

MICROFILM DIVIDER

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



ROLL NUMBER

DESCRIPTION

2174

2001 SENATE HUMAN SERVICES

SB 2174

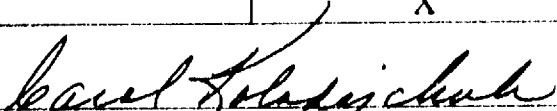
2001 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2174

Senate Human Services Committee

☐ Conference Committee

Hearing Date January 17, 2001

Tape Number		Side A	Side B	Meter #
	1	X		45
January 24, 2001	1	X		44.3
January 24, 2001	1		X	
Committee Clerk Signature				

Minutes:

The hearing was opened on SB 2174

SENATOR TIM MATHERN introduced the bill (written testimony). SENATOR KILZER:

How does this check in with Social Security disability? SENATOR MATHERN: I have not checked into that specifically; there is a relationship because what one receives in Social Security disability also affects eligibility. SENATOR POLOVITZ: If my parents at age of 80 were divorced they would have come out much better off financially. SENATOR MATHERN: If one spouse is working and the other is disabled and applies for medical assistance the system does encourage divorce to obtain eligibility for aid. This bill does not isolate family support and responsibility. SENATOR ERBELE: We need to encourage family responsibility. Should we raise the eligibility income line of the healthy spouse? SENATOR MATHERN: This would be one of the options.

CURTIS VOLESKY, Director of Medicaid Eligibility, Dept Human Services, explains some of the Medicaid options available (Written Testimony). SENATOR MATHERN: What are the possibilities of taking Federal impoverishment situations for LTC and applying same to Medicaid? Would that be okay with the Feds? MR. VOLESKY: It could work with income and maybe assets under the new Federal regulations. They just came out Friday. SENATOR KILZER: What are asset levels preventing spousal impoverishment? MR. VOLESKY: The t impoverishment level currently allows \$3,000 for spouse in the institution; communal spouse to have \$87,000 in assets. Look at combined assets - must spend down their assets to that level; then there would be eligibility. No difference for dependents in asset level; increase in income level roughly around \$500 per individual.

RAYLYNN LAUDERDALE, People First of ND, supports bill (written testimony).

SENATOR MATHERN: Would your group have a suggestion on how this can be done financially? MS. LAUDERDALE: Income level could be raised. Would like to see them be able to be equal to middle class lifestyle. It is sad to force people into poverty because of a disability.

The hearing on SB2174 was closed.

January 24, 2001, Tape 1, Side A, Meter 44.3

SENATOR LEE opened the discussion on SB 2174. SENATOR MATHERN discussed the amendments. There are two options: the bill to disregard the income of the spouse of the disabled lest they lead the persons to get a divorce because of the eligibility requirements. It was illegal to do this prior to last Friday and if we did it, it would be very expensive to do it. The second amendment would be to change this into a study for LC to work on during the interim.

Page 3

Senate Human Services Committee

Bill/Resolution Number SB 2174

Hearing Date January 17, 2001

The cost for the 1st option is about \$750,000 with \$200,000 in state funds per biennium. We have 127 individuals, 48 new members

MR. VOLESKY: In the realm of the new clients and total 127 clients the cost would be \$738,000 total, \$504,000 Federal money and \$233,000 state money. The cap would be \$2175 per month with the cap. It is \$491. Now. SENATOR MATHERN moved the amendment of 1/22/01. The motion failed for lack of second. SENATOR MATHERN moved the 2nd amendment 1/22/01 that determines a study resolution of the problem. SENATOR POLOVITZ seconded the motion. The amendment was discussed. Study resolution would be done by Legislative Council. SENATOR MATHERN moved a DO PASS AS AMENDED. SENATOR POLOVITZ seconded the motion. Roll call vote carried 6-0. SENATOR KILZER will carry the bill.

FISCAL NOTE
 Requested by Legislative Council
 01/30/2001

Bill/Resolution No.:

Amendment to: SB 2174

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.*

	1999-2001 Biennium		2001-2003 Biennium		2003-2005 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.*

1999-2001 Biennium			2001-2003 Biennium			2003-2005 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.*

The amendment to the bill provides for the Legislative Council to conduct a study regarding the feasibility of altering medical assistance requirements to permit the disregard of income of the spouse of a disabled person. There is no fiscal impact based on the amendment. The fiscal impact will need to be evaluated after the results of the study are known.

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
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Phone Number: 328-2397

Date Prepared: 01/30/2001

FISCAL NOTE
Requested by Legislative Council
12/28/2000

Bill/Resolution No.: SB 2174

Amendment to:

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.*

	1999-2001 Biennium		2001-2003 Biennium		2003-2005 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.*

1999-2001 Biennium			2001-2003 Biennium			2003-2005 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 proposes a change to income consideration of a disabled spouse when determining eligibility for the Medicaid program. This bill would not have a fiscal impact on the Department of Human Services as proposed since it would not be an allowed change under current federal regulations.

