

2019 SENATE HUMAN SERVICES COMMITTEE

SB 2154

2019 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB2154
1/15/2019
Job 30809

- Subcommittee
 Conference Committee

Committee Clerk: Justin Velez/ Mary Jo Wocken

Explanation or reason for introduction of bill/resolution:

Relating to hospital discharge policies

Minutes:

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Madam Chair Lee opened the hearing for SB2154.

(00:22-2:45) Nicole Poolman, State Senator from District 7 representing Bismarck and Lincoln, ND. Introduced SB2154 and testified in favor of SB2154. Attachment #1 for testimony.

Madam Chair Lee: In the second case that you described because I know that happened, the problem is maybe less with the hospital than with the fact that there wasn't a person capable of being the caregiver who was doing this. So was there any availability of home health workers, home and community based services being brought in to help that person because it isn't unusual with the excitement and the distraction of leaving the hospital even for a person who is mentally acute, to remember everything. So, that is an issue and I don't know how we fix. Was there any reference at all at the time or did the family pursue it all having any home nurse help or any home community services?

Senator Poolman: They were sent home without any of that in place and without asking about any of that. So that was my first concern. Then it took a long time for my Dad to be able to coordinate those services, starting from ground zero on his own without any help from professionals. So he kind of had to go on line and look it up to who he could call.

Madam Chair Lee: That is unfortunate. Was this in a rural or urban area of the state?

Senator Poolman: Rural. **Madam Chair Lee:** There is a bigger issue with service providers in the rural area. We will try to work on that.

Senator Poolman: I want to make the point, some people are doing a great job and that we're just trying to do a little better.

(04:35-25:25) Josh Askvig, State Director for AARP North Dakota. Testifying in favor of SB 2154. Please see Attachments 2-4 for testimony. Please see Attachment #5 for testimony of Kim Jacobson from Cummings, North Dakota.

Senator Rohr: How similar is the verbiage between the 40 states?

Mr. Josh Askvig: They can vary greatly. Most of them, in a broad categorization each one is a little bit unique. Some are very strict timelines and descriptive ways in which hospitals must do things and some are flexible. Ours lean more to the flexible route.

Senator Rohr: I find it at times a little misleading when someone says its passed in 40 states, but it's not the same act in 40 states. It's got the same title, it's got the same basic intent but the actual delivery of it is sometimes I think it makes it sound like we've got this exact same thing everywhere and it's not a full and true statement. Knowing that healthcare is one of the most regulated industries in the world, did you try another route prior to going straight to a new regulation?

Mr. Josh Askvig: First, to respond to your earlier statement about not being applicable. All of the care acts across the 40 states contain the three basic provisions. At least part of it, so well it wouldn't be state writes there laws a little bit differently, they are the same basic intent in all instances. Your second question, we met with the hospitals if there would be any other options or avenues but it's always been a public policy decision and we think the right place for that decision to get made.

Senator Rohr: Specifically, on page 2 it talks about in lines 9 through 15 the districts policies and procedures being sub-standard. From my basic research I looked and there are 50 hospitals in ND and all hospitals have to comply with regulations and additionally 14 more of them have to comply with drug regulations so what does this add on top of those regulations that are already in place that admittedly are not always being implemented in the same way. So I am not immune to the fact that this isn't always happening the right way, it's just. What will be adding one more regulation change in the fact that it's already required?

Mr. Josh Askvig: We have a chart that actually details the difference between the Care act, the accreditation and the Joint Commission Standards as part of it. Essentially, I will sum it up in this, that there are loopholes in the Joint Commission Standards and CMS regulations that attract and looks to close most around relating to almost all of them focus entirely on family member. As we mentioned earlier, most of them give and I would tell you our interpretation of those instructions also provide even larger loopholes in terms in when instruction must be done and how it should be done. So it essentially closes what we find as loopholes in those instances. If you think we are only working on this at the state level; we have also offered comment to CMS as they've updated their rules along these same lines.

Madam Chair Lee: People are likely to name a spouse as their caregiver. If it's a real capable person that's not a big deal, but for individuals who have been married for 60 years may be mentally acute, but physically unable to help with care giving. So where do we, or how do we and part of it is choice of the person makes for like a care giver without thinking so much about whether or not the person is able to do, but more based on someone who is unable to be in attendance every minute of the day.

Mr. Josh Askvig: I point at two things, specifically in the bill on page 3, lines 20 and 21 talks about consulting with the caregiver for assistance. It is pretty general language and we could certainly look at if you would like to adjust that section. We didn't want to be overly descriptive but in other states they are stricter. There may be instances that the person they think is their caregiver can't do that. When I first approached my Mom who cares for my grandmother at the time we were having this discussion, we were having higher care needs. I said to Mom that you haven't told your caregiver as his Mom replied that she wasn't a caregiver, I replied really. How does Grandma get her groceries? Well I take her. What if Grandma needs to go to the doctor's appointment, who goes with her, and his Mom replied, I do. Who would've done that if you wouldn't do that? Sometimes the caregiver doesn't know what they are doing is caregiving. Again, is it perfect, probably not, but is it a step in the right direction. We think so.

Madam Chair Lee: Durable Power of Attorney for healthcare can be done in advance to save some trouble. If you get racked up in a motorcycle crash and they want to amputate their leg and is unconscious, you should have a medical power of attorney for someone to help making that decisions.

Mr. Josh Askvig: There are two things that I would tell you about that. First of all, we agree Durable Power of Attorney is a good idea. I actually figured out I got mine done before my parents which was totally by accident. The second thing is I hope that is the importance of some of the language in here that I might have glossed over. Durable power of attorney might make medical decisions but they might not always be the person who is actually going to be doing the cares at home and so there can be a distinction. There are times where they are should be distinctions between those two.

Madam Chair Lee: I get that part. That is not confusing to me at all, except where somebody could when they are not in the time of stress consider who their care giver might be and if not there needs to be at that point to be some distinctions.

Madam Chair Lee: That you would encourage people to get Durable Powers of Attorney in which they might actually discuss these kinds of things and recognize the need perhaps for home and community based care.

Mr. Josh Askvig: Perfect Senator Lee.

Senator Anderson: I want you to straighten out something for me. If you look on line 6 and 7 on page 2, it clearly says a patients' legal representative can designate this person. Why is this subsection 2 in there down to line 16-22 which seems to put the doctor in the middle between that legal representative and somebody else having to figure out who's right here?

It seems to me that line 6 and 7 ought to take of it, and the doctor shouldn't have to referee about that issue down below. If they can't straighten that out between the patient and the person who's is designated that legal representative, becomes a problem for the hospital as physician then will referee that business. Why is that 16-22 paragraph in there? Is it to solve some problem that you perceive or what?

Mr. Josh Askvig: That first section you mention the line 6 and 7 essentially sometimes people come into the hospital already not able to make those decisions. That clarifies that it's either the patient, if the patient is able to make that decision under legal guardian or legal representative could do. The section below essentially as I read it, and the reason it's in the bill says that the hospital cannot give a legal representative or to designate if the patient can designate who that caregiver is. In other words, the patient is always first in who gets to designate the caregiver and last, those other conditions a line.

Madam Chair Lee: I don't read it exactly the same way. I do have a concern about their language as well. I don't want the Durable Power of Attorney or health care designated person, the one who is going to be making the decisions there to be overturned because the person maybe. I think there is a reason for durable power of attorney for health care and I am not sure that I think that a.) anybody should have to referee and b.) that there should be any question about the fact that they would be involved if the patient would be unable to choose one. Because who decides what that means. What does unable to prove mean?

Mr. Josh Askvig: I don't have a great answer for you on that, but what I would tell you is the way that I read it, is essentially it is trying to reaffirm that that patient gets to make the designation unless there are other circumstances that wouldn't allow that to happen.

Madam Chair Lee: That area is so grey. **Mr. Josh Askvig:** If we need to work on that language we would be happy to do that and quite frankly we can double check, but let us take a look and follow up with our attorney's actually and check on that section as well to see if there is a better way to say it. Or I am suspecting others might raise a question or concern that might have a suggestion to improve it as well.

(40:17-44:06) Kirsten Dvorak, Executive Director of the Arc of North Dakota, Spoke in favor of SB2154. Written Attachment #6 for testimony.

Madam Chair Lee: Your talking about ongoing long term care for someone who has a disability as opposed to the discharge giving things which this bill addresses. I am not saying what your saying isn't important, I get it. What I am trying to point out is that this bill is not going to solve that problem.

Ms. Kirsten Dvorak: That is correct, however, we do have some family members that end up sitting with family members for 24 hours because there isn't staff adequate to sit with that member, so they are responsible for replaying that information to providers.

(45:38-55:24) Melissa Hauer, General Counsel for the Hospital Association hear in North Dakota. Testifying in opposition to SB 2154. Please see Attachment #7 for testimony.

Senator Anderson: It's apparent that there are some issues relative to this or we wouldn't hear the anecdotal story from patients or patients' families who go discharged. Now, you said you would be happy to work with those people, but, how does a person know who to complain too, if for example they were discharged and weren't provided information or adequately in time and so forth? Who do they complain too to find that out? Nobody knows about the hospital association and if you're willing to help?

Ms. Melissa Hauer: All hospitals are required to have a person who accepts patients' grievances or complaints. There's supposed to be notification within the patient's rights that tells you if you have a complaint this is the person you contact for our hospital.

Senator Anderson: Perhaps if the last paragraph of your testimony is correct, maybe what you should do is work with these people so that it mirrors what you're already required to do, and then they could check it off their list and we wouldn't have to listen to the bill every session. What do you think of that possibility?

Ms. Melissa Hauer: That is what we are hoping to try to do in the interim when we sat down and talked about where are these problems and what needs to be done to address them. It's hard to know how to address issues if you don't know what they are or where they are occurring.

Senator Hogan: My husband was in the hospital recently and I was reading the bill of rights and all the patients cover to cover to see how this applies in his particular situation. There was an absence on discharge planning and discharge follow-up kinds of concern and I could not get the feel. So it's something you might want to take a look at. I think sometimes that confusing to people. As soon as I am discharged then who do I complain too. Just put that on your radar screen. The discharge complaint issue is who do you go to? How do you process that, and so many times it's a crisis situation and nobody knows where and how to do that?

Senator Rohr: At the hospital I work at, we actually employ nurses whose entire job is to make what we call discharge phone calls. So within 48 hours of discharging from the hospital, you will receive a phone call asking how it's going; anything that you have any follow-up questions about etc, and that often times is where people will then put those pieces together and say, hey, I didn't learn enough about this and then they try and match you up with the right resources or if you have a complaint get you to the patient representative.

Senator Clemens: So, this is kind of falling along with Senator Anderson's with bringing to, but for more clarity, on my own, has there been extensive one on one discussion with AARP and your association? Have you been doing a lot of discussion to figure out the give and take of this bill?

Ms. Melissa Hauer: We have sat down with members of AARP on at least two occasions. I think we have tried and have asked for examples of where things are going wrong so that is part of what we can do as an association is speak with members who maybe aren't doing things the way they should be. We've tried.

Senator Clemens: You've asked for specifics. Where does the improvement have to be made, but you're not getting that, is that correct?

Ms. Melissa Hauer: Yes that is correct.

(1:00:49-1:06:54) Chris Meeker, M.D. Chief Medical Officer at Sanford Health in Bismarck. Testifying in opposition of SB 2154. Please see Attachment # 8 for testimony.

Senator Rohr: I actually just to thank you for voicing what the conflict in my head is, is that agreeing that the intent behind this is right but the vehicle is not the correct one. That's the conflict that I feel within my own head. The nurse in me wants this done right, but the person who is at the sharp end of stick as that nurse, also knows that this while well intentioned likely will not fix the problem.

(1:07:45-1:11:21) Maggie Seamands, Acting Director of the Case Management and Social Service at Sanford Health. Testifying in opposition to SB 2154. Please see Attachment #9 for testimony.

(1:11:35-1:12:06) Courtney Koebele, representing the North Dakota Medical Association. I also share the concerns presented by the hospital association and Sanford Health especially I would like to add on page 2, section 2, I am also a lawyer, and I do work in this area with a group that talks about advance care planning. She testified in opposition.

Senator Anderson: If we take that paragraph out then, will you support the bill?

Ms. Courtney Koebele: I'm not sure. I have other problems with the bill as well.

Madam Chair Lee: Asks for any other testimony.

Madam Chair Lee: closes the hearing on SB 2154

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Minutes:

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| No Attachments |
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Madam Chair Lee called the Senate Human Services Committee back to order. Committee discussion on SB2154, affectionately referred to as the Care Act.

Senator Anderson: I will move that we remove on page 2, line 16-22, just in case the bill passes, that's the section which seems to be in conflict with lines 5, 6, 7 up above and makes the doctor in the middle between the person who is the patients legal representative and the patient who obviously was appointed a legal representative because they couldn't make up their mind and their likely to say however stands beside the bed is my carrier and the legal representative knows better. So I don't want to get the doctor in the middle of that deal so I remove that section just in case the thing passes on the floor.

Madam Chair Lee: Page 2, line 16-22.

Senator Anderson: Maybe Josh is going to get back to us with but he didn't seem to be really clear about why that paragraph was in there either.

Madam Chair Lee: I think it is sort of like camel. It is informed by a committee. Senator Anderson: Somebody said the patient should be able to decide who they get, well they have already decided when they appointed their legal representative in my opinion.

Madam Chair Lee: Well it isn't that they are all suffering from dementia. In some cases it might be that there has been an injury or illness or something that has knocked them out and they can't.

Senator K. Roers: I think hospitals have processes in place already to determine who can and can't make a decision. I don't think that we need another thing that could possibly conflict with other sections.

Senator Clemens: I found it a little surprising in the hearing and I did talk to Josh Askvig, but the association says AARP has not talked to them about what are the problems and so forth and then Josh talks to me and says we did talk to them.

Madam Chair Lee: He asked for a specific incident and I think they both were telling the truth. Josh talked to them about them in his anecdotes and they want examples of specific incidents.

Senator K. Roers: On this date at this time, and this hospital.

Madam Chair Lee: Yes, exactly. Detailed incidents which is not the same as an anecdote. It might be the same incident, but if I am just telling you what Senator Larson told me about something that happened that he knew, and then I related to you, that's an anecdote. But if Senator Larson puts in writing that on January 12 at such and such a time, and such and such a place, these are the kinds of things that happened and these are the people who talked about it, that's a report. So I don't think either one was being deceptive, I think that Melissa Hauer was saying we are asking for specific examples and he's saying we gave you examples but they are not defining examples. Do you, kind of think that's it?

Madam Chair Lee: **We have an amendment from Senator Anderson before us is there a 2nd? It was seconded by Senator Hogan.** Madam Chair Lee asked for discussion on the amendment. If you delete on page 2 lines 16-22 concerning who gets to make decisions for a person. Any discussion?

**Roll call vote on amendment: 6 Yea, 0 No, 0 Absent
Passes 6-0.**

Madam Chair Lee: This is better as I recall than what we dealt with the last two sessions. But are we putting lipstick on a pig or do we have something that we really want to do here?

Senator K. Roers: I don't know that there is any form of this down that I can be okay with. Being the nurse who gets stuck doing the work, of many regulations. When I read this bill, what it turns it out to be is a line in admission navigator that says, who do you designate as your caregiver that's going to be right next to the same question I already have to ask, that something just worded differently. So I am going to check the box, and fill it out and then at the end on the discharge checklist it's going to say, " did you educate the caregiver" and I am going yes and its not going to change people's behavior. So my concern is that just like Dr. Meeker said, the intent behind this is absolutely fantastic, absolutely what we want to do. We want to provide the best care to our patients, however, I don't believe that this is the vehicle that we will get from the issues that are being seen today to the end stay that people would like to see. I don't know what is in its place but I just hate to pass a bill for the sake of passing a bill so they can say, 41 states have it rather than because this is the right thing for our citizens and for our health care workers.

Senator Clemens: So, you feel that the training and the requirements are where they should be whether everybody is doing it or not. Patients are going home with plenty of instruction and training and so forth?

Senator K. Roers: I am not saying that people are going home with the amount of training that they need. I am saying that the regulations that are in place should account for that. Now that not happening, isn't because there isn't a rule telling them to do it, its' because they are not obeying the law. So, in what they call a "just culture", there's I didn't do it because I didn't know I had to do it; I didn't do it because I knew I had to do it, but I didn't think it was the right thing, I didn't do it because I knew I had to do it, I knew it was the right thing and I didn't care. Where are we at in that spectrum, a lot of same. A lot of those different components but adding one more rule may change the, I didn't know piece, but it still isn't going to fix the other two where I did know.

Madam Chair Lee: I had a question during the discussion of some of the anecdotes as well. That is what is the family's responsibility to assure if the person who is likely to be the caregiver really can't do some of this stuff, and you can't legislate this, but what is the responsibility of family members who live far away. None of my kids live close by. Or those kinds of circumstances to make sure that some arrangements are made. I know it's been stated but the plans for discharge are started right after admission and I believe that the good facilities do that, and I think there are lots of people who are rushed in their work, and sometimes their checking the box and just notifying and I get that part because they are swamped with stuff. Particularly A) with a shortage of workforce and B) with travelling nurses and others who are perfectly capable at their profession but are not, they don't know the family as a community. We don't know in Fargo/West Fargo, Morehead either, but at least we know somebody and if you're in a smaller community your bound to know everybody. But if you're far away or you come from far away that's not the case. So, how do we that, well hopefully with better home and community based services. Somehow maybe we need to put in something about informing in the event that as a suggestion also, may, in some other way that is not in statute that they provide a list of potential service providers with an assist to caregivers. I don't want to put a law in about that, but that maybe part of the solution here. You know when Senator Poolman talked about someone who really wasn't capable of doing the work. If there had been a list of potential providers made available. I don't know why people don't call the ombudsmen. I mean that stuff is posted everywhere.

Senator K. Roers: It might be posted everywhere but I'm a nurse and I don't know about it. I literally don't know anything about it.

Madam Chair Lee: When you walk into a skilled care facility it's posted on every wall.

Senator K. Roers: I am sure that it there, but I've only been in the hospital setting.

Senator Larsen: I am thinking back of the last sessions about what the folks in the red shirts were talking about. Their concern was about when they were going to pick somebody up and put them into the van that they felt that they wanted to get to feel more comfortable with some information and they were kind of being felt like, 'hey we gave you what we need to give you, so load them up and take them away', that's the feeling that I kind of got from the last discussion of that. I think that some of the folks are still feeling that way. I don't anecdotally, it might be the older wife picking up the husband and their saying this is what you've got to do. Everything is meant to be high speed system and their swimming in it. Wait a minute, I need a little bit of help here and they are just still feeling rushed. They might think this might be a point where they can say, 'stop and wait a minute', I want to have more information. I

guess that is the meat of what I feel about this issue. This is now the 3rd session, that I am aware of anyway.

Madam Chair Lee: Could we work with the hospital association do you think to have them develop software recommendations to their membership about including in those instructions at the time of discharge, a list of connections to services that might be available and boy that is going to be varied from one part of the state to the other. But that seems to me to be part of this. I know if you're an hour away it's a big deal to drive 2-hour round trip to help somebody with whatever it happens to be.

Senator Hogan: The other issue is so many people are different manners and you get a big packet of material and it's so overwhelming to them that all of that material overwhelms them. Then they go home and just getting into bed, all of the logistics of this transition especially for seniors, is really overwhelming. It is the situations where there's home care or tubes, or back braces. I mean I think they are really some concern about things they don't know.

Senator K. Roers: It just surprises me how often patients go home with such complicated care and don't qualify for home care. That is something that to this day baffles me and so number one we can't find enough people who work in home care, so even if everybody did qualify for home care, I am not sure how we'd actually execute it. But it does surprise me the degree to which we are expecting care givers to be able to care for a patient. I just don't know how to make it better.

Senator Larsen: Sen. Rohr touched on it a little bit and I think that there is a little bit more to that iceberg and that was the travelling nurses and those folks. I've been in two myself, in the hospital dealing with travelling nurses and my aunt with that and it's been very interesting how the care is way different with travelling nurses than it is with the people that are employed there.

Senator K. Roers: Often their technical skill are.

Senator Larsen: That person, when I think of that person who stiffed me on the morphine to have me leaving that facility in the condition I was in, it was horrible. I don't think I would've got that from somebody who worked there. My aunt with her situation, she didn't have anybody coming and going. We just kind of came and went and they looked at us like you're not on the list of registry thing and were not letting you take her home. We are not letting you do anything with her. How are we going to get her home? I can see some of that stumbling stuff.

Senator Clemens: Getting back to what Senator Hogan talked about, especially the elderly. They are overwhelmed with all this stuff. According to Senator Roers, there are things in place so now we pass this bill and we are just going to overwhelm them even more.

Madam Chair Lee: In duplication.

Senator Hogan: I think the idea is that the caregiver gets some really hands on training on the back brace or the tubes or the wound care, and I think some of that is some of what. It's one thing to get a book that says this is what you should do, it's another thing to have somebody walk through it with you. Sometimes they do, wouldn't you say Senator Rohrs, that sometimes they do and sometime they don't.

Senator K. Roers: Yes, I think that one of the challenges that you also have is especially in a large facility and that's my only experience. I don't have experience with small facilities, so none of my examples will ever be that. But it may be the occupational therapist, like in Senator Poolman's or in the Jacobson, he read her testimony. It may be the occupational therapist who may be the expert in how to apply and how do you leverage the patients' physical therapy whoever that is. Well they have to see ten patients in a day, so are you the caregiver here at the time that person is scheduled to see this patient. Maybe not because you were at work, and now you're here, but the OT expert is now gone. The moving parts are so complex that I don't know that when you have the words, "as soon as practicable before discharge of a patient" you know you will attempt to contact them, provide for opportunity offer instructions and that type of thing I think what you're going to find is people are going to say, it wasn't practical. Oh I tried, it wasn't practical. Again we won't have moved the needle.

