

MICROFILM DIVIDER

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



ROLL NUMBER

DESCRIPTION

3054

2005 HOUSE HUMAN SERVICES

HCR 3054

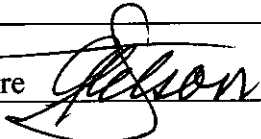
2005 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HCR 3054

House Human Services Committee

☐ Conference Committee

Hearing Date Feb. 23, 2005

Tape Number	Side A	Side B	Meter #
2	x		910-4010
Committee Clerk Signature 			

Minutes:

Chairman Price opened hearing on HCR 3054.

Rep. Wrangham: This proposes a special study. There is a solution to find, I urge you to do everything you can to see that this bill is passed. I appreciate the committee's cooperation and stand for questions.

Sen. J. Lee: This bill mirrors the information on Russell Silver syndrome, SB 2395. This HCR 3054/ SB 2395, in both cases, intend to look at families with unusual medical situations. This particular situation we have looked at is Russell Silver syndrome. I know that there are other unusual medical situations other than this one, but with this legislation, we may be able to assist others. I do urge your favorable consideration on this and will attempt to answer any questions.

Bruce Murry, Protection and Advocacy Project. See Attached Testimony.

MR1361.

Danene Feist: See Attached Testimony.

Rep. Kaldor: Can you elaborate your statement in regards to ND being a 209 B state.

D. Feist: I believe I will let Dave Zentner comment on that.

David Zentner: Director of Medical Services, Dept. HS. Before the SSI days, ND did it own thing for the aged, blind and disabled. When the SSI program became federalized, states had the option using the SSI criteria, or if they had more restrictive criteria, they could apply that, that's what is the 209 D state process in the federal eligibility guidelines. There are a few differences on assets, that we have in our program that the federal govt. doesn't have. This goes back into the 80's.

Rep. Potter: Regarding the Federal definitions vs. state definitions. Is that just 209 D area?

Bruce Murry: The statutes are very similar, as the program for these services are set up in administrative code. To access these services, MR guidelines are followed and these also involve DD waiver. Some conditions do fall outside of these guidelines.

Roxann Romanick: See attached testimony.

Linda Schatz: I would like to make you aware of some of the other areas that need your attention. Part C. Designation, participating IDEA, ? med. My son 's med.'s cost \$1,600 per dose at Fairview Med. Center. End case defect, we can not seem to get the Dr. to tell what his condition really is. If we did not have these medical procedures, my son would be dead by the age of 10. We have been to Minneapolis 3 times in 4 months. I take care of my son during the week, as my husband works, and then I work as a nurse on the weekends. Thnak you for listening and I hope you will find it in your hearts to pass this bill.

Chairman Price: Anyone else to testify? Close hearing

Page 3

House Human Services Committee

Bill/Resolution Number HCR 3054

Hearing Date February 23, 2005

Chairman Price opened discussion on HCR 3054.

Rep. Porter: Do Pass and placed on the Consent Calendar.

Rep. Kaldor: Second

Vote: 9-0-3. Carrier: Rep. Uglem

Date: 2/23/05

Roll Call Vote #: /

2005 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. HR 3054

House _____ Committee Human Services

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Do Pass & place on Consent Calendar

Motion Made By Rep Parth Seconded By Rep Kaldor

Representatives	Yes	No	Representatives	Yes	No
Chairman C.S. Price	✓		Rep.L. Kaldor	✓	
V Chrm.G. Kreidt	✓		Rep.L. Potter	✓	
Rep. V. Pietsch	✓		Rep.S. Sandvig	AB	
Rep.J.O. Nelson	AB				
Rep.W.R. Devlin	AB				
Rep.T. Porter	✓				
Rep.G. Uglem	✓				
Rep C. Damschen	✓				
Rep.R. Weisz	✓				

Total () 9 No 0

Absent 3

Floor Assignment Rep Uglem

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

REPORT OF STANDING COMMITTEE (410)
February 25, 2005 8:12 a.m.

Module No: HR-35-3644
Carrier: Uglem
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

HCR 3054: Human Services Committee (Rep. Price, Chairman) recommends DO PASS and BE PLACED ON THE CONSENT CALENDAR (9 YEAS, 0 NAYS, 3 ABSENT AND NOT VOTING). HCR 3054 was placed on the Tenth order on the calendar.

2005 SENATE HUMAN SERVICES

HCR 3054

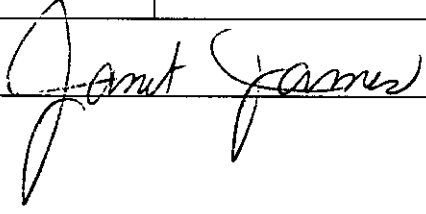
2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HCR 3054

Senate Human Services Committee

☐ Conference Committee

Hearing Date March 21, 2005

Tape Number	Side A	Side B	Meter #
	X		0.0 - 32.8
Committee Clerk Signature 			

Minutes:

Senator Judy Lee, Chairman of the Senate Human Services Committee brought the committee to order.

All members of the committee were present.

Senator Lee opened the hearing on HCR 3054 directing the Legislative Council to study programs providing services to children with special health care needs.

Senator Lee introduced HCR 3054 as cosponsor of the bill stating that the resolution hearing will remain open until Representative Duane Wrangham will be able to testify before the committee. HCR 3054 does tie into the SB 2395 relating to Russell Silver Syndrome and this resolution will help to study where services are adequately provided to the families of these children in North Dakota.

Senator Dick Dever asked if the resolution is more involved than the study put into SB 2395.

Senator Lee answered the hope it that this study will be far more comprehensive and if both the resolution and the bill are passed in tact, they will be combined.

Dorene Feist, (2.2) Director for Family Voices of North Dakota testified in support of HCR 3054. See written testimony, (Attachment #1 and #1 A).

Roxane Romanick (9.5) testified on her own behalf in support of HCR 3054. See written testimony, (Attachment # 2).