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. Welsz	Agency:	Department of Human Services
Phone Number:	328-2397	Date Prepared:	01/12/2001

Date: 1/24/01

Senate HUMAN SERVICES Committee

Legislative Council Amendment Number 10339.0101 file 0200

Motion Made By Sen Mathews Seconded By Sen Palovitz

[illegible]

Absent 0

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

Amendment 2 1/22/01

Roll Call Vote #: 2Date: 11/24/012001 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2174Senate HUMAN SERVICES

Committee

☐ Subcommittee on _____
or
☐ Conference Committee

Legislative Council Amendment Number _____

Action Taken Do Pass as AmendedMotion Made By Sen Mathern Seconded By Sen Palociz

Senators	Yes	No	Senators	Yes	No
Senator Lee, Chairperson	✓		Senator Polovitz	✓	
Senator Kilzer, Vice-Chairperson	✓		Senator Mathern	✓	
Senator Erbele	✓				
Senator Fischer	✓				

Total (Yes) 6 No 0Absent 0Floor Assignment Sen Kilzer

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

REPORT OF STANDING COMMITTEE

SB 2174: Human Services Committee (Sen. Lee, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2174 was placed on the Sixth order on the calendar.

Page 1, line 1, replace "create and enact a new section to chapter 50-24.1 of the North Dakota" with "require a legislative council study."

Page 1, remove line 2

Page 1, replace lines 4 through 8 with:

"SECTION 1. MEDICAL ASSISTANCE - LEGISLATIVE COUNCIL STUDY REQUIRED. The legislative council shall study the feasibility of altering North Dakota medical assistance requirements to permit the disregard of income of the spouse of a disabled individual up to the amount of the cap established under section 1924(d)(3)(C) of the Social Security Act [42 U.S.C. 1396r-5(d)(3)(C)]. The legislative council shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the fifty-eighth legislative assembly."

Renumber accordingly

2001 HOUSE HUMAN SERVICES

SB 2174

2001 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2174

House Human Services Committee

☐ Conference Committee

Hearing Date February 12, 2001

Tape Number	Side A	Side B	Meter #
Tape 1	X		2515 to 3370
Committee Clerk Signature <i>Corinne Easton</i>			

Minutes:

Chairman Price, Vice Chairman Devlin, Rep. Dosch, Rep. Galvin, Rep. Klein, Rep. Pollert, Rep. Porter, Rep. Tieman, Rep. Weiler, Rep. Weisz, Rep. Cleary, Rep. Metcalf, Rep. Niemeier, Rep. Sandvig

Chairman Price: We will open the hearing on SB 2174.

Senator Tim Mathern: Presented SB 2174. The Bill 2174 as originally introduced deals with Medicaid eligibility. The intent of the original bill was to address the public policy matter that still remains about inappropriate incentive we're making in our assistance program. Your committee, this last legislative session and the session before, worked on welfare reform. One of the issues you were concerned about was are we giving incentives to people to be single the way our programs were established. We changed that trying to clarify the public policy issue as we moved into welfare reform. Some sessions before that we changed our eligibility in terms of persons getting care in homes for the elderly, because our policy there was promoting a situation

where if one spouse went into a home we were promoting divorce so the other spouse would not be impoverished. That was changed so that one person can go into a nursing home and the other person don't impoverish. This bill would look at that same issue from the perspective of a family or someone with a disability. Right now the eligibility criteria are such that if someone is disabled in the family, they either need to impoverish the entire family or get a divorce for the disabled member to still receive assistance. I have handed out a testimony by Curtis Volesky, Director of Medicaid Eligibility for the Department of Human Services. Testimony provides information on certain other options that are allowed by federal regulations and how they affect Medicaid eligibility. He also handed out the likely cost of Amended Bill SB 2174.

Rep. Weisz: Can you explain what the cap is now - permitting the disregard of income of the spouse of a disabled individual up to the amount of the cap established under section 1924?

Senator Tim Mathern: Right now we disregard the assets at about \$89,000. I think the income is about \$35-\$40,000 that we disregard.

Rep. Weisz: So in other words, what you are proposing is to disregard that level of asset and income for the spouse of the disabled up to that level not to count?

Rep. Tim Mathern: What I'm suggesting is that we as a state disregard the same amount that we do for someone going into a nursing home. But the actual federal potential for disregard is probably higher yet. I'm asking that we standardize it for what we do in a nursing home situation.

Chairman Price: Mr. Volesky, would you like to make any comments on the bill regarding a study.

Curtis Volesky: Director of Medicaid Eligibility for the Department of Human Services. I think it would be perfectly fine to do a study to see what the impact would be and what we would want

Page 3
House Human Services Committee
Bill/Resolution Number SB 2174
Hearing Date February 12, 2001

to do as a state. I would also like to add that because you were wondering about the income amounts, it comes out to about \$2,175 a month.

Chairman Price: Close hearing on SB 2174.

COMMITTEE WORK:

REP. DEVLIN: Move the amendments.

REP. WEILER: Second.

(10 Yes, 4 No, 0 Absent)

REP. DEVLIN: Motioned for a DO PASS as amended.

REP. DOSCH: Second.

