Health and Human Services Committee September 13, 2019

HOWARD: Welcome to the Health and Human Services Committee. My name is Senator Sara Howard. I represent the 9th Legislative District in Omaha and I serve as Chair of this committee. I'd like to invite the members of the committee to introduce themselves, starting on my right with Senator Murman.

MURMAN: I'm Senator Dave Murman, District 38: south central-- seven counties, south central Nebraska: Clay-- or Clay, Webster, Nuckolls, Franklin, Kearney, Phelps, and southwest Buffalo County.

WALZ: I'm Senator Lynne Walz-- oops-- from District 15, which is all of Dodge County.

ARCH: Senator John Arch, District 14: Papillion, La Vista.

WILLIAMS: Matt Williams, Legislative District 36: Dawson, Custer, and the north portion of Buffalo Counties.

B. HANSEN: Senator Ben Hansen, District 16: Washington, Burt, and Cuming Counties.

HOWARD: Also assisting the committee is our legal counsel, Jennifer Carter, and our committee clerk, Sherry Shaffer. And we do have a committee page who'll be floating in and out. Her name is Brigita. A few notes about our policies and procedures. Please turn off or silence your cell phones. This morning, we'll be hearing-- we'll be receiving one briefing from the department and hearing one interim study. We'll be taking them in the order listed on the agenda outside the room. On each of the tables near the doors to the hearing room, you'll find blue testifier sheets. That's a new color for us; that's very exciting. If you're planning to testify today, please fill out one and hand it to Sherry when you come up to testify. This will help us keep an accurate record of the hearing. Any handouts submitted by the testifiers will also be included as part of the record as exhibits. We would ask, if you do have any handouts, that you please bring 10 copies and give them to the page or give them to Sherry at the beginning. We do use a light system for testifying. Each testifier will have five minutes to testify. When you come up to testify, please begin by stating your name clearly into the microphone, and then please spell both your first and last name. Each interim study hearing will begin with the introducer's opening statement. After the opening, we'll take testimony. And just a reminder: for some of you, this is your first interim study. These do work a little bit different. Testimony is not grouped by supporters or opponents but taken in turn, unless we have invited testimony by the sponsor, in which case we'll take the testimony of those invited first. I will note this at the start of each hearing. If the legislative resolution is a committee resolution, I will introduce it and then return to my seat to proceed with the hearing. We do have a strict no prop policy in this committee. And with that we'll begin today's briefing with Jeremy Brunssen from the Department of Health and Human Services on rate methodology for nursing homes and hospitals. Welcome, Jeremy. And there has been a handout that everyone should have.

JEREMY BRUNSSEN: Good morning, Chairman Howard-- Chairwoman Howard and members of the Health and Human Services Committee. My name is Jeremy Brunssen. I'm the deputy director for finance and program integrity within the Division of Medicaid and Long-Term Care at Nebraska Department of Health and Human Services. So as noted this morning, I'm here to brief you. I have provided you with two PowerPoint presentations. I'd like to start first with the nursing home rate methodology PowerPoint presentation and walk through that, and then when completed, move on, then, to the hospital presentation. Starting with the nursing home presentation, I just want to make sure that you're aware this is a presentation that was provided to stakeholders and to providers in August. So during the month of August, the department did a tour across the state. We visited around 20 facilities, met with administrators, shared some of the plans; and really, it was a great opportunity for us as a department to talk with the administrators and the staff in the various locations across the state. So it's a great value to us to get that feedback one on one. And as part of that as well, we did four formal presentations in Nebraska: one at Scottsbluff, one in Cozad, one in Norfolk, and then one in Omaha. This really-- this presentation is a culmination of a lot of work already done up to that date. There's a little bit of history here, so-- the very first meeting I ever took at the Nebraska Department of Health and Human Services when I started was at the request of Heath Boddy. So we've had this ongoing, really long conversation, not only with Heath and the Health Care Association, but with many other stakeholders as well. We've talked to a lot of providers. And the course of those conversations really led to a point where in March of this year we presented a proposal from the department to make a change to the current methodology and how we pay nursing facilities. That presentation was given during a public meeting, stakehol-- long-term care stakeholder redesign committee meeting. From that meeting, we then received a lot of feedback and met with providers through the course of March, April, and May, and held another meeting in June, at which point we had about 25 stakeholders around the table to talk through some of the changes we've made, based on the feedback received to that point, but then also to walk through five or six key issues that we still hadn't made a decision on. And we're working to have further conversations with the stakeholders that had been reaching out to us directly. So from that point, then, we took that feedback and updated our plans and presented that at the MAC meeting, the Medicaid Advisory Council meeting, and then went out with this presentation and met with providers. So as we go through the slides, note that there might be some things in time and space that are historical, but we'd speak to them in the future tense. And that's why we just wanted to give the same presentation that we've already provided to stakeholders. So why is the department focusing on this? Really, from our perspective, we have heard the feedback from providers. I think we all understand that the current methodology that we have is complex. It's complicated. For better or for worse, it's in regs, so we have to, current day, do what's in our regulations. So it's very prescriptive. It says we must rebase annually. We have about 200 facilities in the state that we take cost reports from on an annual basis and then rebase. That rebase in-- really takes into account for the most part two key factors: how many days did that facility have; and what were the costs for the facility. So it's really a cost-based rebasing process. From that, there are challenges for providers. So year over year, if a provider's cost per day goes up or down, not only subject to itself but in relation or relative to the greater pool of nursing homes, it can have an impact on their rate year to year. The best example I can give on that when we rebase for state fiscal year '20, which is the state fiscal year we started on July 1; while we did receive a very generous appropriation increase for nursing homes specifically, not every nursing home received an actual increase in their year-to-year payment because of the way that we have to rebase today. We had a wide variety as well as what providers saw in terms of provider rate increases. So when we looked at our base rate, which is our level 115, level of care, we had one provider at the bottom end that actually saw a 28 percent decrease year over year in their level 115 rate, and we had a prive-- provider on the other spectrum that had a 40 percent increase year over year because of the factors of rebasing based on the swings in cost and days by all the different 200 facilities within that pool. The other challenge with our current methodology is it doesn't take into account quality or the patient experience. From a Medicaid perspective, those are two things that we're focusing heavily on as part of our focus on the quadruple aim in Medicaid. So we-- we-- we have an issue with that from just a payment policy perspective and it aligning with what objectives we are trying to accomplish as a department for Medicaid beneficiaries. The current methodology also creates currently challenges with equity in terms of what we pay providers for the same types of services being provided to Medicaid beneficiaries. So currently, in the current state fiscal year for level 115, the payment range for that level ranges from one facility at a low of one fifth-- $111.56 a day to the high end of another provider getting $257.50 a day. So there are 23 providers in Nebraska. They get paid less than half the highest cost provider for providing similar types of services. And as a payer of services for beneficiaries, that's a challenge for the department and not something we support in terms of trying to align equity and quality in how we pay. So we have a case study that we provide as a slide on slide 3 that really lays out specifically one of these types of scenarios. Not going to read through all the details. So we've talked a little about what's the issue, why the department is seeking change. So what does the department intend to do? So what we intend to do is make change. There are processes in which we need to follow to do that. One of the things that we've embarked on is making changes to our current regulations. For us to do anything different than what we're doing today, we have to do something with the regs. We have the two forms of law that we adhere to: the statutes and our regs. Our regs do tell us very prescriptively that we-- we have to do what we do today, so we need to change that for us to be able to do something different in the future. We have made proposed regulations and there was a hearing on that on August 14. We've received a lot of feedback. We anticipated receiving a lot of feedback. We're in the process of taking that feedback and making changes to our proposed regulations and have a new released second iteration with a new public hearing that's not yet to be-- it will be scheduled. It just has not been scheduled yet. The-- the department's perspective is we would like to remove the payment methodology from the regs. We want to have language in there and we've heard the feedback of concern from providers and stakeholders about not having the payment methodology in the regs. We see that as something that would live in-- on our Web site in a different place, whether that's a guidance document appendix. We have other services where it's on a fee schedule post-- posted on our Web site. We would like to do something along those lines, but we do understand the concerns, so we have, as part of our second round of iteration of those proposed regs, we are going to be including, or potentially, we're suggesting including, some language around a process by which we would go through stakeholder feedback to change anything in the future, should we want to make a future change to whatever we implement. The other point I would-- I would make on-- on changing the regs; while we won't have the specific language on the methodology in the regs, it still would be in our CMS state plan. So our-- our agreement with our federal partner in order to receive the federal-- federal financial participation-- we would still have the detailed methodology laid out in our state plan. So today it's duplicative. It lives in the SPA, the state plan, and it lives in regs. So we would still have that formally in process with CMS approving any methodologies that we do or any changes we make. There is a public notice around that, but it is not as thorough or similar to the regs process, and we acknowledge that. The other part of this as we go through the slides that you'll see-- we understand that we're not going to be able to accomplish everything in the first go. We see this as the first step in the right direction. There are other suggestions that providers have made to us around what we should do, and other stakeholders have made, but we just can't accomplish everything in-- in the first round. So by not putting it in the regs, it allows us to make iterative continuous improvement to what we want to do and how we want to pay providers in the future, without going through a 12-18 month process to promulgate new regs. So that's another significant consideration from the department's perspective. So if we flip to the next page, we talk a little bit about the regs. Now I'd like to focus on-- so what does the department envision the new payment methodology to look like? So what we've proposed is setting a new single per diem rate for each of the 36 levels of care. So currently, based on how patients are classified based on an assessment that nursing homes do, it identifies a level of care for a patient. And what we'd like to do is, rather than having 200 nursing facilities with 36 levels of care that are all paid differently, we'd like to create one rate per level of care across all facilities. So if you have a patient that's a level 115 at one facility, we would have that same base rate for any other facility, because it's based on the patient's level of care or the amount of resources essentially required if you take care of that person. So we would not have different rates for different field-- facilities. It would be based on purely what's the patients-- with-- what are the level of care for that patient. That's what we consider kind of the base rate. Why we think that's a good thing is we want to get away from doing annual rebasing because of the issues that we talked about with year-to-year volatility for providers. Today we collect those cost reports. It takes us a good nine to ten months to do the rebasing process. And unfortunately, we can't get providers their July 1 rates until often late May or June. So they have very little time to do any planning around any potential changes in their payment rate for Medicaid. And I see that as a challenge. I-- I don't know how facilities can operate not knowing what the revenue stream looks like or when it can volv-- be that volatile. I think that's a problem. So under the new methodology, we would rebase using the 2018 cost reports that we already have in-house, and then, we would then from that point forward essentially apply whatever legislative appropriation increase change that we get to the base rate, so it'd be very transparent. We would have our base rates set. Whatever appropriation direction we receive, we simply apply that percentage to the rates and it flows through without the rebasing. It's very transparent. Everyone gets a rate increase, which, you know, would appear to be the intent of the Legislature when they passed along a 2 percent provider rate increase. We also had meetings and discussed what type of implementation plan we would like to use in implementing a new payment methodology. Depending on the provider, they all have a different perspective, right? So some providers today are being paid less than what that new average, that new base rate, would be and some are being paid more. So those that are being paid less today would like to just implement right away, and then the ones that would have a payment change going down obviously would like to see it phased in over multiple years. So after hearing feedback and talking with providers, the department's proposal is that we implement that in two years. So the first year, we basically take-- we mitigate half of the difference. So if a provider's rate is going up by $20 versus the old methodology to the new, rather than going up by $20 that first year we weight it by 50 percent and they only go up $10 the first year. Same thing for providers that's rate is going down. Rather than going down the full distance between where they're at and where they would be, we would weight it by 50 percent, bring them only down half of the way. And then by year two, which would be July of 2021, then we would have it fully implemented without any weighting to reduce the-- the-- change over time. The other aspect, important aspect, of the new methodology is adding in a quality component. So we talked about equity; now we want to move towards adding quality into how we pay providers. The department, upon-- really, our announcement of our plans and even meeting with providers through the Jun-- June meeting, we were pretty headstrong that we wanted to use the CMS overall star rating. So CMS has a national database that records what's called the CMS star rating, that records-- it looks at facilities on a variety of levels and it basically creates a star rating system, with a five-star facility being the highest quality and a one-star being the lowest. There are different components of that, that the Health Care Association and providers have great concern to us. And after we've met and heard very consistent feedback, we did make the decision to not use the overall star rating, because it does have some components that are on a bell curve, which would mean that some couldn't have the opportunity to move up. So we backed away from that and rather than using the overall, we will use just the quality measure, one of the components of the overall star rating which is not a weighted or a bell curve measure, so everyone has the opportunity to improve their quality score and get a quality enhanced payment. So the way that would work is if someone had a base rate and we assign a 10 percent weighting factor for quality to that facility, they would have a 10 percent more than the base rate. So if they have $150, and it's not $150 but I'm just using it for easy math, if somebody's level of care rate was $150 and then they got a 10 percent add-on for quality, they would then get $15 more and their payment would go to $165. That's essentially how it would work. We have been modeling that payment incentive, what that percentage should be, and we'll be sharing that data here later in the month of September with providers and stakeholders. We are not looking at doing any penalizing weighting, so it's all based on three, four, and five stars. So three star basically means average, four star is above average, and five star is much above average in terms of quality. So we're not looking to penalize but to try to incentivize and pay providers that have earned the higher-quality star ratings. Beyond the-- the star rating, we also wanted to make sure we had some component to address patient safety as part of the quality measure and whether or not we would pay out the quality incentive payment. So what we did is we met internally with our Department of Public Health's sister agent, or sister division, and walked through options that we have, and we landed on what we feel is a very good approach. So what we would do is we would use--

