MICROFILM DIVIDER

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

GREAT SEAL 1889
STATE OF NORTH DAKOTA

ROLL NUMBER	

DESCRIPTION

2326

2007 SENATE HUMAN SERVICES

SB 2326

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2326

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-22-07

Recorder Job Number: 1542

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee, Chairman, opened the hearing on SB 2326 relating to medical assistance and other health coverage for families of children disabilities; and to provide an appropriation.

Senator Tim Mathern (District #11) introduced SB 2326. (Attachment #1)

Senator Warner asked if a bill was passed last session allowing people with disabilities to buy extra Medicaid.

Sen. Mathern replied that a bill was passed last session, however, that really required money to make the program workable. He didn't believe an appropriation was passed to make it workable. This is a new option before us.

Senator J. Lee said what was passed before was a Medicaid buy in for people with disabilities but it wasn't intended for children with ailments. (Meter 4:15)

Sen. Mathern said a person with a disability could buy into that program. This is for the family who might have an income beyond Medicaid eligibility who could buy in because they have a child with a disability.

Caitlin McDonald testified in support of SB 2326 on behalf of the Arc of North Dakota.

(Attachment #2)

Donene Feist testified as a mom and also as the director of the Family Voices of ND in support of SB 2326. (Attachment #3)

Senator Dever asked if this is the vehicle to take advantage of the waiver that has been talked about for the last two years.

Ms. Feist answered that it is a separate piece.

Ms. Feist then introduced her son Zachary who wanted to address the committee.

Zachary Feist (Edgeley, ND) testified that all kids with a disability deserve a chance to be all they can be and with a little help, they can be. (Meter 20:00)

Jennifer Restemayer testified in favor of SB 2326. (Attachment #4)

Mike Schwab (Executive Director for the Arc of Bismarck) asked for support of SB 2326. (Attachment #5) He added that the department of human services did a study or estimate of how many children would be possibly eligible with this option and Donene for writing information from the catalyst center. Both estimates are that over 700 families would possibly benefit from having this legislation.

Testimony was distributed from the ND Disabilities Advocacy Consortium in support of SB 2326. (Attachment #6)

Carlotta McCleary (Executive Director, ND Federation of Families for Children's Mental Health) testified in support of SB 2326. (Attachment #7)

David Boeck (Protection & Advocacy Project) testified in favor of SB 2326. (Attachment #8)

There was no opposing testimony.

Senator J. Lee called for neutral testimony.

Maggie Anderson (Director of Medical Services, Dept. of Human Services) provided information on the appropriation section of this bill. (Attachment #9)

Senator J. Lee asked Ms. Anderson if she would provide the committee with what the incomes would be for 1, 2, and 300% of poverty for families of 2, 3, and 4.

Ms. Anderson said they could provide a chart. (Meter 44:05)

Senator J. Lee said she would like to know what the other ratings are and if they are focusing on just enrolling the child in Medicaid, in which case it would be a family of one, or enrolling the entire family.

Ms. Anderson said this buy in is only for the children but is based on the families income.

Ms. Anderson then explained that for 100% of poverty for a one person household is $817 and for a household of four it is $1,667. At 200% of poverty, one person is $1,634 and a four person household is $3,334. She didn't have the 300% but said they would provide it.

Senator Dever asked if this bill should include the words "within the limits of appropriation".

Ms. Anderson replied that the way it is written there would be no capping the program. (Meter 46:40) It would be in an eligibility category.

David Boeck offered information that at 300% of poverty a family of four is $5,001 and an individual is $2,551.

With no further testimony, the hearing on SB 2326 was closed.

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2326

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-23-07

Recorder Job Number: 1719

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee opened SB 2326 for discussion on the chart that Maggie Anderson provided showing the family size and what the proposed buy in for children would be. (Attachment #10) The way the bill is written provides for the maximum that the feds permit for the Medicaid buy in. (Meter 0.35)

Senator J. Lee didn't favor going all the way to 300% poverty because that's more than some people make in some districts. It would be better to start at a lower level and see what kind of enrollment there is and see if it can be adjusted up. The number of children cannot be limited, but the percentage of poverty can be limited.

(Meter 2:05) The committee discussed 200% of poverty.

(Meter 3:48) Senator J. Lee said maybe what needs to be asked is if there is any practical way that it could be looked at as the child's medical costs as the percentage of the gross income. She said she would check with Maggie to see if they can do some sort of ratio.

Discussion was closed on SB 2326.

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2326

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-29-07

Recorder Job Number: 2192

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee, Chairman, brought the committee to order to discuss SB 2326. Maggie Anderson from the Dept. of Human Services was present and provided the committee with a chart for Medicaid buy in at 200% poverty. (Attachment #11) Senator J. Lee asked Ms. Anderson if the feds would let them do something such as a ratio of medical expenses to income or a net income being part of the medical costs.

Ms. Anderson said that within the deficit reduction act the only flexibility comes in terms of premiums they are allowed to attach. 200% of poverty would be able to go with a 5% premium and 200-300% of poverty could go with a 7 ½% premium. It's tied to income in that way.

Senator J. Lee asked about a net income.

Ms. Anderson replied that when they built the fiscal information for both the 200 and 300 it is assumed net. (Meter 2:10) The dept. always assumes net on an income unless they are told differently.

Senator J. Lee referred to a chart Ms. Anderson had shown them that had six different percentages of poverty and asked if all of those are net with the same disregards as CHIPs has.

Ms. Anderson said that not all of them have the same disregard as CHIP. Right now Medicaid has an additional disregard for self employed people that they don't have in SCHIP. (Meter 3:15)

Senator J. Lee asked about the possibility of tying this in with food stamps.

Ms. Anderson thought that food stamps were at 100% of poverty so it is much lower.

School lunch is 185% and WIC is 185%.

Senator J. Lee asked if there was a recommendation that Ms. Anderson and her colleagues could give about where to start with this.

Ms. Anderson (Meter 6:00) talked about tweaking Medicaid percentage for children 6-19.

Discussion on SB 2326 was closed until further information could be received from the department.

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2326

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-31-07

Recorder Job Number: 2359, 2451, 2453

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee called the committee to order and opened SB 2326 for information from Maggie Anderson, Dept. of Human Services.

Maggie Anderson explained a chart prepared for the committee on comparison of health care coverage options for children. (Attachment 12) (Meter 1:00)

Senator J. Lee thought the ones covered by the Katie Becket waiver had to be otherwise candidates for some kind of institutional setting so the waiver would permit those children to be cared for at home.

Ms. Anderson addressed the requirements for the Katie Becket eligibility option and the Medicaid waiver. (Meter 11:35)

Senator Warner asked when they calculate costs for this population having extraordinarily high medical costs, if they take that into effect or if they just use the average for Medicaid.

Ms. Anderson explained that for the fiscal note for SB 2326 they looked at the Medicaid population who are not institutionalized and they took an average. (Meter 13:00)

Senator Warner asked if there are any lifetime caps on Medicare.

Ms. Anderson replied no.

Senator J. Lee asked Ms. Anderson how she sees the waiver and the buy in blending.

Ms. Anderson answered that what they estimated specifically for the waiver was they would need $1.3 million to serve 15 children for the biennium and the waiver for children with extraordinary medical needs. (Meter 14:00) It is possible to do both with almost the original appropriation.

There was more discussion on the buy in and the waiver. They could implement both but the language in the bill would have to be altered.

(Meter 19:20) There was discussion on what the most practical thing to do would be and levels of poverty.

Senator Erbele asked if there are children out there to fill up the programs.

Ms. Anderson said it is reasonable to believe they would have an onslaught of children.

Senator J. Lee asked if Ms. Anderson and the dept. could help with the language for an amendment to do what had been discussed.

Ms. Anderson said they would be happy to.

The committee agreed that an amendment should include the waiver and 200% and one FTE.

Discussion on SB 2326 was closed.

Job #2451

Senator J. Lee opened SB 2326 for consideration of amendment provided by Ms. Anderson.

After reviewing the amendment it was noted that a FTE was not included.

Ms. Anderson said they would redo the amendment to include it.

Job #2453

Ms. Anderson presented the committee with a corrected proposed amendment which included the FTE. (Attachment #13)

Senator Warner moved to accept the Anderson amendment to SB 2326.

Seconded by Senator Erbele.

Roll call vote 6-0-0. Amendment accepted.

Senator Dever moved a Do Pass as amended on SB 2316 and rerefer to Appropriations.

Seconded by Senator Pomeroy.

Roll call vote 6-0-0. Motion carried. Carrier is Senator Dever.

Date: 1-31-07

Roll Call Vote #: 1

2007 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2326

Senate **HUMAN SERVICES** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Anderson amendment including FTE

Motion Made By Sen Warner Seconded By Sen. Erbele

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V. Chair	✓		Senator Jim Pomeroy	✓	
Senator Dick Dever	✓		Senator John M. Warner	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment

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

Date: 1-31-07

Roll Call Vote #: 2

2007 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2326

Senate **HUMAN SERVICES** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 70622.0101

Action Taken DP / amend / approp.

Motion Made By Sen. Dever Seconded By Sen. Pomeroy

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V. Chair	✓		Senator Jim Pomeroy	✓	
Senator Dick Dever	✓		Senator John M. Warner	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment Senator Dever

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

REPORT OF STANDING COMMITTEE

SB 2326: 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** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2326 was placed on the Sixth order on the calendar.

Page 1, line 11, after "<u>disabilities</u>" insert "<u>and whose net income does not exceed two hundred percent of the federal poverty line</u>"

Page 1, line 13, replace "$929,594" with "$1,059,932"

Page 1, line 14, replace "$1,507,317" with "$1,673,835"

Page 1, line 18, after "disabilities" insert "and for implementing the waiver described in North Dakota Century Code section 50-24.1-26 to provide in-home services to children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care" and after the period insert "The department of human services is authorized one full-time equivalent position for implementing the programs described in this Act."

Renumber accordingly

2007 SENATE APPROPRIATIONS

SB 2326

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2326

Senate Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: 02-08-07

Recorder Job Number: 3101

Committee Clerk Signature	

Minutes:

Chairman Holmberg opened the hearing on SB 2326.

Senator Tim Mathern, District 11, Fargo, introduced SB 2326 indicating the bill would allow families to buy into the medicaid program.

Bruce Murry, Attorney, ND Protection and Advocacy Project, presented written testimony (1) indicating how the Deficit Reduction Act allows and creates the Medicaid buyin for families with children with disabilities.

Mike Schwab, Executive Director, The Arc of Bismarck and representing The Arc of Cass County, presented written testimony (2) urging support of SB 2326. He indicated this legislation provides families of lower-middle income and middle income status to buy in to Medicaid for their child with disabilities.

Donene Feist, Edgeley, Mom, Director, Family Voices of North Dakota, distributed written testimony (4), testimony (3) of Zachary Feist, Edgeley, publication (5)Family Voices of ND, and Catalyst Center for Children and Youth publication (5a) in support of SB 2326. She discussed significant benefits that would be had by families affected, she discussed her personal situation, and presented real life situations of other families.

Carlotta McCleary, Executive Director, ND Federation of Families for Children's Mental Health (NDFFCMH), presented written testimony (6) in support of SB 2326. She discussed the problems families face with their insurance companies and how this bill will help in these situations.

Jennifer Restemayer, Bismarck, presented written testimony (7) in support of SB 2326. She indicated that as a parent of a child with MPS, a rare genetic disorder, requiring high costs of medical bills, the family opportunity act and SB 2326 provides hope for families in like situations.

Derek Zietz, parent of child with rare medical disorder, presented written testimony (8) testifying in support of SB 2326.

Mary L. Rennich, parent, Bismarck, presented written testimony (9) and published information about the Rennich Family Story in support of SB 2326.

Chairman Holmberg closed the hearing on SB 2326.

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2326

Senate Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: 02-08-07

Recorder Job Number: 3228

Committee Clerk Signature Alice Delzer

Minutes:

Chairman Holmberg opened the hearing on SB 2326 on February 8, 2007 relating to Medical Assistance and Health Coverage for Families of Children with Disabilities. He stated that Legislative Council had been asked to prepare amendment. It is a challenging bill and we will wait to move on this bill until we get the amendment from Legislative Council.

The hearing on SB 2326 closed.

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2326

Senate Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: 02/09/07

Recorder Job Number: 3271

Committee Clerk Signature	

Minutes:

Chairman Holmberg opened the hearing on SB 2326.

Senator Mathern indicated the purpose of this bill is for families to use the Medicaid program to help pay for the medical costs involved for their disabled child. These families pay a premium based on their net income. The federal government has money there as does the state. He indicated the difference of families at 200 percent of poverty versus those at 300 percent of poverty. He indicated that what happens if the family is not on medicaid, worse scenario is they eventually use up all of their resources and the whole family ends up on assistance and using sources of a variety of state programs. This bill would help those families stay above water and out of the system.

Questions were raised as to what the net income would be for families at 300 percent of poverty. The response was $75,000-$85,000. Additional questions were raised about the cost of a typical disabled child's medication, the average ND income, what would prevent insurance companies from dropping the family from coverage.

Maggie from Department of Human Services responded to several financial impact questions that were raised.

Senator Krauter moved a DO pass without amendments, Senator Bowman seconded.

Discussion followed. A roll call vote was taken resulting in 12 yes, 1 no, and 1 absent.

Senator Dever will carry the bill.

Chairman Holmberg closed the hearing on SB 2326.

Date:
Roll Call Vote #:

2007 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2326

Senate Appropriations Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass W/O Amend

Motion Made By Krauter Seconded By Bowman

Senators	Yes	No	Senators	Yes	No
Senator Ray Holmberg, Chrm	✓		Senator Aaron Krauter	✓	
Senator Bill Bowman, V Chrm	✓		Senator Elroy N. Lindaas	✓	
Senator Tony Grindberg, V Chrm	✓		Senator Tim Mathern	✓	
Senator Randel Christmann	✓		Senator Larry J. Robinson	✓	
Senator Tom Fischer	✓		Senator Tom Seymour	✓	
Senator Ralph L. Kilzer		✓	Senator Harvey Tallackson		
Senator Karen K. Krebsbach	✓				
Senator Rich Wardner	✓				

Total (Yes) 12 No 1

Absent 1

Floor Assignment Dever Hum Serv

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

REPORT OF STANDING COMMITTEE

SB 2326, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman) recommends **DO PASS** (12 YEAS, 1 NAY, 1 ABSENT AND NOT VOTING). Engrossed SB 2326 was placed on the Eleventh order on the calendar.

2007 HOUSE HUMAN SERVICES

SB 2326

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2326

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: February 27, 2007

Recorder Job Number: 3953

Committee Clerk Signature	Judy Schock

Minutes:

Chairman Price: We will open the hearing on SB 2326.

Representative Jasper Schneider District 21, Fargo, ND: I am a co sponsor of the bill and **Senator Tim Mathern, District 11 of Fargo** asked me to present the bill as he could not be here. The bill is a Medicaid buy in option for families with children with disabilities. See attached testimony.

Maggie Anderson, Director of Medical Services for the Department of Human Services: See attached testimony, and attachments of dollars for bills and attachments of guidelines for income levels.

Representative Porter: On the attachment caring for children 170% poverty. What program is that one?

Ms. Anderson: That is the program BC/BS runs for children that are in access of Medicaid or healthy steps guidelines. The way the current process works for health care coverage so a family could complete an application and turn it into their county office or state office. If it fails Medicaid it will be tested for Healthy Steps, or S CHIPS. If it fails for those we have an arrangement with BC/BS and we send in an electronic file to them with names and information. It is a very basic plan and funded by private funds.

Representative Weisz: The premium costs, is that just the average costs to Medicaid?

Ms. Anderson: We calculated that by looking at recipient liability and situations where families were currently not in the income guidelines where they were with the high risk liability are all factored into it.

Bruce Murry, lawyer with the ND Protection and Advocacy Project: See attached testimony, charts and budget projections.

Representative Conrad: Explain the difference between the 200-300%. Are you saying we would have more children if went to (couldn't hear) system?

Mr. Murry: If we went to 300% of the federal poverty level, that would approve more families because the families between 200-300% other wise would not have made it. There would be approximately an additional 376 children. Each of those additional children would average about an $1100.00, where as the first 402 children average about $1410.00. By extending the program to 300% because the families kick in more of their share. They can deduct out of pocket medical expense, child care, elder care, and insurance in addition to taxes.

Donene Feist from Edgely, ND: See attached testimony, testimony from Zachary when he testified on the Senate side, and also a booklet of other family stories along with waiver and buy in information. Many families fall through the cracks.

Vickey Peterson, reading the Kaseman I am very honored to read the testimony of Ariana. She passed away last Friday February 21.

Caitlin McDonald, I am here on behalf of the Arc of ND: We strongly support SB 2326. See attached testimony.

Jennifer Restemayer: See attached testimony. At the end of the testimony Jennifer introduces her daughter Allison.

Carlotta McCleary, Executive Director of the ND Federation of Families for Children's Mental Health. See attached testimony.

James M. Moench, Executive Director of the ND Disabilities Advocacy Consortium: See attached testimony.

Mike Schwab, Executive Director for the Arc of Bismarck: See attached testimony.

Chairman Price: Anyone else to testify on SB 2326? Any opposition on SB 2326? Hearing none we will close the hearing on SB 2326.

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2326

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: March 7, 2007

Recorder Job Number: 4601

Committee Clerk Signature	Judy Schock

Minutes:

Rep. Kaldor: I move a do pass and re-refer to appropriations.

Rep. Porter: I second that.

Rep. Price: Is there any discussion?

Rep. Porter: We have made huge strides in these areas from what we started a couple sessions ago. The huge voids that we had in the system and the gaps that were created by our system and some of the language coming from within the agencies are making huge steps. I think this is a huge step in the right direction. I sure hope that it has favorable following in appropriations and it comes to a great policy for families inside of the state of ND.

Rep. Price: When we look back to the people who dealt with this bill and that it has now been approved.

Rep. Porter: During the last session the department was opposed to us doing something. Everybody stuck to their guns and we put pressure to them. All of a sudden this is the next best thing. The process works.

Rep. Price: We will take a roll call vote on a do pass. The do pass motion passes with a vote of 11-0-1. Is there a volunteer to carry this?

Rep. Uglem: I will.

Date: 3/7
Roll Call Vote #: 1

2007 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. "Click here to type Bill/Resolution No."

House HUMAN SERVICES SB 2326 Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass RR/App

Motion Made By Rep. Kaldor Seconded By Rep. Porter

Representatives	Yes	No	Representatives	Yes	No
Clara Sue Price – Chairman	✓		Kari L Conrad	✓	
Vonnie Pietsch – Vice Chairman	✓		Lee Kaldor	✓	
Chuck Damschen	✓		Louise Potter	✓	
Patrick R. Hatlestad	✓		Jasper Schneider	✓	
Curt Hofstad	✓				
Todd Porter	✓				
Gerry Uglem	✓				
Robin Weisz					

Total (Yes) 11 "Click here to type Yes Vote" No 0 "Click here to type No Vote"

Absent 1

Floor Assignment Rep. Uglem

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

REPORT OF STANDING COMMITTEE

SB 2326, as engrossed: Human Services Committee (Rep. Price, Chairman) recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (11 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). Engrossed SB 2326 was rereferred to the **Appropriations Committee**.

2007 HOUSE APPROPRIATIONS

SB 2326

2007 HOUSE STANDING COMMITTEE MINUTES

Bill No. SB 2326

House Appropriations Committee
Human Resources Division

☐ Check here for Conference Committee

Hearing Date: March 14, 2007 10 AM

Recorder Job Number: 5068

Committee Clerk Signature

Minutes:

Chairman Pollert opened the hearing on SB 2326

Rep. Uglen testified: (see written testimony + handout)

Senator Lee: Introduced the bill and said it is important to remember that we want to support working families and that is really what happens here. If these are families of working parents that are Medicaid eligible in other ways it will be covered. This is to try and help those families that above those levels. It is a small number of families that are affected, but it is just a crushing burden for these families to provide care that all of us would agree we would want our children to have if we were those families. The Senate message is we really think this is an important issue to deal with and it is a better way to do it this way rather than piece meal way we have been addressing it and we certainly hope you will see your way clear to pass 2326.

Senator Dever: (See testimony) I simply brought my floor speech.

Bruce Murry: Lawyer with Protection and Advocacy Project (See testimony) Flip over to the family budget on the back. These were developed consulting real families. The family in the first column is trying to purchase a moderate home. They don't quite balance out yet with the mortgage I have for them so they may need to keep shopping for a more modest home. I just wanted to give you some family budgets that would fit this bill and these would be 225% of the poverty level.

Donese Feist from Edgeley, ND: (see testimony) (Zachary Feist testimony)

Rep. Metcalf: We talk about a 200% and 225%. What difference would it make to you as a family, the difference between the two.

Donese Feist: At 200% we are not going to be able to enroll as many families as we would at 225 even at 300% the families that could possible be enrolled are 800; so it is all based on income. Net income for family of 4 is $40,000. This would not help my family right now, but there are other families it would help. They would be able to buy into Medicaid, which means they would have more comprehensive coverage so what private insurance did not cover medical assistance could. So they would not be going 30-40 thousand dollars in debt to get the help they need for their children.