11 YES 3 NO 0 ABSENT CARRIED BY REP. POLLERT

10339.0201
Title.0300

Prepared by the Legislative Council staff for
Representative Devlin
February 12, 2001

VR
2/12/01

HOUSE AMENDMENTS TO SB 2174

HOUSE HS

2-13-01

1

Page 1, line 1, replace "require" with "provide for"

Page 1, line 4, remove "**REQUIRED**" and replace "study" with "consider studying"

Renumber accordingly

Date: 2-12-01
Roll Call Vote #: 1

2001 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. HB 2174

House Human Services Committee

☐ Subcommittee on _____
or
☐ Conference Committee

Legislative Council Amendment Number _____

Action Taken moved motion to Amend

Motion Made By Rep. Devlin Seconded By Rep. Weiler

Representatives	Yes	No	Representatives	Yes	No
Rep. Clara Sue Price, Chairmar	✓		Rep. Audrey Cleary		✓
Rep. William Devlin, V, Chairman	✓		Rep. Ralph Metcalf		✓
Rep. Mark Dosch	✓		Rep. Carol Niemeier		✓
Rep. Pat Galvin	✓		Rep. Sally Sandvig		✓
Rep. Frank Klein	✓				
Rep. Chet Pollert	✓				
Rep. Todd Porter	✓				
Rep. Wayne Tieman	✓				
Rep. Dave Weiler	✓				
Rep. Robin Weisz	✓				

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

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

Date: 2-12-01
Roll Call Vote #: 2

2001 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB 2174

House Human Services Committee

☐ Subcommittee on _____
or
☐ Conference Committee

Legislative Council Amendment Number _____

Action Taken Do PASS as amended

Motion Made By Rep. Devlin Seconded By Rep. Dosch

Representatives	Yes	No	Representatives	Yes	No
Rep. Clara Sue Price, Chairman	✓		Rep. Audrey Cleary		✓
Rep. William Devlin, V, Chairman	✓		Rep. Ralph Metcalf		✓
Rep. Mark Dosch	✓		Rep. Carol Niemeier		✓
Rep. Pat Galvin	✓		Rep. Sally Sandvig	✓	
Rep. Frank Klein	✓				
Rep. Chet Pollert	✓				
Rep. Todd Porter	✓				
Rep. Wayne Tieman	✓				
Rep. Dave Weiler	✓				
Rep. Robin Weisz	✓				

Total (Yes) 11 No 3

Absent _____

Floor Assignment Rep. Pollert

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

REPORT OF STANDING COMMITTEE (410)
February 13, 2001 8:52 a.m.

Module No: HR-26-3150
Carrier: Pollert
Insert LC: 10339.0201 Title: .0300

REPORT OF STANDING COMMITTEE

SB 2174: Human Services Committee (Rep. Price, Chairman) recommends
AMENDMENTS AS FOLLOWS and when so amended, recommends **DO PASS**
(11 YEAS, 3 NAYS, 0 ABSENT AND NOT VOTING). SB 2174 was placed on the Sixth
order on the calendar.

Page 1, line 1, replace "require" with "provide for"

Page 1, line 4, remove "**REQUIRED**" and replace "study" with "consider studying"

Renumber accordingly

2001 TESTIMONY

SB 2174

SB 2174

January 10, 2000

North Dakota Legislator:

At our last Southwest Regional Eligibility Workers Meeting we discussed the problems and struggles our clients have in dealing with high out of pocket medical costs. We are concerned and know, for many of our clients with the high medical costs incurred and their share of expenses, it is a choice of getting the medical treatment, taking their medication or buying food.

There are actually two areas of concern: one is the low income levels for our medically needy families, and the other is emergency medical treatment for non-covered individuals.

Federal regulations previously limited the medically needy income levels and only allowed them to be increased based on the consumer price index (CPI). The federal regulations are currently being changed to allow states to effectively increase their medically needy income levels to any amount. North Dakota's current levels average at 51% of poverty, with some as low as 41.8% of poverty.

Our State has requested Aged, Blind and Disabled cases to go to 100% of poverty level, however bringing all medical needy cases to 100% of poverty level is what our clients need. We are asking your support in granting the funding for these medically needy levels, so that our State has the funding to support the needs of our clients. As you well know, we can have all the flexibility in the world to administer programs or have federal laws giving increased medical levels, but without your support to increase funds to address these issues, hands are tied at our state office level, and again our clients are left without services.

Our other concern is people with short term emergencies, which would be people who don't qualify for any other programs, and without medical help could become disabled for life. We have emergency services available for illegal aliens in our state, but not for our citizens. Emergency services can be received in Minnesota and Colorado we are told, but yet we have no State monies set aside for these types of funding. County general assistance can not fund the types of emergencies that arise. The monies just aren't there.

We want economic development to keep our people in State however don't give them health care when other States do. Is that an incentive?? We would hope that you would be able to set aside

some State monies for Emergency Assistance. Having Emergency funds could save the state from paying long term medical costs in the future.

Again, we ask that you look at our concerns, and consider supporting the funding of programs to give our clients the health care that they need. Children who aren't healthy can't learn, and parents who aren't healthy can't care for their children.

I have enclosed some case scenarios for your review.

Sincerely,

Marlene Cook
Legislative Committee
SouthWest Elig. Workers Assoc.

Case Scenarios:

1. Couple in their 50's, no children under 21, low or no employment. He comes in and has had a heart attack, won't be disabled for more than year according to Social Security. No money to pay for hospital stay or further tests, procedures or medication to take to continue to be stable. At this point there are no medical programs to fit their needs.

2. Couple in 40's, no children under 21, no medical insurance, low employment. She has had colon problems, cancer in family, and needs to have extensive tests. No programs to cover this or procedures after tests, unless would be disabled for 12 months by Social Security. At this point, can't afford tests, so don't have them done as we don't have programs to cover.

3. This was actual case in 11-00. Single parent, with 17 year old son. Father had wages of \$1320.61. Rent is \$275, they pay for all utilities, food stamps of \$10.00 and they both have a recipient liability of \$558.27 as they both fail 1931 income levels and child fails poverty level budgeting. This is a case where they would probably go without care for this month as their liability is too high with other bills to pay as the \$1320.61 is gross and not net income. The liability would be the same for an elderly couple in their own home.

