

2017 HOUSE HUMAN SERVICES

HB 1038

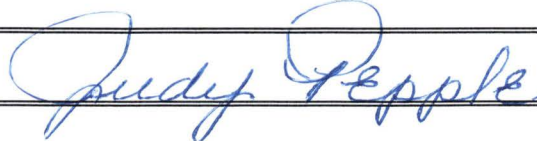
2017 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

House Bill 1038
1/4/2017
26546

- Subcommittee
 Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

To provide appropriations to the North Dakota State University Extension Service and to the department of human services; to provide for the establishment of a caregiver resource center website.

Minutes:

1,2,3,4,5,6,7

Chairman Weisz: called meeting to order

Bill read

Chairman Weisz: asked if there is anyone to testify
Rep Hogan is coming to testify

2:45

Rep. Hogan

Was Chairman of Interim Human Services committee

You will hear two bills relating to family caregivers that were both passed unanimously in the interim committee.

(Attachment # 1)

How do we help people stay at home?

Did a study that is available if you want it.

Pilot projects done. Each one was different depending on what was available in that county.

Website will be expanded and made easier to use for families.

Dr. Strommen will go through this later.

We hope you will consider this.

9:15

Chairman Weisz: In section 2, the \$200,00 is 100% federal?

Rep. Hogan: Yes

Chairman Weisz: Any idea how stable the ongoing source is?

Rep. Hogan: Yes, in the past it has been stable.

Chairman Weisz: Question 4 of course there is additional appropriation for SPED. What percent increase is that, do you know?

Rep. Hogan: Yes, I do. Essentially we went back and applied the percentage of increases that we got from 2009 until 2016 for all of the other programs, so we just adjusted the scale to reflect that.

Chairman Weisz: The current budget doesn't have any increase for SPED?

Rep. Hogan: I don't believe it does. I think it probably has the 1% that Gov. Dalrymple's budget had in it. That is something the appropriations committee will have to work through.

Chairman Weisz: Any questions

Representative Schneider: When we are talking about keeping people at home it is obviously the personal costs and the emotional costs and the motivation to do that, but are you aware what the average nursing home monthly cost is in North Dakota?

Rep. Hogan: I know the annual cost is \$90,000. So keeping people at home is really significant. I think you will have testimony on this bill about that.

Chairman Weisz: Further questions from the committee?
I guess I have a question. In section 1 where you are doing the training. How does that training fit in with current QSP training for example?

Rep. Hogan: That is a great question because the QSP training is targeted not so much for families. It is targeted at people that are getting paid. So it's a different model and I think the specifics of that training because it is a well-established program. We actually looked at specific programs which have been effective in other states. So when we looked at them it is really a family support model. It is someone to call when you have an emergency. It is not so much the direct service stuff as it is support. I think Dr. Strommen will be able to answer that question better than I can.

Chairman Weisz: Thank you

Chairman Weisz: Further testimony of in support of HB1038
14:00

Jane Strommen, NDSU Extension Service
I was a member of the team that did the Family Caregivers Study. This morning I am just going to provide a very high level view of the findings of the study.
(Attachment 2 and 3)

(Final report link is in the attachment.)

Chairman Weisz: Any questions from the committee?

Vice Chairman Rohr: You indicated that your data is from 116 stake holders, but throughout your presentation you indicated that there is a discrepancy between the rural and the urban services that are provided to the patients. Do you think your data is really representative of the rural area? What were your percentages of rural vs. urban?

Jane Strommen: We were very intentional that we received surveys from across the state. We tried to be sure we had a good mix. We had responses from the tribal communities, the veteran's organizations as well. We did not track exactly the zip codes because it was an online survey.

Chairman Weisz: Representative P. Anderson: Is there a way to track the amount of movement from rural to urban based on the lack of care giving? If mom lives in a small rural community and daughter lives in Bismarck, so the elderly are moving to where the children are. Would they stay if there were care giving for them in the rural setting?

Jane Strommen: That is a great question. To my knowledge there is not a study or research or a way to track that. But lots said they couldn't find local help. It meant that they either moved mom or she was moved into a facility that provided a high cost level of care.

29:13

Chairman Weisz: Any more questions from the committee?

Chairman Weisz: further testimony in support of HB 1038?

30:00

Josh Askvig, State Director for AARP North Dakota (Attachment 4, 5)

Thank you for giving me the opportunity to speak in support of HB 1038. I know this committee digs in, but I didn't know we would do this on day 2. I appreciate the way you are doing this. We know there is approximately 62,100 care givers in North Dakota today. They provide approximately 58,000,000 hours of uncompensated care. If you were to pay them a decent hourly rate, it would be valued at over \$860,000,000 that otherwise someone else would have to do. The role of caregivers has greatly expanded.

(Attachment #6)

Fully support HB 1038 and urge you to give it a do pass.

End of testimony

43:56

Chairman Weisz: The pilot project you talk about, are we expanding or starting something new?

Josh Askvig: It does exist in North Dakota. Dr. Strommen would probably be better able to

tell you where that is at. I know that it does exist, but doesn't get to all locations.

Chairman Weisz: Further questions from the committee?

Chairman Weisz: further testimony

Moira Solberg, Director of Volunteer Caregivers for the Elderly
Attachment # 7, but no written testimony given.

Eleven years ago I was able to take care of my father when he was on his death bed. I was able to spend a week with him in his warm, farm house with the rest of my family. The only assistance they got were the words of wisdom from the visiting nurse that taught us how to give the medication, how to take care of him, and what the process of death was. We had not idea, because as a lay person you don't watch people die. Those tools were critical for us to have the honor of sitting by his bedside and holding his hand while he passed on. The organization that I am with, I am going to call it boots on the ground. We are volunteers that go into the houses and try to coordinate services for the elderly to keep them home. We do it free of charge with a minimal fee. We run our entire program on under \$30,000 and we probably saved over \$400,000 in health care costs. The first page of the bill. Looks at the price tag that it cost ND \$197,580 for the information portion of it. Then you flip to the handout I gave you and you look down and it says, "ND nursing home rates". If you can take 2 people out of a nursing home for one year you will have paid for this program already. We underestimate how expensive it is to have someone in a nursing home. If you can get someone at home that will take care of them and it is an honor for them to be home, you have someone who cares for them personally. It is not just a paid person coming in and checking on them. That's what we owe our elderly in helping them provide that.

48:50

Chairman Weisz: Are there questions from the committee?

Chairman Weisz: Further testimony in support of HB 1038?

Chairman Weisz: Is there any testimony in opposition to HB 1038?

Chairman Weisz: Seeing none, we are closing hearing on HB 1038

2017 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

HB 1038
2/6/2017
27936

- Subcommittee
 Conference Committee

Committee Clerk Signature

Judy Tepple

Explanation or reason for introduction of bill/resolution:

To provide appropriations for NDSU Extension service and to the Dept. of Human Services; to provide for the establishment of a caregiver resource website.

Minutes:

Chairman Weisz: Called committee to order
Opened the discussion on HB 1038. I am not sure if you remember what this is, but there are several appropriations on this bill. We will take it up and go through it section by section.

Representative Porter: Remind me on section 3. Did anyone say what this would cost?

Chairman Weisz: My understanding was that they thought they could do this within their budget at this time. They already had a website, so it shouldn't be so expensive to do it.

Representative Porter: Move an amendment to HB 1038. I would remove section 1 and section 4.

Representative Seibel: second

Chairman Weisz: section one included \$200,000 for the university extension. It is listed as a pilot project, but in reality they are already doing this, so it would be to expand the program, to do family training. Section four really strictly a budget. It expands SPED services. It adds another 1.5 million for SPED. I support this, but in the revenue realities we are looking at right now the appropriations committee is going to have to figure out the balance between SPED and expanded SPED and how it fits in with the rest of long term care. This is the amendment. So do we have discussion? It is stripping out section 1 and section 4.

Representative Schneider: On section one even though \$197,580 is not pocket change, but this is a program to support the people who keep folks out of nursing home care for which costs are enormous. Even if it is a handful of people that have to go to the nursing home because they feel they are not getting the support they need to keep their folks at home. I think that is a justifiable cost to include training and support that might avoid nursing home placement.

Representative McWilliams: Is there any way to quantify that? Like say if we spend \$200,000 to try to keep people out of nursing homes that over the course of the biennium it could save us say \$200,000, \$300,000, or \$400,000? Is there any way to put a number to that?

Chairman Weisz: No. That is part of the problem, it is complex and complicated. You can never show that we spent \$200,000 or 2 million, or 20 million. You can argue that it will and it should, but you can't prove it. You can't quantify it and say we spent \$200,000 and it kept 5 people out of the nursing home. I run into that every time I show up in appropriations. I can argue it is pay now or pay later, but I can't prove that I am going to save it later. That is part of the issue when we look at some of these things. It certainly should save us money, but you can't prove it.

Representative Schneider: Is there a harm to leaving the sections in and let appropriations deal with it?

Chairman Weisz: We could do that. I think as far as SPED, because that is already part of an ongoing a program probably whether we send it or not, but on the other sections we are looking at doing something new. There we would have some legitimacy to saying we like this program and asking them to find some money if possible. SPED will be balanced against long term care and other issues.

Representative McWilliams: I was looking at Rep. Hogan's testimony and it says that it is all federal as a one-time project.

Chairman Weisz: Section 2 is federal, but section 1 is general fund. That isn't part of this amendment at this time. Section 1 would be general fund dollars.

Representative Skroch: Did I understand that there is already money going to a pilot project?

Chairman Weisz: They already have a training program, but they want to expand it to include family care giver training. That would be the pilot part.

Representative P. Anderson: I could support taking out section 4, but not section 1.

Roll call vote taken to accept the amendment to remove sections 1 and 4.
Roll call vote carried Yes 9 No 3 Absent 2

Chairman Weisz: All we have left is section 2 which does appropriate \$200,000 of federal funds for the purpose of administering the Life Span Respite Care Program and section 3 which is the care giver website and section 5 which is the study.
Are there any further amendments?

Representative Porter: do pass as amended and refer it back to appropriation.

Chairman Weisz: Ok we have a motion for a do pass as amended and to refer it back to appropriations. This bill will not go on the floor. It will go straight to appropriations. I have to carry it in front of appropriations and support the committee's recommendation. In this case the \$200,000 is the only thing that appropriations is going to look at. They won't care

about anything else that is in the bill, because they are strictly on the money. Then they will make the recommendation to bring it back down to the floor if they agree, then whoever is carrying this bill will carry it on the floor. If they change it or recommend a do not pass, then they will carry it on the floor.

Chairman Weisz: We have a motion for a do pass as amended

Is there any discussion on the bill? Seeing none, the clerk will call the roll.

Representative McWilliams: second

Chairman Weisz: Roll call vote for a do pass as amended and refer back to appropriations on HB 1038

Roll call vote taken yes 12 No 0 Absent 2

Motion carried.

Do I have a volunteer to carry this bill?

Representative Seibel: I will carry it.

February 6, 2017

*2/6/17
JRE
WJL*

PROPOSED AMENDMENTS TO HOUSE BILL NO. 1038

Page 1, line 1, remove "appropriations to the North Dakota state university extension"

Page 1, line 2, replace "service and" with "an appropriation"

Page 1, remove lines 5 through 12

Page 1, remove lines 23 and 24

Page 2, remove lines 1 through 5

Renumber accordingly

Date: 2/6/17
Roll Call Vote #: 1

2017 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. HB 1038

House Human Services Committee

Amendment LC# or Description: Subcommittee
Remove Sections 1 & 4

Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
Other Actions: Reconsider _____

Motion Made By Rep. Porter Seconded By Rep. Seibel

Representatives	Yes	No	Representatives	Yes	No
Chairman Weisz	✓		Rep. P. Anderson		✓
Vice Chairman Rohr	✓		Rep. Schneider		✓
Rep. B. Anderson	ab.				
Rep. D. Anderson	✓				
Rep. Damschen	✓				
Rep. Devlin	ab.				
Rep. Kiefert	✓				
Rep. McWilliams		✓			
Rep. Porter	✓				
Rep. Seibel	✓				
Rep. Skroch	✓				
Rep. Westlind	✓				

Total (Yes) 9 No 3
Absent absent 2
Floor Assignment _____

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

Date: 2/6/17
Roll Call Vote #: 2

2017 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. HB 1038

House Human Services Committee

Subcommittee

Amendment LC# or Description: _____

Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
Other Actions: Reconsider _____

Motion Made By Rep. Porter Seconded By Rep. McWilliams

Representatives	Yes	No	Representatives	Yes	No
Chairman Weisz	✓		Rep. P. Anderson	✓	
Vice Chairman Rohr	✓		Rep. Schneider	✓	
Rep. B. Anderson	✓				
Rep. D. Anderson	ab.				
Rep. Damschen	✓				
Rep. Devlin	ab.				
Rep. Kiefert	✓				
Rep. McWilliams	✓				
Rep. Porter	✓				
Rep. Seibel	✓				
Rep. Skroch	✓				
Rep. Westlind	✓				

Total (Yes) 12 No 0

Absent 2

Floor Assignment Rep. Seibel

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

REPORT OF STANDING COMMITTEE

HB 1038: Human Services Committee (Rep. Weisz, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (12 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). HB 1038 was placed on the Sixth order on the calendar.

Page 1, line 1, remove "appropriations to the North Dakota state university extension"

Page 1, line 2, replace "service and" with "an appropriation"

Page 1, remove lines 5 through 12

Page 1, remove lines 23 and 24

Page 2, remove lines 1 through 5

Renumber accordingly

2017 HOUSE APPROPRIATIONS

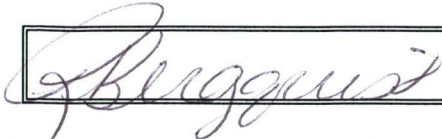
HB 1038

2017 HOUSE STANDING COMMITTEE MINUTES

Appropriations Committee
Roughrider Room, State Capitol

HB 1038
2/9/2017
28167/28172

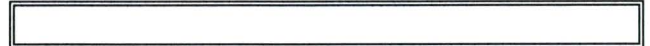
- Subcommittee
 Conference Committee



Explanation or reason for introduction of bill/resolution:

To provide for the establishment of a caregiver resource center website; and to provide for a report.

Minutes:



Chairman Delzer: HB 1038

Representative Weisz, District 14: This one has to do with the care giver act, there's only one section in here that still has any money. This came about because there is federal funding available and so it says *there's appropriation from special funds derived from federal funds and other income, the sum of 200 thousand dollars to the department of human services for the purpose of administering a lifespan respite care program.*

Chairman Delzer: Where do they get the federal money?

Representative Weisz: I looked that up and I'm not even sure what federal agency that's coming from.

Chairman Delzer: Do they have the spending authority in the budget?

Representative Weisz: That discussion didn't come up and I think that's why it's here.

Chairman Delzer: And yet in all honestly, normally they have all kinds of excesses money.

Chairman Delzer: Questions by the committee?

Recording number 28172 HB1038 was brought back up by the committee

Chairman Delzer: HB 1038, they are looking at 200 thousand. Representative Pollert can decided whether or not they want to extend the human service budget federal authority by 200 thousand if we pass the bill. I don't see any real problems with it. What's your wishes?

Representative Monson: I will make a motion for a Do Pass

Representative Sanford: Seconded

Chairman Delzer: Further discussion?

This was one of the ones that came out of interim human service committee, I think there was quite a few bills with quite a bit of money. Policy committee did look hard at it and they decided that there was some federal money available, and that puts this forward with that. Anything we pass over to the senate, who knows how it's going to come back.

Chairman Delzer: Is there any further discussion on the care giver part? It says lifespan respite care program, and care giver resources center web site, and they need to report to the legislative management.

Representative Kempenich: *Shall provide recommendations on options to increase the number and level of services and funding*, so this will be looked into and then there be another budget item two years from now?

Chairman Delzer: I'm sure it's going to be reported, separate report to the management committee but it's the department of human services looking at it, if they think it should go forward I would guess they will be asking for it in their budget process.

Representative Kempenich: Like section 4 that is lined out, that must have been part of it.

Representative Pollert: Under the grants line, there is an increase of 200 thousand dollars, all federal funds, for the lifespan respite care program which we used to expand and enhance respite systems including emergency respite services training and recruiting respite workers and volunteers in assisting care givers and gaining access to needed services.

Chairman Delzer: So the money is in the budget?

Representative Pollert: I don't think we asked to move it because it's federal funds but we would have to adopt it to put it into HB 1012

Representative Monson: When I look more closely at this, it says *special funds derived from federal funds and other income*. So it's still the same number though.

Representative Pollert: We'll double check to make sure, but I am sure that it is 200 thousand and I would just as soon wait on this because I think it's in the budget.

Chairman Delzer: We can go ahead a take the motion and sit on it until you check it out.

Chairman Delzer: Further discussion? If not, we have a motion for Do Pass on HB 1038

A Roll Call vote was taken. Yea: 16 Nay: 2 Absent: 3

Motion Carries and we will have Representative Seibel carry that bill.

Date: 2/9/2017
 Roll Call Vote #: 1

**2017 HOUSE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. HB 1038**

House Appropriations Committee

Subcommittee

Amendment LC# or Description: _____

Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
 Other Actions: Reconsider _____

Motion Made By Representative Monson Seconded By Representative Sanford

Representatives	Yes	No	Representatives	Yes	No
Chairman Delzer	X				
Representative Kempenich	X		Representative Streyle		X
Representative: Boehning	X		Representative Vigesaa	X	
Representative: Brabandt	X				
Representative Brandenburg	X				
Representative Kading		X	Representative Boe	X	
Representative Kreidt	A		Representative Delmore	A	
Representative Martinson	X		Representative Holman	X	
Representative Meier	X				
Representative Monson	X				
Representative Nathe	X				
Representative J. Nelson	X				
Representative Pollert	X				
Representative Sanford	X				
Representative Schatz	X				
Representative Schmidt	A				

Total (Yes) 16 No 2

Absent 3

Floor Assignment Representative Seibel

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

REPORT OF STANDING COMMITTEE

HB 1038, as engrossed: Appropriations Committee (Rep. Delzer, Chairman)
recommends **DO PASS** (16 YEAS, 2 NAYS, 3 ABSENT AND NOT VOTING).
Engrossed HB 1038 was placed on the Eleventh order on the calendar.

2017 SENATE HUMAN SERVICES

HB 1038

2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

HB 1038
3/8/2017
Job Number 28881

- Subcommittee
 Conference Committee

Committee Clerk Signature

Mame Quinn

Explanation or reason for introduction of bill/resolution:

A bill to provide an appropriation to the department of human services, to provide for the establishment of a caregiver resource center website; and to provide for a report.

Minutes:

2 Attachments

Chair J. Lee: Brought the hearing to order, all members were present.

Representative Kathy Hogan, Chair Interim Human Services Committee (0:35-7:00) introduced the bill, please see attachment #1.

Senator Heckaman: Was the decision in the House financial?

Rep. Hogan: Yes, absolutely.

Senator Heckaman: Ok, I wasn't sure if they found a way to absorb some of these into other programs.

Rep. Hogan: Not to my knowledge.

Senator Piepkorn: Near the bottom of your testimony, the study making the five recommendations, tell me about that, #2 for example, sustained and enhanced funding for programs that support family caregivers, tell me more.

Rep. Hogan: There are a range of support programs, like the Homemaker Program, if there's a couple that needs housekeeping or someone to grocery shop, for some families, that's the difference between being able to stay in their homes or not. The Homemaker Program was cut 50%; we have 400-500 clients who will lose services, our concern was if you lose the support services, that aren't expensive, you're going to end up with people in basic or nursing care. We have to remember the balance between home and community based services. If you lose the home and community base, the unintended consequence is going to be higher levels of care. There's a whole range of services, a very comprehensive model. We want to maintain those support services.

Senator Heckaman: Do you know what happened to the Homemaker Program in the budget?

Rep. Hogan: The reimbursement rate lowered, the Homemakers got cut significantly.

Nancy Nikolas Maier, Director of Aging Services Division: During the allotment the rate was reduced, there was a lot of public information on how that might impact people. When we went through the process with CMS to submit our DD rate, it was a 10% reduction. Then there was no OAR in the executive budget to restore the rate where people get paid for personal care.

Chair J. Lee: So the personal care hasn't been reduced the same way the Homemaker care has been.

Ms. Nikolas-Maier: That's correct.

Senator Kreun: In your testimony, Rep. Hogan, 62,000 family caregivers in ND? Out of that how many require our services?