Rep. Metcalf: I am concerned about the additional costs? Does that 300% have any affect on that additional costs or is that going to be the same?

Donese Feist: We will always have costs.

Roxanne Romonic: Read testimony from Derek Zietz family: (written testimony).

Carlotta McCleary: (written testimony)

Rep. Wieland: You stated in your testimony that at least 1 in 10 children and adolescent have a serious emotional disturbance. Can you be specific what document you got that information from with Department of Health and Human Services?

Carlotta McCleary: It comes from the Surgeon Generals Report and again from the Bush Commission on Mental Health and on their website on facts about mental health.

Jennifer Restemayer: (written testimony)

Mike Schwab, Executive Director for the Arc of Bismarck: (written testimony)

Maggie Anderson: Director of Medical Services for the Department of Human Services:

(see testimony)

Rep. Nelson: I was looking through the amendment that was added. Was the amendment to provide the in home services?

Maggie Anderson: The amendment did two things: The bill was introduced to implement the buy in of 300% of poverty so the amendment dropped that to 200% and then the amendment added the dollars to fund the waiver with children with extra ordinary health needs.

Rep. Ekstrom: Is the department aware of any families with more than one child with these kinds of special needs? Is there a need to half that premium?

Maggie Anderson: We do not know about any of those.

Rep. Kerzman: At 300% how many families would be eligible to review this?

Maggie Anderson: I can get you that; I believe it is 778. yes .

Rep. Nelson: The 225% of poverty was mentioned; do you have that information about how many more eligible children come at that level?

Maggie Anderson: No we do not. We built it based on the 300% when the Senate requested the amendment to 200. No committee has asked us for that information. Would you want that information?

Chairman Pollert: Yes I would like that information.

Missy Barenko from Dickinson: Discussed has a 9 year old daughter and told her story of the choices she has had to make to contend with the situation and how her family and her other four children and how they make choices to be sure the money goes around. This would make a huge difference with our family.

Opposed: None

Hearing closed.

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. **SB 2326**

House Appropriations Committee
Human Resources Division

☐ Check here for Conference Committee

Hearing Date: 3-23-07

Recorder Job Number: 5515

Committee Clerk Signature

Minutes:

Chairman Pollert: SB 2326 is the bill referred to as the Medicaid Buy-In…any discussion?

Rep Bellew: If I'm not mistaken this is a new program, is this correct?

Chairman Pollert: Yes, that's correct. Just a review…it deals with the 200% poverty level…a simple way to say it is it acts as a second insurance…that's the mechanics of it. We know it deals with the families with children that have medical problems.

Rep Ekstrom: I think what I like best about this is that it takes a more comprehensive approach…I think all of us have been here long enough to know that we get children or folks coming in with a very specific disease and we've done pretty well by those folks and I think this covers a whole group of people…we may only have one case of a particular illness but the effect on those families is profound…this is in no way beginning to cover their cost...this just gives them one more tool…this is not the first provider of services…this is after their own insurance takes care of them. So if you're have a child that's going to cap out with the Blue Cross/Blue Shield maximum of something like $2M, this will kick in and help.

Rep Kerzman: If you look at some of the testimony, this is a new program but I think it's really a cost effective program. With the department in for the Medicaid buy in you actually get a portion of that to be part of the way matched. From Maggie Anderson's testimony the buy in for the children would be about $900T of which $300T are general funds and just for 15 children, what the expected enrollment is…the annual cost $44T a child and that estimated expenditures for the biennium are $1.3M of which almost $500T are general funds so a little over ½ of that you could buy the insurance to cover a lot more children. The I'm reading this, it's really a cost effective program…it probably would make a few more eligible but in the long run, I think it would benefit the state…I think we could save money.

Chairman Pollert: I think the testimony showed I think 400 families would be affected by that. Any other discussion?

Rep Kerzman: I move a DO PASS

Rep Wieland: I second it

Chairman Pollert: Any discussion? If not we'll take a roll call vote.

Yes 5 No 3 Absent 0 Carrier Rep Kerzman

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2326

House Appropriations Committee

☐ Check here for Conference Committee

Hearing Date: 3-26-07

Recorder Job Number: 5560

Committee Clerk Signature	Holly N. Ssd

Minutes:

Chairman Svedjan opened the hearing on SB 2326.

Rep Kerzman moved a Do Pass on SB 2326

Rep Ekstrom seconded the motion

Rep Kerzman: This is a Medicaid buy in. As it was delivered from the policy committee it was a win win situation for ND. It allows the dept to seek a waiver for Medicaid buy in and it would allow families with up to 200% of poverty level who have very sick children to be able to have Medicaid insurance cover those instances. What we're doing now is doing it on a case by case basis. It's actually costing us more money and there would be a sliding fee scale that families would have to participate in. The information that we got from the dept, that with the federal dollars in there, it would not cost us any more money. It should be cost effective. They're estimating at about $117 per child is what the insurance would cost. The appropriation is in here for about $1M of general funds and about $1.6M of federal. There would be one full time employee to administer the program.

Chairman Svedjan: For clarification - $117 per child - is that per month? (yes)

Chairman Svedjan: Is this a new program?

Rep Kerzman: Yes, it is. And as soon as you open it up more people will be eligible that is why the increase.

Chairman Svedjan: With particular relevance to the children, what relevance would this program have to what we've done with chips so far this session?

Rep Kerzman: I think the children that we are talking about have greater needs than CHIPS.

Chairman Svedjan: You mentioned Russell Silver Syndrome - would this program capture those special health needs.

Rep Kerzman: I believe they would.

Chairman Kerzman: Are we still appropriating money for Russell Silver Syndrome and PKU. Would we end up with a duplication?

Rep Kerzman: I think it's about $100,000 in the program. I asked the dept to look into that.

Rep Wald: How many children are eligible?

Rep Kerzman: About 402.

Rep Wald: And that requires another FTE?

Rep Kerzman: It requires another FTE to seek the waiver and administer the program.

Rep Pollert: For a family of four - 100% of poverty level the income is $20,004 . 150% of poverty is $30, 984. 200% of poverty is $40,008.

Chairman Svedjan: Is the annual average income in ND $36,000?

Rep Skarphol: I think that the highest average wage county is Oliver and I think it's $39,000. That's the average wage. The $40,008 is gross income. Are we insuring the child with disabilities or the whole family?

Rep Kerzman: It's just the child.

Chairman Svedjan: The program would insure only children, not the families of the children and it's on a sliding scale.

Rep Skarphol: What other disabilities are we talking about?

Rep Kerzman: We are talking all special needs. We did not discuss that in committee.

Rep Nelson: I think the group that would be covered would be medically fragile children. They may need special care - there is a definition for these children and it allows them to stay in the home. If they weren't at home it would cost the state a lot more money.

Rep Ekstrom: The one child that we heard about - her costs are running between 7and 10 thousand dollars a month for her medications. She is fairly young right now, by the age of 10 they are estimating she will cap out the $2M on Blue Cross Blue Shield.

Chairman Svedjan: What happens to the revenue received by virtue of the sliding fee scale?

Rep Kerzman: It offsets the cost of the premium.

Rep Pollert: Some figures to help out - 402 children disabled, 15 special health care children. On the part of income - for 2006 (based on 300%) for a family of four this amount would be $6668/month net income. Medicaid becomes the backup player.

Rep Skarphol: What does net income trlate into as far as gross?

Rep Pollert: Add another 20-25%. I'd have to have actual numbers.

Rep Skarphol: Based on Rep Ekstrom's numbers with regard to these special needs and the fact that we are taking care of a very small number now and have the potential for 400, are we looking at much larger general fund need than what is here. Is the beginning of a rather large ongong expenditure in the future.

Rep Pollert: This one's at 200%. In future biennium's you will probably have a bill coming forward for 225% of the poverty level.

Rep Aarsvold: Who's caring for these children now and what are the costs that we incur through social services for instance?

Rep Pollert: Many may claim medical bankruptcy. Many families try to get under another program - some do and many don't. That's why the bill is here.

Rep Metcalf: This is for those who are destitute. They have to relinquish custody of their child to the courts so that the courts support them. If the courts support them, we know where that money comes from. It won't take long for the families to turn this over to the courts. We shouldn't take these kids away from the parents when Medicaid will pay for them. Any one of us could have a child born with these syndromes that we are talking about.

Rep Wieland: I want to clear up the net/gross issue. $40,008 has to be gross.

Rep Skarphol: Could we ask Maggie Anderson to come up and address the issue.

Maggie Anderson, Division of Medical Services, Dept of Human Services: The information in the bill is net income. Everyone is allowed the same deduction in Medicaid so if they don't have like a work training deduction or medical insurance or expense deduction, they don't have the deduction, so they don't get it. But their income is still compared to these guidelines. These guidelines can be used as either net or gross depending on state policy and state law. In ND we use net income. So it would be 200% net.

Rep Aarsvold: We all toured facilities with wards of the state, and in many cases those are costing the state hundreds of thousands of dollars so it does not seem unreasonable to provide this kind of insurance.

Rep Kempenich: Did you identify any offsetting reductions in other programs if we did this?

Rep Kerzman: I think we had to wait and see what this bill was going to come out first and then the conference committee can iron out the differences. I don't recall any commensurate reductions in other program.

A Roll Call Vote was taken on the Do Pass Motion on SB 2326

(yes) 16 (no) 7 (absent) 1

Carrier: Rep Uglem

Date: 03-23-07
Roll Call Vote #:

2007 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2326

House HUMAN RESOURCES DIVISION Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass

Motion Made By Rep. Kerzman Seconded By Rep. Wieland

Representatives	Yes	No	Representatives	Yes	No
Chairman Pollet		X	**Rep. Nelson**	X	
Vice Chairman Bellew		X	**Rep. Kerzman**	X	
Rep. Wieland	X		**Rep. Metcalf**	X	
Rep. Kreidt		X	**Rep. Ekstrom**	X	

Total (Yes) 5 No 3

Absent

Floor Assignment Rep. Kerzman

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

Date: 3/26/07
Roll Call Vote #: 1

2007 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2326

House Appropriations Full Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number ——

Action Taken Do Pass

Motion Made By Kerzman Seconded By Ekstrom

Representatives	Yes	No	Representatives	Yes	No
Chairman Svedjan		✓			
Vice Chairman Kempenich		✓			
Representative Wald		✓	Representative Aarsvold	✓	
Representative Monson		✓	Representative Gulleson	—	
Representative Hawken	✓				
Representative Klein	✓				
Representative Martinson	✓				
Representative Carlson	✓		Representative Glassheim	✓	
Representative Carlisle	✓		Representative Kroeber	✓	
Representative Skarphol	✓		Representative Williams	✓	
Representative Thoreson	✓				
Representative Pollert		✓	Representative Ekstrom	✓	
Representative Bellew		✓	Representative Kerzman	✓	
Representative Kreidt		✓	Representative Metcalf	✓	
Representative Nelson	✓				
Representative Wieland	✓				

Total (Yes) 16 No 7

Absent 1

Floor Assignment Rep. Uglem

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

REPORT OF STANDING COMMITTEE

SB 2326, as engrossed: Appropriations Committee (Rep. Svedjan, Chairman) recommends **DO PASS** (16 YEAS, 7 NAYS, 1 ABSENT AND NOT VOTING). Engrossed SB 2326 was placed on the Fourteenth order on the calendar.

2007 TESTIMONY

SB 2326

Attachment #1

SB 2326
Human Service Committee
January 22, 2007

Madam Chairman Judy Lee and members of the Senate Human Services Committee. My name is Tim Mathern, Senator from District 11 in Fargo. I am here to introduce SB 2326.

One issue of concern to many of my constituents is access to affordable insurance and the cost of health care in general. While this bill does not address all of these concerns it does respond to some of the greatest needs.

Often there are extraordinary financial and social challenges for a family who has a child where there are disabilities involved. Often medical bills can become overwhelming.

Section 1 of this bill directs the Department of Human Services to establish a "buy in" program to give some support to these families. The support is permitting these families to become a part of the Medicaid program by meeting certain criteria and participating in the program. In return, they become eligible for coverage offered by the already established Medicaid progam.

Someone from the Department of Human Services will explain the potential program and the costs noted in Section 2 of the bill. Families are here to share their stories.

I see Senate Bill 2326 as establishing a method of taking advantage of federal resources available to us as a state and supporting the families who struggle with the challenges a disability brings.

I will leave discussion of further details and the fiscal note to others. I ask for your support of SB 2326. The families in your district will be most appreciative of your concern and your practical response by establishing this buy in Medicaid option.

Thank you.

Attachment # 2

January 22, 2007

SENATE HUMAN SERVICES COMMITTEE
SB 2326

CHAIRMAN LEE AND COMMITTEE MEMBERS:

My name is Caitlin McDonald. I'm appearing here today on behalf of The Arc of North Dakota. **We strongly support SB 2326 and urge a do pass.**

The Arc is an open membership organization made up of people with mental retardation and other related developmental disabilities, their families, friends, interested citizens, and professionals in the disability field.

It is organized on three levels: local chapters, state chapters and the national organization. All three levels provide opportunities to engage policy-makers in efforts to improve public policy affecting people with mental retardation and related developmental disabilities and their families.

The Arc of North Dakota has over 1,500 committed members and friends...your neighbors and constituents...in chapters in Grand Forks, Fargo, Valley City, Jamestown, Bismarck, Dickinson and Bowman.

Our **Mission Statement** is to improve the quality of life for children and adults with mental, retardation and related developmental disabilities and their families through advocacy, education and family support services.

Public policy advocacy is an essential component of the Arc movement, and that's why we're here today. Arc members have worked together over the past 50 years to secure family support services, special education, health care, leisure opportunities, vocational training, community housing and other community support services.

Middle income families of children with special health care needs often face difficult choices to provide health care for their families. These can include bankruptcy, surrendering custody of the children to the state to assure Medicaid coverage for them or spending down their resources or turning down raises to stay eligible for Medicaid.

[OVER]

This bill allows working families to purchase Medicaid to act as a wrap-around for medically necessary services denied by their private insurance carriers.

This is not an entitlement program. Families must maintain their own private insurance if they have it. They must use a significant portion of their income to pay for it. However, in most cases, threes costs will be significantly less expensive that the out-of-pocket costs they are paying now for the actual services.

Therefore, we respectfully request that you give SB 2225 a do pass. If you have any questions, I will be happy to try to answer them. THANK YOU FOR YOUR TIME AND CONSIDERATION.

Attachment #3

Madame Chair and Committee Members,

My name is Donene Feist from Edgeley, North Dakota. I am here today on two levels, first and foremost as mom of Zachary and second as the Family Voices of North Dakota State Director. I want to extend a special thanks to you Madame Chair and members of the committee in bringing forth this very important bill for families of children with disabilities.

The Family Opportunity Act is an important piece of legislation for a number of reasons. The FOA as it passed in Congress gave states the option to create a Medicaid "buy in" or purchase coverage under the Medicaid program for families of children with disabilities.

With the passage of the Family Opportunity Act in North Dakota, families will benefit in the following ways:

- Children with significant disabilities can receive the health care services they need to reach their potential. Children will no longer be denied care or have limited care and so their health will most likely improve because they are given the care they need at the appropriate time and spend less time in the emergency rooms or hospitals which will bring down the cost of care.
- Parents can accept raises, promotions or new jobs that increase family income above the poverty line.
- Fewer parents will have to choose between paying for the health care for their child or other necessary family expenses such as food, clothing and shelter.
- Fewer parents will have to place their child out of the home in order to access appropriate health services or forgo custody of their child in order to access appropriate health services.

Parents of children with special health needs and disabilities are unjustly punished for working hard to support and provide for their families. This bill is a major step forward for the families who have been denied opportunities so that their children with special health needs and disabilities can get the care they need. It will remove some of the barriers that prevent families from staying together and staying employed—while giving hope and freedom to those who deserve it most

Let me provide a bit of history for you on this bill as I have followed this legislation since the beginning. This piece of legislation was initiated several years ago in 2001. It passed in the Senate twice prior to full passage of both Houses in 2005 in the Deficit Reduction Act.

This is important for many reasons some of which I will describe later. This was introduced by Senators Grassley and Kennedy; and Representatives Sessions of Texas and Waxman of California to Congress. On the House side it was introduced as the Dylan Lee James Act. In Congress, this bill had overwhelming support with a combined 270 sponsors in the House and Senate.

Why Dylan Lee James? Dylan Lee James was born with Down syndrome as well as a severe heart defect, which ultimately led to his untimely death. While spending enormous amounts of financial resources to assist in the health care of Dylan, his family was shocked to find that they would be declared "ineligible" for government assistance for Dylan after his father accepted a bonus at work. The passage of this legislation would change this course for many families.

A#3

I was honored and humbled to be in attendance when this vital legislation was introduced; to describe the atmosphere of the room was electric. As Senator Grassley provided information and each additional speaker presented to families, children with disabilities, advocates, and staff from every walk of life from around the country, true tears of hope, my own included filled the room. At times, I still tear up thinking of that day because of its impact. For the families in attendance, in many ways, we knew this was not the cure all or end all but it certainly was the rope of hope which we could grab onto and help many families across the country that faced the same struggles as we did. Many North Dakota families shared their stories some of whom are in the booklet that I share with you today. I am proud that families from North Dakota as well as those from around the country made a cornerstone in history.

The relief the Family Opportunity Act provides is crucial to millions of middle-income families across the country that have children with disabilities who require expensive health care. My hope is that we will continue to make history and implement this important legislation for families in North Dakota, as it is the right thing to do and builds upon the workers with disabilities legislation passed in North Dakota several years ago.

Many middle-income families in North Dakota that have children with significant disabilities do not have access to affordable and adequate health insurance to cover their children's chronic health care needs.

Most employer provided health insurance does not provide for the comprehensive medical care that these children need. This must be clearly understood. Just because families have health insurance does not mean their needs are being met. Many of these families are under insured as private insurance simply does not meet the health needs of these complex children.

The coverage they need is available through Medicaid, but they cannot access it because their family earnings are too high to qualify. Medicaid by all standards provides **the most** comprehensive health care for this population of children. Far too many of these families are faced with the stark choice of becoming impoverished in order to gain access to Medicaid as their only feasible health care option for their children. Other equally unacceptable options that these families have to consider are an out-of-home placement or the relinquishment of custody of their child with a disability so that they will ensure Medicaid coverage of their child's health care needs. These families have to face bankruptcy, impoverishment, or the loss of their child to secure what most American families take for granted - comprehensive health care for their children. This legislation provides reasonable solutions: access to health care and assistance for families in acquiring the appropriate health care coverage.

In our own personal story, because of our son's health needs, we have faced medical bankruptcy, and it is an ugly situation to be in. In comparison to the many other families our story is just one of many. His costs are not as extensive as many other families and yet here I am, facing bankruptcy. This bill will not help my family now, it is too late for us, and it is too late for Dylan Lee James but it is in your hands now to help many others. I personally don't want to see other families have to go through what we have gone through.

Our story is not unique. Zachary has a severe hearing impairment and a compromised immune system due to other illnesses; he receives extensive speech therapy, hearing aides, adaptive equipment etc. Our insurance plan as comprehensive as it is for most of my family **simply did not** cover Zachary's needs because of its limited benefits package. We did what we had to do, so Zach could become all that he could be.

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I remember vividly, the day Zachary was diagnosed and will never forget being told by the physician and specialist as I was holding him on my lap and my husband holding our daughter how she (10 months younger) would always excel much further than what Zach would be capable of doing. My head was swimming in dizziness, and I was physically ill with worry on how we would ever afford and meet his needs with the information that was being presented to us.

As parents it is our job to do what you have to do to meet the needs of your children. Those of you who may not have a child with special needs or a disability, just for a moment envision the most frightening moment you had in raising your child. In those moments you protect, nurture and simply put do what needs to be done to help your child get through. Now envision your own child having a significant medical issues and taking care of the health needs of these children day in and day out. Imagine deciding whether to buy milk or drive your child to therapy, not being able to go to the dentist because the other medical bills were just too high.

These families are faced with decisions that no family should have to face. The choices we make often shuffle between necessity and basic human needs. While we are masters of pulling ourselves up by our boot straps, that ability gets harder and harder. We become exhausted, isolated and feel defeated. This comes from personal experience, and yet somehow in that weakness there is strength to keep going because here is this kiddo who keeps you moving forward.

Families then in order to express what it will take to meet their needs have to open their lives up for public viewing and scrutiny. It is not easy to tell policy makers your story, your financial situation, it exposes the most private moments of a family. I am sharing mine in hopes that it will help you understand and make sound policy decisions on behalf of these families. In my mind, all of the families in North Dakota are heroic in their own way.

Zachary is now 16 years old. He is my hero. He is independent, mature, athletic, and compassionate and for his youth has more insight than many adults. He is the one who reminds me when I have become sour at the world of the beauty within. He is the reason who quite honestly at times has caused me to have an out of body experience as I become more than enthusiastic at the Edgeley Kulm Rebel football games. He is the one who has taught me that any dream is achievable. He who we were told would lag so far behind and unable to do certain things is living proof.