basically, we would create a gateway for ensuring that there are no major patient safety issues in the facility before we applied a payment incentive for quality. So as long as a facility does not have any G-level or above substantiated deficiencies in a year or any single IJ which is an immediate jeopardy substantiated deficiency, they would still qualify for the quality payment. If they would-- if a facility would have that in the prior fiscal year, they would not qualify for the quality payment because there are documented deficiencies from a patient safety perspective from our public health division. So in conclusion, we have a slide that basically walks through other considerations, things that aren't in the current first version of what we would plan to implement for a new payment methodology. And some of these things are things that the department really has heard good feedback on from providers and we don't disagree. Part of our challenge is we don't have necessarily great data to say we absolutely can support adjusting a facility's payments for some of these things, or we don't have good tools to measure to get data to drive that, things like provider access shortage areas. We would love to find a way to pay high Medicaid providers an incentive or pay them more. But there are a lot of questions about what's the right threshold and what's the right amount. And you know, from our perspective, it's a challenge for us to justify something because we don't have data that says, we absolutely are sure that if we do this it's the right thing to do. And when we start moving that money around, we're taking money from the pot of money that sets the base rate and distributing it, so it could thin out the total dollars in the base rate. So that's really the conclusion of the nursing facility payment methodology update. I would say that we are continuing to work for it. I'm happy to announce, for those of you that don't subscribe to our Web page, we actually just yesterday got a landing page put on our Web site that is basically going to be continuing to provide updates on the nursing facility payment project that we're discussing here today and that Web site is live as of yesterday, and I can send out the link to the committee afterwards if that would be helpful. Essentially, if you go to our DHHS Web site and go to Medicaid and then click on providers, in the middle of the page there is seven or eight boxes. It's one of those boxes. If you could click on that, it'll-- it'll take you there and you can subscribe so you get updates along the way as we post additional work to that in progress. So I don't know if you want to take questions on that or if you want to move on to the next section before--

HOWARD: What do you prefer? Do you want to ask questions now on nursing facilities and then go to hospitals? Do you want to do nursing facilities first? OK. So are there any questions regarding nursing facilities that you heard from Jeremy?

ARCH: I think we all have questions.

HOWARD: All right. Let's start with Senator Williams. We'll go by seniority.

WILLIAMS: Thank you, Chairman Howard, and thank you, Jeremy, for being here, and thank you also for your trips across the state and in particular, your meetings in my legislative district and meeting with the nursing home in-- in Gothenburg. That was very helpful for them to understand this process. I've got a handful of questions that may touch on a few things. One that I think people would be interested in is this methodology, which-- which I applaud and have hopefully understood now because I had the opportunity to hear this several times. Would you explain how this fits in with what you have seen other states in this-- in this space?

JEREMY BRUNSSEN: So-- we are pioneering in a lot of ways in terms of moving to this new methodology. There are a few other states that have what we would consider kind of a flat payment methodology, but all of them do things a little bit different. But Nebraska would certainly be moving into new ground in that space, so we'd be pioneering in many ways. And we have had the chance to meet with CMS, and actually, we-- I was in Baltimore a few weeks ago and we started talking through this. One of the reasons we were there is I wanted to get their feedback on-- on what we're considering and they're very favorable to our approach. So--

WILLIAMS: One of the things I wanted to get into is-- is your discussion about having the removal of this process from the regs. And I-- I think, as you might guess, for those of us that take seriously our role of oversight, that gives us some heartburn. And I'm not sure I understand what your-- when you use the terminology that you would like to put the process in regs versus the actual payment methodology, what that means, what that difference is. And the other thing I would like you to address is you mentioned that it might-- it seems right now, it's a little bit redund-- well, let's start with the first part and then I'll-- then I'll-- otherwise we're going to get confused.

JEREMY BRUNSSEN: Sure. So rather than having the prescriptive, written-out process in the regs-- the methodology today, I think it's, like, 85 pages. It's a really-- that's a lot of stuff in there and it's very prescriptive. So what we would propose is that we have something in there that would follow or would still comply with public meetings law that would basically say, in order for the department to make any future changes to the methodology they will follow this process. They'll hold a hearing or a public meeting, and we'll schedule it and give providers X number of days in advance of that actual taking effect. So I don't have the exact language here for you today, but that's kind of what we're thinking of in terms of process, provide-- provider notice, get feedback and comments and respond to those, and those-- that would be the process that we would be referring to.

WILLIAMS: I-- I-- I think it's fair to say there's going to be some-- need to be some further discussion about that so that we feel that we can handle our oversight. The other thing, the second part of that question I was going into: you mentioned in your testimony that-- that possibly having this rate methodology in-- in regs was redundant because of the CMS state plan that has to be done. How-- walk through for us the process of changing the state plan and what the Legislature's role of oversight, if any, is in going through that state plan.

JEREMY BRUNSSEN: I'll be honest. I do not know what the Legislature's role is in terms of the state plan. What I can talk to is what we do on the state plan process side for the state. So-- so we-- again, I think it's important to know the state plan is essentially our contract.

WILLIAMS: But-- but my point with that question is simply that there may be a method that's outside of it. But do we have any participation in that method that would give us a-- would-- would check our box to feel comfortable that we are doing our responsibility to the state of Nebraska as being the overseers?

JEREMY BRUNSSEN: Not from a state plan perspective. I'm not aware of anything in the process that requires a legislative sign-off.

WILLIAMS: Moving to a little bit different area, the-- the star rating component and-- and only using the quality component of that and I really appreciate the fact that-- that-- right now nothing is in the methodology that rewards quality and you're trying to build that in. When the-- the star rating-- how quickly is the star rating changed, and in particular, that quality component? I-- I have heard from nursing homes that they-- occasionally, that they've had an incident. They've gotten downgraded because of it and to get that black mark removed doesn't seem to happen very quickly. Do you have any yet?

JEREMY BRUNSSEN: Well, I think that it depends. It's a bit of a complicated answer to the-- to your question, but-- I know that the CMS star rating is updated at least quarterly. It's updated multiple times throughout the year. The department's position would be-- we would want to actually use-- we would use those star ratings at two intervals in the year to-- to assess the star rating when we weight payments. So May 1 for the rates that would be effective July through December and then November 1 for the rates that would be effective or for the weighting to the rates that would be effective January through June. I do-- I am aware that in the recent past there has been a situation where there's been a freeze, for lack of better terms, on updating the quality-- updating the CMS star rating system by CMS. I think it was around quality scores that were tied to incidents in facilities. I don't have all the detail, but I am aware that there is certainly concerns, and I hear those concerns. The quality star rating is not perfect but it is the best nationally standard measure that we have available.

WILLIAMS: OK. We have some nursing homes that are operated in a not-for-profit method-- or form of ownership, some-- any difference with your methodology in the treatment of the-- the reimbursement rates for nonprofits versus those that are designed for profit?

JEREMY BRUNSSEN: So no. So I-- I will say, we've looked at things across various facets of facilities, so whether they're urban, rural, profit, nonprofit, other things like that. And the challenge that we have is that when we look at the data, there's-- they're not only anomalies, there-- there's no absolute consistent trend that says, if you're this type of facility, you always should-- the outcome is always the same. You know, we have looked at and we've heard concerns from certain nonprofit providers about that, about differences between the nonprofit and the for-profit. Today, really, the difference is that for-profit entities have taxes that can be computed as part of their cost and obviously, nonprofits don't. So that wouldn't be the case in the future. We have looked to look at what is the impact on for-profits versus nonprofits' tax status. And it was like a 60/40 split. So 60 percent of for-profits were going up, and 40 percent were going down; and 40 percent of nonprofits were going up, and 60 percent were going down. Again, it's not exactly 50/50 but it's not a tale that says, all nonprofits are X or all for-profits are Y.

WILLIAMS: One final question for me, and-- and maybe this is a disoss-- discussion we can have later, too, is I think one of the areas of frustration that the Legislature has had is that we appropriate a pool of dollars that are to go to nursing home reimbursement. And there's the feeling, at least at the end of the year, that not all of that money is being used and paid out to the nursing homes and that that happens because of a-- a structure of statistical analysis that the department uses across all of the nursing homes. It says there's X number of nursing homes, there's X number of Medicaid patients, there's number of Medicaid days, and the department may be very conservative in their approach to that so that they don't out-- overpay what's been appropriated. But at the end of the year, there may be several million dollars left in that pool that never gets paid out. Could you address how that system works and if there is an improvement that could be made there?

JEREMY BRUNSSEN: Yes. So [LAUGH] the-- the current process has been consistent and we've not changed that-- the department has not changed how we've done that through the years. So in years where utilization was going up, we treated it the same as in years where utilization was going down. We always use the most recent completed year days and rates and-- and cost. So we always treated that the same. There is a difference this year in that prior to this year, actually, in the legislative appropriation bills, the department has not received a set amount of money. It was kind of an implied amount that we had to back into using historical spending days. But fortunately in LB294 this year, we actually got a set pool of money. So that was helpful for us in going through and processing or developing what the-- the rates would be. There are always components of provider rate increases and components of utilization. Utilization dollars can't be used to address rates. Because if we actually see utilization change and we put that money in the actual rate, then it can create extreme misses in terms of where we should be spending versus what we are appropriated.

WILLIAMS: OK. Thank you.

HOWARD: Thank you. Other questions? Senator Arch.