Rep. Hogan: That's a very good question, we haven't had an infrastructure to answer that question. AAPR has surveyed those caregivers, they have some survey data on that. My personal emphasis, 30% needs some kind of support, it may be information, training, respite; and over the duration of caring for a family member, what they need will change. The system has to respond to those changes.

Senator Kreun: In the qualification process, does North Dakota go through the family's financial capability of assistance for these programs?

Rep. Hogan: Absolutely. Almost all the programs we've been describing have financial criteria, other than things like information and referral and some of the raining programs. It depends on the type of program, but direct service programs, like Homemakers have income guidelines.

Chair J. Lee: Think of the individual caring for a spouse with a stroke, or Alzheimer's, the caregiver gets worn out. Referenced Fargo article and personal friend.

Rep. Hogan: As you become aware of it, you see it more and more. Many people do this every day; this is real.

Chair J. Lee: Caring for someone with dementia who wanders is stressful. The amendment came from the Human Services committee; it was a fiscal decision. The service program for elderly and disabled (SPED) provides those services to somebody who is at home. An expanded SPED is a little bit broader service provision, both are income related. There hasn't been a change since 2009.

Mike Chausse, AARP (16:20-25:25) testified in favor, please see attachment #2, suggested an amendment.

Senator Piepkorn: Do you know what the requirements are to access that \$200,000 in Federal funds in section 1?

Mr. Chausee: Of the lifespan respite program? I don't know the exact details of how it gets awarded, somebody in the room probably can. The list of states, since 2006 was the first one that was granted to states, it's up to 3 years.

No Opposition or Neutral testimony.

Senator Piepkorn: Just that question about accessing the \$200,000 from the federal funds.

Nancy Nikolas-Maier, Director of Aging Services Division: It's a competitive grant, awarded to states, we would have to write the grant, there's a 25% match requirement either federal or in kind, we would be awarded up to \$200,000 over a three-year period to enhance respite programs, look for gaps, reach out and collaborate with other community partners. There are 16 states left that haven't had one of these grants, it's a competitive process.

Senator Piepkorn: Of the 62,000 family caregivers that come from everywhere in the population, how many are they serving?

Ms. Maier: That depends, it's mostly one on one care, but a daughter providing for both parents, or several people sharing an apartment, having one person come and care for them happens too.

V-Chair Larsen: This is about the NDSU Extension Service; it says they have a pilot program and they trained folks in three 6-week workshops; how long has this been going on?

Josh Askvig, AARP of ND: I had most contact with Jane Strommen, from Extension, I don't have exact answer, I know I have only seen it in last 2 years, it was a pilot for them. Extension has a number of different areas where they work this was one in family and consumer science that they were testing out. The pilot in the bill would be to take it further out.

Chair J. Lee: I met with Dr. Strommen, they were doing this work the idea of having an extension, because they are in every county; having that network was really important, there's not a venue this program could flow through in some of the rural areas, it would be a hub out of which that information could flow.

Chair J. Lee: closed the public hearing.

Half a loaf is better than none, we have half a loaf; the caregiver website will be helpful we move to a study; if we want any discussion about any further restorations now would be the time. Three of the sections are in there, two of them have been removed because of the cost, as much as I would like to see the SPED program ramped up, I think that's unrealistic.

Senator Heckaman: Can you refresh my memory, we had a caregiver bill in the Senate.

Chair J. Lee: I'd like to know where it is, this was a separate free standing bill.

Mr. Askvig: There were two bills that came out of the interim, one that focused on supports, the 2nd regarding hospital discharge policies. For your full awareness the House had a version of 2215 which you will have a hearing on. it doesn't look like what you passed out. It's 1039 and 2215 are the same. Then you have 1038 which is different. That's the difference between them.

Chair J. Lee: But it isn't dead yet?

Mr. Askvig: They haven't had a hearing on it yet.

Chair J. Lee: Closed the hearing on HB 1038.

2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

HB 1038
3/13/2017
Job Number 29113

- Subcommittee
 Conference Committee

Committee Clerk Signature

Mary Jo Nacker for Mame Johnson

Explanation or reason for introduction of bill/resolution:

A bill to provide an appropriation to the department of human services, to provide for the establishment of a caregiver resource center website; and to provide for a report.

Minutes:

No attachments

Chair J. Lee: It came to us with federal dollars.

Senator Heckaman: I don't understand why we aren't accepting those dollars.

Chair J. Lee: I don't either, but let's start. **Senator Heckaman:** I don't know what the reason was. I was on the wrong bill.

Sen. J. Lee: It is 1038 at \$200,000 in Section 1. **Senator Heckaman:** He wanted Section 1 out of the original bill. **Sen. J. Lee:** who did? Michael? **Senator Heckaman:** Yes, Michael. I asked him in section from the original bill back in. That's on a pilot project for caregiver training, that's not in general funds. That's different I was in the wrong place. **Sen. J. Lee:** that's the 2000 version in the 3000 version is deleted.

Senator Clemens: What's lifespan respite care?

Chair J. Lee: If I were a caregiver for dementia, respite care allows someone to come in and take care, it's just the name of it for the federal program is called. It is all federal funds. Establish a plan for people who are care givers. There are thousands of them in ND who are helping with this.

Senator Heckaman: That was the part, he was questioning section 1 being put back in from the original 2000 version. I hate to start messing with this other bill.

Mike Chaussee wanted the section 1 from the 2000 version put back into the 3000 version of the bill.

Chair J. Lee: SPED increase wasn't in. It hasn't been changed since 2009. That is something we have to remember in the next session. It doesn't have to come all the way up to today's

rate based on inflation and all that kind of stuff, but there's got to be an increase because fewer and fewer people are able to use the service. Maybe we can live with the bill as it is.

Senator Anderson: The way the bill is, it doesn't cost us anything, right? **Sen. J. Lee** replied no.

Senator Anderson: I move do pass
V-Chair Larsen: Second

Senator Heckaman: I am wondering if this is the one where I asked about in Section 2 if we should join that. I am okay with it.

Sen. J. Lee: Now 1039 is the same as 2215.

Senator Kreun: So we are leaving this bill alone looking at the \$200,000 that's on line 6 and that is what funding source? **Sen. J. Lee:** From fed funds. **Senator Kreun:** So, why would that be a problem?

Chair J. Lee: It wasn't. That's why it is still in the bill.

Senator Heckaman: the part that was the problem was in the original bill there was a part they wanted to put back in here, so that's why this is number 2001.

Senator Piepkorn: What about the cost for establishing the caregiver resource center website?

Chair J. Lee: It sounded to me like they were just going to be able to do that. Make a link on the department site. I would like to see it include SPED and expanded SPED on line 19. We can lobby the legislature management including that in there.

Senator Kreun: What's Section 3 then?

Chair J. Lee: A study, focuses on long term care as well as community based services enhance community services, the problem is trying to find somebody to do this.

Motion passes 7-0-0

Senator Kreun will carry.

Date: 3/13 2017

Roll Call Vote #: 1

2017 SENATE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1038

Senate Human Services Committee

Subcommittee

Amendment LC# or Description: _____

Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
Other Actions: Reconsider _____

Motion Made By Sen. Anderson Seconded By Sen. #Larsen

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee (Chairman)	X		Senator Joan Heckaman	X	
Senator Oley Larsen (Vice-Chair)	X		Senator Merrill Piepkorn	X	
Senator Howard C. Anderson, Jr.	X				
Senator David A. Clemens	X				
Senator Curt Kreun	X				

Total (Yes) 7 No 0

Absent 0

Floor Assignment Sen. Kreun

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

REPORT OF STANDING COMMITTEE

HB 1038, as engrossed: Human Services Committee (Sen. J. Lee, Chairman)
recommends **DO PASS** (7 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING).
Engrossed HB 1038 was placed on the Fourteenth order on the calendar.

2017 SENATE APPROPRIATIONS

HB 1038

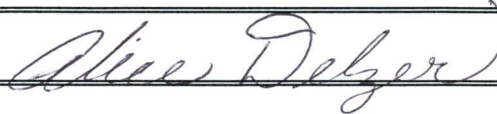
2017 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee
Harvest Room, State Capitol

HB 1038
3/21/2017
JOB # 29506

- Subcommittee
 Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide an appropriation to the department of human services; to provide for the establishment of a caregiver resource center website; and to provide for a report.

Minutes:

1.AARP Testimony presented by Mike Chaussee

Chairman Holmberg: called the Committee back to order on HB 1038 at 10:45 am in the Harvest Room. All committee members were present. Michael Johnson, Legislative Council and Sheila Peterson, OMB were also present. Michael will say something about it. It was an interim bill from the Human Services Committee.

Michael Johnson, Legislative Council (0.00.37-0.02.36) explained the bill to the committee. It is a study of Family Caregivers Supports services. Just to point out a couple, there are a couple of sections that are different than in the Human Services Committee. There was a section that was removed related to providing an appropriation of \$197,000 from the general fund as a pilot project for caregiver training and then there's a section that was removed that would provide an appropriation of \$1.5m from the general fund to DHS related to SPED inflationary increases, and that's everything in this bill.

Chairman Holmberg: This bill will go to the committee that has SPED and those things in it, the DHS subcommittee – which is Senator Kilzer, Chair; Senators Erbele, Dever & Mathern.

Mike Chaussee, AARP North Dakota: (0.3.10-0.08.31) We support this bill and are providing written Testimony attached # 1, AARP, a testimony stating they support HB 1038, which they call the Family Caregiver Supports bill. He then shared that AARP is committed to Family Caregivers, we think they are the key piece to the puzzle to keep people in their homes as long as possible. He referenced a survey they did in November-December of 2016 on page 6 of testimony. At the top of that we have found that about 90% of people said they want their family members to stay at home as long as possible. These family caregivers really help them do that. So, why family caregivers? One for that. Two, we found that there are about 62,000 of them operating in the state in that same survey. We found that 47% of North Dakotans, either are a family caregiver currently, or say they've done that work in the past. We estimate that work to be about 58m hours and valued at about \$860m. So what do they do? We know a lot about the fact that they do chores, and help them bathe, help people go

to the store and back, but in that same survey we also found that 64% of those caregivers are managing medication at home and another 60% are helping do more complex nursing tasks, like injections and transferring of people from place to place. So, why do they need the help? I am going to the survey again, in your packet, (page 5) there is a bar graph, that 60% of these caregivers say they are stressed out, half of them say they don't sleep like they should, 30% don't exercise, they also spend a lot of money, on the next page, this is a national, family caregiving and out-of-pocket costs – 2016 Report. It says that family caregivers tend to spend about \$7,000 a year of their own money in these caregiving tasks. That becomes a problem too. And again another reason why we support, but they still do the job. What kind of helps do they need? The next couple of pages in your packet are the Executive Summary of NDSU study which is a good refresher and reminder of some of the suggestions that the study has done in our state to help family caregivers. The conclusions show that the caregivers need to know where to turn to get help. They need some training on how to manage the patient's care, the health care and even their finances but also how to manage their own lives. So that was one of the recommendations. And then finally they need a break. They need some sort of respite. So that brings us to the conclusions and the reasons we are here and the pieces that are found in HB 1038 and the main appropriation piece is this access to the Lifespan Respite Care Program Grant. It's all federal money, \$200,000. More than 30 states access this grant. I am looking at the rest of the states that have done it and it tracks back to 2006. A couple of the states have done it multiple times. Some of the things they have done with that money is expand respite care services, communication and education programs. Another piece that I found really interesting is partnerships that they've used this money to create with the faith groups in communities and those sorts of things and we are pretty excited with DHS about that and then some training for respite care providers to get some of the relief in the homes for the caregivers. DHS is already working on an updated website. This will allocate resources to a caregiver specific portion of that website. They will look at balancing the resources and the attention given to home community based care versus long term care facilities. All this is about helping people who are not getting paid. We know their job is stressful, time consuming, expensive, and we think it saves the state millions of dollars so we would ask that you recommend a Do Pass on HB 1038.

V. Chairman Krebsbach: Could you address the two sections that were removed and what you feel about those?

Mr. Chaussee: The first section is the pilot project, I was here last week and asking as part of the DHS bill to have that money brought back in. That's one of the powerful tools for caregivers site that NDSU, it's a train the trainers type of program. We would love it if that money was brought back, the \$200,000. I can send some information of what that money would be used for. I would talk to NDSU if the program went through. The other piece would be adjusting the SPED (Service Payments for Elderly & Disabled). 2009 was the last time it was adjusted for inflation and so we think there are people that now earn money because of the inflationary status that they've gained so they have earned themselves out of the program.

Chairman Holmberg: Is there any consideration in House Appropriations to put additional money into SPED or was this section just removed? He was told it was removed very quickly. The hearing on HB 1038 was closed.

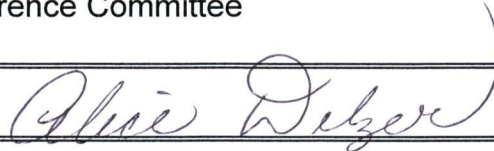
2017 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee
Harvest Room, State Capitol

HB 1038
3/31/2017
JOB # 29875

Subcommittee
 Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A Subcommittee hearing regarding the bill addressing the Establishment of a caregiver resource center website (DHS)

Minutes:

No testimony submitted

Chairman Kilzer called the Subcommittee to order on HB 1038 in the Harvest Room at 11:00 am. Let the record show that all subcommittee members are present: Chairman Kilzer; Senator Erbele, Senator Dever and Senator Mathern. Michael Johnson, Legislative Council and Lori Laschkewitsch, OMB were also present.

Chairman Kilzer: This bill was heard on March 21. The only agency to testify was AARP in support of the bill. they did prefer the first edition, which I had not seen. The original bill did contain some provisions that would have cost us some money. This is an engrossment. It looks like there would be no monetary obligation of the state. It would be a \$200,000 grant to the DHS for respite care services. I am not sure what the word respite means, but apparently has something to do with family and volunteer members doing much needed and gratuitous care of elderly people. Do you have any directions that the subcommittee would like to take before I would request how this would fit in, whether it was an OAR and it's connection to House Bill 1012.

Senator Mathern: This came about through an interim care study. It had more features to it after it came out of the interim relating to the involvements of the extension service and DHS and a lot of other organizations. It's been pared down to this. It's a wish that this money be raised from the federal government. I think we just ought to send it back. No change it at all. It has potential of good. If we try to amend it or send it back to the House, I don't think it will go anywhere. I think we need to pass it the way it is and it's done.

Senator Dever: The money is federal money, is there department time or FTE necessary to put this together?

Chairman Kilzer: I would ask someone to come from the department to tell us more about FTE and how it would mesh in to the main bill which is 1012.

Maggie Anderson: Interim Director for DHS: The Department had also \$200,000 of federal authority built into our 17-19 budget request for this same lifespan respite care program and the House removed that because they knew the money was in 1038. And so we had planned to do this with existing staff. We are not requesting an additional FTE or any other resources to do it. So if you pass 1038, it would be then consistent with what we were otherwise going to do within our budget request.

Chairman Kilzer: Which division was it in in the executive budget? He was told aging services.

Senator Dever: I don't know what other consideration we might need to make on this.

Chairman Kilzer: Our choices are to have a motion to give a favorable Do Pass on this bill.

Senator Erbele moved the bill. 2nd by Senator Dever.

Chairman Kilzer: Would you call the roll on 1038 to move this bill as is?

A Roll Call vote was taken. Yea: 4; Nay: 0; Absent:0.

The subcommittee hearing on HB 1038 was adjourned.

2017 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee
Harvest Room, State Capitol

HB 1038
4/4/2017
JOB # 29910

- Subcommittee
 Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A DO PASS for the establishment of a caregiver resource center website (DHS)

Minutes:

No Testimony submitted

Chairman Holmberg: called the Committee to order on HB 1038. Roll call was taken. All committee members were present. Michael Johnson, Legislative Council and Becky Deichert, OMB were also present.

Chairman Holmberg: Gave an update on the bills that still are in Committee and have not been passed out of committee yet. **(0.04.25)**

Senator Mathern: commented that HB 1040 is ready to go.

Senator Kilzer: We have no new amendments. It's a straight up and down bill. What it is \$200,000 for respite care. It goes for training for family members to take care of people. The bill had money for a pilot project for NDSU for trainers, and money for SPED, those were removed by the House.

Senator Kilzer: Moved a Do Pass. 2nd by Senator Mathern.

Chairman Holmberg: Call the roll on a Do Pass on HB 1038. This goes back to Human Services.

A Roll Call vote was taken. Yea: 14; Nay: 0; Absent:0. Senator Kreun from the Department of Human Services Committee will carry the bill.

The hearing was closed on HB 1038.

Date: 3-31-17

Roll Call Vote #: 1

2017 SENATE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1038

Senate Appropriations Committee

Subcommittee

Amendment LC# or Description: _____

- Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
Other Actions: Reconsider _____

Motion Made By Erbele Seconded By Dever

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg			Senator Mathern	<input checked="" type="checkbox"/>	
Vice Chair Krebsbach			Senator Grabinger		
Vice Chair Bowman			Senator Robinson		
Senator Erbele	<input checked="" type="checkbox"/>				
Senator Wanzek					
Senator Kilzer	<input checked="" type="checkbox"/>				
Senator Lee					
Senator Dever	<input checked="" type="checkbox"/>				
Senator Sorvaag					
Senator Oehlke					
Senator Hogue					

Total (Yes) 4 No 0

Absent 0

Floor Assignment _____

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

Do pass the Bill as is.

Date: 4-4-17

Roll Call Vote #: 1

2017 SENATE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1038

Senate Appropriations Committee

Subcommittee

Amendment LC# or Description: _____

- Recommendation: Adopt Amendment
 Do Pass Do Not Pass Without Committee Recommendation
 As Amended Rerefer to Appropriations
 Place on Consent Calendar
Other Actions: Reconsider _____

Motion Made By Kilzer Seconded By Mathern

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg	✓		Senator Mathern	✓	
Vice Chair Krebsbach	✓		Senator Grabinger	✓	
Vice Chair Bowman	✓		Senator Robinson	✓	
Senator Erbele	✓				
Senator Wanzek	✓				
Senator Kilzer	✓				
Senator Lee	✓				
Senator Dever	2				
Senator Sorvaag	✓				
Senator Oehlke	✓				
Senator Hogue	✓				

Total (Yes) 14 No 0

Absent 0

Floor Assignment Human Services

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

REPORT OF STANDING COMMITTEE

HB 1038, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman)
recommends **DO PASS** (14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING).
Engrossed HB 1038 was placed on the Fourteenth order on the calendar.

2017 TESTIMONY

HB 1038

HB 1038
Att. 1
1-4-17

TESTIMONY
HB 1038
House Human Service Committee
January 4, 2017
Representative Kathy Hogan

Mr. Chairman and members of the Committee, my name is Representative Kathy Hogan I chaired the interim human service committee. This morning you will hear two bills related to family caregiving that both passed unanimously in the Interim Committee.

In 2013, over 62,000 family caregivers provided 58 million hours of unpaid care valued at \$860 million in North Dakota. These caregivers are spouses, adult children, other family members, neighbors, and friends. Family caregivers provide a range of daily activities such as; transportation, personal care, cooking, managing finances, grocery shopping, and much more. Finding ways to support North Dakota's family caregivers and bridge the gaps where they may be struggling, is good public policy.

We started with a comprehensive study done by the ND Extension services of the current resources, the unmet needs and recommendations for policy and program changes. This study is available at http://www.legis.nd.gov/files/committees/64-2014%20appendices/17_5110_03000appendixi.pdf

The study made five broad recommendations.

1. The need to maintain a focus on family caregiver needs as ND's population ages.
2. Sustain and enhance funding for programs that support family caregivers, such as homemakers, respite care.
3. Improve information for family care givers so that they may access current resource
4. Improve training for both caregivers and professions on the family caregiver role
5. Improve family care giver supports, particularly in rural areas.

HB 1038 provides three appropriation requests:

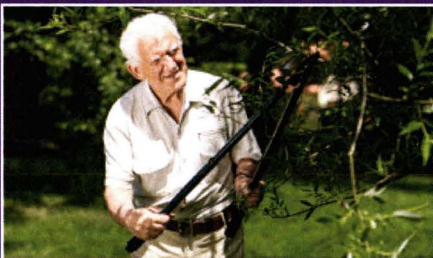
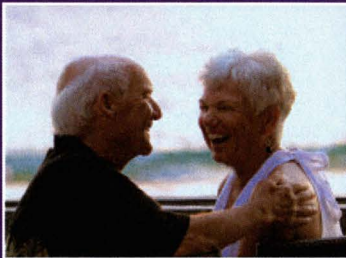
1. Provides one-time funding of \$197,000 to establish a pilot project to expand local training programs to train family caregiver,
2. Allows access to federal funds for a Lifespan Respite Care Program,
3. The bill also directs DHS to establish and promote a caregiver resource center website without any funding
4. Provides an inflationary adjustment to the SPED sliding fee schedule which haven't been adjusted since 2009.