Would we as his parents done anything differently…actually no, **there were NO other options**. In providing his health care needs, we went deeper and deeper into debt, what choice did we have?? Was it worth it, look at him and you tell me. I say, **Absolutely!** He talks, he communicates, he has held jobs, he is in all sports, and excels in everything he does. Had we not gone the distance, had we given up and be beaten would he be doing these things…we will never know, as it wasn't something we took lightly or willing to compromise. Would a program such as the Family Opportunity Act have helped us? No doubt about it.

Families shouldn't have to impoverish themselves to get the help they need for their children, worry about whether a pay raise will raise their income eligibility and they lose Medicaid as a vital support for their family. **For families of children with disabilities and special health care needs, we are in a state of emergency.** This bill changes that course.

In closing, let me say this….The Department of Human Services has prepared an OAR for this legislation. I am also providing to you information from the Catalyst Center, a national organization on health care financing which provided states with the impact of what this

A#3

legislation would mean for states. Their methodology compares considerably with what the Department has prepared.

A significant problem is many families fall through the cracks. Many parents of these children have to drop out of the workforce or keep themselves in a low-paying job just to remain eligible for Medicaid. In effect, the system is forcing parents to choose between near-poverty and their children's health care. We need to fix that. It will close the health care gap for North Dakotas most vulnerable children, and enable these families. It is also an essential investment in the health and independence of these young people that will strengthen North Dakota families and children.

Medicaid is an essential program for children and youth with special health care needs. Its comprehensive benefits should serve as a model for <u>all</u> children and youth needing specialized health care services, whether publicly or privately funded. For children and youth whose primary private health coverage benefits are limited, secondary health care coverage, like Medicaid, is essential. It allows us to create options for families with children with special health needs and disabilities to buy into Medicaid while continuing to work. Parents would pay for Medicaid coverage on a sliding scale.

This legislation is pro-work because it lets parents work without losing their children's health coverage, pro-family because it encourages parents to work and build a better life for their children, and it's pro-taxpayer because it means more parents continue to earn money, pay taxes and pay their own way for Medicaid coverage for their children.

Let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child's most basic human rights. This bill will embrace the needs of families and move us forward in the right direction.

Again, I thank you for allowing me the time to provide input on this vital bill for families

Donene Feist

PO Box 163, Edgeley, North Dakota

(701) 493-2333

A#3

November, 2006

CATALYST CENTER IMPROVING FINANCING OF CARE *for Children & Youth* WITH SPECIAL HEALTH CARE NEEDS

Methodology for Estimating the Impact of State Implementation of the Family Opportunity Act

Passed as part of the Deficit Reduction Act of 2005, the Family Opportunity Act (FOA) allows states the option of extending income eligibility and creating a buy-in program to expand Medicaid coverage to children with severe disabilities who have family incomes up to 300% of the Federal Poverty Level (FPL).

The Catalyst Center has developed a methodology for estimating the impact of state implementation of the FOA. **Please note: our methodology bases its estimates on national survey and administrative data. As a result, the estimates are not customized according to state-specific criteria such as SCHIP and Medicaid benefit comparability and family income eligibility for SCHIP.**[1] We suggest using the estimates generated by this model as an initial estimate of the impact of the FOA, and encourage interested parties to contact us to discuss strategies for refining the estimates using state-specific data.

Basic Assumptions

In order to estimate the number of children who will enroll in Medicaid under the FOA, we begin by making an assumption regarding the fraction of CSHCN[2] between 100% and 300% of FPL who are functionally eligible for Medicaid. We assume it is roughly similar but not exactly the same as the fraction of CSHCN below 100% of FPL who are functionally eligible for Supplemental Security Income (SSI). Under this assumption, it makes sense to think that the fraction of CSHCN between 100% and 300% of FPL who enroll in Medicaid will be slightly smaller than the fraction of children under 100% of FPL who are currently enrolled in SSI. We say 'slightly smaller than' rather than 'equal to' because we assume that:

- Families above 100% of FPL may be less aware, at least initially, of the new option of Medicaid coverage under the FOA than families whose children are eligible for SSI;
- The potential stigma associated by some with Medicaid coverage may discourage enrollment of families above 100% of FPL; and,

- States will impose a modest premium requirement under the FOA. This may discourage enrollment among the uninsured who cannot afford the premiums and among privately insured families whose out-of-pocket costs do not exceed the cost of the premiums.

Approach and Additional Assumptions

Our approach is described in detail below, including the additional assumptions we have made in developing our estimates.

1. We use the 2001 National Survey of Children with Special Health Care Needs (NSCSHCN), conducted by the National Center for Health Statistics, as our basic data source.[3] This survey provides the most recent data available on a large national probability sample of children, with information on the number of CSHCN, the number of children receiving SSI benefits and type of coverage (public, private or uninsured).

2. As shown in **Table 1:** among CSHCN in families with incomes below 100% of FPL, SSI enrollment in 2001 was 28% for those without private insurance, and 18% for those with private insurance. Among CSHCN with family incomes above 100% of FPL, SSI enrollment decreases dramatically, primarily because many fewer children in families with survey-reported income above 100% of FPL are income eligible for the program.

3. We trend the data in **Table 1** forward to 2005 and adjust for missing data on income and private insurance status. In the 2001 CSHCN survey, there are an estimated 707,000 children receiving SSI. Program administrative data indicated that there were 844,000[4] children receiving SSI in December 2000. The difference between the survey and administrative data are likely due to missing data in the survey and a small amount of under-reporting of SSI coverage in the survey. SSI enrollment for children grew between December 2001 and December 2005, reaching 1,034,000[5] in December 2005. We assume that SSI enrollment grew in each income and private insurance category proportionally.

   We adjust for missing data in the 2001 survey, again assuming that CSHCN with missing data on income or private insurance status are distributed proportionally to children without missing data, and we trend the 2001 count of the number of children to 2005 using data from the census on the growth in the number of children between 2001 and 2005. The trended and adjusted data are shown in **Table 2.**

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Table 1. Proportion of CSHCN, 0-17, receiving SSI, by family income and private insurance status, 2001

Family Income (% of FPL)	Without Private Insurance		With Private Insurance	
	Number of CSHCN	% Receiving SSI	Number of CSHCN	% Receiving SSI
< 100%	782,695	28.0%	283,255	18.4%
100-200	871,943	17.6%	998,643	8.3%
200-300	253,470	12.3%	1,288,119	3.8%
300-400	110,172	10.6%	1,293,996	3.1%
400% +	105,216	16.0%	2,302,272	2.2%
Total	2,123,496	20.4%	6,166,285	4.5%

Number of CSHCN with missing data on insurance, income, or SSI receipt: 1,030,000.

Source: 2001 National Survey of CHSCN.

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Table 2. Proportion of CSHCN, 0-18 receiving SSI, by family income and private insurance status, estimates for 2005

Family Income (% of FPL)	Without Private Insurance		With Private Insurance	
	Number of CSHCN	% Receiving SSI	Number of CSHCN	% Receiving SSI
< 100%	960,371	35.7%	347,556	23.5%
100-200	1,069,879	22.5%	1,225,341	10.6%
200-300	311,009	15.7%	1,580,529	4.9%
300-400	135,182	13.5%	1,587,741	3.9%
400% +	129,101	20.4%	2,824,901	2.8%
Total	2,605,542	26.0%	7,566,067	5.7%

Source: 2001 National Survey of CHSCN.

Note: Estimates for 2005 are constructed by multiplying the numerator of the 2001 estimates by the ratio of (1,034,000/707,442) (which is the ratio of the number of < 18 SSI recipients in 2005 to the number of < 18 CSHCN SSI recipients in the 2001 NSCHSCN), and further multiplying this number by 1.07 to include 18 year olds, and multiplying the denominator of the 2001 estimates by the estimated growth in the < 18 population from 2001 to 2005 (which is 2%), by the ratio (9.32/8.39) (which is the ratio of the estimated number of CSHCN in the 2001 data divided by the estimated number of the CSHCN in the 2001 data with valid data for income, private insurance status, and SSI receipt), and by 1.07 to account for the inclusion of 18 year olds in the final estimates.

A#3

4. Because the FOA extends Medicaid eligibility to youth who are 18 years old, and both the National Survey of Children With Special Health Care Needs and Social Security Administration data only include youth through the age of 17, we make an additional adjustment in **Table 2** to increase the number of potentially eligible children at each income level and for each insurance category by 7%. This percent was derived by examining Social Security Administration data by age category. Since youth aged 13-17 represent approximately 35% of all children on SSI across a 5-year spread, we assume an equal distribution of 7% per year in this age spread, and so we add another 7% to the total number of "children" on SSI to account for 18-year-olds, as well as to the numerator of children potentially eligible for coverage under the FOA.

5. As shown in **Table 2,** we estimate that approximately 36% of CSHCN below 100% of FPL without private insurance were enrolled in SSI in 2005. The percentage enrolled in SSI drops to 22% among CSHCN between 100% and 200% of FPL, and to 16% among CSHCN between 200% and 300% of FPL. Among children who are covered by private insurance, the SSI percentages are 23%, 11%, and 5% for CSHCN in the three income groups.

6. As discussed above, we assume that if a state implements the FOA and increases income eligibility for Medicaid up to 300% of FPL, the fraction of CSHCN who enroll in Medicaid in families between 100% and 300% of FPL will increase to levels that are close to, although not equal to, the fraction of children below 100% of FPL who are currently enrolled in SSI. As shown in **Table 3,** we assume that enrollment in Medicaid will increase to 32% among CSHCN in families with incomes between 100% and 200% of FPL, and 28% in families with incomes between 200% and 300% of FPL. These estimates are close to the 36% of CSHCN below 100% of FPL who are enrolled in SSI, but clearly somewhat lower than that figure.

   We have estimated the income-gradient in enrollment using our best judgment and analysis of the income-gradient in enrollment in SCHIP. In making these estimates we assume that a state will impose nominal premiums for coverage. If premiums are higher, enrollment is likely to be substantially lower than we have estimated here. In making these estimates we have not made any explicit adjustment for differences in the

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prevalence of disability among CSHCN above 100% of FPL. The Catalyst Center is currently working on an analysis to estimate whether there is less disability among CSHCN as income increases; if that analysis indicates that the level of disability among CSHCN does decline with family income, we will adjust estimated Medicaid participation downwards among children above 100% of FPL.

Similarly, among CSHCN with private insurance, we assume that Medicaid participation will be 19% in families with incomes between 100% and 200% of FPL, and 15% in families between 200% and 300%, compared to an SSI enrollment rate of 23% among CSHCN in families with incomes below 100% of FPL. The caveats about our assumptions regarding children without private insurance also apply to these estimates for children with private insurance.

Under these assumptions, as shown in **Table 3,** an estimated 133,000 children without private insurance and an estimated 247,000 children with private insurance would enroll in Medicaid under the FOA, *if* it were true that none of these children were currently eligible for Medicaid or SCHIP. (See #8 for adjustments to these estimates in states with SCHIP coverage up to 200% of FPL).

7. In the next step, we adjust the national numbers for different state circumstances. In the example, we use the 2001 national survey of CSHCN to estimate the number of CSHCN in a specific state in each income group and for each insurance status (private or public), adjusting the numbers for missing survey data on income or insurance status. The 2001 data then is trended forward to 2005 using the national growth rate in the number of children.

8. The next adjustment estimates the impact of the FOA on changes for children without private coverage between 100% and 200% of FPL. This is dependent on the configuration of the SCHIP program in each state, specifically the financial eligibility criteria and the comparability of SCHIP and Medicaid benefits. In this example, we assume all children without private insurance under 200% of FPL are eligible for SCHIP and that the SCHIP benefits are comparable to Medicaid benefits. Therefore, children between 100% and 200% of FPL who become eligible for Medicaid under the FOA are already eligible for SCHIP and are likely to be enrolled in the program already. While a few children may switch from SCHIP to Medicaid after the FOA is implemented, it will not have a

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Table 3. Estimated nationwide effect of FOA on enrollment in Medicaid, 2005

Family Income (% of FPL)	Without Private Insurance					With Private Insurance					Total
	Number of CSHCN	Estimated 2005 SSI Enrollment	Estimated Enrollment in Medicaid Post-FOA	Difference	Estimated Number of FOA Children	Number of CSHCN	Estimated 2005 SSI Enrollment	Estimated Enrollment in Medicaid Post-FOA	Difference	Estimated Number of FOA Children	
100-200	1,069,879	22.5%	32%	9.5%	101,879	1,225,341	10.6%	19%	8.4%	102,966	
200-300	311,009	15.7%	28%	12.3%	38,185	1,580,529	4.9%	15%	10.1%	159,714	
Total					140,065					262,680	402,745

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major impact on costs since the benefits are comparable across programs. In states where SCHIP eligibility is less than 200% of FPL or SCHIP benefits are substantially different from Medicaid benefits, different adjustments must be made.

9. Using Congressional Budget Office (CBO) estimates,[6] we multiply the number of children eligible for coverage under the FOA by the average cost of coverage for SSI-enrolled Medicaid children. That is, we multiply the number of FOA-eligible children with private insurance by $7,000, and the number without private insurance by $12,800 to obtain the full cost of covering these children. The CBO cost estimates use 2006 as the base, thus we trend this amount forward by 5% per year to 2008.

10. In the last step, we calculate the cost to the state general fund of implementing the FOA by subtracting the FMAP (Federal Medical Assistance Percentage), i.e., the portion of the total expenditures that will be paid by the federal government.

For Further Information

For further information about the Catalyst Center's methodology or obtaining a state-specific impact estimate, please contact Meg Comeau, Project Director, at 617-426-4447, extension 27, or mcomeau@bu.edu.

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[1] For example, the model assumes a ceiling of 200% of FPL for SCHIP eligibility.

[2] Children with Special Health Care Needs

[3] 2001 National Survey of Children with Special Health Care Needs. Data for estimates were obtained from the National Survey of Children with Special Health Care Needs Data Resource Center, http://www.cshcndata.org.

[4] 2006 Annual Report of the SSI Program, http://www.ssa.gov/OACT/SSIR/SSI06/tables.html.

[5] Ibid.

[6] Congressional Budget Office Cost Estimate, S. 622 Family Opportunity Act of 2003, September 23, 2003, http://www.cbo.gov/showdoc.cfm?index= 4570&sequence=0.

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Table 4. Estimated FOA effect on enrollment and Medicaid expenditures, [Sample State], 2005

		Without Private Insurance	With Private Insurance	Selected Totals	Catalyst Center Methodology Ref.
Estimated number of CSHCN in [State]					
Family Income (% of FPL)	100-200	1,747	3,245		Section 1 (page 2)
	200-300	473	4,304		
	Total	2,220	7,549		
Estimated percentage point increase in Medicaid in [State]					
Family Income (% of FPL)	100-200	9.5%	8.4%		Section 6 (pages 5-6)
	200-300	12.3%	10.1%		
Estimated FOA effect on enrollment					
Family Income (% of FPL)	100-200	9.5%	8.4%		Section 7 (page 6)
	200-300	12.3%	10.1%		
FOA enrollment adjusted for SCHIP					
Family Income (% of FPL)	100-200	0	273		Section 8 (pages 6, 8)
	200-300	58	435		
	Total	58	708	766	
Estimated 2006 Medicaid expenditures per child (Federal and State)		$12,800	$7,000		Section 9 (page 8)
State Medicaid Percentage		35.28%			Section 10 (page 8)
Estimated annual increase in Medicaid expenditures per child		5%			Section 9 (page 8)
[State] General Fund Expenditures, 2008		$288,875	$1,926,684	$2,215,559	Section 10 (page 8)

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Table 5. Supplementary Data, [Sample State]

	United States	[State]
Number of children in SSI, 2005[4]	1,034,000	952
Number of children in SSI, 2001[3]	707,442	N/A
Number of children 0-17, 2001	73,119,741	158,451
Number of CSHCN 0-17, 2001	9,356,463	19,651
2005 SSI/CSHCN	10.8%	4.7%
CSHCN/All children	12.8%	12.4%
Children in SSI/All children	1.4%	0.6%
CSHCN without private insurance		
100%-200% FPL	980,281	1,601
200%-300% FPL	284,963	433
CSHCN with private insurance		
100%-200% FPL	1,122,724	2,973
200%-300% FPL	1,448,167	3,944
% CSHCN without private insurance		
100%-200% FPL	10.5%	8.1%
200%-300% FPL	3.0%	2.2%
% CSHCN with private insurance		
100%-200% FPL	12.0%	15.1%
200%-300% FPL	15.5%	20.1%

Methodology for Estimating the Impact of State Implementation of the Family Opportunity Act, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, November, 2006. The Catalyst Center is funded by the Maternal and Child Health Bureau of the Health Services and Resources Administration, U.S. Department of Health and Human Services, under grant #U41MCO4494.

Attachment # 4

Madame Chair and Committee Members,

My name is Jennifer Restemayer. I am excited to be here today to testify in favor of Senate Bill 2326, a Medicaid Buy in Bill for families of children with disabilities who are over the income guidelines for Medical Assistance or Medicaid.

My daughter, Allison, was diagnosed with MPS 1, a rare Genetic Disorder, in January of 2003. MPS 1 is progressive and degenerative, it affects every system in her body including her brain. Allison is at a very high risk for developmental decline. Allison is now 5 years old, and attending Kindergarten. Allison is very fortunate, she has a treatment available. She gets an Enzyme Replacement Therapy(ERT). ERT is a **weekly** I.V. infusion that usually takes about 4 hours once the IV is started. The cost of the drug is very high. We receive shipment of Allison's medication and supplies every two weeks. The cost billed to our insurance is $6,970.88 every two weeks. Our family has insurance under Blue Cross Blue Shield of MN, and luckily we are covered well right now. We have an annual out of pocket max, and after we have paid that, we are covered at 100% after our office co-pay. However, BCBS, has the right to change the way we are covered at any time, with only providing us with a 30 day written notice. I do not know what we will do if that would happen. One year of **just** Allison's medication would be $167,301.12. If we owed even 10% of that out of pocket, my family would not be able to pay for it. Allison has a 2 million dollar lifetime max on her insurance policy. We estimate that Allison could hit her lifetime max before she turns 10 years old. If at that time Allison does not qualify for state services, I do not know how we will make it.

We have applied for Medicaid and were denied because the recipient liability for Allison exceeds monthly medical expenses. Allison's recipient liability is set at $3,648.22. That means that our families out of pocket for Allison would have to exceed $3,648.22 per month before Medicaid would help. I do not know a middle class family that could afford to pay $3,648.22 in medical expenses every month. We have also applied for services through the Department of Disabilities. Allison was denied eligibility at age 3 because she is not Mentally Retarded. We had another round of developmental testing done in August 2006,at the University of MN, and unfortunately her test scores were down. The Dr's fear that this could be the start of her developmental decline. I hope and pray and believe that they are wrong. I took the new information we received from the developmental testing and re-applied for DD Services. Allison was denied again. Even though her test scores show a downward trend, she is not yet impaired enough to qualify for state services. In other words, Allison may be starting to decline cognitively, but until she declines enough to reach a level to be classified as Mentally Retarded, she will not qualify.

Our insurance through BCBS of MN has provided good coverage for Allison, but is not without its problems. This spring and summer, Allison had ear infection after ear infection. Her ear tubes became blocked and were not serving their purpose, because of the blocked tubes and the fluid behind them, Allison's hearing became very bad very fast. Allison needs to be at the

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University of MN for any procedure requiring her to be put under anesthesia because of her complex diagnosis, her issues in her neck and spine, her very narrow airway, and her heart condition. Once new ear tubes were placed, her hearing did not get back to the level she was hearing at last spring. Allison needed bilateral hearing aides. Hearing aides are not covered at all in our insurance plan. We were quoted $5,200.00 for her hearing aides by our local provider. I was lucky enough to have a relative who sells hearing aides, so we were able to get them for cost, $2,800.00. Unfortunately, our local provider charges a fee to service hearing aides that are not purchase through them. The fee was $700.00. Not covered by insurance at all.

Families like mine need a little extra help. We need to feel like we are not alone in trying to ensure that our children do not decline, to keep them as healthy as we can for as long as possible. My daughter is not the only child with a terminal diagnosis that does not qualify for state services. Families like mine need to know that we have a little support. We do not need to live knowing that we will have our child for a short time, live with the constant stress of how we will pay the medical bills from month to month, try to give our children as wonderful of a childhood as possible. Yet, ultimately be forced to take them from cradle-to-coffin despite our great efforts to avoid just that.

My husband and I live with the stress of not knowing how we will cover Allison's medical bills if our insurance company should change the way they cover her, or **when** she hits her lifetime max. The Family Opportunity Act, or the Medicaid buy in would help **so many** middle class families in our state to feel secure in being able to provide for their children with special needs. Senate Bill 2326 is a ray of **hope** for my family. Thank you for taking the time to listen.

Jennifer Restemayer
2217 E. Capitol Ave
Bismarck, ND 58501
(701)222-0493

Attachment # 5

SB 2326 – Family Opportunity Act (Medicaid Buy-In)

Senate Human Services Committee
Madame Chair – Sen. Lee
January 22, 2007

Madame Chair and members of the Committee, my name is Mike Schwab, Executive Director for The Arc of Bismarck. I am representing The Arc of Bismarck and The Arc of Cass County and our constituents today.

