a disability or long-term illness (i.e., the *Adult Respite Demonstration*) and the other is focused on caregivers of children who have a substantial disability (*Children's Respite Demonstration*).

The third demonstration will provide community-based alternatives to Medicaid funded psychiatric residential treatment facilities for children under age 21.

The fourth demonstration will address workforce shortage issues by testing the extent to which workforce shortages and instabilities might be addressed through (a) better coordination with the Temporary Assistance for Needy Families (TANF) program and (b) the availability of vouchers for worker health insurance or for tuition and day care credits; and (c) other recruitment or retention programs to increase the size and stability of the community service direct care work force.

**Q6** *What will the demonstrations accomplish?*

**A6** The demonstrations will permit CMS and States to assess and gain valuable experience regarding the management of a respite service, another home and community-based service option, and better methods to attract and retain direct service workers. Through the demonstrations, CMS and States will be able to evaluate the impact of various interventions on the cost and utilization of Medicaid community and facility based services, which may then influence more long-term structural changes to the Medicaid program.

**Q7** *How are the demonstrations different from what States can offer under the Home and Community Based Services (HCBS) waivers?*

**A7** Respite Demonstrations  
Although approximately two-thirds of HCBS waivers include some respite

2

benefit, such programs are (a) limited to people who already require an institutional level of care, (b) may have long waiting lists, and (c) often provide a full package of services rather than a targeted service such as respite. In contrast, the demonstrations will enable States to expand their respite services to target individuals who (a) do not have an institutional level of care need or (b) have a long-term illness. Under this demonstration States may also increase their capacity to provide respite services to those on HCBS waiting lists.

#### Alternatives to Residential Treatment Facilities.

Medicaid provides inpatient psychiatric services for children under age 21 in hospitals. The statute also extends these Medicaid benefits to children in psychiatric residential treatment facilities. However, psychiatric residential treatment facilities are not considered to meet the definition of hospital so they do not qualify as institutions against which States may measure 1915(c) waiver costs. However, over the last decade, psychiatric residential treatment facilities have become the primary provider for children with serious emotional disturbances requiring an institutional level of care. Since they are not recognized as hospitals, States have been unable to use the 1915(c) waiver authority to provide home and community-based alternatives to care, which would keep the children in their homes and with their families. This demonstration will enable states to establish a home and community-based waiver as an alternative to care in a psychiatric residential treatment facility.

#### Workforce Demonstration

This demonstration will not expand services to Medicaid beneficiaries but rather gather better research on recruitment and retention strategies of direct service workers who provide the necessary supports and services to enable an individual with a disability to live in the community.

#### Spousal Exemption

**Q8** *What would the new spousal exemption provision permit than is not currently permitted?*

**A8** This proposal would extend Medicaid eligibility for spouses of disabled individuals who return to work. Under current law, individuals with disabilities who return to work may preserve their Medicaid eligibility. However, they might be discouraged from returning to work because the income they earn could jeopardize their spouse's Medicaid eligibility. This proposal would extend to the spouse the same Medicaid coverage protection now offered to the disabled worker under a revision to section 1619(b) of the Social Security Act.

#### Medicaid presumptive eligibility for institutionally qualified individuals who are discharged from hospitals into the community

3

**Q9** *What is "presumptive eligibility"?*

**A9** It allows a State to presume that an individual who meets the eligibility criteria for an institutional level of care in a Nursing Facility or Intermediate Care Facility for the Mentally Retarded (ICF/MR) will meet Medicaid eligibility criteria once the application/determination process is complete. The state is held harmless for any benefits paid on the person's behalf if a formal eligibility determination subsequently establishes that the person was not in fact eligible during the presumptive period. This allows a State to move quickly to access Medicaid funded services prior to completion of that process.

**Q10** *Will this be a requirement for States?*

**A10** No. This will be an option made available to States.

**Q11** *Why is there a need for this option?*

**A11** Individuals with disabilities and families have expressed a concern that waiting one-to-three months for a Medicaid eligibility decision introduces an element of uncertainty that makes community services appear risky to the individual or family. Such uncertainty leads to higher rates of institutional placement than necessary.

Hospitals now represent the single most frequent source of nursing facility admissions. Nursing homes offer natural advantages to hospital discharge planning staff- they can offer on short notice a pre-packaged array of services including room and board, and nursing home staff are skilled at expediting Medicaid applications. The relative speed with which a Medicaid application can be filed when a nursing home is involved often translates into a "default" decision to place the individual in a nursing home rather than returning home or attempting a community arrangement through HCBS waiver services.

**Q12** *Is there precedent for such an option?*

**A12** Yes. Under current statute, states have the option of providing Medicaid to a pregnant woman or child for a specified period of time if a qualified provider or other entity determines that the pregnant woman or child is likely to meet the state's Medicaid income standard.

### **Systems Change Grants**

**Q13** *What are System Change Grants?*

**A13** The Systems Change grants are intended to foster systems changes to enable children and adults of all ages who have a disability or long-term illness to:

4

- 1) Live in the most integrated community setting appropriate to their needs,
- 2) Exercise meaningful choices about their living environments, the providers of services they receive, and the types of supports they use and the manner by which they are received.
- 3) Obtain quality services in a manner as consistent as possible with their community living and preferences.

**Q14** *Were Grants awarded previously?*

**A14** Yes. Nearly \$70 million was distributed in FY 2001. During FY 2002 \$55 million was distributed.

**Q15** *Is there still unmet need for these types of funds?*

**A15** Yes. As an example, during the FY 2002 process States submitted proposals totaling \$240 million. As a result, States were either unfunded or funded at levels less than their request.

**Q16** *How will the funds be utilized in 2004?*

**A16** Funds will be used to fund new or expanded initiatives with a potential focus on the Independence Plus initiative, assuring quality within Home and Community-based Service waivers or innovative ideas proposed by States. Funds may also be used to restore prior grants to requested levels.

**Senate Human Services  
February 3, 2003  
SB 2330**

Chairman Lee and members of the Committee, my name is Teresa Larsen. I am the Executive Director of the N.D. Protection & Advocacy Project (P&A), an Independent State agency that provides advocacy and protective services for individuals with disabilities.

In 1999 the U.S. Supreme Court announced the *Olmstead* decision, a landmark ruling for people with disabilities, which said that it is unlawful discrimination to unnecessarily place them in institutions like nursing homes. The U.S. Department of Health and Human Services issued guidance to the states urging that they develop a plan for full compliance with *Olmstead*. Attachment A provides you with some additional information on this ruling.

In tough economic times, we have to prioritize the funds we spend to meet people's needs. The Governor's proposed budget takes a step forward by increasing the funding for home and community-based services. This will help North Dakota improve the services available to people in need in a way compatible with the *Olmstead* ruling. There are other proposals that are also responsive to *Olmstead* such as SB 2085 (targeted case management and assessments) and SB 2194 (Medicaid Buy-In).

SB 2330 is a huge step towards meeting the intent of *Olmstead*. It will help by not only better balancing the existing financial bias towards nursing facilities, but combined with SB 2085, it will also help address the social bias. It will allow people in need to choose options, usually less expensive, that will enable them to stay in their homes.

I want to give you an example of an individual P&A has been working with that I will call "Steve". He is a 27 year-old that sustained a spinal cord injury approximately two years ago. As a result of the injury, he no longer has physical use of his arms and legs. Steve was recently hospitalized for some minor medical issues and, when ready to be discharged, expected to return to his apartment. In working to re-connect Steve to the services he had prior to

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Teresa Larsen  
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being hospitalized, the home health care agency declared that they would no longer provide services to him because "he is a quad", is too difficult, and needed nursing home care. Steve was adamant about returning to his apartment and, with advocacy help, this became a reality for him. Cost effective home services were arranged to ensure that Steve had adequate support to assist with daily living tasks. While this is a success story for Steve, how many other individuals actually end up in a more expensive nursing facility placement, contrary to need or choice, because this is presented as their only option?

Assessments and planning should start with the premise that the person can live in the community. All too often we hear that hospitalized individuals are presented with the question, "which nursing home would you like to apply for admission to?" instead of "lets talk about what services and supports you might need to return home".

There are currently people on waiting lists for home and community-based services. These individuals are at risk of institutionalization, also a population covered by the *Olmstead* decision. Purchasing home-based services for these individuals will be less costly and can delay, or eliminate all together, the need for more expensive nursing home care.

Along with SB 2085 and SB 2194, SB 2330 rounds out the *Olmstead* package. Thank you for your time and consideration. I will be glad to answer any questions you might have.

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**BACKGROUND ON OLMSTEAD v. L.C.**

The *Olmstead* decision interpreted Title II of the Americans with Disabilities Act (ADA) and its implementing regulation, which oblige states to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." (28 CFR 35.130(d)). In doing so, the U.S. Supreme Court answered the fundamental question of whether it is discrimination to deny people with disabilities services in the most integrated setting appropriate. The Court stated directly that "Unjustified isolation . . . is properly regarded as discrimination based on disability."