There were many other recommendations considered but in light of the current budget situation, the interim committee recommended that this be the first step in addressing the growing challenge of supporting North Dakotans.

Thank you for considering this important issue. I am more than willing to answer any questions.

1-4-17 AH 2
HB 1038

North Dakota Family Caregiver Supports and Services Study

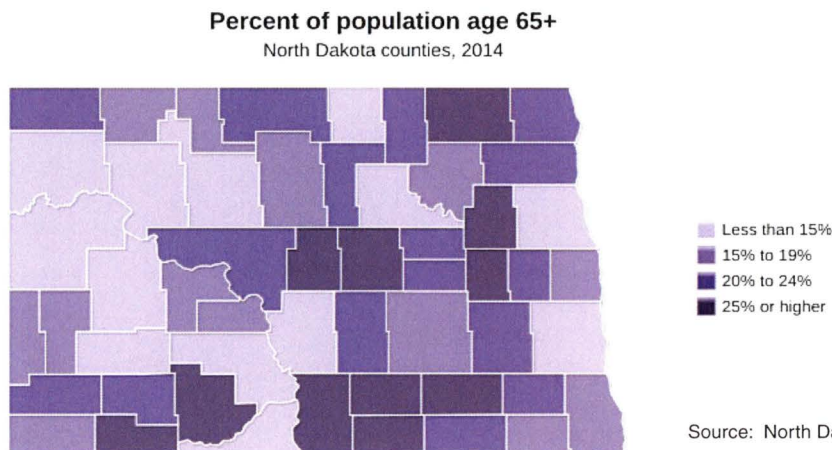


EXECUTIVE SUMMARY

May 10, 2016

Introduction

Between 2011 and 2025, the number of adults ages 65 and older in North Dakota is expected to grow by 50 percent. That means there will be about 50,000 more people aged 65+ by 2025. In 2011, 14.4 percent of North Dakota's population was ages 65 and older and they are expected to be 18 percent of the state's population by 2025.



The U.S. Census Bureau estimated North Dakota to have 17,680 individuals age 85 and older in 2013. This makes up approximately 2.5 percent of the state's total population and puts North Dakota in 7th place in the country for having the oldest residents. Health issues are a common concern for this age group, with the majority indicating difficulties with dressing, vision, hearing loss, memory recall, and going outside of their residences. Between 2010 and 2040, the number of adults 85 years and older in North Dakota is expected to grow by 43 percent, an increase of about 7,200 people. (*Growing ND by the Numbers*, North Dakota Census Office, 2014)

Levels and types of disability are important for planning services and understanding the scope of caregiving needs in North Dakota. In 2014, more than one in three (34 percent) adults ages 65 and older had one or more disabilities (34 percent). The disability rates among American Indian older adults are higher than for white older adults in the state (53 percent compared to 34 percent; 2010-2014).

According to the AARP Public Policy Institute's new report, *Valuing the Invaluable: 2015 Update*, in 2013, North Dakota had 62,100 family caregivers who provided 58 million hours of unpaid care valued at \$860 million. These caregivers are spouses, partners, adult children, other family members, neighbors and friends. Family caregivers provide a range of daily activities, such as transportation, personal care, managing finances grocery shopping and much more. Finding ways to support North Dakota's family caregivers and bridge the gaps where they may be struggling, is the focus of the current report.

Executive Summary

Between January and May, 2016, North Dakota State University was contracted by the North Dakota State Legislative Human Services Committee to conduct the study “Identifying Gaps in Family Caregiver Supports and Services in North Dakota”. A team of faculty researchers and graduate students conducted the study that focused on the following five aims:

Aim 1. Identify current public and private resources, services, and supports for family caregivers, both public and private, and by region and/or county.

Aim 2. Identify barriers and challenges family caregivers experience, which includes the need for training, respite care services, medical leave policies, and delegation of tasks to family members and nonmedical aides.

Aim 3. Identify best practice models for family caregiver support programs from other states.

Aim 4. Identify emerging practices and technology that can enhance caregiver and patient home supports.

Aim 5. Provide recommendations to the interim committee.

A brief summary of the major findings for each aim is provided next. For a comprehensive overview of the methodology and findings for each aim, see the appropriate full chapter.

Aim 1. Current Resources for Family Caregivers in ND

We inventoried and **created a database of family caregiver resources, services, and supports** across the eight geographic regions of North Dakota. The categories of services and resources identified cover areas of support related to: managing the logistics of caregiving, direct support in providing care, improving caregiver’s ability to provide care, and fostering the wellbeing of the caregiver. Maps were created for each category to identify availability of services across the state, and are presented in the body of the report.

Categories of Family Caregiver Resources, Services, and Supports

Managing Caregiving Logistics	Direct Support in Providing Care	Improving Caregivers’ Ability to Provide Care	Fostering Caregivers’ Wellbeing
Advocacy Services	Adult Day Care	Meal Services	Emotional Support
Assistive Technology & Equipment	Dementia Care	Training & Education	Respite
Care Management	Home Health Care	Transportation	Key: Evenly Represented Rural / Urban Divide
Information & Referral	Homemaker / Chore	Volunteer Services	
	Hospice		
	Personal Care		

Within these categories, **further examination is required** to fully identify gaps in service related to:

- **Availability** (Are services available across the designated region / county?)
- **Accessibility** (Does the travel distance to the service create a barrier?)
- **Appropriateness** (Do services address actual needs?)
- **Affordability** (Can families afford to pay for available services?)
- **Awareness** (Do families and communities know about these services?)

Each of these factors present challenges and need to be addressed if the service needs of family caregivers are to be met.

Aim 2. Barriers and Challenges of Family Caregiving

Caregivers' Perspective

(based on data from 398 family caregivers across ND from 2014-2016):

North Dakota Family Caregivers are likely to be:

- Women
- Spouses (followed by children)
- Older adults
- Working full or part-time

Caregiving Tasks

- Shopping, transportation, & chores most common tasks
- 80% provide nursing cares, yet 50% report receiving no training
- 50% report insufficient respite from caregiving

Common benefits of caregiving:

- Satisfaction of giving back
- Helping maintain independence
- Love and appreciation

Common challenges of caregiving:

- Lack of sufficient respite
- Need help finding available services and resources
- Lack of knowledge and training about providing care
- Caregiver stress and burden
- Financial burden

Stakeholders' Perspective

(based on data from 116 stakeholders across ND in 2016):

Represented service sectors:

- Healthcare
- Long-term care
- Social services
- Aging services
- Community-based organizations
- State & local government
- Advocacy agencies
- Faith-based organizations
- Veteran's organizations
- Tribal agencies

Common challenges/unmet needs of families and service organizations

- Financial costs
- Lack of support
- Lack of available services
- Respite
- Finding and navigating services
- Lack of training
- Rurality

Stakeholder recommendations

- Improve funding
- Increase respite care
- Increase education and training
- Increase overall services available
- Foster outreach and awareness

Veterans' groups: have special needs related to coordinated services with the VA, particularly challenging in rural ND

American Indian Tribes: coordinating services between Tribal and state programs is a challenge. Support to family caregivers should be provided in a culturally sensitive way.

Aim 3. Best Practices for Family Caregiver Support Programs

BEST	
Availability of Help / Support	<ul style="list-style-type: none"> • Telephone-based psycho-educational interventions • Virtual care • Community nurses
Financial cost of care / Funding	<ul style="list-style-type: none"> • Sliding scales and vouchers • Increasing access to paid family medical leave • Long-term care planning
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> • Interactive training (e.g. role playing) • Comprehensive discharge planning • Long-term education programming • Preventative care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> • In-home care • Health education programs

Aim 4. Emerging Practices and Technology to Enhance Caregiver Supports

EMERGING	
Availability of Help / Support	<ul style="list-style-type: none"> • Person-centered care (i.e., Money Follows the Person) • Mobile adult day care (i.e., especially in rural areas) • Working with college students • Technology (i.e., smart-homes, robotic applications, etc.) • Socially Assistive Robots • Smart Wear
Financial cost of care / Funding	<ul style="list-style-type: none"> • Telemedicine reduced hospitalization • Co-op models • Tax credits for caregiving
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> • Home visits upon discharge • Virtual learning modules in hospital waiting rooms • Use social media to increase awareness • Trainings for employers about eldercare • Mobile apps for long distance care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> • Online emotional support groups • Employ Behavioral Risk Factor Surveillance System’s (BRFSS) caregiver module to detect caregiver burden

A series of examples of both best and emerging practices are discussed in the body of the report. Additionally, challenges related to implementing these new practices are discussed.

CHALLENGES	
Logistics and Implementation	Limitations and Caveats
<ul style="list-style-type: none"> • Balancing the needs of care recipient and caregiver • Increasing costs • Staffing shortage • Rurality 	<ul style="list-style-type: none"> • Budget Cuts • Lack of flexibility in federal programs (i.e. Medicare) • Lack time to learn and implement technologies

Aim 5. Conclusions and Recommendations

The primary goal of family caregiving is to help older adults to maintain their independence and well-being. This study concludes that, even though family caregiving is rewarding, North Dakota family caregivers are vulnerable due to lack of support.

Key Study Conclusions and Ensuing Recommendations

Conclusions	Recommendations
The high costs of care and lack of funding for services to support caregiving prove enormously challenging for North Dakota caregivers.	Improve avenues for sustainable funding for family caregivers and programs that support them
Both caregivers and stakeholders clearly indicated that insufficient access to respite care is one of the most salient gaps in the services provided to North Dakota family caregivers.	Increase access to respite care across the state
Caregivers reported difficulty finding, connecting to, and navigating available services and resources.	Improve outreach (i.e., marketing) and resources (i.e., technology) to help family caregivers find, connect to, and navigate available services
Family caregivers lacked training related to the logistics and management of caregiving, including the provision of support in activities of daily living.	Create programs and policies to foster an increase in the training and education of both informal and professional caregivers
Both caregivers and stakeholders reported the challenge of lack of available and appropriate services especially in rural regions.	Close the gaps in caregiver support services in rural areas

Overarching Recommendations

Several overarching recommendations cut across the various conclusions:

- Develop family caregiving taskforce consisting of caregivers, service providers, and community leaders to create recommendations to address the service gaps identified in this study.
- Explore ways to lift restrictive eligibility criteria and cut the red tape, or expand funding opportunities to include those not currently financially eligible.
- Increase service availability for respite care, care management, training and education, emotional support, volunteer programs and a range of direct care supports (adult day care, homemaker/chore, dementia care, and personal care).
- Improve resources to address caregiver well-being (including preventative, screening, and intervention care).

Acknowledgments

This study was solicited and funded by the North Dakota Legislative Management. As provided in Section 1 of 2015 House Bill No. 1279, the study was to develop a resource directory of services available to support family caregivers, to identify unmet needs, and prepare recommendations for legislative or administrative consideration. The study required input from stakeholders, including representatives of hospitals, social and clinical providers, advocacy organizations, veterans' organizations, tribal governments, state and local agencies and institutions, and caregivers in the state.

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In addition, we want to express our gratitude to the County Social Service staff who shared their expertise about local family caregiver resources and to the many stakeholders who were willing to share their perspective and insights with us. It is our hope this study will uncover ways in which we can better serve family caregivers.

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AND FAMILY SCIENCE

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**Family Caregiver Study:
Final Report Summary
for
House Human Service
Committee**

January 4, 2017

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Family Caregiver Resources

Aim 1: Identify current public and private resources, services, and supports for family caregivers, by region and/or county.

- Create database of:
 - a) informal community supports
 - b) private community supports
 - c) governmental supports

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Family Caregiver Resources

19 categories of services/supports were determined

Managing the Logistics of Caregiving	Direct Support in Providing Care	Improving Caregivers' Ability to Provide Care	Fostering Caregivers' Well-being
Advocacy Services	Adult Day Care	Meal Services	Emotional Support
Assistive Technology & Equipment	Dementia Care	Training and Education	Respite
Care Management	Home Health Care	Transportation	
Information and Referral	Homemaker/Chore	Volunteer Services	
	Hospice		
	Personal Care		
	Parish Nurses		
	Public Nurses		
	Qualified Service Providers		

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Study Conclusions

- **Services related to managing caregiving are more developed than many other caregiving services across ND:**
 - Information and referral, assistive technology and equipment, and advocacy services seem to be evenly represented across the state
 - Care management is one area that would support managing the logistics of caregiving that seems to be lacking across the state

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Map of Assistive Technology/Equipment

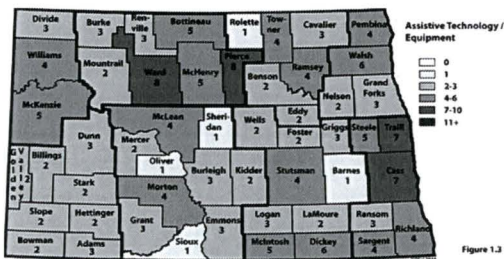


Figure 1.3

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Map of Care Management

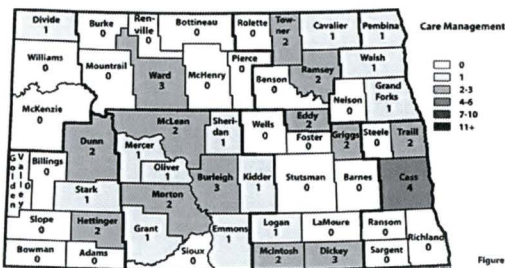


Figure 1.7

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- **There is a clear rural/urban divide in resources that provide direct eldercare support:**
 - In urban areas we find a strong representation of direct care services (such as adult day care, dementia care, hospice, home health care, homemaker and personal care)
 - However, these direct care services seem to be lacking in rural areas across the state

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Map of Adult Day Care

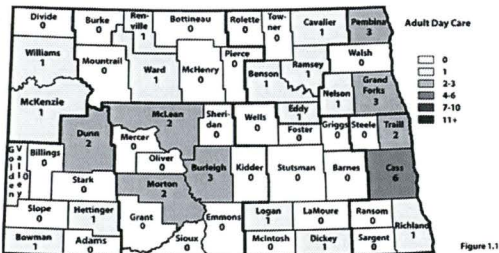


Figure 1.1

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Map of Dementia Care

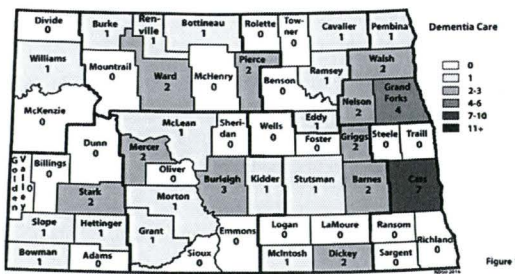


Figure 1.6

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- Some services (such as training and education, transportation, meal services, and volunteer services) indirectly help caregivers by improving the caregiver's ability to provide care him or herself.

– Of these, training and education, transportation, and volunteer services seem to be lacking across the state

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Map of Training and Education

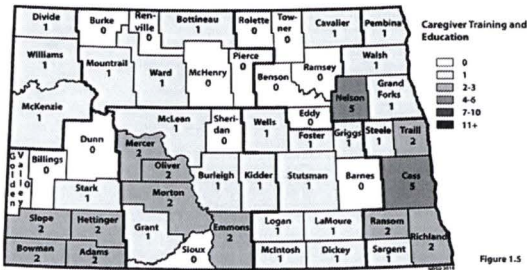


Figure 1.5

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Map of Volunteer Services

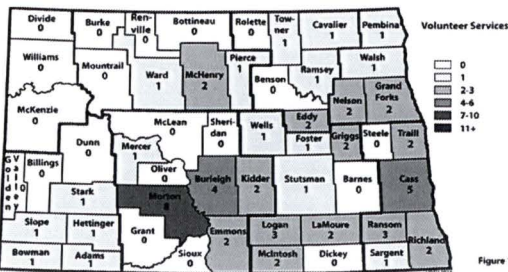


Figure 1.18

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- **Respite care and emotional support have a primary aim of helping to foster well-being of the caregiver.**

- These services are under represented across North Dakota, which is concerning because if the well-being of the caregiver is not a priority, seniors and their families may be put at risk.

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Map of Respite Care

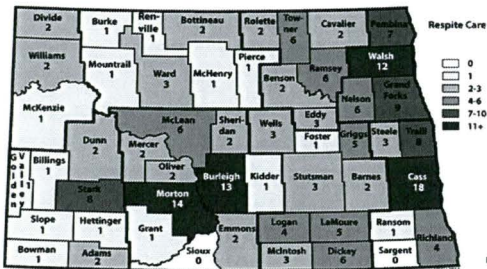


Figure 1.16

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Family Caregiver Challenges and Barriers

Aim 2: Identify barriers and challenges family caregivers experience.

Phase A. Study of Family Caregivers

- AARP-ND, survey of caregivers (2015-16)
- Family Caregiver Support Program (2014, 2015)

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Caregivers' Perspective
(based on data from 398 family caregivers across ND from 2014-2016):

North Dakota Family Caregivers are likely to be:

- Women
- Older adults
- Spouses (followed by children)
- Working full or part-time

Caregiving Tasks

- Shopping, transportation, & chores most common tasks
- 80% provide nursing cares, yet 50% report receiving no training
- 50% report insufficient respite from caregiving

Common benefits of caregiving:

- Satisfaction of giving back
- Helping maintain independence
- Love and appreciation

Common challenges of caregiving:

- Lack of sufficient respite
- Need help finding available services and resources
- Lack of knowledge and training about providing care
- Caregiver stress and burden
- Financial burden

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Caregivers' Perspective
AARP Caregiver Survey Data

Figure 2.9: What should the ND legislature know as they look to improve supports for family caregivers?

Category	Value
Easing financial burden	25
More respite time	18
Need for an easier way to find resources	10
Ensuring proper care	9

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Caregiver's Perspective
ND Family Caregiver Support Program

Figure 2.14: What other services would have been helpful?

Category	Value
ADL/IADL assistance	31
Respite/emotional support	28
Time	16
Physical assistance	13
Financial assistance	11

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Stakeholders' Perspective

- Phase B. Stakeholders Survey (NDSU, 2016)
 - Survey stakeholders across ND (online and interview)
 - Types of questions asked:
 - Challenges faced by caregivers and organizations providing services & supports
 - Barriers to using caregiver services & supports
 - Ways to improve services & supports for family caregivers

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Stakeholders' Perspective (based on data from 116 stakeholders across ND in 2016):

Represented service sectors:

- Healthcare
- Long-term care
- Social services
- Aging services
- Community-based organizations
- State & local government
- Advocacy agencies
- Faith-based organizations
- Veteran's organizations
- Tribal agencies

Common challenges/unmet needs of families and service organizations

- Financial costs
- Lack of support
- Rurality
- Lack of available services
- Respite
- Finding and navigating services
- Lack of training

Stakeholder recommendations

- Improve funding
- Increase respite care
- Increase education and training
- Increase overall services available
- Foster outreach and awareness

Veterans' groups: have special needs related to coordinated services with the VA, particularly challenging in rural ND

American Indian Tribes: coordinating services between Tribal and state programs is a challenge. Support to family caregivers should be provided in a culturally sensitive way.

