

# MICROFILM DIVIDER

OMB/RECORDS MANAGEMENT DIVISION

SFN 2053 (2/85) 5M



ROLL NUMBER

DESCRIPTION

4018

2007 SENATE HUMAN SERVICES

SCR 4018

## 2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SCR 4018

Senate Human Services Committee

Check here for Conference Committee

Hearing Date: 2-05-07

Recorder Job Number: 2777, 2779

Committee Clerk Signature

*Mary K Monson*

Minutes:

Senator J. Lee, Chairman, opened the hearing on SCR 4018 expressing support for long-term care choices, including home and community-based services, for North Dakotans with disabilities and older adults.

Senator Erbele took possession of the gavel when Senator J. Lee introduced SCR 4018.

Senator J. Lee (District 13) reported that there has been a task force working hard on providing North Dakota's response to the Olmstead decision. This is the result of that work. Everyone agreed that we would like to remain at home as long as we can and the services being provided to enable that is very important. When we no longer can live in our own homes, we should be able to look forward to living in the most homelike environment that we can. That is the basis for this resolution.

Carol Olson (Executive Director of Dept. of Human Services) testified in support of SCR 4018.

(Attached testimony #1 includes Executive Order by Governor John Hoeven, August 7, 2001.)

Janis Cheney (Member of the Olmstead Commission, State Director of AARP in ND) testified in support of SCR 4018.

Senator Dever asked if the Olmstead Commission continues to work or are all the initiatives now in place elsewhere.

Ms. Cheney said it was her understanding from the last meeting that the commission will continue to work and monitor progress.

Teresa Larsen (Executive Director of the Protection Advocacy Project, Member of the Olmstead Committee) reported that they support the resolution. The values that are stated are very much in line with what the Commission has been working towards for a number of years. One of the issues before the Appropriations Committee right now looks at OAR #4 which is about a transition of people from the development center into the community. It was a task force that was mandated by senate appropriations and passed last session. It had the department put a task force together to put together a plan to be institutionalized as much as possible from the developmental center. That plan has been put in place as directed but they are hoping there will be funding for that.

Senator J. Lee asked if there is any other recommendation of the Olmstead Commission that, at this point, is not a part of the budget that they should be aware of.

Ms. Larsen thought there might be some other OAR's. (Meter 7:37)

Senator J. Lee asked Ms. Larson to explain SPED.

Ms. Larsen deferred to Linda Wright.

Linda Wright (Director of Aging Services Division, Dept. of Human Services) explained that SPED is service payments for elderly and disabled which was approved by the state legislature in 1983. It provides a variety of home and community based services for eligible individuals that have to meet some financial eligibility as well as functional abilities so a person can stay at home as long as possible. It is funded 95% from general funds and 5% from county funds.

Linda Wright distributed testimony from Amy Armstrong (Project Coordinator for Real Choice Systems Change Grant) (Attachment #2)

Roxanne Romanick (Parent of little girl with Downs Syndrome) (See attachment #3) A lot of the emphasis of this resolution is around long term care for older citizens but it starts for all of us when a disability occurs. The support to raise children with dignity is so critical to how they become as citizens.

Representative Boucher (District #9) testified as a sponsor and supporter of SCR 4018. It outlines a process to look at what goes on in terms of providing care for the elderly and disabled citizens and those people in need across the state of ND. Although many aspects of care for the elderly and disabled are very well managed, there are many gaps and holes in the delivery system starting with home and community based care up to skilled nursing care and what exists in between. What he hears is that not every person who is in need of care is in need of the same kind of care nor do they want the same kinds of care. ND has an aging population and a larger number of people reaching that point in their life where they need those services.

There was no opposing or neutral testimony.

The hearing on SCR 4018 was closed.

**Job #2779**

Senator Erbele moved a Do Pass on SCR 4018. Seconded by Senator Heckaman.

Roll call vote 6-0-0. Passed. Carrier is Senator Heckaman.