4. December, 1998 case. Couple, he is 61, disabled and on medicaid, she is 56 and not on medicaid. She received \$300 gross wages, he received \$1362.00 in Social Security disability. They had to pay \$971.31 as recipient liability for medical costs and yet pay all of their rent, utilities etc. As of January, 2001, they would pay \$930.31. In spousal cases, the ineligible spouse at home can have income level of \$2175.00 as of January, 2001 before they would have to pay any medical costs, and the above couple both living in their own home, who have high monthly medication costs have to pay \$930.31 and try to live besides.

5. November, 2000 case. Lady is 67 years old and receives \$772.50 in SSA benefits. Her recipient liability is \$252.00 and her medications run \$217.27 per month so this is all out of pocket expense. She received 39.00 in food stamps. How can this woman pay for utilities, house insurance and upkeep, car insurance and gas to even maintain a vehicle. Not eating properly or taking her medication on a regular basis, will she end up in long term care??? What choices does she have???

These are a few of the case examples taken from past caseloads. When our clients sit in tears asking if we couldn't possibly do more for them to pay for medication, increase their food stamps, it is very difficult to give them the answer "no, at this time, that is all the program allows" knowing full well the decisions they need to make.

Another real issue, is for the clients that receive SSA benefits and the clients who receive SSI. IF they have never worked, they receive SSI, and have zero liability, but they have worked all their life and receive basically the same amount of income, they have to pay a recipient liability for medical costs. This is not fair to the individuals who have worked all these years.

Senate Human Services Committee
January 17, 2001

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

Senate Bill 2174 is a simple bill that creates an exemption of the spouse's income for the purpose of determining medical assistance eligibility by amending Chapter 50-24.1 of the ND Century Code. However, though the bill is simple the issue is not simple and the costs involved are not minor. But I ask you to consider this public policy matter from a long term perspective and I ask that we work with the ND DHS and with each other as a committee most concerned about these matters, to come up with a workable solution.

I introduced the bill because someone, who does not wish to be identified, contacted me stating that she was encouraged to divorce her husband who has a disability so that he could become eligible for Medicaid assistance and so that she would not lose all her income and assets. It is a situation where even though they are of meager resources and income, they were such that there is no eligibility for assistance. My concern is that we have gone through such situations before and eventually have found that the policy needed to be changed because of unintended negative consequences.

I note for example the original program to help widows and abandoned mothers and children which became our AFDC program. Essentially the program provided assistance only if there was one parent in the home. This led to a long term sociological change regarding single parenthood in welfare which was eventually found to be counter productive to family life and stability for children. This program has now been drastically changed with welfare reform and the earned income tax credit program in great part to correct this policy. We also learned that the placement of persons into nursing homes impoverished the remaining stay at home spouse which then created further dependency on that person's part. We have now changed that to allow the at home spouse to retain resources for self sufficiency so that that person can remain a productive person and support. I suggest as we have learned in these areas, we ought to move in the direction of exempting the spouse's income in the case of a disability in the family in order to encourage the spouses to stay together. This provides a support system and prevents persons from making a financial choice about their marital commitment. This benefits us all in the long term.

The department has given me information about the costs involved in such a change and have also given some options to consider, I ask that we consider the testimony of the Department and then come to a decision as to how we can both provide assistance where needed while also supporting family life and marital commitment.

Thank you for your consideration and attention.

Training Services

People First provides . . .

Beginning Steps to Self Advocacy

- A two-part session using a consumer-friendly method to learn self-advocacy skills.

Self Determination

- An in-depth look through the eyes of self advocates and others speaking openly about the struggle for self determination.

People First Language

- A humorous approach teaching effective language putting the person first and the disability second.

Sensitivity Training

- Learn to identify unintentional barriers and interact effectively with people who have a disability. Step into their shoes and experience firsthand the situations they encounter in everyday life. Great for transit systems, service providers, and disability organizations.

CONTACT PEOPLE FIRST TO
SCHEDULE TRAINING SESSIONS

LOCAL SELF ADVOCACY ORGANIZATIONS

BISMARCK/MANDAN

American People
400 E. Broadway, #616
Bismarck, ND 58501
(701) 328-2950

BOWMAN

Bowman Advocators USA
(Contact People First)

DEVILS LAKE

Lake Region SA Group
P. O. Box 11
Devils Lake, ND 58301
(701) 662-8681

DICKINSON

Good People SA
(Contact People First)

FARGO

United Voices
2533 University Dr. S
Fargo, ND 58103
(701) 293-8191

GRAFTON

Red River Valley SA
311 S. 4th St., Suite 112
Grand Forks, ND 58201
(701) 795-3168

HARVEY

Harvey Self Advocacy
409 W. Brewster
Harvey, ND 58341
(701) 324-4636

JAMESTOWN

People First of Jamestown
624 2nd Ave. NE
Jamestown, ND 58401
(701) 252-7109

MINOT

Magic City Self Advocates
MSU-Memorial Hall # 407
Minot, ND 58707
(701) 858-3356

NEW ROCKFORD

Helping People SA
120 11th Street
New Rockford, ND 58356
(701) 947-2147

VALLEY CITY

People United
P.O. Box 242
Valley City, ND 58072
(701) 945-2840

WAHPETON

3-Rivers Self Advocacy
701 6th Street S.
Wahpeton, ND 58075
(701) 642-2442

WILLISTON

We The People
P.O. Box 2472
Williston, ND 58802
(701) 774-4345

PF

**We Are
People First . . .
Disability Second**

**People
First
of
North
Dakota**

FOR FURTHER INFORMATION CONTACT
PEOPLE FIRST OF NORTH DAKOTA

What is People First?