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Best Practices & Emerging Practice Models

- Aims 3 & 4. Identify best practice models for family caregiver support programs from other states, and emerging practices/technology that can enhance family caregiver support.
 - Extensive review of research literature and practice sites

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Best Practices for Family Caregiver Support Programs

BEST	
Availability of Help / Support	<ul style="list-style-type: none"> Telephone-based psycho-educational interventions Virtual care Community nurses
Financial cost of care / Funding	<ul style="list-style-type: none"> Sliding scales and vouchers Increasing access to paid family medical leave Long-term care planning
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> Interactive training (e.g. role playing) Comprehensive discharge planning Long-term education programming Preventative care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> In-home care Health education programs

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Emerging Practices & Technology to Enhance Caregiver Supports

EMERGING	
Availability of Help / Support	<ul style="list-style-type: none"> Person-centered care (i.e., Money Follows the Person) Mobile adult day care (i.e., especially in rural areas) Working with college students Technology (i.e., smart homes, robotic applications, etc.) Socially Assistive Robots Smart Wear
Financial cost of care / Funding	<ul style="list-style-type: none"> Telemedicine reduced hospitalization Co-op models Tax credits for caregiving
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> Home visits upon discharge Virtual learning modules in hospital waiting rooms Use social media to increase awareness Trainings for employers about eldercare Mobile apps for long distance care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> Online emotional support groups Employ Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module to detect caregiver burden

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Best and Emerging Practice Challenges

Challenges	
Logistics and Implementation	Limitations and Caveats
<ul style="list-style-type: none"> Balancing the needs of care recipient and caregiver Increasing costs Staffing shortage Rurality 	<ul style="list-style-type: none"> Budget Cuts Lack of flexibility in federal programs (i.e. Medicare) Lack time to learn and implement technologies

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Caregiver Best & Emerging Practices: Key Conclusions

- Service coordination and collaboration is essential
- Technology offers opportunities
- Training is critical

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Study Recommendations

- Aim 5: Provide recommendations for best practices for community and technology supports, policy needs, and top priorities for family caregiver supports and services.


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Research Conclusions & Recommendations

Conclusions	Recommendations
The high costs of care and lack of funding for services to support caregiving prove enormously challenging for North Dakota caregivers.	Improve avenues for sustainable funding for family caregivers and programs that support them
Both caregivers and stakeholders clearly indicated that insufficient access to respite care is one of the most salient gaps in the services provided to North Dakota family caregivers.	Increase access to respite care across the state
Caregivers reported difficulty finding, connecting to, and navigating available services and resources.	Improve outreach (i.e., marketing) and resources (i.e., technology) to help family caregivers find, connect to, and navigate available services
Family caregivers lacked training related to the logistics and management of caregiving, including the provision of support in activities of daily living.	Create programs and policies to foster an increase in the training and education of both informal and professional caregivers
Both caregivers and stakeholders reported the challenge of lack of available and appropriate services especially in rural regions.	Close the gaps in caregiver support services in rural areas

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Final Report of Study



www.ag.ndsu.edu/aging/posts/nd-family-caregiver-supports-and-services-study
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Acknowledgements:

<p><u>Study funded by:</u> North Dakota Legislature Management</p>	<p><u>Data Sources:</u> AARP – ND Family Caregiver Support Program</p>
<p><u>Graduate Assistants:</u> Dustin Elliott, M.S. Kia Callahan, B.S. Erica Raguse, B.S.</p>	<p><u>Data Collection Support:</u> ND County Social Services ND Aging Services</p>

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Thank you!

Questions?

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HB 1038
Att. 4 1-4-17



North Dakota

January 4, 2017

House Human Services Committee

SUPPORT HB 1038

Josh Askvig

701-989-0129 – jaskvig@aarp.org

Chairman Weisz and members of the House Human Services Committee, for the record my name is Josh Askvig and I am the State Director for AARP North Dakota. Thank you for the opportunity to provide comments in **SUPPORT of HB 1038**- the Family Caregiver supports bill.

Dr. Ethel Percy Andrus, a retired educator and AARP's founder, became an activist in the 1940s when she found a retired teacher living in a chicken coop because she could afford nothing else. Dr. Andrus couldn't ignore the need for health and financial security in America and set the wheels in motion for what would become AARP. We are a nonprofit, nonpartisan membership organization with more than 87,000 members in North Dakota and 38 million nationwide. We help people turn their goals and dreams into 'Real Possibilities' by changing the way America defines aging, including here in North Dakota.

AARP has been raising the profile of family caregivers in North Dakota and across the country. Through our research we know that there are approximately **62,100 individual caregivers in North Dakota that provide over 58 million hours of uncompensated care valued at over \$860 million.** In recent years, the role of family caregivers has greatly expanded from coordinating and providing personal care and household chores to include medical or nursing tasks such as wound care and injections. For the individuals doing this work in North Dakota it is a labor of love, but it comes with stress, burnout and often times at a cost to their own health and financial stability. Providing support for these caregivers is critical toward ensuring that individuals can safely stay in their homes as they age. Our loved ones can remain independent at home with caregiver support.

As part of our efforts to show the unrecognized work that family caregivers do in North Dakota, we have been collecting stories of caregivers here in North Dakota. The stories and information we collected during the Interim was shared with Dr. Jane

Strommen's team and helped inform the "North Dakota Family Caregiver Supports Study" (hereafter NDSU Study). Before we get into the specifics of the bill, I wanted to draw your attention to one of the attachments to my testimony. It is entitled "Voices of North Dakota Caregivers - What they do might surprise you." It highlights some of the real stories of struggles caregivers face, while ensuring their loved ones can remain independent and safe at home. They do this while saving the state millions in healthcare and support costs. One particularly touching story is from a caregiver in one of our rural communities in North Dakota. This story comes from Mr. Larry Hinderer from Carson. Larry takes care of his wife with multiple sclerosis, every day, 24 hours a day. He does the cooking, bathing, and other necessary tasks that allow Larry and his wife to stay at home rather than move away from their homestead. It's a tough job, but for Larry and the other 62,100 North Dakota caregivers, it's a labor of love.

Larry's story is one of many in North Dakota. As you read through the book you will see these individuals want to assist their loved ones stay safe and stay at home. Now, our North Dakota caregivers need your support of the NDSU Study recommendations to get the tools they need to stay on the job, saving the State of North Dakota money in the short-term and over time. The Study makes some excellent recommendations. Dr. Jane Strommen and her team of Dr. Gregory Sanders and Dr. Heather Fuller at North Dakota State University did a fantastic job and we support the proposals in the NDSU Study.

We would love to have all of the recommendations highlighted in their study completed today, but we are realistic in knowing that it will take some time for them to be fleshed out, considered and then put into action. We are excited about HB1038 as an important step in ensuring family caregivers get the assistance they need to stay on the job.

Family Caregiver Training (Section 1)-

One of the key conclusions from the NDSU study was that "Family caregivers lacked training related to the logistics and management of caregiving, including the provision of support in activities of daily living. The NDSU Study specifically recommended the need to enhance and increase training for caregivers. Section 1 of the bill aims to build on a known successful caregiving training program. *Powerful Tools for Caregivers* is designed to help family caregivers address these issues. However, the current funding for the program limits the scope of where they can provide the training. We know that family caregivers who complete a training program are far less likely to suffer from burnout, they have reduced stress, and are better equipped to help their loved ones remain at home, safely and independently. We support the funding in this section to ensure that ALL North Dakota Caregivers have access to this model training program.

Lifespan Respite Care Program (Section 2)-

One of the top concerns raised by caregivers and stakeholders during the NDSU Study

was the need for more respite for caregivers. North Dakota currently has the Family Caregiver Respite Program, but we can and should do more. The NDSU researchers found that North Dakota may be eligible for an additional federal grant from the Lifespan Respite Care Program. This grant program would allow the state to expand and enhance respite services in North Dakota. Additionally, it would allow us to streamline access and improve coordination of respite services. Last, it would assist in improving the quality of respite care services and filling in gaps where necessary. We are excited to see its inclusion in Section 2 of HB 1038, which ensures the ND Department of Human Services (DHS) will apply for the grant and, if successful, can put the funding toward its intended use.

Aging and Disability Resource Link (ADRL) improvements (Section 3)-

The NDSU Study highlighted the confusion and frustration caregivers face in finding and accessing services for their loved ones or themselves. In fact, just behind the financial cost of care, this was the biggest challenge identified by family caregivers in the research. Under the recommendation "Improve resources to help family caregivers find, connect to, and navigate available services," there are three proposed strategies. They include identifying marketing and communication strategies to promote the existing ADRL, creating a caregiver resource center within the ADRL to increase access to existing programs and services, and creating a comprehensive guide to caregiving for North Dakota caregivers. This bill takes the first step in addressing those recommendations by ensuring the Department of Human Services creates a Caregiver Resource Center within the existing ADRL (section 3 of the bill). In meetings and conversations with DHS, we understand they can do this without an additional appropriation, which is probably music to your ears and we are excited to see the work progress. However, we would be remiss if we didn't ask that you consider adding funding in this bill to ensure that once created by DHS, that they have the ability to ensure North Dakotans know about the ADRL and the assistance it can provide in aiding family caregivers help their loved ones. Promoting the regional ADRL toll-free numbers for aging and disability resources should be prioritized.

SPED sliding fee schedule (section 4)-

Specifically, the sliding fee schedule for state-funded Service Payments for the Elderly and Disabled (SPED) has not been adjusted since 2009. Having these fee schedules "frozen" for over eight years means many individuals who have had small cost-of-living adjustments in their Social Security benefits are actually falling behind. They are now being charged above what their actual income can support for needed services due to these schedules not keeping up with inflation. Individuals are not utilizing these services because of the fee schedule, which means the full workload falls on caregivers contributing to their burnout and stress. The fee schedule should be updated and then the schedule should be indexed with an automatic inflator so it does not fall behind again. Adjusting the schedule will ensure individuals needing SPED

supports can remain independent at home and assist caregivers in knowing their loved ones are getting needed services at an affordable rate. We fully support Section 4 to ensure that family caregivers can line up assistance from professionals when the care they are providing goes beyond their ability to provide the care necessary for a loved to remain independent at home.

Home- and Community-Based Service Funding (Section 5)-

Last, we wanted to take a moment to note that North Dakota continues to have a significant imbalance in the funding it provides for individuals to get services and supports in a home setting versus an institutional setting. While we commend the department for the steps they have made toward balancing that effort, we believe there is more that could and should be done. According to the *Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (see attachment), North Dakota ranks last out of the 50 states and District of Columbia when it comes to the “percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities.” This study indicator shows how a state’s Medicaid spending is used to provide supports for older individuals. Being in last place is never a positive rating. According to the report, North Dakota spent only 14.5% of its budget on HCBS for long term care supports based on 2014 data. This finding is a root cause of many of the issues highlighted in the NDSU Study. Consumer confusion and frustration about ADRL services, high costs of care, an underfunded respite care program - all of these are direct results of the state imbalance of its dollars towards institutional care instead of home- and community-based services.

It’s imperative that the 2017-19 Legislature look at moving toward a more balanced approach in how we fund and support individuals living independently. The language in this bill directs DHS to make recommendations on how to best restructure our funding model regarding long term services and supports. The state should also take advantage of technical assistance offered with the Money Follows the Person Demonstration and look to lessons learned or best practices from other states to help with the state’s rebalancing plan.

Chairman Weisz and Members of the Committee, we appreciate your thorough consideration of family caregiver support bills this session. We want to thank the Interim Human Service Committee members for the work they started on this important issue. The NDSU Study is a great roadmap of how North Dakota can build upon its foundation of caregiver support. As we have said - and as Larry says in his story - North Dakotans want to stay at home as they age. Again, we appreciate the opportunity to provide comments. **We fully support HB1038 and recommend a DO PASS from this committee.**

HB 1038 #5
1-4-17



The COMMONWEALTH FUND



North Dakota: 2014 State Long-Term Services and Supports Scorecard Results

Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers takes a multi-dimensional approach to measure state-level performance of long-term services and supports (LTSS) systems that assist older people, adults with disabilities, and family caregivers. The full report is available at www.longtermscorecard.org

Purpose: The *Scorecard* measures system performance from the viewpoint of service users and their families. It is designed to help states improve the performance of their LTSS systems so that older people and adults with disabilities in *all* states can exercise choice and control over their lives, thereby maximizing their independence and well-being. State policymakers often control key indicators measured, and they can influence others through oversight activities and incentives.

Results: The *Scorecard* examines state performance, both overall and along five key dimensions. Each dimension comprises 3 to 6 data indicators, for a total of 26. It also measures changes in performance since the first *Scorecard* (2011), wherever possible (on 19 of the 26 indicators). The table below summarizes current performance and change in performance at the dimension level. State ranks on each indicator appear on the next page.

Dimension	Rank	Number of indicators with trend *	Number of indicators showing: **		
			Substantial improvement	Little or no change	Substantial decline
OVERALL	33	19	7	8	4
Affordability & Access	48	6	2	3	1
Choice of Setting & Provider	34	4	4	0	0
Quality of Care & Quality of Life	3	4	1	1	2
Support for Family Caregivers	27	3	0	2	1
Effective Transitions	29	2	0	2	0

* Trend cannot be shown if data are missing for either the current or baseline data year. In each state, 16 to 19 indicators have enough data to calculate a trend. ** See full report for how change is defined.

Impact of Improved Performance: If North Dakota improved its performance to the level of the highest performing state:

- 3,502 more low/moderate-income adults with ADL disabilities would be covered by Medicaid.
- 774 more new users of Medicaid LTSS would first receive services in the community.
- 774 nursing home residents with low care needs would instead receive LTSS in the community.
- 328 more people entering nursing homes would be able to return to the community within 100 days.
- 650 more people who have been in a nursing home for 90 days or more would be able to move back to the community.

North Dakota: 2014 State Long-Term Services and Supports Scorecard Dimension and Indicator Data

Dimension and Indicator (Current Data Year)	Baseline Rate	Current Rate	Rank	Change	All States Median	Top State Rate
OVERALL RANK			33			
Affordability and Access			48			
Median annual nursing home private pay cost as a percentage of median household income age 65+ (2013)	233%	249%	33	↔	234%	168%
Median annual home care private pay cost as a percentage of median household income age 65+ (2013)	113%	103%	50	↔	84%	47%
Private long-term care insurance policies in effect per 1,000 population age 40+ (2011)	107	102	5	↔	44	130
Percent of adults age 21+ with ADL disability at or below 250% of poverty receiving Medicaid or other government assistance health insurance (2011-12)	53.6%	46.1%	48	✖	51.4%	78.1%
Medicaid LTSS participant years per 100 adults age 21+ with ADL disability in nursing homes or at/below 250% poverty in the community (2009)	34.1	40.4	25	✓	42.3	85.2
ADRC functions (composite indicator, scale 0-70) (2012)	**	42	42	✓	54	67
Choice of Setting and Provider			34			
Percent of Medicaid and state LTSS spending going to HCBS for older people & adults w/ physical disabilities (2011)	10.7%	14.5%	51	✓	31.4%	65.4%
Percent of new Medicaid aged/disabled LTSS users first receiving services in the community (2009)	31.1%	35.7%	36	✓	50.7%	81.9%
Number of people participant-directing services per 1,000 adults age 18+ with disabilities (2013)	*	10.5	22	*	8.8	127.3
Home health and personal care aides per 1,000 population age 65+ (2010-12)	20	31	29	✓	33	76
Assisted living and residential care units per 1,000 population age 65+ (2012-13)	37	45	7	✓	27	125
Quality of Life and Quality of Care			3			
Percent of adults age 18+ with disabilities in the community usually or always getting needed support (2010)	71.9%	72.9%	23	↔	71.8%	79.1%
Percent of adults age 18+ with disabilities in the community satisfied or very satisfied with life (2010)	91.0%	89.5%	5	✖	86.7%	92.1%
Rate of employment for adults with ADL disability ages 18–64 relative to rate of employment for adults without ADL disability ages 18–64 (2011-12)	44.4%	30.2%	7	✖	23.4%	37.2%
Percent of high-risk nursing home residents with pressure sores (2013)	*	4.4%	4	*	5.9%	3.0%
Nursing home staffing turnover: ratio of employee terminations to the average number of active employees (2010)	33.6%	29.2%	9	✓	38.1%	15.4%
Percent of long-stay nursing home residents who are receiving an antipsychotic medication (2013)	*	18.6%	15	*	20.2%	11.9%
Support for Family Caregivers			27			
Legal and system supports for family caregivers (composite indicator, scale 0-14.5) (2012-13)	**	2.40	33	↔	3.00	8.00
Number of health maintenance tasks able to be delegated to LTSS workers (out of 16 tasks) (2013)	13	13	18	↔	9.5	16
Family caregivers without much worry or stress, with enough time, well-rested (2011-12)	66.2%	61.9%	20	✖	61.6%	72.8%
Effective Transitions			29			
Percent of nursing home residents with low care needs (2010)	16.1%	15.1%	36	↔	11.7%	1.1%
Percent of home health patients with a hospital admission (2012)	*	24.1%	14	*	25.5%	18.9%
Percent of long-stay nursing home residents hospitalized within a six-month period (2010)	13.4%	13.6%	13	↔	18.9%	7.3%
Percent of nursing home residents with moderate to severe dementia with one or more potentially burdensome transitions at end of life (2009)	*	12.9%	8	*	20.3%	7.1%
Percent of new nursing home stays lasting 100 days or more (2009)	*	23.4%	41	*	19.8%	10.3%
Percent of people with 90+ day nursing home stays successfully transitioning back to the community (2009)	*	5.1%	50	*	7.9%	15.8%

* Comparable data not available for baseline and/or current year. Change in performance cannot be calculated without baseline and current data.
 ** Composite measure. Baseline rate is not shown as some components of the measure are only available for the current year. Change in performance is based only on those components with comparable prior data. See page 73 and page 83 in *Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* for more detail. Notes: ADL = Activities of Daily Living; ADRC = Aging and Disability Resource Center; HCBS = Home and Community Based Services; LTSS = Long Term Services and Supports.
 Please refer to Appendix B2 on page 97 in the report for full indicator descriptions, data sources, and other notes about methodology; for baseline data years, please see Exhibit 2 on page 11. The full report is available at www.longtermscorecard.org


Key for Change:	
✓	Performance improvement
↔	Little or no change in performance
✖	Performance decline

HB1038 ATT 6 1-4-17

VOICES OF NORTH DAKOTA FAMILY CAREGIVERS

What they do might surprise you

 I  CaregiversSM

 Real Possibilities



I  CaregiversSM

 Real Possibilities

aarp.org/iheartcaregivers

All images are stock photos.



Table of Contents

Introduction	2
Who Are North Dakota Family Caregivers	3
Hospital Transitions	5
Workplace Flexibility	9
Respite Care	13
Conclusion	16
Recommendations	17



In North Dakota, more than 62,000 family caregivers help parents, spouses, children with disabilities and other loved ones live independently at home.

They provide a wide range of services for their loved ones, including bathing, dressing, transportation, grocery shopping, meal preparation, housework, and managing finances. They often serve as care coordinators, communicating with health professionals and accompanying their loved ones to medical appointments. Family caregivers provide emotional support, too.

Caregiving, once one of the most personal and private family matters, is now becoming a very public issue. Today caregiving for an older relative affects real people in North Dakota from all walks of life from women, men, farmers and business leaders, to teachers, laborers, and lawyers plus many more.

The voices of North Dakota family caregivers matter, and we at AARP are commit-

ted to sharing them for all to hear. When we set out to gather the voices of North Dakota family caregivers, we had no idea what we would uncover. Our goal in creating this publication was to bring together North Dakota caregiver facts, data about caregivers, and most importantly stories and experiences of North Dakota caregivers presented “in their own words” style.

Finally, the last few pages of this booklet contain recommendations to improve family caregiver supports in North Dakota. They have been evaluated by North Dakota State University Extension and the Interim Human Services Committee. We fully support these recommendations and encourage the Governor, Legislature, businesses, and local communities to implement them.

Josh Askvig

*AARP North Dakota
State Director*

Mike Chaussee

*AARP North Dakota
Associate State Director, Advocacy*

WHO ARE NORTH DAKOTA FAMILY CAREGIVERS?

Across North Dakota, family caregivers give their hearts every day, helping their parents, spouses, and other loved ones stay at home.