ARCH: Thank you. And I was-- I had a chance to hear one of your presentations so I've been processing some of this over that time. But-- Senator Williams asked quite a few of the questions that I think we probably all had on our mind. But I've got it-- I've got a couple more. You-- you indicated that you anticipated another revision of the regs-- proposed regs-- and-- and you'll be putting those out. One of the-- one of the things that I picked up that you anticipate changing would be including this process for reviewing of-- of any changes coming forward. Anything, any other big items that you have received feedback on, that you-- you anticipate putting into those next series of regs-- next revised regs?

JEREMY BRUNSSEN: Unfortunately, nothing I can speak to. That-- that process of accepting or going through the feedback that was received and then providing responses is still, I would say, relatively early in the process, and that doesn't live within my unit at Medicaid. That's within our regulatory and-- and regulations unit, so I haven't seen all the comments. We just were aware through our tours across the state. And then also I asked some questions like, what are some big, you know, what are the themes; and that-- that was definitely one of the-- I think-- what we heard was the biggest theme from the feedback at the first hearing.

ARCH: OK. Just-- just so I understand, and I know that the formula is complex and our present formula-- sometimes it rewards the wrong things, it incents the wrong things. But in general, why are-- why is there such disparity between-- in those rates? Why is there-- why is there such a broad difference between the highest paid and the lowest paid under our current methodology?

JEREMY BRUNSSEN: I wish I had a great answer but I don't. It's-- it's really looking at the two components for-- primarily the two components: what were the costs for the facility, and what were the days. And so it really comes down to calculating costs per day. You know, certainly, there are other factors that play into that, what is a payer mix, some things like that. I think what you see over time is that the actual rate outlier that spread between the high and the low has grown, year over year. So providers that are at the-- kind of at the bottom end of that, they have to keep tightening their belt because their rate isn't increasing at the same rate as other providers or it's decreasing. So then they have less revenue so their reaction the next year is, we've got to tighten our belt to get by. And then the next year the rate go down again. And so it just kind of is an endless cycle that just continues to, you know, compound.

ARCH: And-- and if you-- if you were a-- a smaller provider and you had fewer patients in your facility in an-- in an area where you were Medicaid-- a large Medicaid population, what-- what would you see in rates like that in a facility? Would those be higher rates because you have fewer patients to divide your costs? Is that-- is that how that would work?

JEREMY BRUNSSEN: It's a combination. Yeah, I think it's a combination. So right-- if you have fewer days to spread your costs over, you have higher costs per day.

ARCH: Yeah.

JEREMY BRUNSSEN: But payer mix certainly matters a lot as well. And there are a lot of instances where we can find in the data, you know: high cost, low Medicaid provider; high cost, high Medicaid provider.

ARCH: Right.

JEREMY BRUNSSEN: It's-- it's pretty spread--

ARCH: Though--

JEREMY BRUNSSEN: --and that's the challenges, you know. To be honest, I'm not a nursing home administrator and I-- I know they have a very challenging job. And I think this is a challenging issue all around.

ARCH: I guess, I'm-- I'm just thinking about in particular the-- the facilities that-- that may be in that-- in-- in-- in that situation where you-- you have a fewer number of patients, your population is not large, but you're a service that's providing to that area, and in-- you're in that higher rate. You're going to-- you're going to take a pretty significant hit when those rates go down and you start averaging. And I-- I didn't know if there were categories of nursing homes that would experience that more than others but-- that would, you know, that would be a concern, obviously.

JEREMY BRUNSSEN: Noted. I-- I understand that, and I think that's-- that's where we're trying to do, look at it from our-- so I think from my perspective, I step back and say, you know, what is-- what is our role in Medicaid? Provide Medicaid services to those in need, and, you know, we look at that and we-- we pay for Medicaid services. So what are we trying to do is-- is what I-- what I look at it, from our kind of global view is, how do we distribute the money that we have in the way that we try to get it to the most people possible, and do it in an equitable way, and pay for quality? And so that's-- that's-- I don't think we're going to find any one solution that's going to fix everything and work for everybody. So it's-- it's a challenging issue.

ARCH: Thank you.

HOWARD: Other questions?

WALZ: Yeah. I have a couple--

HOWARD: Senator Walz.

WALZ: --couple of questions. Thank you, and thanks for everything that you did over the past few months, visiting the nursing facilities. The last piece that you talked about was safety eligibility. Is that what you called it?

JEREMY BRUNSSEN: So patient safety, essentially.

WALZ: OK. So there are, I would imagine, some facilities that have had safety issues for a long time. How would the department support and work with those facilities to make sure that they can come into compliance and become eligible?

JEREMY BRUNSSEN: So--

WALZ: If they're having safety issues, how can we support them?

JEREMY BRUNSSEN: I-- unfortunately, I'm probably not the right person to answer that question. That lives more in our public health department than in the Medicaid agency because we are, basically-- we're a pair of services. We're here-- I mean, I'm happy to help do whatever I can, but that's probably not as much a Medicaid thing as a public health.

WALZ: Uh-huh.

JEREMY BRUNSSEN: I know that, you know, there are- that obviously, that would be something that we would be willing to do, is-- is to look at how do we partner. That's what we are, is-- that's what payers do often. And so I-- I just don't know that I have a good answer for you on that today.

WALZ: OK. And then my other question is-- will there be additional dollars or will you take into account the facilities that provide services to people who have mental health challenges?

JEREMY BRUNSSEN: Glad you brought that up, Senator Walz. So one of the things that we've heard from providers and we agree with is specifically around the concern that the current assessment tool that's used doesn't really capture mental or behavioral health issues very well. It's really very much on the physical health side. So we've had that feedback, is there a way that we can identify and weight payments or do something along those lines? And that's-- that's one of those things that we don't have good information or a good process around trying to do in Phase 1 of this. But that's one of those things that potentially in the future, we still want to look at how can we use thing-- use data and address those types of issues. And so it's a concern of ours as well. And I think that's an important consideration as well, that we want to try to find a way to, you know, to put that type of information into how we pay for provider-- pay providers for providing services.

WALZ: All right. Thank you.

HOWARD: Senator Cavanaugh.

CAVANAUGH: Thank you. Thank you for being here today and for preparing this-- this information. It's very helpful. So one of the questions I have, I guess, is what percentage of providers would see a decrease in rates?

JEREMY BRUNSSEN: I actually prepared that in advance of-- thinking I would get that question. So I will find it really quick. I-- I want to say that there were-- it was almost 50/50 but not quite. So there were

106-- I know the number offhand-- 106 facilities that would see a decrease and 91 that we'd anticipate seeing an increase.

CAVANAUGH: OK.

JEREMY BRUNSSEN: So-- sorry I don't have the percentage.

CAVANAUGH: No, that's OK. The numbers are helpful. I can do that math [LAUGHS]. So as Senator Williams was talking about appropriated funds that are-- are going unused and you talked about utilization versus rates, I think everyone in this room would agree that our healthcare, our nursing facilities aren't exactly, like, flush with money. So if there's money that we've appropriated that's going unused, is there something that can be done in this rate methodology to increase the rates? I know that you talked about utilization versus rates. But based on the historic, what's happened-- what's happened over time with that utilization, can you account for-- this is-- this is how much money we have; this is how much money we're not using; we probably should look at increasing that base rate even more, so that we are use-- utilizing those funds that are being appropriated for us to utilize?

JEREMY BRUNSSEN: So I think there are a couple of things happening there I can try to address. And the first is-- over the course of, I would say, the last five years, we've seen that decrease in utilization just in general, in nursing homes when we look at it in aggregate. The actual spend that we had over those years was relatively flat. The last few years, actually, we've spent close to $20 million more so it's 18 and 19 more than what we had been spending the prior year, even though we didn't have an increase. And that's because of some of the issues that we have going on with the current payment rate and how we have to "retro settle" any facilities that are purchased in the middle of a state fiscal year. There's a real-- odd process around it, but-- so I think what you're getting at, though, is to look retrospectively at the end of the year and say, this was the amount appropriated, here's what was spent, and try to retro settle retroactively. We haven't considered that in the past. What I think the question would become, so what happens on the other end? What if we spend more than we were appropriated? Are we clawing back or what's-- we would need to understand, you know, what does that look like holistically from a budget perspective.

CAVANAUGH: When was the last time you spent more than was-- what was appropriated?

JEREMY BRUNSSEN: That's a challenge. We technically have never had a set appropriation until this year. [LAUGH]. So I can tell you, though, in that year that we went from $323 million to $343 million, we certainly didn't get a $20 million appropriation for nursing homes.

CAVANAUGH: OK.

JEREMY BRUNSSEN: So--

CAVANAUGH: And then we were talking-- you-- you talked about the regulations process, and Senator Williams asked some questions about the regulations process and methodology, taking the methodology out of the regulations. Why? Why is that something that you're seeking to do? I understand that's an 85-page document, but what is the rationale in doing that? And-- and also while you are speaking to that, could you speak to what concerns you heard from providers?

JEREMY BRUNSSEN: Sure. So-- and speaking to why we want to do it, for the reasons I really said on the first page. It does take usually more than a year for us to make any changes. We don't see that as a best practice. When we look at most payers that we-- most payees, most of the folks that we-- benefits or services that we pay, they're not-- the actual methodology isn't prescriptive in the regs. It's posted on our Web site on a fee schedule or another place so we can make those changes. So today I have good examples where if I have providers-- and I can tell you that there are people in the room behind me who have asked me to do rate studies, and we looked at it and we determined, you know what. Nebraska isn't paying appropriately. We are paying less than other Medicaid programs, and we can actually take that information and take action on it. We can't do that today. There's nothing we can do. If it's in the regs that we follow this process, we have to follow that process or we're not following the rule of law in terms of doing what we are prescribed to do. So we don't see that as a best practice. We also think that, as I mentioned, we might want to continually try to improve how we're paying nursing home-- nursing homes in the future. And if it's prescribed in regs, it'll take us time to do that, maybe longer than what would seem appropriate.

CAVANAUGH: Did you consider the option of prescribing in regs to allow for more proactive action to be taken?

JEREMY BRUNSSEN: So--

CAVANAUGH: Is there anything prohibiting that happening, not on just the Web site but in the regs?

JEREMY BRUNSSEN: If we'd say this is specifically how we do it in the regs, I don't know that we would have the ability to do anything other than what we put in the regs. So I-- I would welcome any feedback on what that language might look like.

CAVANAUGH: Thank you.

JEREMY BRUNSSEN: Thank you.

HOWARD: Other questions? Senator Hansen.

B. HANSEN: Thank you. Are there any other states that use this form of payment methodology, that you know of?

JEREMY BRUNSSEN: So yeah-- similar to Senator Arch's question, I don't know that there's anybody that has this exact formula. There are some states that have what we call, like, flat rates, which is essentially what this is, but they don't do it the same way. They might do-- rather than paying a rate per level of care like we do, they might weight all the patients in that facility and pay a flat rate to that facility based on how many patients are at all the different levels of care. But this would be fairly new and unique.

B. HANSEN: OK. And do you foresee any different payment methodologies for those facilities in receivership at all, or will there be any kind of difference?

JEREMY BRUNSSEN: So from a Medicaid payment perspective, we pay for services rendered to clients. So whether-- it doesn't matter if it's a receivership facility or different type of facility. We pay based on Medicaid days. So anytime that the receiver receives extra money, it's actually through a separate fund, and it has to be approved by CMS and I think that's what you're referring to is that-- that's a CMP, a simple mo-- civil monetary penalties fund where it's to try to help transition patients and stabilize facilities. But Medicaid only pays for days based on the rates as calculated in the regs.