Under the Court's decision, **states are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services** when: (a) the state's treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported disability services.

Significantly, the Court suggested that a state could establish compliance with Title II of the ADA if it demonstrates that it has:

- ✦ a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and
- ✦ a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

On 1/14/00, the U.S. Department of Health & Human Services (HHS) sent a letter to all state Medicaid directors regarding *Olmstead* and what states needed to do to comply with the decision. The enclosure to this letter offers some recommendations about key principles and practices for states to consider as they develop a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings.

It strongly recommends that States:

1. Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up;
2. **Take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities;**
3. **Ensure the availability of community-integrated services;**
4. **Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings;**
5. Take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan.

Deanna Hall  
Operator's Signature

10/22/03  
Date

**Testimony**  
**North Dakota Disabilities Advocacy Consortium**

**SB 2330**  
**Money follows the Individual**

Senate Human Services Committee  
February 3, 2003

Chairperson Lee, members of the Senate Human Services Committee, I am James M. Moench, Executive Director of the North Dakota Disabilities Advocacy Consortium (NDDAC). The Consortium is made up of 25 organizations concerned with addressing the issues that affect people with disabilities. We are very interested in improving the ability of people with disabilities to fully participate in all aspects of life in North Dakota.

The Consortium fully supports SB 2330 which provides for personal choice. The Governor in his budget and the legislature are showing more understanding of the benefits of home and community based services. The benefits include the obvious cost saving, but more important are the intangibles. The person with a disability receiving services is recognized as an individual who has the right to choose the path that fits his or her capabilities and desires. The provisions included in SB 2330 support and further the rights of the individual. What could be a more basic American right than the right to determine one's own individual path in life. Also once the services and benefits are identified and chosen, these services and benefits would follow the individual.

I have provided the committee with a news release dated January 23, 2003 entitled, **President will propose \$1.75 billion program to help transition Americans with disabilities from institutions to community living.**

President Bush in his budget this month will be proposing a "Money Follows the Individual" Rebalancing Demonstration program of \$350 million for FY 2004. North Dakota should position itself to implement SB 2330, given the President's initiative and the possibility of federal support. The President's proposal builds on the existing state success stories in Texas, Wisconsin, Michigan and Washington. This initiative and the others outlined in this announcement clearly demonstrate the nation's interest in promoting the use of home and community based services. North Dakota is clearly on the right path. Passing SB 2330 could add our state the list of success stories.

I appreciate this opportunity to testify on behalf of the NDDAC and look forward to working with you during the course of this legislative session. Thank you.

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10/22/03

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Provided  
by:



North Dakota  
Disabilities  
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Consortium

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EMBARGOED FOR RELEASE:  
Thursday, Jan 23, 2003

Contact: HHS Press Office  
(202) 690-6343

**PRESIDENT WILL PROPOSE \$1.75 BILLION PROGRAM  
TO HELP TRANSITION AMERICANS WITH DISABILITIES  
FROM INSTITUTIONS TO COMMUNITY LIVING**

In his budget next month, President Bush will propose a new \$1.75 billion, five-year program to help Americans with disabilities transition from nursing homes or other institutions to living in the community.

The proposal is one of several new efforts to be included in the FY 2004 budget for the President's New Freedom Initiative, a nationwide effort to integrate people with disabilities more fully into society. Altogether, the President's New Freedom budget proposals will represent \$2.1 billion in planned new spending over five years, with \$417 million in new spending proposed for FY 2004.

The proposals build on recommendations made to the President last year in "Delivering on the Promise," a comprehensive survey of federal policies and rules that may impede community living for those with disabilities.

"The New Freedom Initiative was one of the earliest actions announced by the President in his first days in office," said HHS Secretary Tommy G. Thompson. "The President and I are committed to changing policies that unnecessarily confine people with disabilities in institutional settings. We want to work with the states and the disability community to change old programs and develop new ones that will serve people with disabilities in the settings that work best for them."

Proposals in the FY 2004 budget will include:

- "Money Follows the Individual" Rebalancing Demonstration -- \$1.75 billion over five years, with \$350 million proposed for FY 2004. This five-year demonstration would assist states in developing and implementing a strategy to "re-balance" their long term care systems so that there are more cost-effective choices between institutional and community options, including financing Medicaid services for individuals who transition from institutions to the community. Federal grant funds would pay the full cost of home and community-based waiver services for one year, after which the participating states would agree to continue care at the regular Medicaid matching rate. This significant demonstration would build upon existing state success stories in Texas,

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Wisconsin, Michigan and Washington. It also provide incentives to states for increased use of home and community-based services and would help provide information on costs of different approaches.

- **New Freedom Initiative Demonstrations** -- \$220 million over five years, with \$11 million proposed for FY 2004. This initiative would fund four demonstrations that promote home and community-based care alternatives. Two of the demonstrations provide respite care services for caregivers of adults with disabilities or long-term illness and children with substantial disabilities. Another demonstration provides community-based care alternatives for children who are currently residing in psychiatric residential treatment facilities. The President proposed these demonstrations for FY 2003, but it is not expected that Congress will include this in its final FY 2003 appropriations.
- **Spousal Exemption** -- \$95 million over five years, with \$16 million proposed for FY 2004. This proposal would continue Medicaid eligibility for spouses of disabled individuals who return to work. Under current law, individuals with disabilities might be discouraged from returning to work because the income they earn could jeopardize their spouse's Medicaid eligibility. This proposal would extend to the spouse the same Medicaid coverage protection now offered to the disabled worker.

The budget will also propose to establish a new state option enabling Medicaid presumptive eligibility for institutionally qualified individuals who are discharged from hospitals into the community. This would make it more feasible to discharge a person who has been hospitalized to the community, rather than to an alternative institutional setting, or to ensure that the institutional placement is of short duration.

Expanding on an existing effort, the FY 2004 budget will also include \$40 million for "Systems Change Grants" to support states in their planning to create new systems to support people with disabilities in the community instead of in institutions.

In addition to the "Systems Change Grants," HHS has worked with 40 states and the District of Columbia to design and implement Ticket-to-Work provisions. And last year HHS offered an "Independence Plus" waiver template to help states develop consumer directed services.

Last year, the President named his New Freedom Commission on Mental Health, and charged it with conducting a comprehensive study of the United States mental health service delivery system, including both private and public sector providers, and advising him on methods of improving the system. Secretary Thompson also created a new Office on Disability within HHS in 2002 to coordinate activities across the Department and serve as a focused contact point for disability issues.

"Improving our programs for people with disabilities, including the need to tackle the institutional bias in some programs, is a daunting task," Secretary Thompson said. "It

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will require sustained effort over many years. We've made a start with the most comprehensive survey ever taken of problems and opportunities in federal programs, as well as new structures to support our efforts. The President's budget proposals will take us to the next level, with substantial demonstration activities and more help for Americans with disabilities to enter and stay in the workforce."

###

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# ND Disabilities Advocacy Consortium

## Member List

Dakota Center for Independent Living  
Mental Health Association in ND  
The Arc of Cass County  
ND Statewide Independent Living Council  
The Arc of Bismarck  
Bismarck Public Schools  
ND Federation of Families for Children's Mental Health  
People First of ND  
ND Center for Persons With Disabilities  
Friendship Inc.  
ND Protection & Advocacy Project  
Options Inc.  
Independence Inc.  
ND Association for Persons in Supported Employment  
ND Association of the Blind  
ND IPAT Consumer Advisory Committee  
ND Association of the Deaf  
Freedom Resource Center for Independent Living Inc.  
The Arc of ND  
ND Fair Housing Council  
ND Association for the Disabled  
Family Voices of ND  
American People Self-Advocacy Association  
United Voices

## Associate Member

North Dakota Nurses Association

and growing.....



Updated 12/13/02

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**TESTIMONY**  
**SENATE HUMAN SERVICES**  
**SENATE BILL 2330**  
**JUDY LEE, CHAIRMAN**  
**FEBRUARY 3, 2003**

Chairman Lee and members of the Senate Human Services Committee, my name is Linda Wright, Director of the Aging Services Division, Department of Human Services.

I appear before you today to testify in support of this bill. Senate Bill 2330 would support the Department of Human Services in applying for an 1115 Demonstration Medicaid Waiver. This is part of President Bush's New Freedom Initiative.

The attachment, which was generated by the Centers for Medicare and Medicaid Services, describes the purpose of this initiative. The Department of Human Services already has 1915© Waivers for Aged and Disabled, Traumatic Brain Injury, and Developmental Disabilities. The approval of this bill would allow us to apply for an 1115 Demonstration Waiver which would allow eligible families and individuals to receive a cash allowance to obtain personal assistant services and related supports. In other words, this would provide greater control to the individual client or family.