62,100
family caregivers

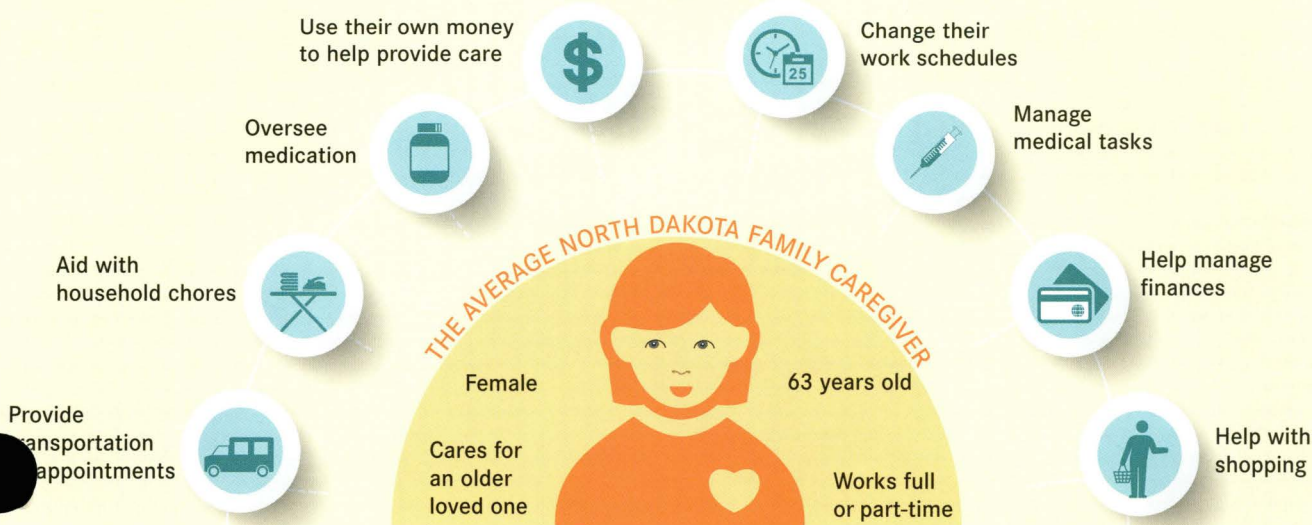


Provide 58 million hours
of unpaid care annually



Estimated at \$860 million
in unpaid care annually

While they wouldn't have it any other way,
family caregivers have a huge job. They:





HOSPITAL TRANSITIONS: When a patient moves from a hospital setting to either home or another care facility.

Despite the vast importance of family caregivers in the individual's day-to-day care, many caregivers find that they are often left out of discussions involving a patient's care while in the hospital and, upon the patient's discharge, receive little to no instruction on the tasks they are expected to perform. The federal Centers for Medicare and Medicaid Services (CMS) estimates that \$17 billion in Medicare funds is spent each year on un-

necessary hospital readmissions. Additionally, hospitals desire to avoid the imposition of new readmission penalties under the federal Patient Protection and Affordable Care Act (ACA).

The following testimonials are just some of the things that the family caregivers of North Dakota are saying about the importance of hospital transitions.

“Caregivers need better training from professionals before sending patients home from (the) hospital.”

—Carol, Bismarck

“(Legislators) should know the difficulty we have in hospital situations to get info about parent's condition and prognosis even with “release info” forms. Many caregivers are surprised to learn that so many additional costs are involved in patient care; so “awareness” should be in media, nursing home pamphlets, etc.”

—Terry, Bismarck

HOSPITAL TRANSITIONS

“Though I did receive directions for my “nursing tasks,” it was a problem because I received conflicting instructions from several persons before we exited the hospital. I believe that careful, consistent, oral, and written directions would have been of great assistance to me. Also, since my largest problem was wound care, if materials were provided for me, or if I were even told where to get them, I would have been better able to care for my husband.”

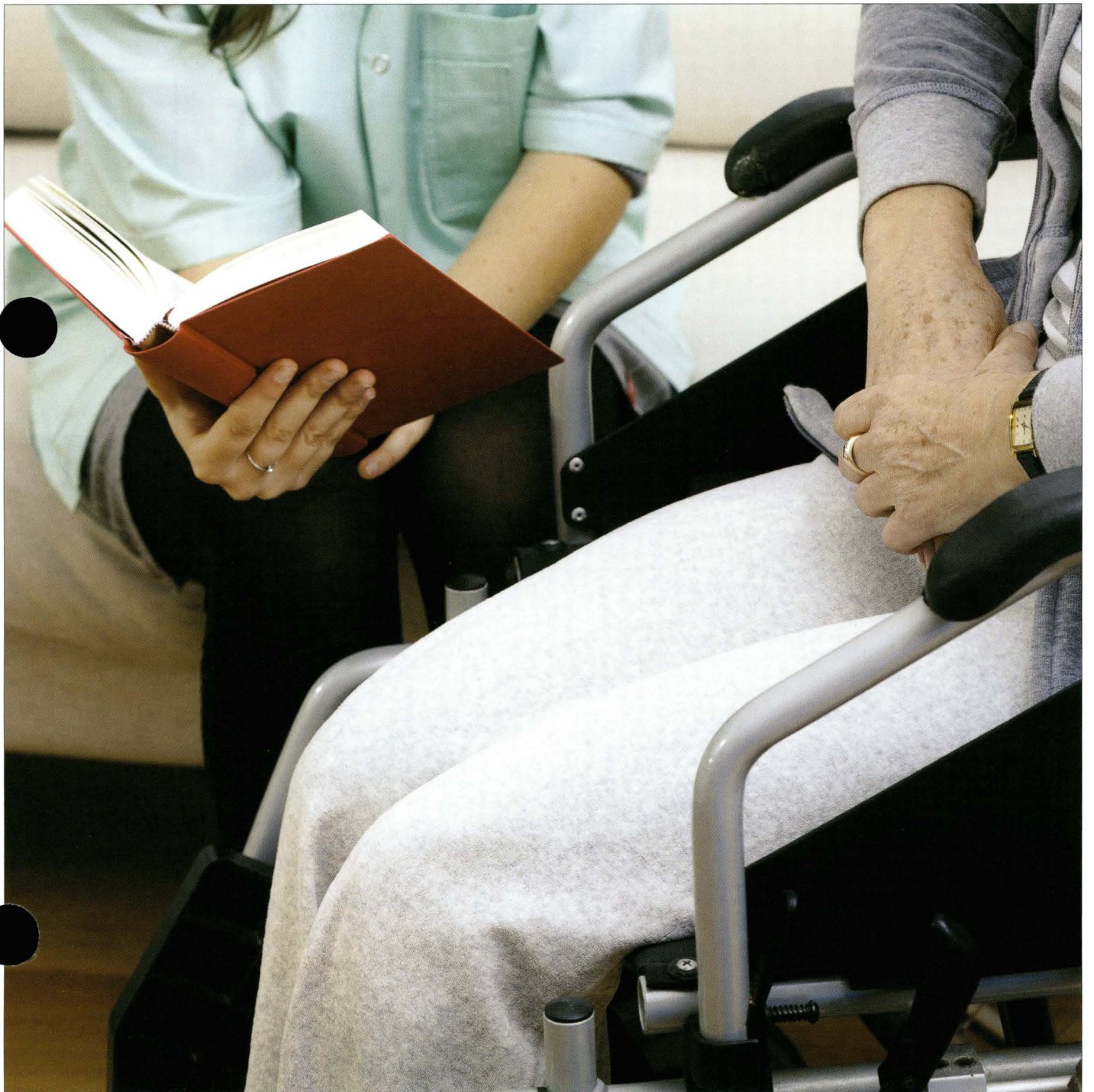
—Marilyn, Mayville

“I was the caregiver for my son while he fought cancer and lost the battle... There were times when I needed more discussion about his care. I didn’t realize that the morphine he was taking would cause some memory loss and confusion.”

—Vel Rae, Fargo

“Doctors need to be more aware of what will happen to patients after they leave the hospital. Will the patient’s needs for nutrition, exercise, socialization, and medical appointments be met? Older people need someone caring and responsible who knows the situation and is willing to do whatever needs to be done to optimize the older person’s quality of life... Cooperation among medical professionals and family members is the key to success, the key to keeping older people in their homes, happy and healthy and enjoying life as much as possible.”

—Janet, Bismarck





WORKPLACE FLEXIBILITY: Workplace policies that allow family caregivers to successfully balance their career and caregiving duties.

Workplace flexibility will help to support family caregivers who work full-time while providing care for their loved ones.

Today, many North Dakota workers have no family leave, or paid or unpaid sick leave through their employers. And, each day, working family caregivers may face the loss of pay or the loss of their jobs. Making expanded leave available for family caregivers will help them manage their caregiving responsibilities without having to choose between their jobs and their loved ones.

Consider that as the population continues to age, more and more adults are finding themselves in caregiving situations. Roughly 20 percent of the American workforce serves as unpaid caregivers. This number is expected to grow as individuals work longer and begin caring for spouses or other family members. So even at a small workplace, chances are a couple of people are family caregivers. 74% of family caregivers have worked at a paying job at

some point during their caregiving experience and 61% are currently employed. So when we talk about “working caregivers,” or caregivers who are employed outside the home, we’re not talking about some subset. We’re talking about the majority of family caregivers. In a recent national survey, one in five retirees left the workforce earlier than planned because of having to care for an ill spouse or other family member. The average length of caregiving is 4.3 years.

A recent Interim Human Services Committee study on family caregivers found that 92% of family caregivers reported having a poor work/life balance as a caregiving challenge. In that same survey, 65% of family caregivers reported unsupportive workplace policies as a challenge.

The following testimonials are just some of the things that the caregivers of North Dakota are saying about the importance of workplace flexibility.

WORKPLACE FLEXIBILITY

“My job has been flexible but my time away requires me to make time up or not get paid. I also help take care of my granddaughter due to my daughter being a nurse. I don’t seem to find time to take care of my own needs.”

—Sherry, Bismarck

“I work full-time and appreciate the flexibility at my job to be able to use sick leave to be at doctor’s appointments, etc. I wish that all working caregivers had this option.”

—Merry, Granville

“I care for my 90-year-old aunt Margaret. She is in assisted living so gets personal care and meals covered. My husband and I assist her to medical appointments, financial paperwork, shopping, and any other tasks that may come up that assisted living cannot provide. We work full-time and it is a challenge to balance all her needs. I enjoy helping her and being there for her. I often wonder if she had not been able to afford expensive costs of assisted living, where would she be?”

—Katie, Bismarck





RESPITE CARE: Temporary relief to family caregivers from their caregiving duties.

Respite care helps to support family caregivers, many who are on call 24 hours a day, seven days a week, by giving them a hard-earned, well-deserved break – allowing them to recharge and continue the essential role they serve in helping their loved ones live safely at home. Family caregivers often put aside their own needs – skipping doctors’ appointments, developing poor eating habits, and not getting enough sleep.

Family caregivers need some relief. National, state, and local surveys have shown

respite care to be the most frequently requested service from family caregivers. Caregivers commonly experience emotional strain and mental health problems, especially depression. Women are more likely to have experienced stress and worry than men. Similarly, women were less likely to feel as if they had enough time and feel well-rested than men.

The following testimonials are just some of the things that the caregivers of North Dakota are saying about the importance of respite care.

“The most rewarding part of my 24/7 caregiving job is knowing my husband can stay with me in our home and can be well taken care of. No one knows the obstacles facing handicapped people until they are involved in the care of someone. I could write a book on things that could improve his life and mine. We would be willing to help anyone who would like to visit with us about this. I am glad I can care for my husband. It would be nice to have a little more time for myself without worrying about him.”

—Donna, Velva

RESPIRE CARE

"I lost my dad four months ago, and my mom doesn't have much time left. I cherish the time I have. It is very difficult because I work FT (full-time) and PT (part-time) and I take care of my granddaughter two nights a week."

—Mary, Bismarck

"I'm solo caregiving 24/7, it's a full-time job. I haven't had a break now for about 15 years."

—Larry, Carson

"Forty-eight years ago when I promised my husband I would 'have and hold' him 'in sickness and health,' I had no idea that his sickness would destroy my health. Five years ago he was diagnosed with dementia that was so limiting that someone has to watch over him 24/7... A little more help from North Dakota would have made such a difference in our lives."

—Pat, West Fargo



CONCLUSION:

AARP North Dakota believes the words of family caregivers help tell the story.

These testimonials combined with the research done by the North Dakota State University Extension entitled the *North Dakota Family Caregiver Supports and Services Study* show the need to make improvements to family caregiver supports in North Dakota.

A couple of highlights from the research:

- > Roughly 50% of our state's family caregivers performing medical or nursing tasks do not get the appropriate instruction or training to perform these tasks.
- > North Dakota family caregivers struggle to find assistance to get the breaks (respite care) they need to alleviate burn-out.
- > Family caregivers in North Dakota are unaware of the services and supports available for their loved one or themselves.
- > Even when they learn about the services, navigating the complex web of supports, programs, and information is confusing. Even the researchers with advanced education said they found it difficult to navigate the existing information sites and materials.
- > Working North Dakota family caregivers struggle to find an appropriate work and life balance.

* Full report can be found at: <https://www.ag.ndsu.edu/aging/documents/nd-family-caregiver-supports-and-services-study>.

RECOMMENDATIONS to Support Family Caregivers.

The report outlines five categories of recommendations to improve family caregiver supports in North Dakota.

1. Create programs and policies to foster an increase in the training and education of both informal and professional caregivers. (This recommendation includes the need to provide in-person instruction about medical/nursing tasks that the caregiver will need to provide at home.)
2. Increase access to respite care across the state.
3. Improve outreach (i.e. marketing) and resources (i.e. technology) to help family caregivers find, connect to, and navigate available services.
4. Close the gaps in caregiver support services in rural areas.
5. Improve avenues for sustainable funding for family caregivers and programs that support them.

These recommendations speak to the issues outlined above. We look forward to working to pass legislation and implement policies that improve the lives of family caregivers and their loved ones in North Dakota.

Read more stories from
North Dakota family caregivers,
or share your own.

aarp.org/iheartcaregivers

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www.aarp.org/nd

AARP Real Possibilities in

North Dakota

 AARPND

 @AARP_ND

HB 1038 #7
1-4-17

North Dakota

Assisted Living Facility Monthly Rates (One Bedroom - Single Occupancy)

Region	Minimum	Rate Range Median	Maximum	Median Annual Rate ¹	Five-Year Annual Growth ²
USA	\$600	\$3,600	\$11,250	\$43,200	2%
North Dakota - Whole State	\$959	\$3,239	\$5,250	\$38,865	3%
Bismarck	\$1,050	\$3,418	\$4,025	\$41,010	6%
Fargo	\$2,051	\$3,625	\$4,600	\$43,500	10%
Grand Forks	\$1,181	\$2,865	\$5,250	\$34,374	-7%
North Dakota - Rest of State	\$959	\$3,474	\$4,602	\$41,682	3%

Nursing Home Daily Rates (Semi-Private Room)

Region	Minimum	Rate Range Median	Maximum	Median Annual Rate ¹	Five-Year Annual Growth ²
USA	\$90	\$220	\$1,255	\$80,300	4%
North Dakota - Whole State	\$155	\$275	\$407	\$100,375	8%
Bismarck	\$190	\$273	\$391	\$99,601	5%
Fargo	\$180	\$263	\$384	\$96,141	9%
Grand Forks	\$155	\$276	\$363	\$100,663	10%
North Dakota - Rest of State	\$170	\$273	\$407	\$99,463	9%

Nursing Home Daily Rates (Private Room)

Region	Minimum	Rate Range Median	Maximum	Median Annual Rate ¹	Five-Year Annual Growth ²
USA	\$101	\$250	\$1,255	\$91,250	4%
North Dakota - Whole State	\$169	\$288	\$407	\$104,938	7%
Bismarck	\$195	\$279	\$399	\$101,791	5%
Fargo	\$263	\$287	\$384	\$104,755	9%
Grand Forks	\$167	\$286	\$378	\$104,313	11%
North Dakota - Rest of State	\$182	\$290	\$407	\$105,704	7%

North Dakota

Homemaker Services Hourly Rates

Region	Minimum	Rate Range Median	Maximum	Median Annual Rate ¹	Five-Year Annual Growth ²
USA	\$8	\$20	\$40	\$44,616	2%
North Dakota - Whole State	\$18	\$26	\$30	\$59,854	4%
Bismarck	\$25	\$25	\$25	\$57,200	N/A
Fargo	\$18	\$24	\$29	\$54,912	2%
Grand Forks	\$27	\$27	\$27	\$62,142	4%
North Dakota - Rest of State	\$30	\$30	\$30	\$68,640	7%

Home Health Aide Services Hourly Rates

Region	Minimum	Rate Range Median	Maximum	Median Annual Rate ¹	Five-Year Annual Growth ²
USA	\$8	\$20	\$40	\$45,760	1%
North Dakota - Whole State	\$18	\$27	\$30	\$62,142	4%
Bismarck	\$25	\$25	\$25	\$57,200	N/A
Fargo	\$18	\$24	\$29	\$54,912	2%
Grand Forks	\$27	\$27	\$27	\$62,142	4%
North Dakota - Rest of State	\$30	\$30	\$30	\$68,640	7%

Adult Day Health Care Daily Rates

Region	Minimum	Rate Range Median	Maximum	Median Annual Rate ¹	Five-Year Annual Growth ²
USA	\$10	\$69	\$242	\$17,904	3%
North Dakota - Whole State	\$42	\$75	\$135	\$19,562	6%
Bismarck	\$75	\$75	\$75	\$19,562	6%
Fargo	\$42	\$42	\$42	\$10,920	1%
Grand Forks	\$70	\$70	\$70	\$18,200	9%
North Dakota - Rest of State	\$60	\$75	\$135	\$19,609	-1%

Testimony on HB 1038 and 1039
House Human Services Committee
1/4/2017
Ellen Schafer
815 Munich Drive
Bismarck, North Dakota 58504
701-400-7691

My name is Ellen Schafer and I am a volunteer for AARP. I am here today in support of the Caregiver Act that would ensure that family caregivers are kept informed, provided explanations, and education for tasks the caregiver will be required to provide at home after a loved one is discharged from the hospital. I feel it is very important that family caregivers be able to appropriately perform tasks for their loved ones before they are discharged from a hospital. In the hospital, nurses have 24 hours to ensure that a family member knows how to adequately perform tasks such as monitoring and adjusting one's diabetic medications according to one's glucose results, pain medications, pain pumps, wound care, or caring for a colostomy appliance, or even help with setting up ones medications. This initial education process should begin in the hospital. Learning these cares can often be overwhelming to someone who does not have a medical background. Once a patient is home from the hospital, home health nurses have limited hours in one's home. Usually a home health care visit consists of 3 hours a week for several weeks where they could reinforce the education learned in a hospital and help the patient monitor and adapt care learned from a hospital to one's home environment setting.

I am in support of increased access to respite care to support family caregivers. Family caregivers in North Dakota don't ask for much. They take on huge responsibilities that can be overwhelming, stressful, and exhausting to care for their older parents, spouses, adults and children with disabilities and other loved ones. They do it without compensation and they do it in the patient's home, where an overwhelming number of North Dakotans say they want to remain as long as possible. These dedicated family caregivers need your support. More than 62,000 North Dakotans identify themselves as family caregivers. By caring for their loved ones in their homes, they save the state more than \$860 million by keeping them out of taxpayer-funded nursing homes and from returning to hospital emergency rooms. Caregivers provide care to their loved ones 24 hours a day 7 days a week and often go without a break when no other family members are available. National state and local surveys have shown respite care to be the most frequently

requested service from family caregivers. If one is able to receive help with respite care, they return refreshed and will be able to adequately provide the care their loved ones require.

I would like to share my experience with caring for my mom. Under the family medical leave act, I was able to take 3 months away from my job as a nurse to care for my mom who was dying from cancer. I was more than honored to be able to provide the care my mom needed so that she could stay in her own home. As my mom's disease progressed, I had little relief from my siblings who were not either financially able to take time away from their jobs or they lived over 100 miles from my mom. As my mom grew weaker, I slept on the floor by her side so that if she was up during the night I would hear her moving about and I did not want her to get up and fall. In doing this, I could help her with whatever her needs might have been. I distinctly remember the morning before my mom died. It was about 4am and I was trying to catch a few winks at her feet. It amazed me how little sleep she needed during this time and I was exhausted. My mom sat up and was sitting on the couch. I recall her exact words, "Ellen why won't you sit up and talk to me," and I recall my exact answer to her, "Oh Mom I am so tired." Had I known that these were almost the last words with my mom I would have gladly sat up and talked to her. I recall mom's words too, "Ellen is it supposed to hurt this bad," and I said "no mom" and contacted a hospice nurse to come and start a morphine drip right away. Fortunately for my mom, I was a nurse and knew the medical system and could get her the help she needed. Not every family is fortunate to have a nurse in their family to help care for their loved ones.

HB 1038
1
3/8
Pg. 1

TESTIMONY
Senate Human Services Committee
HB 1038
March 8, 2017
Representative Kathy Hogan

Chairman Lee and members of the Senate Human Service Committee, my name is Kathy Hogan, and I represent District 21 the heart of Fargo. This morning I am supporting an interim committee bill that was the result of the Family Support Study that was done through the Interim Human Service Committee.

In 2013, over 62,000 family caregivers provided 58 million hours of unpaid care valued at \$860 million in North Dakota. These caregivers are spouses, adult children, other family members, neighbors, and friends. Family caregivers provide a range of daily activities such as; transportation, personal care, cooking, managing finances, grocery shopping, and much more. Support North Dakota's family caregivers and bridge the gaps where they may be struggling, is good public policy.