B. HANSEN: OK. And just one more-- more for clarification. Senator Walz kind of touched on it about maintaining the physical aspect of the buildings. Would the quality, like the star system, does that come into play about how a physical building is itself, the quality of the-- the facility itself--

JEREMY BRUNSSEN: So--

B. HANSEN: --[INAUDIBLE] care?

JEREMY BRUNSSEN: -- the quality score specifically, I don't have the exact measures, but typically that's a clinical measure set. So that's not going to probably take into account like facility, you know, things. So it's going to be more patient quality meh-- measures, quality care measures.

B. HANSEN: OK. Thank you.

HOWARD: Senator Arch.

ARCH: One more question came to mind. Did it-- in your-- in your considering of a single rate methodology, did you ever consider some type of a-- of a factor like a "dispro" share payment where you have a high Medicaid provider, essential service, you know, in there that that type of a consideration, knowing that that particular provider is going to be inordinately stressed, but necessary for providing Medicaid services to that population? Did you ever-- did you ever consider that-- that kind of a factor in-- in additional-- in addition to your quality incentive to those that are providing a high amount of Medicaid services?

JEREMY BRUNSSEN: So I would say, not in the current methodology. It's very similar to what-- where we would like to look to try to do something in that space, by looking at the-- trying to identify an appropriate amount to put towards high Medicaid providers. The challenge with, like, the DSH payment is that's-- that's a federal money for a program that would be-- mean that we would have to either pull that money out of the base today or get appropriated that extra money to do something. I think it's similar to trying to identify a way to pay high Medicaid providers, kind of a weighting factor. It's very similar, though. I think it's a legitimate good idea. We just don't have a great way to implement it right-- right now identified.

HOWARD: Are there questions? I have a few, Mr. Brunssen. I want to-- and thank you for visiting with us today because I know this is a lot of information. And we still have to talk about hospitals. So long-term care-- we've had a discussion in this committee about long-term care moving into a managed care setting. And can you tell me a little bit about the department's reasoning behind modifying the payment methodology at the same time as they're pursuing a move into managed care?

JEREMY BRUNSSEN: Well-- I-- I would-- I would say that we're not actively pursuing a move into managed care at this time. I think that our director has been fairly public in stating that he does see their value in being a long-term-- I think you call it a long-term march or a slow march to long-term care being carved into managed care. But I-- to me, I see we have an issue and in my role as a deputy director in Medicaid, I see it as my responsibility to try to address the issue. I don't see this in any way married to managed care. I see this as an issue that the department sees and wants to try to find a solution to. In Medicaid, we've had a saying lately. It's-- if you know better you do better. And so that's kind of where I'm coming from is I just think that we have an opportunity to improve it. And I don't think it's tied in my mind nor has it been in discussions about, this is, like, something to do in order to get into managed care. It's really-- we just see it as an issue we think we want an opportunity to fix.

HOWARD: Great. And tell me a little bit about how you've been working with stakeholders. So-- I know that-- and when you promulgate rules and regs, do you have to accept or modify based on the feedback that you receive?

JEREMY BRUNSSEN: Not my area, so what I do know is that we are required and we believe-- we are responding to all the comments and feedback. I don't know what we're "binded" to actually do beyond, to respond. To be frank, that's not my area. So I would-- I'll have to defer that question. I can follow up.

HOWARD: And then do you want to tell us about how you're working with stakeholders to address their concerns?

JEREMY BRUNSSEN: Sure. So I think, you know, my process has been-- I've tried to meet with everyone that's ever asked, you know, beyond just meeting with on-- on the tour. We have continuous meetings going on. So next week I'm actually-- we have a meeting to meet with the special needs providers. So there is kind of a subset of nursing homes that provide kind of a special service, you know, ventilator units, TBI waiver, TBI services for traumatic brain injury, kind of clinically medically complex children-- pediatric. So we're meeting with them through this process next week. We-- we met once previously kind of in a formal-- form-- formal setting so that way we can talk about because they do provide a kind of a unique set of services. So how do we transition them in a way that they can be successful and continue to provide the value they do to Nebraska Medicaid and to our beneficiaries? I do have still some provider meetings ongoing in the next few weeks as well, and so my plan is to continue to communicate. Part of the other, more formal plan was creating our-- our landing page on the Web site, so that way we can try to share everything consistently. I've been having a lot of meetings with providers and stakeholders, and part of the reason that we wanted to go out and do this listening tour is so that everyone heard the same thing and tried to be more-- be as transparent as possible in what we're doing. And so my approach is that we'll continue to post updates on our Web site. We're going to start sharing the data modeling that we are doing today by the end of September with the stakeholders, with the providers, so that way they can see how the department expects this to impact them, and they can look at that in-- in conjunction with what I'm sure their accounting teams are already doing. And we'll continue to have meetings with stakeholders to walk through that process.

HOWARD: Without the rate methodology or with the rate methodology being removed from the rules and regulations, what sort of obligation does the department have in terms of sharing changes and modifications to their-- to the provider rates in the future?

JEREMY BRUNSSEN: So I think it's a key component. We-- we understand, like, Medicaid doesn't provide the services to our beneficiaries. Believe me, we understand that. Providers are absolutely crucial. They are a key piece of our ecosystem. So there is no intent at all to do anything to-- to harm the ecosystem. It's trying to address issues that are currently in place. So that's, you know, why we've heard the feedback on removing the actual methodology and why we do want to put something in that provides some formal process for providers so that way, it not only informs them, but does hold us accountable to do what we say we're going to do.

HOWARD: So-- so right now, as-- as promulgated, there would be no requirement for you to sharing modifications to the rates.

JEREMY BRUNSSEN: Well, I think-- we-- based on how the-- the first round were set, there was none of that language in there.

HOWARD: OK.

JEREMY BRUNSSEN: But we are doing a second hearing and including that-- that language.

HOWARD: Tell me a little bit about your timeline for that.

JEREMY BRUNSSEN: Well, I don't know that. We do not have a second hearing date scheduled yet, but I would-- we're working through obviously responding to the comments or gathering that feedback and-- and putting responses together to the first round and then modifying the proposed regulations for the second hearing. I don't have an exact date. I know our goal would be, obviously, as soon as possible. I know that there are hearings scheduled because, as you know, there are-- every chapter is being worked on today. So I think there are hearings scheduled now through September, so no sooner than that would we have another hearing. I would anticipate December, January, somewhere in that time frame, but I don't have an exact date.

HOWARD: And then would we-- would-- would redlined copies of the modifications be posted then?

JEREMY BRUNSSEN: So I do know there have been conversations around redlined copies of any proposed regulation changes. The--our DHHS C-- CEO, Ms. Smith, has been talking with providers about that. I don't know that I have the exact language, but I do know that she's heard the concern. And I think part of the challenge is for you-- for everyone's knowledge is-- there are large amounts of regs that were completely rewritten so the red lines were pretty much entirely a red line. And the intent was just to try to set a clean set up and here's the new proposed regs. But we've heard the feedback that it's confusing for stakeholders to sift through that. So I know that there are some processes being put in place to try to kind of get back to the-- the redline version. I can't speak to the exact details, but I do know that that's been a concern and that we're going to be addressing that.

HOWARD: I know we'd be very grateful--

JEREMY BRUNSSEN: Uh-huh.

HOWARD: --to get redline copies. You mentioned that almost every chapter of-- of the department's rules and regs are being touched in this modification cycle.

JEREMY BRUNSSEN: Well, through-- through a process of cleaning up redundant, unnecessary language, yes. So a lot of chapters of regs are being repromulgated or going through the process. And I'm-- again, gets out of my area, so I can't really speak to it in great detail but that's-- yes, that's happening.

HOWARD: I know our office has received over 100 rules and regs that have been modified. Are we anticipating more?

JEREMY BRUNSSEN: I-- I do not know where it's at, in terms of the-- where-- how many have been done and how many are on pace. I'm sorry, I don't have that. It's not me. [LAUGHS]

HOWARD: Thank you for trying to answer that question. Dp you want to tell us a little bit about the hospital changes?

JEREMY BRUNSSEN: Yep. All right. So on our second slide deck-- again this-- this is information that has been shared with stakeholders in the hospital community. What I will say is this is not the exact slide deck that was presented back in July to stakeholders as part of the work we're doing on outpatient services payment methodology changes. And the reason that is not is because that deck was over 40 pages and it was very technical and I could not communicate it to you in a way that would probably be very understandable, because I am not a clinician and we have other folks on our team that are really in the weeds. I've been working just to support this project more at a higher level. So I wanted to try to pull out what's the high-level important information that we'd want to share to try to explain, you know, the who, what, why, where, when kind of things, so that way you understand the intent and where we're going with the hospital. So what we are working on in the department is updating how we pay for outpatient hospital services so it doesn't touch all of the hospital services. It touches kind of a smaller subset of the outpatient. So it's not the inpatient side. And what we're doing is, again, similar to the nursing home side, moving away from a cost-based reimbursement system towards more of a kind of a standardized fixed-type of payment system. It's a bit different. So what it's called is-- is called EAPG, which is short for enhanced ambulatory patient groups. It's a 3M product. We currently use a 3M product on the inpatient side called APRDRGs. And what it does is it essentially takes and it groups procedures and medical visits that are similar in characteristics and resources required to do the procedure or visit, and it puts it in a group. And then the payment for that-- that group is based on the average resource utilization for that service. Our intent is to implement this new payment methodology in January of 2020. This has been a project that's been discussed and worked on and in multiple phases, really, since before I started in October 2016. So it's not a new one, but it's been something that's kind of been started and stopped over the years for good reason that we'll get into as we go through the deck. Currently, we pay for outpatient hospital services basically 84 percent of the cost-to-charge ratio. So we get cost reports, and then we also have to compare what are the actual charge masters for the hospitals, and then we pay 84 percent of what is a percentage of their cost-to-charge. So you know, many times it's, you know, 20 to 50 percent of the cost-to-charge ratio. So if we get a bill, we pay 84 percent of the 20 or 50 percent of the actual charge. So it's-- it's kind of a complex process, but it's a cost-based methodology that's hospital specific. There are around a little over 500 actual groups that are part of the EAPG system. We are looking at implementing this only for noncritical access hospitals in Nebraska. Currently, you know, we-- we originally had critical access hospitals included in the transition. And based on feedback from NHA and others, we removed the critical access hospitals from-- from that group. And for good reason; they get paid 100 percent of the cost-to-charge ratio and we actually end up doing settlements for all the critical access hospitals, anyways. It is very delayed. We do them downstream. So from our perspective-- and there are a lot critical access hospitals-- there are only, I think, 33 hospitals that would be part of this change as well so it's much smaller in scale. It would apply to hospital outpatient services, emergency department services so pretty, pretty much across various settings. So what it does, you know, I'm going to flip through these slides a little bit more quickly; there are more slides, but it does basically look at different types of procedures. So I'm going to be moving to Slide 5. And it creates basically-- it looks at what's been billed or what's been coded by the hospital to determine what is the main procedure, if there is any significant procedure a visit, and then there could be other smaller, what they call ancillary, services that are included in that visit or in that service that's provided when that claim is submitted and it assigns it to an EAPG or a group. And then payments are weighted based on information on what are the similar, what are the typical resources required to perform that group of services. So if you look at Slide 6, there's a graphic on basically a pricing formula that walks through kind of how it works at a high level. So we take our Nebraska-specific 2017 claims data, and then we essentially trend it forward with inflationary factor to see what is our payment rate if we were doing-- what would we have paid in 2020 to get to kind of our-- our base amount. And then from there, we unders-- we can back into what is the actual rate by EAPG and then what is our-- our base rate by facility. And from there, then, each payment is assigned a relative weight which is based on the grouper. So that's basically a national 3M database that looks at the average resource requirement to perform the set of services that fell into that grouper. Things can happen from that pace forward, so there might be multiple kind of similar types of services that, you know, maybe there's a bilateral procedure where if something's done on both legs and so that, rather than pay each one separately at the full price, it pays 150 percent and pays once so it bumps it up by 50 percent. There are all sorts of, you know, activities like that that happen throughout the payment process. And then also we can put in what's called a policy adjuster so through the process of taking and modeling the data, if we see that a payment is traditionally coming in at $1,000 historically in Nebraska data, but based on the 3M national weights it's paying at $3,000 or $100, we can actually create a policy adjuster to level it out to be more consistent with what we've seen historically in Nebraska. So we have ways to take the national data set and try to kind of smooth that out to be more Nebraska-based, based on our data. And then it pays out on the detail line. There can be multiple EAPGs paid out on a single claim as well. So moving on to Slide 7, the timing of the implementation, like we mentioned, we would be implementing in January, we would-- we have done all our modeling on the most current version and that's the version we would go live with. We would not plan on doing an update in 2020 to give providers kind of a steady launch and some continuity through the change. Like we mentioned, it would not include critical access hospitals. It would primarily be the hospitals in Nebraska that are not critical access. We would, as we mentioned, use a 2017 data set. And then it's the same data that we used to set our capitation rates for MCOs, so it's consistent data from how we set payments to MCOs to how the-- the outpatient services are loaded in the modeling and the payment rate development for the EAPGs. As we roll this out, similar to the nursing home side, our goal was to have budget neutrality. We weren't trying to pay more or pay less. We are trying to project payment to be the same. Through that process, we set up or we mirrored our inpatient side where we have six what we call peer groups. Peer groups are facilities that are designated as urban, metro, rural, children's, rehab, and surgical; and then within each peer group, the model should-- it drives to budget neutrality within that peer group. Within that peer group, there could be hospitals getting payments up or down based on their cost-to-charge ratio and payments historically versus kind of the normed average for that group based on the EAPGs. So similar concept but just much smaller in scale to the nursing home. We originally had been using on a basis of developing our inflation rate or trend factor for our payment rates 1.4 percent, which is what historically, prior to '17, we'd seen in our data. We received concern and feedback from the Hospital Association that they felt that that was too low and made some suggestions or requests for us to consider. And after we went back and looked at the data we have agreed to go ahead and use the market basket index inflationary factor or kind of trend that the cost from '17 forward to '20, using that per the request, so that we have done that. So that's, you know, obviously not counting, then, any provider rate increases that we were appropriated in July, which would be then added into the-- the projected payment amounts for the base rates moving forward as well. 3M, which is the owner of the-- the software, updates their-- their software annually, typically in January, but by the end of the first quarter of each calendar year.