The Medicaid Waiver must be cost neutral, therefore, there is no fiscal note for Senate Bill 2330.

The Department of Human Services encourages a do pass vote on this bill. It is a "win-win" for the client, the family and the state of North Dakota by providing another option for individuals who need assistance, but wish to remain at home.

This concludes my testimony. I would be happy to try to answer any questions at this time.

## ***Independence Plus: A Demonstration Program for Family or Individual Directed Community Services***

This initiative expedites the ability of states to offer families with a member who requires long-term supports and services, or individuals who require long-term supports and services, greater opportunities to take charge of their own health and direct their own services. Families and individuals will exercise greater choice, control and responsibility for their services within cost neutral standards. Two template versions will be available to enable states to tailor the program to their preferences; the §1115 Demonstration Template and the 1915(c) Waiver Template. These templates further the interests of the administration, states and beneficiaries. The program builds on the experience and research from a number of pioneer states that have pre-tested these concepts.

### **The Goals of the Templates**

1. The templates will assist states to develop programs that will permit individuals needing long-term supports and services to obtain assistance while living with their family or in their own home. This will be accomplished by:
  - Recognizing the essential role of the family or individual in the planning and purchasing of health care supports and services by providing family or individual control over an agreed resource amount.
  - Increasing family and individual satisfaction through the promotion of personal control and choice - a major theme expressed during the *New Freedom Initiative* - National Listening Session.
  - Encouraging cost effective decision-making in the purchase of supports and services.
  - Allowing eligible families and individuals to receive a cash allowance (in the §1115 Demonstration) or individual budget (in the 1915(c) Waiver) to obtain personal assistant services and related supports.
  - Promoting solutions to the problem of worker availability.
  - Providing fiscal/employer agent and supports brokerage services to support and sustain families or individuals as they direct their own services.
  - Delaying or avoiding institutional or other high cost out-of-home placement by strengthening supports to families or individuals.
2. The templates will provide states the tools, resources and guidance to create effective programs and continue the CMS commitment to create a "culture of responsiveness" by:
  - Assisting states with meeting their legal obligations under the Americans with Disabilities Act (ADA) and the Supreme Court *Olmstead* decision.
  - Providing flexibility for states seeking to increase the opportunities afforded families and individuals in deciding how best to enlist or sustain home and community services.
  - Incorporating the essential elements of self direction such as person-centered planning, individual budgets, participant protections and quality assurance and improvements.
  - Providing states with streamlined and standardized application formats to reduce the administrative burden for preparing proposal submissions and to reduce the Federal review period.

### **Features of the Templates**

- Electronic format for easier submission.
- Database platform to enable electronic tracking, sorting, querying and analyzing.
- Structured series of check boxes to facilitate completion.
- Pop-up instructions imbedded in the check boxes offering completion instructions.
- Technical Guide for developing the 1915(c) Waiver or the §1115 Demonstration applications.
- Additional features of the §1115 Demonstration include simplified/streamlined budget

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neutrality model and sample terms and conditions.

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## SB 2330

For the record my name is Chuck Stebbins, and I am with the Freedom Resource center for Independent Living in Fargo.

I am here in support of SB 2330. Money following the individual out into the community instead of into the institutions is a step forward, it is dignified, and it is budget neutral. It is forward step in improving the HCBS system and giving people a better choice along the continuum of care. Home and Community based Services are a more cost effective way to deliver Long Term Care. The AARP, The Graying of ND, and people in the DHS would agree with that.

You've have heard it enough by now I'm sure that the numbers, pie charts, bar graphs, percentiles, and projected numbers of people, is probably etched upon your brain never to be erased. I know I am tired of sorting through them to come up with a solid argument for the improvement of the HCBS system. Which I believe we have done.

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The numbers you have heard from the people in the DHS on people who use and are projected to use HCBS are as real as the numbers you have heard and seen from the Long Term Care lobby. In fact I believe the numbers are higher when you factor in all those using HCBS, Optional Medicaid services, respite, hospice, etc. The difference is location, where you can get the services. The biggest difference is choice. Passing this bill will give people that choice. Whether to stay in a nursing home, or whether to move out into their own place with the same amount of money that kept them there. Budget neutral. Of course I understand that it's not that simple. There are a lot of variables in this that will be looked at. But that is a good thing, because the whole darn system needs to be stream-lined anyway. I believe that the numbers speak for themselves, so you don't need to hear them again from me. Those of us advocating for this shift to HCBS have no financial interest, we have nothing to gain but independence for

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people who want a choice. That shift is fast approaching with the baby boomers. Feedback has told us that you have not heard enough from the HCBS constituency out there. I am a bit frustrated with that, because we have worked hard to date on getting that word out to you. We cannot control what people will do with the information that we give them. That is their choice. Unlike the nursing home constituency, our voice is rooted in independence. The people, who are using HCBS, are using HCBS to stay out of the nursing homes. They are living independently in the community and home of their choice. We are not in a position to show you a captive audience. It is easier for you to see the numbers in nursing homes and other institutions simply because of location, restricted location. You could go out right now and visit the nursing homes in the Bismarck Mandan area and see the number of people that would be affected by your decisions. It is much harder for you to go out and see the numbers that are living in their own homes. Getting people here today was difficult

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because of personal cares that has to be done. Taking a shower, take a crap, brush your teeth, and eat breakfast. This does not happen fast. It takes me two hours on the days that I need it, to get out of bed, do a duty, take a shower, back dressed and in my chair. Now, I need very little, but some need more. Having this hearing at this time on a Monday morning, eliminated some people you really need to hear from.

It is also in line with what is coming down from the feds.

Demonstration projects, as you have heard, will be available to the states. I would hope that you would want to be in line for a few more federal dollars. 1.75 billion Over five years will certainly to some extent helps any oncoming short fall for 2005. But only if you make the move now to have the money follows the individual. It's an investment. Just like everything that we are advocating for with HCBS. You have seen and heard the projections for nursing home costs, and you have seen and heard the projections for HCBS.....people will want a choice. We need to prepare for it.

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Don't prepare for it, you will be in this same position in 2005, and on to 2007. The one difference will be that you will see more and more people coming out and pushing you harder. It will always be a cheaper choice, laced with a whole lot of dignity backed by a larger voice. Every one in a nursing home right now, regardless of the age has some kind of disability. We've just had a hard time connecting over the years.....until now. The numbers are growing and there is no way to stop that. The state needs to change the way it provides Long Term Care. The future is all about choice. The future is all about providing that choice. The future is in your hands right here, right now. Please recommend a do pass for SB 2330. Thank you I would be happy to answer any questions you may have.

Chuck Stebbins  
Freedom Resource Center  
2701 9th Ave SW  
Fargo, ND 58103

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Deanna Stebbins  
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10/22/03  
Date

Dec 27, 2002

Dear Doc. Hansen  
I am writing in regard to  
the program for disabled persons.  
I have severe arthritis plus  
Post Polio Syndrome. I walk in the  
house with a walk, but spend most  
of the time in a wheel chair without  
the help of a homecare aide I  
would not be able to stay in my  
home.

We need more money to be furnished  
to this program. Services could be  
cut without more money as other  
prices go up.

Thank you very much for your  
consideration for Home Health in  
your next budget

Sincerely,  
Debra Kramer  
412 N 12th  
Fargo, ND  
58107

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Debra Kramer  
Operator's Signature

10/22/03  
Date

December 27 2002

Governor John Hoeven  
State Capitol  
Bismarck, ND 58505

Dear Governor Hoeven:

Home care services have been good for me. Otherwise, I would have to live in a nursing facility and I do not want to do that for the rest of my life. I did live in a nursing facility for nineteen years and moved to my own apartment around four years ago. I like my independence as much as possible. I can do things I want to do and still get help when I need it.

I want the state to continue to offer in-home services.

Sincerely,

*Harriet Blow*  
Harriet Blow

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*Deanna Hallmark*  
Operator's Signature

10/22/03  
Date

Date: December 20, 2002

From: Marsha Carstensen  
1251 - 54<sup>th</sup> Ave S Apt 107  
Fargo, ND 58104  
701-235-6332  
marshalcar@aol.com

To: Governor John Hoeven

Subject: North Dakota Legislative Assembly SPED Reduction in the pay to family members.

I feel that there needs to be a revision to the North Dakota Legislative Assembly decision to cut the payment to Quality Service Providers if they are live-in family members. I think that the total income for the family unit should be considered. In most households there is more than one member providing income, in ours there is not. I am single.