There was a comprehensive study done by the ND Extension services of the current resources, the unmet needs and recommendations for policy and program changes. This study is available on line in the legislative management report from the Interim Human Service Committee.

The study made five broad recommendations.

1. The need to maintain a focus on family caregiver needs as ND's population ages.
2. Sustain and enhance funding for programs that support family caregivers, such as homemakers, respite care.
3. Improve information for family care givers so that they may access current resource
4. Improve training for both caregivers and professions on the family caregiver role
5. Improve family care giver supports, particularly in rural areas.

1038
#1
3/8
Pg. 2

HB 1038 originally provided three appropriation requests:

1. Provides one-time funding of \$197,000 to establish a pilot project to expand local training programs to train family caregiver,
2. Allows access to federal funds for a Lifespan Respite Care Program,
3. The bill also directs DHS to establish and promote a caregiver resource center website without any funding
4. Provides an inflationary adjustment to the SPED sliding fee schedule which haven't been adjusted since 2009.

I have attached a copy of the original bill for your information

Original Section 1 Not included in the revised bill

Original Section 2 Became Section 1

Original Section 3 Became Section 2

Original Section 4 No included in the revised bil

Original Section 5 Became Section 3

Thank you Madam Chair and I would be more than willing to answer any questions.

HB 1038
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3/8
Pg. 1

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Sixty-fifth
Legislative Assembly
of North Dakota

HOUSE BILL NO. 1038

Introduced by

Legislative Management

(Human Services Committee)

1 A BILL for an Act to provide appropriations to the North Dakota state university extension
2 service and to the department of human services; to provide for the establishment of a
3 caregiver resource center website; and to provide for a report.

4 **BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

5 **SECTION 1. APPROPRIATION - NORTH DAKOTA STATE UNIVERSITY EXTENSION**
6 **SERVICE - PILOT PROJECT FOR CAREGIVER TRAINING.** There is appropriated out of any
7 moneys in the general fund in the state treasury, not otherwise appropriated, the sum of
8 \$197,580, or so much of the sum as may be necessary, to the North Dakota state university
9 extension service for the purpose of establishing a pilot project to expand local training
10 programs to include family caregiver training, for the biennium beginning July 1, 2017, and
11 ending June 30, 2019. The funding provided in this section is considered a one-time funding
12 item.

13 **SECTION 2. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - LIFESPAN**
14 **RESPITE CARE PROGRAM.** There is appropriated from special funds derived from federal
15 funds and other income, the sum of \$200,000, or so much of the sum as may be necessary, to
16 the department of human services for the purpose of administering a lifespan respite care
17 program, including public information about the program, for the biennium beginning July 1,
18 2017, and ending June 30, 2019.

19 **SECTION 3. DEPARTMENT OF HUMAN SERVICES - CAREGIVER RESOURCE**
20 **CENTER WEBSITE.** The department of human services shall establish and promote a
21 caregiver resource center website for the biennium beginning July 1, 2017, and ending June 30,
22 2019.

23 **SECTION 4. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - SERVICE**
24 **PAYMENTS FOR ELDERLY AND DISABLED SLIDING FEE SCALE.** There is appropriated out

1038
#1a
3/2
Pg. 2

Sixty-fifth
Legislative Assembly

1 of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of
2 \$1,535,000, or so much of the sum as may be necessary, to the department of human services
3 for the purpose of providing an inflationary adjustment to the service payments for elderly and
4 disabled program sliding fee schedule be commensurate with provider inflationary increases
5 since 2009, for the biennium beginning July 1, 2017, and ending June 30, 2019.

6 **SECTION 5. DEPARTMENT OF HUMAN SERVICES - LONG-TERM CARE SERVICES -**
7 **REPORT TO LEGISLATIVE MANAGEMENT.** The department of human services shall review
8 services and related funding provided within its long-term care division for the 2015-17 and
9 2017-19 bienniums. The department of human services shall report to the legislative
10 management during the 2017-18 interim on the levels of funding provided for and spent on
11 nursing home services and home- and community-based services by program during these time
12 periods and shall provide recommendations on options to increase the number and level of
13 services and funding provided for home- and community-based services for the 2019-21
14 biennium.

HB 1038
#2
3/8
Pg. 1



Real Possibilities in

North Dakota

March 8, 2017

Senate Human Services Committee

SUPPORT HB 1038

Mike Chaussee – AARP North Dakota

mchaussee@aarp.org, (701) 390-0161

Chairman Lee and members of the Senate Human Services Committee, I am Mike Chaussee with AARP North Dakota. Thank you for the opportunity to provide comments in **SUPPORT of HB 1038** – or as we call it, the Family Caregiver supports bill.

Dr. Ethel Percy Andrus, a retired educator and AARP's founder, became an activist in the 1940s when she found a retired teacher living in a chicken coop because she could afford nothing else. Dr. Andrus couldn't ignore the need for health and financial security in America and set the wheels in motion for what would become AARP. We are a nonprofit, nonpartisan membership organization with more than 87,000 members in North Dakota and 38 million nationwide. We help people turn their goals and dreams into 'Real Possibilities' by changing the way America defines aging, including here in North Dakota.

AARP has been raising the profile of family caregivers in North Dakota and across the country. Through our research we know that there are approximately **62,100 individual caregivers in North Dakota that provide over 58 million hours of uncompensated care valued at over \$860 million.** In recent years, the role of family caregivers has greatly expanded. It now includes coordinating and providing personal care and household chores as well as completing medical or nursing tasks such as wound care and injections. In a recent study of nearly 1,000 North Dakotans 45-years-old and older – AARP found that nearly half of people surveyed (47%) say they are currently acting or have previously acted as an uncompensated family caregiver. Of those, 64-percent say they oversee medication management and 61-percent are responsible for other nursing tasks. And they're performing those duties regularly, most often, according to the survey, they're doing that work daily.

For the individuals doing this work in North Dakota it is a labor of love, but it comes with stress, burnout and often times at a cost to their own health and financial stability.

1038
#2
3/8
Pg. 2

According to findings from the same study, 60-percent of current and former family caregivers in North Dakota feel stressed out. About half of them say it's hard to get rest, a third don't get the exercise they need and more than a quarter say they are financially strained because of the caregiving work (see attached documents for additional information). To shed a little more light on the financial stress put on family caregivers, AARP took on a national research effort. In that study (results also attached) AARP found average out-of-pocket expenses run nearly \$7,000 for uncompensated caregivers.

Providing support for these caregivers is critical toward ensuring that individuals can safely stay in their homes as they age, something North Dakotans believe is important. In fact, 70-percent of the people we talked to believe living independently at home, with caregiver assistance, is the ideal situation when basic tasks become difficult.

As part of our efforts to show the unrecognized work that family caregivers do in North Dakota, we have also been collecting stories of caregivers here in North Dakota. The stories and information we collected during the Interim was shared with Dr. Jane Strommen's team and helped inform the "North Dakota Family Caregiver Supports Study" (hereafter NDSU Study). One particularly touching story is from a caregiver in one of our rural communities in North Dakota. Mr. Larry Hinderer from Carson takes care of his wife, who has multiple sclerosis. He told us he provides care for her 24 hours a day, seven days a week. He does the cooking, bathing, and other necessary tasks that allow both of them to stay at home. When we asked him how long he's been at it, he said he hasn't had a break in 15 years.

Larry, and North Dakotas other family caregivers need our support. The NDSU Study makes some excellent recommendations on how to keep family caregivers on the job. Dr. Jane Strommen and her team of Dr. Gregory Sanders and Dr. Heather Fuller at North Dakota State University did a fantastic job and we support the proposals in the NDSU Study.

We would love to have all of the recommendations highlighted in their study completed today, but we are realistic in knowing that it will take some time for them to be fleshed out, considered and then put into action. We believe **HB1038** is an important first step in ensuring family caregivers get the assistance they need.

Lifespan Respite Care Program (Section 1)

One of the top concerns raised by caregivers and stakeholders during the NDSU Study was the need for more respite for caregivers. That concern also showed up in the

1038
#2
3/8
Pg.3

AARP research done in December, 2016 (cited earlier). According to that study, more than 90-percent of people agree respite care support is important. North Dakota currently has the Family Caregiver Respite Program, but we can and should do more. The NDSU researchers found that North Dakota may be eligible for an additional federal grant (up to \$200,000) from the Lifespan Respite Care Program. This grant program would allow the state to expand and enhance respite services in North Dakota. Additionally, it would allow us to streamline access and improve coordination of respite services. Last, it would assist in improving the quality of respite care services and filling in gaps where necessary. According to the U.S. Department of Health and Human Services, 35 states and the District of Columbia have taken advantage of this grant.

Aging and Disability Resource Link (ADRL) improvements (Section 2)

The NDSU Study highlighted the confusion and frustration caregivers face in finding and accessing services for their loved ones or themselves. In fact, just behind the financial cost of care, this was the biggest challenge identified by family caregivers in the research. Under the recommendation, "Improve resources to help family caregivers find, connect to, and navigate available services," there are three proposed strategies. They include identifying marketing and communication strategies to promote the existing ADRL, creating a caregiver resource center within the ADRL to increase access to existing programs and services, and creating a comprehensive guide to caregiving for North Dakota caregivers. This bill takes the first step in addressing those recommendations by ensuring the Department of Human Services creates a Caregiver Resource Center within the existing ADRL. In meetings and conversations with DHS, we understand they can do this without an additional appropriation, which is probably music to your ears and we are excited to see the work progress. Promoting the regional ADRL toll-free numbers for aging and disability resources should also be prioritized.

Home- and Community-Based Service Funding (Section 3)

North Dakota continues to have a significant imbalance in the funding it provides for individuals to get services and supports in a home setting versus an institutional setting. While we commend the department for the steps they have made toward balancing that effort, we believe there is more that could and should be done. According to the *Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (see attachment), North Dakota ranks last out of the 50 states and District of Columbia when it comes to the "percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities." This study indicator shows how a state's Medicaid spending is used to provide supports for

1038
#2
3/9
pg.4

older individuals. According to the report, North Dakota spent only 14.5% of its budget on HCBS for long term care supports based on 2012 data.

It's imperative that the 2017-19 Legislature look at moving toward a more balanced approach in how we fund and support individuals living independently. The language in this bill directs DHS to make recommendations on how to best restructure our funding model regarding long term services and supports. The state should also take advantage of technical assistance offered with the Money Follows the Person Demonstration and look to lessons learned or best practices from other states to help with the state's rebalancing plan.

Finally, we'd like to highlight a key piece of this puzzle that was removed from the original bill. It focused on providing training to caregivers. Something both the NDSU study and AARP survey show caregivers say they desperately need.

Family Caregiver Training

Powerful Tools for Caregivers is a program delivered through the North Dakota Extension Service. It is designed to help provide assistance to caregivers in reducing stress, communicating, dealing with emotions and making tough decisions. However, the current funding for the program limits the scope of where they can provide the training. We know that family caregivers who complete a training program are far less likely to suffer from burnout, which can keep them on the job for longer, saving the state money and providing for their loved one so they can remain at home.

The original bill had \$197,580 allocated to the NDSU Extension Services. We would like you to consider adding this money back into the bill with one slight modification from the original. Instead of directly appropriating the money to NDSU Extension, it probably makes sense to grant the money through the Department of Human Services. This is one-time funding for a pilot project to expand local training programs.

Chairman Lee and Members of the Committee, we appreciate your thorough consideration of family caregiver support bills this session. We want to thank the Interim Human Service Committee members for the work they started on this important issue. The NDSU Study is a great roadmap of how North Dakota can build upon its foundation of caregiver support. As we have said, North Dakotans want to stay at home as they age. This bill helps them do so.

Again, we appreciate the opportunity to provide comments.

We fully support HB1038 and recommend a DO PASS from this committee.

1038
#2
3/8
Pg. 01

North Dakota Family Caregiver Supports and Services Study



EXECUTIVE SUMMARY

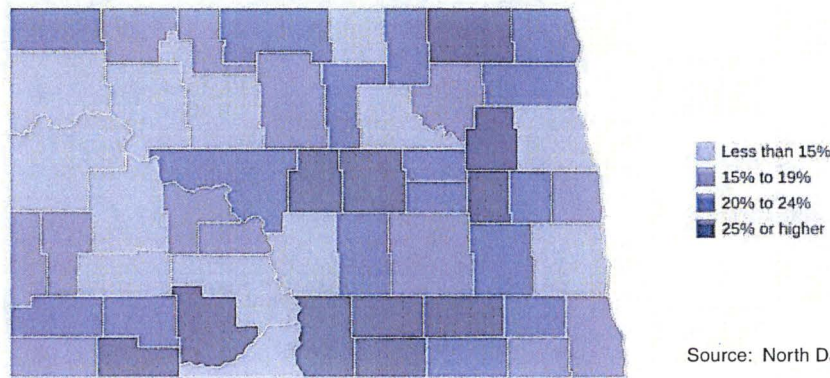
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1038
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Introduction

Between 2011 and 2025, the number of adults ages 65 and older in North Dakota is expected to grow by 50 percent. That means there will be about 50,000 more people aged 65+ by 2025. In 2011, 14.4 percent of North Dakota's population was ages 65 and older and they are expected to be 18 percent of the state's population by 2025.

Percent of population age 65+
North Dakota counties, 2014



The U.S. Census Bureau estimated North Dakota to have 17,680 individuals age 85 and older in 2013. This makes up approximately 2.5 percent of the state's total population and puts North Dakota in 7th place in the country for having the oldest residents. Health issues are a common concern for this age group, with the majority indicating difficulties with dressing, vision, hearing loss, memory recall, and going outside of their residences. Between 2010 and 2040, the number of adults 85 years and older in North Dakota is expected to grow by 43 percent, an increase of about 7,200 people. (*Growing ND by the Numbers*, North Dakota Census Office, 2014)

Levels and types of disability are important for planning services and understanding the scope of caregiving needs in North Dakota. In 2014, more than one in three (34 percent) adults ages 65 and older had one or more disabilities (34 percent). The disability rates among American Indian older adults are higher than for white older adults in the state (53 percent compared to 34 percent; 2010-2014).

According to the AARP Public Policy Institute's new report, *Valuing the Invaluable: 2015 Update*, in 2013, North Dakota had 62,100 family caregivers who provided 58 million hours of unpaid care valued at \$860 million. These caregivers are spouses, partners, adult children, other family members, neighbors and friends. Family caregivers provide a range of daily activities, such as transportation, personal care, managing finances grocery shopping and much more. Finding ways to support North Dakota's family caregivers and bridge the gaps where they may be struggling, is the focus of the current report.

Executive Summary

Between January and May, 2016, North Dakota State University was contracted by the North Dakota State Legislative Human Services Committee to conduct the study “Identifying Gaps in Family Caregiver Supports and Services in North Dakota”. A team of faculty researchers and graduate students conducted the study that focused on the following five aims:

Aim 1. Identify current public and private resources, services, and supports for family caregivers, both public and private, and by region and/or county.

Aim 2. Identify barriers and challenges family caregivers experience, which includes the need for training, respite care services, medical leave policies, and delegation of tasks to family members and nonmedical aides.

Aim 3. Identify best practice models for family caregiver support programs from other states.

Aim 4. Identify emerging practices and technology that can enhance caregiver and patient home supports.

Aim 5. Provide recommendations to the interim committee.

A brief summary of the major findings for each aim is provided next. For a comprehensive overview of the methodology and findings for each aim, see the appropriate full chapter.

1038
#2
3/8

Aim 1. Current Resources for Family Caregivers in ND

We inventoried and **created a database of family caregiver resources, services, and supports** across the eight geographic regions of North Dakota. The categories of services and resources identified cover areas of support related to: managing the logistics of caregiving, direct support in providing care, improving caregiver’s ability to provide care, and fostering the wellbeing of the caregiver. Maps were created for each category to identify availability of services across the state, and are presented in the body of the report.

Categories of Family Caregiver Resources, Services, and Supports

Managing Caregiving Logistics	Direct Support in Providing Care	Improving Caregivers’ Ability to Provide Care	Fostering Caregivers’ Wellbeing
Advocacy Services	Adult Day Care	Meal Services	Emotional Support
Assistive Technology & Equipment	Dementia Care	Training & Education	Respite
Care Management	Home Health Care	Transportation	Key: Evenly Represented Rural / Urban Divide
Information & Referral	Homemaker / Chore	Volunteer Services	
	Hospice		
	Personal Care		

Within these categories, **further examination is required** to fully identify gaps in service related to:

- **Availability** (Are services available across the designated region / county?)
- **Accessibility** (Does the travel distance to the service create a barrier?)
- **Appropriateness** (Do services address actual needs?)
- **Affordability** (Can families afford to pay for available services?)
- **Awareness** (Do families and communities know about these services?)

Each of these factors present challenges and need to be addressed if the service needs of family caregivers are to be met.

Aim 2. Barriers and Challenges of Family Caregiving

Caregivers' Perspective

(based on data from 398 family caregivers across ND from 2014-2016):

North Dakota Family Caregivers are likely to be:

- Women
- Spouses (followed by children)
- Older adults
- Working full or part-time

Caregiving Tasks

- Shopping, transportation, & chores most common tasks
- 80% provide nursing cares, yet 50% report receiving no training
- 50% report insufficient respite from caregiving

Common benefits of caregiving:

- Satisfaction of giving back
- Helping maintain independence
- Love and appreciation

Common challenges of caregiving:

- Lack of sufficient respite
- Need help finding available services and resources
- Lack of knowledge and training about providing care
- Caregiver stress and burden
- Financial burden

Stakeholders' Perspective

(based on data from 116 stakeholders across ND in 2016):

Represented service sectors:

- Healthcare
- Long-term care
- Social services
- Aging services
- Community-based organizations
- State & local government
- Advocacy agencies
- Faith-based organizations
- Veteran's organizations
- Tribal agencies

Common challenges/unmet needs of families and service organizations

- Financial costs
- Lack of support
- Rurality
- Lack of available services
- Respite
- Finding and navigating services
- Lack of training

Stakeholder recommendations

- Improve funding
- Increase respite care
- Increase education and training
- Increase overall services available
- Foster outreach and awareness

Veterans' groups: have special needs related to coordinated services with the VA, particularly challenging in rural ND

American Indian Tribes: coordinating services between Tribal and state programs is a challenge. Support to family caregivers should be provided in a culturally sensitive way.

1038
#2
3/8

Aim 3. Best Practices for Family Caregiver Support Programs

BEST	
Availability of Help / Support	<ul style="list-style-type: none"> • Telephone-based psycho-educational interventions • Virtual care • Community nurses
Financial cost of care / Funding	<ul style="list-style-type: none"> • Sliding scales and vouchers • Increasing access to paid family medical leave • Long-term care planning
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> • Interactive training (e.g. role playing) • Comprehensive discharge planning • Long-term education programming • Preventative care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> • In-home care • Health education programs

Aim 4. Emerging Practices and Technology to Enhance Caregiver Supports

EMERGING	
Availability of Help / Support	<ul style="list-style-type: none"> • Person-centered care (i.e., Money Follows the Person) • Mobile adult day care (i.e., especially in rural areas) • Working with college students • Technology (i.e., smart-homes, robotic applications, etc.) • Socially Assistive Robots • Smart Wear
Financial cost of care / Funding	<ul style="list-style-type: none"> • Telemedicine reduced hospitalization • Co-op models • Tax credits for caregiving
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> • Home visits upon discharge • Virtual learning modules in hospital waiting rooms • Use social media to increase awareness • Trainings for employers about eldercare • Mobile apps for long distance care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> • Online emotional support groups • Employ Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module to detect caregiver burden

A series of examples of both best and emerging practices are discussed in the body of the report. Additionally, challenges related to implementing these new practices are discussed.

CHALLENGES	
Logistics and Implementation	Limitations and Caveats
<ul style="list-style-type: none"> • Balancing the needs of care recipient and caregiver • Increasing costs • Staffing shortage • Rurality 	<ul style="list-style-type: none"> • Budget Cuts • Lack of flexibility in federal programs (i.e. Medicare) • Lack time to learn and implement technologies

Aim 5. Conclusions and Recommendations

The primary goal of family caregiving is to help older adults to maintain their independence and well-being. This study concludes that, even though family caregiving is rewarding, North Dakota family caregivers are vulnerable due to lack of support.