Our intent would be that we update our version of EAPG no more than once a year, but no less than every three years. So for example, in 2020, we wouldn't plan on updating the version because we would just be implementing it, and we want to give some time for stability. And then each year as software updates are made, we can look at what are the impacts of the software updates, how material they are, and whether or not it's, you know, a good time to update the actual version. With the software updates, all the codes that get deleted or added are still created and mapped to whatever version the state is using for EAPGs at that time. On Slide 10, you can see the process and some of the communication that we've had throughout the past few years on the EAPG project. We've had a few set go-live dates on this project. Our biggest hiccups in the past have been around the fact that we were trying to implement this in the Heritage Health program, but we were using pre-Heritage Health data with managed care entities that were no longer in the market. So when we come to issues we're trying to validate data, we couldn't get to what we needed to do to feel comfortable that the data set we were working from was representative enough of what we expected the future experience to look like and what those projected payments to be would be. So we had-- we did make decisions to delay that at points in time because we wanted to make sure that we were working from as good a data as possible. It's never going to be perfect but it would-- it's in a place where we feel very comfortable moving forward, having worked through the data and have had time to have providers look at it as well and provide feedback concerns and have us research specific claim issues and that kind of thing. So moving on to Slide 11, these are some dates that were talked about during the July 2019 stakeholder meeting at-- I think it was at the NHA office here in Lincoln. So we continue to accept provider feedback. I think, even just a week and a half ago, we had a provider that we met with at the State Office Building to continue to work through some provider feedback. Our intent was to publish on our state Web site the new EAPG base rates on September 1. However, because we were modifying the inflationary factor with NHA, we weren't able to meet that date. But we do anticipate having that done next week, and we did share the draft rates with some stakeholders on Monday of this past week. And historically, everyone has had access to what we-- what the proposed rates were. We shared data sets and models with providers throughout the course of the last few years as well, instead of several different iterations. There is provider education coming out around the new payment methodology. I think the good news is providers still bill in code the same way they have. It just basically comes in and groups those services into groupers and pays based on the new EAPG model. There are MCOs already pay using the EAPG model in other states. We've already begun, and in some cases, testing is already completed. Each MCO is on a little bit different timeline in terms of claims payment, testing, and processing. So we do have no concerns about claim readiness to pay claims in the new grouper model when it's live in January. Moving on to Slide 12-- it's the slide that we provided that 3M has as part of their information publicly available on the Web site around the EAPGs. There are currently 11 other states that use EAPGs in their Medicaid markets. So we're not new but we're also, you know, kind of one of many that's already doing it. There are other states that do use other fixed-payment type structures, fee schedules, Medicare-like, APCs other types of more prospective type payment systems. Less and less are on the cost basis and like we are today. So we just happened to choose the EAPG for our preferred method of moving forward. I think that's most of what I have on the hospital changes. Really, no changes on the inpatient side. This focuses on the outpatient side of the house. So welcome any questions.

HOWARD: Thank you. Are there questions? Senator Arch.

ARCH: Yeah, this has been in the works for a long time now.

JEREMY BRUNSSEN: Yeah.

ARCH: And-- and I know that you used the-- you used the term when it came to the data that it was in a-- you wanted to make sure it was representative enough of-- of-- of actual. And in reality, I think several of the iterations, and I lost track but when I was in the industry, it was-- if we-- the first round was-- I mean, the data was just corrupt. It was-- just corrupted. It was-- it was-- it just wasn't-- it wasn't correct. And then I think you did a second analysis. Then you sent that-- you sent that data out, you cleaned it up, sent it out again. Has there been-- has there been a third analysis?

JEREMY BRUNSSEN: I-- I don't have the exact schedule with me, but I do know that data has been shared multiple times in the last year. I can follow up with exactly [INAUDIBLE].

ARCH: OK. So it's been several--

JEREMY BRUNSSEN: Yeah.

ARCH: --it's been several iterations. What you're saying now is that you are confident that the data that is being analyzed, that is being used to base new EAPG rates on, is correct, it's clean.

JEREMY BRUNSSEN: I-- I believe so, based on all the feedback that I've seen. Again, I'm not working day to day in this project, but I meet with my administrator on my team, as well as an outside consultant, Navigant, on what's going on, what's the feedback from providers, the work that's being done. What I would say is that all of this is also always subject to assuming that the actual utilization of those services is consistent over time, which isn't the case, right? Case made changes--

ARCH: Right.

JEREMY BRUNSSEN: --based on the actual needs of whatever patients are walking in the doors of the facilities.

ARCH: Another question, does it require hospitals to-- to all agree on the grouper that's being used, the 3M grouper?

JEREMY BRUNSSEN: So--

ARCH: Is that what all hospitals will have to use going forward?

JEREMY BRUNSSEN: So my-- my understanding is that Nebraska is creating a Nebraska Medicaid-specific EAPG grouper within the 3M suite of products, so they have a standard set. We've done slight modifications; we've really tried to stay true to the national 3M product for this version so it would be a standard grouper system. There are different peer groups that have different base rates--

ARCH: Right.

JEREMY BRUNSSEN: --but it's the standard groupers process across all the state.

ARCH: OK. Thank you.

HOWARD: All right. Any other questions? Seeing none, thank you so much for visiting with us today.

JEREMY BRUNSSEN: Thank you. I appreciate it.

HOWARD: Very informative. All right. This will conclude our briefing on the rate methodology for nursing homes and hospitals. And we will open the hearing for LR244, Senator Hansen's interim study to examine discrepancies in reimbursement under the medical assistance program between the three Heritage Health Managed Care plans and the impacts of applying a multiple procedure payment reduction policy to therapy services. So it's a big interim--

B. HANSEN: I tried to pick a longer one so--

HOWARD: Yeah [LAUGHTER] All right. And for this one we do have invited testimony to start, and then it will be public testimony after those first four. Welcome, Senator Hansen.

B. HANSEN: Thank you, Chairperson Howard, members of the Health and Human Services Committee. My name is Senator Ben Hansen, representing District 16. I'm here to open-- today to open on my interim study LR244. The Nebraska Physical Therapy Association brought to me this study with concerns related to a specific new policy being implemented by one of the state's contracted Medicaid managed care companies, UnitedHealth. As a medical professional, I am aware-- I'm fully aware of the challenges in the Medicaid system and the low reimbursement for providers. I introduced this interim study to allow rehabilitative care and therapy providers impacted by this change to provide detail on implementation of the new payment policy, its real impact on patients and providers in the Medicaid system, and to answer questions. Grace Knott, president of the Physical Therapy Association, will follow me and provide additional detail. After Grace, two additional providers will be testifying on another recent change that has just come to our attention also being implemented by UnitedHealth. We felt this hearing was an opportunity to bring the impact of this change to your attention and should not take too much of your time today, hopefully. Thank you.

HOWARD: All right. Any questions for Senator Hansen? Seeing none--

B. HANSEN: Thank you.

HOWARD: Our first testifier, Grace Knott.

GRACE KNOTT: You can pass these out [INAUDIBLE] Thank you.

HOWARD: Go right ahead.

GRACE KNOTT: OK. Good morning, Senator Howard and members of the Health and Human Services Committee. My name is Grace Knott. That's G-r-a-c-e, Knott, K-n-o-t-t. I am currently president of the Nebraska Physical Therapy Association. I would like to thank Senator Hansen for introducing LR244 on behalf of all therapy providers. I'm here today to provide background and answer questions about a current payment policy-- and it is current, it is not a new policy-- by UnitedHealthcare Community Plan in their contract with the state of

Nebraska to deliver Medicaid services. This pay-- this payment policy, which is-- is resulting in approximately 10 to 14 percent payment reduction from the Medicaid fee schedule for therapy services. The other two managed care organizations of Heritage Health, Nebraska Total Care and Nebraska WellCare, does not apply this payment policy. This affects physical therapists at other therapy providers that utilizes the codes associated with therapy services, such as occupational therapists and speech language pathologists. This payment policy is called a multiple procedure payment reduction, or MPPR, abbreviated. It was designed originally to avoid duplicate payment for practice expenses when multiple procedures are delivered to the same patient on the same date of service. Each procedure code is reimbursed on a-- based on a relative value unit, which includes three components, including the actual work performed by the medical provider, the expense of the practice, and malpractice insurance overhead cost. This policy was first applied to surgical procedures that occurred during the same time, such as wound debridement of two separate wounds. So again we use-- it's all part of the common procedure codes or CPT codes, same as physician uses. The surgeon has a room prepared, staff present, instruments sterilized so the second wound practice expense would be less, resulting in less payment for the second wound that was debrided. The Centers for Medicaid and Medicare Services, CMS, started applying this policy to the "Always Therapy" services on January 1, 2011, despite the objection of therapy stakeholders. Full implementation of this policy occurred on April 1, 2013, when 50 percent of the practice expense, which was part of the relative value unit, was reduced for any subsequent units of service after the first unit. This resulted in approximately 8 to 15 percent reduction in payment for therapy providers treating patients with Medicare benefits. The American Physical Therapy Association continues to assert that application of MPPR to physical medicine services is a flawed policy because a practice expense values for these CPT codes or charge codes were already reduced to avoid duplication during the American Medical Association relative value uptake committee process. In fact, the time spent on the preservice and postservice activities was spread across three units of service, based on the assessment that a typical therapy visit is approximately 45 minutes. So they took that practice expense when they determined the relative value unit and had already spread it across three units. The fact that certain efficiencies exist where multiple therapy services are provided in a single session was explicitly taken into account when relative values were established for these codes. Therefore, an additional cut to the practice expense of therapy service codes is arbitrary and restricts patient access to vital therapy services. Even with the continued opposition of the APTA on the MPPR policy, several nonfederal insurers have implemented MPPR policy for therapy services. Several states do have implement-- regulations in place that excludes insurers from implementing the MPPR policy. And we hope Nebraska can be one of them.