My mother and I were in an automobile accident two years ago. As a result of that accident my mother requires constant supervision. She is 80 years old and already had multiple health problems - a stroke that limits the use of her right side; open heart surgery, congestive heart failure, atrial fibrillation, polymyalgia, diverticulitis; she has a pacemaker, asthma, emphysema and hypothyroidism. All of these conditions require constant monitoring and prescription adjustments. The accident left her with a fractured left shoulder, which required surgical replacement, but because of her heart conditions, surgery was not feasible and she was left with very limited mobility on her left side. She also sustained impact fractures to both knees, making walking difficult. This requires 24-hour supervision, as her doctors fear that she would not be able to survive a broken hip.

I too was injured in the accident. I suffered a les franc fracture to my right foot and I am limited to two hours a day on my feet. I am 50 years old and have carpal tunnel syndrome in both wrists, sciatica of the right hip and fibromyalgia affecting my neck and both shoulders.

On the SPED program, I was able to take care of my mother in our apartment and make \$40.00 per day as an independent contractor for the state of North Dakota. Now, just because I am a family member, it has been reduced to \$22.00 per day before taxes. I still do the same amount of work 24 hours a day, 7 days a week giving my mother exceptional care. I am doing my best to keep my mother out of a nursing home, which would cost the state far more than the extra \$18.00 a day the state was paying me, and I am giving my mother quality one-on-one care that she would never receive in a nursing home.

I have tried to find a work-from-home job to make up for the loss of pay, but all of the employment agencies in Fargo, including Job Service told me that there are none available.

If this situation cannot be remedied, I fear that I will have to drop my own health insurance in order to pay for my mother's prescriptions.

Thank you for your time and consideration.

Yours truly,



Marsha Carstensen

Dear Governor Hoover

I am a personal care provider with Casa Co. Social Services

I am writing on behalf of my clients who are being affected by the cuts with home maker services.

My clients look forward to the times that I come to take them grocery shopping. They have a chance to get out of their homes & be with other people. They have a chance to feel "normal". They have a reason to smile. All because they were able to be out & about for a couple of hrs. Now that time is being cut & these people are again house bound. For some, the next step may mean being more dependent on friends & family to assist. For others who have no one to help, end up having to leave the security of their homes & move into a nursing home.

I feel by providers assisting clients by taking them shopping for a couple of hrs would be much cheaper than having the client move to a nursing home.

For me, it is not that much to ask for, but in my clients it is their life.

Check if these cuts could again be reviewed.

Thank you  
Caroline Branning

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Deanna Ballito  
Operator's Signature

10/22/03  
Date

December 27, 2002

Governor Hoeven  
State Capitol Building  
Bismarck, ND

Dear Governor Hoeven:

I am writing to let you know how my in-home services have helped me this past year. My children contacted Cass County Social Services, after I had been hospitalized in Feb. 2002. I was weak, have macular degeneration, and had some significant memory problems, which caused concern for my children with my living independently.

We were not sure if things would work out for me, to remain in my own home. I did not want to go into a nursing home. The services I received were very convenient, and allowed me to remain in my own home. I was not able to use the grocery bus to get my groceries, as I needed a constant escort when I walked, to help me at the checkout counter, to locate and carry my grocery items, and to assist me in putting them away. These services helped me get through a very difficult time. I was not able to walk to get to the meal site, which is about ¼ mile away. With services, I had help planning my meal, and purchasing the necessary groceries for me to make an easy meal for my self. My eyesight has worsened, and with the services, I have been allowed to remain independent.

I do have a daughter in town, but she is employed full time. My son lives in Minneapolis, and both were very pleased that I could get services, including lifeline in case I needed it. My family has been pleased with the services I have received. I have recovered some, and do not want to take any services that I do not deserve. I am writing this to let you know that these services have allowed me to remain in my own home, and I feel these services should be continued for others that are in similar situations, where a nursing facility would not be appropriate.

Sincerely,

*Myrtle Grace*

Myrtle Grace  
224 9 ½ Ave W  
West Fargo, ND 58078

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*Deanna O'Fallon*  
Operator's Signature

*10/22/03*  
Date

Dec 27, 02

Governor Hoeven  
State Capitol  
Bismarck, ND 58105

Dear Governor Hoeven:

I am 98 years old and live in Fargo in a retired Senior Citizens apartment. I have been receiving inhome services since I left a nursing home in 2000. I am very thankful for the services I receive and believe that I would be in a nursing home with out my services. I can not lift, bend or carry due to my arthritides. I have arthritides in my knees, shoulders and elbows & my back. My care provider has helped me with cleaning & grocery shopping, laundry and changes my bed. She hangs up my clothes for me as I can not reach. She has been able to take me out shopping for personal items which includes yarn. I continue to crochet as I need to keep my hands active so I don't lose the use of them. My provider comes on Tuesdays and Thursdays and usually stays 1-2 hours. I would like to see these services continue as I hope to not return to the nursing home.

Annus Kruessler  
1201 2nd ave N # 806  
Fargo ND 58102

December 27, 2002

Governor Hoeven  
State Capitol Bldg  
Bismarck, N. D

Dear Governor Hoeven:

I am in a wheel chair, and cannot get out of my home without help. My only outlet was when I had Non-medical transportation to assist me in getting out. The provider also assists with laundry, cleaning and shopping.

My daughter was helping me with doing these chores. She has Multiple Sclerosis, and she is no longer able to take me for my errands, or shopping.

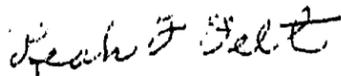
I enjoyed going shopping with my provider, as I liked to pick out my own things. Her choice would not always be my choice. I like looking at the different variety of fruits, vegetables, and meat products.

I not only need the transportation to the store, but also need the escort services, to reach items off the high or low shelves. She also helped me carry in my groceries and would put them away. When we were out, she would drive through my drive-in bank if I needed to do my banking matters.

I am 87 years old and try to make ends meet. This year my Social Security cost of living was increased by \$2.00. My Medicare went up \$3.70 and my secondary insurance, Blue Plus HMO, increased a monthly amount of \$10. By receiving help from Sped Services, I was able to get out and around, with out spending more of my income. I have been receiving a total amount of Sped services of \$276.50 a month, which has allowed me to maintain my independence. Before these recent cuts, I received about 4 hours a week services, whereas, I now will receive 2 hours a week services, with no chance of going along to the store. (\$30 of the \$276.50 is the monthly fee for my Lifeline service.)

Please consider Making Home and Community Based services for elderly and disabled of North Dakota a top priority.

Sincerely,



Leah Felt  
806 2<sup>nd</sup> St W  
West Fargo, ND 58078

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Operator's Signature

10/22/03  
Date

Dear Your Honor

In writing to express my feelings  
towards homecare Paul Simon  
and why I feel that the full  
service should be continued I have  
been and I'm not able to do  
or get out by myself and if it  
wouldn't be for all the help I  
get I would I wouldn't be able  
to live independently and I'm  
long my housework takes me for  
hours, I am able to be out  
among other people. Please  
remember by all my love  
and people the apartment is out  
of about

Thank you  
Gauda Warden

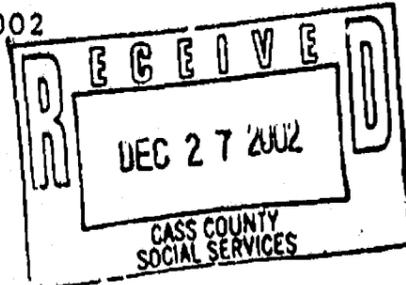
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Deanna Warden  
Operator's Signature

10/22/03  
Date

1645 9th Avenue South  
Fargo, ND 581103-2517  
Phone: (701) 235-0944

December 25, 2002



Delana Duffy-Aziz  
CASS COUNTY SOCIAL SERVICES  
1010 2nd Avenue South  
P.O. Box 3106  
Fargo, ND 58108-3106

Ms. Duffy-Aziz:

I am writing in regards to the Home & Community Based Services for the Elderly and Disabled.

I am a caregiver and provider for my 82 year old Mother, Helen Hill. She was a victim of a stroke which caused the loss of eyesight in one eye. She has severe arthritis with cartilage damage in her ankle making it difficult for her to walk. Last summer she had surgery to remove a cancerous growth in her intestines. During her hospitalization for this procedure, she fell resulting in a broken hip. It was necessary for her to be in a nursing home for 6 weeks for the required therapy.

The nursing home was a nightmare for us. First of all, I feel it is necessary to state that Mother is a very patient tolerant person. She has never been demanding of others. She found the food to be unacceptable...even the coffee was very poor. She had to remind the nursing staff when it was time for her medications and at time had to wait for an hour and a half for them to bring her pain medication. When she asked for additional blankets because her arthritis was acting up it would take them an hour to bring it for her. She found the shower experience dreadful, as she felt like she was being put thru a car wash. I was most upset with this experience and couldn't believe they have the nerve to charge over \$3,000.00 a month for shoddy services. We were both grateful when I was able to bring her home. I quit my job as it was evident she could not care for herself and undergo the necessary chemotherapy ordered by her doctor.