Key Study Conclusions and Ensuing Recommendations

Conclusions	Recommendations
The high costs of care and lack of funding for services to support caregiving prove enormously challenging for North Dakota caregivers.	Improve avenues for sustainable funding for family caregivers and programs that support them
Both caregivers and stakeholders clearly indicated that insufficient access to respite care is one of the most salient gaps in the services provided to North Dakota family caregivers.	Increase access to respite care across the state
Caregivers reported difficulty finding, connecting to, and navigating available services and resources.	Improve outreach (i.e., marketing) and resources (i.e., technology) to help family caregivers find, connect to, and navigate available services
Family caregivers lacked training related to the logistics and management of caregiving, including the provision of support in activities of daily living.	Create programs and policies to foster an increase in the training and education of both informal and professional caregivers
Both caregivers and stakeholders reported the challenge of lack of available and appropriate services especially in rural regions.	Close the gaps in caregiver support services in rural areas

Overarching Recommendations

Several overarching recommendations cut across the various conclusions:

- Develop family caregiving taskforce consisting of caregivers, service providers, and community leaders to create recommendations to address the service gaps identified in this study.
- Explore ways to lift restrictive eligibility criteria and cut the red tape, or expand funding opportunities to include those not currently financially eligible.
- Increase service availability for respite care, care management, training and education, emotional support, volunteer programs and a range of direct care supports (adult day care, homemaker/chore, dementia care, and personal care).
- Improve resources to address caregiver well-being (including preventative, screening, and intervention care).

1038
#2
3/8
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Acknowledgments

This study was solicited and funded by the North Dakota Legislative Management. As provided in Section 1 of 2015 House Bill No. 1279, the study was to develop a resource directory of services available to support family caregivers, to identify unmet needs, and prepare recommendations for legislative or administrative consideration. The study required input from stakeholders, including representatives of hospitals, social and clinical providers, advocacy organizations, veterans' organizations, tribal governments, state and local agencies and institutions, and caregivers in the state.

We would like to thank the following individuals for their assistance with this project: Sheryl Pfliger and Mary Weltz, Aging Services; Kristen Hasbargen, Association of County Social Service Directors; Josh Askvig, AARP of ND; Anuchida Scholz, NDSU Graduate Student, and Deborah Tanner, NDSU Ag Communications.

In addition, we want to express our gratitude to the County Social Service staff who shared their expertise about local family caregiver resources and to the many stakeholders who were willing to share their perspective and insights with us. It is our hope this study will uncover ways in which we can better serve family caregivers.

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NDSU HUMAN DEVELOPMENT
AND FAMILY SCIENCE

NDSU EXTENSION
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North Dakota Caregivers Do More Than Care for Loved Ones – They Save N.D. \$860 Million a Year

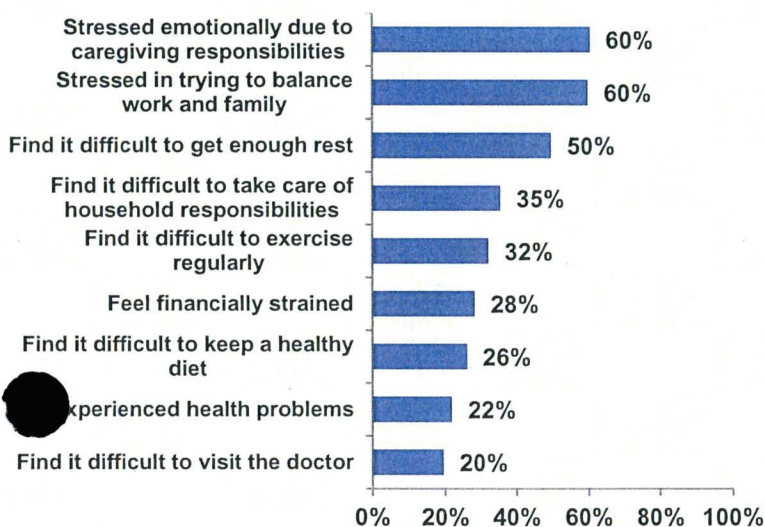
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3/8
Pg. b1

We've known for some time the value of uncompensated family caregivers. Previous studies show more than 62,000 family caregivers in North Dakota provide 58 million hours of service - at no cost to the state.

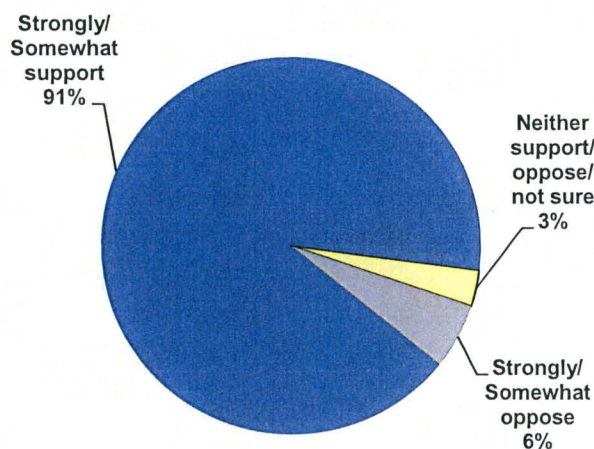
A new AARP North Dakota study opened our eyes to their experiences and needs.

Current and former North Dakota caregivers report feeling stressed out, financially strained and face health problems of their own. And they believe a break now and then would help.

Experiences of North Dakota Caregivers Age 45+*
(n=440 current or former caregivers)



Support for a Respite Care Proposal Among North Dakota Likely Voters Age 45+ (n=877)



*Stressed out in trying to balance work and family was only asked to working caregivers (n=279)

70% of North Dakota residents age 45+ believe living independently at home, with caregiver assistance is the ideal situation when basic tasks become difficult. They strongly support policy options to help.

HOUSE BILL 1038 PROVIDES SUPPORT FOR FAMILY CAREGIVERS

- **HB 1038** allows DHS to apply for FEDERAL money to participate in the Lifespan Respite Care Program (joining 35 other states).
- **HB 1038** asks DHS to establish and promote a caregiver resource website.
- **HB 1038** requires DHS to study, then develop a plan to better balance institutional based versus home and community based services. Currently, funding is weighted heavily toward institutions.

(According to ND DHS 2015-17 appropriation: Amount spent on nursing homes = \$514 million, amount spent on HCBS = \$91 million)

1038
#2
3/8
Pg. 62

Methodology:

AARP North Dakota commissioned a telephone survey of 1,004 residents age 45+ to learn about their experiences with family caregiving. The sample utilized RDD landline and cell phones. This report highlights results from residents interviewed from November 18 through December 27, 2016. The data was weighted by age and gender to reflect residents in North Dakota age 45+. The survey has a margin of sampling error of ±3.2 percent. The survey annotation will be made available at www.aarp.org/research.

AARP is a nonprofit, nonpartisan organization, with a membership of nearly 38 million that helps people turn their goals and dreams into 'Real Possibilities' by changing the way America defines aging. With staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, AARP works to strengthen communities and promote the issues that matter most to families such as healthcare security, financial security, and personal fulfillment. AARP also advocates for individuals in the marketplace by selecting products and services of high quality and value to carry the AARP name. As a trusted source for news and information, AARP produces the world's largest circulation magazine, AARP The Magazine and AARP Bulletin. AARP does not endorse candidates for public office or make contributions to political campaigns or candidates. To learn more, visit www.aarp.org or follow @aarp and our CEO @JoAnn_Jenkins on Twitter.

AARP staff from the North Dakota State Office, Campaigns, State Advocacy and Strategy Integration (SASI), and AARP Research contributed to the design, implementation, and reporting of this study. Special thanks go to AARP staff including Joshua Askvig, Lyle Halvorson, and Michael Chaussee – AARP North Dakota State Office; Chryste Hall, Scott Musser, and Pricilla Hume – Campaigns; Denise Gaines – SASI; and Brittne Nelson, Angela Houghton, and Cheryl Barnes – AARP Research. Please contact Terri Guengerich at 202-434-6306 for more information regarding this survey.

AARP Research | For more information about this survey,
please contact Terri Guengerich at:

202.434.6306 or e-mail tguengerich@aarp.org



Family Caregiving and Out-of-Pocket Costs: 2016 Report

The purpose of this study was to explore the out-of-pocket costs of caregiving and the financial strain on the family caregiver. In addition to out-of-pocket costs, this study also looks at other financial and personal strains family caregivers may experience. For example, many family caregivers may need to cut back on spending in other areas (e.g., personal spending, basic living expenses, retirement savings, etc.) due to the costs of caregiving.

Key Findings

- + Family caregivers, on average, are spending roughly \$7,000 (\$6,954) per year on out-of-pocket costs related to caregiving. A financial strain measure (average annual family caregiver expense divided by the caregivers' annual incomes) shows family caregivers are spending, on average, nearly 20% of their income on caregiving expenses.
- + Household expenses garner the largest share of family caregivers' expenses with 41% of total spending. This includes rent/mortgage payments, home modifications, as well as other household expenses. Medical expenses account for the second largest share (25%). This includes in-facility care, insurance costs, and other medical expenses.
- + Long-distance caregivers (defined as those living more than one hour away from their care recipient) incurred the highest out-of-pocket costs (\$11,923) compared to caregivers living with or close by their care recipients.
- + Those caring for an adult with dementia reported nearly twice the out-of-pocket costs than those caring for someone who does not have dementia (\$10,697 vs. \$5,758).
- + The individuals most "highly financially-strained" tend to be lower income, non-White/non-Asian family caregivers, and caring for someone who needs assistance with at least one Activity of Daily Living (ADL). There are, however, subgroups in every income group that are "highly financially-strained".
- + More than half of family caregivers (56%) experience at least one work-related strain. This may take the form of working different hours, fewer/more hours, and taking time off (whether paid or unpaid).

Methodology

- + This study was conducted using a mixed method approach that included both a survey and diary component in order to calculate an annual figure of out-of-pocket spending for each family caregiver. This study utilized GfK's national, probability-based online Knowledge Panel®. The study was conducted from July 18, 2016 to August 28, 2016 among 1,864 family caregivers.



1038
#2
3/8
Pg. 64

Making a difference

NDSU EXTENSION SERVICE

NORTH DAKOTA STATE UNIVERSITY

Powerful Tools for Caregivers - North Dakota

The Situation

The vast majority of older North Dakotans want to stay living in their home as they age. At any given time, 80,000 family caregivers in North Dakota provide the majority of assistance to make this a reality for many. They help with transportation, personal care, managing finances, grocery shopping, and much more.

Caregiving can be a rewarding experience but can also be filled with enormous physical, emotional, and financial challenges. It is essential for caregivers to maintain their own health and well-being while managing caregiving responsibilities. Yet, most caregivers receive little or no training to care for themselves.

In North Dakota, family caregivers provide unpaid care valued at an estimated \$830 million annually. Family members are saving the state money by helping their loved ones remain at home longer, delaying more costly levels of care.

Extension Response

The Powerful Tools for Caregivers (PTC) Program is a national evidence-based program which was brought to North Dakota by the NDSU Extension Service. As a pilot program, seven Extension Agents became trained as Class Leaders and offered three 6-week workshops.

Class Participants learned tools for taking care of themselves, such as:

- reducing stress
- changing negative self-talk
- communicating feelings and needs to others
- setting limits and asking for help
- dealing with emotions such as anger, guilt and depression
- making tough caregiving decisions
- locating helpful resources

Impacts

Analysis of the retrospective pre- and post-surveys measured 16 participants' knowledge, confidence, ability, and behavior change needed to be more comfortable with their role as a caregiver.

Our surveys showed significant improvement in the following areas:

- Confidence in asking for help with tasks needed for caregiving
- Understanding their emotions are a normal response to caregiving
- Asserting themselves with others to get their needs met
- Taking time for themselves without feeling guilty
- Doing something to make themselves feel better when discouraged
- Finding positive ways to cope with the stress of caregiving
- Being more positive about their role as a caregiver
- Making decisions related to caregiving

Based on the program's positive results, PTC will become a core program and another Class Leader training will be offered to train additional Extension Agents, as workshops need to be co-led by two trained leaders.

Feedback

"This workshop has been a great strength for me and my future." *Participant*

Contact

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North Dakota

HB 1038
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p. 1

March 21, 2017
Senate Appropriations Committee
SUPPORT HB 1038

Mike Chaussee – AARP North Dakota
mchaussee@aarp.org, (701) 390-0161

Chairman Holmberg and members of the Senate Appropriations Committee, I am Mike Chaussee with AARP North Dakota. Thank you for the opportunity to provide comments in **SUPPORT of HB 1038** – or as we call it, the Family Caregiver Supports bill.

Dr. Ethel Percy Andrus, a retired educator and AARP’s founder, became an activist in the 1940s when she found a retired teacher living in a chicken coop because she could afford nothing else. Dr. Andrus couldn’t ignore the need for health and financial security in America and set the wheels in motion for what would become AARP. We are a nonprofit, nonpartisan membership organization with more than 87,000 members in North Dakota and 38 million nationwide. We help people turn their goals and dreams into 'Real Possibilities' by changing the way America defines aging, including here in North Dakota.

AARP has been raising the profile of family caregivers in North Dakota and across the country. Through our research we know that there are approximately **62,100 individual caregivers in North Dakota that provide over 58 million hours of uncompensated care valued at over \$860 million.** In recent years, the role of family caregivers has greatly expanded. It now includes coordinating and providing personal care and household chores as well as completing medical or nursing tasks such as wound care and injections. In a recent study of nearly 1,000 North Dakotans 45-years-old and older – AARP found that nearly half of people surveyed (47%) say they are currently acting or have previously acted as an uncompensated family caregiver. Of those, 64-percent say they oversee medication management and 61-percent are responsible for other nursing tasks. And they’re performing those duties regularly, most often, according to the survey, they’re doing that work daily.

For the individuals doing this work in North Dakota it is a labor of love, but it comes with stress, burnout and often times at a cost to their own health and financial stability.

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According to findings from the same study, 60-percent of current and former family caregivers in North Dakota feel stressed out. About half of them say it's hard to get rest, a third don't get the exercise they need and more than a quarter say they are financially strained because of the caregiving work (see attached documents for additional information). To shed a little more light on the financial stress put on family caregivers, AARP took on a national research effort. In that study (results also attached) AARP found average out-of-pocket expenses run nearly \$7,000 for uncompensated caregivers.

Providing support for these caregivers is critical toward ensuring that individuals can safely stay in their homes as they age, something North Dakotans believe is important. In fact, 70-percent of the people we talked to believe living independently at home, with caregiver assistance, is the ideal situation when basic tasks become difficult.

As part of our efforts to show the unrecognized work that family caregivers do in North Dakota, we have also been collecting stories of caregivers here in North Dakota. The stories and information we collected during the Interim was shared with Dr. Jane Strommen's team and helped inform the "North Dakota Family Caregiver Supports Study" (hereafter NDSU Study). One particularly touching story is from a caregiver in one of our rural communities in North Dakota. Mr. Larry Hinderer from Carson takes care of his wife, who has multiple sclerosis. He told us he provides care for her 24 hours a day, seven days a week. He does the cooking, bathing, and other necessary tasks that allow both of them to stay at home. When we asked him how long he's been at it, he said he hasn't had a break in 15 years.

Larry, and North Dakotas other family caregivers need our support. The NDSU Study makes some excellent recommendations on how to keep family caregivers on the job. Dr. Jane Strommen and her team of Dr. Gregory Sanders and Dr. Heather Fuller at North Dakota State University did a fantastic job and we support the proposals in the NDSU Study.

We would love to have all of the recommendations highlighted in their study completed today, but we are realistic in knowing that it will take some time for them to be fleshed out, considered and then put into action. We believe **HB1038** is an important first step in ensuring family caregivers get the assistance they need.

Lifespan Respite Care Program (Section 1)

One of the top concerns raised by caregivers and stakeholders during the NDSU Study was the need for more respite for caregivers. That concern also showed up in the AARP research done in December, 2016 (cited earlier). According to that study, more than 90-percent of people agree respite care support is important. North Dakota currently has the Family Caregiver Respite Program, but we can and should do more. The NDSU researchers found that North Dakota may be eligible for an additional federal grant (up to \$200,000) from the Lifespan Respite Care Program. This grant program would allow the state to expand and enhance respite services in North Dakota. Additionally, it would allow us to streamline access and improve coordination of respite services. Last, it would assist in improving the quality of respite care services and filling in gaps where necessary. According to the U.S. Department of Health and Human Services, 35 states and the District of Columbia have taken advantage of this grant.

Aging and Disability Resource Link (ADRL) improvements (Section 2)

The NDSU Study highlighted the confusion and frustration caregivers face in finding and accessing services for their loved ones or themselves. In fact, just behind the financial cost of care, this was the biggest challenge identified by family caregivers in the research. Under the recommendation, "Improve resources to help family caregivers find, connect to, and navigate available services," there are three proposed strategies. They include identifying marketing and communication strategies to promote the existing ADRL, creating a caregiver resource center within the ADRL to increase access to existing programs and services, and creating a comprehensive guide to caregiving for North Dakota caregivers. This bill takes the first step in addressing those recommendations by ensuring the Department of Human Services creates a Caregiver Resource Center within the existing ADRL. In meetings and conversations with DHS, we understand they can do this without an additional appropriation, which is probably music to your ears and we are excited to see the work progress.

Home- and Community-Based Service Funding (Section 3)

North Dakota continues to have a significant imbalance in the funding it provides for individuals to get services and supports in a home setting versus an institutional setting. While we commend the department for the steps they have made toward balancing that effort, we believe there is more that could and should be done. According to the *Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (see attachment), North Dakota ranks last out of the 50 states and District

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of Columbia when it comes to the “percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities.” This study indicator shows how a state’s Medicaid spending is used to provide supports for older individuals. According to the report, North Dakota spent only 14.5% of its budget on HCBS for long term care supports based on 2012 data.

It’s imperative that the 2017-19 Legislature look at moving toward a more balanced approach in how we fund and support individuals living independently. The language in this bill directs DHS to make recommendations on how to best restructure our funding model regarding long term services and supports.

Again, we appreciate the opportunity to provide comments.

We fully support HB1038 and recommend a DO PASS from this committee.

North Dakota Caregivers Do More Than Care for Loved Ones – They Save N.D. \$860 Million a Year

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We've known for some time the value of uncompensated family caregivers. Previous studies show more than 62,000 family caregivers in North Dakota provide 58 million hours of service - at no cost to the state.

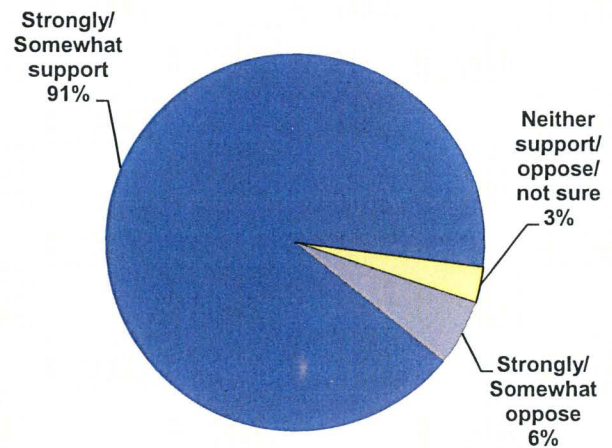
A new AARP North Dakota study opened our eyes to their experiences and needs.

Current and former North Dakota caregivers report feeling stressed out, financially strained and face health problems of their own. And they believe a break now and then would help.

Experiences of North Dakota Caregivers Age 45+*
(n=440 current or former caregivers)



Support for a Respite Care Proposal Among North Dakota Likely Voters Age 45+ (n=877)



*Stressed out in trying to balance work and family was only asked to working caregivers (n=279)

70% of North Dakota residents age 45+ believe living independently at home, with caregiver assistance is the ideal situation when basic tasks become difficult. They strongly support policy options to help.

HOUSE BILL 1038 PROVIDES SUPPORT FOR FAMILY CAREGIVERS

- **HB 1038** allows DHS to apply for FEDERAL money to participate in the Lifespan Respite Care Program (joining 35 other states).
- **HB 1038** asks DHS to establish and promote a caregiver resource website.
- **HB 1038** requires DHS to study, then develop a plan to better balance institutional based versus home and community based services. Currently, funding is weighted heavily toward institutions.