Date: 2-5-07

Roll Call Vote #: 1

2007 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SCR 4018

Senate HUMAN SERVICES Committee

Check here for Conference Committee

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

Action Taken Do Pass

Motion Made By Sen. Erbele Seconded By Sen. Heckaman

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 Heckaman

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

**REPORT OF STANDING COMMITTEE**

**SCR 4018: Human Services Committee (Sen. J. Lee, Chairman) recommends DO PASS**  
(6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SCR 4018 was placed on the  
Eleventh order on the calendar.

2007 HOUSE HUMAN SERVICES

SCR 4018



## 2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SCR 4018

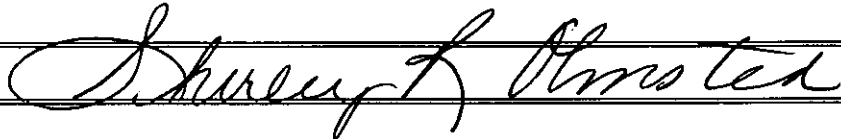
House Human Services Committee

Check here for Conference Committee

Hearing Date: March 20, 2007

Recorder Job Number: 5329

Committee Clerk Signature



Minutes:

**Chairman Price** opened the hearing on SCR 4018 and asked the clerk to read the title.

**Representative Merle Boucher**, from District #9, came forward to testify on SCR 4018. See the attached written testimony marked as Item #1. This is an ongoing issue and I think it has been neglected for all too long. I would like you to take a long serious look at this and the menu of services and activities that would allow our citizens to access services that are considered best suited to meet their individual needs in harmony with their personal choices.

**Senator Judy Lee**, District #13, came forward in support of SCR 4018. She was a part of the Olmstead Commission which has been as a result of a court decision requiring all the states to examine how we can provide for our citizens in this environment. There has been a lot of information shared by the folks who have worked on that commission and this is just going to indicate the legislatures support for this effort. Representative Boucher mentioned that there are some very good things going on at the Samaritan Home in Arthur, ND and the outreach in Casselton and the incorporation of community volunteers as well as facilities and how it provides services. The single port of entry was discussed in other bills as you know and there needs to be some kind of way to help people who may have aging parents with needs and to

try to help them stay in their homes particularly in the rural areas. We would like your support on this resolution.

**Ms. Janis Cheney**, State Director of AARP of North Dakota, came forward in support of the resolution. See written testimony marked as Item #2.

**Carol K. Olson**, Executive Director of the Department of Human Services came forward in support of SCR 4018. See attached written testimony marked as Item #3. One of the challenges that they were able to participate in was the choices grant. This grant totaled \$900,000.00. This is just one of the first steps in achieving some of the goals that we have set out with our Olmstead committee. They have an Olmstead working plan and the governor has approved it. We will be continually bringing that up to date because we have actually established dates to finish certain parts of the plan. You will be hearing more from the Olmstead Commission in the future. It is not dying off on the vine and is an active working commission that will continue in the future.

**Representative Potter** said in your testimony you said the state was committed to the community based alternatives with this Olmstead decision plan for individuals with disabilities. Has the committee dealt with the elderly? It doesn't sound like they have dealt with the elderly.

**Ms. Olson** said the lawsuit was dealing with people with disabilities. This is a disability centered lawsuit and it was in regards to two sisters who had a mental disability. The lawsuit stemmed from that. If you remember the ARC lawsuit in North Dakota, that focused on the adult center in Grafton. Before we even started pursuing the Olmstead Commission in the year 2000 I requested the attorney from the department to put together a white paper to pick up from where the ARC lawsuit left off and to bring us up to date as to where we had come within services to those with disabilities to date. We actually followed through with the Olmstead Commission after Governor Hoeven appointed it and worked forward from there. It

has been an ongoing project within the Department of Human Services to track and to work proactively. The ARC lawsuit put North Dakota in a position and most other states are behind the eight ball because they did not have something like this that occurred in North Dakota so we were ahead of other states in regard to the Olmstead decision. This is focused on the disabled population.