Written testimony in support of HCR 3054 from **Blair Aasland** (12.0) was presented to the committee by Roxane Romanick, (See Attachment #3).

Written testimony in support of HCR 3054 from **Jennifer Restemayer** (13.2) was presented to the committee by Roxane Romanick, (See Attachment #3A).

Linda Schatz (15.1) testified on her own behalf as a parent of a special needs child, in support of HCR 3054. See written testimony (Attachment #4).

David Boeck (18.4) representing the Protection and Advocacy Project testified in support of HRC 3054. See written testimony (Attachment 5).

Senator John Warner stated the committee has struggled defining what constitutes "special health care needs" and defining the population that should be severed by that definition.

David Boeck answered that other states have these definitions and the best route for the state would be to follow the federal definitions that are broader and serve better.

Senator Warner asked for a definition of 209B.

David Boeck explained that coverage of medical and other needs for disabled and elderly people was split among the state and federal governments. In 1973, the federal government created the SSI program that would provide minimal income, so that the sates do not have to worry about

providing subsistent income. In return the state would take part of the Medicaid program. Under 209B, a provision was added that the eligibility requirement could be used that were in place in January 1, 1972. North Dakota is one of the eleven states that still use the 1972 income and resource guideline criteria to determine eligibility for services. The state does allow some increase in terms of income and resources but have every right to stay at the 1972 level. The other 39 states use the SSI income level, so when Social Security determines that someone is eligible for SSI, the state automatically accepts that person eligible for Medicaid. There is a huge amount of administrative expense that needs to be engaged in to determine the eligibility because of the difference in criteria. A lot of money would be saved if the state would move to the system of accepting the Social Security criteria for SSI proposes.

Senator Dever asked if the waiver in Minnesota that was mentioned, the Katie Beckett waiver.

David Boeck confirmed this and stated that Minnesota was also a 209B state.

Donene Feist commented that the asset disregard for children is only true to a point and that children who fall into that age disabled category, do not have that disregard unless they are moved to a different children's program under Medicaid.

Mary Rennich (28.2) testified on her own behalf and her two disabled children in support of HCR 3054. See written testimony (Attachment 6).

Senator Lee asked for testimony in a neutral and opposing position and hearing none closed the hearing on HCR 3054.

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. **HCR 3054**

Senate Human Services Committee

☐ Conference Committee

Hearing Date March 22, 2005

Tape Number	Side A	Side B	Meter #
1	x		598-800
Committee Clerk Signature <i>Diane Davis</i>			

Resolution directing the Legislative Council to study state programs providing services to children with special health care needs to determine whether the programs are effective in meeting these special health care needs, whether there are gaps in the state's system for providing services to children with special health care needs.

Chairman J. Lee re-opens hearing on HCR 3054.

Representative Dwight Wrangham - This is a study that could result in some real positive actions to help our very youngest and very vulnerable citizens. Asked to please approve.

Senator Lee - Mentioned they had talked about the fact that there is a study resolution component as in the RS bill, but this is a little more far reaching and hope it is the one selected.

Close the hearing HCR 3054

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Senate Human Services Committee

Bill/Resolution Number **HCR 3054**

Hearing Date March 22, 2005

(meter #786)

Senator Warner moved for do pass

Senator Lyson seconded

Roll taken - 5-0

Senator Warner will carry

(meter #843)

Date: 3-22-05
Roll Call Vote #: 1

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. *HCR 3054*

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass

Motion Made By Joe Warren Seconded By Sam Lipson

[illegible]

Total (Yes) 5 No 9

Absent

Floor Assignment *See Annex*

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

REPORT OF STANDING COMMITTEE (410)
March 22, 2005 11:43 a.m.

Module No: SR-52-5717
Carrier: Warner
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

HCR 3054: Human Services Committee (Sen. J. Lee, Chairman) recommends DO PASS
(5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HCR 3054 was placed on the
Fourteenth order on the calendar.

2005 TESTIMONY

HCR 3054

#1

TESTIMONY - PROTECTION AND ADVOCACY PROJECT
HCR 3054 - HOUSE HUMAN SERVICES COMMITTEE
HONORABLE CLARA SUE PRICE, CHAIRMAN
February 23, 2005 2:30 p.m.

Chairman Price, and members of the House Judiciary Committee, I am Bruce Murry, a staff attorney for the North Dakota Protection and Advocacy Project (P&A).

P&A respectfully requests that this committee make a favorable recommendation for HCR 3054 and support the Legislative Council prioritizing it after passage.

Many parents with whom P&A works confirm the trends cited in the resolution. Parents report mounting debts because of deductibles, co-pays, and uninsured needs. Parents worry they will neglect the needs of their other children to serve those of a child with extraordinary health care needs. Even parents that are able to plan ahead for the birth of a child may find the family's budget cannot sustain the expenses for a child with extraordinary health care needs. The results can include bankruptcy, lost homes, lost jobs, relinquishing custody of a child to the state, or placing the child in an institution. Worst of all, a treatable condition might leave a child to face disabilities that could have been avoided.

P&A encourages the Legislature to study and take action to reduce gaps in services to children with extraordinary health care needs.

Thank you for your consideration. I would be happy to answer any questions.

Testimony HCR 3054

Madam Chair, Committee Members, thank you for the opportunity to provide input regarding a study for children with special health care needs, in HCR 3054.

My name is Donene Feist, and I live in Edgeley North Dakota. As the Director for Family Voices of North Dakota and have come on my day off to provide you with important information as you consider this study. Family Voices is a health information and education center for families of children with special health care needs in North Dakota.

This study is important not just from the view point of families but agencies alike. Many agencies are involved in this very complicated system of care. Department of Human Services, Medicaid, DD Division, Early Intervention, Children's Special Health Services, Medicaid, Mental Health Services, VR, and the Department of Public Instruction. I hear from families each and every day, the struggles they have with the various gaps in the system. As the mother of two children with special needs, I understand what these families are going through.

To my knowledge there has not been a study to identify these children, appropriate systems of care, whether the needs are being met and that we have adequately addressed public policy to meet those needs.