I have illustrated on my graphic in front of you how this policy affects payment to our physical and occupational therapist providers. As you can see on the graphic, I have demonstrated the impact on this policy on reimbursement to a physical therapist following treatment to a patient with shoulder pain and disability. I have compared what we have received in the past without MPPR if this patient was a Medicare patient, if they were a Medicaid beneficiary with one of the other Heritage Health managed care organizations, and then what the payment would be if they had UnitedHealthcare Community Plan. So in my illustration, the patient was seen for 45 minutes, received an education on his shoulder, and performed functional activities to strengthen his shoulder and develop new motor patterns to decrease pain. He received progressive resistive exercise to improve his rotator cuff muscles and shoulder mobilization passive stretching to the shoulder joint. The insurance company was billed for one unit of therapeutic exercise, one unit of therapeutic activities, and one unit of manual therapy. As this graphic shows, if this patient has Medicaid-- had Medicare, the physical therapist before MPPR would receive $170.91 for that therapy session. With the MPPR policy applied to a Medicare patient, it reduced it to $93.57. It must be noted that many insurers' fee schedule is higher than Medicare. So again, if you're looking at reimbursement, Medicare is more, even starting on the lower end of the fee schedule. Comparing now, if the patient had Nebraska Total Care and paying by the Nebraska Medicaid fee schedule, this reduces payment to $66.88 for that therapy session, a reduction compared to Medicare of 28.5 percent. Now we look at UnitedHealthcare applying the MPPR policy and this reduces payment to $57.50, which is a 14 percent reduction compared to what Nebraska Total Care or Nebraska WellCare would pay, and a difference of $36.07 from a Medicare payment. Problem is, this makes it below the cost of providing care to Nebraska citizens who are receiving Medicaid benefits.

HOWARD: Ms. Knott?

GRACE KNOTT: Yes.

HOWARD: I'm actually going to take a pause and see if there are questions because we've got your red light on.

GRACE KNOTT: Oh, shoot.

HOWARD: No, that's all right. [LAUGHTER] I was a little worried that this was single-spaced.

GRACE KNOTT: All right. I see a light in front of me now. [LAUGHS].

HOWARD: So let's see if there are any questions from the committee about the MPPR. Senator Williams.

WILLIAMS: Thank you, Chairperson Howard, and thank you for coming. Are-- is there a concluding remark that you would like to make?

GRACE KNOTT: Sure. Yes. [LAUGHTER]

WILLIAMS: Thank you. Would you like to make that remark now?

GRACE KNOTT: Oh, gosh. Let me gather my thoughts here. Three things. Number one, in any sort of medical practice, you have a variety of insurance companies that pay you. You hope that, again, it is the right combination and order so that way you can make a living if you're a private practice practitioner. I worry about the clinics that have a high Medicaid, such as a pediatric clinic. You'll be hearing from the occupational therapists and speech therapists regarding the impact that this has, as well as rural clinics or in urban areas that have a high Medicaid population here. I believe strongly in the benefits of therapy services and I believe some of it is arbitrary trying to take a-- to reduce payment. When we take a look at-- with physical therapy, we know we can decrease downstream costs, keeping people out of nursing homes, keeping people in their homes, keeping people productive citizens of the state of Nebraska.

WILLIAMS: Thank you.

GRACE KNOTT: Thank you.

HOWARD: Senator Cavanaugh.

CAVANAUGH: Thank you, Chairwoman Howard. Thank you for being here. I'm looking at your-- your spreadsheet, and you mentioned that just starting at the $107.91 doesn't even account for that. Insurance companies have a higher rate of reimbursement.

GRACE KNOTT: Right. That's correct.

CAVANAUGH: Which we do hear oftentimes that it's hard to take Medicare patients for that--

GRACE KNOTT: Right.

CAVANAUGH: --reason. So I just kind of want to acknowledge that and that we see a 46.71 percent difference from UnitedHealthcare's reimbursement to just Medicare. If we were to include just like Blue Cross's reimbursement--

GRACE KNOTT: Right.

CAVANAUGH: --it would be even higher.

GRACE KNOTT: It would be a lot higher.

CAVANAUGH: OK. Thank you.

GRACE KNOTT: Uh-huh.

HOWARD: Other questions? So ju-- I just want to make sure that we understand the MPPR. So--

GRACE KNOTT: Yeah it's a cop-- it's complicated.

HOWARD: --it's complicated andso help me as I try to walk through it. So there's a fee schedule set forth by the state of Nebraska.

GRACE KNOTT: Right. That's correct.

HOWARD: And then, you would-- say, you have three visits, and on the first visit you would get the full fee, and then the next visits it could go down--

GRACE KNOTT: No. In that visit.

HOWARD: In that first visit.

GRACE KNOTT: Visit.

HOWARD: OK.

GRACE KNOTT: Usually, for most physical and occupational therapy providers, we get paid-- most of the codes that we use, is a time-based code. And so it's every 15 minutes is what it is. And so I broke down into three different procedures that a therapist might use. So you only get that full price on the first one. The subsequent is less.

HOWARD: OK. And then, is that the same between all of the managed care companies across the board?

GRACE KNOTT: No. Nebraska Total Care and Nebraska WellCare does not apply the MPPR policy. So with the same Medicaid beneficiary, depending on what managed care they have, if they have UnitedHealthcare, that therapy provider is getting less than what they would get from Nebraska Total Care. So they're not paying from the Medicaid fee schedule.

HOWARD: OK.

GRACE KNOTT: And so they, I presume, where are they using that extra money that they're not paying to the therapy providers?

HOWARD: Uh-huh, uh-huh. OK. Thank you. Any other questions? Seeing none, thank you for your testimony today.

GRACE KNOTT: Thank you.

HOWARD: Our next testifier is Candice Mullendore. Good morning. Whenever you're ready.

CANDICE MULLENDORE: Good morning. My name is Candice Mullendore, C-a-n-d-i-c-e M-u-l-l-e-n-d-o-r-e.Senator Howard and the members of the Health and Human Services Committee, thank you for allowing me to testify before you today. I'm an occupational therapist who owns a pediatric practice in the Omaha area that provides occupational, physical, and speech therapy to children. I've been practicing for 22 years, the last 12 years in private practice. I am also here representing the Nebraska Occupational Therapy Association. Recently, changes in the Medicaid managed care authorization process by Nebraska

Total Care and UnitedHealthcare Community Plan have negatively impacted the patients and families Nebraska occupational, physical, and speech therapists serve. In August of this year, UnitedHealthcare announced a change in policy requiring prior authorization for all therapy effective September 15, which is Sunday. This new policy requires physicians to enter evaluations, reevaluations, and complete peer-to-peer reviews on any therapy denial. Prior to this policy change, UHC had a posttherapy audit process. The timeline from the first training on the new authorization process to the day providers could input authorizations was three business days. Additionally, the communication to providers and physicians from UHC was poor, and many physicians and providers still do not know about the policy change. This is particularly true in rural Nebraska. Lastly, UnitedHealthcare has had contradictory statements made during the training that have resulted in children being denied therapy services. UHC's rollout of this policy change has been hasty, confusing, inefficient, and has resulted in a significant burden on physicians and therapy providers. Unfortunately, UHC is not the only MCO that is having a negative impact on therapy services for children. On April 1, Nebraska Total Care moved from an outside company conducting posttherapy service reviews to require prior authorizations. Our state organizations for occupational, physical, and speech therapy conducted a survey of the membership regarding these authorizations. I won't read those numbers because I'm afraid I'm going to run out of time like Grace, so I am going to let you read those, but it was a significant reduction in therapy services being provided to those patients. They also have done-- they have also reduced the amount of therapy that you can receive. So if a patient was receiving therapy one ti-- or two times a week, Nebraska Total Care has gone to a policy of approving one time a week. In order to help you better understand how this will fail the patients and families, I want to tell you about a child that was being seen for speech therapy for feeding, two times a week initially. It was decreased to one time a week with significant progress. This patient was receiving those services under their primary health care insurance. Once the patient went to United or Total Health Care with secondary coverage, they would only authorize 4 visits in 90 days. That is about one time a month. The patient regressed significantly with feeding, is now unable to maintain a bolus, which means they chew up their food and move it back and do a swallow. And they also are unable to initiate a swallow, which leads to risk for aspiration. This was a skill that that child previously had, and he-- oops-- and he also is decreasing overall quantity of food that he can intake. His mom reports the school noticed right away how much he'd declined over the summer with feeding. In January he will resume therapy under his primary insurance and must work hard to regain many of the skills he had until Nebraska Total Care reduced his therapy. This leads into why I will be introducing the Kerber family to you. Victoria is a patient at my clinic that has UnitedHealthcare Community Plan as secondary coverage. On September 10, we were notified that UnitedHealthcare required additional information for speech therapy authorization request. UnitedHealthcare gave us less than 24 hours to try to attain that clinical information and submit it to them. By the morning of September 11, UHC denied her speech therapy services before we were able to provide any additional information. This denial means that Victoria's physician, not her speech therapist, must complete the peer-to-peer review and present the speech therapy findings to another physician in order to attempt to get more speech therapy services for Victoria. As a caveat, her physician is amazing and is allowing our speech therapist to conference call in on the peer-to-peer review so. If UnitedHealthcare Community Plan denies the peer-to-peer review, Victoria will go without speech therapy, much like the child I described earlier, until January. Sorry. This upsets me. I'm afraid that Victoria is going to lose the skills that she has worked so hard this year to obtain if she goes without speech therapy. I feel that this is a complete failure by the managed care contractors for these very vulnerable patients and their families. Mr. Kerber will follow me to tell you Victoria's story, so that you can better understand how important therapy is to people like Victoria and their families and the many Medicaid patients across the state. I'll take any questions you have.

HOWARD: Are there questions? Senator Cavanaugh.

CAVANAUGH: Thank you, Chairwoman Howard. Thank you for being here today. First of all, I have to say I wasn't smiling at your testimonies. I can't help--

CANDICE MULLENDORE: No, that's fine. She's adorable.

CAVANAUGH: [INAUDIBLE] Victoria's smiling [INAUDIBLE].

CANDICE MULLENDORE: It's okay. She's adorable.

CAVANAUGH: I am a heat-seeking missile to children, so I love seeing her there clapping and she looks like she's just having a great old time. So thank you for being here, Victoria, and advocating for yourself. We're hearing this, myself, and I believe other members of the committee and-- and the Legislature, about-- about some of the concerns that you've expressed here today, and I appreciate you being here to share those with us. [LAUGHS]. Sorry. It's a-- it's a little emotional for me too. So what-- what would you like us to say to the department about this? What is that-- what is the outcome that-- that would best suit your clients?