Senator Hogan: Those were compromised languages to try and give that but if it helped some would it be worth it?

Madam Chair Lee: Well, I guess I would rather see some effort made to walk through the hospital association and the various professional associations to see if they would take some personal responsibility to enhance it in certain cases. How can we make it easier for them without making it harder for them to do the kind of care that needs to be done? I see a couple of examples that I can think of, where the spouse is perfectly capable person but extra ordinary wound care that they were expected to do, there should have been home and community based services for those two people I can think of. They learned about it and they were willing to do it and in one case older people, but they were incapable people. But that is a big deal. Not everybody can do.

Senator K. Roers: Senator Larson I am a nurse and I don't like wounds much.

Madam Chair Lee: I think burns are the worst. We know the need and I really agreed with what Dr. Meeker said and I don't know that this is the vehicle that we all agree the same thing has to be done. Maybe we should and I can do this, just to send a message out to the hospital associations and Ms. Courtney Koebele with the docs and some of these others and see if we can come up with some continuing education. They are all overworked to, and I get that part. Workforce is so much a part of this whole thing, but if we could just tweek some of those areas because we can't legislate competence. If Kristen is capable of doing it even if she is not a nurse, but I take that away, then maybe I am not a capable caregiver but she would be even if she were not professionally trained for it.

Senator Clemens: This is a little irregular but what if we sat down with the association, and AARP and said look, 'can we come to an agreement here what we need to make a good bill out of this'?

Madam Chair Lee: I don't its irregular to have a conversation about it.

Senator Clemens: I mean altogether at the table. Let's work out a bill here.

Madam Chair Lee: We can do as an afternoon committee discussion. What a good idea! Is there anybody who doesn't think this is worth a shot?

Senator Larsen: I've always heard about these, they have to have one through five on your care, do you fill that out when you're getting off the bed and being wheeled out or do they mail that to you in the bill?

Senator K. Roers: No, you have to use an outside agency, you cannot provide the survey to the patient while they are in the hospital. It has to be sent through an outside agency that you contract with so that you can't mess with your own data. So, for example, Sen. Roers had an appointment on the 1st and by about the 5 or 6th I had an email because in my account I said you could email it to me rather than mail it to me. So generally within a week of discharge is what they try and get it to hit your mail box and then we see the percentage of patients who return it within the first seven days is the highest and then it decreases the longer and further away you are from your appointment.

Senator Larsen: What is the percentage of people returning the survey? Is there anything you can find?

Senator K. Roers: I could probably get that data for you, what the national average is, but I don't believe it. It's higher than you think but it's not ginormous. I could get the ballpark for you, for your own information if you like.

Senator Hogan: It's just a capacity that to even fill the form out if you're overwhelmed with somebody with, it's not small. When people say we don't have the documentation well we don't get it because if you're really angry and overwhelmed you're not going to fill out a form.

Senator K. Roers: Actually they say that the people who are most likely to fill it out are the people who have fantastic experience and one who have a horrible experience. So you get very little of the middle.

Madam Chair Lee: I think that for the people that are involved in the care giving it is such a distracting time when you're looking at how am I going to cope with this when this person come home, and what do I do. You don't really know until you kind of get into it. Then you realize maybe you're overwhelmed.

Senator Larsen: The reason why I think there may be a disconnect in this particular issue is because you never hear this issue about cancer and we're hearing this so my experience with cancer is you go in there and it's your first appointment. Man I've got the prostate cancer and boom there is a lady right there and this is what you do, here's how you are, this is where we go, they walk you through that whole process and then ask how it's going, here's some gas cards, and you never hear of having this issue about the after care about

cancer and when I come home and what do I do with these pills and so forth. So, there is a disconnect between the care of that existing and entering strategy and this whatever this is.

Senator K. Roers: I think part of that is a disease process like that is kind of replicable. You can anticipate the stages where with more complex medical issue or even some surgical issues. You can go in so many different directions and the needs where my background is oncology, so with cancer you have some pretty set mild-stones that people hit and you can coach them through that process, plus in areas like heart services and cancer services they've employed this concept called a nurse navigator and that navigator is likely that person that kind of came to you and was like here is the process were going to go through this; these are the appointments, I am going to help you make sure everything stays coordinated and again it's because those are very replicate-able, but also I will admit, those are the high reimbursement areas. We get much higher levels of reimbursement for cancer and heart than you do for general, medical or other things like that.

Senator Clemens: There is a huge population that really needs the help and I think we are kind of on the borderline of. I hate to vote no on this and throw the whole thing out if there's a compromise that would appeal to everybody. Then maybe we won't have to look at next year or next session.

Senator Hogan: I was on the first bill which was radically different from this bill. This is a pretty mild bill compared to the 2016 bill. Sometimes the language of 3 years ago, and passed in California. I like the negotiations.

Madam Chair Lee: Dean Winger is at the podium right now, but I talked with Dave Bowman and he said they would come over as quickly as they could. But I would be curious for those who are familiar Dean Winger runs the medical school and a remarkable guy, and Dave Bowman is the administrator who is unfortunately about to retire in Grand Forks and Altru, but a heck of a guy too. They are actually in large part responsible for the new medical school building and all the good things that are happening at UND and am tickled that they are here. But what we could do is, send an invitation of who we want in addition to the medical, or we could ask the Board of Medicine, Bonnie Storbakken as long as she promises not to bring any more paper.

Senator K. Roers: The doctor writes the order and the nurses who actually does all the work. I think we need to make sure that the Nurses' Association is at the table also.

Madam Chair Lee: I am wondering if it should be the Nurses' Association, or do you also want the APRN's coming in, I mean because they are not all the same.

Senator K. Roers: No, but again their component. Shirley Miller from the Nurses Association.

Madam Chair Lee: So if we invite the Nurses' Association, and the Medical Association and Hospital Association, and Josh and Mike from AARP that's enough to gather around the table. Is there anything else that we want on for on our list here? If we have Courtney, Sherry Miller, Melissa, Josh and Mike, so maybe we can do it tomorrow if they could do it

tomorrow. This isn't going to involve the Department of Human Services and their budget cuts tomorrow. So I am trying to be respectful of their stuff going on.

Madam Chair Lee: We'll look at Wednesday, Red River Room, at 2:30 pm.

2019 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2154
1/16/2019
Job # 30934

- Subcommittee
 Conference Committee

Committee Clerk: Justin Velez

Explanation or reason for introduction of bill/resolution:

Relating to hospital discharge policies.

Minutes:

No Attachments

Madam Chair Lee and the Senate Human Services Committee brought together Josh Askvig and Mike Chausee of AARP, and Tim Blasl and Melissa Hauer of the North Dakota Hospital Association to meet so that the two organizations could come to a consensus on SB 2154.

Madam Chair Lee: The problem is how do we figure out a way to interact with them in a way so that they know who the home and community based supports might be that could ease them during that first week or two. It's hard for people who need specific care after discharge like wound care or constant observation. We have a lot of counties where there isn't a lot of community based providers. I think the deal is, the committee doesn't have the answer so maybe among you we may be able to come up with something here. We are all in the same boat, how do we all start paddling in the same direction.

Senator K. Roers: One of things that were thrown out yesterday was, how do you provide that list of home and community based services? The thing about that, is you may not even qualify for that, so I can give you the list and you're going to call them and they will tell you I'm sorry but you don't qualify. I fear that creating a list like that also creates a false expectation. In the same way that I give you this list of instructions, and a list of services and contacts may not be the thing that we are looking for either. I think the challenge is, how do you change the hearts and minds of people who aren't doing this correctly? How do you get them to see the value in including that caregiver in the discharge instructions to ensure a smooth transition?

Madam Chair Lee: Also how do get every hospital to train and employ community health workers because I see that as being one of the biggest tools in order to help these people. Some of the larger systems have people who may call to see how the recovery process is going, some places don't have it.

Senator Hogan: I really appreciated Dr. Meekers testimony yesterday where he listed the CMS requirements. I took those requirements and tried to cross-reference them with the CARE's bill, and these patient caregivers are active partners in the discharge plan, which is both that designation and notification process. The notification and designation are kind of the steps to meet this CMS requirement. I don't know what process patient caregivers are active partners. If somehow we could begin to language something where everybody wins, if that's the CMS standard then maybe we are not as far apart as we think we are.

Senator K. Roers: I wonder if the maintaining policies and procedures, some of the stuff that is in 2 through the end here could actually be the requirement of a policy rather than, I feel like it's a regulation that now the department of health are coming in and doing our validation survey and now they are going to say show me where you charted this and it's a little more prescriptive where if it was something more of each hospital will develop and maintain policies regarding this, it would loosen that regulation burden especially for those who are doing it right. While still making sure we are saying this is important and something that we want you to make sure is being payed attention to.

Senator Hogan: If patient caregivers are active partners for CMS as a requirement, how do you document that?

Tim Blasl, President of the North Dakota Hospital Association: Josh, I have a question for you. I know you have talked about you have been visiting with hospitals around the state, I was a part of those discussions but, was there any sort of light bulb that went on or education that they provided. Were there areas that maybe aren't doing it well and we need to visit with those hospitals? Is there one hospital or is there a group of them?

Josh Askvig, AARP: So everyone is aware we have always believed in sitting down and having a discussion, to directly your answer Tim; two things, what I said yesterday was in our conversations with you all. Some of the teach-back stuff that you guys did at your conference recently, I thought it was good content, but even that stuff was all patient only focused. Even the video that showed, this is how to do it, it's only talking about a patient and that aspect of it. The point we are trying to make and continuing to have the dialogue on, for patients who are aware and able that's great. There are a lot of instances where that is not the case so making sure that person when they go home that the person who is actually going to have to do that actually happens. I want to be clear about two things, I know you guys asked about stories yesterday and we have a sheet that we would happily pass out but there isn't really a week that goes by that we don't hear someone tell stories about this. I agree finding common ground makes sense and I will tell you, if we can construct something that says the policies would include these things, that is what we were intending to do. If you look at the bill from last session that was essentially what that bill said and that was the bill that we negotiated with that we thought, we had agreement on but that didn't work either. If that is something we are going to look at, we would be happy to take a look at that and maybe not be as prescriptive in the language. To answer the question that Senator Lee started with which is, how do we help those folks who are nervous scared and worried about how they can help their loved ones heal. We care about caregivers and this is what we are trying to do to ensure that we put some basic constructs in place that show that we are trying to help those caregivers do it better.

Senator K. Roers: I wonder if another opportunity for working together would be, you may have some resources at your disposal to help create the education that you really want to see and how do we then share that with the hospital members for them to utilize with their staff and not have to create something from scratch and meets the standard that you are really aiming for.

Mike Chausee: We have created a library of videos. There are states that even in their statute will say it doesn't have to be face to face in the training you can use a video instead. There were states that wanted to have that prescriptive. We would probably be ok with that. The options are there and she even talked about consultants and other services that we could provide. The other thing about being the 41st state to hopefully pass this, is that other states are starting to get into this, learning what works and doesn't work. Some of the cool stuff that I have heard of are the taskforces that have been formed in hospitals and hospital groups that focus just in the care giving aspect and those are great, part of that is bringing it to the state and local level rather than it being this national standard. A conversation and a collaboration is better. Promotionally, we wouldn't even have to bring the national folks into this. We would celebrate this and use our resources to let people know not only what they can do, but how they can collaborate and make life easier on the hospitals.

Senator Clemens: I think it is difficult to address a problem if you don't know what the problem is. I think for the hospitals to get a grasp of what is needed, they need to have some specifics on what is the problem. We are talking in a lot of generalities here and I worked in quality control in manufacturing and there is a rule in manufacturing that we consider the parts of a system or a machine, 20% of your parts are responsible for 80% of your problems. I think if AARP could come forward with, this is what we are seeing, you will find out that there are a few things that are causing the problems. Until we have that conversation, I think it's going to be very difficult for the hospitals to be able to address that. It's hard for them to say they are going to fix the problem assuming there is something wrong with everything. What are the problems?

Tim Blasl: You said it perfect. That is what we tried to do during the interim with both Josh and Mike. We sat down a couple different times to show us examples. If there are issues we want to address that but, we didn't have example so that makes it hard to address the problems. If there are issues, there are no doubts that the Hospital Association and our members want to address this. We are not sure of the exact issue and that's why when I asked, you have been talking to hospitals, what have you been hearing. Is it apart of the state, just one hospital, and where is this happening?

Senator Anderson: I wonder if simplification of this business wouldn't be helpful and that is if the hospitals could write down what they see is their obligation under their joint commission standards or the CMS standards for training the patients. Then we had a documentation piece for that they could accept. For example, we have a check box that says this patient would like a caregiver yes or no and then if they designate that caregiver, obviously that is going to be in the patients file. It seems to me that would do two things; it would accomplish part of what we are talking about here and it would give the hospital a defense against any CMS or joint commission group that comes in and says you didn't properly take care of this patient for these reasons. Also, the training piece and so forth. The big hospitals probably have a training piece that they use but I don't know if the smaller ones would be happy to

have something that we could run by AARP or somebody else that talks to this process. It seems to me like those two or three pieces are things that the hospitals need to do already. When we say what are the problems here, we all have those anecdotal stories but without looking in detail at that story we don't know if the hospital was inadequate in their training or if the patient was distracted or if there were four people in the room saying I'm going to take care of this guy and the wrong one got the training but the patient hadn't picked a particular one. I suspect that if we looked at the details, we could identify and correct them on a detailed basis, but to say a broad brush we probably won't accomplish a lot because we are still going to make the same mistakes.

Senator Clemens: I want to just give a quick example that I experienced when I was field testing on quality control and my job was to go check out with the customer and see how they were appreciating our machine. They weren't using the wheel loader that we had given them, and we were wondering what was wrong with our machinery, why aren't they using ours in comparison to another one. I talked to the people and asked what was wrong with our machine for them not to use it. Their answer was; because it doesn't have a radio. We put a radio in it and they used our machine. The point is on a 500,000-dollar machine all it needed was a radio and you can relate that to this problem. It might be the smallest little thing that is causing some problems and if that was fixed then the whole system would work.

Josh Askvig: I want to point to a couple of things, to push back on this idea that we haven't provided any evidence. We have done three surveys now in the last six years. Phone surveys, professionally conducted that continued to show that there are folks around the state indicating that the different steps aren't happening. I understand the question about specifics and I will address that in two ways. I will admit we probably weren't as totally forthcoming as we were last interim as we should have been in part because we tried that three years ago and thought we had an agreement and it didn't happen. That is not their fault, they are new. I hope you can at least understand why we would might have been a little bit reluctant to give them a lot of ammo which they used last time against us. Some of you are aware of what happened. I want to be clear about that. I have some of the stories we have collected here and I would be happy to pass them out if you think that would be helpful, but I will tell you a lot of those people are embarrassed. They don't want to come forward; they think it is their fault.

Madam Chair Lee: I think it could be blind. People privacy is a big deal but, if you know that I had a problem as a patient who was released from xyz hospital, that could be part of your data. You would know what hospital it was but, the patient has to write the review and there has to be a chance for the hospital to respond also and figure out what is the communication issue is. I know our hospitals are rushed and all of that. There are certain things that might be helpful and useful to folks who are leaving the hospital.

Senator K. Roers: I think there are varying degrees of that. We try very hard in hospitals to keep people away from Dr. Google and Dr. YouTube. You could try to create videos like that which also depends on what electronic medical record you use and then in conjunction there are patient education systems that most, especially the big hospitals will actually purchase a license from. At Sanford we use cranes, and that allows us to actually insert links into their profile, but again you have to have a certain level of technology sophistication for me to be able to send that to you and you be able to utilize it appropriately. I'm just trying to think

through my discharge navigator. I know when I educate the patient I have to say who I educated. Most of the time the discharge paperwork is filled out after the patient has left the building. I would love to say you do it as you go but most of it is checking boxes for the sake of checking boxes and not actually your flow. If there was a question in there stating, with all discharge education who was educated, something to that affect that would help bring a reminder that it is not supposed to be just the patient. Again, that would be a check box and that would most likely be something that is filled out after the patient has left.

Mike Chausee: I do appreciate Tim's question about the stories and stuff and they did ask, and we did gather. We actually made a big effort. You can see this from the ones that we provided there that we are not talking about someone who can spot a radio, we are talking about novices who don't do healthcare that are looking for what went wrong in healthcare. When we hear stories its often, these quick little anecdotes about this happened to me or I could have used that when I was leaving. Yesterday, we had six volunteers who heard Josh's testimony and on the way out of the hearing everyone starts telling us their stories. We have been talking about this for years. It's a bunch that need help. The surveys that some people see as, these hospitals still aren't doing their jobs, I see the big picture with bringing in the Care act or publicity and knowledge of these things as a positive. The first one I saw when I started, that 50% of the caregivers said they weren't getting trained. Then we did one last session and it was at 33%, this shows that the hospitals are probably doing their jobs. The one we did just before is now at 27%, so now I'm thinking the more we talk about and the more of the big picture is out there, it's getting better. I am fully supportive of the bill, I think we need something kind of out there in state level just to focus on, but even talking about is and hospitals going whoa, we need to do this, it has gotten better. This broad awareness, letting people know, I can ask this question or this should be happening and hospitals saying we can do better and how about we do this. It builds momentum and a positive outcome.

Senator Hogan: I keep going back to the CMS requirements which really aren't there. Do you know how hospitals engage to make sure their primary caregivers are active partners and have you surveyed your hospitals about their experience to see the other side? From the hospital side, how responsive are you identifying active caregivers prior to discharge and how do you assess their availability and capability? CMS coming in and looking at this is one view, but as an organization to look at those kinds of standards with a different view. Instead of being defensive about it.

Senator K. Roers: When you generally ask who the caregiver is, is when they are coming in the door and you don't know what the needs are going to be going out the door. It's a challenge to assess that caregiver for their ability if it's going to be a Band-Aid or wound vac. It's a challenge.

Senator Hogan: That standard about hospitals consider the availability and capability of the caregiver to provide in-home care. That is a CMS standard and that is a complex standard.

Senator Clemens: I know this probably doesn't encompass all the complaints or concerns that you have, just going off of the list you gave me, 75% of these issues are coming from Fargo and Bismarck. This is what I'm kind of getting at, maybe the hospitals in Fargo and Bismarck have more people and maybe they don't have enough staff but it might worth the

while just to talk to them and say you are showing a considerable amount of the total issues. They could be more conscience about how they are discharging their patients.

Madam Chair Lee: Are there more concerns expressed in the larger hospitals or in the critical access hospitals or does it make any difference?

Josh Askvig: I think it's a great question and there are two parts to this answer. A lot of our collection is from the places where we often go so we spend a lot of time in Bismarck, Fargo, Minot, and Grand Forks so to be fair, that is part of the reason why you see that piece too. Our national office has been having discussions with critical access hospitals across the country about how they handle family caregiver supports and one of the initial observations is they might actually do it a little bit better, you can't hold me to that but it was an interesting tidbit that I heard back when we were having the conversation. We are trying to us telephone services to connect across the broader part of the state to see if it is showing up a prevalently in other places and I can't answer that directly for you right now.

Madam Chair Lee: An example from when I was actively involved in real estate. I was helping this couple get their house sold and he was extremely difficult. You know what we figured out, he couldn't read. I always go through the contract word by word and I could read upside down, I would go through a sentence or so and he would hammer about how he was suspicious and was sure that he was being cheated. It just took a ton of time to get this guy's confidence up a little more and his wife was fine with us, but that is a part of the challenge that we can't fix with legislation or anything else. When you are trying figure out what the caregiver is going to be able to do, what are the capabilities in things like reading or technology.

Senator Anderson: When I looked through these things, 90% of them could have been solved by somebody not making an error or assuming that the wife could do something when she is not capable. I don't know how legislation fixes that. There are a couple of them where the process wasn't correct, but that's why I say when you look at these things case by case, unless you can analyze them and find out what the real problem was it is hard to fix that. I have been in the hospital a lot of time and got pretty good care but, once and a while I get out and my problem has always been that the people that I go to for follow-up care they didn't really understand how to do it. When you come home with your leg chopped off, there aren't many of the local people who have seen a wound like that, even the nurse or the local nurse practitioner doesn't understand how to take care of that because they haven't seen it before. Some of those things we are not going to solve by legislation. Generally speaking, I always got good care and maybe that is because my wife asked the right questions. I do think that if you could work together and do the things that I pointed out where the hospitals could write down for us what they are required to do and get some documentation that they did it, and then provide some training pieces maybe we could reduce these things down closer to zero.

Senator Hogan: Has this issue come up at any of your Hospital Association meetings? Do you have sessions on this kind of implementation because other states have had some good engagement from Hospital Associations? Have you had a chance to work with them on their experience?

Tim Blasl: From the American Hospital Associations perspective, all the meetings I've been to, we haven't talked a lot of about this. There hasn't been a lot of discussion within the National Association on the caregiver.

Senator Hogan: It might be an interesting question to survey because I know other states have supported it and so it would be interesting to get a sense of their view and the Hospital Associations reaction in the 40 states that have passed this.

Madam Chair Lee: Maybe the Hospital Association is a good source. In addition to AARP.

Senator Hogan: Maybe we could do something collaboratively with the Hospital Association and AARP.

Tim Blasl: I would be glad to inquire at the national level.

Madam Chair Lee: I think it's important we don't tell you what to do, when we don't even know how it should be done. I would like to be able to continue to work with this group and figure out how we can all live with whatever we are doing, knowing there's no perfection here because everything is case specific.

Tim Blasl: Could there be some additional education on the standards that we need to follow, yes. From my perspective, this is not my bill and I would think that from AARP maybe they should bring some things forward on changes because I don't see us changing our position the way it is written.