The Federal Maternal and Child Health Bureau definition of a child with special health care needs is this: Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Adopted by the American Academy of Pediatrics (October 1998). Maternal and Child Health Bureau. McPherson M, Arango P, Fox HB,

The National Survey for children with special health care needs was conducted for the first time in 2001 to identify prevalence and impact of children with special health care needs:

This survey identifies 12.4% or 18,652 of ND Children have a special health care need. Maternal and Child Health Bureau/SLAITS data
<http://www.cshcndata.org/DesktopDefault.aspx>

In Document 1. I have provided you with dialogue that families have shared with me in the last few months. For many of the families included in this dialogue, the situation at hand isn't whether there are appropriate services out there to assist these families. The problem is accessing these services. For families there are significant unmet needs that need to be addressed. For some families have to go through extreme measures in order to access services.

Issue 1: Children, birth to 3, who are identified as having a special health care need, may also qualify for services under Part C of the Individuals with Disabilities Education Act. These services are funded through Developmental Disabilities Division of the Department of Human Services. In order to qualify, children must have a 25% delay in 2 or more areas of development, 50% in one area, be high risk for developing a developmental delay or be found eligible under informed clinical opinion by a physician or an evaluation team. Children who qualify for Part C services also qualify for the DD Home and Community Based waiver. The child that qualifies is eligible for Medicaid due to an income and asset disregard of a family's resources.

As you can see from diagram 1 (below) there were 1,785 identified as having a special health care need in ND, while 592 children were being served on 1/13/95. for early intervention services.

	0 - 2 yrs old	3 - 5 yrs old	6 - 11 yrs old	12 - 17 yrs old	18 - 24 yrs old	Total
%	9.1	15.8	29.4	30.7	15.0	100.0
CI	(6.8 - 11.3)	(13.0 - 18.5)	(26.1 - 32.8)	(27.4 - 34.0)	(12.5 - 17.5)	
n	77	136	263	286	150	
Weighted Est.	1,785	3,097	5,786	6,034	2,950	

Issue 2. There is the misconception that if families have insurance that it will cover the needs of these children. This misconception is common but for families dealing with these issues from day to day knows that this is not

reality. Medicaid and Children's Special Health Services become the gap filler for many of these children.

Of the 18,652 children in ND with a special health care need
4.7% are currently uninsured.

31% are currently insured with coverage that is not adequate.

Of those children 12.9% have been without insurance at some point during the last year.

2.4% or 3,818 have a condition that result in functional limitations

4.3% or 6,821 have conditions managed with prescription medication

2.2% or 3,537 have a condition with results in above routine use of medical, mental health or other services

3.5% or 5,476 children have conditions that require prescription medications and above routine use of services.

Issue 3: Part C services or Early Intervention ends when a child turns 3.

In order to continue receiving MR-DD Case Management and related services under the Home and Community Based waiver and thus be eligible for continued Medicaid coverage under the income and asset disregard, children must go through an eligibility re-determination. This re-determination is based upon a mental retardation diagnosis or having a developmental delay that resembles mental retardation. If a child does not meet the criteria for MR-DD eligibility, they no longer have access to the benefits under the HCBS waiver. The loss of the services can be great for families, but the loss of Medicaid can be critical. Even though families' primary insurance is accessed as primary, Medicaid assisted them with ancillary services such as PT, OT Speech, Medications, Nutrition services etc. as these services under private insurance have limitations annually.

If the family is able to meet the income guidelines under Medicaid, they will continue to maintain many of the services, however for many families they will not. Many families have high recipient liabilities each month that are far beyond their capabilities.

In some ways the ND DD definition is more restrictive than the Federal definition as essentially the individual has to have severe developmental disabilities or qualify under the ICF/MR definition.

The Federal DD definition: As defined in the DD Act, the term ``developmental disabilities'' means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments that is manifested before the individual attains age 22 and is likely to continue indefinitely.

Issue 4: Not all of these children will receive Part B services under the Individuals with Disabilities Education Act through the Department of Public Instruction. In the 2002-2003 school year, 14,312 children ages 0-21 received special education services in our schools. Only those children who have a diagnosis in which affects their ability to learn will receive services under IDEA.

There are children who have a disability that substantially limit their participation in or access to school programs but who do not need special education. So for some children even though they may have a disability or special health need, if it indeed does not affect their ability to learn, may not receive these services in the school setting.

Issue 5: We know in ND that as of December of 2004 there were only 937 children under the age of 18 who received Social Security Income due to their disability and income guidelines. Many children will be medically eligible for SSI as having a disability, however because of family income will be over the eligibility guidelines. Most states if the child is SSI eligible they will also be Medicaid eligible. However, as ND is a 209 b state, our criteria is a bit more stringent and hence this may not always be the case.

These are just a few of the issues and gaps in the system that families face. What happens to those families? Do they file bankruptcy, divorce, move out of state, impoverish themselves, and work several jobs?

As I stated before, the gaps for families are many. We need to better identify who these children are, their needs of these children in order to address whether the current systems are adequate. This study could help us determine adequate services, planning for the future as these children grow older, how to better serve those who are falling in the gaps.

I also think it is important that the legislative council include the agencies, providers, families and advocates as part of the study in order to fully understand the need/gap areas and work in a collaborative way to meet the needs of these families in ND. A similar study has been proposed in SB 2395, the language a bit broader in this resolution. Which sets the framework to look at the entire system of care.

Madame Chair and Committee Members, families are not seeking a hand-out. What they are seeking is a hand, to grab on to in a very fragmented system in order to keep from drowning. This study has the potential to be the first step in closing the huge gaps in this very complicated system.