I am here to ask for your support in passing an important piece of legislation. SB 2326 would offer middle-income families of children with disabilities the option of buying-into Medicaid. Currently, these children meet the definition of "disability" as defined by Social Security but are ineligible for Medicaid because their families make too much money. Because of this restriction, families are often un-insured or underinsured because health insurance is not available through their employer, it is too expensive, or offers a limited number of benefits.

In addition, parents are often times forced to remain in the same job to keep health insurance or to decline employment in order to access state/federal benefits. Giving parents the option of buying into Medicaid and paying on a sliding fee scale would provide children with disabilities in these families access to the full range of Medicaid services.

This provision would allow the state to cover young children with "potentially severe disabilities", and promises improved overall health. It would also help with the prevention of future disabilities and these children would have a better chance to live full and healthy lives with their families in their home communities where they belong.

This legislation offers stability, rehabilitation, and recovery to children with severe and chronic disabilities this may also include the early on-set of mental illnesses. It also breaks the link between forced poverty and Medicaid. It also builds on the work incentives law that was enacted in 1999.

We would like to thank you for your continued support of children and their families and ask that you pass SB 2326. Thank you for your time and attention today.

Respectfully Submitted,

Michael D. Schwab
The Arc of Bismarck
The Arc of Cass County

Attachment #6

Testimony
North Dakota Disabilities Advocacy Consortium

SB 2326
North Dakota Family Opportunity Act

Same to Sen House Human Services

Senate Human Services Committee
January 22, 2007

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 22 organizations concerned with addressing the issues that affect people with disabilities (see attached list). We are very interested in improving the ability of people with disabilities and their families to fully participate in all aspects of life in North Dakota.

The NDDAC believes that North Dakota has a great opportunity to implement an innovative option provided for as part of the Deficit Reduction Act of 2005 [Pub.L.109-171; 120 Stat. 4; 42 U.S.C 1396] with the adoption of the federal Family Opportunity Act. That program is essentially a Medicaid Buy-in Program for children. By passing the Family Opportunity Act provisions contained in SB 2326, North Dakota will be establishing and implementing a buy-in program that will provide medical assistance and other health coverage options of families of children with disabilities.

The NDDAC strongly supports SB 2326, the North Dakota Family Opportunity Act and urges the Senate Human Services Committee to give this bill a do pass.

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

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NORTH DAKOTA DISABILITIES ADVOCACY CONSORTIUM

2006 Membership

1. AARP
2. Dakota Center for Independent Living
3. Family Voices of North Dakota
4. Freedom Resource Center for Independent Living
5. Independence Center for Independent Living
6. ND APSE: The Network on Employment
7. ND Association of the Blind
8. ND Association of the Deaf
9. ND Association for the Disabled
10. ND Center for Persons with Disabilities (NDCPD)
11. ND Children's Caucus
12. Fair Housing of the Dakotas
13. ND Fed. of Families for Children's Mental Health
14. ND Human Rights Coalition
15. ND IPAT Consumer Advisory Committee
16. ND Mental Health Assn.
17. ND Statewide Living Council
18. Options Resource Center for Independent Living
19. Protection & Advocacy Project
20. The Arc of Bismarck
21. The Arc of Cass County
22. The Arc of North Dakota

Updated: July 10, 2006

Attachment # 7

TESTIMONY: SENATE BILL 2326
SENATE HUMAN SERVICES COMMITTEE

JUDY LEE, CHAIRWOMAN

January 22, 2007

Chairman Lee and members of the Committee: my name is Carlotta McCleary. I am the Executive Director for the ND Federation of Families for Children's Mental Health (NDFFCMH). The Federation of Families is a parent run organization that focuses on the needs of children with emotional, behavioral and mental disorders and their families. On behalf of the Federation, I am here to testify in support of SB2326.

According to U. S. Department of Health and Human Services, studies show that at least one in five children and adolescents have a mental health disorder. At least one in 10, or about 6 million people, have a serious emotional disturbance. Two thirds are not getting the help they need. The estimate of North Dakota's total child count with a serious emotional disturbance is 15,770 youth. According to the Department of Human Services the number of children and adolescents diagnosed with a severe emotional disturbance who received publicly funded services in FY 2005 was 1,692. The estimated number of children and adolescents diagnosed with severe emotional disturbance in need of service is 3,217.

The NDFFCMH believes children and their families must receive supports necessary to remain with their families; out-of-home placement must be considered as a last resort. When children cannot remain with their families, out-of-home placement must be viewed as temporary and an extension of the family. This treatment must be available close to the child's home and family members must be involved in all decisions regarding their child.

Children are presenting with more complex issues at an earlier age and in greater numbers while at the same time, North Dakota's child count is decreasing. According to the Department of Public Instruction there is a significant increase of children qualifying for special education in the category of emotional disturbance. Specifically the number of children enrolled in special education programs doubled between 1993 and 2004. According to the Department of Human Services the eight regional human service centers also report that children are referred at younger ages and are presenting with multiple and more complex issues. In 2005, each child admitted to ND Psychiatric Residential Treatment Facilities presented with an average of 6-co-occuring Axis I diagnosis.

In 1994, the Division of Mental Health Services received a16.8 million five-year grant from the Center for Mental Health services targeting children and adolescents diagnosed with serious emotional disturbances. The comprehensive System of Care that was developed was called Partnerships Project; services were care coordination, respite care non-hospital crisis case aide, school-based day treatment, flexible funds, safe beds and intensive in-home family therapy. North Dakota was able to sustain core services from

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Partnerships Project, which include care coordination, case aide, flexible funds and crisis residential services-safe beds.

According to The United States General Accounting Office, in 2003 they reported 12,700 cases of children were placed in the child welfare and juvenile justice systems to access mental health services. According to the 2003 New Freedom Commission on Mental Health Federal, State and local governments must work together with family and provider organizations to eliminate the practice of trading custody for care and to find a more family friendly solution. North Dakota is one of 13 states that have passed laws that prohibit DHS from requiring custody relinquishment in order for parents to obtain out-of-home treatment for their children. However, ND currently has no laws to improve access. North Dakota's Voluntary Treatment program serves an average of 16 children per biennium. The Voluntary Treatment Program ran out of funding the first six months of the biennium.

The NDFFCMH would like to see the Family Opportunity Act fully implemented. This would allow families access to care that their children desperately need. Children would gain access to community-based services such as Partnerships, which would enable then to remain at home. For some families the cost of treatment has prevented them from getting this care. This often leads families to relinquish custody of their children in order to obtain treatment. North Dakota's Voluntary Treatment Program is for children who are eligible for Medicaid. Families who aren't eligible for Medicaid have limited coverage from their insurance or they don't have any coverage for out-of home treatment. Thereby forcing parents to relinquish custody of their children, which makes them eligible for Medicaid. This bill allows families to gain access to needed treatment.

Thank you for your time.

Carlotta McCleary, Executive Director
ND Federation of Families for Children's Mental Health
PO Box 3061
Bismarck, ND 58502

Phone/Fax: (701) 222-3310
Email: carlottamccleary@bis.midco.net

Attachment # 8

Senate Human Services Committee
Sixtieth Legislative Assembly of North Dakota
Senate Bill No. 2326
January 22, 2007

Good morning, Chairman Lee and Members of the Senate Human Services Committee. I am David Boeck, a State employee and lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project advocates on behalf of people with disabilities.

For several consecutive legislative sessions, the Legislature has wrestled with improving health care coverage for children with extraordinary health care needs. Last session, this Committee worked with the House Human Services Committee on Senate Bill 2395, which later became law. During the interim, members of this Committee and other legislators have continued to look for ways to help families who have children with extraordinary health needs.

SB 2326 would implement a Medicaid option made available through the federal Family Opportunity Act, which is part of the federal Deficit Reduction Act of 2005.

This measure would allow families of modest means who have a child with disabilities, to purchase Medicaid coverage for that child. This measure would apply only to families with annual incomes below 300% of federal poverty level. The monthly premium would be 7.5% of income, the same income percentage through which Workers with Disabilities can purchase Medicaid coverage in North Dakota.

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Most North Dakota families of children with disabilities earning 300% of poverty level income could not rent a fully accessible apartment without public assistance. A family eligible for this program would be able to continue working and rent a fully accessible apartment or possibly buy a modest home.

The benefits to children with disabilities and their families would be immense.

Thank you for the opportunity to testify in favor of this legislation. Please let me know if you have questions.

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TESTIMONY: SENATE BILL 2326
SENATE APPROPRIATIONS COMMITTEE

SENATOR RAY HOLMBERG, CHAIRMAN

January 22, 2007

Chairman Holmberg and members of the Committee: my name is Carlotta McCleary. I am the Executive Director for the ND Federation of Families for Children's Mental Health (NDFFCMH). The Federation of Families is a parent run organization that focuses on the needs of children with emotional, behavioral and mental disorders and their families. On behalf of the Federation, I am here to testify in support of SB 2326.

According to U. S. Department of Health and Human Services, studies show that at least one in five children and adolescents have a mental health disorder. At least one in 10, or about 6 million people, have a serious emotional disturbance. Two thirds are not getting the help they need. The estimate of North Dakota's total child count with a serious emotional disturbance is 15,770 youth. According to the Department of Human Services the number of children and adolescents diagnosed with a severe emotional disturbance who received publicly funded services in FY 2005 was 1,692. The estimated number of children and adolescents diagnosed with severe emotional disturbance in need of service is 3,217.

These problems take a number of forms. The children may be self-abusive or aggressive toward others; or they may be withdrawn, fearful, or depressed. Some with the most serious disorders may be out of touch with reality and have unusual fantasies or hallucinations.

Families may face many problems; the absence of appropriate childcare prevents many families from participating in social or recreational activities and they experience isolation from friends and relatives. Often, family members must learn to cope with the difficulty and demanding behaviors of their children, and may face the staggering costs for special treatment, education, or other services.

According to the Larry Burd Study on the interim report of cost and service use for children with severe emotional disturbance in North Dakota: Parents Cost Study; there is an impact on parental employment, time spent and costs that are not reimbursed to the family. These cost are excess costs in terms of time and money for this group of children. These cost are in excess of the time and money parents spend on other children. Thus these costs are due to the efforts to treat the child with emotional and behavior problems. All costs (time and money) are not reimbursed from any source and represent the parental (family) contribution to the effort to treat these problems.

Here are some of his findings:

There was an impact on parental employment, 20% now work only part time, 22% had to quit work and 16% are with a different job. Also noted were loss of income at $5,354.55 per year, vacation time cost at $547.50 per year, sick leave cost at $365.00 per year and missed work cost at $602.25 per year.

Time spent for travel, meetings and loss of sleep; total lost time was 790 hours per year. Costs to a family that are not reimbursed such as miles traveled $6,905.50, travel costs $1,022.00, purchases $3,204.70, co pay or other medical costs $1,357.80, Repairs $3,073.30, extra help $1,314.00, other costs $923.45 and extra telephone costs $219.00.

In conclusion the study found parents paying an excess of $17,983.55 to care for a child with an emotional behavioral or mental disorder for a year.

The NDFFCMH believes children and their families must receive supports necessary to remain with their families; out-of-home placement must be considered as a last resort. When children cannot remain with their families, out-of-home placement must be viewed as temporary and an extension of the family. This treatment must be available close to the child's home and family members must be involved in all decisions regarding their child.

Children are presenting with more complex issues at an earlier age and in greater numbers while at the same time, North Dakota's child count is decreasing. According to the Department of Public Instruction there is a significant increase of children qualifying for special education in the category of emotional disturbance. Specifically the number of children enrolled in special education programs doubled between 1993 and 2004. According to the Department of Human Services the eight regional human service centers also report that children are referred at younger ages and are presenting with multiple and more complex issues. In 2005, each child admitted to ND Psychiatric Residential Treatment Facilities presented with an average of 6-co-occuring Axis I diagnosis.

In 1994, the Division of Mental Health Services received a16.8 million five-year grant from the Center for Mental Health services targeting children and adolescents diagnosed with serious emotional disturbances. The comprehensive System of Care that was developed was called Partnerships Project; services were care coordination, respite care non-hospital crisis case aide, school-based day treatment, flexible funds, safe beds and intensive in-home family therapy. North Dakota was able to sustain core services from Partnerships Project, which include care coordination, case aide, flexible funds and crisis residential services-safe beds.

According to The United States General Accounting Office, in 2003 they reported 12,700 cases of children were placed in the child welfare and juvenile justice systems to access mental health services. According to the 2003 New Freedom Commission on Mental Health Federal, State and local governments must work together with family and provider organizations to eliminate the practice of trading custody for care and to find a more family friendly solution. North Dakota is one of 13 states that have passed laws that prohibit DHS from requiring custody relinquishment in order for parents to obtain out-of-home treatment for their children. However, ND currently has no laws to improve access. North Dakota's Voluntary Treatment program serves an average of 16 children per biennium. The Voluntary Treatment Program ran out of funding the first six months of the biennium.

The NDFFCMH would like to see the Family Opportunity Act fully implemented. This would allow families access to care that their children desperately need. Children would gain access to community-based services such as Partnerships, which would enable then to remain at home. For some families the cost of treatment has prevented them from getting this care. This often leads families to relinquish custody of their children in order to obtain treatment. North Dakota's Voluntary Treatment Program is for children who are eligible for Medicaid. Families who aren't eligible for Medicaid have limited coverage from their insurance or they don't have any coverage for out-of home treatment. Thereby forcing parents to relinquish custody of their children, which makes them eligible for Medicaid. This bill allows families to gain access to needed treatment.

Thank you for your time.

Carlotta McCleary, Executive Director
ND Federation of Families for Children's Mental Health
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Attachment #9

Testimony
Senate Bill 2326 – Department of Human Services
Senate Human Services Committee
Senator Judy Lee, Chairman
January 22, 2007

Chairman Lee, members of the Human Services Committee, I am Maggie Anderson, Director of Medical Services for the Department of Human Services. I appear today to provide information on the appropriation section of this bill.

The Deficit Reduction Act of 2005 enacted a new eligibility category that would allow families with incomes up to 300 percent of the federal poverty level to "buy in" to Medicaid for a child with a disability. This bill proposed to add this eligibility category to the North Dakota Medicaid program. As you may recall, 2005 Senate Bill 2395 directed the Department of Human Services to apply for a waiver to provide in-home services to children with extraordinary needs who would otherwise require hospitalization or nursing facility care. Over the interim, the Department convened a group of stakeholders for the purpose of gathering input for and writing this waiver. 2005 Senate Bill 2395 did not contain an appropriation, and the Department was unable to include the funding for this waiver in our Budget request. However, as we prepared Optional Adjustment Requests (OARs), it was determined that we would prepare an OAR that would encompass the cost to implement both the waiver and the Buy-In for Children. As a reference Attachment A is a document prepared for the Interim Budget Committee on Human Services, which provides information on the Waiver, the Buy In for Children and on another option for coverage, the Katie Beckett Eligibility Option.

#9

What is represented in the appropriation section of this bill is only the funding to implement the Medicaid Buy-In. It does **not** contain sufficient funds to implement the Waiver.

The estimate for the Buy-In for Children is based on an expected enrollment of 778 children. Based on an average monthly cost per child of $157.43, the estimated cost is $2,939,533, which is offset by premiums which would be collected of $873,288. The premium is estimated to be $117 per child per month. Families who have health insurance would **only** pay a premium if their current out of pocket expenses for their premiums are less than five percent of their gross income. Therefore, once all expenses and premiums are offset, the expected grant expenditures for the Buy In for Children would be $2,066,245 of which $744,261 are general funds.

Additionally, there would be expenses related to administration. Specifically, there would be expenditures for overtime for Department staff to process the premium payments. This is estimated to be $63,840 for the biennium. Also, there would be enhancements to MMIS and the Vision system. The estimated cost for the modifications is $306,726.

The estimated grant, overtime, and system enhancement expenditures are included in the appropriation section of this bill. The Department's OAR requested a Full Time Equivalent (FTE) for the development, implementation, and operation of this program. The appropriation section does not authorize the addition of the FTE or provide funding for the FTE. Funding for the FTE for the 2007-2009 Biennium would be $103,462 of which $51,731 would be general funds. Without the FTE, other projects or efforts would need to be postponed or cancelled in order to implement

#9

this program; therefore, we respectfully request an amendment to this bill to authorize an FTE for the Department and to provide the additional funding.

I would be happy to answer any questions that you may have.

ttachment A

North Dakota Department of Human Services - Medical Services Division
Joint Committee Hearing – Budget Committee on Health Care / Budget Committee on Human Services
September 12, 2006

	Waiver-Special Health Care Needs	Medicaid Buy-In for Children	Katie Beckett Eligibility Option
Overview Description	A Home and Community Based Waiver is designed to reduce extended hospitalizations and prevent skilled nursing facility placements for children who are medically fragile by providing assistance for families who require long term supports and services to maintain their child in a family home setting while meeting their child's unique medical needs.	The Family Opportunity Act, authorized by Congress in 2006 as part of the Deficit Reduction Act (DRA), allows states to create Medicaid buy-in programs targeted at children who meet the Social Security standard for disability, but who come from families with incomes above standard Medicaid eligibility limits. States do not need a federal waiver to implement a buy-in program under this law. States would need legislative approval and appropriation, as well as CMS approval.	The Katie Beckett Eligibility Option is an optional eligibility category that allows children with long-term disabilities or complex medical needs, living at home, to access Medicaid services.
Group That Would Be Covered	Medically Fragile children ages 3 to 18. Medically Fragile children are at times medically stable but still may require skilled nursing care, specialized therapy, and specialized medical equipment and supplies to enhance or sustain their lives. To qualify for the waiver, children would need to meet nursing facility or hospital level of care criteria. For the waiver, the State would develop and use a tool to help evaluate the intensity of the care needed by medically fragile children.	Disabled Children 18 and under, whose family income does not exceed 300% of poverty (could be lower, at state option). In 2006, for a family of 4, this amount would be $6668.00 per month (**net income**). Assets are not considered. Based on Federal implementation guidelines, eligibility for these buy-in programs will be phased in starting in October 2007 when children 6 and under will be eligible for the program. Children ages 7-13 will be added in October 2008, and children from 14-18 will be eligible beginning October 2009.	Children 18 and under who do not have income or assets in their name in excess of the current standards for a child living in an institution. Without the Katie Beckett Eligibility Option, the income of legally liable relatives is counted when the individual is cared for at home.
Medical Conditions of Group	Children must meet Institutional (hospital or nursing facility) Level of Care criteria in order to qualify for waiver services. If not for the waiver, a child would require services in a hospital or nursing facility. Initial enrollment will be based on the greatest need.	Children must be determined to be disabled under Social Security Act guidelines.	Children must be determined to be disabled under Social Security Act guidelines and require a level of care at home that is typically provided in an Institution.
Number of Children Covered	15	Estimated 778 (Includes about 31 that would switch from medically needy).	Estimate not available at this time.
Estimated Cost / Year	The estimated cost per year would be $44,769 per Child ($671,535 total for 15 children) This includes both Medicaid State Plan and Waiver Services	$2,066,245 per biennium. This includes an offset of premiums estimated to be over $800,000.	Estimate not available at this time. #6

Attachment A

	Waiver-Special Health Care Needs	Medicaid Buy-In for Children	Katie Beckett Eligibility Option
Services Offered	All Medicaid Services. Proposed waiver services include: ▶ In-home Support ▶ Respite ▶ Excess medically related expenses not covered by the State Plan ▶ Case Management Medicaid waivers are required by federal law to be cost neutral. The overall cost of waiver services cannot cost more than institutionalization. (This figure does not include Medicaid State Plan costs.)	All Medicaid Services.	All Medicaid Services. The cost to Medicaid cannot exceed the cost Medicaid would pay if the child were in an institution.
Cost to Family (RL / Premium)	The family will not incur a Medicaid Recipient Liability as the family income and assets will not be an eligibility consideration.	Premium equal to 5% of family's gross income. The law requires participating families to first take advantage of employer-sponsored health insurance options (if available and if the employer pays at least half of the monthly premium cost). These premiums would be offset by the family's private insurance premiums. Recipient Liability would not apply.	Premiums and/or Recipient Liability would not apply.
Program Caps / Limits	Waivers allow a cap on enrollment. States may also determine the individual cost limit at less than institutional costs or have no individual cost limit. The Department of Human Services is proposing a waiver that caps the number of individuals enrolled and the amount of waiver services each individual may obtain per year.	All who meet program requirements would be allowed to buy-in. Limits within the Medicaid program would apply.	All who meet eligibility requirements would access Medicaid. Limits within the Medicaid program would apply.
Other			ND Medicaid covers children to age 21 under the medically needy option, versus 18 under the Katie Beckett option. We can cover the individual under the child category instead of as a disabled child, which allows us to disregard family assets. Under medically needy we also do not have to monitor, or limit, costs to insure they are less than if the child were in an institution. Many of these children are likely receiving HCBS, so only the child's income is considered during full calendar months in which the child receives HCBS.