**Representative Potter** said from the reading that she had done, she thought the Olmstead decision had been stretched to include the elderly at this point as well. That is why I was wondering if we were including the elderly as a result of the Olmstead decision.

**Ms. Olson** said yes they were including them. When they look at the home community based services and choices you are absolutely correct. We are expanding that beyond the disabled population. In the department we are having internal discussions where we talk about home and community based services. We don't look at it just for the elderly either. We look at it for the disabled population as well. We are broadening that definition of that internally in the department and hopefully we will be taking that outside the department and talking about it more publicly. It is a continuum of care. Senator Lee made a comment last session that has stuck with me. She said truly those that are disabled and are in a group home or something similar to that such as an institution certainly are in long term care because that disability is long term to death. We are looking at the aging population and the disabled.

**Representative Kaldor** said in looking at this resolution and reading your testimony, one of the things that I have been hearing from back home and haven't been able to provide a very good explanation, is the inconsistency to be eligible for SPED. They are telling me that the eligibility requirements are more stringent or people are not qualified as easily as they were in the past. How can we rectify that with this resolution? Am I totally off base with this?

**Ms. Olson** said the SPED population has been a dilemma for them in the department. We cannot figure out why our utilization of that program is down. We have asked the counties if they can help us figure it out. We have to budget for fewer folks this biennium because we cannot support the request to fund it at a higher level because we didn't reach the appropriated amount this biennium. The counties do not have an explanation for it. In the interim coming up that will be one of the priorities in the department to work with the counties and the data collection to try to figure out why that is going on. We know they are not dying or going into nursing homes. There could be a number of reasons that they are not accessing this program. The seniors that would normally be given that program are healthier, they have more income that they have had in years past and perhaps they are meeting their needs better. We are going to be looking into that to try to find out what is going on.

**Representative Kaldor** asked if we have an inflation adjustment in those eligibility requirements or is that static.

**Ms. Olson** said she did not know the answer to that question. She said she could ask someone in Medicaid to answer that.

**Representative Conrad** said this resolution is a statement of our intent, but in your testimony you said you would carry out your commitment taking into account the resources available to the state and those with disabilities. I am wondering how we are addressing this differently that we did with Grafton. It was constantly said that we did it with what we could and what we had available. The federal court said it was not good enough. Are we increasing our resources as it costs money to do these things? The statement in the policy is great but if it doesn't have the money to back it up it is really not very important.

**Ms. Olson** said she was going to ask Melissa Hauer to respond to that question because it is actually in the language of the Olmstead decision if I am not mistaken.

**Ms. Melissa Hauer** came forward at the request of Ms. Olson. She is an attorney for the Human Services Department. That language actually comes from the Olmstead decision. The state has an obligation if three things happen. Number one is if the professionals believe that is an appropriate environment. The second thing is if the individual wants that and third if the resources are available to the state and they can allow that to happen without burdening other people. You don't want to take the resources away from one population to give to the other population. The state needs to see what resources are available. The language that we put in comes directly from the Olmstead decision.

**Representative Conrad** asked if we are increasing our resources to do this or are we holding our budget flat?

**Ms. Olson** said that is a hard question to answer. We are refocusing our attention to balancing the resources more fairly in regards to what is being funded. I think what you are talking about is in previous times there have been a great deal of funding that has gone into the traditional nursing home area. That has been a decision that the state has made and that is the direction that they have gone. What the department is doing is looking at other alternatives and other available ways to fund areas that qualify for either waivers or grants or other directions that we can go to fund home based services. We have worked with the RCR for a grant that we have been working on for the last two years and that grant is about to run out. This grant focuses on a single point of entry. Once we have established a single point of entry system which allows both private and public paid seniors the ability to go to one source that could enlighten them and educate them as to how many choices are available for them, that also is going to help them move into more community based services. If the children of an elderly parent all live in other states, and the parent is in need of services. The children want that parent to be in a safe and secure environment where their needs are going to be met.