People First is . . .

A state-wide self advocacy organization made up of people with disabilities. It is a human rights movement. As self advocates, we look at our strengths to enhance the quality of life. We believe that people in our communities should see *the person first, the disability second.*



Self advocates of North Dakota join the national self-advocacy movement. Representatives from each participating local self-advocacy organization join together to unify efforts in addressing systemic issues.

All People First programs and activities shall be accessible to people with disabilities. If you need this material in an alternative format, contact:

People First of North Dakota

What is Self Advocacy?

Self Advocacy is . . .



= Speaking For Yourself



= Knowing And Defending Your Rights



= Taking Responsibility For Your Actions



= Solving Problems And Making Decisions



= Asking For Help Because You Want And Need It

Contributing To The Community



Our Motto ... "TEA York"

We Are Working To Improve . . .

T = TRANSPORTATION



E = EMPLOYMENT



A = ACCESSIBILITY



M = MEMBERSHIP



People First of North Dakota

400 E. Broadway, Suite 515

Bismarck, ND 58501

(701) 250-6745 Office

1-888-695-9225 Toll Free

(701) 328-3934 Fax

pfnd@btigate.com E-Mail

Examples of People First Language

Labels Not to Use

the handicapped or disabled

the mentally retarded
he's retarded

my son is autistic

she's a Downs kid, a mongoloid

he's learning disabled

I'm a paraplegic

she's crippled

he's a dwarf (or midget)

she's emotionally disturbed

he's wheelchair bound or
confined to a wheelchair

normal and/or healthy kids

he's in special ed

birth defect

handicapped parking,
bathrooms, etc.

she has a problem with . . .

People First Language

people with disabilities

people with mental retardation
he has a cognitive impairment

my son has autism

she has Down syndrome

he has a learning disability

I have paraplegia

she has a physical disability

she has a mobility impairment

he's of short stature

she has an emotional disability

he uses a wheelchair
or a mobility chair

typical kids or
kids without disabilities

he receives special ed services

congenital disability

accessible parking,
bathrooms, etc.

she has a need for . . .

Keep thinking! There are lots more examples out there!
And practice, practice, practice. Old habits die hard!

This document may be copied in its entirety.

As a courtesy, please let me know you'll be using it.

Kathie Snow, 250 Sunnywood Lane Woodland Park, CO 80863-9434

Voice 719-687-8194, Fax 687-8114, e-mail: KSSnow@aol.com

(Rev. 1/98)

To achieve

INCLUSION,

COMMUNITY,

and FREEDOM

*for people with disabilities,
we must use*

People First Language

A commentary by Kathie Snow

The difference between
the right word

and the almost right word
is the difference between lightning
and the lightning bug.

Mark Twain

The beginning of wisdom is to call things by their right names.

Old Chinese Proverb

Who are "the handicapped"?

Society's *myths* tell us they are:

- people who "suffer" from the "tragedy" of "birth defects" ...
- paraplegic "heroes" "struggling" to become "normal" ...
- "victims" of diseases "fighting" to regain their lives ...
- categorically ... "the disabled, the retarded, the autistic, the blind, the deaf, the learning disabled" and more.

Who are they, really?

They are moms and dads and sons and daughters ... employees and employers ... scientists (Stephen Hawking) ... friends and neighbors ... movie stars (Marlee Matlin) ... leaders and followers ... students and teachers ... they are ... **people**.

They are people, first.

Are you myopic or do you wear glasses?

Are you cancerous or do you have cancer?

Are you freckled or do you have freckles?

Are you handicapped/disabled or do you *have* a disability?

People First Language describes what a person HAS, not what a person IS!

People First Language puts the person before the disability.

Disability has been defined as

a body function that operates differently.

Contrast that meaning with:

A published origin of "handicap" refers to "hand in cap," a game where winners were penalized or put at a *disadvantage*.

A legendary origin of the word refers to a person with a disability having to *beg on the street* with "cap in hand."

"Handicapped," "Disabled," or People with Disabilities:

Which description is more accurate?

Using "the handicapped," and even "the disabled," usually evokes negative feelings (sadness, pity, fear, and more) and creates a stereotypical perception that people with disabilities are all alike. All people who have brown hair are not alike. All people who have disabilities are not alike. Many people who have disabilities would never think of themselves as "handicapped."

The disability community is the largest minority group in our country. It includes people of both genders and from all religions, ethnic backgrounds, and socioeconomic levels. About the only things people with disabilities have in common with *one another* are 1) having a body function that operates differently and 2) facing prejudice and discrimination. Unique to the disability community is that it's the only minority group that any American can join *in the split second of an accident*.

If/when it happens to you, will you have more in common with others with disabilities or with your family, friends, and co-workers?

The Disability Rights Movement is following in the footsteps of the Civil Rights Movement of the '60s and the Women's Movement of the '70s. While people with disabilities and advocates work to end discrimination and segregation in education, employment, and our communities at large, we must *all* work to end the prejudicial language that creates an invisible barrier to being included in the ordinary mainstream of life.

"Disability is a natural condition of the human experience."