Madam Chair Lee: I don't want to create a burden for anybody who is working on this, that doesn't accomplish anything and especially for the people who are being served. I keep coming back to the ability to have someone like a community health support person. If I get home and can't put the sling on I shouldn't have to call the hospital or the doctor, I should be able to call the community support person who might be able to come over and visit and show me how to do it. We haven't come to a conclusion here but maybe we can come back and chat a little bit next week about this. I think we all want the same goal here which is the best thing for the patients without driving everybody crazy. I am happy to have us get together again, if anyone wants to do that in smaller groups in the meantime, please feel free to do that.

Madam Chair Lee closes the discussion on SB 2154.

2019 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2154
2/11/2019
Job #32495

- Subcommittee
 Conference Committee

Committee Clerk Signature: Justin Velez and Alicia Larsgaard

Explanation or reason for introduction of bill/resolution:

A BILL for an Act to create and enact chapter 23-49 of the North Dakota Century Code, relating to hospital discharge policies.

Minutes:

Attachments: 1

Madam Chair Lee: Opened the discussion on SB 2154.

(01:20-06:50) Josh Askwig, AARP of North Dakota: Gave the committee an overview of the proposed amendments for SB 2154. Please see Attachment #1 for proposed amendments. The one in front of you is the hog house amendment. The first section essential replaces the whole bill. I want to thank Tim and Mellissa from the Hospital Association. I think they would say it is not exactly what they would like but it will work. We would say the same thing. The first part of the bill is definitions. I think the highlight for you is that it clearly defines what an informal caregiver is and it talks about when the designation should occur. There is another section where it should not interfere because that is just the definition. It helps better illustrate for both caregivers, patients, and hospitals as to when that should occur. The other section still maintains the flexibility. We went through the chart we had emailed you all that talked about the differences between the care act, administrative rules, COPs, and accreditation. When we came back, Mellissa and Tim shared some additional information with us about some of the guidelines and the implementation of those. We came to a place where what you see in front of you is a lot of what makes it clear that ND recognizes care givers, the importance of them, and doesn't overburden them. The other good thing about this is that we are planning to do some education around hospital discharge processes regardless of what happens this session. We have already been talking to them about partnering up to do that. The first section says that they have a discharge planning process that applies to all patients and that the policies and procedures are in writing. The second part gets to the designation and notification in the care act and insuring that the patients or the patient's informal caregiver puts that recognition in. The other pieces in C make sure that is communicated to both the patient and the patient's informal care giver. This leaves some flexibility for those instances when patients don't designate care givers. The last piece I would tell you is the one we really like. That is making sure that hospitals did into what is a patient going to need when they leave here, involving that care giver and making sure that caregiver gets involved. Some do already, and for others, this will be a helpful reminder to make sure

we continue to make strides to improve. The part I think we really gravitate to is the third part which might seem a little awkward to write in statute but I think it reaffirms that using those repeated reviews of instructions and making sure that patients and their care givers get a chance to engage in that and understand what it is they are being asked to do. This is an amendment and a bill that we will be happy to move forward with.

(06:57-08:11) Tim Blasl, North Dakota Hospital Association: A lot of work went into this on both sides. I thank both Josh and Mike. This bill is a compromise. We are going to get an alert out to our members today to make this public. We did not receive any negative feedback. A lot of what you see in the bill is in the hospitals that we have already. I think it is a win-win for everyone. Josh did a good job explaining the amendments. I know Mellissa put a lot of work into this. With that, I will stand for questions.

Madam Chair Lee: I really appreciate all the work you put forth on this.

Senator K. Roers: Moved to Further Amend the bill.

Senator Anderson: Seconded.

Madam Chair Lee: Any Discussion?

A Roll Call Vote Was Taken: 6 yeas, 0 nays, 0 absent.

Motion Carried.

Senator Roers: Moved a Do Pass as Amended.

Senator Anderson: Seconded.

Madam Chair Lee: Any Discussion?

A Roll Call Vote Was Taken: 6 yeas, 0 nays, 0 absent.

Motion Carried.

Senator Roers will carry the bill.

2019 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2154
2/13/2019
Job # 32692

- Subcommittee
 Conference Committee

Committee Clerk: Justin Velez

Explanation or reason for introduction of bill/resolution:

Relating to hospital discharge policies.

Minutes:

No Attachments

Jennifer Clark, Legislative Council: There are three changes made here. One, we took away that very first definition of aftercare assistance. The second change we made was, the “hospital shall as appropriate communicate the plan to the patient or their informal caregiver or representative”. We did that same thing “as appropriate” at the very end “as appropriate a hospital shall educate or train a patient”.

Madam Chair Lee: So the “as appropriate” is new?

Jennifer Clark: Yes.

Madam Chair Lee asks the representatives from AARP and the North Dakota Hospital Association if they would like to add any other information and agreed with the committee that with the new amendments that both parties are satisfied.

Senator Hogan: I move the **reconsideration** of SB 2154.
Seconded by Senator K. Roers

VOICE VOTE TAKEN
MOTION CARRIES

Senator Hogan: I move to **ADOPT AMENDMENT 19.0699.01002**
Seconded by Senator Clemens

ROLL CALL VOTE TAKEN
6 YEA, 0 NAY, 0 ABSENT
MOTION CARRIES TO ADOPT AMENDMENT 19.0699.01002

Senator O. Larsen: I move a **DO PASS, AS AMENDED**
Seconded by Senator Anderson

Senate Human Services Committee

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Page 2

ROLL CALL VOTE TAKEN

6 YEA, 0 NAY, 0 ABSENT

MOTION CARRIES DO PASS, AS AMENDED

Madam Chair Lee closes the discussion on SB 2154.

PROPOSED AMENDMENTS TO SENATE BILL NO. 2154

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact chapter 23-49 of the North Dakota Century Code, relating to hospital discharge policies.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. Chapter 23-49 of the North Dakota Century Code is created and enacted as follows:

23-49-01. Definitions.

As used in this chapter:

1. "Discharge" means the exit or release of a patient from inpatient care in a hospital to the residence of the patient.
2. "Informal caregiver" means an individual who is at least eighteen years of age, who a patient, or the patient's legal representative, designates at admission as a lay caregiver, and who following the discharge of the patient is willing and able to perform post hospital care for the patient at the patient's residence.
3. "Post-hospital care" means care directly related to a patient's condition at the time of discharge and which is provided by an informal caregiver to the patient in the patient's residence.
4. "Residence" means the dwelling a patient considers to be the patient's home. The term does not include a hospital or rehabilitation facility.

23-49-02. Patient and Caregiver Discharge Planning Involvement and Documentation

1. A hospital must have in effect a discharge planning process that applies to all patients. A hospital's policies and procedures must be specified in writing.
2. A hospital must identify at an early stage of hospitalization all patients who are likely to suffer adverse health consequences upon discharge if there is no adequate discharge planning and actively:
 - a. Involve such a patient throughout the discharge planning process and, as needed, the patient's informal caregiver or representative or both;

- b. Document in the patient's medical record the patient's discharge plan;
- c. Communicate the plan to the patient and, as needed, the patient's informal caregiver or representative or both;
- d. Document in the patient's medical record the arrangements made for initial implementation of the discharge plan, including any training and materials provided to the patient, the patient's informal caregiver, or representative.

23-49-03. Training or After Care Tasks

1. A hospital shall counsel a patient, the patient's informal caregiver, or representative as needed to prepare the patient for post-hospital care, which may include providing in-hospital education or training to the patient or to the patient's informal caregiver or representative.
2. The education or training provided by a hospital to a patient, the patient's informal caregiver, or representative must be tailored to the patient's identified needs which may include medications, treatment modalities, physical and occupational therapies, psychosocial needs, appointments, and other follow-up activities.
3. Teaching methods used by a hospital may include repeated review of instructions with return demonstrations or repeat-backs by a patient or the patient's informal caregiver or representative.

Renumber accordingly

February 11, 2019

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PROPOSED AMENDMENTS TO SENATE BILL NO. 2154

Page 1, line 15, replace "Lay" with "Informal"

Page 1, line 15, replace "old" with "of age"

Page 1, line 16, after "designates" insert "at admission"

Page 1, line 17, replace "aftercare assistance" with "posthospital care"

Page 1, line 19, remove """Patient" means an individual who is or was receiving inpatient medical care in a"

Page 1, line 20 replace "hospital" with """Posthospital care" means care directly related to a patient's condition at the time of discharge and which is provided by an informal caregiver to the patient in the patient's residence"

Page 2, line 1, replace "Aftercare assistance policies - Designation of lay caregiver" with "Patient and caregiver discharge planning, involvement, and documentation"

Page 2, line 2, replace "evidence-based" with "a written"

Page 2, line 2, after "discharge" insert "planning process, including"

Page 2, line 3, after "procedures" insert ", which applies to all patients"

Page 2, remove lines 4 through 15

Page 2, line 16, remove "A hospital may not give a legal representative who is an agent under a durable power"

Page 2, remove lines 17 through 31

Page 3, replace lines 1 through 11 with:

At an early stage of hospitalization, a hospital shall identify patients who are likely to suffer adverse health consequences if discharged without adequate discharge planning. A hospital shall involve a patient throughout the discharge planning process. As appropriate, a hospital shall involve the patient's informal caregiver or legal representative in the discharge planning process. A hospital shall:

- a. Document the patient's discharge plan in the patient's medical record.
- b. Communicate the plan to the patient, the patient's informal caregiver, or the patient's representative.
- c. Document the arrangements made for initial implementation of the patient's discharge plan in the patient's medical record, including any training or materials provided to the patient, the patient's informal caregiver, or the patient's representative."

Page 3, line 12, replace "Notification of transfer or discharge" with "Posthospital care training"

282

Page 3, remove lines 13 through 30

Page 4, replace lines 1 through 23 with:

- "1. A hospital shall educate or train a patient, the patient's informal caregiver, or the patient's representative to prepare the patient for posthospital care.
2. The education or training provided by hospital staff to a patient, the patient's informal caregiver, or the patient's representative must be tailored to the patient's identified needs, including medications, treatment modalities, physical and occupational therapies, psychosocial needs, appointments, or other posthospital care.
3. Education and training provided by a hospital may include repeated review of the training and materials with a patient, the patient's informal caregiver, or the patient's representative."

Renumber accordingly

February 13, 2019

SK
1302

PROPOSED AMENDMENTS TO SENATE BILL NO. 2154

Page 1, line 8, remove "Aftercare assistance" means assistance provided by a lay caregiver to a patient"

Page 1, remove lines 9 through 12

Page 1, line 13, remove "2."

Page 1, line 15, replace "3." with "2."

Page 1, line 15, replace "Lay" with "Informal"

Page 1, line 15, replace "old" with "of age"

Page 1, line 16, after "designates" insert "at admission"

Page 1, line 17, replace "aftercare assistance" with "posthospital care"

Page 1, replace lines 19 and 20 with:

"3. "Posthospital care" means care directly related to a patient's condition at the time of discharge and which is provided by an informal caregiver to the patient in the patient's residence."

Page 1, line 21, replace "5." with "4."

Page 2, line 1, replace **"Aftercare assistance policies - Designation of lay caregiver"** with **"Patient and caregiver discharge planning, involvement, and documentation"**

Page 2, line 2, replace "evidence-based" with "a written"

Page 2, line 2, after "discharge" insert "planning process, including"

Page 2, line 3, after "procedures" insert ", which applies to all patients"

Page 2, remove lines 4 through 15

Page 2, line 16, remove "A hospital may not give a legal representative who is an agent under a durable power"

Page 2, remove lines 17 through 31

Page 3, replace lines 1 through 11 with "At an early stage of hospitalization, a hospital shall identify patients who are likely to suffer adverse health consequences if discharged without adequate discharge planning. A hospital shall involve a patient throughout the discharge planning process. As appropriate, a hospital shall involve the patient's informal caregiver or legal representative in the discharge planning process. A hospital shall:

- a. Document the patient's discharge plan in the patient's medical record.
- b. As appropriate, communicate the plan to the patient, the patient's informal caregiver, or the patient's representative.

WBL

- c. Document the arrangements made for initial implementation of the patient's discharge plan in the patient's medical record, including any training or materials provided to the patient, the patient's informal caregiver, or the patient's representative."

Page 3, line 12, replace "**Notification of transfer or discharge**" with "**Posthospital care training**"

Page 3, remove lines 13 through 30

Page 4, replace lines 1 through 23 with:

- "1. As appropriate, a hospital shall educate or train a patient, the patient's informal caregiver, or the patient's representative to prepare the patient for posthospital care.
2. The education or training provided by hospital staff to a patient, the patient's informal caregiver, or the patient's representative must be tailored to the patient's identified needs, including medications, treatment modalities, physical and occupational therapies, psychosocial needs, appointments, or other posthospital care.
3. Education and training provided by a hospital may include repeated review of the training and materials with a patient, the patient's informal caregiver, or the patient's representative."

Renumber accordingly

**2019 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. 2154**

Senate Human Services Committee

Subcommittee

Amendment LC# or Description: See below

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. Hogan

| Senators | Yes | No | Senators | Yes | No |
|-------------------|-----|----|---------------|-----|----|
| Chair Lee | X | | Senator Hogan | X | |
| Vice Chair Larsen | X | | | | |
| Senator Anderson | X | | | | |
| Senator Clemens | X | | | | |
| Senator Roers | X | | | | |
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Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

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

Remove on page 2, line 16 - line 22.

**2019 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. 2154**

Senate Human Services Committee

Subcommittee

Amendment LC# or Description: 19. 0699. 01001

- 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 Roers Seconded By Anderson

| Senators | Yes | No | Senators | Yes | No |
|-------------------------|-----|----|------------------|-----|----|
| Sen. Judy Lee | X | | Sen. Kathy Hogan | X | |
| Sen. Oley Larsen | X | | | | |
| Sen. Howard C. Anderson | X | | | | |
| Sen. David Clemens | X | | | | |
| Sen. Kristin Roers | X | | | | |
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Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

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

Date: 2/11/19
 Roll Call Vote #: 2

**2019 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. 2154**

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 Roers Seconded By Anderson

| Senators | Yes | No | Senators | Yes | No |
|-------------------------|-----|----|------------------|-----|----|
| Sen. Judy Lee | x | | Sen. Kathy Hogan | x | |
| Sen. Oley Larsen | x | | | | |
| Sen. Howard C. Anderson | x | | | | |
| Sen. David Clemens | x | | | | |
| Sen. Kristin Roers | x | | | | |
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Total (Yes) 6 No 0

Absent 0

Floor Assignment Roers

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

**2019 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. 2154**

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. Hogan Seconded By Sen. K. Roers

| Senators | Yes | No | Senators | Yes | No |
|-------------------|-----|----|---------------|-----|----|
| Chair Lee | | | Senator Hogan | | |
| Vice Chair Larsen | | | | | |
| Senator Anderson | | | | | |
| Senator Clemens | | | | | |
| Senator Roers | | | | | |
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*VOICE VOTE
 MOTION CARRIES*

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

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

**2019 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO.**

Senate Human Services Committee

Subcommittee

Amendment LC# or Description: 19.0699.01002

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. Hogan Seconded By Sen. Clemens

| Senators | Yes | No | Senators | Yes | No |
|-------------------|-----|----|---------------|-----|----|
| Chair Lee | X | | Senator Hogan | X | |
| Vice Chair Larsen | X | | | | |
| Senator Anderson | X | | | | |
| Senator Clemens | X | | | | |
| Senator Roers | X | | | | |
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Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

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

Date: 2/13/19
 Roll Call Vote #: 3

**2019 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO.**

Senate Human Services Committee

Subcommittee

Amendment LC# or Description: 19.0699.01002

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. O. Larsen Seconded By Sen. Anderson

| Senators | Yes | No | Senators | Yes | No |
|-------------------|-----|----|---------------|-----|----|
| Chair Lee | X | | Senator Hogan | X | |
| Vice Chair Larsen | X | | | | |
| Senator Anderson | X | | | | |
| Senator Clemens | X | | | | |
| Senator Roers | X | | | | |
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Total (Yes) 6 No 0

Absent 0

Floor Assignment Sen. K. Roers

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

REPORT OF STANDING COMMITTEE

SB 2154: Human Services Committee (Sen. J. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2154 was placed on the Sixth order on the calendar.

Page 1, line 15, replace "Lay" with "Informal"

Page 1, line 15, replace "old" with "of age"

Page 1, line 16, after "designates" insert "at admission"

Page 1, line 17, replace "aftercare assistance" with "posthospital care"

Page 1, line 19, remove ""Patient" means an individual who is or was receiving inpatient medical care in a"

Page 1, line 20 replace "hospital" with ""Posthospital care" means care directly related to a patient's condition at the time of discharge and which is provided by an informal caregiver to the patient in the patient's residence"

Page 2, line 1, replace "Aftercare assistance policies - Designation of lay caregiver" with "Patient and caregiver discharge planning, involvement, and documentation"

Page 2, line 2, replace "evidence-based" with "a written"

Page 2, line 2, after "discharge" insert "planning process, including"

Page 2, line 3, after "procedures" insert ", which applies to all patients"

Page 2, remove lines 4 through 15

Page 2, line 16, remove "A hospital may not give a legal representative who is an agent under a durable power"

Page 2, remove lines 17 through 31

Page 3, replace lines 1 through 11 with:

At an early stage of hospitalization, a hospital shall identify patients who are likely to suffer adverse health consequences if discharged without adequate discharge planning. A hospital shall involve a patient throughout the discharge planning process. As appropriate, a hospital shall involve the patient's informal caregiver or legal representative in the discharge planning process. A hospital shall:

- a. Document the patient's discharge plan in the patient's medical record.
- b. Communicate the plan to the patient, the patient's informal caregiver, or the patient's representative.
- c. Document the arrangements made for initial implementation of the patient's discharge plan in the patient's medical record, including any training or materials provided to the patient, the patient's informal caregiver, or the patient's representative."

Page 3, line 12, replace "Notification of transfer or discharge" with "Posthospital care training"

Page 3, remove lines 13 through 30

Page 4, replace lines 1 through 23 with:

- "1. A hospital shall educate or train a patient, the patient's informal caregiver, or the patient's representative to prepare the patient for posthospital care.
2. The education or training provided by hospital staff to a patient, the patient's informal caregiver, or the patient's representative must be tailored to the patient's identified needs, including medications, treatment modalities, physical and occupational therapies, psychosocial needs, appointments, or other posthospital care.
3. Education and training provided by a hospital may include repeated review of the training and materials with a patient, the patient's informal caregiver, or the patient's representative."

Renumber accordingly

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SB 2154: Human Services Committee (Sen. J. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2154 was placed on the Sixth order on the calendar.

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Page 1, remove lines 9 through 12

Page 1, line 13, remove "2."

Page 1, line 15, replace "3." with "2."

Page 1, line 15, replace "Lay" with "Informal"

Page 1, line 15, replace "old" with "of age"

Page 1, line 16, after "designates" insert "at admission"

Page 1, line 17, replace "aftercare assistance" with "posthospital care"

Page 1, replace lines 19 and 20 with:

"3. "Posthospital care" means care directly related to a patient's condition at the time of discharge and which is provided by an informal caregiver to the patient in the patient's residence."

Page 1, line 21, replace "5." with "4."

Page 2, line 1, replace **"Aftercare assistance policies - Designation of lay caregiver"** with **"Patient and caregiver discharge planning, involvement, and documentation"**

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Page 2, remove lines 4 through 15

Page 2, line 16, remove "A hospital may not give a legal representative who is an agent under a durable power"

Page 2, remove lines 17 through 31

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b. As appropriate, communicate the plan to the patient, the patient's informal caregiver, or the patient's representative.

- c. Document the arrangements made for initial implementation of the patient's discharge plan in the patient's medical record, including any training or materials provided to the patient, the patient's informal caregiver, or the patient's representative."

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3. Education and training provided by a hospital may include repeated review of the training and materials with a patient, the patient's informal caregiver, or the patient's representative."

Renumber accordingly

2019 HOUSE HUMAN SERVICES

SB 2154

2019 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

SB 2154
3/5/2019
33212

- Subcommittee
 Conference Committee

Committee Clerk: Nicole Klaman by Marjorie Conley

Explanation or reason for introduction of bill/resolution:

Relating to hospital discharge policies.

Minutes:

Attachments 1, 2, 3

Chairman Weisz: Open hearing on SB 2154.

Senator Nicole Poolman: Introduced bill, see **attachment 1**
(0:02:14)

Rep. Lisa Meier: Support for SB 2154. This bill allows a very good component towards patient care when a patient is discharged from the hospital. This allows consistency for a patient being discharged from the hospital and the caregiver.

Mike Chaussee, AARP ND: In support, written testimony provided see **attachment 2**. It's intended to create a better working relationship between hospitals and informal caregiver.
(0:13:34)

Rep. Kathy Skroch: 860 million dollars saved. How is this determined and what wage is used to estimate at it is volunteer hours.

Mike Chaussee: I believe they used the Medicaid reimbursement rate, will get back to you.

Rep. Skroch: 63% currently or formerly have been caregivers. What is the obstacle that requires this bill?

Mike Chaussee: Some do not know how to provide specific cares and to receive training. Example of a lady whose mother was in a sling.

Rep. Skroch: How was the cost estimated to the providers?

Mike Chaussee: We do not have exact numbers. There were things tied to cost we feel we negotiated or compromised on.

Rep. Greg Westlind: Public Health Electronic Coding, Conditions of Participation., what will be gained by putting this into ND law?
0: 17:18

Mike Chaussee: Bring “informal caregiver” term into state statute so it can be understood better.

Rep. Westlind: I sit on the hospital board in Cando and I see nothing in this bill that is beyond Medicare and Medicaid expectations upon discharge.

Mike Chaussee: it’s about who is getting that training and making sure they are invited to that conversation.

Rep. Bill Tveit: My wife and I are caregivers indirectly for a 92 year old lady. My wife received excellent training upon discharge. But our local hospital was not so great.

0:21:20

Tim Blasl, President of the ND Hospital Association: In support, see written **attachment 3**. We think this is a win win for both sides.

Rep. Rohr: Liability was the big deal. What changed?

Tim Blasl: Our position was we felt as though we were doing this already, so we are fine with it.