(According to ND DHS 2015-17 appropriation: Amount spent on nursing homes = \$514 million, amount spent on HCBS = \$91 million)

1 of 6

Methodology:

AARP North Dakota commissioned a telephone survey of 1,004 residents age 45+ to learn about their experiences with family caregiving. The sample utilized RDD landline and cell phones. This report highlights results from residents interviewed from November 18 through December 27, 2016. The data was weighted by age and gender to reflect residents in North Dakota age 45+. The survey has a margin of sampling error of ± 3.2 percent. The survey annotation will be made available at www.aarp.org/research.

AARP is a nonprofit, nonpartisan organization, with a membership of nearly 38 million that helps people turn their goals and dreams into 'Real Possibilities' by changing the way America defines aging. With staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, AARP works to strengthen communities and promote the issues that matter most to families such as healthcare security, financial security, and personal fulfillment. AARP also advocates for individuals in the marketplace by selecting products and services of high quality and value to carry the AARP name. As a trusted source for news and information, AARP produces the world's largest circulation magazine, AARP The Magazine and AARP Bulletin. AARP does not endorse candidates for public office or make contributions to political campaigns or candidates. To learn more, visit www.aarp.org or follow @aarp and our CEO @JoAnn_Jenkins on Twitter.

AARP staff from the North Dakota State Office, Campaigns, State Advocacy and Strategy Integration (SASI), and AARP Research contributed to the design, implementation, and reporting of this study. Special thanks go to AARP staff including Joshua Askvig, Lyle Halvorson, and Michael Chaussee – AARP North Dakota State Office; Chryste Hall, Scott Musser, and Pricilla Hume – Campaigns; Denise Gaines – SASI; and Brittne Nelson, Angela Houghton, and Cheryl Barnes – AARP Research. Please contact Terri Guengerich at 202-434-6306 for more information regarding this survey.

AARP Research | For more information about this survey,
please contact Terri Guengerich at:

202.434.6306 or e-mail tguengerich@aarp.org



Family Caregiving and Out-of-Pocket Costs: 2016 Report

The purpose of this study was to explore the out-of-pocket costs of caregiving and the financial strain on the family caregiver. In addition to out-of-pocket costs, this study also looks at other financial and personal strains family caregivers may experience. For example, many family caregivers may need to cut back on spending in other areas (e.g., personal spending, basic living expenses, retirement savings, etc.) due to the costs of caregiving.

Key Findings

- + Family caregivers, on average, are spending roughly \$7,000 (\$6,954) per year on out-of-pocket costs related to caregiving. A financial strain measure (average annual family caregiver expense divided by the caregivers' annual incomes) shows family caregivers are spending, on average, nearly 20% of their income on caregiving expenses.
- + Household expenses garner the largest share of family caregivers' expenses with 41% of total spending. This includes rent/mortgage payments, home modifications, as well as other household expenses. Medical expenses account for the second largest share (25%). This includes in-facility care, insurance costs, and other medical expenses.
- + Long-distance caregivers (defined as those living more than one hour away from their care recipient) incurred the highest out-of-pocket costs (\$11,923) compared to caregivers living with or close by their care recipients.
- + Those caring for an adult with dementia reported nearly twice the out-of-pocket costs than those caring for someone who does not have dementia (\$10,697 vs. \$5,758).
- + The individuals most "highly financially-strained" tend to be lower income, non-White/non-Asian family caregivers, and caring for someone who needs assistance with at least one Activity of Daily Living (ADL). There are, however, subgroups in every income group that are "highly financially-strained".
- + More than half of family caregivers (56%) experience at least one work-related strain. This may take the form of working different hours, fewer/more hours, and taking time off (whether paid or unpaid).

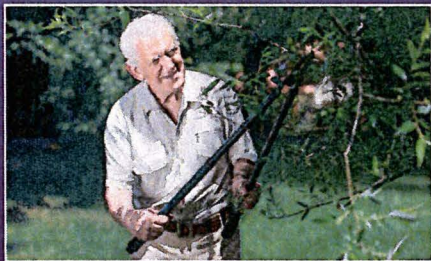
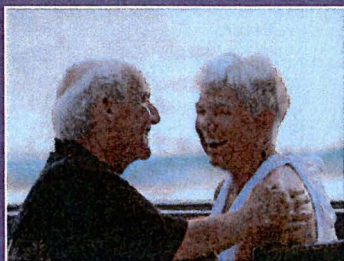
Methodology

- + This study was conducted using a mixed method approach that included both a survey and diary component in order to calculate an annual figure of out-of-pocket spending for each family caregiver. This study utilized GfK's national, probability-based online Knowledge Panel®. The study was conducted from July 18, 2016 to August 28, 2016 among 1,864 family caregivers.



1 / p 8

North Dakota Family Caregiver Supports and Services Study



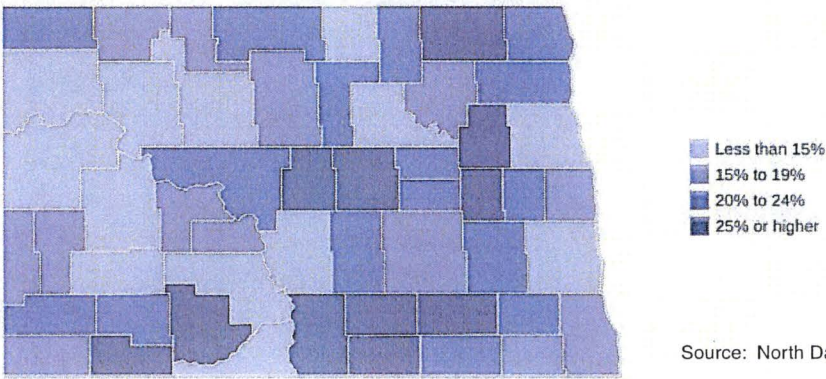
EXECUTIVE SUMMARY
May 10, 2016

#1 p 9

Introduction

Between 2011 and 2025, the number of adults ages 65 and older in North Dakota is expected to grow by 50 percent. That means there will be about 50,000 more people aged 65+ by 2025. In 2011, 14.4 percent of North Dakota's population was ages 65 and older and they are expected to be 18 percent of the state's population by 2025.

Percent of population age 65+
North Dakota counties, 2014



Source: North Dakota Compass

The U.S. Census Bureau estimated North Dakota to have 17,680 individuals age 85 and older in 2013. This makes up approximately 2.5 percent of the state's total population and puts North Dakota in 7th place in the country for having the oldest residents. Health issues are a common concern for this age group, with the majority indicating difficulties with dressing, vision, hearing loss, memory recall, and going outside of their residences. Between 2010 and 2040, the number of adults 85 years and older in North Dakota is expected to grow by 43 percent, an increase of about 7,200 people. (*Growing ND by the Numbers*, North Dakota Census Office, 2014)

Levels and types of disability are important for planning services and understanding the scope of caregiving needs in North Dakota. In 2014, more than one in three (34 percent) adults ages 65 and older had one or more disabilities (34 percent). The disability rates among American Indian older adults are higher than for white older adults in the state (53 percent compared to 34 percent; 2010-2014).

According to the AARP Public Policy Institute's new report, *Valuing the Invaluable: 2015 Update*, in 2013, North Dakota had 62,100 family caregivers who provided 58 million hours of unpaid care valued at \$860 million. These caregivers are spouses, partners, adult children, other family members, neighbors and friends. Family caregivers provide a range of daily activities, such as transportation, personal care, managing finances grocery shopping and much more. Finding ways to support North Dakota's family caregivers and bridge the gaps where they may be struggling, is the focus of the current report.

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p10

Executive Summary

Between January and May, 2016, North Dakota State University was contracted by the North Dakota State Legislative Human Services Committee to conduct the study “Identifying Gaps in Family Caregiver Supports and Services in North Dakota”. A team of faculty researchers and graduate students conducted the study that focused on the following five aims:

Aim 1. Identify current public and private resources, services, and supports for family caregivers, both public and private, and by region and/or county.

Aim 2. Identify barriers and challenges family caregivers experience, which includes the need for training, respite care services, medical leave policies, and delegation of tasks to family members and nonmedical aides.

Aim 3. Identify best practice models for family caregiver support programs from other states.

Aim 4. Identify emerging practices and technology that can enhance caregiver and patient home supports.

Aim 5. Provide recommendations to the interim committee.

A brief summary of the major findings for each aim is provided next. For a comprehensive overview of the methodology and findings for each aim, see the appropriate full chapter.

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P11

Aim 1. Current Resources for Family Caregivers in ND

We inventoried and **created a database of family caregiver resources, services, and supports** across the eight geographic regions of North Dakota. The categories of services and resources identified cover areas of support related to: managing the logistics of caregiving, direct support in providing care, improving caregiver’s ability to provide care, and fostering the wellbeing of the caregiver. Maps were created for each category to identify availability of services across the state, and are presented in the body of the report.

Categories of Family Caregiver Resources, Services, and Supports

Managing Caregiving Logistics	Direct Support in Providing Care	Improving Caregivers’ Ability to Provide Care	Fostering Caregivers’ Wellbeing
Advocacy Services	Adult Day Care	Meal Services	Emotional Support
Assistive Technology & Equipment	Dementia Care	Training & Education	Respite
Care Management	Home Health Care	Transportation	Key: <input type="checkbox"/> Evenly Represented <input type="checkbox"/> Rural / Urban Divide
Information & Referral	Homemaker / Chore	Volunteer Services	
	Hospice		
	Personal Care		

Within these categories, **further examination is required** to fully identify gaps in service related to:

- **Availability** (Are services available across the designated region / county?)
- **Accessibility** (Does the travel distance to the service create a barrier?)
- **Appropriateness** (Do services address actual needs?)
- **Affordability** (Can families afford to pay for available services?)
- **Awareness** (Do families and communities know about these services?)

Each of these factors present challenges and need to be addressed if the service needs of family caregivers are to be met.

Aim 2. Barriers and Challenges of Family Caregiving

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p12

Caregivers' Perspective

(based on data from 398 family caregivers across ND from 2014-2016):

North Dakota Family Caregivers are likely to be:
<ul style="list-style-type: none">• Women• Older adults• Spouses (followed by children)• Working full or part-time
Caregiving Tasks
<ul style="list-style-type: none">• Shopping, transportation, & chores most common tasks• 80% provide nursing cares, yet 50% report receiving no training• 50% report insufficient respite from caregiving
Common benefits of caregiving:
<ul style="list-style-type: none">• Satisfaction of giving back• Helping maintain independence• Love and appreciation
Common challenges of caregiving:
<ul style="list-style-type: none">• Lack of sufficient respite• Need help finding available services and resources• Lack of knowledge and training about providing care• Caregiver stress and burden• Financial burden

Stakeholders' Perspective

(based on data from 116 stakeholders across ND in 2016):

Represented service sectors:
<ul style="list-style-type: none">• Healthcare• Community-based organizations• Faith-based organizations• Long-term care• Social services• State & local government• Veteran's organizations• Aging services• Advocacy agencies• Tribal agencies
Common challenges/unmet needs of families and service organizations
<ul style="list-style-type: none">• Financial costs• Lack of available services• Finding and navigating services• Lack of support• Respite• Lack of training• Rurality
Stakeholder recommendations
<ul style="list-style-type: none">• Improve funding• Increase education and training• Foster outreach and awareness• Increase respite care• Increase overall services available
Veterans' groups: have special needs related to coordinated services with the VA, particularly challenging in rural ND
American Indian Tribes: coordinating services between Tribal and state programs is a challenge. Support to family caregivers should be provided in a culturally sensitive way.

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P13

Aim 3. Best Practices for Family Caregiver Support Programs

BEST	
Availability of Help / Support	<ul style="list-style-type: none"> • Telephone-based psycho-educational interventions • Virtual care • Community nurses
Financial cost of care / Funding	<ul style="list-style-type: none"> • Sliding scales and vouchers • Increasing access to paid family medical leave • Long-term care planning
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> • Interactive training (e.g. role playing) • Comprehensive discharge planning • Long-term education programming • Preventative care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> • In-home care • Health education programs

Aim 4. Emerging Practices and Technology to Enhance Caregiver Supports

EMERGING	
Availability of Help / Support	<ul style="list-style-type: none"> • Person-centered care (i.e., Money Follows the Person) • Mobile adult day care (i.e., especially in rural areas) • Working with college students • Technology (i.e., smart-homes, robotic applications, etc.) • Socially Assistive Robots • Smart Wear
Financial cost of care / Funding	<ul style="list-style-type: none"> • Telemedicine reduced hospitalization • Co-op models • Tax credits for caregiving
Knowledge and ability to provide needed cares	<ul style="list-style-type: none"> • Home visits upon discharge • Virtual learning modules in hospital waiting rooms • Use social media to increase awareness • Trainings for employers about eldercare • Mobile apps for long distance care
Respite / Well-being of Caregiver	<ul style="list-style-type: none"> • Online emotional support groups • Employ Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module to detect caregiver burden

A series of examples of both best and emerging practices are discussed in the body of the report. Additionally, challenges related to implementing these new practices are discussed.

CHALLENGES	
Logistics and Implementation	Limitations and Caveats
<ul style="list-style-type: none"> • Balancing the needs of care recipient and caregiver • Increasing costs • Staffing shortage • Rurality 	<ul style="list-style-type: none"> • Budget Cuts • Lack of flexibility in federal programs (i.e. Medicare) • Lack time to learn and implement technologies

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P 124

Aim 5. Conclusions and Recommendations

The primary goal of family caregiving is to help older adults to maintain their independence and well-being. This study concludes that, even though family caregiving is rewarding, North Dakota family caregivers are vulnerable due to lack of support.

Key Study Conclusions and Ensuing Recommendations

Conclusions	Recommendations
The high costs of care and lack of funding for services to support caregiving prove enormously challenging for North Dakota caregivers.	Improve avenues for sustainable funding for family caregivers and programs that support them
Both caregivers and stakeholders clearly indicated that insufficient access to respite care is one of the most salient gaps in the services provided to North Dakota family caregivers.	Increase access to respite care across the state
Caregivers reported difficulty finding, connecting to, and navigating available services and resources.	Improve outreach (i.e., marketing) and resources (i.e., technology) to help family caregivers find, connect to, and navigate available services
Family caregivers lacked training related to the logistics and management of caregiving, including the provision of support in activities of daily living.	Create programs and policies to foster an increase in the training and education of both informal and professional caregivers
Both caregivers and stakeholders reported the challenge of lack of available and appropriate services especially in rural regions.	Close the gaps in caregiver support services in rural areas

Overarching Recommendations

Several overarching recommendations cut across the various conclusions:

- Develop family caregiving taskforce consisting of caregivers, service providers, and community leaders to create recommendations to address the service gaps identified in this study.
- Explore ways to lift restrictive eligibility criteria and cut the red tape, or expand funding opportunities to include those not currently financially eligible.
- Increase service availability for respite care, care management, training and education, emotional support, volunteer programs and a range of direct care supports (adult day care, homemaker/chore, dementia care, and personal care).
- Improve resources to address caregiver well-being (including preventative, screening, and intervention care).

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p15

Acknowledgments

This study was solicited and funded by the North Dakota Legislative Management. As provided in Section 1 of 2015 House Bill No. 1279, the study was to develop a resource directory of services available to support family caregivers, to identify unmet needs, and prepare recommendations for legislative or administrative consideration. The study required input from stakeholders, including representatives of hospitals, social and clinical providers, advocacy organizations, veterans' organizations, tribal governments, state and local agencies and institutions, and caregivers in the state.

We would like to thank the following individuals for their assistance with this project: Sheryl Pfliger and Mary Weltz, Aging Services; Kristen Hasbargen, Association of County Social Service Directors; Josh Askvig, AARP of ND; Anuchida Scholz, NDSU Graduate Student, and Deborah Tanner, NDSU Ag Communications.

In addition, we want to express our gratitude to the County Social Service staff who shared their expertise about local family caregiver resources and to the many stakeholders who were willing to share their perspective and insights with us. It is our hope this study will uncover ways in which we can better serve family caregivers.

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NDSU HUMAN DEVELOPMENT
AND FAMILY SCIENCE

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North Dakota: 2014 State Long-Term Services and Supports Scorecard Dimension and Indicator Data

Dimension and Indicator (Current Data Year)	Baseline Rate	Current Rate	Rank	Change	All States Median	Top State Rate
OVERALL RANK			33			
Affordability and Access			48			
Median annual nursing home private pay cost as a percentage of median household income age 65+ (2013)	233%	249%	33	↔	234%	168%
Median annual home care private pay cost as a percentage of median household income age 65+ (2013)	113%	103%	50	↔	84%	47%
Private long-term care insurance policies in effect per 1,000 population age 40+ (2011)	107	102	5	↔	44	130
Percent of adults age 21+ with ADL disability at or below 250% of poverty receiving Medicaid or other government assistance health insurance (2011-12)	53.6%	46.1%	48	✖	51.4%	78.1%
Medicaid LTSS participant years per 100 adults age 21+ with ADL disability in nursing homes or at/below 250% poverty in the community (2009)	34.1	40.4	25	✓	42.3	85.2
ADRC functions (composite indicator, scale 0-70) (2012)	**	42	42	✓	54	67
Choice of Setting and Provider			34			
Percent of Medicaid and state LTSS spending going to HCBS for older people & adults w/ physical disabilities (2011)	10.7%	14.5%	51	✓	31.4%	65.4%
Percent of new Medicaid aged/disabled LTSS users first receiving services in the community (2009)	31.1%	35.7%	36	✓	50.7%	81.9%
Number of people participant-directing services per 1,000 adults age 18+ with disabilities (2013)	*	10.5	22	*	8.8	127.3
Home health and personal care aides per 1,000 population age 65+ (2010-12)	20	31	29	✓	33	76
Assisted living and residential care units per 1,000 population age 65+ (2012-13)	37	45	7	✓	27	125
Quality of Life and Quality of Care			3			
Percent of adults age 18+ with disabilities in the community usually or always getting needed support (2010)	71.9%	72.9%	23	↔	71.8%	79.1%
Percent of adults age 18+ with disabilities in the community satisfied or very satisfied with life (2010)	91.0%	89.5%	5	✖	86.7%	92.1%
Rate of employment for adults with ADL disability ages 18-64 relative to rate of employment for adults without ADL disability ages 18-64 (2011-12)	44.4%	30.2%	7	✖	23.4%	37.2%
Percent of high-risk nursing home residents with pressure sores (2013)	*	4.4%	4	*	5.9%	3.0%
Nursing home staffing turnover: ratio of employee terminations to the average number of active employees (2010)	33.6%	29.2%	9	✓	38.1%	15.4%
Percent of long-stay nursing home residents who are receiving an antipsychotic medication (2013)	*	18.6%	15	*	20.2%	11.9%
Support for Family Caregivers			27			
Legal and system supports for family caregivers (composite indicator, scale 0-14.5) (2012-13)	**	2.40	33	↔	3.00	8.00
Number of health maintenance tasks able to be delegated to LTSS workers (out of 16 tasks) (2013)	13	13	18	↔	9.5	16
Family caregivers without much worry or stress, with enough time, well-rested (2011-12)	66.2%	61.9%	20	✖	61.6%	72.8%
Effective Transitions			29			
Percent of nursing home residents with low care needs (2010)	16.1%	15.1%	36	↔	11.7%	1.1%
Percent of home health patients with a hospital admission (2012)	*	24.1%	14	*	25.5%	18.9%
Percent of long-stay nursing home residents hospitalized within a six-month period (2010)	13.4%	13.6%	13	↔	18.9%	7.3%
Percent of nursing home residents with moderate to severe dementia with one or more potentially burdensome transitions at end of life (2009)	*	12.9%	8	*	20.3%	7.1%
Percent of new nursing home stays lasting 100 days or more (2009)	*	23.4%	41	*	19.8%	10.3%
Percent of people with 90+ day nursing home stays successfully transitioning back to the community (2009)	*	5.1%	50	*	7.9%	15.8%

* Comparable data not available for baseline and/or current year. Change in performance cannot be calculated without baseline and current data.
 ** Composite measure. Baseline rate is not shown as some components of the measure are only available for the current year. Change in performance is based only on those components with comparable prior data. See page 73 and page 83 in *Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* for more detail. Notes: ADL = Activities of Daily Living; ADRC = Aging and Disability Resource Center; HCBS = Home and Community Based Services; LTSS = Long Term Services and Supports.
 Please refer to Appendix B2 on page 97 in the report for full indicator descriptions, data sources, and other notes about methodology; for baseline data years, please see Exhibit 2 on page 11. The full report is available at www.longtermscorecard.org

Key for Change:	
✓	Performance improvement
↔	Little or no change in performance
✖	Performance decline

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P14