The U.S. Developmental Disabilities Act and The Bill of Rights Act, 1993

Disability is not the "problem." We need to rid ourselves of the word "problem" when talking about people's needs! A person who wears glasses doesn't walk around saying, "I have a problem seeing." She would say, "I wear (need) glasses." Recognize that a "problem" is really a need.

The real problem is attitudinal/barriers.

There have always been people with disabilities in our world and there always will be.

- **If educators** - and our society at large - perceived children with disabilities as individuals who have the potential to learn, who have the need to the same education as their brothers and sisters, and who have a future in the adult world of work, we wouldn't have to fight for inclusive education.
- **If employers** - and our society at large - believed adults with disabilities have valuable job skills (because they received a quality education), we wouldn't have to fight for real jobs for real pay in the real community.
- **If business owners** - and our society at large - viewed people with disabilities as consumers with money to spend (because they're wage earners), we wouldn't have to fight for accessible entrances and other accommodations.

Many people who do not now have a disability

will have one in the future.

Others will have a family member or friend who acquires a disability. If you acquire a disability in your lifetime, how will you want to be described? How will you want to be *treated*? Disability issues are issues that affect *all* Americans!

Using People First Language is a crucial issue.

If people with disabilities are to be included in all aspects of our communities - in the very ordinary, very wonderful, very typical activities most people take for granted - then they must talk about themselves in the very ordinary, very wonderful, very typical language other people use about themselves.

.....

Children with disabilities are children, first. The only labels they need are their names! Parents must not talk about their children in the clinical terms used by medical practitioners.

A disability label is simply a medical diagnosis!

Since the parent of a child who wears glasses (medical diagnosis: myopia) doesn't say, "My daughter is myopic.", why does the parent of a child who has a medical diagnosis of mental retardation say, "My daughter is retarded."?

.....

Adults with disabilities are adults, first. The only labels they need are their names! They must not talk about themselves the way service providers talk about them.

A disability label is simply a medical diagnosis!

Since an adult with a medical diagnosis of cancer doesn't say, "I'm cancerous.", why does an adult with a medical diagnosis of cerebral palsy say, "I'm disabled."?

Our society, "handicapped" & "disabled" are all-encompassing terms that are misused.

- People with hearing or vision impairments don't need "handicapped" parking or restrooms. People with mobility impairments do need **accessible** parking and restrooms.
- If a "handicapped" entrance has a ramp for people who use wheelchairs, does the doorway have Braille signage for people with visual impairments?
- Accommodations that enable people with disabilities to access a facility - regardless of their disabilities - are **accessible**!
- "Disabled" is not acceptable, either. Our society "corrupts" the meaning of certain words. When the traffic report mentions a traffic jam, you'll often hear, "There's a disabled vehicle on the highway." "Disabled," in that context, means "broken down." People with disabilities are not broken!
- If a new toaster doesn't work, we return it, say "it's defective," and get a new one! Do we do that with babies who have birth "defects"? The proper term is "congenital disability."

When we understand the meanings of words and how they're misused, we realize they are the tip of the iceberg of inappropriate and unacceptable language.

When people with disabilities are referred to by their medical diagnoses, we have devalued them as human beings. When we devalue others, we devalue ourselves.

When we start calling things by their right names, when we recognize that people with disabilities are people *first*, we can begin to see how people with disabilities are more *like* people without disabilities than they are *different*. When we understand that disability labels are simply medical diagnoses, we can put them in their proper perspective. People who wear glasses are not "the myopic;" people with cancer are not "the cancerous."

My son, Benjamin, is 11 years old.

He loves the Lone Ranger, ice cream, and playing on the computer. He has blonde hair, blue eyes, and cerebral palsy. His disability is only one small piece of his life. For many people with disabilities, their medical diagnoses define who they are!

When I introduce myself to people I don't tell them I'll never be a prima ballerina. Like others, I focus on my strengths, the things I do well, not on what I can't do. Don't you do the same?

I don't say, "My son can't write with a pencil." I say, "My son uses a computer to do his school work." I don't say, "My son can't walk." I say, "My son uses a walker and a wheelchair." And Benjamin isn't "wheelchair bound." He's *free* when he uses it - free to go when and where he wants to go!

We know that a person's self-image is strongly tied to the words used to describe that person. We've been told that descriptions can become a self-fulfilling prophecy. If a child is told she is stupid or slow or lazy, she will probably become that. If told she's brilliant, she'll probably become that.

People with disabilities, having been described by their medical diagnoses all their lives, often must *convince themselves* that they are capable and have potential for success. Parents must convince themselves *and* their children that their kids are capable and have potential for success. If you don't believe in yourself, it's hard for others to believe in you!

We have the power to change all this for current and future generations. People First Language can change how people with disabilities feel about themselves. People First Language can change how society views and treats people with disabilities.

Benjamin goes ballistic when he hears "handicapped."

I hope when he's grown, labels will be extinct.

People First Language is right. Just do it - NOW!

TESTIMONY BEFORE THE SENATE
HUMAN SERVICES COMMITTEE
REGARDING SB 2174
JANUARY 17, 2001

Chairman Lee and members of the Committee. I am Raylynn Lauderdale, Executive Director for *People First of North Dakota*. *People First* is a statewide self-advocacy organization working to enhance the quality of life for people with disabilities.

Many people with disabilities have a great need for medical assistance. Without this assistance, their quality of life would be drastically reduced. Disability should not have to be equated with poverty. If an individual has a disability and must consider their spouse's income, then only those with limited income can qualify.