CANDICE MULLENDORE: The initial outcome would be for the-- a delay in the UnitedHealthcare rollout of the prior authorization process. And the fact that we had three business days to even understand what was going on if we-- people are drowning and the fact that the information is not rolled out in an effective manner, so that many physicians-- I received a phone call yesterday for a physician that was, like, what?

What do-- what do-- I have no idea. So that's our initial, is for UnitedHealthcare to somehow put a delay to this process. We don't disagree with the prior authorization process that is happening across the nation. We want them to do it in a considerate manner and effective with communication so that it can be-- not impact kiddos like Victoria in a negative manner. Our second ask would be that we really feel there needs to be some sort of increase in oversight for the MCOs. They have been making changes that-- I don't really understand the process or how that happens. But the process is affecting patients. So I think those are probably our two asks.

CAVANAUGH: OK. One additional question. The preauthorization process and the peer-to-peer review-- I'm not familiar with this as a standard pra-- practice. Is this something that if-- in your profession, are you aware of other states requiring?

CANDICE MULLENDORE: Yes. So-- fortunately or unfortunately, Nebraska is one of five states to be the first to have this rolled out with UnitedHealthcare.

CAVANAUGH: So this is a new practice, even now.

CANDICE MULLENDORE: This is a new pra-- well, this is a new practice for UnitedHealthcare. There are quite a few private insurances that require some prior authorizations. WellCare requires a prior authorization, but well--

CAVANAUGH: Not as-- I, I mean, prior authorizations are kind of different than this. This sounds like a very complicated process.

CANDICE MULLENDORE: Well, so WellCare has a prior authorization process that is similar. And so about two and a half years ago when the MCOs started, WellCare was struggling; and they formed a coalition and actually invited a bunch of therapists on their team to help develop a portal for their prior authorizations. And by doing that, their prior authorization system is seamless. It is awesome. This prior authorization system for UHC is new. I believe the only other state that started before us was September 1, but we are one of the first five states to get all of this in September. There are private companies, private insurance companies that require prior authorizations, so it's not necessarily something we're unfamiliar with. Their process is cumbersome, I will say antiquated, and is not provider friendly. The administrative burden on the physicians is astronomical. And we have to support those physicians in getting all the information that they need. And I-- I'm not sure that UHC realizes the impact it's having. I can tell you that in my clinic alone, we spent over 400 man-hours because I have a lot of Medicaid patients [LAUGHS] that have UHC. And so each authorization took about 30 minutes. I had to put in 300 authorizations, and then I had a lot of other physicians who needed to talk to and do stuff like that, so that was the burden just on my clinic.

CAVANAUGH: Thank you.

CANDICE MULLENDORE: You're welcome.

HOWARD: Other questions? And I just want to make sure I understand the-- how this prior authorization would work. So first-- provider-- a physician would refer to you.

CANDICE MULLENDORE: Yes.

HOWARD: And does the referral need prior authorization?

CANDICE MULLENDORE: No. So typically in the past, what happens is the physician would send us a referral, and we would see the patient, and we would be able to see that patient for however many visits, and then the provider would submit for additional visits from one of the MCOs. What they have changed is the physician puts in the referral, we get the referral for the evaluation, we see the child, we do our evaluation. Then we have to send our evaluation back to the physician so that physician may review our evaluation. They have to sign off in it. They have to fax it back to us. Then we put it into the UnitedHealthcare system to ask for therapy visits. And that-- I-- I know that you've seen some flow charts, but that could take up to 14 to 28 days, assuming the physician gets it and isn't on vacation and can get it back to you. I don't know if that answer your question.

CAVANAUGH: It-- it--

CANDICE MULLENDORE: It's really complicated.

CAVANAUGH: It does. It seems-- it seems really complicated, but so-- say, like, if I sprained my ankle--

CANDICE MULLENDORE: Uh-huh.

CAVANAUGH: --then-- and they recommend a PT visit for me. Then what happens? So the physician sends me to a PT for an eval--

CANDICE MULLENDORE: Yes.

CAVANAUGH: --who has to get a prior authorization for the eval.

CANDICE MULLENDORE: Yes.

CAVANAUGH: And then they evaluate my sprained ankle. They say, yes, you need PT. They put together a document. They send that to the physician. The physician then sends it back to you. And then you send it to UnitedHealthcare for another prior authorization--

CANDICE MULLENDORE: For the therapy services.

CAVANAUGH: --for this service on my ankle.

CANDICE MULLENDORE: Yes.

CAVANAUGH: And then-- and then maybe I would get some help.

CANDICE MULLENDORE: Yes. [LAUGHS] And they, by Neb--

WILLIAMS: After 14 days.

CAVANAUGH: After 14 days?

CANDICE MULLENDORE: Yeah, but by Nebraska's state-- pardon?

________________: [INAUDIBLE]

CANDICE MULLENDORE: Oh, yes. The Nebraska state law, they have to respond within 14 days. I will say UnitedHealthcare's authorization process is running about five days right now. They just started, so I-- I-- but yes, that could be a delay. You know, if you see me today and I, let's say I have enough time to write up your evaluation by Monday. I send it to the physician on Monday. Physicians are busy. They may get to it Tuesday or Wednesday. They send it back to me. Then Thursday or Friday, I'm submitting it and you're already a week out from your injury. And then after I submit it, we don't know how long UHC will take to get back to us. The-- one of the major issues that we have with UnitedHealthcare is that they, in the past, if you came to see me for a sprained ankle, I would have authorization for therapy or for an evaluation as well as therapy. So I could say, Senator Hansen, we're going to do some ultrasound and give you some exercises and send you home because you're clearly in pain, and I want to be able to, you know, make sure that you're doing OK over the weekend. Now we no longer get any therapy visits. We are only allowed to do the evaluation. So if you came to me today, I would say, Senator-- or

Senator Howard, I'm sorry. You know, you have the sprained ankle but I don't have authorization to do any treatment. Now I really don't know of any therapist that would honestly do that to a patient. But you know, legally, we are not supposed to provide any treatment during the evaluation. And so then we'll be back to, hopefully, you getting in next Friday or, you know, in the following week. So it will result in delay of care.

HOWARD: And tell me a little bit about-- have you asked the department to-- to work on the delay? Have you-- have you requested anything from them?

CANDICE MULLENDORE: Yeah. Our state associations, which is occupational, speech, and physical therapy, sent a letter to Dr. Van Patton to ask him to help us in this. And he told us that we needed to go back to UnitedHealthcare and have those discussions, which we have been able to secure a meeting with UnitedHealthCare on September 30. But in the meantime we've got this mess, I'll call it.

HOWARD: And then what if physicians know about this change? Because it sounds like it was-- you had a training or you-- there was a training for PT/OT folks, but was there a training for physicians?

CANDICE MULLENDORE: Well, so-- I'm not sure how they notified physicians other than a form letter. When we, the occupational and physical and speech therapy associations found out about it, we contacted the Nebraska Medical Association, the Nebraska chapter of the American Academy of Pediatrics, and one other one, and they had not heard of it. And this was in August. And so they kind of helped educate their providers, but many of these doctors-- I'm not sure that a form letter that came to, you know, Dr. Jones's clinic would get to that doctor and would they read it and understand it. So we have, personally, at my clinic, we spent a lot of time educating the physicians-- not physicians, usually their assistants, over the phone about what they need to do in order to put authorizations in. They-- they were allowed to go to the training. Initially UnitedHealthcare said that they would provide training on September 13. So today or Sunday. And we really, really pushed them and we were able to get them to provide some training on August 27. There were two trainings and there were, at least in the training I was in, there were two representatives from physicians' clinics, but there were a lot of call-ins. So I don't know how many of those were physicians.

HOWARD: And this is my last question and we'll see if the committee has any others. But are there any other specialty groups where a plan of care is created and it has to be approved back by the general practitioner?

CANDICE MULLENDORE: No.

HOWARD: OK. All right. Are there any other questions from the committee? Senator Cavanaugh.

CAVANAUGH: Just a timeline question. You mentioned the 14 days because of the authorization process. Does-- and you don't know when UHC will respond. Is there any requirement for a time period [INAUDIBLE]?

CANDICE MULLENDORE: Yes, the state law is that they have to respond within 14 days.

CAVANAUGH: OK.

CANDICE MULLENDORE: So--

CAVANAUGH: So the physicians have to respond within 14 days.

CANDICE MULLENDORE: Oh, no, I'm sorry--

CAVANAUGH: [INAUDIBLE].

CANDICE MULLENDORE: --for the physicians-- no, there's no time requirement for physicians.

CAVANAUGH: OK. But the UHC does have to respond within 14 days.

CANDICE MULLENDORE: Yes, by the time we get the information, and they are supposed to respond within 14 days.

CAVANAUGH: Thank you.

HOWARD: All right. Any other questions? Seeing none, thank you for your testimony today. Our next testifier is David Kerber. Good morning.

DAVID KERBER: Good morning. If I go before the light starts, do I get more time?

HOWARD: All right. Go [LAUGHTER].

DAVID KERBER: All right. Senator Howard and members of the Health and Human Services Committee, my name is David Kerber, D-a-v-i-d K-e-r-b-e-r. I am a resident of Nebraska's 14th District, represented by Senator Arch. Thank you for the opportunity to speak with you today. Thanks, Senator Hansen, for bringing this to the attention of the committee. Over here is my wife Abbie and our youngest daughter, Victoria. I think of myself as a fairly unemotional person, but this girl just-- does-- melts my heart in a way no one else ever has. Victoria has a rare medical condition. It's called a genetic deletion. Essentially, a portion of her DNA is just missing. It's a random genetic mutation. Nobody did anything wrong. It's just something that happened to her that she gets to deal with. As best we know, there are 11 people in the world known with a similar genetic deletion as hers. So anytime we ask a doctor what's going to happen, the answer is the same. It's, we don't know. After 18 days in intensive care, she came home with a feeding tube because she-- her muscles were not strong enough for her to eat. Before she was one year old, she had her skull reconstructed because the-- the plates in her skull had fused prematurely. And she'll have a similar surgery again sometime next year. Everything that comes naturally to our first three children has-- has been a challenge for Victoria. So-- she's three years old. She's not mobile. She's not verbal. We needed a professional to help us understand that she didn't touch anything because her hands were too sensitive. So it took months of special techniques and equipment to desensitize her hands so that now, after a year of treatment, she will-- she will pick up toys. She will turn them over. She will play with them. She'll push the buttons. She never pushes the red button. [LAUGHTER] And-- took three months of practice. She learned to go from laying down to put weight on her elbow and then transfer weight to her hand and then push herself up. [LAUGHTER] She remembers, too. After a year in occupational therapy, she can-- we can put food on a-- on a spoon and hand it to her and she'll take the spoon and put it in her mouth and hand it back. And hopefully, with more work, she'll be able to take the spoon and pick up the food on her own. Working with a speech therapist, she's able to start to communicate with us with sign language, so she'll-- she'll say, more or all done, things like that, and hopefully, someday, maybe she'll say Mom and Dad. We don't worry too much about it. She's-- she's fighting a battle that only she understands. Nobody else can go through it and we think she's doing a great job. We called her Victoria Grace because we think she will have victory by grace and she will overcome everything in her path. But the thing is, she can't do it alone. She needs help like we all do. And her mother and I love her very much. But we need the help of compassionate, trained professionals who understand these-- these specific circumstances and-- and who have lent their tremendous talents to helping children like Victoria. Our private insurance has been wonderful. But private insurance was not meant to deal with a circumstance like Victoria's. Private insurance, physical, speech, occupational therapy would run out after about two months every year. And that's where Medicaid benefits have been essential to her. And we've-- we've done that. And now, with no explanation, those benefits are going away, and we don't really know why, and we don't understand why. Her underlying condition hasn't changed. I can say, I'm-- I'm not a medical expert, right? But I'm a-- I'm a professional. Have been work-- worked in the world for a long time. I'm a veteran entrepreneur. I can tell when an organization has kind of lost track of what their mission is and what they're here to do. And my ask of the committee is that you reach out to UnitedHealthcare as they administer this program and remind them why they do what they do, the people that they are put in charge of serving, and the impact of their decisions, and ask them to carry out that duty faithfully. Thank you.