Attachment # 10

Maggie D. Anderson
01/23/2007 01:11 PM

To: Judy E. Lee <jlee@nd.gov>, Robert S. Erbele <rerbele@nd.gov>, Dick D. Dever <ddever@nd.gov>, Joan M. Heckaman <jheckaman@nd.gov>, John M. Warner <jwarner@nd.gov>, Jim R. Pomeroy <jpomeroy@nd.gov>
cc: Carol K. Olson/DHS/NoDak@NoDak, Brenda M. Weisz/DHS/NoDak@NoDak, LeeAnn G. Thiel/DHS/NoDak@NoDak, Debra A. McDermott/DHS/NoDak@NoDak, soelke@state.nd.us, sofisb@state.nd.us, Curtis A. Volesky/DHS/NoDak@NoDak
Subject: SB 2326 - Medicaid Buy In for Children

Senator Lee and Committee Members

Monday, during the hearing on SB 2326, you requested a chart with the various income eligibility levels. I am attaching the chart we currently use for Medicaid and Healthy Steps, with a column added for the 300% of poverty, which would be the maximum allowed with the Medicaid Buy-In for Children.

1-22-07 Income Chart with 300%.(

Senator Dever also asked if there was a way to limit the number of children who could be served with the Medicaid Buy-In. If SB 2326 were enacted, as introduced, it would create a new, optional Medicaid eligibility category. We contacted the Centers for Medicare and Medicaid Services (CMS) and were told that it would not be possible to limit the number of children enrolled. Just as we would be unable to limit the number of individuals enrolled in other Medicaid eligibility categories (categorically needy, Workers with Disabilities, medically needy, etc.) CMS indicates we would be unable to limit the enrollment in this category.

Please note: it would be possible to adjust the percentage of poverty that is used for the Medicaid Buy In, up to 300% (maximum). It may be better to start lower and expand as funding allows. as adjusting the poverty level downward after implementation may result in children enrolled losing coverage. If you are interested in this option, we would be happy to provide additional information.

Please contact me if you have additional questions.
Maggie

Maggie Anderson, Director
Division of Medical Services
600 East Boulevard Avenue
Bismarck, ND 58505-0250
(T) 701-328-1603 (F) 701-328-1544
e-mail: soandm@nd.gov

INCOME LEVELS EFFECTIVE JANUARY 1, 2007

Family Size	Family Coverage (1931)	Med. Needy	SSI (Effective 01/01/07)	Children Age 6 to 19 and QMB 100% of Poverty	SLMB 120% of Poverty	Preg. Women Child to Age 6 133% of Poverty	QI-1 135% of Poverty	Healthy Steps 140% of Poverty	Caring for Children 170% of Poverty	Transitional Medicaid 185% of Poverty	Women's Way 200% of Poverty	Workers with Disabilities 225% of Poverty	PROPOSED Buy-In for Children 300% of PL
1	$311	$ 500	$623	$ 817	$ 980	$1087	$1103	$1144	$1389	$ 1511	$1634	$1837	$ 2,451
2	417	516	934	1100	1320	1463	1485	1540	1870	2035	2200	2475	3,300
3	523	666		1384	1660	1840	1868	1937	2353	2560	2767	3112	4,152
4	629	800		1667	2000	2217	2250	2334	2834	3084	3334	3750	5,001
5	735	908		1950	2340	2594	2633	2730	3315	3608	3900	4387	5,850
6	841	1008		2234	2680	2971	3015	3127	3798	4132	4467	5025	6,702
7	947	1083		2517	3020	3348	3398	3524	4279	4656	5034	5662	7,551
8	1053	1141		2800	3360	3724	3780	3920	4760	5180	5600	6300	8,400
9	1159	1200		3084	3700	4101	4163	4317	5243	5705	6167	6937	9,252
10	1265	1250		3368	4040	4478	4546	4714	5726	6230	6734	7574	10,104
+1*	107	57		284	340	377	383	397	483	525	567	637	852

Spousal Impoverishment Levels

Community Spouse Minimum Asset Allowance (Effective 01/01/07)	Community Spouse Maximum Asset Allowance (Effective 01/01/06)	Community Spouse Income Level (Effective 01/01/03)	Income Level for each Additional Individual (Effective 04/01/06)
$20,328	$101,640	$2,267	$550

Average Cost of Nursing Care

Average Monthly Cost of Care (Effective 01/01/07)	Average Daily Cost of Care (Effective 01/01/07)
$ 4865	$ 159.96

Note: LTC income level increased from $40 to $50 effective with the benefit month of 01/01/02

Rev. 12/200

A#10

U:\Legislative Information\2007\Medicaid Income Level Chart (Rev 2006-12).doc

1-29-07
Maggie Anderson

Attachment # 11

North Dakota Department of Human Services

SB 2326

Medicaid Buy-In at 200% Poverty
Requested by Senate Human Services

Estimated Expenditures	$1,518,885
Offset of Premiums	$602,316
Net.Expenditures	$916,569
General	$330,148
Federal	$586,421
Administrative	
Full Time Equivalent	$103,462
System Changes	$306,726
Staff Overtime	$63,840
Total Administrative	$474,028
General	$237,014
Federal	$237,014
Total	$1,390,597
General	$567,162
Federal	$823,435

The Medicaid Buy-In for Children is estimated to serve 402 Children at 200% of poverty.

SB2326

North Dakota Department of Human Services
Medical Services Division

Comparison of Health Care Coverage Options for Children

Bill No	HB 1047	HB 1463	SB 2326	SB 2326	SB 2412*			
Proposed Coverage	SCHIP 200% Net	SCHIP 200% Gross	Medicaid Buy-In @ 300%*	Medicaid Buy-In @200%	Children to 300% and Pregnant Women	Medicaid @ 133% 6 to 19 yr olds	SCHIP @ 185% Gross	150% (net) for Healthy Steps
Potential Children	2,480 (Denied Healthy Steps)	2,040 (Denied Healthy Steps)	778 children	402 children		2,700	1,640	1,200
Census Data / Uninsured	24,505 (2,279)	24,505 (2,279)			60,791 (5,654)			
Fiscal Estimate	7,806,035	6,085,362	2,540,373	1,390,597	10,316,175	4,126,968	5,253,235	3,875,868
General Funds	7,806,035	1,534,761	981,325	567,162		1,486,534		977,106
Federal Funds	0	4,550,601	1,559,048	823,435		2,640,434		2,898,762
Other		1. 80 curent children would lose coverage 2. Bill indicates only if Federal Funds become available	*Does not match to SB 2326 as the proposed bill does not contain the FTE expenses		Bill proposes to fund with special funds	Would be offset by savings to Healthy Steps 2,450 children @ $207.31/month. Total $6,468,072 General $1,630,601 Federal $4,837,471	1. 120 current children would lose coverage	Only if federal funds are available. Otherwise, all general funds

Denied Healthy Steps – Number of children denied Healthy Steps coverage from July 1, 2005 through June 30, 2006, who would have qualifid at 200% net and 200% Gross.

Census Data / Uninsured – Number of children source: Census data; Uninsured Estimate (9.3%); Source: Current Population Survey Annual Social & Economic Supplement

Options – Increase Medicaid Coverage

Current:	6 to 19 yr olds	100% (net)
	0 to 6 yr olds	133% (net)
	Healthy Steps	140% (net)

Example: Move Medicaid to 140% (net). Children currently on Healthy Steps, may be eligible for Medicaid. Some would stay on Healthy Steps because of how we treat self-employment income difference.
This would free up the SCHIP allotment to cover kids at a higher level, such as 200% (net).
This option would also result in staffing and system changes

Maximum Medicaid Coverage is essentially unlimited as North Dakota is a 1902(r)(2) state.

Maximum Healthy Steps Coverage is 200%; however, based on disregards available, the percentage could be higher.

Waiver for Children with Extra-Ordinary Health Care Needs authorized in 2005 SB 2395 is currently not funded.
(Estimated Cost $1,343,070 : $492,720 General Funds and $850,350 Federal funds)

WIC and USDA Child Nutrition continue to use 185% (gross) for program eligibility.

A#12

Attachment #13

PROPOSED AMENDMENTS TO SENATE BILL NO. 2326

Page 1, line 11, after "disabilities" insert "whose net income does not exceed two hundred percent of the federal poverty line"

Page 1, line 13, replace "929,594" with "1,059,932"

Page 1, line 14, replace "1,507,317" with "1,673,835"

Page 1, line 18, after "disabilities" insert "and for implementing the waiver described in section 50-24.1-26 to provide in-home services to children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care"

Page 1, line 18, after the period, insert "The department of human services is authorized one full-time equivalent position for implementing the programs described in this Act."

Renumber accordingly

SB 2326 A #3

FAMILY VOICES OF NORTH DAKOTA

Family Voices of North Dakota
PO Box 163
Edgeley. ND 58433
701-493-2634 or
888-522-9654
January 2007

NORTH DAKOTA FAMILY STORIES
RAISING & CARING FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS
What's Working.... What's Not...

> **"As each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child's most basic human rights."** ***Polly Arango***

Purpose

Family Voices of North Dakota provides information and resources to families who have children and youth with special health care needs and disabilities. During this past year, when staff spoke with families, attended or presented at statewide and regional conferences, many families had stories to share, ideas to suggest and problems that needed solutions.

We asked that they send these to the office and were surprised by the volume we received.

As legislators, program managers and others who make decision about the levels of funding, types of programs to keep, fund or in some cases limit or worse eliminate, we thought this collection of real stories from real families from North Dakota would be helpful to share.

A family situation can change from day to day, for these families, one never knows. Families want what is best for their child, they want to be able to go to work and stay employed and to be tax payers instead o tax recipients.

Contact Family Voices for copy —

Inside:

Stuart, Watt, Sloan & Beck Family Stories 2-5
Baranko, Schmid, Smith & Restemeyer Family Stories 4-9
Goldade, Gadnestad, Mikkelson & Axtmann Family Stories 10-12
Tweten, Kaseman & Dudgeon, Clohan & Kulink Family Stories 12-17
Wohl, Rask, Haa- stad, Feist 18-22
Larson, Roorda, Hoffmann, Kupferschmidt, Walters Klimpel & Romanick Family Stories 23-30
Rennich & McMahon Family Stories 31-32
Data 33-34

Information regarding services

> **Quote from Mom from Ypsilanti, North Dakota...."We aren't born knowing about any of these programs or services, just stumble along, and so much depends upon some perceptive and compassionate social worker stepping up to bat for us, because that is the person who knows what is out there for us when we haven't got a clue and are way too overloaded to guess where to look next. "**

DISCLAIMER: The Comments and opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of Family Voices of North Dakota, the funding agency or its working partnerships.

January 29, 2007

Dear Chairman and Members of the Committee:

My name is Darcy Andahl, I live n Bismarck, ND . I'm here in support of more funding for the Centers for Independent Living Centers in North Dakota.. The Dakota Center for Independent Living has helped me with my finances. Dakota CIL was my rep-payee and helped me become independent and do my own payee. They helped me with money management skills.

Thank You for your time. If you have any questions you can contact me.

Sincerely,

Darcy Andahl

Darcy Andahl

Darcy Andahl
158 E Indiana Ave. #104
Bismarck ND 58504-5706
Phone: (701) 250-6549
dandahl@bis.midco.net

January 29, 2007

Dear Chairman and Members of the Committee:

I am a person with a disability; I have Buergher's disease caused from smoking and second hand smoke. This is a circulatory disease that caused me to lose all my toes on my right foot, teeth, gallbladder and can be triggered from second-hand smoke.

I learned about Dakota Center for Independent Living from a friend. I am asking for more funding for these centers. Because of the Independent centers, I have been able to live independently.
The staff and my counselor referred me to Vocational Rehabilitation, where I was able to get teeth, and they helped me to get a job and go to college, also Community Action helped me with the career closet and financial planning.

The Independent Living Centers resources have helped me to become a productive member in society. I was at a low point in my life and because of the independent living centers; I have improved my self-esteem, and self-worth.

Please help them with more funding so that they can help more people in the future.

Thank you,

Sincerely,

Charmaine Y Boehler

Charmaine Y. Boehler
509 17th St. N.W. Apt. #1
Mandan, North Dakota 58554-1823
Phone: (701) 667-2938
E-mail: char_zap@yahoo.com

Mr. Chairman and members of the committee,

I had a stroke in April, 2006. I was 56 years old and single. My doctor and the power of attorney that I had then, wanted to put me in a nursing home for therapy and because of the stroke. I wanted to go back to my home. My friend, who is now my power of attorney for my health, contacted Dakota Center for Independent Living.

With their help, I was able to go home. I am doing great and I am doing what I want to do!

Since Dec. 2006, I have been going to a nursing home twice a week……..

I AM EMPLOYED AT A NURSING HOME!

Please support funding for centers for independent living.

Thank you,

Shirley Pavlicek

Shirley Pavlicek
822 25th street west
Dickinson, N. Dak. 58601

January 30, 2007

Dear Chairman and Members of the Committee:

I am a person with a disability. I didn't know about Dakota Center for Independent Living until I went to Vocational Rehabilitation and my counselor there told me about DCIL and explained to me what they where about. My counselor said that I should give DCIL a call and see if they could help me get my Learners Permit. I started studying with one of the Independent Living Counselors there and after a year or so I took my test several times. My IL Counselor really helped me a lot, she encouraged me quite a bit. Then after getting my Learning Permit I took the Driving part of the test and passed. I am so grateful for the staff at DCIL, with out their help I'd never gotten my drivers licenses to be more independent. I continue to go to DCIL for their Social and Recreation activities as much as I can.

I'm asking that you please give more funding to the Independent Living Centers so they can help more people in the community like me.

Sincerely,

Bonnie Murry

Bonnie Murry
2605 East Ave. F #9
Bismarck ND 58501

January 30, 2007

Dear Mr. Chairman and Members of the Committee:

My name is Kenyon Derheim and I am writing in support of increased funding for Centers for Independent Living.

My job coach told me about DCIL. When I first went to Dakota Center for Independent Living I was living in my car because I had no place to live and my life wasn't very good. The staff at DCIL helped me find an apartment, furniture, and dishes. Staff also helped me in get a letter from my doctor so that I could have a companion dog in my apartment to help with my loneliness.

I've been in my apartment for 3 months and am working full time. My life has turned around 100% and I feel better then I have in my whole life. I hope you increase funding for Centers for Independent Living because I don't know where I would be without them.

Sincerely,

Kenyon Derheim

Kenyon Derheim
1503 ½ East Rosser
Bismarck, ND 58501

January 30, 2007

Dear Chair Person and members of the Committee:

My name is David Stewart and I am asking for more funding for Indecent Living Centers. I am a individual with a disability who's involved with the Dakota Center for Independent Living. Dakota CIL was once my rep-payee, while there they taught me how to handle my own finances to make me more independent. I was also involved with there social recreational program. witch has helped me to be more scalable with other people.

Since my involvement with DCIL I have became employed as a part time Peer Mentor. With out the help of the Dakota Center for Independent Living I would not have been able to accomplish what I have in the past and live independently as I am now. They have been a help to my life situation.

I am asking to please add more funding for Independent Living Centers so other people like myself has the same opportunity that I had.

Thank You for your time. I'd is happy to answer any questions that you may have. If so Please e-mail me or call at the numbers below.

Sincerely,

David Stewart

David Stewart
725 south 12 th st # 68
Bismarck ND 58504
Ph 701 -258-5518
Email: STWDV8@aol.com

January 31, 2007

Dear Mr. Chairman and Members of the Committee:

My name is Doug Olauson. I am a person with a disability. I was once a consumer of Dakota Center for Independent Living in that time they helped me set up with Transportation and with Vocational Rehabilitation. Also was active in there Social and Recreational Program.

I took a Peer Support Training Class that was offered at DCIL which taught me to understand people with different types of disabilities other then my own. I went through Partners and Policy making Training that was once part of DCIL which taught me how to become a better advocate for people with disabilities. I am now employed by DCIL as a part-time Social and Recreational Assistant. Since I've been part of DCIL I've become a more productive citizen and sit on many organizations in the community.

Please give additional funding for Centers Independent Living so other can have the same chances as I did, so they can live as independent as every other citizen in the community. Thank you for giving me this opportunity to address for more funding for the Centers for Independent Living in North Dakota. I'd be happy to answer any questions you may Have at this time. If so you can reach me at the number below.

Sincerely,

Doug Olauson

Doug Olauson
408 N 2nd Street #6
Bismarck ND 58501
701-572-7246

9

Feb. 8, 2007

Dear Chair members:

Hello,

I am here this morning to express my gratitude for the tremendous support my family has received from the state of North Dakota. My husband David and I have had the fortune and unfortunate circumstances of raising two children with difficult to diagnose disabilities.

Our son Jesse, who is now 18, finally has a somewhat accurate diagnosis of Autism, and mood disorder. Because he is adopted at birth, we have worked hard to obtain support for his medical needs, through adoption subsidy. this allows us to receive some support from Medicaid. We are also grateful for the chance to place Jesse for 2 years out of our home, at the North Dakota boys Ranch for uncontrolled mood swings. Because of the funding, we were able to keep our parental rights and when he returned to our home and family last year, there was a smooth transition back to a whole family again.

Our son Sam, had the unfortunate luck of being born with a rare disability, causing severe seizures, lack of muscle control, and the need for full-time feeding, medicating and care.

If we did not have help from Medicaid, and my husband's work insurance, we could not keep our children. We most certainly would not be a family, we most certainly would have had to sell our modest home , and decalre bankruptcy. Without the respite care we receive, we would NOT have been able to mentally or physically face the challenges of caring for our two wonderful but complicated boys.

Please remember to support funding for children in our state who have special healthcare needs, and help families to sustain some sense of normal life, and keep families together as it should be.

I want to tell you how grateful we are for your time and energy you are all spending for our families. Thank you for doing all you can for families like mine.

Sincerely,

Mary L. Rennich

258-2064

10

Rennich Family Story

Health Issue: Lissencephaly, Autism Spectrum Disorder

Issue: Child not DD eligible, needs assistance, narrowly defined DD Definition

Insurance Coverage: Medicaid, Private Insurance

Recommendations: Access to appropriate medical supplies

Family Story from:

Mary Rennich 7060 Horseshoe Bend, Bismarck, North Dakota

Thank you for taking the time to read our stories and working hard to find the necessary funds we need to raise our children in our own homes, as it should be for all families.

My name is Mary Rennich, and along with my husband David, we are raising our two sons who both have disabilities. Our son Sammy, is now 16, and has severe seizures almost daily, and a rare and severely disabling brain malformation called Lissencephaly. Our 18 year old adopted son Jesse, has been diagnosed with autism spectrum disorder, or Asperger syndrome, and severe progressive scoliosis. Over the last 16 years, we have had incredible medical expenses which we could not begin to add up, but we know that without the help of the state of North Dakota, the federal government and our private insurance through my husband's employer, we would not be able to keep our children in our own home.

We are so very grateful for the D. D. subsidy and Medicaid for Sam, who has a diagnosis qualifying him for D. D. services, and the respite care we cannot live without for work, and for time to recharge. As for Jesse, he is not able to receive D. D. services for his disability needs because of the mental retardation status required by Human Services. Although he is able to function in some areas independently, - but- areas such as taking required mood stabilizing medications, keeping safe with others, maintaining a job, etc, Jesse will need some assistance / funding throughout his life to help him to be a happy, healthy, productive, working tax payer. some of these services will be, mental health counseling, Voc. Rehab., and life skills assistance. Many, many individuals in our state need funding that cannot be accessed because they currently do not fit into the narrowly designed guidelines. The state needs to find a way to help those children who do not fit neatly into the D. D. guidelines.

Please continue to learn more about the children in our state that need funding for special health concerns, particularly in the area of mental health. At times it appears it is an invisible disability, but can be devastating and costly if it is not addressed. Thank you- all of you, for working for our families again- in this legislative session.

"Many, many individuals in our state need funding that cannot be accessed because they currently do not fit into the narrowly designed guidelines."

2326
Rep Gerry Uglem

Mr. Chairman, Committee members.

The Deficit Reduction act of 2005 enacted a new eligibility category that would allow families with incomes up to 300 percent of the federal poverty level to "buy –in" to Medicaid for a child with a disability. This bill proposes to add this eligibility category to the ND Medicaid program, with eligibility up to 200 percent of the federal poverty level.

The estimate for the 'buy-in' for children at 200 percent of the federal poverty level is based on an expected enrollment of 402 children. The expected grant expenditures for the "buy-in" for children would be $916,569 of which $330,148 are general funds.

The 2005 Senate Bill 2395 directed the Department of Human Services to Apply for a waiver to provide in-home services to children with extraordinary needs who would otherwise require hospitalization or nursing facility care. The 2005 Senate Bill did not contain an appropriation, and the department was unable to include the funding for this waiver in the 2007-2009 budget. This bill contains an appropriation to fund the waiver.

The estimate for the Waiver for Children with Extraordinary Health Care Needs is based on an expected enrollment of 15 children, at an annual cost of $44,769 per child. The estimated biennial expenditures for the Waiver are $1,343,070 of which $492,720 are general funds.

With additional administration expenditures: overtime to process premium payments, enhancements to MMIS and the Vision system, and an FTE for the development, implementation, and operation of the "buy-in" and the Waiver.