The children are going to move with what they know best and in the past and even today that would be into a nursing environment or something similar. That is fine and the department is 100% in favor of the nursing home facilities. We need to have nursing homes however if there are alternatives out there, they should know and have access to that information. If we have a single point of entry system established in the State of ND where one telephone call or one contact to that single point of entry will lay it all out to the children as to what is available to their parents. They can then feel comfortable that they are making the right decision for their parents.

**Chairman Price** asked for further questions. Hearing none, the hearing was closed.

## 2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SCR 4018

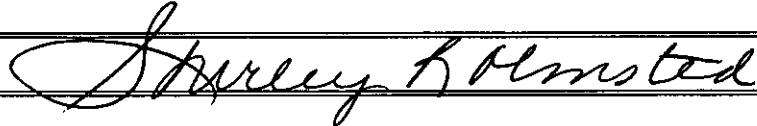
House Human Services Committee

Check here for Conference Committee

Hearing Date: March 20, 2007

Recorder Job Number: 5330

Committee Clerk Signature



Minutes:

**Mr. Jim Jacobson**, director of the Protective Services Unit of the North Dakota Protection and Advocacy Project (P&A) came forward in support of SCR 4018. See written testimony attached and marked as Item #1. (Mr. Jacobson was told this was before the Senate Human Services Committee so the testimony is marked accordingly. Chairman Price said it was fine as he had prepared it.

**Chairman Price** asked for further testimony in favor of SCR 4018. Hearing none, she asked for opposition to SCR 4018. Hearing none, the hearing was closed on SCR 4018.

## 2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SCR 4018

House Human Services Committee

Check here for Conference Committee

Hearing Date: March 20, 2007

Recorder Job Number: 5333 (Beginning at 36:22 on tape)

Committee Clerk Signature *Anne Perry Permette*

Minutes:

**Chairman Price** asked the committee to consider SCR 4018.

**Representative Porter** made a motion for a **do pass on SCR 4018 and place it on the consent calendar.**

**Representative Hatlestad** seconded the motion.

**Chairman Price** asked for discussion. Hearing none, she called a voice vote. The motion carried.

**Representative Hofstad** will carry this to the floor.



Date: 3/20  
Roll Call Vote #: 1

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

House HUMAN SERVICES SCR 4018 Committee

Check here for Conference Committee

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

Action Taken Do Pass Consent Calendar

Motion Made By Rep. Porter Seconded By Rep. Hatlestad

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) 12 "Click here to type Yes Vote" No 0 "Click here to type No Vote"

Absent 0

Floor Assignment Rep. Hofstad

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

REPORT OF STANDING COMMITTEE (410)  
March 20, 2007 12:27 p.m.

Module No: HR-52-5737  
Carrier: Hofstad  
Insert LC: . Title: .

**REPORT OF STANDING COMMITTEE**

**SCR 4018: Human Services Committee (Rep. Price, Chairman) recommends DO PASS and BE PLACED ON THE CONSENT CALENDAR (12 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SCR 4018 was placed on the Tenth order on the calendar.**

2007 TESTIMONY

SCR 4018

Same  
to House

**Testimony**  
**SCR 4018 – Department of Human Services**  
**Senate Human Services Committee**  
**Senator Judy Lee, Chairman**  
**February 5, 2007**

Chairman Lee, members of the Senate Human Services Committee, I am Carol K. Olson, the Executive Director of the Department of Human Services. I am here today to testify in support of Senate Concurrent Resolution number 4018.

On August 7, 2001, by Executive Order<sup>1</sup>, Governor John Hoeven, created the North Dakota Olmstead Commission. This Commission was created to deal with the issues raised by the United States Supreme Court decision in *Olmstead v. L.C.*<sup>2</sup> which addressed the Americans with Disabilities Act of 1990. The decision states that there may be a violation of the ADA if a State fails to find community placements for institutionalized individuals with disabilities in certain circumstances.