Rep. Skroch: Is there any protection in the law if they error in medication giving or wound dressing?

Tim Blasl: Good question which I do not have the answer.

Chairman Weisz: Nothing would change regarding informal caregivers.

Tim Blasl: We have done a lot of work with the hospitals and they do support the engrossed bill.

Pat Pinns, former educator, competitive speech coach: In favor, written testimony not provided. How could you vote against anything with the 4 letter word CARE. It’s so important for people to become educated in how to care for their loved ones, that is what this does.

(27:57)

Chairman Weisz: Any more in support? Opposition? Neutral?

Closed hearing on SB 2154.

2019 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

SB 2154
3/5/2019
33301

- Subcommittee
 Conference Committee

Committee Clerk: Nicole Klaman by Marjorie Conley

Explanation or reason for introduction of bill/resolution:

Relating to hospital discharge policies

Minutes:

Chairman Weisz: Reopened SB 2154.

Rep. Rohr: Made a motion for Do Pass on SB 2154.

Rep. Schneider: Second.

Rep. Damschen: I think I heard the hospital association say they wouldn't have to do anything different if this passed. I question the motivation for passing it.

Chairman Weisz: I think that if it was a codified state law it might have more uniformity for the providers and for them to better do what they are already supposed to be doing.

Roll Call Vote for a Do Pass on SB 2154. Yes 10 No 3 Absent 1

Rep. Fegley is the **Carrier**.

Closed.

Date: 3-5-19
 Roll Call Vote #: 1

**2019 HOUSE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. SB 2154**

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. Rohr Seconded By Rep. Schneider

| Representatives | Yes | No | Representatives | Yes | No |
|-------------------------------|-----|----|--------------------|-----|----|
| Robin Weisz - Chairman | X | | Gretchen Dobervich | X | |
| Karen M. Rohr – Vice Chairman | X | | Mary Schneider | X | |
| Dick Anderson | X | | | | |
| Chuck Damschen | | X | | | |
| Bill Devlin | | X | | | |
| Clayton Fegley | X | | | | |
| Dwight Kiefert | X | | | | |
| Todd Porter | X | | | | |
| Matthew Ruby | X | | | | |
| Bill Tveit | X | | | | |
| Greg Westlind | | X | | | |
| Kathy Skroch | A | | | | |
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Total (Yes) 10 No 3

Absent 1

Floor Assignment Rep. Fegley

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

REPORT OF STANDING COMMITTEE

SB 2154, as engrossed: Human Services Committee (Rep. Weisz, Chairman)
recommends **DO PASS** (10 YEAS, 3 NAYS, 1 ABSENT AND NOT VOTING).
Engrossed SB 2154 was placed on the Fourteenth order on the calendar.

2019 TESTIMONY

SB 2154

SB 2154
1/15/19
#1 pg.1

Nicole Poolman

Senate Human Services Testimony

SB 2154

January 15, 2019 11:00 am

Good morning, Chair Lee and members of the committee, my name is Nicole Poolman, state senator from District 7 representing Bismarck and Lincoln. I'm here today to introduce SB 2154, a bill to provide training to caregivers before they leave the hospital. North Dakotans believe caregivers should be taught how to care for loved ones before they leave, and some hospitals are doing a wonderful job in this area. Others are not. Thirty percent of North Dakota's caregivers say they received no instruction on the duties they had to perform before they left the hospital. We experienced both good and bad examples of caregiver training in my own family, so I understand how dire the consequences can be if training is not provided.

Caregivers in North Dakota provide 58 million hours of care at a value of more than \$860 million to the state of North Dakota. At a time when we struggle to provide funding to long term care facilities, these caregivers are saving tax payers millions of dollars. The least we can do is provide training to allow them to care for their loved ones safely.

By the year 2025, the population of those age 65 and older will grow by 50,000. We need to support the caregivers who will undoubtedly save the state millions of dollars in the very near future. I urge you to join the 40 other states that have passed this legislation and respectfully ask for your support of SB 2154.



Real Possibilities in

North Dakota

SB 2154
1/15/19
#2 pg. 1

January 15, 2019
Senate Human Services Committee
Testimony on Hospital to Home Transitions – The CARE Act
Josh Askvig – AARP North Dakota
jaskvig@aarp.org or 701-989-0129

Chairman Lee, members of the Senate Human Services Committee, I am Josh Askvig, State Director for AARP North Dakota. Thank you for the opportunity to appear before you today to share more about AARP’s thoughts on how to help our state’s 62,100 unpaid family caregivers do their jobs.

Most of you know the story of our founder Dr. Ethel Percy Andrus. In case you have forgotten, let me remind you, Dr. Andrus, a retired educator, became an activist in the 1940s when she found a retired teacher living in a chicken coop because she could afford nothing else. She 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 88,000 members in North Dakota and 38 million nationwide. We understand the priorities and dreams of people 50-plus and are committed to helping them live life to the fullest, including here in North Dakota.

We know caregivers are a vital part of the health care model in North Dakota. In fact, as hospitals continue to discharge patients earlier the role of family caregivers is as important as ever. According to a New York Times article published in 2016 the average hospital stay has dropped from more than seven days in 1980 to about four-and-a-half days when the article was written. Those shorter hospital stays means more and more complex care is being done at home.

Senate Bill 2154, The CARE Act, is designed to invite unpaid family caregivers into the health care process early to form relationships with doctors and nurses so when the patient does go home, they are best prepared to help their loved ones get better.

The bill requires hospitals to ask patients if they would like to designate a ‘lay’ caregiver. We use that language because while most caregivers are family members, they are not all. And we want to make sure people like neighbors or volunteer parish nurses are included.

If the patient identifies a lay caregiver, and the caregiver is placed in the official record, hospitals are asked to cooperate with caregivers in two additional ways. First, if a patient is to be transferred or discharged, that the hospital makes a reasonable attempt to contact the caregiver. We think this is a crucial moment for

SB 2154
1/15/19
#2 pg. 2

patients and caregivers because it truly is the moment when the caregiver takes over. If they don't know it's happening, they are already behind in their caregiving work.

The last thing this bill asks hospitals to do is provide some instruction or demonstration of the tasks the caregiver will perform once the patient goes home. While the bill is labeled 'hospital discharge policies' we believe there are a number of opportunities for this training to happen during a patient stay. This instruction does not have to happen only at the stressful discharge moment. It can occur at any time during the stay.

Let me walk you through the specifics of the bill.

Page 1, Lines 6-22- this part of the bill provides definitions to ensure clarity in the remainder of the bill. Specifically, it outlines what constitutes an aftercare task, most importantly including those complex medical or nursing tasks outlined above would be included. Also, it provides a definition of discharge. It provides a clear definition of who is considered a caregiver for the purposes of the bill. It also provides a definition of patient and residence for clarity of the other sections we will go through below.

Page 2, Lines 1-31 AND Page 3, lines 1-11- Outlines how hospitals would meet the first key provision of the CARE Act, ensuring patients and/or their legal guardians can designate who will be helping them heal at home. A couple of items to note in this section. The bill ensures that patients can designate a lay caregiver before discharge, page 2 lines 4-8. The bill also allows hospital discharge procedures can follow national standards, page 2 lines 9-15. On page 2 lines 16-22 ensure that the patient is the individual who designates the lay caregiver unless there is a guardian or the judgement of the physician declares a need for the Power of Attorney to complete this task.

Lines 23-25 address a concern we have heard from individuals and groups concerned about this bill, "What if a caregiver is not designated?" This subsection says the hospital simply has to note in the medical chart that no lay caregiver was designated to be compliant with the designation standards. Item "4." in this section notes that if a lay caregiver is designated the hospital shall record that information in the medical chart. It also ensures before releasing any medical information, hospital policies, HIPPA and other pertinent federal and state privacy laws must be followed. Page 3 lines 10 and 11 just note that if the lay caregiver becomes incapacitated that a new caregiver can be designated.

The next section 23-49-03 is the second provision of the CARE Act, notifying lay caregivers of the transfer or discharge of the patient. While a short section there are a couple of important pieces. First, line 13 ensures that the lay caregiver must be designated to be notified. The remainder of the section gives the hospital wide latitude of when they notify the lay caregiver of the discharge or transfer. This is important because hospitals have told us in previous discussions, they are concerned about meeting specific timelines. The section also notes they are to "attempt to notify the lay caregiver." Nothing in the section states they MUST reach the lay caregiver as some hospitals have claimed in the past.

Section 23-49-04 implements the 3rd key provision of the CARE Act, ensuring lay caregivers get some basic instruction of what they are to perform at home to help their loved one heal, and ensuring they can do so safely. Specifically, the section notes the hospital shall attempt to consult with the lay caregiver about the aftercare assistance. This is important as it may also help identify home healthcare needs if the caregiver will not be able or is unwilling to provide certain cares. Additionally, the section ensures lay caregivers can get some basic instruction to safely perform home care tasks they will take on AND an opportunity to ask questions.

Section 23-49-05 is the piece of the bill that addresses concerns hospitals raised in previous discussions. Specifically:

1. Here the bill addresses a major hospital concern we heard as we discussed this bill, the question of liability. This section clearly states that a hospital cannot be held liable for mistakes made by a caregiver in home setting, as long as they follow the provisions of the statute. Relatedly, we also contacted our colleagues in states where the CARE Act has been made law and none of them have reported a liability case resulting from this bill.
2. Ensures that hospitals can discharge patients in a timely manner. This section specifically was written to address concerns we heard about how the CARE Act would cause delays in discharge proceedings. You will likely hear they feel it conflicts with one of the sections above. As I described the above section says they have to provide an “opportunity” for instruction before discharge.
3. Clarifies that legal healthcare directives, power of attorney designations, and placement decisions take precedents. It also ensures that a patient is not required to designate a lay caregiver and that designated caregivers are NOT required to perform aftercare.

It is worth noting that this bill has changed dramatically from the initial bill discussed in previous sessions due to significant and appreciated input from North Dakota hospitals. We were thankful for the opportunity to work with them and are disappointed that despite a majority of hospital associations around the country having not resisted this bill, in ND we still seem to be at an impasse.

Through our continued dialogue and discussions, we have learned a few points we think are important to bring up here. First, it seems clear that even hospitals recognize the need for improving caregiver involvement. For example, we know that Quality Health Associates, the ND Quality Improvement Network offered and that some hospitals took training in “teachback planning” as part of the discharge process, indicating at least an awareness of the need to do more. While a good step, the teachback training we reviewed seems to miss including the caregiver.

You will hear testimony in opposition of this bill in which hospitals will tell you they are already doing all of this. And we will admit there has been improvement (likely because we have been calling attention to it for three sessions now), but still in a survey we took of family caregivers just two months ago, ONE in FOUR tell us they received no instruction. Numbers can be read in many different ways, but let me paint the picture this way, of a thousand hospital patients in North Dakota – 250 of

them say they go home with no instruction of how to perform the tasks they'll be doing. In our minds, that is a very significant number that we think we have an opportunity to reduce.

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Further, one of the shared goals hospitals, caregivers and AARP have in this is to eliminate or at least reduce hospital readmissions. I pulled out for you the recent *North Dakota Care Coordination Quarterly Report- July 2018* produced by the Great Plains Quality Innovation Network which includes information on hospital readmissions rates in North Dakota. As you can see on page 3, there is a 1 year trend line of readmission rates by large community, the US, and ND. Here is the good news, ND is below the national trend line. Here is the bad news, ND's trend line is up, in fact each of our communities, while they have had dips, the overall trend line is higher than the starting point, even while the national trend line has steadily dipped.

Why do I bring up readmission rates, it's a measure hospitals are acutely aware and are being measured. One example of the CARE Act's benefits can be highlighted in a 2016 press release from the New Jersey Hospital Association. That release which touted New Jersey's reductions in readmission rates by 13.3 percent, cited the CARE Act, among other measures as to how it happened. The release said, "New Jersey's CARE Act, which defined processes for hospitals to work with patients, families and caregivers to ensure they have the information and support they need before being discharged from the hospital. NJHA worked collaboratively with policymakers to craft the bill and with AARP to promote implementation." Clearly they recognize the value of ensuring family caregivers are included in the healing process.

More poignantly, a University of Pittsburgh Health Policy Institute study found that integrating caregivers into discharge planning resulted in a 25 percent reduction in risk of the elderly patient being readmitted to the hospital within 90 days, and a 24 percent reduction in risk of being readmitted within 180 days, when compared with control groups where no such integration occurred. It is pretty clear integrating caregivers is a good idea.

In fact, some findings from a November/December survey of North Dakotan's 45+ reinforce that notion. Of current and former family caregivers, 93 PERCENT say it is extremely or very important they receive instruction from the hospital.

We agree, and in part because of the types of things they'll be doing. That same survey shows that **62 percent, so almost two-thirds, of current and former family caregivers report managing medications. Fifty-six percent say they perform complex medical tasks like wound care and giving injections.** These are significant roles taken on by loved ones who deserve every opportunity to succeed. We know even the simplest nursing or medical tasks can be confusing and stressful for experienced caregivers, much less those who may be taking on the role for the first time.

I'd like to take a moment now to talk about AARP's work across the country on the CARE Act. The bill has now passed in 40 states and territories including Montana,

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Kansas, Wyoming, Nebraska, Minnesota, and most recently Missouri. And we keep gathering data about what states are doing as a result. An article published recently by our Public Policy Institute identifies a number of innovative ideas that have emerged as a result of passage of the bill.

- Hospital staff who said “we already do what the CARE Act requires” responded with appreciation that the CARE Act helped standardize how their respective hospitals interacted with family caregivers and maybe more importantly, helped them identify a difference between the person doing the care and someone else who may be the Power of Attorney or a guardian.
- One hospital expanded its call center and now provides a 24/7 toll-free line for family caregivers to call post-discharge.
- Another hospital group created an advisory council of caregivers to help them better understand their needs.

AARP also knows it has a role to play in the process and is helping hospitals across the country in implementation of the CARE Act including providing consultation and we’ve created an expanding library of videos that hospitals and caregivers can access to help with the instruction and for reminders later on.

As you can see, we are committed to this bill and to supporting family caregivers in North Dakota and across the country.

We’re asking you today to support those caregivers with a ‘do pass’ recommendation on the CARE Act. It’s a bill that has NO COST to the state and will help caregivers do their jobs better today and for many years into the future. It opens the door for hospitals to innovate and create relationships with the people who are taking on larger caregiving roles as patients are sent home much earlier than just a few decades ago.

I want to end this testimony with a story that we just recently heard from someone you might know, Kim Jacobson. Recently, our Advocacy Director Mike Chaussee and I were driving home from one of our visits when we were called my Miss Jacobson. Miss Jacobson’s testimony is attached and I will read it.

Thank you for listening and I’d be happy to answer any questions you might have.

Josh Askvig
State Director, AARP North Dakota

Spotlight

From *Home Alone* to the CARE Act: Collaboration for Family Caregivers

Susan C. Reinhard
AARP Public Policy Institute

Elaine Ryan,
AARP State Advocacy and Strategy Integration

The 2012 report *Home Alone: Family Caregivers Providing Complex Chronic Care* broke new ground by uncovering the complex medical/nursing tasks that family caregivers are performing with little guidance or support. The Caregiver Advise, Record and Enable (CARE) Act rapidly translated that research into state policies across most of the nation—with 39 states and territories having enacted it thus far, in just three years. The swift speed of this policy adoption signals a recognition by state policymakers of significant unmet family caregiver needs. Now, the Home Alone AllianceSM is focusing on moving policy into practice by identifying innovative practices and creating instructional resources for family caregivers and the professionals who support them.

Introduction

Decades of research document the extensive care and support that family members, neighbors, and friends give to people who have long-term or chronic health needs.^{1,2,3} Most of this research, however, focuses on the personal care and household chores that these family caregivers provide, such as shopping, cooking, bathing, dressing, and many other activities of daily living (ADLs) and instrumental activities of daily living (IADLs) delineated more than half a century ago as falling within the family caregiver's inventory of potential tasks.⁴

Missing from that inventory has been the complex care tasks that family caregivers are expected to do, specifically medical/nursing tasks. Medical/nursing tasks include managing multiple medications,

administering injections, performing wound care, and managing special equipment, among many others. These tasks are the types of duties that nurses and other health care professionals were professionally trained to perform.

In search of a better understanding of the family caregiver's complete job description, the AARP Public Policy Institute (PPI) and the United Hospital Fund (UHF) undertook the first national study of family caregivers to determine what types of medical/nursing tasks they perform and how frequently they perform them. Funded by The John A. Hartford Foundation, *Home Alone: Family Caregivers Providing Complex Chronic Care* (known as *Home Alone*) was a nationally representative population-based online survey that found that almost half (46 percent) of



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family caregivers perform these tasks.⁵ *Home Alone* brought widespread attention to the huge gap between what family caregivers are expected to perform and the instructions and guidance provided to them. It documented their fears of making a mistake or hurting their family members.⁶ By putting a spotlight on these significant unmet needs, this research tapped into something powerful in the lives of millions of family caregivers across the country.

Translating Research into State Policy across the Nation

Home Alone is a powerful example of research driving policy and ultimately transforming practice. When it was released in October 2012, the reaction from researchers, the media, and advocates was immediate and widespread. The term “medical/nursing tasks” put a name on something that people understood at a personal level. They were either doing these tasks themselves, or they knew someone else who was expected to do them. They had their own stories, their own experiences. And they were relieved to know they were not alone, that there was validation of the complexity of their work, and that their anxieties in doing the clinical work that professionals do was shared by other family caregivers.

This strong reaction to the *Home Alone* report findings from such a broad base of individuals and organizations was a call to action to provide greater supports for family caregivers and those they care for. With repeated input from caregiver organizations and experts at the state and national levels, the AARP State Advocacy and Strategy Integration (SASI) team translated the *Home Alone* findings into model state legislation in the form of the Caregiver Advise, Record, and Enable (CARE) Act. In May 2014, Oklahoma became the first state to make the CARE Act law. Less than three years later, it is law in 39 states and territories as of July 2017. Several other states continue to consider it in 2017 (see Figure 1).

When developing the CARE Act model bill, AARP focused on the need to acknowledge the critical role of family caregivers who are on the front lines of the health care team, yet have little knowledge of how to perform the wide array of complex tasks they are asked to perform in the home. It put in place simple rule changes in hospital

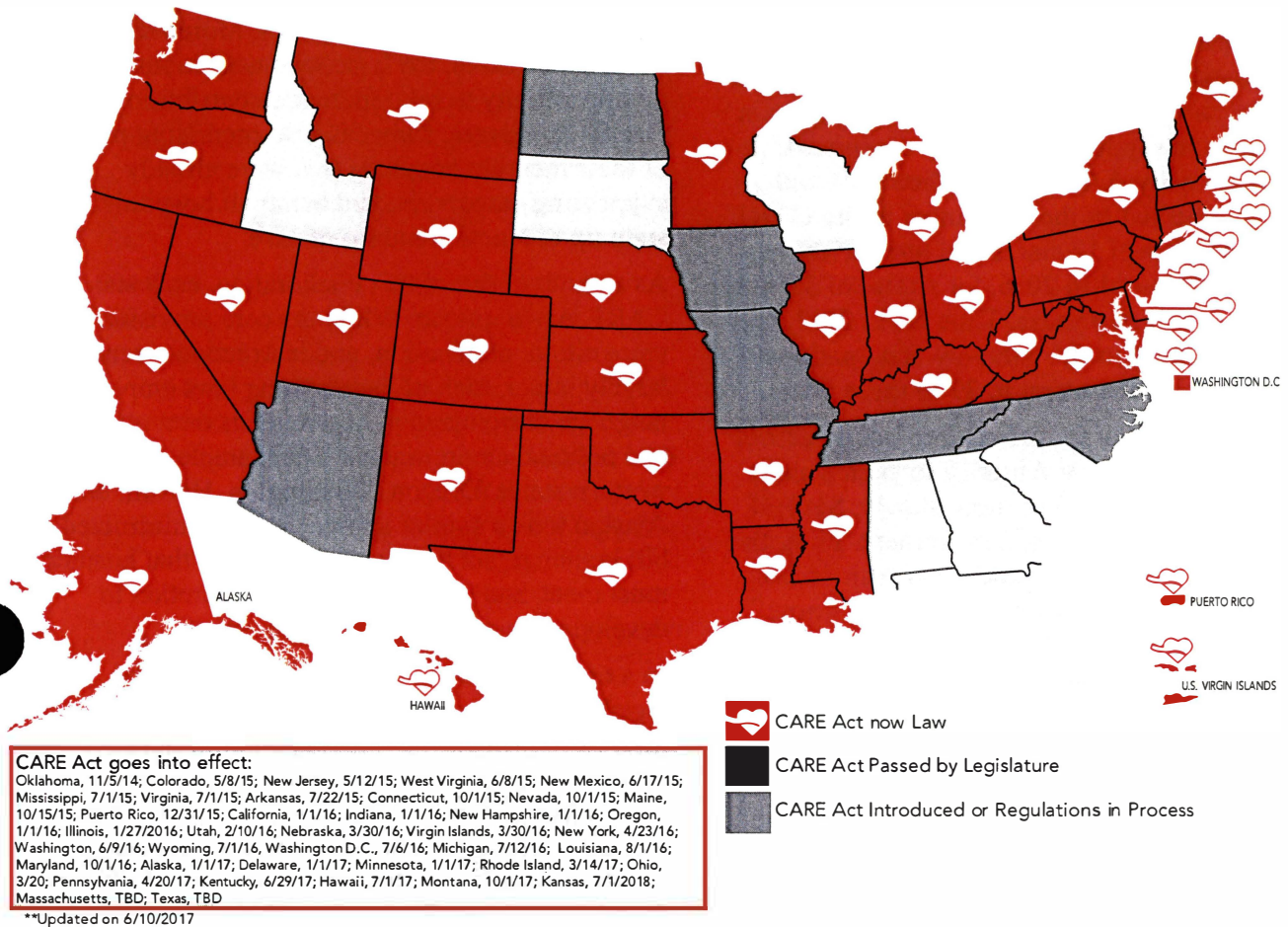
admission and discharge practices. Specifically, AARP targeted three key areas for change. First, caregivers need more visibility, not only during the admission process, but also throughout the family member’s hospital stay. Second, family caregivers need adequate notice prior to the hospital discharge so that they can purchase the necessary medical supplies and food, arrange time off from work or arrange care if needed, and make other home preparations. Third, family caregivers need simple instruction on the medical/nursing tasks they will be performing at home. Family caregivers are often handed paperwork on discharge day with little or no explanation of the actual tasks.