I have been providing housekeeping, laundry services for her. Also take care of transporting her for medical appointments, shop for groceries, medication and personal needs. I assist her with bathing, shampooing and dressing plus providing her with assistance when she ill in the middle of the night. She is content here at my home and feels secure and cared for. She never has to wait for her medication or any other service she may need. We have both been grateful for Home & Community Based Service Program.

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*Delana Duffy-Aziz*  
Operator's Signature

10/22/03

Date

My mother is aware that she would have to be in a nursing home if I were unable to care for her. We prefer that she remain at home with me. Our earlier experience with the nursing home will stay with us both forever.

I am amazed that nursing homes are fighting the Home Based Services. Most of the time it is difficult to find an opening when one is needed. The care provided by these institutions is extremely poor and unacceptable. In my opinion from what I have seen, these institutions are a death sentence for the elderly.

The State of North Dakota has a reputation for being behind the times and unfortunately we're looking at another issue that takes advantage of the disabled and elderly. Doesn't it make sense to pay a family member or caregiver then spend \$3,000.00 a month for a nursing home or pay workers \$10.00 an hour to provide the needed services?

I would like to see the fee increase as last fall's cut in pay was devastating. The cut to \$9.50 a day was a real blow and has taken a toll on my savings. You need to realize caregiver's have personal expenses as well. I need to pay for health insurance, auto insurance, groceries etc.

I would like to have our lawmakers spend a month in a nursing home to see for themselves what quality of life is provided for their residents.

They may also wish to consider what cost it would be if people under this program are moved into nursing homes or have to have the countys provide care as required for any quality of life. They would have a budget extremely in the red.

I will be happy to discuss this program with anyone having questions. I will also call the legislators involved with this issue if you can provide me with the necessary information.

Sincerely,

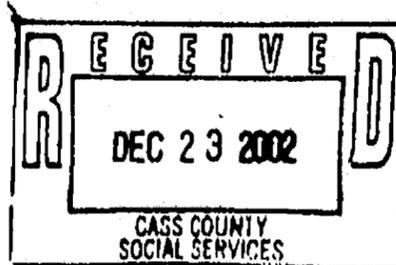
*Alice Hill*

Alice Hill

CC: Cheryl Ritter

1038 1<sup>st</sup> Street North  
Fargo, ND 58102

December 20, 2002



Dear Governor Hoeven:

*I am writing in regards to the cuts that have been going on in the service programs for the disabled. My story goes back a few years, which will help you to understand what it is like to be living on Social Services, Disability or SSI programs. My husband Charles died this year, March 3, 2002. Prior to his death we were living in New Horizon's Manor a building which was built to accommodate the disabled population. About two years ago, maybe three, talk went through the building about changing it to an Assistive Living Facility. As time progressed it did indeed become an Assistive Living facility. We had an aide living with us at that time to care for my husband who had Muscular Dystrophy. Matt, the aide was going to be graduating soon so would no longer be Charles' aide. Since the building was under contract for Assistive living once Matt left we would not be able to have our own choice of who was to take care of Charles. CCRI (the ones with the contract) had informed me that my husband was too disabled to qualify for the Assistive living program so he would have to go into a nursing home. So we had to move. We found a place that would work for two wheelchairs (no small task let me assure you) but then because of cuts back then we weren't able to find someone who would work as a live-in attendant for the \$1200 per month. We had alcoholics apply and believe it or not street people were applying also. We were terrified. I was able to help my husband somewhat (I had polio and confined to a wheelchair) but the lifting was very hard on my back. I kept trying to find someone but no one would work for such low wages we were told.*

*To make a long story short, he went into a nursing home. It tore us apart. Then about a year and a half later he is gone. Why couldn't he*

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*Deanna Wallin*  
Operator's Signature

10/22/03

Date

**stay at home where we could have had that year and a half together?  
Because of the cuts!**

**Now today, I am in need of services. I couldn't find anyone who would work for me that I could trust. I am legally blind, hard of hearing and in a wheelchair. My mother started helping me because I couldn't find anyone who would do the work they were being paid to do. She started living with me because of my limited hearing. Someone tried to break into my apartment patio door one night and I couldn't hear what was going on. The state was paying her almost \$1,000.00 per month. They have cut her to \$400 per month now. This is so frightening to me. I know the state doesn't owe me a living. But I would gladly work if I were able to find something where they will accept a hard of hearing, almost blind person in a wheelchair. I even worked with Vocational Rehabilitation to try and go to work. BOTH Vocational Rehabilitation and Social Security warned me AGAINST working because of my medical needs. What am I to do? I am not able to make it on the \$565 a month I am expected to live on, Your cutting the programs so that it is almost impossible to get SAFE help, you have raised our Cost Of Living increase to a small \$3.00 a month, and to top that off, cut our dentist visits to once a year and now we have to pay \$3.00 per bottle for most of our medications. The Three dollars you gave us as a Cost of Living Increase will only pay for one bottle of medication. What next?**

**I am an American Citizen is that my draw back? I don't know what to do. I am searching for an accessible apartment for myself as you read this letter. It is too difficult for me in my mother's home. The housing authority tells me I have to find a place to live that is under \$505. Per month to qualify for help. The apartments in Fargo that have any type of accessible apartments in them are 690 and up. Do you believe that! Not to mention I would have to pay out of my pocket for further accessible needs such as removal of pads under the carpets, remove cabinet from under bathroom sinks, and if there is no dishwasher - remove cabinet from under kitchen sink, lower closet rods, raised**

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**Deanna Waller**  
Operator's Signature

10/22/03

Date

toilet, etc. My last apartment cost me \$900 out of pocket just for making it so I could use it. Then the Rent, Deposit, light deposit, telephone deposits, etc. on top of that. There are friends, I know, had to take bad apartments because of the low Maximum for housing (505) for a single person.

Governor Hoeven I appreciate being able to write this letter to you to air my feelings about the program cuts and low income that our people are forced to live with. By our people, I mean those of us who want to be off government assistance but are unable to do so at this point in our lives) are forced to live on. I would give anything if I could be a taxpayer but there isn't anything I can do about it. I am going to be going to talk to Freedom Resource Center for Independent Living to discuss the "Ticket to Work" program that Social Security is trying out now, but if I can't get help with aides and medical benefits it seems so hopeless to me. If you would develop a Medical plan for those of us who have medical needs but still would like to take work we would have a fighting chance for independence. For example If we could work and earn enough money to cover what we would need for our monthly expenses, then some wouldn't need the SSI checks coming in (or at lease part of it anyway) I honestly feel that we would be of benefit to our country instead of feeling that we are a burden instead.

Please stop cutting our programs, stop cutting the Social Security programs that benefit the elderly and the handicap. Why do you hurt those who can not defend themselves?

Sincerely,

*Shirley Ann Robideau*

Shirley Ann Robideau

Oct. 28, 2002

My name is Gaylon Hawkins. I have been a North Dakota resident since 1961. I have resided at 2510 Evergreen Road in Fargo since 1977. In response to a request from AARP, I have provided the following personal story in regard to Home and Community Based services that I and my family receive.

I received debilitating injuries from an accident in 1989. I have been under Social Security Disability since that time. North Dakota Workers Compensation was the lead responsible insurer at the time of the accident. I also, had private insurance through Hartford. By 1994, only Social Security was still in effect, even though I am still disabled.

In July of 1994, our adult son, Chad, had a motorcycle accident with resulted in a traumatic brain injury. By September of 1994, he had been placed in a nursing home. His insurance ran out and his care then paid by Social Security and Medicaid. He was not receiving any additional therapy. By July of 1995, Chad had recovered enough to be aware of his surroundings. He was 26 years old and was very depressed. My wife, Barbara, and I removed him from the nursing home and provided 24x7 care in our home. This care continues today. At the time of the accident, we lived in a debt free home. The decision to provide this care was a burden, however, the results have been dramatic. Chad, has learned to talk, assist in caring for himself and gets around with a wheelchair and walker. He continues to improve to this day. According to published reports, Chad's care at the nursing home was approximately \$267 per day. North Dakota Human Services pays Barbara and I \$60 per day to provide the same basic services. The love and affection is priceless.

We also take care of his two children, Mary and Sam, who were place with us permanently by the court in 1998. During the past four years we have also had our other four grandchildren living with us during some difficult times for their mother, our daughter. The alternative would have been to let our grandchildren slip into the Foster care program. Under Foster Care, the cost per child is over \$1,000 per month per child according to published reports regarding North Dakota Foster Care Programs. The most that Mary and Sam have ever qualified for under our guardianship is \$107 per child per

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Gaylon Hawkins  
Operator's Signature

10/28/02  
Date

month. Currently, they qualify for zero TANF benefits because Chad has \$491 income per month from Social Security Disability and Mary and Sam receive \$10 each from Social Security. This amounts to \$511 income per month, which is over the limit. Savings to the taxpayers, over \$2,000 per month in not having to pay foster care for Sam and Mary. Cost of love and self-esteem for Chad, Sam and Mary--- priceless.