The recommendation for this resolution came out of the Olmstead Commission. The Commission consists of the following or their designees: a representative of the Office of the Governor; the Attorney General; the Executive Director of the Department of Human Services; the Director of the Office of Management & Budget; the Executive Director of the Indian Affairs Commission; a member of the North Dakota Senate; two members of the North Dakota House of Representatives; a representative of the Mental Health Association of North Dakota; a representative of the Arc of North Dakota; a representative of the North Dakota Protection and Advocacy Project; a representative of the AARP of

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<sup>1</sup> Executive Order No. 2001-07

<sup>2</sup> *Olmstead v L.C. ex rel. Zimring*, 527 U.S. 581, 119 S.Ct. 2176, 144 L.Ed.2d 540 (1999)

North Dakota; a representative of the North Dakota State Council for Independent Living; and a representative of the public at large.

The Commission appointed a workgroup from its members to work collaboratively to develop an "Olmstead Plan" as suggested in the *Olmstead* decision for the State of North Dakota. This resolution came as a result of the efforts to develop an Olmstead Plan and was designed to be a definitive statement of the State's undertaking to enhance community services for individuals with disabilities. It recognizes that the State of North Dakota is committed to community-based alternatives for individuals with disabilities, whenever such placement is appropriate, the affected persons do not oppose such placement and the State can reasonably accommodate the placement, taking into account the resources available to the State and the needs of others with disabilities. This resolution would send a message that the State pledges to provide an array of care choices to individuals with disabilities so that these individuals may live in a community setting whenever it is desired and appropriate.

This concludes my testimony. I would be happy to respond any questions you may have. Thank you.



— State of —  
**North Dakota**

Office of the Governor

John Hoeven  
Governor

**EXECUTIVE ORDER 2001-07**

**WHEREAS**, the State of North Dakota is committed to community-based alternatives for individuals with disabilities, whenever treatment professionals determine that such placement is appropriate, the affected persons do not oppose such placement and the State can reasonably accommodate the placement, taking into account the resources available to the State and the needs of others with disabilities; and

**WHEREAS**, on June 19, 2001, President George W. Bush issued an Executive Order directing the United States Attorney General, the Secretaries of Health and Human Services, Education, Labor and Housing and Urban Development to work closely with individual States to implement the decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), particularly with those States that choose to develop comprehensive, effective plans to provide services to qualified individuals under the criteria set forth in *Olmstead*; and

**WHEREAS**, it is in the best interest of all North Dakotans to continue our strong effort to provide community-based placement for individuals with disabilities in a manner consistent with the needs and resources of our State.

**NOW, THEREFORE**, I, John Hoeven, Governor of the State of North Dakota, do hereby establish the North Dakota *Olmstead* Commission to develop a plan to implement the *Olmstead* decision by providing appropriate community-based placement for individuals with disabilities, consistent with the needs and available resources of the State.

Such a plan shall be submitted to me in the form of recommendations for executive and legislative consideration no later than the convening of the 2003 legislative session.

The commission shall consist of the following:

A representative of the Office of the Governor, who shall serve as Co-Chair.

The Attorney General, or his designee.

The Executive Director of the Department of Human Services, or her designee, who shall serve as Co-Chair.

The Director of the Office of Management and Budget, or his designee.

A member of the North Dakota Senate.

Two members of the North Dakota House of Representatives.

A representative of the Mental Health Association of North Dakota.

A representative of the ARC of North Dakota.

A representative of the North Dakota Protection and Advocacy Project.

A representative of the AARP of North Dakota.

A representative of the North Dakota State Council for Independent Living.

A member of the public at large.


I shall select all representatives, giving consideration to nominations submitted by each entity represented on the commission.

This order is issued pursuant to Article V, Sections 1 and 7 of the North Dakota Constitution. This order is intended only to improve the internal management of the State of North Dakota and does not create any enforceable right or benefit.

Executed at Bismarck, North Dakota, this 7<sup>th</sup> day of August, 2001.