Total appropriations in the bill are $1,059,932 general funds, and $1,673,835 Funds.

SB 2326 Medicaid "buy-in" and waiver for children with extraordinary needs

	per child	number of kids	less premium	general funds	Fed funds	total funds
200% "buy-in"	$157	402	$602,316	$330,148	$586,421	$916,569
waiver	$44,769	15		$492,720	$850,350	$1,343,070
Administration						
overtime				$31,920	$31,920	$63,840
MMIS & Vision system				$153,413	$153,413	$306,826
1 FTE				$51,732	$51,730	$103,462
Total cost in SB2326				$1,059,933	$1,673,834	$2,733,767

Floor Speech on SB 2326
Medicaid Buy-in and Medicaid Waiver
Senator Dick Dever

Mr. President, this is a story about two very special young girls, and a whole bunch of children in similar circumstances. They're super girls actually. They are intelligent, full of life, and full of energy. They have the ability to steal the heart of a Senator.

The first girl you met two years ago when she was two years old. She was healthy except that she had a condition known as Russel Silver Syndrome. She is a special girl with an extremely rare condition. If left without treatment, she would continue to be the size of a two year old. Thanks to your actions then, she has grown 8 ½ inches, and is a healthy, normal sized four year old. The bill two years ago asked the Department to apply for a waiver to allow Medicaid to supplement the payment expenses for up to 15 children with extraordinary medical needs. SB 2326 provides the funding to support that waiver.

I met the other little girl last summer at an event called "Buddy Walk". She is a sweet, five year old also with MPS 1, a rare genetic disorder. MPS 1 is progressive and degenerative, it affects every system in her body including her brain. For treatment she receives Enzyme Replacement Therapy as a weekly I.V. infusion. The cost of the medication billed to her parent's insurance is $ 6,907.88 every two weeks or $ 167,301.12 every year. Her parents estimate that she will hit her lifetime limit of $ 2 million dollars on her insurance by the time she is 10 years old. Children in her circumstance would be eligible for the Medicaid Buy-in portion of this bill. It is estimated that 402 children would be affected.

As a part of the Deficit Reduction Act, Congress passed the Family Opportunity Act. The Act allows for a Medicaid Buy-in program for families up to 300% of poverty. This bill provides for that program up to 200% of poverty. We can only limit the number of people on the program by setting the poverty guidelines. It is the feeling of the Human Service Committee that we should start low and go up later.

The bill affects 15 children with extraordinary medical needs and 402 children with disabilities. You may wonder how we can take care of so many children with only a little over a million dollars.

The answer is that the parents are working parents with insurance. Medicaid is a payer of last resort. With this bill, the parents won't need to get a divorce; they won't need to impoverish themselves; they won't need to leave the state to get the care they need for their children. This bill simply provides them the help they need to deal with some extraordinary expenses that most of us have trouble even relating to.

Early in this session, I heard someone say that "If we take care of the truly needy, people will appreciate it. If we take care of the truly greedy, people will resent it." People will appreciate passage of this bill, and so will your Human Services Committee.

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Chairman Pollert and Committee Members,

My name is Donene Feist from Edgeley, North Dakota. I am here today on two levels, first and foremost as mom of Zachary and second as the Family Voices of North Dakota State Director. I want to extend a special thanks to members of the committee in bringing forth this very important bill for families of children with disabilities.

The Family Opportunity Act or the Medicaid Buy-in is an important piece of legislation for a number of reasons. The FOA as it passed in Congress gave states the option to create a Medicaid "buy in" or purchase coverage under the Medicaid program as a supplement for families of children with disabilities.

With the passage of the Family Opportunity Act in North Dakota, families will benefit through Buying In to Medicaid in the following ways:

- Children with significant disabilities can receive the health care services they need to reach their potential. Children will no longer be denied care or have limited care and so their health will most likely improve because they are given the care they need at the appropriate time and spend less time in the emergency rooms or hospitals which will bring down the cost of care.
- Parents can accept raises, promotions or new jobs that increase family income above the poverty line.
- Fewer parents will have to choose between paying for the health care for their child or other necessary family expenses such as food, clothing and shelter.
- Fewer parents will have to place their child out of the home in order to access appropriate health services or forgo custody of their child in order to access appropriate health services.

Parents of children with special health needs and disabilities are unjustly punished for working hard to support and provide for their families. This bill is a major step forward for the families who have been denied opportunities so that their children with special health needs and disabilities can get the care they need. It will remove some of the barriers that prevent families from staying together and staying employed—while giving hope and freedom to those who deserve it most

Let me provide a bit of history for you on this bill as I have followed this legislation since the beginning. This piece of legislation was initiated several years ago in 2001. It passed in the Senate twice prior to full passage of both Houses in 2005 in the Deficit Reduction Act.

This is important for many reasons some of which I will describe later. This was introduced by Senators Grassley and Kennedy; and Representatives Sessions of Texas and Waxman of California to Congress. On the House side it was introduced as the Dylan Lee James Act. In Congress, this bill had overwhelming support with a combined 270 sponsors in the House and Senate.

Why Dylan Lee James? Dylan Lee James was born with Down syndrome as well as a severe heart defect, which ultimately led to his untimely death. While spending enormous amounts of financial resources to assist in the health care of Dylan, his family was shocked to find that they would be declared "ineligible" for government assistance for Dylan after his father accepted a bonus at work. The passage of this legislation would change this course for many families.

I was honored and humbled to be in attendance when this vital legislation was introduced; to describe the atmosphere of the room was electric. As Senator Grassley provided information and each additional speaker presented to families, children with disabilities, advocates, and staff from every walk of life from around the country, true tears of hope, my own included filled the room. At times, I still tear up thinking of that day because of its impact. For the families in attendance, in many ways, we knew this was not the cure all or end all but it certainly was the rope of hope which we could grab onto and help many families across the country that faced the same struggles as we did. Many North Dakota families shared their stories some of whom are in the booklet that I share with you today. I am proud that families from North Dakota as well as those from around the country made a cornerstone in history.

The relief the Family Opportunity Act provides is crucial to millions of middle-income families across the country that have children with disabilities who require expensive health care. My hope is that we will continue to make history and implement this important legislation for families in North Dakota, as it is the right thing to do and builds upon the workers with disabilities legislation passed in North Dakota several years ago.

Many middle-income families in North Dakota that have children with significant disabilities do not have access to affordable and adequate health insurance to cover their children's chronic health care needs.

Most employer provided health insurance does not provide for the comprehensive medical care that these children need. This must be clearly understood. Just because families have health insurance does not mean their needs are being met. Many of these families are under insured as private insurance simply does not meet the health needs of these complex children.

The coverage they need is available through Medicaid, but they cannot access it because their family earnings are too high to qualify. Medicaid by all standards provides the most comprehensive health care for this population of children. Far too many of these families are faced with the stark choice of becoming impoverished in order to gain access to Medicaid as their only feasible health care option for their children. Other equally unacceptable options that these families have to consider are an out-of-home placement or the relinquishment of custody of their child with a disability so that they will ensure Medicaid coverage of their child's health care needs. These families have to face bankruptcy, impoverishment, or the loss of their child to secure what most American families take for granted - comprehensive health care for their children. This legislation provides reasonable solutions: access to health care and assistance as Medicaid would be a supplement family's health care insurance buy allowing them to Buy-In to acquire appropriate health care coverage for their child.

In our own personal story, because of our son's health needs, we have faced medical bankruptcy, and it is an ugly situation to be in. In comparison to the many other families our story is just one of many. His costs are not as extensive as many other families and yet here I am, facing bankruptcy. This bill will not help my family now, it is too late for us, and it is too late for Dylan Lee James but it is in your hands now to help many others. I personally don't want to see other families have to go through what we have gone through.

Our story is not unique. Zachary has a severe hearing impairment and a compromised immune system due to other illnesses; he receives extensive speech therapy, hearing aides, adaptive equipment etc. Our insurance plan as comprehensive as it is for most of my family simply did not cover Zachary's needs because of its limited benefits package. We did what we had to do, so Zach could become all that he could be.

I remember vividly, the day Zachary was diagnosed and will never forget being told by the physician and specialist as I was holding him on my lap and my husband holding our daughter how she (10 months younger) would always excel much further than what Zach would be capable of doing. My head swam in dizziness, and I was physically ill with worry on how we would ever afford and meet his needs with the information that was being presented to us.

As parents it is our job to do what you have to do to meet the needs of your children. Those of you who may not have a child with special needs or a disability, just for a moment envision the most frightening moment you had in raising your child. In those moments you protect, nurture and simply put do what needs to be done to help your child get through. Now envision your own child having a significant medical issues and taking care of the health needs of these children day in and day out. Imagine deciding whether to buy milk or drive your child to therapy, not being able to go to the dentist because the other medical bills were just too high.

These families are faced with decisions that no family should have to face. The choices we make often shuffle between necessity and basic human needs. While we are masters of pulling ourselves up by our boot straps, that ability gets harder and harder. We become exhausted, isolated and feel defeated. This comes from personal experience, and yet somehow in that weakness there is strength to keep going because here is this kiddo who keeps you moving forward.

Families then in order to express what it will take to meet their needs have to open their lives up for public viewing and scrutiny. It is not easy to tell policy makers your story, your financial situation, it exposes the most private moments of a family. I am sharing mine in hopes that it will help you understand and make sound policy decisions on behalf of these families. In my mind, all of the families in North Dakota are heroic in their own way.

Zachary is now 16 years old. He is my hero. He is independent, mature, athletic, and compassionate and for his youth has more insight than many adults. He is the one who reminds me when I have become sour at the world of the beauty within. He is the reason who quite honestly at times has caused me to have an out of body experience as I become more than enthusiastic at the Edgeley Kulm Rebel football games. He is the one who has taught me that any dream is achievable. He who we were told would lag so far behind and unable to do certain things is living proof.

Would we as his parents done anything differently…actually no, there were NO other options. In providing his health care needs, we went deeper and deeper into debt, what choice did we have?? Was it worth it, look at him and you tell me. I say, Absolutely! He talks, he communicates, he has held jobs, he is in all sports, and excels in everything he does. Had we not gone the distance, had we given up and be beaten would he be doing these things…we will never know, as it wasn't something we took lightly or willing to compromise. Would a program such as the Family Opportunity Act have helped us? No doubt about it.

Families shouldn't have to impoverish themselves to get the help they need for their children, worry about whether a pay raise will raise their income eligibility and they lose Medicaid as a vital support for their family. For families of children with disabilities and special health care needs, we are in a state of emergency. This bill changes that course.

In closing, let me say this….The Department of Human Services has prepared an OAR for this legislation, as you know it passed on unanimous consent in the Senate. I hope you will consider, however raising the FPL of this bill to 225% of the FPL to match the workers with disabilities buy-in from previous sessions. It is my belief that while workers with disabilities may have a 2 member household, many do not have children they are providing for. Raising it to 225% would seem more equitable with what has already been passed in previous sessions and those in 3-4 family households or more have higher out of pocket expenses overall.

I am also providing to you information from the Catalyst Center, a national organization on health care financing which provided states with the impact of what this legislation would mean for states. Their methodology compares considerably with what the Department has prepared.

A significant problem is many families fall through the cracks. In effect, the system is forcing parents to choose between near-poverty and their children's health care. We need to fix that. It will close the health care gap for North Dakotas most vulnerable children, and enable these families. It is also an essential investment in the health and independence of these young people that will strengthen North Dakota families and children.

Medicaid's comprehensive benefits should serve as a model for <u>all</u> children and youth needing specialized health care services, whether publicly or privately funded. For children and youth whose primary private health coverage benefits are limited, secondary health care coverage, like Medicaid, is essential.

This legislation is pro-work because it lets parents work without losing their children's health coverage, pro-family because it encourages parents to work and build a better life for their children, and it's pro-taxpayer because it means more parents continue to earn money, pay taxes and pay their own way for Medicaid coverage for their children.

Let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child's most basic human rights. This bill will embrace the needs of families and move us forward in the right direction.

Again, I thank you for allowing me the time to provide input on this vital bill for families

Donene Feist

PO Box 163, Edgeley, North Dakota Phone: (701) 493-2333

Chair and Committee Members

My name is Zachary Feist, from Edgeley, North Dakota.

You may wonder what a kid might have to say about a bill like this. Actually plenty but not to many ask us.

All kids with disabilities deserve a chance to be all that they can be. Not all kids with disabilities get that chance.

I have seen the looks and felt how kids with disabilities are treated. It is a terrible feeling.

There are plenty of families like mine who have struggled because of the health needs that a child like me may have.

But with a little help, all kids with a disability can be all that we can be.

We can achieve our dreams, because someone believes in us. I am hoping that you will believe in us.

I am glad that my parents never gave up, didn't give in or I may not be standing here with you today.

I am glad that they didn't listen to the doctors who said I wouldn't be able to do many things.

I think I have done a pretty good job in proving them all wrong and hope to continue to do so, but I wouldn't be able to do it without support or health care.

Sometimes the little people don't get heard. I came here to make sure that we get heard, families need help!!

My hope is that the other families and kids with disabilities in North Dakota will have that chance.

I hope for the other kids you will give them that chance. Thank you

Zachary Feist
Edgeley North Dakota

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SB 2326 – Family Opportunity Act (Medicaid Buy-In)

Senate Appropriations Committee
Chairman – Senator Holmberg
February 8, 2007

Same given to House Human Services

Chairman Holmberg and members of the Committee, my name is Mike Schwab, Executive Director for The Arc of Bismarck. I am representing The Arc of Bismarck and The Arc of Cass County and our constituents today.

I am here to ask for your support in passing an important piece of legislation. SB 2326 would offer low-middle income and middle-income families of children with disabilities the option of buying-into Medicaid. Currently, these children meet the definition of "disability" as defined by Social Security but are not eligible for Medicaid because their families earn a little too much money. Because of this, families are often un-insured or underinsured because health insurance is not available through their employer, it is too expensive, or offers a limited number of benefits. Typically, unless it is a group policy, most insurance companies will not cover "pre-existing" conditions, therefore the child gets denied coverage.

In addition, parents are often times forced to remain in the same job to keep health insurance or to decline employment in order to access state/federal benefits. Giving parents the option of buying into Medicaid and paying on a sliding fee scale would provide children with disabilities in these families access to the full range of Medicaid services.

This provision would allow the state to cover young children with "potentially severe disabilities", and promises improved overall health. It would also help with the prevention of future disabilities and these children would have a better chance to live full and healthy lives with their families in their homes, where they belong.

This legislation offers stability, rehabilitation, and recovery to children with severe and chronic disabilities this may also include the early on-set of mental illnesses. It also breaks the link between forced poverty and Medicaid. It also builds on the work incentives law that was enacted in 1999.

SB 2326 allows families whose net income does not exceed 200% of the federal poverty level to buy-into Medicaid. While this is a step in the right direction, the "workers with disabilities coverage" for adults (Medicaid Buy-In for adults – passed in 2003), is set at 225% of the poverty level. Most of the individuals that access that program are single working individuals. SB 2326 is designed to support families. We ask that you consider raising the federal poverty level to at least 225%.

By passing SB 2326, you are also allowing the necessary funds to become available to implement the "waiver for children with extraordinary medical needs. The development and direction of this waiver became existing law last session (SB 2395 was passed by the Senate unanimously).

We would like to thank you for your continued support of children and their families and ask that you pass SB 2326. Thank you for your time and attention today.

Respectfully Submitted,

Michael D. Schwab
The Arc of Bismarck
The Arc of Cass County

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TESTIMONY – PROTECTION AND ADVOCACY PROJECT
SENATE BILL 232~~5~~6 (2007) – CHILDREN'S FOA BUY-IN

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SENATE APPROPRIATIONS COMMITTEE
Honorable Ray Holmberg, Chairman

February 8, 2007

Chairman Holmberg, and members of the Senate Appropriations Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A).

The federal Deficit Reduction Act allows states to create a buy-in for Medicaid for children with disabilities. The buy-in could be available for families with a child with disabilities who earn up to 300% of the federal poverty level (FPL) in gross income. The current proposal for 200% FPL, based on net income, would serve fewer children, but would be a strong step forward.

On the reverse are three typical family budgets at 300% FPL. High out of pocket expenses for children with disabilities make many families at 300% FPL insolvent. Two of the three families would become solvent with the addition of the FOA buy-in. These families would then be more stable, better able to contribute to society, and their children could receive needed health care.

Thank you very much for your time and consideration.

		Home Purchase			*Rental*			Rental	
FOA Family Budget		1 Ch w/d	1 Ch w/d		1 Ch w/d	1 Ch w/d		2 Ch w/d	2 Ch w/d
expenses		Fam' 4 FOA	Fam' 4 now		Fam' 2 FOA	Fam' 2 now		Fam' 4 FOA	Fam' 4 now
	Mortg/Rent	1200	1200		*600*	600		740	740
	Stu Loan	240	240		*120*	120		240	240
	Rx Dx Optom	*150*	370		*100*	185		*150*	370
	School Lunch	96	96		*48*	48		96	96
	util	197	197		*56*	56		56	56
	food	685	685		*480*	480		685	685
	AT	0	0		*0*	0		0	0
	Phone/comm	145	145		*145*	145		145	145
	Car Pmt	250	250		*175*	175		250	250
	car mtce	75	75		*75*	75		75	75
	car ins	77	77		*70*	70		77	77
	fuel	200	200		*120*	120		200	200
	Extracurric	100	100		*50*	50		100	100
	Child Care	894	894		*447*	447		894	894
	Vacation	0	0		*0*	0		0	0
	Donat/Gift	*50*	50		*25*	25		*50*	50
	Clothes	100	100		*50*	50		100	100
	house misc	75	75		*75*	75		75	75
	Fam Hlth Ins	500	500		*300*	500		500	500
	Ind w/d Hlth	*375*	*830*		*247*	*830*		*375*	*1660*
	TOTAL	**5409**	**6084**		**3183.125**	**4051**		4808	6313
balance	***balance***	***-709***	***-1384***		***11.875***	***-856***		**-108**	**-1613**
300% FPL		5000	5000		3295	3295		5000	5000
Tax w EITC		-300	-300		-100	-100		-300	-300
Net Inc.		4700	4700		3195	3195		4700	4700
	Premiums = 7.5%								
	Estimates lower of DOJ or NDSU by P&A Graduate Intern								

Research for FOA

1. Mortgage/Rent

Mortgage:

I contacted two realty places in Grand Forks and two in Bismarck and asked for ranges of a modest three bedroom accessible home.

Grand Forks:

Greenberg Realty = $150,000 - $165,000
Crary Realty = $130,000 - $170,000
So I used $150,000 as the price for the home in Grand Forks and called a lender, Bremer, and had them figure the mortgage payment based on a 30 year mortgage, 6% interest, minimum down payment and the payment came out to be **$1,293** (this includes tax and insurance)

Bismarck

Century 21 – Morrison Realty = $140,000 -$150,000
Alliance Real Estate = $130,000
So I used $140,000 as the price for the home in Bismarck and called a lender, Wells Fargo, and had them figure the mortgage payment based on a 30 year mortgage, 6% interest, minimum down payment and the payment came out to be **$1,130** (this includes tax and insurance)
I then averaged these two payments and came up with **$1,211.50** and rounded this down to **$1,200**.

Rent:

-http://grandforks.oodle.com/housing/rent?marketdata=1
2 bedroom: $640
3 bedroom: $860
- Grand Forks Housing Authority (701-746-2545, and spoke with Mary)
1405 1st Ave. N.
Grand Forks, 58203
2 bedroom: $615
3 bedroom: $779, rounded to $780
- Bismarck Housing Authority. (701-255-2540). Referred me to the Apartment Association (701-255-7396). They don't track data like that and suggested I go to their website and average the apartments that were advertised at the time of 11/15/06.
2 bedroom: $ 547, rounded to $550
3 bedroom: $590

I then averaged the three data amounts I had:

	2 bedroom	3 bedroom
	640	860
	615	780
	547	590
Average	**$600**	$743, or **$740**

2. Student Loans

http://www.studentdoc.com/student-loan-debt.html

College Student Loan Debt

A recent study by the National Center for Education Statistics (1) shows that about 50% of recent college graduate have student loans, with an average student loan debt of **$10,000**. The average cost of college increases at twice the rate of inflation; the College Board (2) estimates that public school costs an average of about $13,000 a year and private schools costs $28,000.

http://www.finaid.org/loans/consolidation.phtml
10 year term, $10,000 at 6.8% (that is the new interest rate) has a monthly payment of $115.08 per month.

http://nces.ed.gov/programs/quarterly/vol_7/1_2/5_5.asp#tab_A

Type of degree-granting institution	**All graduates**	**Borrowers**	**Borrowers in repayment**		**Median debt burden**
	Percent who had borrowed	**Average amount borrowed**	**Average annual salary**	**Average monthly loan payment**	
	1992–93		1994		
U.S. total (excluding Puerto Rico)	49.3	$12,100	$28,300	$170	6.7
Total (50 states, DC, and Puerto Rico)	49.3	12,100	28,300	160	6.7
Public 4-year nondoctoral	48.0	9,800	25,000	140	6.6
Public 4-year doctoral	45.5	10,600	29,400	150	5.9
Private not-for-profit 4-year nondoctoral	57.5	14,100	27,300	180	7.8
Private not-for-profit doctoral	49.5	16,800	28,900	220	8.5
	1999–2000		2001		
U.S. total (excluding Puerto Rico)	65.5	$19,400	$34,100	$210	6.9
Total (50 states, DC, and Puerto Rico)	65.4	19,300	34,100	210	6.9
Public 4-year nondoctoral	63.1	**15,000**	32,500	**170**	5.8
Public 4-year doctoral	63.6	17,500	34,300	200	6.7
Private not-for-profit 4-year nondoctoral	71.5	20,900	32,300	230	8.0
Private not-for-profit doctoral	65.4	28,000	37,500	260	7.7

SOURCE: U.S. Department of Education, National Center for Education Statistics, 1993/94 and 2000/01 Baccalaureate and Beyond Longitudinal Study (B&B:93/94 and B&B:2000/01).