The CARE Act was specifically crafted to address the gap between what professionals expect family caregivers to do and what guidance they receive to get it done. While the specific provisions of the law vary from state to state, the CARE Act generally requires hospitals to provide patients (of any age or diagnosis) an opportunity to identify a family caregiver. If the patient identifies a caregiver, that individual’s name and contact information is recorded in the hospital’s health record. The hospital is required to notify the family caregiver as soon as possible when the individual will be discharged or transferred to a facility (such as a nursing or rehabilitation facility)—and offer consultation about the discharge plan and the caregiver’s role in that plan.

Most important, the hospital must offer the family caregiver instructions on how to perform the medical/nursing tasks that are included in the discharge plan and answer questions about those tasks. A family caregiver can be a relative, neighbor, partner, or friend—anyone the patient identifies as the person(s) who will be assisting with care post-discharge, particularly medical/nursing tasks. Patients are not obligated to identify anyone as their family caregiver, and individuals are not obligated to perform these tasks if designated as the family caregiver. Rather, the CARE Act requires hospitals to make sure patients and families have the opportunity to receive the information and instruction they need to ensure smooth hospital discharges and care transitions.

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FIGURE 1
States with the CARE Act Enacted or under Consideration, July 2017



Not surprisingly, the CARE Act’s focus and spirit have resonated with people. In AARP survey research conducted at both national and state levels, the results consistently have shown strong bipartisan support for the CARE Act provisions, and those findings have bolstered efforts to move forward in the states.⁷ The CARE Act became the centerpiece of a multiyear, multistate, and multifaceted Family Caregiving campaign within AARP.

AARP state offices in Oklahoma and New Jersey established the strategic foundation for enacting the CARE Act. Each office secured strong legislative sponsors, engaged members in advocacy, and used the personal stories of volunteers who shared how they could have benefited from the CARE Act. In Oklahoma, the CARE Act was sponsored by a

Republican senator who had a personal experience with family caregiving for his father. Indeed, the majority of the bill sponsors of the CARE Act across the country were moved to introduce the legislation because they considered it to be a common sense solution to provide some basic supports to family caregivers. In New Jersey, the bipartisan group of sponsors included the speaker of the assembly, who made the bill a priority. Because of these strategies, both bills received near unanimous approval by the states’ legislative bodies.

Also indicative of the legislation’s resonance, strong media coverage helped advance the CARE Act in each state as well. The “PBS News Hour” covered the Oklahoma consideration of the bill, featuring family caregivers in Oklahoma who struggled with

providing complex care for their family members.⁸ In New Jersey, state publications repeatedly ran stories about the need for and value of the CARE Act.⁹

The enactments in 2014 sent a strong signal to states around the nation that the CARE Act could bridge the partisan divide to set in statute certain common sense supports for family caregivers. In 2015 advocacy by AARP state office staff and volunteers resulted in the enactment of the CARE Act in an additional 17 states and territories; 16 more states followed in 2016, for a total of 35 states and territories in two years. Thus far in 2017, four more states joined in this state-by-state national movement, bring the count to 39 in three years.

It is rare for research to diffuse into policy across more than two-thirds of America in such a short time. Policy usually moves more slowly. Several factors played into this rapid movement. First, the research made sense to people: “Yes, this is a big problem for me and/or for many people I know.” Second, the simplicity of the legislation to clearly meet the newly revealed, substantiated unmet needs of family caregivers was significant. The common response was “Really, this isn’t already required?” And the honest answer was “No.” Third, the passion of volunteer advocates was unrelenting at a local level, where the policy makers live. And finally, this was never seen as a political or partisan issue. It was seen as an “every person” issue.

It is also important to emphasize that the development of the CARE Act was a collaborative process in every state. AARP state offices sought input from and worked closely with a wide network of stakeholders. Depending on the state, this collaboration involved legislators, disease-specific advocacy groups such as the Alzheimer’s Association, the American Cancer Society’s Cancer Action Network, aging services providers, nursing associations, and state hospital associations. These stakeholders helped to tailor the bill language to fit the state environment. In some states, the hospital association initially opposed the bill and would not join discussions. Typically, they claimed, “we already teach family caregivers, so there is no need for this bill.” But thanks largely to the strong and persistent voices of consumers who were eager to

tell their personal stories to their state legislators, their thinking evolved. And, indeed state legislators themselves drew from their own personal experiences as family caregivers. Moreover, in many other cases, the hospital associations saw an opportunity to recognize the contributions of family caregivers, showcase the promising practices of their member hospitals that were already supporting caregivers, and bring all hospitals in the state up to a new standard of care.

As a result of this close collaboration, each state’s CARE Act is unique. While the core provisions—recognition, notification, and instruction—remain largely intact, each of the resulting laws employs language customized to best meet its own regulatory and political environments. For example, several western states (Oregon, Washington, Hawaii, and Alaska) took a similar approach. They minimized the bill language, set forth clear objectives that hospitals must meet, and gave hospitals the discretion to develop policies to meet those objectives.

In a creative deviation, Utah did not take the legislative route to implement the CARE Act, instead implementing it through administrative action. In doing so, AARP Utah worked closely with officials at a state agency, the state hospital association, and other stakeholders to develop regulatory language. The rule was drafted, opened for comment, and finalized in 2016. Other states are starting to see value in this approach and two (Arizona and Tennessee) are currently developing regulations for promulgation.

Many of the changes to the model bill have been enhancements to the original language. For example, the New Jersey CARE Act provides flexibility for family caregivers to select whether they want to receive a live demonstration or view an instructional video. It also requires the hospital to provide a phone number for the caregiver to call for additional information after they go home. And in Delaware, the bill specifically ties the recording of the caregiver’s name to the patient’s electronic medical record and the state’s Health Information Network.

With additional states continuing to pursue the enactment of the law in 2017, the CARE Act continues to stand as the centerpiece of a multiyear,

multistate family caregiving effort. And in those states that already have the law in place, AARP and other stakeholders are working to ensure that the laws are effectively implemented; that family caregivers, providers, and regulators are aware of the CARE Act; and that they know how to utilize it and ensure the benefits of a transformative new policy that sprang forth from the *Home Alone* report.

Moving from Research and Policy to Practice

Given the rapid translation of research to policy, the Public Policy Institute is moving forward on three fronts to accelerate changes in practice:

- Conducting a national scan of how states, hospitals, and health systems implement the CARE Act to uncover innovative and promising practices
- Developing consumer-friendly, evidence-based resources for family caregivers and the clinicians who support them, particularly instructional videos
- Creating the Home Alone AllianceSM to spark widespread culture change

These three collaborative initiatives are closely intertwined and are intended to leverage the expertise and actions of many family caregiving experts, thought leaders, and organizations. They are also focused on rapid diffusion of innovation at the system and local levels, where family caregivers often both experience their challenges and seek help.

Scanning the States for Innovation

The CARE Act legislation creates an opportunity for hospitals to integrate the support of family caregivers throughout their systems. In many cases, there is a need to change how professionals interact with family caregivers. While the goal is to change practice across settings, the CARE Act focuses on hospitals and health systems.

In the fall of 2016, the Public Policy Institute began a national scan of the implementation of the CARE Act. Based on recommendations from a distinguished group of advisers, research teams led by nurse researchers conducted pilot site visits in several hospitals in New Jersey and New York to

gain a better understanding of how health systems implement the tenets of the CARE Act into hospital policies and change practice. Simultaneously, the AARP SASI team collaborated with AARP's state offices to determine how state governments provide oversight and how consumers learn about their rights under the law.

The goal is to conduct a full national scan focusing on implementation strategies and to identify and rapidly disseminate innovative and promising practices. By conducting on-site interviews with a cross-section of hospital staff and family caregivers, the Public Policy Institute's research teams are developing qualitative information on challenges, learnings, and potential promising practices. There is a strong focus on the need to address multicultural family caregiving and implementation issues in rural and urban settings as well as academic and community hospital environments. Interviews will also be conducted with key state stakeholders (e.g., AARP state offices and other consumer advocacy organizations, professional groups, hospital associations). These conversations will help achieve a clearer and more holistic view of the law's implementation across the state, assess stakeholder awareness of the CARE Act, and potentially identify opportunities for further stakeholder engagement with the law moving forward.

Early learnings from the 2016 pilot site visits include the following:

- Multiple hospital staff and leadership reported that while they initially thought "we already do what the CARE Act requires," the implementation process allowed them to standardize how their respective hospitals interact with family caregivers throughout the discharge process.
- Individual hospitals and health systems have begun certain processes or initiatives that show promise and could scale nationally. One hospital, for example, expanded its call center capacity to create a 24/7 toll-free line for family caregivers to call for support post-discharge. Registered nurses staff the phones and either provide support immediately or forward requests to expert nurses or physicians and follow up with caregivers in short order.

- One hospital provided insight into the training need for hospital registrars who begin the admission process to differentiate among the “next of kin,” “guardian,” or “family caregiver” who may be the same person or two or three different people. The CARE Act is directed to the person who will be giving the actual care.

In addition to publishing and broadly communicating promising practices that could fuel both expedited and high-quality implementation across the nation, this scan seeks to inform interdisciplinary training for health system professionals on identifying, communicating, instructing, and supporting family caregivers throughout a hospital stay and when they are back in the community.

Developing Tools for Family Caregivers

After an extensive search for resources that help guide family caregivers on how to perform a range of complex medical/nursing tasks, the dearth of such help became evident. In collaboration with the Betty Irene Moore School of Nursing at the University of California, Davis, the United Hospital Fund, and the Family Caregiver Alliance (the “founding partners”), we convened experts in the fields of family caregiving, instructional technology, adult learning, and clinical practice. The consensus was that there was a need for a set of guiding principles for developing instructional videos for family caregivers as a starting point.

Focus groups with family caregivers revealed how family caregivers say they learn best through video instruction, providing “dos and don’ts” for how to create video resources.¹⁰ Based on these guidelines, we developed a pilot series of videos focused on helping family caregivers learn how to administer medications, including injections.¹¹ These videos emphasize caregivers seeing themselves learning how to perform a task, rather than seeing only a professional demonstrating it. They capture the sense of anxiety that lay people experience, but emphasize empowerment in learning how to do what they will be doing for their family member. The videos also feature depictions of multicultural caregivers learning in both hospital and home settings. In March 2017 we released a second video series instructing family caregivers on mobility

tasks, in partnership with the US Department of Veterans Affairs.¹² In an effort to provide culturally competent resources, most of the videos are available in Spanish, and these in-language videos reflect Hispanic cultural norms.

Going forward, through the support of the Home Alone AllianceSM discussed below, the goals include the following:

- Collaborating with members of the Home Alone AllianceSM to produce several series of instructional videos to include more on medication administration, wound care, peritoneal dialysis, and other medical/nursing tasks
- Producing videos that feature male caregivers, millennials, and other under-represented caregivers; 40 percent of caregivers are men and one in four are millennials¹³
- Prioritizing a multicultural focus with in-language productions, particularly in Spanish
- Collaborating with schools of nursing and other disciplines to adapt these videos for training professionals to better instruct and support family caregivers providing complex care

Creating the Home Alone AllianceSM to Spark Culture Change

In December 2016 the Public Policy Institute formally launched the Home Alone AllianceSM in collaboration with its founding partners (Figure 2). The HAA brings together collaborators from the public, private, and nonprofit sectors as a catalyst for change in the way health care organizations and professionals interface with family caregivers.

As the hub of research, outreach, convenings, and resource development, the HAA will be a focal point for coordination, idea generation, and collaboration among stakeholders committed to supporting family caregivers engaged in complex care (Figure 3).

Between the initial *Home Alone* report, the success of enacting the CARE Act in more than two-

To learn more about the Home Alone AllianceSM and to access the instructional videos, visit www.aarp.org/nolongeralone.

FIGURE 2
Home Alone AllianceSM Members

- American Journal of Nursing
- Atlas of Caregiving
- Betty Irene Moore School of Nursing at UC-Davis
- Center to Advance Palliative Care
- Coalition to Transform Advanced Care
- Easterseals
- Family Caregiver Alliance
- Hartford Institute for Geriatric Nursing
- Home Instead Senior Care
- The John A. Hartford Foundation
- National Alliance for Caregiving
- National League for Nursing
- Nurses Improving Care for Healthsystem Elders (NICHE)
- NYU Rory Meyers College of Nursing
- Rosalynn Carter Institute for Caregiving
- United Hospital Fund
- US Department of Veterans Affairs

thirds of the country in a short period of time, and creating an initial set of resources for family caregivers, AARP and its colleagues have made significant advancements in supporting family caregivers who perform complex medical/nursing tasks. But there is still more work to be done. We need to attain a better understanding of how health systems are implementing the CARE Act, for example, to identify and diffuse promising practices, to inform training of nurses and other clinicians, and to see where gaps remain. In addition, there is still much to learn about the broad range of family caregivers who perform complex medical/nursing tasks. Finally, we need to continue to further develop and refine resources, including instructional content, that directly support family caregivers performing these complex tasks.

By meeting each of these needs, the Home Alone AllianceSM seeks to improve care for individuals supported by family caregivers. Through integrating research and resource development and supplementing these with convenings and outreach, the HAA intends to catalyze sustainable change in how professionals in health systems interact with and support family caregivers, especially those performing complex medical/nursing tasks. The network of the current 15 HAA members runs deep into environments and systems that reach clinicians, providers, educators, family caregiver organizations, faith-based communities, multicultural communities, and policymakers. This alliance is committed to fueling a national culture change in how to better support those who are the very core of health and long-term services and supports—family caregivers.

FIGURE 3
The Home Alone Alliance'sSM Work



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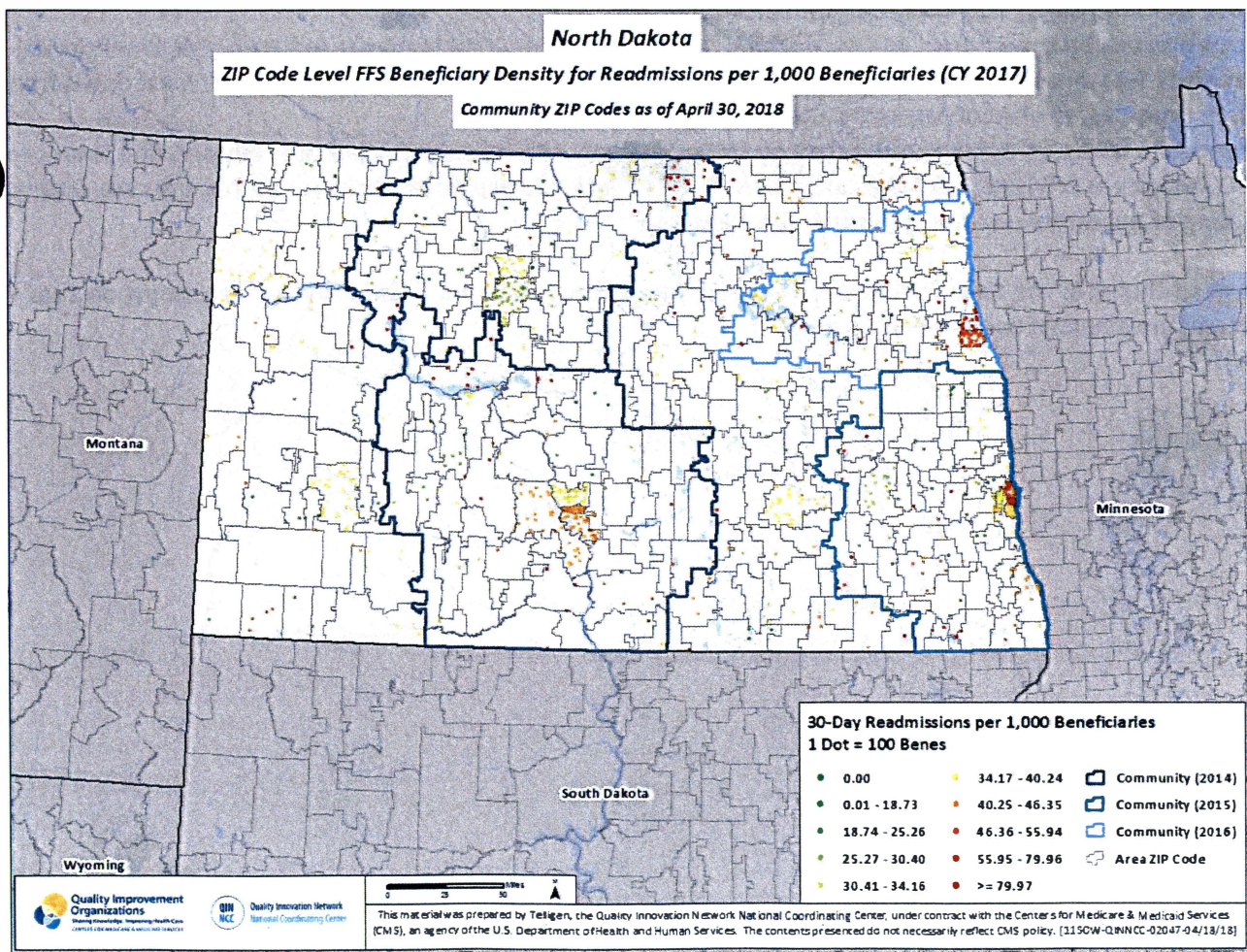


Background

Communities across the Great Plains Quality Innovation Network (QIN) region are collaborating to improve care coordination and medication safety. The Great Plains QIN is the Quality Innovation Network-Quality Improvement Organization (QIN-QIO) for North Dakota, South Dakota, Nebraska and Kansas. The communities across the Great Plains QIN are diverse; however, the goals of the communities are the same. The goals are to reduce avoidable hospital admissions and readmissions, including those caused by high risk medications (HRM) related to adverse drug events (ADE), improve medication safety and increase the number of nights Medicare beneficiaries stay at home. Quality Health Associates of North Dakota (QHA), as a partner in the Great Plains QIN, is sharing data with the communities in North Dakota.

Communities

Communities are identified based on two factors: 1) where each ZIP code's Medicare beneficiaries received most of their care and 2) where most of a hospital's Medicare patients reside. The areas where these two factors experienced the most overlap resulted in these communities. The map below displays ZIP code level readmissions per 1,000 FFS beneficiaries for all valid ZIP codes in the state/territory. The map includes an overlay displaying all current care coordination communities.



This material was prepared by the Great Plains Quality Innovation Network, the Medicare Quality Improvement Organization for Kansas, Nebraska, North Dakota and South Dakota, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. 11SOW-GPQIN-ND-C3-46/0316 (Revised 07/18)

Data Overview and Definitions

Medicare claims data provided to the Great Plains QIN by the National Coordinating Center (NCC) was used to calculate the measures contained in this report. Readmissions are defined as "all-cause" readmissions to any hospital within 30 days of discharge. We refer to the initial hospital admission as the "index discharge" and the second return admission as the "readmission." None of the measures are risk adjusted.

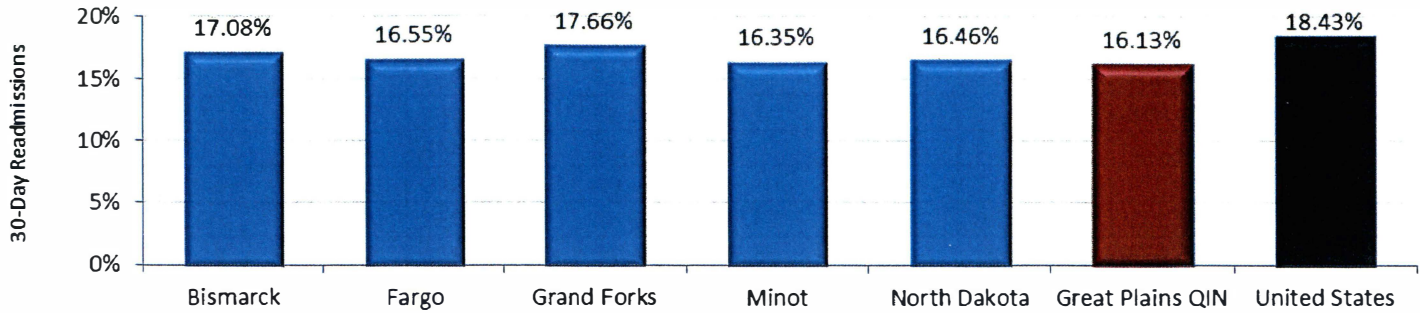
Community-level measures included are:

- **30-day Hospital Readmission Rate and Trends:** The percentage of hospital readmissions within 30 days of discharge
- **Acute Care Utilization Rate:** Hospital Admissions, 30-Day Hospital Readmissions, Emergency Department (ED) Visits (without admission), and Observation Stays per 1000 Medicare FFS Beneficiaries
- **Composite Measure of Unplanned Care:** All Admissions, ED Visits, and Observation Stays per 1000 Medicare FFS Beneficiaries; Includes separate graphs for each acute care setting.
- **Hospital Discharge Rate per Location:** Home (Community), Home Health, Hospice, and Skilled Nursing Facility
- **30-Day Hospital Readmission Rate per Discharge Location:** As Above
- **Top Five DRG Bundles for Admissions**
- **Top Five DRG Bundles for 30-Day Readmissions**
- **Potential Opportunity for Improving End-of-Life Care:** Hospital care utilization of Beneficiaries at End-of-Life
- **Admissions by Drug Class:** Hospital Admissions per 1000 Medicare FFS High Risk Beneficiaries; beneficiaries were identified as high risk if they take three or more medications of which at least one is from the three drug classes of Anticoagulants, Diabetic Agents, and Opioids
- **Readmissions by Drug Class:** 30-Day Hospital Readmissions per 1000 Medicare FFS High Risk Beneficiaries; beneficiaries were identified as high risk if they take three or more medications of which at least one is from the three drug classes of Anticoagulants, Diabetic Agents, and Opioids
- **Composite Measure of Unplanned Care by Drug Class:** All Admissions, ED Visits, and Observation Stays per 1000 Medicare FFS High Risk Medication Beneficiaries; Includes separate graphs for each acute care setting.
- **Timing of Readmission after Potential ADE Discharge**

The measures included in the Care Coordination Quarterly Report may vary from issue to issue depending on data availability and the needs of community partners.