This family situation has caused considerable mental, physical and financial hardship for Barbara and I. We realize that letting our children and grandchildren go to foster care or nursing home care would have be the best thing for our financial stability, however, we could not do it.

In 1994, Barbara and I lived in a debt free home. We now have a \$100,000 mortgage. Under current legislation, It is obvious that the State and Federal government feel that they do a better job of caring the disabled and displaced. The care Chad can receive in a nursing home is worth \$200 per day more that what his parents can provide. The worth of Foster Care is \$2,000 per month better than the care provided by the Grandparents.

I am not saying that there is not need for the government to be involved in safeguarding the disabled or displaced individuals. However, when family is willing to take the responsibility, they should not be penalized by an attitude of "out of sight, out mind". Even the IRS has ruled that the ND Human Services payment that Barbara and I receive for the care of Chad is non-taxable medical income. Their decision was based on the fact that the dollar amount does not cover the bare minimum requirements of the care given.

The suggestions I have to the law makers are as follows:

1. Since North Dakota has a state controlled Workers Compensation Bureau, it would make sense to simply pass a law that any insurance company sell disability insurance in the state not be allowed to use any Workers Compensation regulations to defer coverage to the insured, period. The worker pays a premium for this additional coverage and should be entitled to all benefits. If the insurance company does not agree, then don't sell the policy.
2. Families that choose to provide care for the elderly and/or disabled family member should be compensated fairly for saving the taxpayers a

significant amount of money in caring for that person. If Barbara and I had received half of what it cost to have Chad in a nursing home, we would not have had to put a \$100,000 mortgage on our home over the past 7 years.

3. Grandparents who accept the responsibility of raising their grandchildren have made a decision to disregard their retirement plans in the best interest of these children. Providing financial assistance to these grandparents would be the best investment that could possibly be made and significantly less than the current Foster Care payments for the same children.

Thank you for listening to my story. Hopefully it has some impact.

Gaylon Hawkins.

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Deanna Hall  
Operator's Signature

10/22/03  
Date



December 20, 2002

## Social Services

Kathy Hogan  
Executive Director

Adult Services  
701-241-5747

Family & Children Services  
701-241-5765

Fax 701-241-5775

P.O. Box 3106  
Fargo, ND 58108

◆ ◆ ◆

Administration  
701-241-5761

Economic Assistance  
701-241-5761

Fax 701-239-6820

P.O. Box 2986  
Fargo, ND 58108

TDD 701-239-6784

Cass County Government Annex  
1010 - 2nd Avenue South  
Fargo, North Dakota 58103

Governor John Hoeven  
State Capitol  
Bismarck, ND 58505

Dear Governor Hoeven:

I am writing to talk to you about the Home and Community Based Service Program in the State of North Dakota. These services are provided for the purpose of assisting frail elderly or persons with disabilities to remain in their own homes in lieu of institutional care. In Cass County alone we are serving 526 elderly and disabled individuals. Their needs range from those who require minimal help to those requiring 24-hour care.

I would like to briefly tell you about a couple of the people we are serving at home. One is a woman who has a congenital deformity. She lived in a nursing home for many years. A few years ago she moved into a handicapped accessible apartment and with the aid of adaptive equipment and assisted living services through the Medicaid Waiver, she is living independently and is very happy to have her own home. We have 5 clients who are ventilator dependent. They are cared for at home by family members. Their disabling conditions range from ALS and Muscular Dystrophy to quadriplegia. Their family care providers are extraordinary individuals who make a lot of personal sacrifices in order to care for their loved ones at home. They are all grateful there are programs that allow them to do this. I believe that most people prefer to remain in their own comfortable and familiar surroundings for as long as possible.

Currently the SPED Program, which funds the services for the majority of our clients, is frozen. Many of our referrals come from the hospital discharge planners. This means that many elderly individuals will be discharged home in a weakened state without services, other than Medicare. Typically Medicare only pays for a short time and then the state funded services pick up the client. Logically these individuals will either be at risk or will be forced to accept nursing facility care at a greater cost to us all. Service providers and recipients are grateful for your proposed increase in funding for our programs over the next biennium, however, I am aware that the Long Term Care Industry is lobbying for more funding. I am hoping that increased funding for them will not mean decreased funding for in-home services. Nursing facilities have a legitimate place in the continuum of care, but so do Home and Community Based Services. Historically the nursing home industry has received the

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Deanna Hall  
Operator's Signature

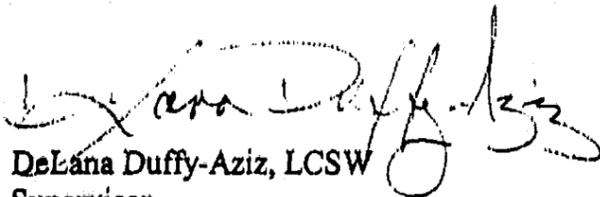
10/22/03  
Date

HOEVEN, John  
Letter - Page 2  
12/20/02  
D. Duffy-Aziz, LCSW

majority of the long-term care funding dollars. The health of the nursing home industry has been tied to the economic development of rural North Dakota. However, continuing down this path will be costly and excuses the nursing home industry from having to change, diversify, and be creative about how they deliver services.

I would be honored if you would consider visiting our County. We would be glad to show you first hand what we do and introduce you to some of the people we serve.

Sincerely,

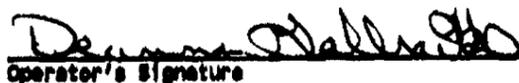


DeLana Duffy-Aziz, LCSW  
Supervisor  
Adult Service Unit

DDA/tme

pc: Carol Olson, ND Dept of Human Services, 600 East Blvd, Dept  
#325, Judicial Wing/State Capitol, Bismarck, ND 58505-0250

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12/22/03  
Date

December 27, 2002

To whom it may concern,

I have my father living with my daughter and I. He has COPD, lung disease. He is on continuous oxygen. We have an oxygen condenser machine at home. The oxygen humidifier has to be cleaned every other day and filled with distilled water. Tubing needs to be changed every month or when needed. He has nebulizer treatments he uses four times a day. The nebulizer has to be cleaned every other day with vinegar. The tubing is changed once a month or as needed also.

I monitor his oxygen level every morning before I got to work and at night. I have to call for his medication and go pick it up at the pharmacy. I also set up his medication for him to take. I help him with all his daily activities such as; laundry, cleaning his room and bedding, shower and washing his hair, meal preparation, shopping, banking, taking him for his haircut, and doctor appointments which I have to take time off from work.

I am very fortunate to be able to have my father live with us. It is good for his self-esteem and mentality, being around the family. Living here along with his granddaughter keeps him lively and in good spirits.

Having family in a nursing home, you feel obligated to visit and can never stay long. It's better to keep family with you as long as you can. When you are able to see them everyday, they feel more comfortable and not lonely.

With these cut backs, they took away his lifeline, which was a security for him and myself when I am at work he could get help if there were any problems. Without the lifeline, I now have to check on him throughout the day to make sure he is doing ok. Along with losing his lifeline, he doesn't get any help in paying for medications and incontinent pads, which are costly.

I don't see why you are trying to put more people in nursing homes, because that would be costing us more money and there is such a long waiting list that we could never get into one anyway. This solution would be costing \$3,000-\$4,000 for the state compared to \$1,000 we used to get. We now only receive \$500 a month, which doesn't even begin to cover all the expenses.

I would appreciate it if you reconsider your decision of cutting the budget for home care. Thank you for your time.

Sincerely,



Sheryl Brekke  
3230 2<sup>nd</sup> St. N  
Fargo, ND 58102

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Operator's Signature

10/22/03  
Date

Paula Strom-Sell

1122 28th Street North  
Fargo, ND 58102-3199

Telex (701) 236-3299  
Contact: (218) 281-1429

Dec. 27, 02

Governor Hoven  
600 Boulevard E.  
State Capital  
Bismarck, ND

RE: Objection to Budget Cuts in Home Health Care

Dear Governor:

It is my understanding that you and the legislature plan on cutting the Home Health Care budget from last year which will drastically reduce the programs they administer. Your plan has already provided for a nice increase in their budget. Yet, you plan on cutting services from Home Health Care and taking the funds from there to add to the nursing home budget. I strongly object to this budget adjustment.

Our parents are elderly and disabled and totally rely on the services from Home Health Care. Without those services, we would have to put them in a nursing home. They would totally lose their independence. That is an insult to them who have spent their working life here in North Dakota and paying taxes to support programs for those young people who are now administering the nursing homes that will take funds from the programs that helps them sustain their independence. This is neither right nor is it fair.