If a couple is of middle class, why do we expect them to reach poverty in order to assist them with the enormous medical bills that are incurred with a majority of disabilities? In the long run, this couple will be able to contribute more to the economic development of the community when not having to live in poverty. Plus, the individual with a disability is able to maintain dignity and respect as a contributing member of a family rather than the member who drains all resources to maintain life.

Since the beginning of the self-advocacy movement in the United States, people with disabilities ask that *PEOPLE FIRST LANGUAGE* be used when referring to them. Therefore, I ask that you pass this bill, but change the language to read:

"may not consider the income of a spouse of a person with a disability."

Respectfully,

Raylynn Lauderdale
People First of North Dakota
400 E. Broadway, Suite 515
Bismarck, ND 58501
701-250-6745



PEOPLE FIRST LANGUAGE GUIDELINES

WHEN REFERRING TO A PERSON'S DISABILITY,
TRY USING **PEOPLE FIRST LANGUAGE**.

PEOPLE FIRST LANGUAGE	LABELS <i>NOT</i> TO USE
People with disabilities	The handicapped or disabled
People with mental retardation He has a cognitive impairment	The mentally retarded He's retarded
My son has autism	My son is autistic
She has Down Syndrome	She's a Downs kid, a mongoloid
He has a learning disability	He's learning disabled
I have paraplegia	I'm a paraplegic
She has a physical disability She has a mobility impairment	She's crippled
He's of short stature	He's a dwarf (or midget)
She has an emotional disability	She's emotionally disturbed
He uses a wheelchair	He's wheelchair bound or confined to a wheelchair
A typical person or a person without a disability	Normal and/or healthy person
He receives special education services	He's in special education
Congenital disability	Birth defect
Accessible parking, bathrooms, etc.	Handicapped parking, bathrooms, etc.
She has a need for. . .	She has a problem with. . .

- Do not refer to a person's disability unless it is relevant... REMEMBER, people are **PEOPLE FIRST, DISABILITY SECOND!**
- Use *disability* rather than *handicap* to refer to a person's disability.
- Avoid negative or sensational descriptions of a person's disability.
- Don't use "*normal*" to describe people without disabilities; instead say *people without disabilities* or *typical*, if comparisons are necessary.
- Never assume that a person with a communication disorder also has a cognitive disability such as mental retardation.
- Don't portray people with disabilities as overly courageous, brave, special, or super human.

FOR MORE INFORMATION CONTACT
PEOPLE FIRST AT 701-250-6745 OR 1-888-695-9225

TESTIMONY ON SB 2174
JANUARY 17, 2001

Chairman Lee, members of the committee, I am Curtis Volesky, Director of Medicaid Eligibility for the Department of Human Services. As you may be aware, federal regulations prohibit Medicaid from completely disregarding a spouse's income as proposed in this bill. The fiscal note indicates there would be no fiscal impact because we cannot make the change per federal regulations. We could actually make the change, however, it would jeopardize all federal funding for the Medicaid program. With that in mind, Senator Mathern requested that I provide information on certain other options that are allowed by federal regulations and how they affect Medicaid eligibility.

Federal regulations have always placed many limitations on Medicaid, primarily with regard to disregards, deductions and income limits for the medically needy coverage. As of last Friday there was a change in those regulations to give us much more flexibility. Those changes now allow us to create disregards and establish income levels that we feel are appropriate for our recipients. Unfortunately, the regulations still prohibit Medicaid from completely disregarding a spouse's income. I will describe some options that we now can do and will explain their effect on Medicaid.

- The first option is to provide for an income level increase for all medically needy individuals. If this level was increased to 100% of the poverty level, it would help aged, blind and disabled individuals by decreasing the amount of income that would have to be applied toward their medical expenses. A medically needy income level change would also benefit caretakers of children and children age 19 to 21. It would have no effect on other children as they are now eligible at either 100% or 133% of the poverty level. The medically needy income level would not have to be at 100% of poverty, but could be at an amount that is higher or lower than 100% of the poverty level. Eligibility determination systems could easily accommodate this change.
- A slightly less costly change would be to limit the income level

2,315,000 694,000 State funds

increase to aged, blind and disabled individuals. This would allow all Medicaid individuals, except caretakers of children and older children, to be eligible for Medicaid at the higher level. This option would require some system changes because of the difference between the aged, blind and disabled and the caretakers/older children.

- A third option would be to only increase the medically needy income level for blind and disabled individuals. This would require more system changes than the previous change. It would also be more complicated for policy and systems because of the different treatment for aged individuals. It may also be perceived as unfair as aged individuals in similar situations would receive fewer benefits. Also, a disabled person who turns age 65 would have a reduction in benefits to deal with.
- The fourth option would be to disregard specific income. While federal rules do not allow us to disregard all income, they do allow us to disregard a certain type or a certain amount of income. Income disregards could be limited to certain individuals, such as only for blind and disabled recipients, or by type of income, such as veterans income, social security income, or earned income, etc. This option is probably closest to the original bill proposal. It would require more extensive system and policy changes and would be more complicated. Again, this may be perceived as unfair to aged individuals in similar situations and a disabled person who turns age 65 would have a reduction in benefits to deal with.
- The final option, and the most ideal, would be to increase the income level for all Medicaid recipients to 133% of the poverty level. This, of course, would also be the most costly. It would provide a fair and simple coverage for all recipients who are currently eligible at lower levels and it would dramatically simplify eligibility determinations and systems. Today we have 51 different categories of eligibility for recipients. Different family members are often in different categories with different income levels and requirements. This option would be easier for

recipients to understand as the entire family would be eligible at the same level and they would not have to report as often.