Thank you for your time

Donene Feist
PO Box 163
Edgeley, ND 58433

701-493-2634
701-709-0168

Document 1 for HCR 3054

1. My 2 children have a rare diagnosis and are terminal. Not only do we not qualify for assistance, we feel very isolated and alone. Why can't there be anything for families who have medically needy children?
2. My husband and I have been told that we should get a divorce in order for me to financially qualify for Medicaid so we wouldn't have to worry about our daughter receiving her treatments.
3. Our son was recently diagnosed with a very rare disorder called slow channel myasthenic syndrome. He was put on a ventilator at 3 days old and has been on it ever since. Our concerns center around the coverage of his care once insurance runs out on him, which could be anywhere from 5-8 years. We never questioned our move back home until we had our son and found out that had we stayed in Minnesota (or moved to South Dakota, where our home health agency is based) our son, on his own based on his condition, would qualify for Medicaid regardless of our income or assets.
4. As a young parent it becomes hard to get any type of financial stability established. As soon as one gets a little bit of money saved, then you lose the assistance that you were on. Our son has cerebral palsy, how are we supposed to provide him the support he needs?
5. I am the proud mother of a little girl 5 years old and was born with Cerebral Palsy and a Seizure Disorder. We are a middle class family that qualifies for very little assistance in our state. We were told by the ND Medical Assistance Office to move to MN. That MN would be a better place for us to live with our child w/special needs. ND prides itself on a great place to raise a family. They really should only take pride in the fact it's a great place to live IF you have typically developing children. We have had many financial struggles since our daughter was born. I am not blaming her, I am not blaming anyone, unfortunately our state fails to see the importance of continuing to support and provide adequate funds for these children.
6. We have been forced to accept low average paying jobs so that our daughter will still be eligible to receive her benefits. Without her benefits, we would be in financial debt the rest of our life paying off her medical bills.

Every time she ends up in the hospital the bill has been between \$20,000 and as high as \$450,000. On an average, she ends up in the hospital twice a year. This doesn't include her \$200 a month pharmacy bill, \$800 a month for physical therapy, and she used to receive speech therapy which was \$1,800 a month. Her medical bills a month are about \$1,500 to \$2,000, depending on how many times she has to see the doctor and tests she receives. Families like mine are falling in the cracks, especially the families of medically needy children.

7. We have a 2 year old son with a rare congenital condition, who is trached, g-tube fed, hypotonic. Our insurance will max out in a couple of years and without Medicaid we will have to leave the state.

8. Our daughter has Down Syndrome; our insurance would not have covered an entire year of twice a week speech and OT. Just the speech therapy would have amounted to about \$900 extra a month for our co-pay and deductible. And we did not qualify for Medicaid. Our marriage is deteriorating as well as our finances. I don't know how much longer we can hang on.

9. Our daughter has recently been hospitalized for an extended period of time and we have run into MANY financial and insurance prob., as well as unable to get assistance due to income guidelines. I would like to know if there are any other options. Is there no help?

10. Our son who is visually impaired, we have insurance but it ran out on us for therapy services and we are above income guidelines to qualify for other benefits. What do we do now?

11. It is darn near impossible especially with the unpredictability of a very medically involved child and illnesses that come up to be able to look ahead even into the next week coming up. Many parents are in this situation. Who can help us?

House of Representatives
Human Services Committee

Re: House Concurrent Resolution No. 3054

Chairperson: Clara Sue Price

Madam Chair Price and members of the House Human Services Committee. My name is Roxane Romanick. I am here today representing myself. I am the mom to two children, the younger one having a diagnosis of Down syndrome, congenital heart defect, and chronic sinusitis. Even though, I'm representing myself today, I have become very familiar with the gaps in medical coverage for children with special health care needs through my involvement with the State Interagency Coordinating Council and my job as an experienced parent through the Region VII Early Intervention program through Bismarck Early Childhood Education Program. At the current time, my daughter's health needs are stable, but if this changed for her, she also would be one of those children that may fall through the cracks even with a diagnosis of Down syndrome.

When our daughter was born, the income and asset disregard associated with being part of the Home and Community based waiver was not in place. She did receive Early Intervention, but did not qualify for Medical Assistance without us incurring a large recipient liability. The medical costs her first year of life (between 3 hospitalizations) was close to \$100,000. Out-of-pocket expenses and incidentals relating to her medical care was roughly \$7,000. This was only for the first year of her life...many families have higher costs for years on end.

In helping families look at transitioning out of the Home and Community Based Waiver, I've learned that this loss of Medical Assistance creates much fear and stress in a family. We have explored many avenues to attempt to get the state to find a way to help families maintain Medical Assistance with no avail. It has also been difficult to determine how many families are experiencing this loss and to come to a collaborative agreement about who is a child with a special health care need. This needs to be a priority for our state to best determine how to support these families.

I am support of this resolution study. Thank you for your time.

Roxane Romanick
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Bismarck, ND 58501
701-258-7421
romanick@bis.midco.net

Testimony HCR 3054

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This study is important not just from the view point of families but agencies alike. Many agencies are involved in this very complicated system of care. Department of Human Services, Medicaid, DD Division, Early Intervention, Children's Special Health Services, Medicaid, Mental Health Services, VR, and the Department of Public Instruction. I hear from families each and every day, the struggles they have with the various gaps in the system. As the mother of two children with special needs, I understand what these families are going through.

As you all know and have been champions, this is very much in line with the study identified in SB2395. My hope that the language from both would be combined to do a full scale study of all the services for children with special health care needs.

To my knowledge there has not been a study to identify these children, appropriate systems of care, whether the needs are being met and that we have adequately addressed public policy to meet those needs.

The Federal Maternal and Child Health Bureau definition of a child with special health care needs is this: Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Adopted by the American Academy of Pediatrics (October 1998). Maternal and Child Health Bureau. McPherson M, Arango P, Fox HB,

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Issue 1: Children, birth to 3, who are identified as having a special health care need, may also qualify for services under Part C of the Individuals with Disabilities Education Act. These services are funded through Developmental Disabilities Division of the Department of Human Services. In order to qualify, children must have a 25% delay in 2 or more areas of development, 50% in one area, be high risk for developing a developmental delay or be found eligible under informed clinical opinion by a physician or an evaluation team. Children who qualify for Part C services also qualify for the DD Home and Community Based waiver. The child that qualifies is eligible for Medicaid due to an income and asset disregard of a family's resources.