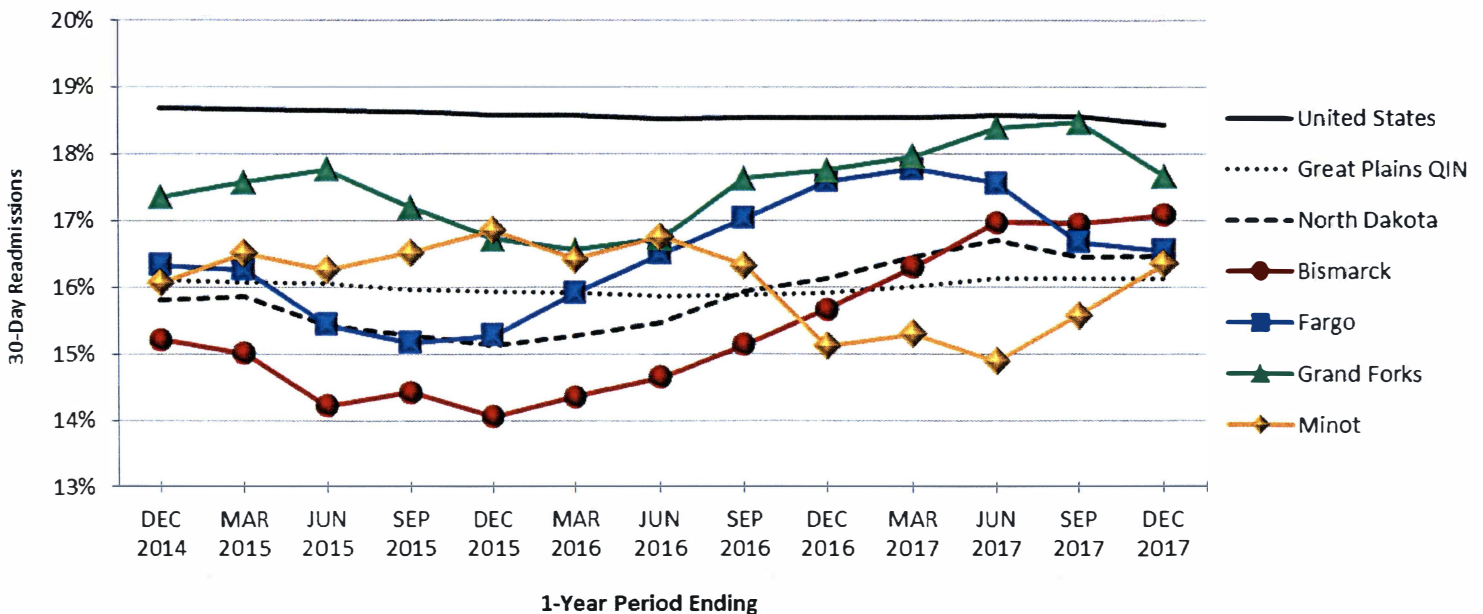
Community Data Highlights

Current Readmission Rates (# of readmissions within 30 days / # of discharges): 01/01/2017 - 12/31/2017



| Community | Discharges | 30-Day Readmissions | 30-Day Readmission Rates |
|------------------|------------|---------------------|--------------------------|
| Bismarck | 5,457 | 932 | 17.08% |
| Fargo | 6,352 | 1,051 | 16.55% |
| Grand Forks | 3,618 | 639 | 17.66% |
| Minot | 3,168 | 518 | 16.35% |
| North Dakota | 24,216 | 3,986 | 16.46% |
| Great Plains QIN | 241,463 | 38,954 | 16.13% |
| United States | 9,842,703 | 1,813,857 | 18.43% |

Readmission Rate Trends:



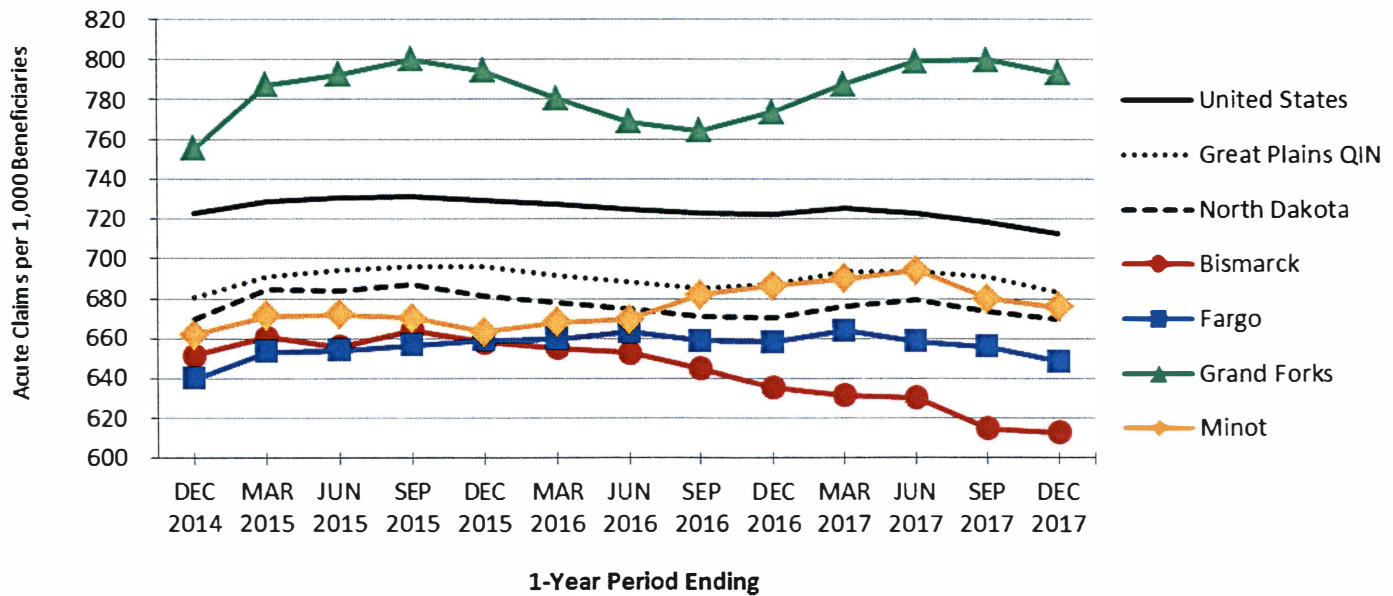
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Acute Care Utilization (per 1,000 Beneficiaries): 01/01/2017 - 12/31/2017

| Community | Benes | Adms | Adms per 1000 Benes | 30-Day Readms | 30-Day Readms per 1000 Benes | ED Visits | ED Visits per 1000 Benes | Obs Stays | Obs Stays per 1000 Benes |
|------------------|------------|------------|---------------------|---------------|------------------------------|------------|--------------------------|-----------|--------------------------|
| Bismarck | 22,603 | 5,665 | 250.63 | 932 | 41.23 | 6,957 | 307.79 | 1,308 | 57.87 |
| Fargo | 26,058 | 6,623 | 254.16 | 1,051 | 40.33 | 9,151 | 351.18 | 1,185 | 45.48 |
| Grand Forks | 14,289 | 3,754 | 262.72 | 639 | 44.72 | 6,448 | 451.26 | 1,156 | 80.90 |
| Minot | 14,376 | 3,337 | 232.12 | 518 | 36.03 | 5,449 | 379.03 | 983 | 68.38 |
| North Dakota | 101,171 | 25,220 | 249.28 | 3,986 | 39.40 | 36,732 | 363.07 | 6,111 | 60.40 |
| Great Plains QIN | 945,478 | 249,347 | 263.73 | 38,954 | 41.20 | 350,848 | 371.08 | 51,308 | 54.27 |
| United States | 38,150,184 | 10,156,604 | 266.23 | 1,813,857 | 47.55 | 14,935,590 | 391.49 | 2,084,449 | 54.64 |

Composite Measure of Unplanned Care: Counts all the Admissions, ED visits and Observation stays per 1,000 beneficiaries.

All Acute-Care Utilization (Admissions, ED visits, Observation Stays) per 1,000 Beneficiaries





A Community for Healthcare

Sept. 14, 2016: New Jersey Makes Strides in Reducing Readmissions

CMS: 13.3 Percent Improvement 2nd Highest Nationwide

New federal data shows that New Jersey hospitals are making tremendous progress in one of the most stubborn healthcare challenges – reducing the rate of hospital readmissions.

New Jersey hospitals have reduced their readmission rate 13.3 percent between 2010 and 2015, according to data released yesterday by the U.S. Centers for Medicare and Medicaid Services. Only one other state – Hawaii, with a 13.4 percent reduction – outpaced New Jersey's improvement.

"Readmissions" occur when a patient is readmitted to the hospital within 30 days of a previous hospital stay. In some instances, a readmission is unavoidable or even planned for further care, but sometimes a readmission signals a poor outcome, medical complication or failure of care coordination or follow-up after the patient leaves the hospital. They're also costly; CMS says hospital readmissions cost the nation's Medicare system \$17 billion annually.

New Jersey hospitals have been engaged in a focused effort to reduce avoidable readmissions as part of Partnership for Patients-New Jersey, a quality improvement initiative led by the New Jersey Hospital Association's Institute for Quality and Patient Safety. The latest CMS data shows their efforts have yielded measurable results.

"This is great news for New Jersey patients. It shows dramatic progress in supporting patients and making sure their recoveries stay on-track once they leave the hospital," said NJHA President and CEO Betsy Ryan. "That's something that has been a challenge for our state, quite frankly, and we've been working very hard to improve. It's most rewarding to see that work pay off."

The national data, reported yesterday in a [CMS blog post](#), shows that New Jersey's 2015 readmission rate stands at 17.6 percent. Its rate is lower than or the same as nine other states and the District of Columbia. That's a significant change from the 2010 report, when New Jersey's rate was 20.3 and ranked as the second highest in the country.

"New Jersey has had difficulty with this issue for a variety of reasons, including socioeconomics, demographics, cultural diversity and a multitude of languages spoken here, among others," said Aline Holmes, RN, DNP, NJHA senior vice president and director of the Institute for Quality and Patient Safety. "But what we see in the past five years of data is that New Jersey is not only improving its own rate, its progress surpasses many other states. That shows real success as New Jersey healthcare providers deliver better care in the hospital and better continuing care and support once a patient leaves the hospital."

NJHA and its members – both hospitals and post-acute care providers – have been engaged in a number of strategies to reduce hospital readmissions. In addition to NJHA's leadership as a federally designated "hospital engagement network" leading the Partnership for Patients-New Jersey effort, other readmissions activities have included:

- NJHA's Collaborative to Reduce Readmissions, a two-year initiative launched in 2010 that brought together hospitals, nursing homes, home health and hospice providers in a joint effort to identify best practices, apply them to their organizations and share data to measure results. This work was the precursor to NJHA's ongoing Partnership for Patients effort.

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- Education programs and conferences in partnership with other healthcare stakeholders including Horizon Blue Cross Blue Shield of New Jersey and Healthcare Quality Strategies Inc.
- NJHA's development of Well on Track, a web-based tool that helps hospitals organize and track follow-up with patients that are discharged from the hospital.
- New Jersey's CARE Act, which defined processes for hospitals to work with patients, families and caregivers to ensure they have the information and support they need before being discharged from the hospital. NJHA worked collaboratively with policymakers to craft the bill and with AARP to promote implementation.

Family Caregivers Need Our Help—And Now It's the Law

The CARE Act mandates preparation and teaching prior to hospital discharge.

If you're a regular *AJN* reader, you're probably familiar with our initiatives over the years aimed at supporting family caregivers. (Our caregiver resources are now grouped into a collection, *Resources to Support Family Caregivers*, which you can access at <http://links.lww.com/AJN/A81>.)

In 2008, we participated in an interdisciplinary state of the science meeting to determine the needs of family caregivers and how nurses and social workers could help meet those needs. During the meeting, the complexities and difficulties of caregiving became all too clear and nursing's failure to adequately prepare and support caregivers all too apparent. (For a poignant report, read Carol Levine's *Home Alone* in her caregiving experience in the September 2008 special report: <http://links.lww.com/AJN/A88>.)

This project jump-started our ongoing work with the AARP Public Policy Institute on family caregiving. I recall listening to focus groups of caregivers, in which a common theme was that nurses didn't seem to have time to teach caregivers how to do certain tasks or to answer questions about posthospital care. The caregivers' stories of trying—and often failing—to find someone to show them what to do were often heartbreaking, and they voiced how unprepared, anxious, and stressed they felt. As a nurse, I was disheartened and embarrassed by our failings. Why weren't there more evidence-based resources for these caregivers, and why didn't nurses have time for discharge planning or patient and family teaching?

In 2011, we developed a series of articles and videos to educate nurses on how to best assess the needs of family caregivers. Then, in 2012, AARP and the United Hospital Fund published the landmark report *Home Alone: Family Caregivers Providing Complex Chronic Care*, which documented that family members were not just assisting with dressing, bathing, and eating, but were managing complex “medical/nursing” tasks such as wound care and tube feeding and giving medications and injections. And many reported receiving little or no training.



Forty million adults care for a family member and that number will only grow.

As noted in the November 2016 *AJN* by Susan C. Reinhard, senior vice president and director of the AARP Public Policy Institute, and Heather M. Young, dean and professor in the Betty Irene Moore School of Nursing at the University of California, these are “the same tasks that made us tremble the first time we performed them as new nurses.”

The report spurred a groundswell of awareness of and support for unpaid family caregivers. AARP led a legislative effort that resulted in the Caregiver Advise, Record, Enable (CARE) Act, which mandates that hospitals identify, coordinate discharge with, and provide care instructions to the person who will provide care at home for a patient upon hospital discharge. The CARE Act is now law in 39 states.

In 2016, working again with AARP and other partners as part of AARP's Home Alone Alliance initiative, *AJN* launched a series of articles and videos to help nurses provide caregivers with the tools they need to administer their family member's medications, from eye drops to injections. The articles review the evidence for the practices nurses should reinforce with caregivers, and are accompanied by videos, produced by AARP and partners, that provide detailed step-by-step instructions for caregivers. And now, starting with this issue, we are launching a new series of articles and videos. These are designed to help nurses prepare caregivers to safely assist with mobility and to prevent falls or manage them if they occur; they will be followed by a series on skin and wound care. Each article includes a tip sheet that nurses can tear out and give to caregivers. The tips review key points and include links to instructional videos, which are available to caregivers on AARP's Home Alone Alliance site in both English and Spanish and can also be accessed on *AJN*'s website.

Over 40 million adults provide care to a family member, and that number will only grow as the number of people living with chronic conditions increases. We hope these articles and videos help hospitals and nurses meet their obligations to family caregivers. ▼

**Testimony
Senate Bill 2154
Senate Human Services Committee
January 15, 2019**

Chairman Lee and members of the Senate Human Service Committee, I am Kim Jacobson from Cummings, North Dakota which is in Traill County, North Dakota. I apologize for not being present for today's hearing. However, please accept my written testimony in support of SB 2154.

When speaking about my family's health, I have often referred to us as "medically challenged." If there is some rare complication or side effect, we are sure to experience it. However, through these experiences I have become strongly determined that all individuals who are hospitalized need to focus on one thing, getting well. For that reason, I am very committed for supporting my loved ones whenever they are hospitalized. To me this means ensuring that a family member is with our sick loved one, to the greatest amount possible, around the clock. My support of SB 2154 stems from my experiences with my daughter, my mother and my father.

I would like to tell you a little bit about my father, Richard Anderson. He is a retired, 81-year-old, stubborn, determined, second generation Swedish farmer and businessman. His experience with discharge planning during a recent accident provides a vivid example on why there is a need for improvement to the discharge process and requirements.

In October 2018, my father came upon road debris while driving his beet truck. The beet truck rolled. My father sustained broken bones in his back, suffered a stress related heart attack, lacerations, bruised ribs and kidneys. He was found unconscious by

the paramedics who needed to remove him from his truck by breaking the windshield. My father was transferred to a major medical center in Fargo by ambulance.

His medical experience started off well with excellent care and care coordination. However, by the time he transitioned to intermediary care, things changed. As family, we stayed with my father continuously. My father had also experienced an exacerbation of COPD during this medical event and his dependency on breathing treatments and oxygen were critical. I knew my 78-year-old mother was also frail. During the past four years she had suffered from breast cancer, thyroid cancer, a severely broken hip and chronic kidney failure. Weak from her injury and illnesses, my mother spends much of her day in a wheelchair or using a walker for assistance. I was very concerned about her ability to care for my stubborn, and frequently non-compliant father, who we both dearly love.

Daily, I asked to speak with the social worker as I knew that discharge planning, should start right away. However, I received no response, and no one was in contact with my mother, myself, nor my brother to discuss her ability to meet my father's needs. Nurses left notes and charted our requests that all went unanswered.

After nearly a week of being at the hospital there was a day where my brother and myself both had to work. I had a board meeting that I needed to attend. I was shocked to learn that during that time a decision had been made to discharge home. As a family, we had continuously mentioned to the doctors and nurses that we felt that discharge to swing bed would best meet his needs. However, this request was denied. I quickly left work, picked up my mother and headed to Fargo. I called and asked for a review of this decision which was also denied before I could even arrive onsite.

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As I pushed my mother in a wheelchair to my father's room, I found an Occupational Therapist with my father. She remarked "*good we need to teach his caregiver how to help Richard with his back brace. Who is his caregiver?*" I asked how frequent he would need assistance and the response was that he needed help whenever he got up, got down and with adjusting the brace throughout the day. In addition, as he could not leave bed without the brace and could not sit up without it on, so he would need someone to place the brace on him while he laid stationary. I explained that while I could assist some, that I worked full-time and that my parents lived independently at home. I detailed my mother's medical conditions.

The OT then requested for my mother to come to the side of the bed, so she could teach her how to pull the brace from under my father and adjust. Just getting out of the wheelchair resulted in my mother nearly falling. However, she persisted but clearly it was a hazard for her to do these tasks. I asked, "*is it your facility's policy to discharge a patient who requires care without assessing the caregiver?*" She looked at me blankly and I again asked the question. She replied "*no, but the discharge paperwork is done. I'm sorry for the inconvenience.*" I remarked inconvenience is reopening paperwork to include more information for decision-making and that this was not an inconvenience for us, but rather this was a life-threatening decision to discharge without full assessment of needs.

Needless to say, my father was discharged late in a day on Friday. There were many issues: incomplete medication list sent the pharmacy, delayed referral and start of home health services, delayed delivery of oxygen unit to their home, etc. Upon getting home, my father was struggling to breathe and needed his nebulizer treatment. It was at

that point that it was realized that his nebulizer was destroyed in the accident. Thank goodness for small North Dakota communities. I called our local pharmacist, at home on a Friday evening and he met me to give me a new unit and told me we will figure out the billing later.

During my father's time in the hospital a large mass had also been found. We were assured that this would be addressed during with discharge planning with a referral to a specialty unit. This did not occur. It was only because we had been there 24/7 and had noted the hospitalist's comments about this concern that we pushed forward and independently followed up with his general practitioner about a referral. It is a good thing we did. My father has now been diagnosed with cancer and is scheduled for surgery on January 21, 2019. However, this should not have been missed in the discharge process.

SB 2154 would provide for a more meaningful engagement of caregivers into discharge planning and assessment process. While my family is fortunate, we have a support system of individuals who are knowledgeable and adept at problem solving. However, many North Dakota individuals do not have this benefit. I urge you to render a "Do Pass" on SB 2154 which would require facilities to take the time to better plan for the ongoing care of their patients.

Senate Human Services

SB 2154

January 15, 2019

Madam Chair Sen. Lee and members of the committee, my name is Kirsten Dvorak executive director of The Arc of North Dakota, which includes all six Arc chapters in North Dakota: Bismarck, Bowman, Dickinson, Fargo, Grand Forks, and Valley City. Our mission is to improve the quality of life of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community.

In the 2015 Braddock State of the State report for North Dakota it was reported that 2,257 people with intellectual and developmental delayed (I/DD) lived with a caregivers that are over 60 years of age or older. This figure will continue to grow, as more caregiving parents of a child with disabilities get older. (Braddock et al., 2017)

In 2017, The Arc of the U.S. Conducted Family & Individual Supports for Disability Supports (FINDS) survey. This purpose of the of FINDS is to understand the experiences that families and caregivers that provide supports to a family member with I/DD. It is estimated that 43.5 million people in the U.S. provide support to a family member who is aging or who has a disability. (National Alliance for Caregiving 2015). All caregivers reported providing health supports.

This includes coordination of health services, communicating with support and health care professionals about progress and needs, and performing medical tasks. (E.g. feeding with a tube, suctioning, and monitoring respiration.) More than half provided two or fewer health-related supports with the remaining 42% provided three or four supports.

Most caregiver report that their family member lives with them.