I hope you and the legislature reconsider this budget change and think of those who have paid taxes all of their lives in order to be taken care of when they retire.

Sincerely,

*Donald & Paula Sell*

Donald and Paula Sell

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*Deanna Waller*  
Operator's Signature

*10/22/03*  
Date

December 27, 2002

Governor John Hoeven  
Governor's Office, Dept. 101  
600 East Blvd Ave  
Bismarck, ND 58505

Dear Governor Hoeven:

I want to thank you for affording me the time to visit with you at election time, when you were campaigning for your fellow Republicans. I was pleasantly surprised that you were so well informed on Home and Community Based Services. (We visited at my home in South Fargo. I am employed by Cass County Social Services in the area of Home and Community Based Services.)

The past couple of months have had many of my elderly and disabled clients concerned regarding the cuts that have occurred with Sped and Expanded Sped Services. The major cuts were in homemaker services, with services going from a maximum of \$185/month to \$135 a month allowed; total loss of Non-medical Transportation and escort services; and Lifeline services have been discontinued for individuals who reside with another individual.

The homemaker cut, has affected the majority of our clients, as most people eligible for HCBS need additional services to remain in their homes. The additional homemaker services generally were needed for the following purposes:

- More laundry services due to incontinence issues;
- Additional housekeeping due to more spills and mishaps by individuals that are blind, or are unsteady; and the physically disabled;
- Assistance with grocery shopping, especially for individuals who wish to go along to the stores, to preserve their independence. These are individuals that need reminders, i.e., individuals with early stage dementia, Traumatic Brain injured, and individuals with sight problems, caused frequently in later years, by Macular Degeneration or Diabetes. Diabetics also tend to need more fresh fruit and vegetables and are losing the chance to go to market on a weekly basis.

With the cut of monthly homemaker services going from \$185 a month to \$135 a month, the extra \$50 a month did provide a client extra homemaking services in the amount of about 4 ¼ hour a month of service, or one extra hour a week. \$185 a month for homemaker services was providing an individual up to an average of 17 hours a month, now at \$135, it only provides about 12 hours a month.

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12/27/02  
Date

Page 2.

Fargo is a large community, and has a good transportation system that assists most individuals in getting around. The HCBS clientele we provide services for, are not able to utilize the public transportation system for multiple reasons. I have noticed that the following groups of individuals seem to be affected by these cuts:

- Individuals with sight problems who want to remain independent, and who are in need of an escort. (These commonly are not the people who were born with sight problems, and have had training in utilizing services, but affect a large majority of diabetics and elderly with macular degeneration.)
- Individuals with closed head injuries, whom are not eligible for the more organized programs. They only require a minimum amount of direction, and can remain independent with a minimum of 1-2 hours of services a week. These services consist of an escort to assist in completing monthly banking, bill paying, grocery shopping, and other necessary services that allows these individuals independence in living in our community.
- The mentally and physically frail individuals are affected by the loss of a person who was an escort and would "remind" them of what is needed, assist them in picking out groceries, assist with some monthly banking practices, and was providing transportation and/or escort services for non medical purposes. These individuals with a little additional help have been able to remain in their own home, instead of being placed in a nursing facility.

Non-Medical Transportation services paid the provider \$7.50 for a weekly round trip and \$1.85 per 15 minutes of time to complete these services. Having a person escort and transport the above individuals maintained a person's dignity while affording them their desire of being independent.

The Lifeline cuts have affected a great many of the individuals who live with and are cared for by family members who maintain an outside job. Again, these individuals are both either physically or mentally frail, and reside with family, as they cannot safely live independently. They do not need 24-hour supervision, and are left alone during the 8-10 hour shift that the family member works. Lifeline services provided an easy, safe way to contact a family member if there was a fall or another concern. The Lifeline services are reasonably priced, and some family members have chosen to have peace of mind by continuing to purchase it for their loved one. Other families have had the Lifeline disconnected, which causes concern and borders on being a protective service issue.

As the elderly population in North Dakota continues to grow, both in size and age, this issue affects a population that normally was said to "care for their own". The majority of the individuals that are on services, have no close relatives to care for them, due to losses, including death or movement out of town, or because of alienation. These individuals do not ask for much from the government, and do not want to reside in a nursing home. They want to remain in their own homes.

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10/22/03  
Date

Page 3.

Many of the individuals on Sped Services and Expanded Sped services need more services than what County funded services are capable of providing. These individuals also need less services than what would be considered for nursing home level of care. Some of our clients have moved into a nursing home, and only in a matter of time, they have been required to leave the nursing home, as they no longer screen for the intensive nursing home services. Many have given up their homes, and have no place to return to.

The population of individuals on Sped and Expanded Sped services are in situations where they need the additional care to remain at home, but do not need the extensive services provided by a nursing facility. Under Sped and Expanded Sped services up to a maximum of \$1200 a month can be used to provide an individual in-home care. HCBS services have provided a continuum of care that allows the person to remain as independent as possible in their own home. This care can be one weekly visit or can be provided up to 3 times a day. This care can assist a person with morning cares, noon cares, and evening cares. With the \$1200 rate, a person can receive 7 day a week services, for 2 shifts of 3 hours a shift, or 3 shifts a day with 2 hours a shift. These cares make it possible for a person to remain safe and independent in his or her own home. The individual that remains in their own home, continues to have the social interaction from their neighbors, and continues to maintain their dignity and peace of mind in their home.

These services will affect the majority of North Dakotans in coming years. On a personal note, before my father's death in September 2001, he chose to remain at home, in rural Western North Dakota to die. He was not financially eligible for HCBS services, but was like most North Dakotans in choosing to remain at home. After his death, our family has continued to have similar private in-home services for my mother. Privately, we pay for Lifeline services, Non-medical Transportation services, and Homemaker services. With the services my mother receives, it provides our family, the knowledge and peace that her needs are being cared for, and allows us family members to continue with our own lives in Eastern North Dakota. For individuals that want to remain in their own homes, and financially need assistance in arranging and providing these services, Sped and Expanded Sped are set up to provide in-home services for the lower income individuals of our State.

Home and Community Based services are very necessary and important services for the residents of North Dakota. Governor Hoeven, please consider a continuation of funding for these important in-home HCBS services

Sincerely,

*Gwen Berg-Nistler*

Gwen Berg-Nistler

1726 Park Blvd,

Fargo, ND 58103

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10/22/03

Date



# There's no place like home

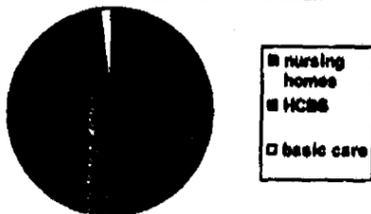
86% of seniors in North Dakota **want to remain in their own homes** as they age and their abilities change. Younger people with disabilities also want to live in community homes, not nursing homes. The number of individuals being served in nursing homes in North Dakota is decreasing while the number of individuals who use home and community based services (HCBS\*) has increased steadily every year from 2,097 in 1995 to 3,079 in 2001.

**The problem:** Funding for the long term care continuum of services is way out of balance with the vast majority of dollars going to nursing homes. North Dakota spends 13% more of its Medical Assistance money for nursing home services than the national average. If North Dakota met the national average, it could save \$43 million in Medicaid expenditures. There are people on waiting lists for HCBS. While waiting, some individuals have gone into nursing homes or into basic care and some have died.

**A solution:** The Governor's proposed budget provides an increase for HCBS (as well as nursing homes). This will help. It makes even more sense, however, to change the system and not put a cap on HCBS. **SB 2330 gives individuals a choice** - Medical Assistance funds would follow the person to whichever service option he or she selects.

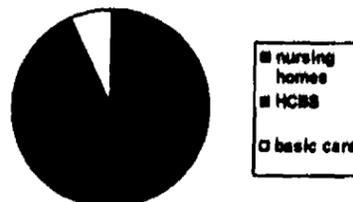
## Proposed 03-05 Budget

### Where the \$ Goes



Nursing homes = \$306.6 million (88%)  
HCBS = \$34.8 million (10%)  
Basic care = \$6.9 million (2%)

### # of Individuals Served



Nursing homes = 3,664 (56%)  
HCBS = 2,428 (37%)  
Basic care = 497 (7%)

**HCBS are cost effective** and are projected to meet the needs for 37% of the individuals with only 10% of the money. For the fiscal year 2002, the average cost per person for nursing home placement was \$23,500; for people under the Medicaid waiver receiving HCBS\*\* it was \$6,100.

\*HCBS = SPED, E-SPED, TBI Waiver, Aged & Disabled Waiver  
\*\*these are people who would qualify for admission to a nursing home

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*Deanna Walbridge*  
Operator's Signature

10/22/03  
Date

Senate Human Services Committee  
February 3, 2003

Madam Chairman Lee and members Of the Human Services Committee,

My name is Tim Mathern. I am the Senator from District 11 in Fargo.