These were the newest statistics I could find on the web from a credible source.

UND has a cost estimator/calculator on their website
UND Financial Aid office: 701-777-3121: Undergrad federal loan average = **$14,000**
Undergrad federal and alternative average = **$30,000**
Mary Financial Aid office: 701-355-8079: Left 2 messages
NDSU Financial Aid office: 701-231-7533: Left 2 messages

To find an average I used $10,000, $15,000, $14,000, and $30,000 and came up with $17,250

I used this website http://www.finaid.org/calculators/loanpayments.phtml to figure loan payment based on 3% interest rate (I assumed consolidation and that the loans were previous to interest going up to 6.8% on student loans); 15 year loan term and the payments were $119.13, so I rounded to **$120** for one individual. For the families with 2 parents I doubled this amount to **$240.**

3. Rx, Dx, optometrist

Optometry - 2 family members need glasses at $300 per pair each year. Add 4 exams each year with exam costing about $100 each year = $1300 a year
Prescriptions - 2 medications per family member = 8 medications total. Used a co-pay of $30 per prescription = $210 a month; $2520 a year
Dental – 4 yearly exams at $150 each = $600 a year.
Add these yearly totals up and get $4420 for a monthly payment of $368, or **$370** for the family of 4 and **$185** for the family of 2.

4. School Lunch

-Bismarck Public Schools: Elementary students pay $.75 for breakfast; lunch is $1.15. (For both meals for 20 days = $38.00) Middle school and senior high students pay $.90 for breakfast; $1.40 for lunch. (For both meals for 20 days = $46.00) Adults pay $1.25 for breakfast; $1.80 for lunch. Reduced breakfast costs $.30; reduced lunch costs $.40. Children who bring their own lunch can purchase a carton of milk for $.30.
-Grand Forks Public Schools:
http://www.gfschools.org/education/sctemp/62f1a43a8d7e22fafb6badfa0a2c9914/Elementary_Meal_Prices.pdf
http://www.gfschools.org/education/sctemp/62f1a43a8d7e22fafb6badfa0a2c9914/Middly__High_School_Meal_Prices.pdf
Middle School/High School: $1.70; For both meals for a month = $56.00 for 20 days
Elementary :$1.60; For both meals for a month - $51.00 for 20 days
*Special meals are included such if the child was on a diabetic diet

For the number I came up with:
I averaged the elementary prices and came up with $44.50
I averaged the middle school/high school prices and came up with $51.00
Then I averaged $44.50 and $51.00 and came up with $47.75 and rounded that to **$48.00** a month and averaged the age 'groups'

5. Utilities

-I contacted Excel Energy and got some averages. For a three bedroom home: $203.00 (This includes gas and electric.) For a 2 bedroom apartment: $28.00 (This only includes electric). For a three bedroom apartment it was $59.00 (This only includes electric.)
-I contacted MDU and got some averages. For a three bedroom home: $190.00 (This includes gas and electric). For a 2 bedroom apartment: $24.00 (This only includes electric.) For a three bedroom apartment: $52.00 (This only includes electric.)
I could not get averages without giving real addresses, so this is only a small sample size. These averages are only based on 1 residence.

City	House	2 Bedroom	3 Bedroom
Grand Forks	203	28	59
Bismarck	190	24	52
Average	196.50, so 197	26	55.5, so 56

6. Food/Groceries

Contacted NDSU Entension 701-780-8229 and spoke with Donna Burnhart. She said that in North Dakota, families spend 15% of their income on food and groceries. I took this multiplied with the net income provided on the budget worksheet.
2 adults/2 children = **$705**
1 adult/1 child = **$480**

7. Phone/Cable/Internet 1-800-244-1111;

Quest-Bundle package - Cable, telephone with unlimited long distance, high speed internet = $97 + tax, about $110.00.
http://pcat.qwest.com/pcat/productDetail.do?salesChannel=Residential&offerId=6624
-Midcontinent: Classic Trio -Classic Cable, local telephone line and broadband internet service = $87.95 + tax, about $95.00.
Cell phone: Verizon – 450 minutes $39.99 + tax, about $43.00
Alltel – 500 minutes $39.99 +tax, about $43.00
I averaged the two packages from Quest and Midcontinent and added $43.00 for the price of a pretty minimum cell phone plan with just one line and came up with $145.50, so **$145**.

8. Car Insurance

I had a hard time getting agents to do quotes as they need s.s. #'s and can't do fictitious quotes, so I did some on Geico's website.

I used a 2001 Dodge Caravan as the vehicle make for insurance. I also used a 2000 Ford Taurus for the single parent and also when the family had two vehicles. Deductible 500, full-coverage. 35 year old male and female with good driving records. And a 25 year old single parent with a good driving record.

I did a quote online with Geico http://www.geico.com/ and got a quote of $419.40 ($838.80 yearly) every 6 months for 1 driver for the Ford Taurus. Monthly payment = $69.90 or **$70.00
I did a quote online with Geico and got a quote for two drivers who are 35 and drive the vehicles listed above. The quote was $464 ($928 yearly) every 6 months for both drivers and both vehicles. Monthly payment = $77.34 or **$77.00**

9. Individual with disability health needs

Carol suggested contacting Steve Dahan, a Medicaid worker at GFCSS. I spoke with him and he said he just didn't have data like that and suggested Medical Services in Bismarck and they also didn't have any figures they could give me. I remember you used the statistic that parent advocates said they spent about $10,000 a year on out of pocket health care, so I just stuck with that #.
1 child = **$830**
2 children = **$1660**

10. Child care

I contacted two childcare providers in Grand Forks and two in Bismarck

-Wonder Years Childcare in GF (701-746-7287): For an infant/toddler (2 and 3 yrs) it is $154.40 weekly ($617.60 monthly) and this includes diapers, wipes, and formula. For an elementary age child before and after school: $89.50 per week ($358 per month) and this includes breakfast/snack and transportation.

- United Lutheran Child Care in GF (701-772-3773): For an infant it is $600.00 per month and this includes diapers, wipes, and formula. For 2-3 year olds it is $470 month and for elementary age for just after school it is $150 month.
- ABC First Steps Learning Centers in Bismarck (701-255-0546): For an infant is $530 per month and this does NOT include diapers, wipes, and formula. For 2 yr olds it is $515, for 3 yr. olds it is $490 and for elementary age child it is $205.
- Kidz First Child Care Center, Inc. in Bismarck (701-221-2778): For an infant it is $465 per month and this does NOT include diapers, wipes, and formula. For 2 yr olds it is $450, for 3 yr. it is $430. For an elementary age child it is $165.

All providers said it would not cost more if there a child has special needs.

For the purpose of this budget I selected I averaged each group

City	Infant	2 yr olds	3 yr olds	Elementary
Grand Forks	617.6	617.6	617.6	358
Grand Forks	600	470	470	205
Bismarck	530	515	490	150
Bismarck	465	450	430	165
Average	**553.15**	**513.15**	**501.9**	**219.5**

Then I averaged the averages together to get an average per child and got $446.93 per child and also averaged the age 'groups'. I rounded this to **$447** per child a month.

8

TESTIMONY
SB 2326
SENATE HUMAN SERVICES COMMITTEE
CHAIR – SENATOR RAY HOMBERG
FEB. 8 2007

Same given to House appropriations

Chairman Homberg and members of the committee. My name is Derek Zietz. I am speaking for myself and I am a parent of a child with a rare medical disorder. I am here today in support of the option for children who are medically fragile to continue receiving Medicaid after they reach the age of 3.

Many of you probably remember my daughter. Her name is Laikyn. Last session senate Bill 2395 helped her in a way that I can only hope other families will have the opportunity to receive. After fighting for our daughter's bill, my wife Heather and I couldn't imagine ever going through something like that again. Yet here I am. I am here because I don't want another family to go through what we went through. Believe me when I say families who have children with chronic health conditions have enough to worry about.

This Medicaid option needs to help children who are medically fragile who fall through the cracks after reaching the age of3. My family had medical insurance, but what a lot of people don't see is that costs a family endures even with insurance can be overwhelming. Families with health insurance that have medically fragile children, pay much more than their health premiums. They pay a never ending flow of medical bills. These children require constant medical care. I never worried about looking at my explanation of benefits the insurance company sent. Even if something was charged wrong, I knew we would reach our out of pocket maximum eventually anyway. There are also many things a family has to pay for that insurance just won't cover. A steady routine of going to the pharmacy is also something you can count on. Let's not forget that some have to travel to see specialists for their child's disorder. A lot of families have a parent who isn't able to work, because their child requires constant care. With the cost of 1 on 1 daycare, going to work just doesn't make any sense.

The situations above are all things that my family went through, and they were just some of the struggles we had to deal with every day. Laikyn qualified for early intervention around 18 months of age and started receiving Medicaid to help combat all of this. But at 2 ½ years of age Laikyn was re-assessed not to have mental retardation. This meant that when Laikyn turned 3, income would no longer be waived, and the assistance my family received would be gone. The problem with my family like so many others is that our daughters condition wasn't going away when she turned 3.

Burleigh County Social Services wrote a letter 3 months before Laikyn turned 3. I would now like to read you that letter.

"To who it may concern:"

"Regarding continuing Medicaid coverage for Laikyn, it appears the family would no longer be eligible for Medicaid due to their income when Laikyn is no longer screened for and receiving home and community based services. Their monthly gross income is approximately $3300 a month and medically needy income limit for a household of 3 $666. This means they would have a few thousand dollars a month recipient liability. There income also exceeds the poverty level income guideline."

Me and my wife Heather discussed this letter, and decided clearly it meant that we had to impoverish ourselves some how to meet the income eligibility. There were no other alternatives in the state of ND to assist families like mine. We discussed many options, impoverishing ourselves, moving, doing fundraisers every year, and even getting a divorce, thinking that being a single parent would help Laikyn receive more coverage. It just wasn't right.

My family has been helped, and we will always be grateful. At the same time I think of all the other families going through what we went through, and it brings memories, and a time of fear I will never forget. How can we not see the dis-service being done to so many families. These children have life long conditions, and the clearly need medical assistance regardless of income. I pray that it can be done in a way that is affordable to families with no loopholes, or ways around it. The poverty level needs to be set at a percent that will benefit families like mine. These families deserve the chance to care for their children without worrying whether or not they will be able to afford it. Lets not make our families in ND choose poverty over staying at work.

Thank you all very much for your time and consideration

Sincerely

Derek Zietz

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SB 2326
Human Service Committee
February 26, 2007

Madam Chairman Price and members of the House Human Services Committee. My name is Tim Mathern, Senator from District 11 in Fargo. I am at a meeting regarding funding from the Bush Foundation for North Dakota projects and asked Represenative Schneider to submit this to your Committee.

One issue of concern to many of our constituents is access to affordable insurance and the high cost of health care in general. While this bill does not address all of these concerns it does respond to some of the greatest needs.

Often there are extraordinary financial and social challenges for a family who has a child dealing with disabilities. Often medical bills and care issues can become overwhelming.

Section 1 of this bill directs the Department of Human Services to establish a "buy in" program to give some support to these families. These families are able to use the Medicaid program by meeting certain criteria and paying a "premium" into the program. They become eligible for coverage offered by the existing Medicaid progam. I submitted the bill to permit families of up to 300% of poverty to enroll in the program though the Senate amended it to 200% of poverty.

Section 2 of the bill gives the costs of the program.

Families are here to share their stories and Maggie Anderson of the Department of Human Services is here to help with the cost details. I see Senate Bill 2326 as establishing a method of taking advantage of federal resources available to us as a state and supporting the families who struggle with the challenges a disability brings.

I ask for your support of SB 2326. The families in your district will be most appreciative of your concern and your practical response by establishing this Medicaid buy in option. Thank you.

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Testimony
Senate Bill 2326 – Department of Human Services
House Human Services Committee
Representative Clara Sue Price, Chairman
February 27, 2007

Chairman Price, members of the House Human Services Committee, I am Maggie Anderson, Director of Medical Services for the Department of Human Services. I appear today to provide information on the appropriation section of this bill.

The Deficit Reduction Act of 2005 enacted a new eligibility category that would allow families with incomes up to 300 percent of the federal poverty level to "buy in" to Medicaid for a child with a disability. This bill, as amended, proposes to add this eligibility category to the North Dakota Medicaid program. Eligibility would be at 200 percent of the federal poverty level.

As you may recall, 2005 Senate Bill 2395 directed the Department of Human Services to apply for a waiver to provide in-home services to children with extraordinary needs who would otherwise require hospitalization or nursing facility care. Over the interim, the Department convened a group of stakeholders for the purpose of gathering input for and writing this waiver. 2005 Senate Bill 2395 did not contain an appropriation, and the Department was unable to include the funding for this waiver in our 2007-2009 Budget request. 2007 Senate Bill 2326, as amended, contains an appropriation to fund the waiver.

As a reference, Attachment A is a document prepared for the Interim Budget Committee on Human Services, which provides information on the

Waiver, the Buy In for Children and on another option for coverage, the Katie Beckett Eligibility Option. Attachment B provides a summary of the remaining 2007 Legislative Bills that impact health care coverage for children. Attachment C provides a summary of the various income eligibility levels.

The estimate for the Buy-In for Children at 200 percent of the federal poverty level is based on an expected enrollment of 402 children. Based on an average monthly cost per child of $157.43, the estimated cost is $1,518,885, which is offset by premiums that would be collected of $602,316. The premium is estimated to be $117 per child per month. Families who have health insurance would **only** pay a premium if their current out of pocket expenses for their premiums are less than five percent of their gross income. Therefore, once all expenses and premiums are offset, the expected grant expenditures for the Buy In for Children would be $916,569 of which $330,148 are general funds.

The estimate for the Waiver for Children with Extraordinary Health Care Needs is based on an expected enrollment of 15 children. Based on an average annual cost of $44,769 per child, the estimated biennial expenditures are $1,343,070 of which $492,720 are general funds.

Additionally, there would be expenses related to administration. Specifically, there would be expenditures for overtime for Department staff to process the premium payments. This is estimated to be $63,840 for the biennium. Also, there would be enhancements to MMIS and the Vision system. The estimated cost for the modifications is $306,826. The estimated grant, overtime, and system enhancement expenditures are included in the appropriation section of this bill. The Appropriation

Section also contains authority for the addition of a Full Time Equivalent (FTE) for the development, implementation, and operation of the Buy-In and the Waiver. Funding for the FTE for the 2007-2009 Biennium would be $103,462 of which $51,732 would be general funds.

I would be happy to answer any questions that you may have.

Attachment B

North Dakota Department of Human Services
Medical Services Division

Comparison of Health Care Coverage Options for Children

Status at Legislative Crossover February 2007

Bill No	To Senate SB 2012	To House SB 2012	SB 2326
Proposed Coverage	SCHIP 140% Net	SCHIP 140% Net	Medicaid Buy-In @200% /Waiver
Potential Children	3,958	4,271	402/15
Census Data / Uninsured			
Fiscal Estimate	19,690,305	21,249,232	2,733,767
General Funds	4,965,555	5,358,560	1,059,932
Federal Funds	14,724,750	15,890,672	1,673,835
Other	The 2007-2009 Budget built on an average of 3,958 children per month	Includes enhancements that would serve an additional 313 children	Includes Funding for Waiver for Children with Extra-Ordinary Health Care Needs
		HB 1463, if adopted as amended, would change SCHIP to 150% and add an additional 1,200 children.	

HB 1463	
Medicaid @ 133% 6 to 19 yr olds	150% (net) for Healthy Steps
2,700	1,200
4,126,968	3,875,868
1,486,534	977,106
2,640,434	2,898,762
Would be offset by savings to Healthy Steps 2,450 children @ $207.31/month. Total $6,468,072 General $1,630,601 Federal $4,837,471	

HB 1463 Appropriation is in SB 2012, as amended	
Total	1,534,814
General Funds	833,039
Federal Funds	701,775

Last Updated 2-16-2007

TESTIMONY – PROTECTION AND ADVOCACY PROJECT
SENATE BILL 2326 (2007) – CHILDREN'S FOA BUY-IN

SENATE APPROPRIATIONS COMMITTEE
Honorable Clara Sue Price, Chairman

February 27, 2007

Chairman Price, and members of the House Appropriations Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A).

The federal Deficit Reduction Act allows states to create a buy-in for Medicaid for children with disabilities. The buy-in is in a part of the law called the Family Opportunity Act (FOA). The FOA buy-in could be available for families with a child with disabilities who earn up to 300% of the federal poverty level (FPL) in gross income. The current proposal for 200% FPL, based on net income, would serve fewer children, but would be a strong step forward.

On the reverse are three typical family budgets at 300% FPL, gross income. Gross income of 300% income is probably slightly higher than 225% net income, depending on individual family expenses. High out of pocket expenses for children with disabilities make many families at 300% FPL insolvent. Two of the three families would become solvent with the addition of the FOA buy-in. These families would then be more stable, better able to contribute to society, and their children could receive needed health care.

Please consider raising the FPL eligibility for the FOA buy-in to at least 225%. This would represent the same income with the Workers with Disabilities buy-in to Medicaid you passed in 2003. A parent of a child with disabilities who used the buy-in would have less money per person in their budget than a single worker. For this reason, please also consider funding the children's buy-in at 300% FPL, net.

Thank you very much for your time and consideration.

P&A Attachment B		Home Purchase			*Rental*			Rental	
FOA Family Budget		1 Ch w/d	1 Ch w/d		1 Ch w/d	1 Ch w/d		2 Ch w/d	2 Ch w/d
expenses		Fam' 4 FOA	Fam' 4 now		Fam' 2 FOA	Fam' 2 now		Fam' 4 FOA	Fam' 4 now
	Mortg/Rent	1200	1200		*600*	600		740	740
	Stu Loan	240	240		*120*	120		240	240
	Rx Dx Optom	*150*	370		*100*	185		*150*	370
	School Lunch	96	96		*48*	48		96	96
	util	197	197		*56*	56		56	56
	food	685	685		*480*	480		685	685
	AT	0	0		*0*	0		0	0
	Phone/comm	145	145		*145*	145		145	145
	Car Pmt	250	250		*175*	175		250	250
	car mtce	75	75		*75*	75		75	75
	car ins	77	77		*70*	70		77	77
	fuel	200	200		*120*	120		200	200
	Extracurric	100	100		*50*	50		100	100
	Child Care	894	894		*447*	447		894	894
	Vacation	0	0		*0*	0		0	0
	Donat/Gift	*50*	50		*25*	25		*50*	50
	Clothes	100	100		*50*	50		100	100
	house misc	75	75		*75*	75		75	75
	Fam Hlth Ins	500	500		*300*	500		500	500
	Ind w/d Hlth	*375*	*830*		*247*	*830*		*375*	*1660*
	TOTAL	**5409**	**6084**		**3183.125**	**4051**		4808	6313
balance	***balance***	***-709***	***-1384***		***11.875***	***-856***		**-108**	**-1613**
300% FPL		5000	5000		3295	3295		5000	5000
Tax w EITC		-300	-300		-100	-100		-300	-300
Net Inc.		4700	4700		3195	3195		4700	4700
	Premiums = 7.5%								
	Estimates lower of DOJ or NDSU by P&A Graduate Intern								

TESTIMONY SB 2326 -- PROTECTION AND ADVOCACY PROJECT February 27, 2007

	300% FPL 778 children	200% FPL 402 children
Fiscal total	$2,540,373.00	$1,390,597.00
Federal Funds	$1,559,048.00	$823,435.00
General Fund (GF)	**$981,325.00**	**$567,162.00**
GF per child	$1,261.34	$1,410.85
Differential GF per ch	$1,101.50	
P&A Estimates:		
Family Contributions	$2,887,135.50	$517,675.50
Differential Contrib.	**$2,369,460.00**	

P&A supports a buy-in under the Family Opportunity Act, especially at 300% or 225% of the Federal Poverty Level (FPL). P&A recommends covering more children by using the 300% FPL if the state can afford the expense.

This comparison of the two proposals shows the costs and benefits of extending coverage to 300%. These amounts are called the differential cost and differential benefit in this document.

The Department's estimates show children in the 200% to 300% range cost less per child to cover -- about $1100 each verses $1260. This is probably because of economies of scale and higher family contributions.