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Issue 3: Part C services or Early Intervention ends when a child turns 3. In order to continue receiving MR-DD Case Management and related services under the Home and Community Based waiver and thus be eligible for continued Medicaid coverage under the income and asset disregard, children must go through an eligibility re-determination. This re-determination is based upon a mental retardation diagnosis or having a developmental delay that resembles mental retardation. If a child does not meet the criteria for MR-DD eligibility, they no longer have access to the benefits under the HCBS waiver. The loss of the services can be great for families, but the loss of Medicaid can be critical. Even though families' primary insurance is accessed as primary, Medicaid assisted them with ancillary services such as PT, OT Speech, Medications, Nutrition services etc. as these services under private insurance have limitations annually.

If the family is able to meet the income guidelines under Medicaid, they will continue to maintain many of the services, however for many families they will not. Many families have high recipient liabilities each month that are far beyond their capabilities.

In some ways the ND DD definition is more restrictive than the Federal definition as essentially the individual has to have severe developmental disabilities or qualify under the ICF/MR definition.

The Federal DD definition: As defined in the DD Act, the term ``developmental disabilities'' means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments that is manifested before the individual attains age 22 and is likely to continue indefinitely.

Issue 4: Not all of these children will receive Part B services under the Individuals with Disabilities Education Act through the Department of Public Instruction. In the 2002-2003 school year, 14,312 children ages 0-21 received special education services in our schools. Only those children who have a diagnosis in which affects their ability to learn will receive services under IDEA.

There are children who have a disability that substantially limit their participation in or access to school programs but who do not need special education. So for some children even though they may have a disability or special health need, if it indeed does not affect their ability to learn, may not receive these services in the school setting.

Issue 5: We know in ND that as of December of 2004 there were only 937 children under the age of 18 who received Social Security Income due to their disability and income guidelines. Many children will be medically eligible for SSI as having a disability, however because of family income will be over the eligibility guidelines. Most states if the child is SSI eligible they will also be Medicaid eligible. However, as ND is a 209 b state, our criteria is a bit more stringent and hence this may not always be the case.

These are just a few of the issues and gaps in the system that families face. What happens to those families? Do they file bankruptcy, divorce, move out of state, impoverish themselves, and work several jobs?

As I stated before, the gaps for families are many. We need to better identify who these children are, their needs of these children in order to address whether the current systems are adequate. This study could help us

determine adequate services, planning for the future as these children grow older, how to better serve those who are falling in the gaps.

I also think it is important that the legislative council include the agencies, providers, families and advocates as part of the study in order to fully understand the need/gap areas and work in a collaborative way to meet the needs of these families in ND. A similar study has been proposed in SB 2395, the language a bit broader in this resolution. Which sets the framework to look at the entire system of care.

Madame Chair and Committee Members, families are not seeking a hand-out. What they are seeking is a hand, to grab on to in a very fragmented system in order to keep from drowning. This study has the potential to be the first step in closing the huge gaps in this very complicated system.

Thank you for your time

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Document 1 for HCR 3054

1. My 2 children have a rare diagnosis and are terminal. Not only do we not qualify for assistance, we feel very isolated and alone. Why can't there be anything for families who have medically needy children?
2. My husband and I have been told that we should get a divorce in order for me to financially qualify for Medicaid so we wouldn't have to worry about our daughter receiving her treatments.
3. Our son was recently diagnosed with a very rare disorder called slow channel myasthenic syndrome. He was put on a ventilator at 3 days old and has been on it ever since. Our concerns center around the coverage of his care once insurance runs out on him, which could be anywhere from 5-8 years. We never questioned our move back home until we had our son and found out that had we stayed in Minnesota (or moved to South Dakota, where our home health agency is based) our son, on his own based on his condition, would qualify for medicaid regardless of our income or assets.
4. As a young parent it becomes hard to get any type of financial stability established. As soon as one gets a little bit of money saved, then you lose the assistance that you were on. Our son has cerebral palsy, how are we supposed to provide him the support he needs?
5. I am the proud mother of a little girl 5 years old and was born with Cerebral Palsy and a Seizure Disorder. We are a middle class family that qualifies for very little assistance in our state. We were told by the ND Medical Assistance Office to move to MN. That MN would be a better place for us to live with our child w/special needs. ND prides itself on a great place to raise a family. They really should only take pride in the fact it's a great place to live IF you have typically developing children. We have had many financial struggles since our daughter was born. I am not blaming her, I am not blaming anyone, unfortunately our state fails to see the importance of continuing to support and provide adequate funds for these children.
6. We have been forced to accept low average paying jobs so that our daughter will still be eligible to receive her benefits. Without her benefits, we would be in financial debt the rest of our life paying off her medical bills.

Every time she ends up in the hospital the bill has been between \$20,000 and as high as \$450,000. On an average, she ends up in the hospital twice a year. This doesn't include her \$200 a month pharmacy bill, \$800 a month for physical therapy, and she used to receive speech therapy which was \$1,800 a month. Her medical bills a month are about \$1,500 to \$2,000, depending on how many times she has to see the doctor and tests she receives. Families like mine are falling in the cracks, especially the families of medically needy children.

7. We have a 2 year old son with a rare congenital condition, who is trached, g-tube fed, hypotonic. Our insurance will max out in a couple of years and without Medicaid we will have to leave the state.

8. Our daughter has Down Syndrome; our insurance would not have covered an entire year of twice a week speech and OT. Just the speech therapy would have amounted to about \$900 extra a month for our co-pay and deductible. And we did not qualify for Medicaid. Our marriage is deteriorating as well as our finances. I don't know how much longer we can hang on.

9. Our daughter has recently been hospitalized for an extended period of time and we have run into MANY financial and insurance prob., as well as unable to get assistance due to income guidelines. I would like to know if there are any other options. Is there no help?

10. Our son who is visually impaired, we have insurance but it ran out on us for therapy services and we are above income guidelines to qualify for other benefits. What do we do now?