The department does not support any of these changes. Funds necessary to support these changes are not included in the Governor's budget. I will be glad to answer any questions regarding my testimony. Thank you.

Likely Cost of Amended Bill SB 2174

Number open clients in household of 2 or more affected = 127

Recipient liability for these individuals = \$32,991.28 per month

12 months = \$395,895.36 (1st year)

+ 2% inflation = 403,813.26

+ 2.2% inflation = 412,697.15 (2nd year)

\$816,510.41 TOTAL

Estimated number of new clients affected = 48

@ \$352,827.77

Total recipients costs \$1,169,338.10

X58%

\$678,216.09

If all RL used every month

Based on history of amounts

Actually used = 58% in
ongoing cases.

Federal financial participation X 69.99%

\$474,683.44 (federal)

\$203,532.65 (state)

Plus estimated system enhancement of 60,000 @ 50% match

Total cost estimate = \$738,216

Federal share = 504,683

State share = 233,533



**NORTH DAKOTA DEPARTMENT
OF HUMAN SERVICES**

John Hoeven, Governor
Carol K. Olson, Executive Director

Legal Advisory Unit

Fax (701) 328-2350
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January 22, 2001

Mr. Mark Manasky
Senate Human Services Committee
State Capitol Building
600 E. Boulevard Ave.
Bismarck, ND 58505

Dear Mr. Manasky:

RE: Proposed amendments to SB 2174

I am told that Senator Tim Mather asked Curtis Volesky of our Medical Services Unit to prepare two alternative amendments to SB 2174. One was to change the bill so that it would have the potential for being approved by federal Medicaid authorities, while remaining as close to the existing bill as possible. The other was to amend the bill into a study resolution.

Please review the attached drafts and let me know whether they are acceptable or whether I need to make changes.

Thank you.

Sincerely,

Kris Jennings
Legal Advisory Unit
Department of Human Services

study resolution

PROPOSED AMENDMENTS TO SENATE BILL NO. 2174

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for the study of the feasibility of altering North Dakota medical assistance requirements to permit the disregard of income of the spouse of a disabled individual up to the amount of the cap established under section 1924(d)(3)(C) of the Social Security Act [42 USC 1396r-5(d)(3)(C)] by the Legislative Assembly."

Let assign to Budget Committee on Human Services

Renumber accordingly

not accepted (lost to second)

Prepared by the North Dakota
Department of Human Services
1/22/01

PROPOSED AMENDMENTS TO SENATE BILL NO. 2174

Page 1, line 6, after "determining" Insert "a disabled individual's"

Page 1, line 7, replace "may not consider the income of a spouse" with "shall disregard a total amount of the otherwise countable income of individuals who are members of a medical assistance unit consisting of two or more individuals, at least one of whom is a disabled individual, equal to the amount of the cap established under section 1924(d)(3)(C) of the Social Security Act [42 USC 13496r-5(d)(3)(C)]."

Page 1, remove line 8

Renumber accordingly

*Hand, Amendment, * 2175 spend independent 2nd 48 add 1 perph*
127 individuals will qualify now
either term than 'spouse'
not 7th 18,000
504,000 Fed
233,000 state
6 county
** 491. now*

ATTENTION: REP. SALLY SANDVIG

2174

TUESDAY 1/16/01

HELLO,

MY NAME IS LORI KOENIG - MY HUSBAND'S NAME IS DARRIN ARNISON. YES, WE HAVE DIFFERENT LAST NAMES - BUT IT IS NOT BY CHOICE - IT'S A NECESSITY. YOU SEE, DARRIN + I ARE NOT MARRIED, ON PAPER - WE WERE MARRIED IN FRONT OF OUR FAMILIES, FRIENDS, + GOD. WHY? YOU ASK - DARRIN IS DISABLED - HE'S BLIND + IN A WHEELCHAIR (AS A RESULT OF CANCER). IF WE WERE MARRIED, MY INCOME WOULD CAUSE HIM TO LOSE EVERYTHING HE WOULD NO LONGER BE ELIGIBLE FOR MEDICAID. MY COMPANIES INSURANCE WOULD NOT PICK HIM UP UNDER MY COVERAGE BECAUSE OF HIS PRE-EXISTING CONDITION. IF WE WERE MARRIED MY INCOME WOULD CAUSE HIM TO LOSE HIS ALL BENEFITS, ALSO. THIS IS WRONG BECAUSE LOVE DOESN'T HAVE A PRICE-TAG + NO ONE SHOULD BE PENALIZED FOR BEING MARRIED OR WANTING TO BE MARRIED. DARRIN + I SHOULD NOT HAVE TO LIVE LIKE THIS. WHAT HAPPENS IF ONE OF US DIES? THE OTHER PARTNER GETS NOTHING - UNFORTUNATELY OUR FAMILIES KNOW HOW WE FEEL + WHAT WE WANT IF SOMETHING HAPPENS TO ONE OF US. I DON'T LIKE BEING DECEITFUL OR FEELING LIKE I'M CHEATING THE GOVERNMENT - BUT WHAT CHOICE DO I HAVE - I LOVE MY HUSBAND + I WILL NOT BE RESPONSIBLE FOR HIM LOSING ANYTHING LET ALONE EVERYTHING.

THANK YOU,

SINCERELY,

Lori Lynn Koenig (WISH IT WAS Lori Lynn Arnison)