Activities of daily living (ADL) such as toileting, eating, dressing, grooming, and hygiene and mobility, which may include transfers, getting in out of bed and chairs. Caregiver's report that support their family member with at least one ADL Daily. Caregivers also reported to giving Instrumental Activities of Daily Living (IADL) such as giving medications, making decisions about everyday matters (e.g. what to wear, when to go to bed), managing finances (paying bills, banking, filling out forms), doing errands, going grocery shopping, simple chores around the home such as dishes, and laundry. Preparing meals, providing transportation to appointments or arranging rides. Providing advocacy, supporting self-advocacy, and organizing/prioritizing tasks. Most caregivers in the FINDS survey report that providing support for at least IADL and more than half-provided between four to eight IADL.

This is just a highlight of what a caregiver to someone with I/DD does throughout the week. This does not include navigating system supports such as job supports, personal care assistants, finding respite providers, arranging social and leisure activities. In addition to providing on-going management of behavior outburst or self-injurious behaviors in some individuals. Individuals

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with I/DD and Autism Spectrum Disorder (ASD) were more likely to need behavioral supports than were individuals with I/DD only.

I have only highlighted some of the stressors and fatigue that are reported by caregivers. The intensity and duration of caregiving responsibilities for individuals with I/DD is greater than that reported by the other caregivers. These responsibilities coupled with challenges finding adequate supports for their family member explain the high level of stress and the need for more attention on caregiver supports.

The Arc of North Dakota asks for do pass on SB 2154 to help in reducing stress and fatigue family members in caring for their family members. We want all of our members to be cared for in a safe matter.

Kirsten Dvorak
Executive Director
701-222-1854

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Vision
The North Dakota Hospital Association will take an active leadership role in major Healthcare issues.

Mission
The North Dakota Hospital Association exists to advance the health status of persons served by the membership.

Testimony: 2019 SB 2154
Senate Human Services Committee
Senator Judy Lee, Chairman
January 15, 2019

Good morning Chairman Lee and Members of the Senate Human Services Committee. I am Melissa Hauer, General Counsel of the North Dakota Hospital Association. I am here to testify regarding 2019 Senate Bill 2154 and ask that you give this bill a **Do Not Pass** recommendation.

The North Dakota Hospital Association represents 47 hospitals in the state. These members include large hospitals, critical access hospitals, and specialty hospitals. Our members appreciate the opportunity to speak to you about their concerns with this bill which deals with aftercare and hospital discharge policies. As you may remember, similar bills were introduced in 2015 and 2017 and they were defeated because they were considered duplicative and unnecessary. These concerns hold true with this bill too. The provisions of the bill are still unnecessary and redundant of discharge planning requirements that hospitals are already required to meet today.

We appreciate the intent of the bill, but hospitals are already highly regulated regarding discharge procedures. Hospitals are required to follow state licensing requirements for discharge procedures and Conditions of Participation in order to participate in Medicare and Medicaid. Accreditation standards also dictate discharge processes. Hospitals are already highly motivated to ensure patients are not readmitted because reimbursement is reduced if a hospital has too many readmissions or if patients indicate on satisfaction surveys that they were not happy with their care.

We are not aware of any findings of government regulators or accrediting bodies that North Dakota hospitals are not following these already well-established discharge policies and procedures. We requested the supporters of this bill to bring problematic discharge experiences (with the patient's consent) to our attention so we may work together to find solutions. We have not been provided with information in response to those requests.

This bill will cause discharge delays. Hospitals' top priority when discharging a patient is to ensure patients and their caregivers have the information and resources needed to ensure the best outcome possible. If required to follow this bill's required documentation, notification, and education of the caregiver, it will delay hospitals' ability to timely discharge a patient. For example, if the caregiver is not responsive to notification, not available when the hospital team is, must travel a long distance, or is not qualified, how is a hospital to proceed? Should it discharge the patient anyway and not fulfill its duty to notify and train the caregiver? Or should it delay the discharge? This puts hospitals in a no-win situation.

At the top of page three, the bill requires hospitals to request written consent from the patient, or the patient's legal representative, to release medical information to the lay caregiver in accordance with the hospital's established procedures for releasing a patient's personal health information and in accordance with existing laws. Hospitals are already subject to HIPAA privacy law and regulations. This provision duplicates federal and state privacy laws and is unnecessary. Hospitals will now have to ensure every patient who has a caregiver signs an appropriate authorization for release of information before it may fulfill its duties under this bill.

The bill would interfere with long established law regarding durable powers of attorney. The bill provides that a hospital may not give a legal representative who is an agent under a durable power of attorney for health care the opportunity to designate a lay caregiver in lieu of the patient's designation of a lay caregiver, unless, in the judgment of the attending physician, the patient is unable to make that health care decision. A durable power of attorney is protection against costly court proceedings in the event you become incompetent. In that situation, your agent can handle your affairs without the need for a guardian or conservator being appointed by a court. This provision of the bill would do away with this longstanding law and put the physician in the middle, requiring a determination of incapacity, when such a determination was clearly not required by the person who signed the power of attorney. It makes a court's involvement in such capacity determinations unclear as well. In short, this requirement invites litigation.

This bill duplicates requirements that hospitals are already required to fulfill. They are therefore unnecessary and raise questions about whether such mandates are really requiring something in addition to what is already obligatory. The bill, for example, mandates hospitals to have written discharge policies and that the hospital provide the patient and uncompensated caregiver "instruction and training" for the patient's aftercare before the patient may be discharged. These duties are already required of hospitals. Does adding them indicate that hospitals must do something more than what is already obligatory? If not, then why are they necessary?

This bill would create additional questions and potential liability for hospitals. Hospitals have no control of the care that would be provided by the caregiver to the patient after discharge. The hospital, however, is required to instruct and train the caregiver. What if the uncompensated caregiver misunderstands or forgets the instructions? What if the care is performed poorly and harms the patient? Is the hospital responsible for failing to ensure the uncompensated caregiver sufficiently understood the discharge plan? Although the bill contains a vague immunity from liability provision, even if it is enforceable, hospitals will still undoubtedly be sued and will incur costs in defending themselves. In addition to civil liability, it is unclear how a violation of this law might affect a hospital's reimbursement, licensing, or accreditation. There is no guidance regarding how non-compliance would impact a hospital. The bill opens the door wide for hospitals to be held responsible for the actions, or inaction, of caregivers after the patient is discharged.

This bill creates expense by requiring additional documentation of care to be provided by the uncompensated caregiver in a non-hospital setting after discharge. This additional documentation will likely require additional time and expense for hospitals. Hospitals already have a shortage of professional staff and this bill is requiring additional work with no additional funds to accomplish the additional documentation, thus creating an unfunded mandate imposed on the hospitals.

In conclusion, hospitals are highly motivated to ensure proper care of patients after discharge. Hospitals are required to do so by federal Conditions of Participation, state licensing requirements, and accreditation standards. We welcome the opportunity to work with families and supporters of this bill to identify and solve poor patient experiences. But we do not support creating a law to solve a problem that we have not been given evidence exists. This is an

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unnecessary, duplicative law being pushed by the agenda of a national organization that does not know the values of our particular state. It will generate additional cost, uncertainty, and potential liability for hospitals while not providing any real benefit for patients.

We oppose this bill and ask that you give this it a **Do Not Pass** recommendation.

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

Respectfully Submitted,

Melissa Hauer, General Counsel
North Dakota Hospital Association

Senate Human Services Committee
Sen. Judy Lee, Chair
January 15, 2019
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#8 pg. 1

Chairman Lee and members of the Senate Human Services Committee, my name is Chris Meeker, M.D. I am a board-certified emergency medicine physician and chief medical officer at Sanford Health in Bismarck.

Sanford Health is dedicated to the integrated delivery of health care—combining research, innovation and quality improvement initiatives to ensure access to affordable, coordinated, high-quality care in the communities we serve.

I appreciate this opportunity to speak to you about Senate Bill 2154 regarding hospital discharge policies. During the 64th and 65th Legislative Assemblies, similar bills were considered and defeated to avoid creating a law that duplicates existing standards and practices.

As noted in previous testimony, comprehensive federal and state requirements minify the language before you today. The standards and processes around discharge planning and patient rights are thorough and detailed. The Centers for Medicare and Medicaid Services (CMS) through their Conditions of Participation (CoP) establish rules around discharge planning, as does the Joint Commission's Standards for Accreditation (TJC).

CMS regulations for Hospital Discharge Planning include:

- Patients have a written discharge plan developed.
- Patients have specific discharge instructions provided in writing.
- Patient goals and preferences for discharge are taken into account.
- Patient caregivers are active partners in the discharge plan.
- Hospitals consider the availability and capability of the caregiver to provide home care.
- Discharge planning begins within 24 hours of admission.
- Discharge planning process is completed prior to discharge.
- Discharge instructions are presented in a way that the patient and caregiver can understand.

All of these requirements must be documented in the patient medical record.

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Additionally, the North Dakota Department of Health provides rules for hospital licensing (Chapter 33-07-01.1): *“Every patient must receive effective discharge planning consistent with identified Patient and family needs from the hospital. Discharge planning must be initiated in a timely manner. Patients, along with necessary medical information, must be transferred or referred to appropriate facilities, agencies, or outpatient services, as needed, for follow-up or ancillary care.”*

It is important to recognize North Dakota’s quality of care routinely outpaces other areas of the country. North Dakota’s hospital readmission rate—a measurement of quality hospital care and discharge planning—is consistently lower than the national average. What’s more, North Dakota’s annual readmission rate continues to decrease, indicating the investment in ongoing quality and process improvement initiatives.

As hospitals transition to value-based care, we are continually incorporating rigorous process improvement strategies to improve patient outcomes. Certainly, we recognize that with thousands of hospital discharges in North Dakota, problems can and do occur. We welcome—and have invited—supporters of this bill to participate in this process by inviting North Dakota patients who endured poor patient discharge experiences. Sanford and other North Dakota hospitals actively embrace patient experience to help us identify areas of improvement and strategize workflow processes to increase quality outcomes.

As an example, Sanford’s Patient Family Advocacy Council routinely engages patients and their family members with hospital staff and leaders to learn from community members’ experiences. It is through thoughtful, intentional patient engagement that meaningful change is accomplished.

In summary, it is our position that the goals of this legislation are already required on both the federal and state level. We respectfully ask that you vote no to adding regulations that duplicate existing requirements.

Thank you for your time and consideration. I am happy to answer any questions.

Chris Meeker, M.D.
Chief Medical Officer
Sanford Health Bismarck
701-323-2601
Chris.Meeker@Sanfordhealth.org

Senate Human Services Committee**Sen. Judy Lee, Chair****January 15, 2019****SB2154**SB 2154
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Chairman Lee and members of the senate Human Services Committee, my name is Maggie Seamands. I am a registered nurse and am board certified in case management at Sanford Health. My primary role is acting Director of the Case Management and Social Service and I have been in my current role for 6 years.

Today I would like to outline for you the discharge planning process that the hospital follows to ensure that we meet the many regulatory requirements as outlined by Dr. Chris Meeker. Discharge planning really does begin at the time of admission. The case manager and/or social worker meets with the patient and/or family to assess the current living situation, identify support systems, identify current services the patient has, as well as durable medical equipment the patient uses. The case manager and social worker also visit with the family about what their goals are for discharge.

This information is then shared with a multidisciplinary team made up of the physician, nursing staff, therapists, and others if needed in order for the team to collectively work with the patient and family to meet their discharge goals if able. During the multidisciplinary team meetings there is discussion about the plan of care for the patient, talk about any changes in their status, discuss any barrier for discharge and any concerns that either the patient or the care team have regarding the patient. If the patient would benefit from receiving services or medical equipment, the social worker provides the patient and family/caregiver a list of possible resources and then assists them by makes referrals accordingly.

During the times that the care team thinks the patient is going to need more care than can be provided at home, our team will talk to the patient and the family about our concerns and will recommend a different discharge option. Ultimately, the patient has the right to make that decision and as long as they are competent, we must respect that decision.

The team is continually reevaluating the discharge plans with the patient and family depending upon any changes that may occur during the hospitalization. Up to two days prior to discharge, the Important Message from Medicare (IMM) notice is given to

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hospitalized inpatients covered by Medicare. This informs patients of their hospital discharge appeal rights and also lets the patient know they have the right to be involved in any decisions about their hospital stay. It lists for the patient contact information if they have any quality of care concerns. There is an entire section that addresses Medicare Discharge Rights. If a patient feels they are being discharged too soon they can file an appeal with the Quality Improvement Organization (QIO).

When the patient is ready for discharge, the patient and/or family is given a written copy of discharge instructions. These discharge instructions include information about the patient's medications, diet, activity, care of any wounds, and follow-up appointments. The case manager or social worker will also follow up with any agency referrals that have been made. The nurse reviews the instructions with the patient and/or family members.

As was outlined by Dr. Meeker, hospitals already have numerous regulations, rules, and standards for discharge planning. None of these regulations are taken lightly by hospitals. We work diligently to ensure that patients have adequate support systems and the tools and resources they need to be successful at discharge. We strive to continually evaluate our processes to ensure that we can make improvements where needed. We take the safety of our patients very seriously and encourage our patients to share their experiences with us so we can work toward ensuring all discharges are safe.

Chairman Lee and Committee Members, thank you for your time and attention.

I would be happy to answer any questions.

Maggie Seamands,
Case Management and Social Services Director
Sanford Health
701-323-8051
Maggie.Seamands@SanfordHealth.org

Stories Supporting the Need for the CARE Act:

Michael, Bismarck: My dad developed a bed sore when he was in the hospital for pneumonia. When he came home we didn't really know what to look for so when it became infected, we didn't catch it right away. He returned to the hospital and we were scared for his life. He was in for a long time fighting the infection. We're blessed that he made it but wish we would have known what to look for. It probably would have prevented the second long stay.

Kim, Fargo: The hospital initially identified my mother as a caregiver, but she has no ability to do it. Not even close. My brother and I took on those duties and watched over him at the hospital 24/7 and we were very persistent. We told the nurses at the hospital there was a window one morning that neither of us could be there to watch Dad. I returned a little earlier from my appointment and when I got to the hospital the discharge was in process! I wasn't notified and my brother and I had been there constantly except for that one morning. We were shocked!

Anonymous, Bismarck: I was helping my mother after she had surgery on her shoulder. One day we decided to give her a bath and removed her sling. After the bath we could not figure out how to put the sling back on (we weren't taught how to do that when Mom was in the hospital). We kept trying but eventually had to go to the emergency room for help.

Merne, Fargo: After being on IV's (only) for four days I was discharged from a Hospital in Fargo after emergency gall bladder surgery. I thought I understood the discharge instructions even though I was still on pain medications. However, after two hours at home I realized that I had a butterfly wing needle in my arm. Fortunately my son knew from his military service in Iraq how to remove it, saving me a visit to the emergency room.

Vel Rae, Fargo: My sister was in the Emergency Room at Sanford for her spiked blood pressure and I think something else, she might have fallen. When she was ready to leave, the nurse put her sheets on the bedside table for her discharge which included supposedly what she was supposed to do when she got home. They didn't talk to her about it and when her daughter looked at them they were for another woman who was there for a migraine headache. Needless to say, my niece was not too happy.

Laura, Bismarck: Patients get sent home with oxygen tanks and cumbersome wheel chairs with little to no instruction. Home health needs to be ordered on every single patient to have at least one post hospitalization visit. Medication set-up needs to be re-organized and checked! Make sure a primary caregiver is present at discharge.

Ellen, Bismarck: A sixth grade relative of mine was hospitalized in Jamestown with a blood sugar reading of 378. She was transferred to a Fargo hospital where she was diagnosed with diabetes and a severe kidney infection. She also was running a temperature of 103 degrees. After almost a week in the hospital she returned home where her grandmother was charged with taking care of her. When they left the hospital her grandmother believed she was to provide 20 units of medication, but she noticed the paperwork read two units. Confused, she wondered why her granddaughter's blood sugar was again in the 300s. So she contacted the doctor and discovered the paperwork was wrong.

More CARE Act Comments:

Janet, Bismarck: Doctors need to be more aware of what will happen to patients after they leave the hospital. Cooperation among medical professionals and family members is the key to success, the key to keeping older people in their homes; happy, healthy and enjoying life as much as possible.

Marilyn, Fargo: 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.

Muriel, Mandan: Training, training! Medical staff needs to put all instructions in writing. So much detail is forgotten during this stressful time and make sure the caregiver and patient DO the instruction themselves – doing is much more effective than just hearing them.

Carly, Tioga: Families are very scared to leave (the hospital) because they don't understand instructions.

Mary Ann, Grand Forks: My frustration was the incorrect assumption that family was not and would not be active caregivers and weren't entitled to good information and training to support our loved one.

Why North Dakota Needs the CARE Act

North Dakota family caregivers help their older loved ones with daily activities like shopping, transportation, meals, and chores. They also:



Manage medications*



Handle nursing and medical tasks*

Today the average hospital stay in the United States is 4.5 days. In 1980 it was 7.3 days. And yet today's patients are older, sicker, and just being discharged earlier. **



1 in 4 North Dakota family caregivers say they did not receive instructions on medical tasks when their loved ones were discharged from the hospital. 1 in 4 is too many.*

This is why AARP North Dakota is fighting for the CARE Act, a commonsense, no-cost bill that requires hospitals to provide instruction on the medical tasks family caregivers will need to do at home.

What is the CARE Act?

The CARE Act features

3

important provisions



Designate

Patients can designate a family caregiver to be recorded in their medical record when they are admitted to the hospital



Notify

Family caregivers are notified before their loved one is discharged from the hospital



Instruct

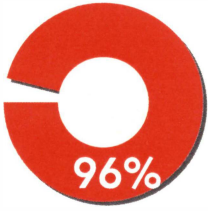
Family caregivers are instructed on the medical tasks they will need to do at home, like cleaning a wound or giving an injection.

* November 2018 survey of 800 North Dakota voters age 40+. Margin of error \pm 3.46%.

**Frakt, A. (2016, January 06). The Hidden Financial Incentives Behind Your Shorter Hospital Stay. The New York Times.

North Dakota Voters Support the CARE Act

Across party lines, North Dakota voters age 40+ overwhelmingly support the CARE Act.



Hospitals should instruct caregivers on medical tasks

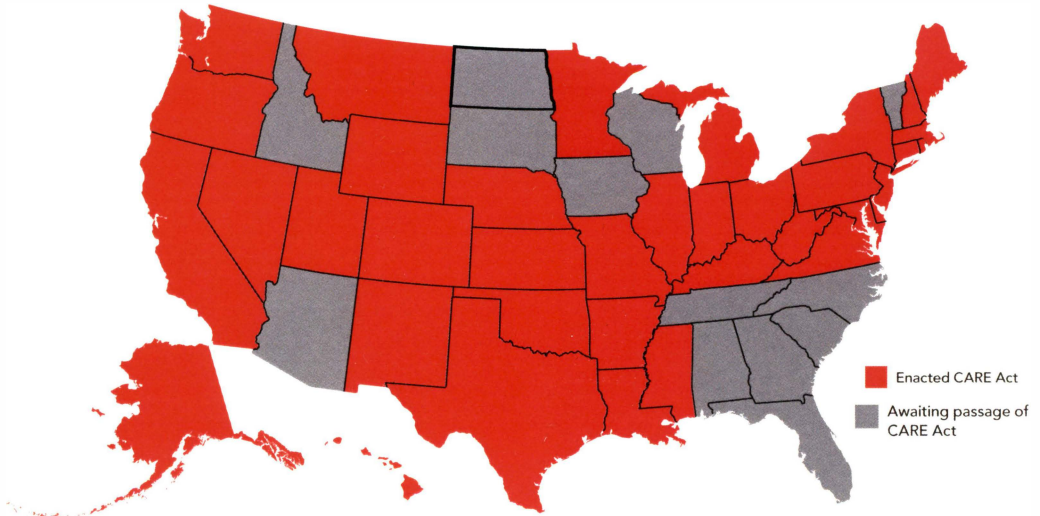


Hospitals should inform caregivers of major decisions



Hospitals should record the name of the family caregiver in the patient's medical record

In states where the CARE Act is law, nurses and other health and social service professionals say it has helped them engage with family caregivers and reduce unnecessary re-hospitalizations.



North Dakota is among only 13 states in this country that have NOT passed the CARE Act and caregiving families outside of North Dakota right now are benefitting from the law's protections.

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PROPOSED AMENDMENTS TO SENATE BILL NO. 2154

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact chapter 23-49 of the North Dakota Century Code, relating to hospital discharge policies.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. Chapter 23-49 of the North Dakota Century Code is created and enacted as follows:

23-49-01. Definitions.

As used in this chapter:

1. "Discharge" means the exit or release of a patient from inpatient care in a hospital to the residence of the patient.
2. "Informal caregiver" means an individual who is at least eighteen years of age, who a patient, or the patient's legal representative, designates at admission as a lay caregiver, and who following the discharge of the patient is willing and able to perform post hospital care for the patient at the patient's residence.
3. "Post-hospital care" means care directly related to a patient's condition at the time of discharge and which is provided by an informal caregiver to the patient in the patient's residence.
4. "Residence" means the dwelling a patient considers to be the patient's home. The term does not include a hospital or rehabilitation facility.

23-49-02. Patient and Caregiver Discharge Planning Involvement and Documentation

1. A hospital must have in effect a discharge planning process that applies to all patients. A hospital's policies and procedures must be specified in writing.
2. A hospital must identify at an early stage of hospitalization all patients who are likely to suffer adverse health consequences upon discharge if there is no adequate discharge planning and actively:
 - a. Involve such a patient throughout the discharge planning process and, as needed, the patient's informal caregiver or representative or both;

- b. Document in the patient's medical record the patient's discharge plan;
- c. Communicate the plan to the patient and, as needed, the patient's informal caregiver or representative or both;
- d. Document in the patient's medical record the arrangements made for initial implementation of the discharge plan, including any training and materials provided to the patient, the patient's informal caregiver, or representative.