11. It is darn near impossible especially with the unpredictability of a very medically involved child and illnesses that come up to be able to look ahead even into the next week coming up. Many parents are in this situation. Who can help us?

TESTIMONY

Senate Human Services Committee

Re: HCR 3054

March 21, 2005

Madam Chair Lee and members of the Senate Human Services Committee, my name is Roxane Romanick and I live in Bismarck, ND. I am here today representing myself but had the privilege of hand-carrying additional pieces of written testimonies by two other families that could not be here today. I am both personally and professionally passionate about this issue of children with special health care needs. Personally, I am mom to two wonderful children, the younger one having a diagnosis of Down syndrome and additional health concerns earlier in her life. Professionally, I serve on the North Dakota Interagency Coordinating Committee and work as an experienced parent specialist for BECEP.

Personally, I know what it's like to be faced with a multitude of pending medical bills and not be sure what will be covered and what won't. We learned about Elizabeth's many medical needs when she was born and there is nothing in the world that would have kept us from doing what we needed to do to make her well, healthy, and strong. Many years ago, people with Down syndrome may not have been awarded the same medical interventions and most were not simply available. Today, children with special health care needs are born into a world where medical advances are many and where it is the norm that families accept, love, and care for their children no matter what. Institutional care is not the norm...families are taking care of their children and sometimes need additional support. Keep in mind that this additional support is a long way from institutional support, both in costs and in compassion.

In helping families transition out of the Home and Community Based Waiver when their child turns 3, the loss of Medical Assistance creates much fear and stress in a family as many of you on this committee already know. We have explored many avenues to attempt to get the state to find a way to help families maintain Medical Assistance with no avail. It has also been difficult to determine how many families are experiencing this loss and to come to a collaborative agreement about who is a child with a special health care need. We need this study.

It appears clear to me that if we have families willing to put their personal stories on the line with this legislative assembly in order to get help then something is not right in North Dakota. What families have done this session is incredibly brave, but what choice did they have? This study has been requested in the past and if accepted, we may not have families having to "go public" to get help. I respectfully request that we figure this out! Please make this study a priority.

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HCR 3054

Madam Chair and Committee Members, thank you for the opportunity to provide written testimony for a study to identify children with Extraordinary Medical Needs.

My name is Blair Aasland and my wife Nicole and daughters Kaitlyn and Ellie live in Fargo. Katie has just turned 3 years old and Ellie is 19 months. They, of course, are very special little girls to us. They are also special in another way; they are among the few in North Dakota with Mitochondrial disease. This disease is a rare genetic disorder which affects the amount of energy for the body to use. A useful analogy is to think of an eight-cylinder car running on only six cylinders.

Mitochondrial disorders differ from other genetic disorders affecting the muscles in a number of ways. Most significantly, although mitochondrial disease can present as a "pure myopathy," meaning that only the skeletal or heart muscles are affected, it more often causes problems in many different organ systems, including the nervous, visual, renal, digestive and circulatory systems. Despite the fact mitochondrial diseases can be so variable and affect so many organ systems, a few symptoms are common to many of these disorders. These include muscle weakness, muscle cramps, extreme fatigue, gastrointestinal problems, droopy eyelids, eye muscle paralysis, retinal degeneration with vision loss, seizures, ataxia (loss of balance and coordination) and learning delays. This is a progressive and degenerative disease with no known cures. At present, there are many more unknowns than proven treatments for these patients.

Kaitlyn recently turned three and her last day on Medicaid is Monday, February 28th. She is currently prescribed two seizure medications and a supplement. These are covered by insurance and the remainder picked up by Medicaid. She is also on four "over the counter" supplements, paid out of pocket. The saving grace for us was the fact that Medicaid picked up the amount not covered by insurance on the prescribed medications. This benefit is ending because Katie has done so well over the past year and has achieved a lot of her goals. Therefore, she is ineligible for services. Keep in mind this is a degenerative disease and she could regress at any time, not just within the first three years of her life. Also, there is not a Mitochondrial expert in Fargo so trips to the Mayo clinic in Rochester and to St. Paul Children's' clinic occur every six months. Once again, ineligible for services and thus reimbursement for the trip is no longer available to us.

The year and a half Katie was on Medicaid was certainly appreciated and was such a stress reliever. My youngest daughter Ellie will soon be on the same "over the counter" medications as Katie and like her sister will lose Medicaid services at the age of three, barring any major medical setbacks. This will place a tremendous amount of financial

stress on our family. I truly hope that my children's' disease continues to stay at bay. But the reality of this disease is that this is truly a degenerative disease and my daughters will continue to regress.

Please consider my family and other families in North Dakota in our situation.

Blair Aasland

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HCR 3054

I would like to thank you for the opportunity to provide testimony today in support of a study to identify the gaps in the state's system for providing services to children with special health care needs.

My name is Jennifer Restemayer, and I would like to tell you a little about my four year old daughter Allison. Allison is a very bright and active child. She amazes me every day with her unique personality, persistence and curiosity. In November of 2002, Allison took a hard fall and we brought her to the walk in clinic to make sure she was OK. At the conclusion of this visit, the Doctor at the walk in clinic sent us home with a photocopy of the PDR that described something called Mucopolysaccharidosis (MPS) or Hurler syndrome. The prognosis said children with MPS1 or Hurler Syndrome are typically bedridden by eight and dead by ten. We had never heard of Hurler Syndrome or MPS until that day. My husband and I were so scared of this disorder, we couldn't even consider the possibility that Allison could be affected by it. We started the testing process...just to rule it out so we could go on with our lives. January 8th 2003, just weeks before her second birthday, Allison was officially diagnosed with MPS 1.