  
\_\_\_\_\_  
JOHN HOEVEN  
Governor

Attest:

  
\_\_\_\_\_  
Secretary of State

\_\_\_\_\_  
Deputy

Amy B. Armstrong  
North Dakota Center for Persons with Disabilities (NDCPD)  
at Minot State University  
Real Choice Systems Change Grant - Rebalancing Initiative (RCR Grant)  
Testimony  
Senate Concurrent Resolution 4018  
Senate Human Services Committee  
Judy Lee, Chairman  
Monday, February, 5, 2007

Chairman Lee and members of the Senate Appropriations Committee, thank you for the opportunity to share testimony in favor of *Senate Concurrent Resolution 4018*, which expresses support for long-term care choices, including home and community-based services, for North Dakotans with disabilities and older adults.

I am Amy Armstrong, Project Director for the North Dakota (ND) Department of Human Service's Real Choice Rebalancing (RCR) Grant facilitated by the North Dakota Center for Persons with Disabilities (NDCPD) at Minot State University.

North Dakota's RCR Grant was awarded to the ND Department of Human Services - Aging Services Division in 2004, by the U.S. Department of Health and Human Services - Centers for Medicare and Medicaid Services (CMS). This grant provides ND federal funding to build state infrastructure to improve community continuum of care service systems. The RCR Grant was also implemented in order to assist North Dakota in complying with the U.S. Supreme Court's *Olmstead Decision* and President Bush's *New Freedom Initiative*, which call upon states to improve access and choice of continuum of care services for the elderly and people with disabilities and to administer services in the least restrictive environment in order that consumers may fully participate in community life. The primary goals of this grant are to improve and streamline access to continuum of care services and consider ways to balance funding for continuum of care services for seniors and adults with disabilities.<sup>1</sup>

With oversight from the ND DHS – Aging Services Division, the RCR Grant

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<sup>1</sup> Armstrong, A. & Kraft, K. (2007). *ND Real Choice Rebalancing Grant Overview Fact Sheet*, Minot, ND: North Center Persons with Disabilities: Minot State University.



Planning and Steering Committees in collaboration with the ND Olmstead Commission, have consistently provided important input, recommendations, and guidance in the development and implementation of project research. The RCR Grant focus group and personal interview data consistently identify that North Dakota seniors and adults with disabilities feel it is important to have the opportunity to live at home and maintain their independence. Consumer, family, and provider focus group participants also indicated the problem of a lack of choices available for continuum of care services and a need for more home and community based service options.<sup>2</sup> In a recent survey conducted by RCR Grant staff, nearly 94% of consumers indicated that continuum of care services were *somewhat important to important* to maintain their independence. Additionally, 81% of consumers surveyed indicated that if the needed continuum of care services were available they would choose to live at home or live more independently.<sup>3</sup>

The RCR grant staff and its committees also gathered and analyzed previously completed research and reports related to North Dakota's continuum of care system. Much information has been gathered and studied in the past 20 years regarding continuum of care issues. Several noteworthy themes throughout these reports include *recurring* recommendations for improving access to case management, development of a streamlined single point of access to services; and assuring that consumers have informed options and better access to services, particularly home and community based services and qualified services providers (QSPs). In addition, many of these reports included recommendations for improving consumer choice and self-direction and balancing funding for continuum of care services.<sup>4</sup>

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<sup>2</sup> Armstrong, A. & Kraft, K. (2006). *ND Real Choice Rebalancing Grant: A Summary of Focus Groups and Personal Interviews conducted in North Dakota*, Minot, ND: North Center Persons with Disabilities: Minot State University.

<sup>3</sup> Armstrong, A. & Kraft, K. (2006). *ND Real Choice Rebalancing Grant: A Summary of Questionnaires Administered to ND Consumers of Continuum of Care Services*, Minot, ND: North Center Persons with Disabilities: Minot State University.

<sup>4</sup> Armstrong, A. & Kraft, K. (2007). *ND Real Choice Rebalancing Grant: A Summary of Studies & Reports Related to ND's Aging Population and People with Disabilities*, Minot, ND: North Center Persons with Disabilities: Minot State University.