I introduced this bill at the request of the Freedom Resource Center. Senate Bill 2330 is a simple bill that creates choices for individuals eligible for the aged and disabled medical assistance waiver. However, though the bill is simple, the issue is not simple and I ask you to give attention to persons that will testify and that you work with service recipients, providers and with the ND Department of Human Services to come up with a workable solution.

The goal is to create more options of care that represent the wishes of persons who use the services.

Thank you for your consideration and attention.

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Deanna Wallin  
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10/22/03  
Date

TESTIMONY BEFORE THE SENATE APPROPRIATIONS COMMITTEE  
SENATE BILL 2330  
FEBRUARY 3, 2003

Mr. Chairman and members of the Senate Appropriations Committee, I am here this morning to give testimony in support of Senate Bill 2330.

My husband and I reside in Mandan in a house we are in the process of buying. We are very much a part of our community and live a very independent life. This is all possible because of Home and Community Based Services which we are able to receive. We haven't always been so lucky.

I lived at Missouri Slope Lutheran Home in Bismarck for 12 years. My independence was very limited and there were not that many choices for young people for things to do to pass the time. You pretty much had to go by their daily schedule. Personal freedom is quite limited in a nursing home. If I would have had more options like the ones this bill offers I probably would not have been there for 12 years. It is such a good feeling to be in charge of your own life.

I am in support of Senate Bill 2330 and would be happy to answer questions

Thank you for allowing me the time to testify before the Senate

Appropriations Committee today.

Carol Herauf  
663-6287

House Human Services Committee  
March 4, 2003

Madam Chairman Price and members of the Human Services Committee,

My name is Tim Mathern. I am the Senator from District 11 in Fargo. Thank you for hearing this bill supporting persons dealing with medical needs and disabilities. Often the choices can range from being in a nursing home to having appropriate services provided at home.

Senate Bill 2330 is a simple bill that creates choices for individuals eligible for the aged and disabled medical assistance waiver. The Department of Human Services is directed to apply for the appropriate waivers and grants. Essentially individuals and families would receive cash assistance to get the services they need.

However, though the bill is simple, the issue is not simple and I ask you to give attention to persons that will testify and that you work with service recipients, providers and with the ND Department of Human Services to move forward with this concept. You will hear that not only are individuals asking for this option, there is no negative fiscal impact to the state's budget with passage of this bill. This relates in part to this being part of federal initiatives and President Bush's concern of granting more freedom to persons needing this type of service.

The goal is to create more options of care that represent the wishes of persons who use the services and to stay cost effective at the same time.

Thank you for your consideration and attention. I ask for your do pass recommendation on SB 2330.

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Deanna Walther  
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10/22/03  
Date

**Testimony**  
**North Dakota Disabilities Advocacy Consortium**

**SB 2330**  
**Money follows the Individual**

**House Human Services Committee**  
**March 4, 2003**

Chairperson Price, members of the House Human Services Committee, I am Susan R. Helgeland, Chair of the North Dakota Disabilities Advocacy Consortium (NDDAC). The Consortium is made up of 25 organizations concerned with addressing the issues that affect people with disabilities. We are very interested in improving the ability of people with disabilities to fully participate in all aspects of life in North Dakota.

The Consortium fully supports SB 2330 which provides for personal choice. The Governor in his budget and the legislature are showing more understanding of the benefits of home and community based services. The benefits include the obvious cost saving, but more important are the intangibles. The person with a disability receiving services is recognized as an individual who has the right to choose the path that fits his or her capabilities and desires. The provisions included in SB 2330 support and further the rights of the individual. What could be a more basic American right than the right to determine one's own individual path in life. Also once the services and benefits are identified and chosen, these services and benefits would follow the individual.

I have provided the committee with a news release dated January 23, 2003 entitled, **President will propose \$1.75 billion program to help transition Americans with disabilities from institutions to community living.**

President Bush in his budget this month will be proposing a "Money Follows the Individual" Rebalancing Demonstration program of \$350 million for FY 2004. North Dakota should position itself to implement SB 2330, given the President's initiative and the possibility of federal support. The President's proposal builds on the existing state success stories in Texas, Wisconsin, Michigan and Washington. This initiative and the others outlined in this announcement clearly demonstrate the nation's interest in promoting the use of home and community based services. North Dakota is clearly on the right path. Passing SB 2330 could add our state the list of success stories.

I appreciate this opportunity to testify on behalf of the North Dakota Disabilities Advocacy Consortium. I will try to answer any questions that you have. Thank you.

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*Susan R. Helgeland*  
Operator's Signature

10/22/03  
Date

**TESTIMONY**  
**HOUSE HUMAN SERVICES**  
**SENATE BILL 2330**  
**CLARA SUE PRICE, CHAIRMAN**  
**FEBRUARY 3, 2003**

Chairman Price and members of the House Human Services Committee, my name is Linda Wright, Director of the Aging Services Division, Department of Human Services.

I appear before you today to testify in support of this bill. Senate Bill 2330 would support the Department of Human Services in applying for a Demonstration Medicaid Waiver, amending a current Medicaid Waiver or applying for a demonstration grant. This is part of President Bush's New Freedom Initiative.

The attachment, which was generated by the Centers for Medicare and Medicaid Services, describes the purpose of this initiative. The Department of Human Services already has 1915(c) Waivers for Aged and Disabled, Traumatic Brain Injury, and Developmental Disabilities. The approval of this bill would allow the Department to apply for a Demonstration Waiver or grant which would seek to increase the opportunities afforded families and individuals in deciding how best to enlist or sustain in home and community based services. In other words, this would provide greater control to the individual client or family and allow the money to follow the client.

The Medicaid Waiver must be cost neutral, therefore, there is no fiscal note for Senate Bill 2330.

One of the initiatives of Independence Plus is "allowing eligible families and individuals to receive a cash allowance (in the 1115 demonstration) or individual budget (in the 1915(c) Waiver) to obtain personal assistant services and related supports. This initiative and the language in SB2330, is in direct

*She forgot to attach the document.*

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*Linda Wright*  
Operator's Signature

10/22/03  
Date

conflict with Section 2 of Senate Bill 2194, which would move personal care out of the Medicaid Waivers and into the Medicaid State Plan.

The Department of Human Services encourages a do pass vote on this bill. It is a "win-win" for the client, the family and the state of North Dakota by providing another option for individuals who need assistance, but wish to remain at home.

This concludes my testimony. I would be happy to try to answer any questions at this time.

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*Deanna Walcott*  
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10/22/03  
Date

**House Human Services**  
**March 4, 2003**  
**SB 2330**  
**Testimony of the Protection & Advocacy Project**

Chairman Price and members of the Committee, my name is Teresa Larsen. I am the Executive Director of the N.D. Protection & Advocacy Project (P&A), an independent State agency that provides advocacy and protective services for individuals with disabilities.

In 1999 the U.S. Supreme Court announced the *Olmstead* decision, a landmark ruling for people with disabilities, which said that it is unlawful discrimination to unnecessarily place them in institutions like nursing homes. The U.S. Department of Health and Human Services issued guidance to the states urging that they develop a plan for full compliance with *Olmstead*. Attachment A provides you with some additional information on this ruling.

SB 2330 is a step towards meeting the intent of *Olmstead*. It will help by not only better balancing the existing financial bias towards nursing facilities, but combined with SB 2085, targeted case management, it will also help address the social bias. It will allow people in need to choose options, usually less expensive, that will enable them to stay in their homes.

I want to give you an example of an individual P&A has been working with that I will call "Steve". He is a 27 year-old that sustained a spinal cord injury approximately two years ago. As a result of the injury, he no longer has physical use of his arms and legs. Steve was recently hospitalized for some minor medical issues and, when ready to be discharged, expected to return to his apartment. In working to re-connect Steve to the services he had prior to being hospitalized, the home health care agency declared that they would no longer provide services to him because "he is a quad", is too difficult, and needed nursing home care. Steve was adamant about returning to his apartment and, with advocacy help, this became a reality for him. Cost effective home services were arranged to ensure that Steve had adequate support to assist with daily living tasks. While this is a success story for Steve,

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Dennis Wallin  
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how many other individuals actually end up in a more expensive nursing facility placement, contrary to need or choice, because this is presented as their only option?

Assessments and planning should start with the premise that the person can live in the community. All too often we hear that hospitalized individuals are presented with the question, "which nursing home would you like to apply for admission to?" instead of "lets talk about what services and supports you might need to return home".

There are currently people on waiting lists for home and community-based services. These individuals are at risk of institutionalization, also a population covered by the *Olmstead* decision. Purchasing home-based services for these individuals will be less costly and can delay, or eliminate all together, the need for more expensive nursing home care.

Please give SB 2330 your support. Thank you for your time and consideration. I will be glad to answer any questions you might have.

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