MPS I is an inherited lysosomal storage disorder caused by the deficiency of an enzyme called alpha-L-iduronidase. This enzyme is required for the breakdown of certain substances in the body known as glycosaminoglycans(GAGS). Without sufficient quantities of this enzyme, GAGs accumulate in virtually all organs of the body, causing progressive damage. The incidence of MPS type 1 is about one in 100,000 births. Though many patients with this disease may have the same enzyme deficiency, patients with this disease have a wide range of symptoms and experience variable degrees of disease severity. Allison has been affected by MPS in many different ways. She has corneal clouding, a mild to moderate hearing loss, Mitral valve thickening and an irregular heartbeat, she also has many orthopaedic problems and is at a very high risk for developmental delay. All of this needs to be monitored very closely. We take Allison to Fairview in Minneapolis every 6 months to monitor her conditions.

Allison qualified for Early Intervention services by her diagnosis. She was able to start therapies shortly after she was diagnosed. Speech Therapy and PT/OT have been wonderful for Allison! However, at age three children have to undergo developmental testing and basically have to have a diagnosis of Mental Retardation to qualify for continued services. Allison scored within the "normal" range for all areas tested. While we were thrilled with her test results, we also knew that this opened up whole new area of problems. We needed Allison to continue to get her therapies! MPS is progressive and degenerative. The typical MPS child STOPS developing, usually as a toddler, and then starts to regress! We need help to keep her on track as long as we possibly can! We worked closely with the Early Intervention team and did find a way for her to continue therapies, but because she was no longer eligible for MR-DD services, she was no longer able to be screened for the Home and Community Based waiver which allowed us to access the income and asset disregard so that she could get Medicaid. Without the Medicaid Waiver it is increasingly difficult for our family to financially provide for Allison's ongoing medical needs.

Financially, Allison's diagnosis has brought up many concerns for my family. She is on a new treatment called Aldurazyme, which consists of an IV infusion once a week, for life. This infusion is a synthetic version of the enzyme Allison is missing. It was approved by the FDA on April 30th, 2003. Unfortunately, the cost of Aldurazyme is very high; it is \$565.00 per vial. The dosage is based on weight; Allison is 34lbs and requires three vials for a cost of \$1,695.00 per infusion. As Allison grows and gains weight, she will require more vials of Aldurazyme and our weekly bill will increase. Our total weekly bills including the Doctor's visit, supplies, the I.V. infusion center and the Aldurazyme, total \$2,130.50 per week, or \$110,786.00 per year.

I have searched and searched for a program within our state to assist our family with the cost of the many medical bills as well as the cost of additional out of pocket expenses that are not covered by our primary insurance. I have found that any family can receive medicaid, but with a recipient liability. Our recipient liability was estimated at \$2,900.00/month. We can not afford to pay that every month before Medicaid kicks in and starts to help. I have talked to many people who work in the Department of Human Services and I have been told that IF my husband and I were to get a divorce, my children and I would qualify for Medicaid based on my income. It has also been suggested that we move our family to Minnesota because there a Medicaid waiver for children with exceptional medical needs. My husband and I have had very serious conversations about what we will do when our savings runs out and we can no longer handle the medical bills and the out of pocket expenses that our insurance does not cover. This is an ongoing source of stress for us.

A study of state programs to identify the current gaps our state has in providing services to children with special health care needs is a great start. I know there are many other families in similar situations as ours, who need help. I believe by identifying and addressing the need, support services would improve the lives of these very special children and their families. SB 2395 also includes a section for a study to identify these children. I would ask that SB 2395 and HCR 3054 work hand in hand to help these families.

Thank you for your time,
Jennifer Restemayer
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Testimony
House Bill 3054
March 21, 2005

Mr. Chairman and Committee Members, my name is Linda Schatz and I am a parent of a child with special health care needs. My son has a very rare primary immune deficiency that affects only a handful of people worldwide. Our physician has referred us to the University of Minnesota for care and those specialists are working with physicians from around the world to identify the appropriate treatment plan for our son due to the rarity of the defect in his immune system.

My son, Jacob, qualifies for early intervention and developmental disabilities case management through the Department of Human Services. This provides him with Medicaid as a secondary insurance, WIC, and family subsidy. Due to the eligibility requirements, he will not qualify for Part B services or continued case management due to the more stringent requirements.

The loss of these services will impact our family. It is difficult to assess the exact financial impact of the loss due to the fact that we do not have a definitive diagnosis and do not know exactly what our treatment plan will be. However, I am able to identify some of the financial impact of the loss of services. The loss of WIC will result in approximately \$120.00 per month to provide pedisure to our son for supplemental nutrition which is not covered by our primary insurance. Our insurance has a \$1250.00 per year annual deductible, not including medications. Until we obtain his diagnosis and have an appropriate treatment plan, we have had to aggressively treat any signs of infections with antibiotics and not only for him, but for all members of our family. He typically receives at least one if not two antibiotics to clear these infections and has had at least one infection every month. The coinsurance of these meds is typically \$15.00 to 30.00 per medication. Another significant financial loss will be the loss of our family subsidy which assists in reimbursing us for our mileage and hotel bills when traveling out of state to our doctor appoints. We travel 850 miles round trip and spend two to three nights in a hotel, plus meals. These trips tend to cost approximately \$500.00. We have traveled to Minneapolis three times in the last 4 months. These loss of services will cost our family approximately 5000.00 per year. These costs are not astronomical, but can greatly affect families who are trying so hard to make it in today's world.

My husband and I are both professional people and have good insurance. My concern is for the other families that do not have the resources that we have. We have borrowed against our retirement to meet financial obligations as a result of our sons illness. If Jacob's illness has affected our family, what does it do to others? We have seen so many recent articles regarding bankruptcies as the result of medical expenses. Our current system does not support families. Many people are encouraged to divorce to meet the income requirements so that they can obtain services. Families are also encouraged to move to out of our state to a state that has better services for children. Is it more appropriate to take people's livelihood away and pay for a whole family on assistance? Or would it be better to provide some financial assistance for children who are medically

complex allowing the family to remain a unit and be taxpaying citizens of North Dakota?
I encourage e you to support HB 3054 and study the gaps in our system. Thank you for
your consideration

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Senate Human Services Committee
Fifty-ninth Legislative Assembly of North Dakota
House Concurrent Resolution No. 3054
March 21, 2005

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

This Committee is already familiar with the difficulties that parents
encounter when trying to provide for their children who have special health
care needs. The Senate has already approved SB 2395. The Legislature
should now look beyond Russell-Silver syndrome, phenylketonuria, and
maple syrup urine disease (RSS/PKU/MSUD).