23-49-03. Training or After Care Tasks

1. A hospital shall counsel a patient, the patient's informal caregiver, or representative as needed to prepare the patient for post-hospital care, which may include providing in-hospital education or training to the patient or to the patient's informal caregiver or representative.
2. The education or training provided by a hospital to a patient, the patient's informal caregiver, or representative must be tailored to the patient's identified needs which may include medications, treatment modalities, physical and occupational therapies, psychosocial needs, appointments, and other follow-up activities.
3. Teaching methods used by a hospital may include repeated review of instructions with return demonstrations or repeat-backs by a patient or the patient's informal caregiver or representative.

Renumber accordingly

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Nicole Poolman

House Human Services Testimony

SB 2154

March 5, 2019 - 9:15 am - Fort Union Room

Good morning, Chairman Weisz and members of the committee, my name is Nicole Poolman, state senator from District 7 representing Bismarck and Lincoln. I'm here today to introduce SB 2154, a bill to provide training to caregivers before they leave the hospital. North Dakotans believe caregivers should be taught how to care for loved ones before they leave, and some hospitals are doing a wonderful job in this area. Others are not. Thirty percent of North Dakota's caregivers say they received no instruction on the duties they had to perform before they left the hospital. We experienced both good and bad examples of caregiver training in my own family, so I understand how dire the consequences can be if training is not provided.

Caregivers in North Dakota provide 58 million hours of care at a value of more than \$860 million to the state of North Dakota. At a time when we struggle to provide funding to long term care facilities, these caregivers are saving tax payers millions of dollars. The least we can do is provide training to allow them to care for their loved ones safely.

By the year 2025, the population of those age 65 and older will grow by 50,000. We need to support the caregivers who will undoubtedly save the state millions of dollars in the very near future. I urge you to join the 40 other states that have passed this legislation and respectfully ask for your support of SB 2154.



Real Possibilities in

North Dakota

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March 5, 2019
House Human Services Committee
SB 2154- Testimony on Hospital to Home Transitions – The CARE Act
AARP North Dakota
jaskvig@aarp.org or 701-989-0129
mikechaussee@aarp.org or 701-390-0161

Chairman Weisz, members of the House Human Services Committee, I am Mike Chaussee with AARP North Dakota.

Most of you know the story of our founder Dr. Ethel Percy Andrus. A retired educator, she became an activist in the 1940s when she found a former colleague of hers 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 88,000 members in North Dakota and 38 million nationwide. We understand the priorities and dreams of people 50-plus and are committed to helping them live life to the fullest.

I'm here today to support Senate Bill 2154 – a bill we at AARP call the CARE Act. It's intended to create a better working relationship between hospitals and the people who will be taking over the health care role once the patient returns home. In the bill we call them 'informal caregivers' – at AARP we often refer to them as 'family caregivers' because so many of them are family members. These more than 62,100 unpaid, often under prepared people save the state more than \$860 million a year by performing 58 million hours of service.

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They are an important piece of the home care model. Without their commitment to their loved ones, many more people would end up in institutional care like nursing homes.

In our research we have discovered that informal caregivers perform household chores, drive to appointments, cook for and bathe their loved ones. We've also learned that more and more often they are performing complex medical tasks like managing medication, changing bandages and giving injections. In a survey of 800 North Dakotans we conducted a couple of months ago we found that 63 percent of current and former caregivers oversee medication and 56 percent perform those complex tasks. These are not easy jobs for people who are well trained, much less those who have little or no training at all.

Before I get into the guts of Senate Bill 2154 and why we at AARP support it, I'd like to take a moment to thank the North Dakota Hospital Association. At the request of some of you on this committee, and from some members of the Senate Human Services Committee, we've collaborated on a bill we both support. The bill in front of you is a compromise that we believe empowers informal caregivers by defining their role in state statute and brings to the forefront how hospitals can help them do their jobs better.

We are particularly supportive of how we've defined 'informal caregiver' in the bill and how we've incorporated that terminology in place of the use of 'representative' in the CoPs. We believe this helps hospitals clearly identify who needs to be involved in the discharge plan.

The language in the section about post-hospital care training goes to the heart of what we're trying to do. We think it's crucial that informal caregivers are specifically identified and included in this section.

I think the most exciting part of what we've accomplished together is what is to come. We will do our part to help educate and provide resources to the hospitals as

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they embrace the value of including and educating caregivers even more than they already do. We've already had some discussion about how we can work together to improve the discharge process and we've even invited them to participate in telephone town hall we're hosting this summer.

Finally, I'd just like to spend another minute or two discussing the need for this collaborative effort.

In our survey conducted a few months ago we targeted North Dakotan's 40 and older. We discovered that almost half of the people surveyed say they either are currently caregiving or have done so in the past (47%). That's a staggering number. So, we know many people are caregivers.

We also found out that more than 90 percent of them need and want instruction from the hospital before they go home, but more than a quarter of them say they are not getting that instruction. We think by working together on the elements within this bill, we can shrink that number greatly.

In states where the CARE Act has passed and implementation has begun, neat things are happening.

The New Jersey Hospital Association credits the CARE Act for a 13 percent decrease in hospital readmissions in the state. A hospital group in another state where the CARE Act passed started a 24/7 helpdesk for caregivers to call when they need help. And another hospital has established a caregiver advisory group to help discover and solve problems. We know these and other innovative solutions will be popping up more and more as the 40 states and territories that have passed the CARE Act work to implement it into their work.

I'd like to end my testimony with a nugget from a Chief Nursing Officer in a state where the CARE Act passed. Here's her quote:

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“When we first saw the legislation we were skeptical. I will say to you, probably after the first week of go-live, I was hooked and I was just 100 percent on board about the benefit of this work and this legislation for patients and caregivers.”

We know patients are being released from the hospital earlier and earlier. We know that people want to remain home for as long as possible. And we know in order to keep them there, someone has to help take care of them. In some instances, outside help is available and affordable. But in many instances, in most instances, that care falls on the shoulders of a loved one. An informal caregiver who goes unpaid and too often unrecognized. They don't have lobbyists, they aren't able to organize, and they often don't know where to turn. That's why we at AARP have taken up the mantle to help support them.

This legislation gives those caregivers the recognition they deserve right away, in the hospital, where they can be included, involved and educated.

Thank you,

AARP North Dakota

Additional Testimony Provided from:
Page of stories collected from caregivers
Bismarck parish nurses group
Kim Jacobson, Traill County

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Vel Rae, Fargo: My sister was in the Emergency Room at Sanford for her spiked blood pressure and I think something else, she might have fallen. When she was ready to leave, the nurse put her sheets on the bedside table for her discharge which included supposedly what she was supposed to do when she got home. They didn't talk to her about it and when her daughter looked at them they were for another woman who was there for a migraine headache. Needless to say, my niece was not too happy.

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More CARE Act Comments:

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To whom this may concern:

As local Faith Community Nurses, one of our tasks is visiting our parishioners in their homes. These visits are done to follow-up after a hospitalization that we have been made aware of by a family member or referred to us by church clergy. We also check on the homebound elderly and help parishioners get set-up with local community resources. Advocating for our parishioners to stay safe in their home is of utmost importance. In our experience, we have been met with some troublesome hospital discharge situations. We are in a very unique position to observe firsthand how improved discharge planning; discharge education and an appointment of a caregiver would alleviate some of the problems that we are seeing and improve the outcome of their discharge. In most cases, we are not involved in their care before a hospitalization nor are we involved in their care while hospitalized. Therefore, we are not a part of their discharge process. Once we come into their home after a discharge, we are able to recognize some major gaps in communication between the patient and the hospital staff. Below are a few examples:

- Elderly patients are being discharged to home under the assumption that a family member will step in as their caregiver. In some cases, this family member is a spouse that is unable to care for the patient at an adequate level. The spouse will report that they can care for the patient but the hospital staff has not assessed the actual situation. There are very obvious cases that the spouse would be unable to properly care for the patient but yet they are sent home with them as their caregiver, anyway. An able and willing caregiver needs to be assessed and appointed. If this is not available, then some sort of in-home support needs to be ordered by the physician and set-up by discharge planners. Even just one home health visit would help to set the patient up for success once they are back home.
- Another example along these same lines is that elderly patients are being sent home with the assumption that their adult children or nieces/nephews will help transition them back into the home. While these family members usually have good intentions, their own family life and work schedule makes it so that proper caregiving does not exist. If a willing and able caregiver is not appointed or if a family member cannot commit enough time to caregiving, then in-home support needs to be set-up before discharge to fill in these gaps, even if it only for the first couple weeks after discharge.
- We have seen patients be discharged and sent home with oxygen tanks, wheelchairs, new medications and multiple scheduled follow-up appointments but they do not understand or have the ability to manage all of these things. They do not have rides to appointments so they end up scrambling to find help or they miss their follow-ups. They do not have the physical strength to manipulate their wheelchair nor do they have room in their small home to maneuver around with it because their home situation has never been assessed. They do not understand how to use their oxygen tanks and they can barely move it around the home alongside them. The new medications that were started in the hospital need to be added to their pillbox but the patient does not have the ability to organize this. Also, we have seen that when a new medication is started in the hospital to replace an old medication, the patient does not understand this and will take both medications once they get home. In cases like these, home health needs to make at least one visit to their home to assess the medication changes and schedules as well as make sure that the hospital equipment works within their home. Another solution would be to appoint and educate a caregiver that could be present at discharge to receive the proper

education. This appointed caregiver could be educated about the medication changes so they can fix the pillbox at home. This caregiver could also advocate for the patient if they know that the medical equipment will not work in the home setting.

- Often times, home health is not set up or even discussed with the patient. In cases that the patient does not qualify for home health, it is still not discussed with them about the in-home support services available to them. Meal delivery services are not discussed or offered upon discharge. The services provided by the local Senior Center are not discussed. The services provided by our ND Department of Aging Services are not discussed. We have wonderful resources in our city that are available to these patients but they are not being discussed or communicated. If some of these services were set while the patient is still in the hospital, the transition to home could be more seamless. Once the patient is discharged to home, they are usually weak, ill and tired. Making these arrangements on their own is close to impossible, in most cases.
- We have also seen a case where a patient was living in an Assisted Living Facility but was under independent care, meaning they were receiving no assistance within the facility. This patient ended up going to the Emergency Room for pain, due to a fall. After the problem was resolved in the ER, the patient was discharged back home to the Assisted Living Facility. It was "assumed" that this patient would have a caregiver when in actuality; this patient was not receiving any services. The ER did not notify the Assisted Living Facility, physical therapy was not ordered and the primary care physician was not notified. Once the patient returned home, the new medications were incorrectly organized and some were found on the floor. This gap in communication could have been resolved by making sure this patient had an appointed caregiver or by calling the assisted living facility to make sure that appropriate care would be provided at the facility.

We are fully aware that the hospital based Registered Nurses working with these patients are doing their best with the time that they have while juggling multiple patients, admissions and discharges. We do not believe that the discharge planning should fall onto their shoulders. It would be impossible for them to take on this task. However, simply appointing an able and willing caregiver is a step in the right. On a broader scale, hospitals need to have some sort of discharge planning team that helps with transitions from **hospital to home**. Case Managers or Discharge Planning Nurses could work with outside entities, such as the ND Department of Aging Services, Meals on Wheels and the local Senior Center. Relationships could be developed between the hospital and private in-home support companies. The hospital could utilize their Home Health program to create a seamless transition from hospital to home. The communication errors, the false assumptions, the inadequate caregivers at the home and the medication set-up errors that we have witnessed could be greatly reduced by having someone assess these patient's situations while they are hospitalized. We want to see that the elderly and disabled people in our community are being set up for **success** once they leave the hospital. We also want to see hospital readmissions reduced, for the patients' and hospital's sake. Most importantly, we want all people to be able to manage their health at home with reduced stress and a higher quality of life.

Thank you,

Faith Community Nurses in Bismarck, ND

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**Testimony
Senate Bill 2154
Senate Human Services Committee
January 15, 2019**

Chairman Lee and members of the Senate Human Service Committee, I am Kim Jacobson from Cummings, North Dakota which is in Traill County, North Dakota. I apologize for not being present for today's hearing. However, please accept my written testimony in support of SB 2154.

When speaking about my family's health, I have often referred to us as "medically challenged." If there is some rare complication or side effect, we are sure to experience it. However, through these experiences I have become strongly determined that all individuals who are hospitalized need to focus on one thing, getting well. For that reason, I am very committed for supporting my loved ones whenever they are hospitalized. To me this means ensuring that a family member is with our sick loved one, to the greatest amount possible, around the clock. My support of SB 2154 stems from my experiences with my daughter, my mother and my father.

I would like to tell you a little bit about my father, Richard Anderson. He is a retired, 81-year-old, stubborn, determined, second generation Swedish farmer and businessman. His experience with discharge planning during a recent accident provides a vivid example on why there is a need for improvement to the discharge process and requirements.

In October 2018, my father came upon road debris while driving his beet truck. The beet truck rolled. My father sustained broken bones in his back, suffered a stress related heart attack, lacerations, bruised ribs and kidneys. He was found unconscious by

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the paramedics who needed to remove him from his truck by breaking the windshield. My father was transferred to a major medical center in Fargo by ambulance.

His medical experience started off well with excellent care and care coordination. However, by the time he transitioned to intermediary care, things changed. As family, we stayed with my father continuously. My father had also experienced an exacerbation of COPD during this medical event and his dependency on breathing treatments and oxygen were critical. I knew my 78-year-old mother was also frail. During the past four years she had suffered from breast cancer, thyroid cancer, a severely broken hip and chronic kidney failure. Weak from her injury and illnesses, my mother spends much of her day in a wheelchair or using a walker for assistance. I was very concerned about her ability to care for my stubborn, and frequently non-compliant father, who we both dearly love.

Daily, I asked to speak with the social worker as I knew that discharge planning, should start right away. However, I received no response, and no one was in contact with my mother, myself, nor my brother to discuss her ability to meet my father's needs. Nurses left notes and charted our requests that all went unanswered.

After nearly a week of being at the hospital there was a day where my brother and myself both had to work. I had a board meeting that I needed to attend. I was shocked to learn that during that time a decision had been made to discharge home. As a family, we had continuously mentioned to the doctors and nurses that we felt that discharge to swing bed would best meet his needs. However, this request was denied. I quickly left work, picked up my mother and headed to Fargo. I called and asked for a review of this decision which was also denied before I could even arrive onsite.

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As I pushed my mother in a wheelchair to my father's room, I found an Occupational Therapist with my father. She remarked "*good we need to teach his caregiver how to help Richard with his back brace. Who is his caregiver?*" I asked how frequent he would need assistance and the response was that he needed help whenever he got up, got down and with adjusting the brace throughout the day. In addition, as he could not leave bed without the brace and could not sit up without it on, so he would need someone to place the brace on him while he laid stationary. I explained that while I could assist some, that I worked full-time and that my parents lived independently at home. I detailed my mother's medical conditions.

The OT then requested for my mother to come to the side of the bed, so she could teach her how to pull the brace from under my father and adjust. Just getting out of the wheelchair resulted in my mother nearly falling. However, she persisted but clearly it was a hazard for her to do these tasks. I asked, "*is it your facility's policy to discharge a patient who requires care without assessing the caregiver?*" She looked at me blankly and I again asked the question. She replied "*no, but the discharge paperwork is done. I'm sorry for the inconvenience.*" I remarked inconvenience is reopening paperwork to include more information for decision-making and that this was not an inconvenience for us, but rather this was a life-threatening decision to discharge without full assessment of needs.

Needless to say, my father was discharged late in a day on Friday. There were many issues: incomplete medication list sent the pharmacy, delayed referral and start of home health services, delayed delivery of oxygen unit to their home, etc. Upon getting home, my father was struggling to breathe and needed his nebulizer treatment. It was at

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that point that it was realized that his nebulizer was destroyed in the accident. Thank goodness for small North Dakota communities. I called our local pharmacist, at home on a Friday evening and he met me to give me a new unit and told me we will figure out the billing later.

During my father's time in the hospital a large mass had also been found. We were assured that this would be addressed during with discharge planning with a referral to a specialty unit. This did not occur. It was only because we had been there 24/7 and had noted the hospitalist's comments about this concern that we pushed forward and independently followed up with his general practitioner about a referral. It is a good thing we did. My father has now been diagnosed with cancer and is scheduled for surgery on January 21, 2019. However, this should not have been missed in the discharge process.

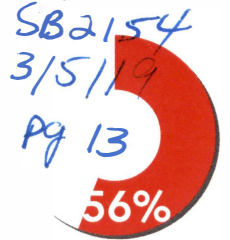
SB 2154 would provide for a more meaningful engagement of caregivers into discharge planning and assessment process. While my family is fortunate, we have a support system of individuals who are knowledgeable and adept at problem solving. However, many North Dakota individuals do not have this benefit. I urge you to render a "Do Pass" on SB 2154 which would require facilities to take the time to better plan for the ongoing care of their patients.

Why North Dakota Needs the CARE Act

North Dakota family caregivers help their older loved ones with daily activities like shopping, transportation, meals, and chores. They also:



Manage medications*



Handle nursing and medical tasks*

Today the average hospital stay in the United States is 4.5 days. In 1980 it was 7.3 days. And yet today's patients are older, sicker, and just being discharged earlier. **



1 in 4 North Dakota family caregivers say they did not receive instructions on medical tasks when their loved ones were discharged from the hospital. 1 in 4 is too many.*

This is why AARP North Dakota is fighting for the CARE Act, a commonsense, no-cost bill that requires hospitals to provide instruction on the medical tasks family caregivers will need to do at home.

What is the CARE Act?

The CARE Act features

3

important provisions



Designate

Patients can designate a family caregiver to be recorded in their medical record when they are admitted to the hospital



Notify

Family caregivers are notified before their loved one is discharged from the hospital



Instruct

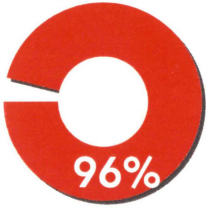
Family caregivers are instructed on the medical tasks they will need to do at home, like cleaning a wound or giving an injection.

* November 2018 survey of 800 North Dakota voters age 40+. Margin of error ± 3.46%.

**Frakt, A. (2016, January 06). The Hidden Financial Incentives Behind Your Shorter Hospital Stay. The New York Times.

North Dakota Voters Support the CARE Act

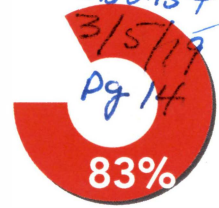
Across party lines, North Dakota voters age 40+ overwhelmingly support the CARE Act.



Hospitals should instruct caregivers on medical tasks

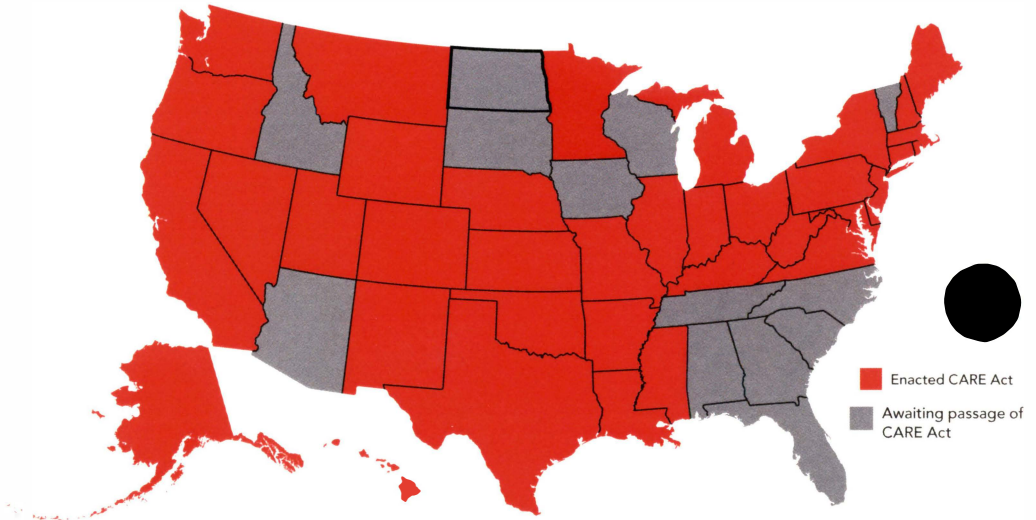


Hospitals should inform caregivers of major decisions



Hospitals should record the name of the family caregiver in the patient's medical record

In states where the CARE Act is law, nurses and other health and social service professionals say it has helped them engage with family caregivers and reduce unnecessary re-hospitalizations.



North Dakota is among only 13 states in this country that have NOT passed the CARE Act and caregiving families outside of North Dakota right now are benefitting from the law's protections.



Vision

The North Dakota Hospital Association will take an active leadership role in major Healthcare issues.

Mission

The North Dakota Hospital Association exists to advance the health status of persons served by the membership.

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**Testimony: 2019 SB 2154
House Human Services Committee
Representative Robin Weisz, Chairman
March 5, 2019**

Good morning Chairman Weisz and Members of the House Human Services Committee. I am Tim Blasl, President of the North Dakota Hospital Association. I am here to ask you to give engrossed Senate Bill 2154 a **Do Pass** recommendation.

The North Dakota Hospital Association represents 47 hospitals in the state. This bill deals with hospital discharge policies. The bill, as introduced, was concerning to our members because hospitals are already highly regulated regarding discharge procedures, including state licensing requirements, Conditions of Participation for Medicare, and accreditation standards.

We worked with the supporters of the bill to find language we could support. The engrossed bill represents that joint effort. The amended bill describes the discharge procedures hospitals follow today. For example, the bill requires hospitals to have written discharge policies and that they involve a patient throughout the discharge planning process. Again, this is what hospitals are doing today.

We support the engrossed bill and ask that you give it a **Do Pass** recommendation. I would be happy to answer any questions you may have. Thank you.

Respectfully Submitted,

Tim Blasl, President,
North Dakota Hospital Association