The RCR Steering Committee will meet through September of 200, to continue its work on the drafting of a North Dakota Real Choice Rebalancing Initiative Strategic Plan. The committee began work on this strategic plan last year and will continue to work and build consensus to complete it. This plan will further ND's efforts to develop ways to make it easier for ND seniors and adults with disabilities to maintain their independence for as long as possible.

The recent data and work of the RCR Grant along with the many previous studies support the need for a streamlined, visible, trusted, and easily accessed continuum of care service system and a need for additional home and community based services that help North Dakotans remain in their communities and live as independently as possible. *Senate Concurrent Resolution 4018* clearly coincides with what North Dakotans have identified as important to them.

Once again, thank you for the opportunity to share this information. Please contact me with any questions.

The RCR Grant research reports, summaries, and other resources mentioned in this testimony are available on the ND Department of Human Services website: <http://www.nd.gov/humanservices/info/pubs/lcccontinuum.html> .

Contact information:

Amy Armstrong, Project Director  
Real Choice Rebalancing Grant  
NDPCD at Minot State University  
Email: amy.armstrong@minotstateu.edu  
Ph: 1-800-233-1737 or 701-858-3578

## Romanick Family Story

**Health Issue:** Down Syndrome

**Issue:** Inclusion

**Insurance Coverage:** private insurance

**Recommendations:**  
Inclusion for all children  
Partnering with families

**Family Story from:**  
Roxanne Romanick

When we first learned about our new baby's diagnosis of Down syndrome, one of the most immediate thoughts is whether or not it was fair to bring her into the world, someone who potentially will require care from her community to raise her. In many cultures and throughout history, this decision was removed from a child's parents. Children with disabilities have been shunned from communities, killed at birth, or taken from parental control and placed in government institutions. Having a child with a disability historically was associated with shame, guilt, and embarrassment. While having a disability is challenging, often children had to grow up feeling like a burden, feeling worthless and unable to contribute, and knowing that the perception of their disability often changed the very

fabric and lifestyle of their family and their community in mostly a negative fashion.

If it were up to me, we'd build a national memorial for all of the families and persons with disabilities in our country that went against "best practice" and pushed forward the message that there is a place in our communities for everyone. As I held my baby for the first time, knowing full well that her diagnosis of Down syndrome was a much a part of her as her fuzzy black hair and her cute button nose, I literally mouthed a prayer of thanks for those pioneers who said it's wrong to tell someone that the best thing for their new baby is to place her in an institution. Have we ever been right when we've promoted segregation?

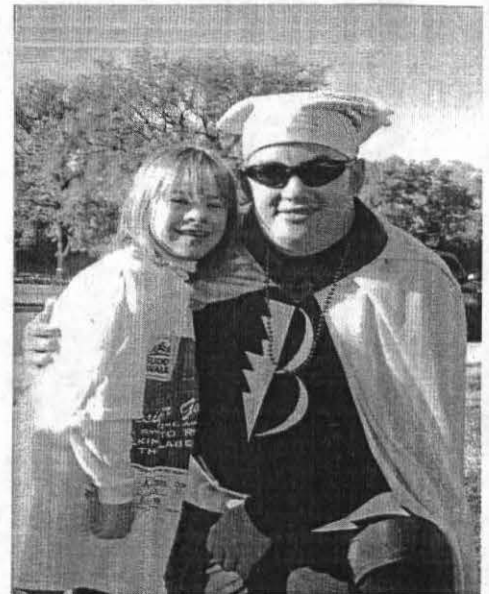
So what about my initial thoughts...is it right to bring someone into the world who we know will require more support than just her family can provide for her? Is it OK that someone may have a little less net income because of needed taxes to support services? Is it OK that someone's child will have to help her out at school, give of their instructional time, or have to wait a little bit longer until she finishes? Is it OK that our group medical premiums are affected to accommodate for special health care needs? These are tough questions and are often the reasons families with children with special health care needs succumb to shame, guilt, and embarrassment.