Of course, North Dakota does not yet have a solution for all children
with RSS/PKU/MSUD. At the same time, we should consider how to help
children who have other special health-care needs.

This Committee has taken an important first step by adding a "Katie
Beckett" waiver program to SB 2395. In less than two years, the Legislature
will learn the strengths and weaknesses of North Dakota's first Katie Beckett
waiver. In the meantime, the Legislative Council should study the
dilemmas, circumstances, and problems that face North Dakota children with
special health-care needs.

I encourage the Legislative Council to undertake that study.

Thank you.

To:

March 20, 2005

The Senate Human Service Committee:

I am here today in regards to HCR 3054, To study children with special Health Care needs, and disabilities to study gaps and address those gaps.

My name is Mary Rennich.

I am the mother of two children, Sam 14 and Jesse 16. Both of our children have unique healthcare needs. Sam has a rare brain abnormality, causing uncontrollable seizures on a daily basis. Because of his worsening seizures, I have been forced to give-up my rewarding job in the Bismarck Public School system as an instructional aide. Due to the erratic nature of Sam's health, I was unable to work with any normalcy. I have been the Parent Mentor coordinator for the University of Mary for the past 5 years, which brings me in personal contact with approximately 30 families who have a child with a disability. These gracious families working with students in healthcare fields, better understand what our families experience on a daily basis.

I am hoping to convey to all of you, the importance of covering the gaps that are seen with our kids in North Dakota. I know that we have some very important services, but I have also felt the pain and anguish when we have not had ANY idea what we would do next for our kids. Unless you are tenacious and energetic, it is an incredible web, finding help for our kids .

Our son Samuel, has a fairly significant disability, and we have had fairly adequate support from DD services including a Medicaid waiver, we hope will continue. We have had to ask my husband's employer to help us when we have been overwhelmed with insurance deductibles and ever present medical costs, running into the tens of thousands of dollars. The most important funding we need, and cannot increase because of lacking funds, is our respite or supportive care. Samuel requires full-time, skilled care, up to 6 medicines three times a day, crushed and dissolved and given through a feeding tube. He is not able to

care for himself alone in any way, and we gladly care and love him. We have accepted the responsibility, and have sacrificed a lot of our young lives, but he is our joy, and we are very willing to provide in home family care as long as we are able.

Our son Jesse, has been another story completely. Jesse was given to us through an open adoption, and we were not aware of the struggles we would have over the next 16 years. Jesse is a very handsome and bright young man, very loving and compassionate. He loves animals and is extremely creative. He was diagnosed with a form of Autism, called Asperger syndrome and a learning disability. He has struggled with school, friends, mood swings, sadness and anger over his brothers suffering, and only recently- is blossoming into a very well adjusted young man. We hope, IF he can continue receiving services through the Dakota Boys Ranch, he will remain stable and eventually return as a graduate of Job Corps as a productive citizen.-

My husband David and I had fought and begged to receive ANY services for Jesse. At our lowest point three years ago, I felt I had to have help from Protection and Advocacy. They were instrumental in helping us to place Jesse at Dakota Boys Ranch for treatment through a voluntary placement, although, it has been difficult not having any local mental health treatment facilities which would have allowed us to keep Jesse in our home and community.

Many families do not have the playing card of adoption to help them in the 11th hour of their anguish to receive any- let alone- adequate mental health support and services for their children. Please know that I speak for many families I know personally, who are depending on all of you to make our system work effectively and adequately as we raise our children to be successful adults.

Thank you very much for your time.

Sincerely,

Mary L. Rennich
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Lee, Judy E.

From: Cathy Haarstad [cathy.haarstad@minotstateu.edu]
Sent: Friday, March 18, 2005 9:46 AM
To: Lee, Judy E.
Subject: HCR3054 Please vote yes to do the study

Dear Senator Lee,

Please vote yes to do the study.

I am sending this message to yourself and four of your colleagues in the Senate. ND has hesitated to apply for a new waiver due to fears about cost. Yet a waiver makes more sense that a tetra option or redefining the DD act because its still allows the state to control costs.

What is really needed is a waiver for a combination of medically needy children and children with significant behavioral disorders (due to a combination of mental retardation and mental illness and/or PDD or ADHD). Many of these children are served in residential treatment facilities out of state which is very costly (although a center just over the border in Minnesota is not as costly as a center in say Florida). Some children need to stay in those facilities (e.g. a child who is deaf, has schizophrenia and mental retardation needs a peer group that can't be found in ND) but many others perhaps could be returned and served in-state through a waiver. As a good steward of state dollars, the DHS will no doubt be looking at that.

Accompanying the waiver must be a pool of flexible funds that DHS can use to address specific needs that can't be covered through any federal dollars (i.e. housing for a youth who has no family and can't be served in a group facility due to behaviors that place others at risk). Without those funds it becomes impossible to individualize the services needed to serve this unique population. The legislature has been reluctant to trust DHS with a pool of flexible funds. By tying the finds to a target population we can be reassured that they will be used for the purposes described here.

Home and community based waivers get money to those families who succeed in spite of tremendous odds to serve very challenging children.

We must be realistic. It would be wonderful if all families could meet the needs of all children. Our society is based on and built around the family unit. No other system of care has ever been able to match what families give to socialize and support children. We can and do hold families accountable for their responsibilities.

Yet people are human and we all have real limitations. When families fall apart under the strain of a medically needy child (we are talking significant cost and time levels not just the typical childhood diseases) or the family is unable to parent a child with significant needs (we are talking about multiple disorders and significant risk levels) and when extended family and community connections are not enough; then we want to live in a society that steps up and helps.

If we don't help, we pick up the pieces later on at even greater cost.

I think these arguments underline the need for a study.

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