The families in the 200% to 300% range would contribute an additional 2.37 million dollars to the program, averaging about $3,200 each per year. If the program were extended to 300%, the differential contributions of these families would pay for almost half of the total program.

Thank you for your consideration of these proposals.

P&A Worksheet for estimates used (need not be attached)

		incomes	yearly premium
base 2007 FPL		$10,210.00	
addl person		$3,480.00	
fam 3		$17,170.00	
	150%	$25,755.00	$1,287.75 at 5%
	200%	$34,340.00	$1,373.60 at 5%
	250%	$42,925.00	$3,219.38 at 7.5%
	300%	$51,510.00	$3,863.25 at 7.5%

Waiver & Buy-In Both are Needed Here is Why...

Prepared by:
Family Voices of North Dakota
Arc of Bismarck
Federation of Families for Children's Mental Health
North Dakota Protection and Advocacy

Both programs will close the gap for children with special health care needs or disabilities who DO NOT meet the MR/DD eligibility

Waiver for children with extraordinary medical needs

Authorized in SB 2395, will serve **the most medically fragile or children ages 3 to 18 with extraordinary health care needs,** to reduce extended hospitalizations & prevent skilled nursing placement and institutionalization

Waiver Program

- Maximum number of children served at any point during the year is 15
- Waivers enable families to access support services in addition to those covered in the Medicaid State Plan
- Waivers allow states to cap and set individual cost limits

To Be Eligible

- Child must meet nursing home level of care and highest level of need
- If the child receives a waivered service there is an asset and income disregard for the child

Impact to Family

Provides long term supports and services to maintain their child in the family home setting while meeting their unique needs

Fact Sheet Developed: 1/30/07

Buy-In for children with disabilities Family Opportunity Act

Buy-In Program

- Authorized by Congress in the Deficit Reduction Act 2005
- Families pay a premium of up to 5% of family's gross income for those up to 200% of FPL, and 7.5% for those up to 300% FPL.
- Would serve approx. 778 children at 300% FPL

To Be Eligible

- **Child must be determined to have a disability under the Social Security Act**
- For children with disabilities under the above definition 0-18 years of age whose family income does not exceed 300% FPL, In 2006 this amount would be $5001 (net monthly income)
- Families are required to accept employer coverage, if employer pays 50% or more

Impact to Family

- Child would have access to all Medicaid Services
- Avoids family bankruptcy, impoverishment and custody relinquishment in order to meet the child's needs

Why This Is A Needed Option

- Private insurance is not comprehensive enough to meet the needs of these children.
- Having access to Medicaid as a secondary resource would cover the high cost care of the child
- Fewer out of home placements
- The Buy-In is pro work as parents pay a premium, pro family as parents can raise their child at home, pro taxpayer as families are encouraged to work, pay taxes and pay their own way

Kaseman Family Story

Health Issue: undiagnosed with severe DD

Issue: Not eligible for nursing care because she is not "home bound" according to insurance. Can not qualify for SSI due to too many assets. Unable of paying for nursing care out of our pocket. NDMA denied medical care in MN

Insurance Coverage:

Medicaid

Recommendations:

Better access to necessary services

Family Story from:

Teresa Kaseman

1115 8th Ave W, West Fargo, ND 58078

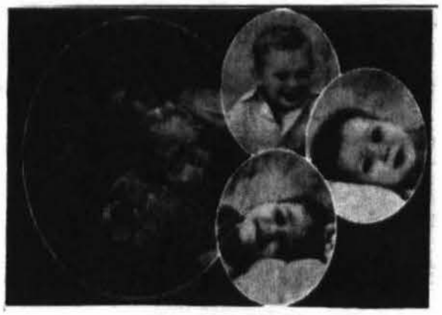
I have three beautiful children named Ariana, Alex and Lucas. Ariana and Lucas have an undiagnosed neurological condition causing severe global developmental delay. Ariana also has various medical complications that keep us hospitalized much more often than we would like. She has many spells where she becomes ill with flu-like symptoms. When I take her to the hospital I am frustrated with the lack of acknowledgement regarding Ariana's issues. The doctors, in their bewilderment, suggest that I go home because they don't know how to help her. From the start I have felt isolated. Ariana's medical team, who I would have expected to provide me with information regarding various programs available to our family, like infant development, NDMA, and other types of financial and supportive assistance, failed me. Even after we had Lucas, I still wait patiently to hear a doctor offer this type of support. I was introduced into the infant development program because of a daycare provider who was intuitive enough to pick up on Ariana's struggles. Luckily, through this program, our family has been provided with essential support Beyond that I've learned what other services are available via word of mouth, from parents and through my own research. Along the way, I've had many professional ask if I need anything. But what I really need is someone to tell me what I have available as a parent of a child with difficulties. Many programs have a budget or age limit. Because of this, all too often, I never realize what I need until it is too late.

Insurance has always been a fight. I spend countless hours calling, appealing and battling for things that Ariana and Lucas require in order to lead a normal life. In my attempt to help provide Ariana proper medical care, I looked into getting nursing staff for her. So far this school year, she has spent 60 of her 75 school days in the hospital. We were denied from insurance because she is not homebound. We have caregivers who come to our home to help but they are underpaid and rarely prepared for my children. I am fearful to leave my children but I am forced to in order to provide for my children financially.

I have also checked in to SSI as a supplement to our income. Based on our income guidelines we would qualify, but we have too many assets. We would be forced to sell a vehicle and deplete our 401k plan and savings accounts. It is an item we are being forced to use before we can obtain help for our children. I considered doing it for a moment but then asked myself what would happen when we retire or if we have some sort of emergency and needed those funds? Will the government take care of my house payments and bills then? Will they be there for us or will they abandon us as they have on so many other occasions?

Our experience with NDMA has been just as futile. When Lucas was born we were swept into the race to find a possible diagnosis again. Ariana had been to every medical professional in North Dakota so we were told to go out of state to Mayo where they were better prepared to deal with complicated children like Ariana and Lucas. We submitted a prior authorization request to NDMA and both Ariana and Lucas were denied. We were told that Ariana was denied because she had already gone through extensive testing and there was nothing more that anyone could do. Lucas was denied because he needed to be seen by the North Dakota medical community before he would be authorized to go out of state. I went to the Protection and Advocacy Agency and we added another appeal to our already full slate. Everyday I come closer to moving to Minnesota.

Having 3 children, two with the same medical condition, has created a new and unique facet in our lives. I love each of my children to the capacity that only a mother's heart can know but with that love comes a heavy burden. There is never enough time to spend with them. Ariana and Lucas take up so much of my day that Alex is often left to play on his own. Ariana is sick so much that I spend my time trying to comfort her pain while Lucas cries in the background begging for me to hold him as well. Therapies, laundry, stretches, proper placement and the multitude of tasks that I should be doing with my children are thrown to the wayside. I find that I barely have time to make supper, give baths, and sit down to read a book with them before a brand new day has come upon me. I wish that I could spend my time being a mother instead of fighting for what they so badly require.



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February 27, 2007

HOUSE HUMAN SERVICES COMMITTEE
SB 2326

CHAIRMAN LEE AND COMMITTEE MEMBERS:

My name is Caitlin McDonald. I'm appearing here today on behalf of The Arc of North Dakota. **<u>We strongly support SB 2326 and urge a do pass.</u>**

Middle income families of children with special health care needs often face difficult choices to provide health care for their families. These can include bankruptcy, surrendering custody of the children to the state to assure Medicaid coverage for them or spending down their resources or turning down raises to stay eligible for Medicaid.

This bill allows working families to purchase Medicaid to act as a wrap-around for medically necessary services denied by their private insurance carriers.

This is not an entitlement program. Families must maintain their own private insurance if they have it. They must use a significant portion of their income to pay for it. However, in most cases, these costs will be significantly less expensive that the out-of-pocket costs they are paying now for the actual services.

Therefore, we respectfully request that you give SB 2326 a do pass. If you have any questions, I will be happy to try to answer them. THANK YOU FOR YOUR TIME AND CONSIDERATION.

The Arc is an advocacy organization. The Arc advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. Together with our network of members and affiliated chapters, we improve systems of supports and services; connect families, inspire communities and influence disability policy.

TESTIMONY: SENATE BILL 2326
HOUSE HUMAN SERVICES COMMITTEE

REPRESENTATIVE PRICE, CHAIRMAN

February 27, 2007

Chairman Price and members of the Committee: my name is Carlotta McCleary. I am the Executive Director for the ND Federation of Families for Children's Mental Health (NDFFCMH). The Federation of Families is a parent run organization that focuses on the needs of children with emotional, behavioral and mental disorders and their families. On behalf of the Federation, I am here to testify in support of SB 2326.

According to U. S. Department of Health and Human Services, studies show that at least one in five children and adolescents have a mental health disorder. At least one in 10, or about 6 million people, have a serious emotional disturbance. Two thirds are not getting the help they need. The estimate of North Dakota's total child count with a serious emotional disturbance is 15,770 youth. According to the Department of Human Services the number of children and adolescents diagnosed with a severe emotional disturbance who received publicly funded services in FY 2005 was 1,692. The estimated number of children and adolescents diagnosed with severe emotional disturbance in need of service is 3,217.

These problems take a number of forms. The children may be self-abusive or aggressive toward others; or they may be withdrawn, fearful, or depressed. Some with the most serious disorders may be out of touch with reality and have unusual fantasies or hallucinations.

Families may face many problems; the absence of appropriate childcare prevents many families from participating in social or recreational activities and they experience isolation from friends and relatives. Often, family members must learn to cope with the difficulty and demanding behaviors of their children, and may face the staggering costs for special treatment, education, or other services.

According to the Larry Burd Study on the interim report of cost and service use for children with severe emotional disturbance in North Dakota: Parents Cost Study; there is an impact on parental employment, time spent and costs that are not reimbursed to the family. These cost are excess costs in terms of time and money for this group of children. These cost are in excess of the time and money parents spend on other children. Thus these costs are due to the efforts to treat the child with emotional and behavior problems. All costs (time and money) are not reimbursed from any source and represent the parental (family) contribution to the effort to treat these problems.

Here are some of his findings:

There was an impact on parental employment, 20% now work only part time, 22% had to quit work and 16% are with a different job. Also noted were loss of income at $5,354.55 per year, vacation time cost at $547.50 per year, sick leave cost at $365.00 per year and missed work cost at $602.25 per year.

Time spent for travel, meetings and loss of sleep; total lost time was 790 hours per year. Costs to a family that are not reimbursed such as miles traveled $6,905.50, travel costs $1,022.00, purchases $3,204.70, co pay or other medical costs $1,357.80, Repairs $3,073.30, extra help $1,314.00, other costs $923.45 and extra telephone costs $219.00.

In conclusion the study found parents paying an excess of $17,983.55 to care for a child with an emotional behavioral or mental disorder for a year.

Workers With Disabilities is at 225% of poverty (Medicaid Buy-in for adults). Most of the individuals are a one-member household. Families have additional the additional expenses because they are a family. Then you add the expenses related to caring for a child with special needs.

The NDFFCMH believes children and their families must receive supports necessary to remain with their families; out-of-home placement must be considered as a last resort. When children cannot remain with their families, out-of-home placement must be viewed as temporary and an extension of the family. This treatment must be available close to the child's home and family members must be involved in all decisions regarding their child.

According to The United States General Accounting Office, in 2003 they reported 12,700 cases of children were placed in the child welfare and juvenile justice systems to access mental health services. According to the 2003 New Freedom Commission on Mental Health Federal, State and local governments must work together with family and provider organizations to eliminate the practice of trading custody for care and to find a more family friendly solution. North Dakota is one of 13 states that have passed laws that prohibit DHS from requiring custody relinquishment in order for parents to obtain out-of-home treatment for their children. However, ND currently has no laws to improve access. North Dakota's Voluntary Treatment program serves an average of 16 children per biennium. The Voluntary Treatment Program ran out of funding the first six months of the biennium.

The NDFFCMH would like to see the Family Opportunity Act fully implemented. This would allow families access to care that their children desperately need. Children would gain access to community-based services such as Partnerships, which would enable then to remain at home. For some families the cost of treatment has prevented them from getting this care. This often leads families to relinquish custody of their children in order to obtain treatment. North Dakota's Voluntary Treatment Program is for children who are eligible for Medicaid. Families who aren't eligible for Medicaid have limited coverage from their insurance or they don't have any coverage for out-of home treatment. Thereby forcing parents to relinquish custody of their children, which makes them eligible for Medicaid. This bill allows families to gain access to needed treatment.

Thank you for your time.

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TESTIMONY – PROTECTION AND ADVOCACY PROJECT
SENATE BILL 2326 – CHILDREN'S FOA BUY-IN

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HOUSE APPROPRIATIONS COMMITTEE
HUMAN RESOURCES DIVISION
Honorable Chet Pollert, Chairman

March 14, 2007

Chairman Pollert, and members of the House Appropriations Human Resources Division, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A).

The Family Opportunity Act (FOA) is part of federal Deficit Reduction Act of 2005. FOA allows states to create a buy-in for Medicaid for children with disabilities. The federal FOA buy-in could be available for families with a child with disabilities who earn up to 300% of the federal poverty level (FPL) in gross income. The current North Dakota proposal for 200% FPL would be a strong step forward.

On the reverse are three typical family budgets at 225% FPL, net income. High out of pocket expenses for children with disabilities make many families at 225% FPL insolvent. Two of the three families would become solvent with the addition of the FOA buy-in. These families would then be more stable, better able to contribute to society, and their children could receive needed health care.

Please consider raising the FPL eligibility for the FOA buy-in to at least 225%. This would represent the same income with the Workers with Disabilities buy-in to Medicaid you passed in 2003. A parent of a child with disabilities who used the buy-in would have less money per person in their budget than a single worker.

Thank you very much for your time and consideration.

		Home Purchase			*Rental*			Rental	
FOA Family Budget		1 Ch w/d	1 Ch w/d		1 Ch w/d	1 Ch w/d		2 Ch w/d	2 Ch w/d
expenses		Fam' 4 FOA	Fam' 4 now		Fam' 2 FOA	Fam' 2 now		Fam' 4 FOA	Fam' 4 now
	Mortg/Rent	900	900		*600*	600		740	740
	Stu Loan	0	0		*0*	0		0	0
	Rx Dx Optom	*100*	370		*75*	185		*100*	370
	School Lunch	80	80		*40*	40		80	80
	util	197	197		*56*	56		56	56
	food	400	400		*200*	200		400	400
	AT	25	25		*25*	25		25	25
	Phone/comm	80	80		*80*	80		40	40
	Car Pmt	250	250		*175*	175		250	250
	car mtce	75	75		*75*	75		75	75
	car ins	77	77		*70*	70		77	77
	fuel	150	150		*75*	75		150	150
	Extracurric	50	50		*25*	25		50	50
	Child Care	894	894		*447*	447		894	894
	Vacation	0	0		*0*	0		0	0
	Donat/Gift	*50*	50		*25*	25		*50*	50
	Clothes	75	100		*40*	40		75	75
	house misc	25	25		*10*	10		20	20
	Fam Hlth Ins	500	500		*300*	500		500	500
	Ind w/d Hlth	*190*	*830*		*125*	*830*		*190*	*1660*
	TOTAL	**4117.8**	**5053**		**2443.15**	**3458**		3771.8	5512
balance	***balance***	***-321.8***	***-2117***		***59.85***	***-1395***		**24.2**	**-2576**
Gross Income 300% FPL*		5590	5000		3425	3295		5590	5000
Tax w EITC		-300	-300		-100	-100		-300	-300
Child, Elder, & Health care		-1494	-1764		-822	-1132		-1494	-1764
Net Inc.		3796	2936		2503	2063		3796	2936
Yearly		45552							
	Premiums = 5% at 200% FPL, 7.5% above								
	Estimates lower of DOJ or NDSU by P&A Graduate Intern, some arbitrarily marked down to balance budget								
	*300% FPL gross approximates 225% FPL net								

The Arc

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SB 2326 - (Medicaid Buy-In and funding for Waiver)

House Appropriations - Human Resources Committee
Chairman – Rep. Pollert
March 14, 2007

Chairman Pollert and members of the Committee, my name is Mike Schwab, Executive Director for The Arc of Bismarck. I am representing The Arc of Bismarck and The Arc of Cass County and our constituents today.

I am here to ask for your support in passing an important piece of legislation. SB 2326 would offer low-middle income and middle-income families of children with disabilities the option of buying-into Medicaid. Currently, these children meet the definition of "disability" as defined by Social Security but are not eligible for Medicaid because their families earn a little too much money. Because of this, families are often un-insured or underinsured because health insurance is not available through their employer, it is too expensive, or offers a limited number of benefits. Typically, unless it is a group policy, most insurance companies will not cover "pre-existing" conditions, therefore the child gets denied coverage.

In addition, parents are often times forced to remain in the same job to keep health insurance or to decline employment in order to access state/federal benefits. Giving parents the option of buying into Medicaid and paying on a sliding fee scale would provide children with disabilities in these families access to the full range of Medicaid services.

This provision would allow the state to cover young children with "potentially severe disabilities", and promises improved overall health. It would also help with the prevention of future disabilities and these children would have a better chance to live full and healthy lives with their families in their homes, where they belong.

This legislation offers stability, rehabilitation, and recovery to children with severe and chronic disabilities this may also include the early on-set of mental illnesses. It also breaks the link between forced poverty and Medicaid. It also builds on the work incentives law that was enacted in 1999.

SB 2326 allows families whose net income does not exceed 200% of the federal poverty level to buy-into Medicaid. While this is a step in the right direction, the "workers with disabilities coverage" for adults (Medicaid Buy-In for adults – passed in 2003), is set at 225% of the poverty level. Most of the individuals that access that program are single working individuals. SB 2326 is designed to support families. We ask that you consider raising the federal poverty level to at least 225%.

By passing SB 2326, you are also allowing the necessary funds to become available to implement the "waiver for children with extraordinary medical needs. The development and direction of this waiver became existing law last session (SB 2395). Funding is needed in order to implement the waiver.

We would like to thank you for your continued support of children and their families and ask that you pass SB 2326. Thank you for your time and attention today.

Respectfully Submitted,

Michael D. Schwab
The Arc of Bismarck
The Arc of Cass County

TESTIMONY: SENATE BILL 2326
HOUSE APPROPRIATIONS
HUMAN RESOURCES DIVISION COMMITTEE
REPRESENTATIVE POLLERT, CHAIRMAN
March 14, 2007

Chairman Pollert and members of the Committee: my name is Carlotta McCleary. I am the Executive Director for the ND Federation of Families for Children's Mental Health (NDFFCMH). The Federation of Families is a parent run organization that focuses on the needs of children with emotional, behavioral and mental disorders and their families. On behalf of the Federation, I am here to testify in support of SB 2326.

According to U. S. Department of Health and Human Services, studies show that at least one in 10 children and adolescents have a serious emotional disturbance. Two thirds are not getting the help they need. Their families may face many problems too. Often, family members must learn to cope with the difficulty and demanding behaviors of their children, and may face the staggering costs for special treatment, education, or other services. For some families the cost of treatment has prevented them from getting this care. This often leads families to relinquish custody of their children in order to obtain treatment.

North Dakota is one of 13 states that have passed laws that prohibit DHS from requiring custody relinquishment in order for parents to obtain out-of-home treatment for their children. However, ND currently has no laws to improve access. North Dakota's Voluntary Treatment Program is for children who are eligible for Medicaid. Families who aren't eligible for Medicaid have limited coverage from their insurance or they don't have any coverage for out-of home treatment. Thereby forcing parents to relinquish custody of their children, which makes them eligible for Medicaid.

According to the Larry Burd Study on the interim report of cost and service use for children with severe emotional disturbance in North Dakota: Parents Cost Study; there is an impact on parental employment, time spent and costs that are not reimbursed to the family. These cost are excess costs in terms of time and money for this group of children. These cost are in excess of the time and money parents spend on other children. Thus these costs are due to the efforts to treat the child with emotional and behavior problems. All costs (time and money) are not reimbursed from any source and represent the parental (family) contribution to the effort to treat these problems.

Here are some of his findings:

There was an impact on parental employment, 20% now work only part time, 22% had to quit work and 16% are with a different job. Also noted were loss of income at $5,354.55 per year, vacation time cost at $547.50 per year, sick leave cost at $365.00 per year and missed work cost at $602.25 per year.

Time spent for travel, meetings and loss of sleep; total lost time was 790 hours per year. Costs to a family that are not reimbursed such as miles traveled $6,905.50, travel costs $1,022.00, purchases $3,204.70, co pay or other medical costs $1,357.80, Repairs $3,073.30, extra help $1,314.00, other costs $923.45 and extra telephone costs $219.00.

In conclusion the study found parents paying an excess of $17,983.55 to care for a child with an emotional behavioral or mental disorder for a year.

Workers With Disabilities is at 225% of poverty (Medicaid Buy-in for adults). Most of the individuals are a one-member household. Families have additional the additional expenses because they are a family. Then you add the expenses related to caring for a child with special needs.

The NDFFCMH would like to see the Family Opportunity Act fully implemented. This bill allows families to gain access to needed treatment.

Thank you for your time.

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