I absolutely refuse to allow shame, guilt, or embarrassment to define my daughter. I'm highly convinced that what she gives back to our community far outweighs what the costs are. In addition, if designed right, the supports that she needs can also benefit others. If we start thinking about how to structure our communities so that they accom-

modate the most vulnerable, the ease in accessibility will benefit many others that we hadn't even thought of assisting.

Is creating a community that has a place for everyone cheap? Is it easy to design? The answer is no, but if I ask "Is it the right thing to do? Is it worth the effort? Will we all benefit?" The answer is yes. I hope that we can partner with each other and I don't walk away feeling like I had to revert to shame, guilt, and embarrassment because I have a child with Down syndrome....that I didn't have to beg and plead. I want to walk away knowing I was at the table because I have the most intimate knowledge of how to create this inclusive community and was a full partner in helping with the ultimate design.

***"I absolutely refuse to allow shame, guilt, or embarrassment to define my daughter. I'm highly convinced that what she gives back to our community far outweighs what the costs are."***



*Item # 1*

TESTIMONY ON SENATE CONCURRENT RESOLUTION 4018  
LONG TERM CARE CHOICES

SENATE HUMAN SERVICES COMMITTEE  
Honorable Judy Lee, Chairman

March 20, 2007

Chairman Lee and members of the Senate Human Services Committee, my name is Jim Jacobson and I am the Director of the Protective Services Unit for the North Dakota Protection and Advocacy Project (P&A). P&A supports Senate Concurrent Resolution 4018.

This study will help ensure that an appropriate continuum of services and options are available to people in North Dakota who require significant levels of support and services. P&A has received many referrals over the years that involve people who are young and living in skilled nursing facilities. Options have increased to help people access the necessary support in alternative settings often allowing a person to stay in their own home.

It is important that North Dakota's service delivery system, both public and private, is working together to ensure that available options are understood. This will ensure that people receive the necessary information to make effective individual choices.

Supporting this resolution will encourage efforts that will make options and choices a reality. Please support Senate Concurrent Resolution 4018.

Thank you.

*Item # 1*

**TESTIMONY SCR 4018  
HOUSE HUMAN SERVICES COMMITTEE  
REPRESENTATIVE PRICE, CHAIR**

Madame Chair and members of the House Human Services Committee. For the record I am Representative Merle Boucher, member of the House of Representatives from District Nine (9).

You all have heard, I'm sure, the quote "the measure of any culture (civilization) is by how well their people attend to the needs of their young, their disabled and their elderly citizens.

SCR 4018 focuses upon our disabled and our elderly North Dakotans. The point is they are North Dakotans; consequently it's our responsibility to attend in an appropriate and responsible manner to their "quality of life" issues. I emphasize "quality of life" issues.

Like all human groups the needs and desires of the disabled and the elderly differ considerably. Addressing their issues in a clinical/academic setting is about providing continuums of care. Continuum of care conceptually is a menu of services and activities that allow our citizens to access services that are considered best suited to meet their individual needs in harmony with their personal choices.

Knowing that you all are perhaps more informed about the menu that makes up a continuum of care. I will not spend valuable time giving a (my) definition of the concept.

I would like to suggest that you include in your discussions the need for a "single point of entry plan."

I am asking that the House Human Services Committee give a DO PASS on SCR 4018.

Thank you for your consideration.

Respectfully submitted:

Merle Boucher, Minority Leader  
North Dakota House of Representatives

Item # 2



*The power to make it better.®*

**House Human Services Committee  
SCR 4018  
March 20, 2007**

Chairman Price and members of the committee, my name is Janis Cheney, State Director of AARP North Dakota. Today, on behalf of our 80,500 North Dakotan members, I stand in support of Senate Concurrent Resolution 4018.

This resolution emerges from the recommendation of the North Dakota Olmstead Commission. It demonstrates our commitment to move the state's long-term care system forward for every citizen. By offering real choices for quality care, North Dakotans can maintain their independence and dignity within the community setting. We have the responsibility to provide our citizens with the long-term care options they need and deserve.

Thank you.