HOWARD: Thank you for your testimony today. Are there any questions from the committee? Senator Arch.

ARCH: Mr. Kerber, it's nice to meet you.

DAVID KERBER: You too.

ARCH: I'm not sure I knocked on your door or not, but if--

DAVID KERBER: You would have met my wife [LAUGHTER].

ARCH: It's nice to meet you.

DAVID KERBER: Uh-huh.

ARCH: Have you-- have you had communications with UnitedHealth? Have you had ongoing issues and discussions, and have-- have-- have they-- have they given you response, have they--?

DAVID KERBER: I might have to defer to counsel a little bit on that. Have we talked to UnitedHealthcare directly regarding this?

ABBIE KERBER: We have not talked to them directly. We know that, without the Medicaid, we wouldn't have--

DAVID KERBER: Right.

ABBIE KERBER: --had very long with--

DAVID KERBER: Right.

ABBIE KERBER: --therapy sessions, and so thankfully, at that point Medicaid had stepped in.

DAVID KERBER: Yeah. Also UnitedHealthcare is our private insurer as well.

ARCH: I see.

DAVID KERBER: So we've-- we've definitely communicated with them about that.

ARCH: Sure.

DAVID KERBER: I don't think we've communicated with them regarding Medicaid.

HOWARD: David, can I trouble you to actually repeat what your wife said because the microphone probably didn't catch it?

DAVID KERBER: Sure thing. We have communicated UnitedHealthcare in their capacity as our private insurer but not as regards to Medicaid.

ARCH: Thank you.

HOWARD: Any other questions? Seeing none, thank you--

DAVID KERBER: Thank you very much.

HOWARD: --for your testimony today. And our next testifier is Jessica Thoene. Good morning.

JESSICA THOENE: Good morning. My name is Jessica Thoene, T-h-o-e-n-e, and I'm here on behalf of Nebraska Speech, Language and Hearing

Association [SIC], so thank you, Senator Howard, and fellow members of the Health and Human Services Committee. My testimony is gonna be a little bit redundant because Candice did such a-- a good job of kind of summarizing, and you guys asked a lot of questions about what's going on and the reason that we're here today. So I'm a speech-language pathologist. I'm the owner of Alpha Rehabilitation, which is a private practice in Kearney, Nebraska. Alpha Rehabilitation is a small, hometown clinic that has provided physical, occupational, and speech therapy services for 15 years. I'm testifying today on behalf of the patients I serve and the members of the Nebraska Speech-Language and Hearing Association [SIC] to voice my concerns with the prior authorization process that UnitedHealthcare Community Plan intends to implement on September 15, 2019. UnitedHealthcare Community Plan has informed our members and physicians that we will be required to follow a double preauthorization process. The current process is physicians are able to write a script for a referral and the therapist conducts the evaluation. The treatment is authorized by the insurance company after the evaluation is complete. In the current system, as the Medicaid policy mandates, therapists have consistent contact with physicians who certify a new plan of care every 60 days. The charts in your handout outline the both-- the best-case scenario and the worst-case scenario with prior authorization and amounts of time that the patient would wait for care. The best-case scenario, as you've heard, is 14 days. The worst-case scenario is 36. And a patient with immediate need for injury or illness will not be treated. The authorization process that UnitedHealthcare Company has developed will increase administrative burden of additional 20 to 30 minutes on a patient for authorization for physicians, and 20 to 30 minutes on-- for patients for therapists. None of this time is reimbursable time. The administrative burden of these new process is unrealistic in an already broken system where reimbursement barely covers the costs to provide this therapy service. Our members are in a difficult position to try to sustain the additional costs of resources while serving the patients. Our associations are concerned that providers will discontinue service to Medicaid clients, which will reduce the network of therapists. This is already an issue in outstate, Nebraska, where there are limited number of therapists to help these clients. Speech-language pathologists have been told that not only they need to contact the physician to request prior authorization for Medicaid beneficiaries, that, for the children, that they will also need to contact the school system and begin requesting information. This week I had a call from the principal across the street from my practice that was upset because a parent was in his office begging to get an Individual Educational Plan, an IEP. An IEP is put together by the school system and the school staff to allow children to access the educational environment. I educated the parent that this request was not initiated by our office but required by UnitedHealthcare Community Plan for the child to reservice-- to receive services. This child did not even have an IEP. The parent misunderstood the information that was provided to her by the UnitedHealthcare Community Plan. They'd requested information that had no bearing on medical treatment. This is just one example of an added administrative burden and confusion for patients and parents. The child, as an example, has medical needs that the school cannot address and does not currently have an IEP. The IEP was required by UnitedHealthcare Community Plan as a request for the authorization process for continued service. So it was requested of the patient. We have seen a trend in policy change in managed care plans with decreasing access to services. I've had to face parents and give-- who have given up on the system. I've had to discharge patients that I know badly need speech-language pathology services. We have been plagued with continuous changes in policies, with continuous changes in authorization, recertifications for service. Hours and hours of unpaid administrative work goes into providing these services. This proposed change by UnitedHealthcare community plan creates administrative burden that is hard to absorb in a small clinic and overwhelming in a large clinic. I ask that you reach out to the parents, visit our clinics, review the research on data, the many benefits of therapy for Nebraskans. This includes evidence-based practice research that supports therapy in lieu of an opioid for pain management or early referral for services that prevent long-term cost to the state, research that supports therapy for autism and other diagnosis. The therapy that allows-- this therapy allows therapists to focus on their expertise and resources to improve patient safety, functional abilities, pain management, and the best possible outcomes. Think of the quality of life that is granted to a patient that receives therapy services. We would like to respectfully request that the help with your oversight, the help to ensure policy changes are made through the Legislature or Health and Human Service Administration rather than the managed care plans. This help would ensure that the policy and guideline changes are in compliance with state regulations. Thank you.

HOWARD: I really butchered your last name. I'm so sorry.

JESSICA THOENE: No. That's OK. Most people do [LAUGHS].

HOWARD: [INAUDIBLE] All right. Are there questions from the committee? Senator Cavanaugh.

CAVANAUGH: Thank you. Thank you for being here--

JESSICA THOENE: Uh-huh.

CAVANAUGH: --and for your testimony. Kind of a red flag for me is the IEP.

JESSICA THOENE: Yeah, it's very discerning, because again, it-- it-- the time frame, even to try to track down an IEP-- an IEP is set by the school system. So as a private practice, I have no control over what's going on in the school system.

CAVANAUGH: Right. I mean, it's-- it is an individualized education plan.

JESSICA THOENE: Yeah.

CAVANAUGH: So UnitedHealthcare was requiring this parent to have an IEP submitted for the approval process?

JESSICA THOENE: Yes.

CAVANAUGH: But the IEP is done between the parents and the school, not between the providers.

JESSICA THOENE: Exactly.

CAVANAUGH: OK. Just wanted to make sure--

JESSICA THOENE: Yeah.

CAVANAUGH: --I understood this correctly.

JESSICA THOENE: [LAUGHS] Yeah.

CAVANAUGH: So it's not based on any sort of medical evaluation process that currently exists for the child.

JESSICA THOENE: Absolutely not.

CAVANAUGH: OK. Great. Thank you.

HOWARD: Any other questions?

CAVANAUGH: Oh, I have one more.

HOWARD: Oh, sure.

CAVANAUGH: Sorry. And maybe you can answer this or not, in education but-- are IEPs-- aren't those typically classified, like, with the parents and the school? It's not something--

JESSICA THOENE: Yeah.

CAVANAUGH: --that's publically available.

JESSICA THOENE: I can actually answer that question because I contract with school systems. So I-- I serve in an educational environment as well as a private practice. So an individual education plan is-- is determined by teachers, the school psychologist, maybe the school speech pathologist. But the goal of that, of an IEP, is to allow the child to access the educational environment. So any modifications, any adoptions that they might need during the day, they sit together as a team and say, how can we let this child in this school building access the educational environment? So we're really comparing two separate things. And since we don't have input as medical practitioners in there and they cannot provide medical services in the school system, they are very, very different and they don't really mesh.

CAVANAUGH: OK. Thank you.

HOWARD: All right. Any other questions? Seeing none, thank you for your testimony today.

JESSICA THOENE: OK. Thank you.

HOWARD: Is there anyone else wishing to testify for LR244? Good morning.

MATT SCHAEFER: Good morning, Chair Howard, members of the committee. My name is Matt Schaefer, M-a-t-t S-c-h-a-e-f-e-r, testifying today on behalf of the Nebraska Medical Association and its member physicians. While not the original subject of the interim study, the NMA also wants to express its concern over the recently announced policy changes from UnitedHealthcare to require that prior authorization before a physician can refer to a therapy services provider. The MA has serious concerns about this delay in care Medicaid patients will experience as a result of this change, particularly patients who are referred to therapy services due to an injury or chronic pain. National research is showing that there's substantial benefit for therapy services in reducing pain for the patient if it's at-- if it's accessed in a timely manner. Thus, if there is a delay in that care, it's possible that additional prescriptions may be required, which potentially may be opioids, in order to bridge the gap between that initial visit and the therapy starting. This would be a clear step back for reforms that we've undergone to limit the need and reliance on opioids for pain management. Additionally, this policy change will result in a substantial administrative burden for physicians, as you've already heard about. A note again that it's a multistep prior authorization process, one that we've not seen used in other instances of prior authorization, and we've not been provided any data showing that there are issues with the amount of therapy services not being medically necessary in Nebraska. And thus, this change really appears to be arbitrary and unnecessary. And really, we're wondering where the oversight from HHS is here. Why are MCOs allowed to make such a substantial change in the middle of a plan year with little notice, no input from providers, no input from the Legislature, and no input from the public? Instead of improving quality outcomes or the patient experience, we're worried that this change will heart-- will harm the relationship between therapy service providers and physicians and their patients, potentially decrease the effectiveness of that plan of care, and potentially increase the use of opioids for pain management. Thank you.

HOWARD: Thank you. Are there questions? Seeing none, thank you for your testimony today. Is there anyone else wishing to testify for LR244? Seeing none, Senator Hansen waives closing. And that will conclude our interim hearings for the-- for the morning. We'll be back at 1:30 this afternoon.

[BREAK]

MURMAN: [RECORDER MALFUNCTION]-- I'm Senator Murman, District 38, south central Nebraska. Seven counties: Clay, Webster, Nuckolls, Franklin, Kearney, Phelps, and part of Buffalo County.

WALZ: I'm Lynne Walz and I represent District 15, which is all Dodge County.

ARCH: Senator John Arch, I represent District 14, which is Papillion and La Vista in Sarpy County.

WILLIAMS: Matt Williams, Legislative District 36: Dawson, Custer, and the north portion of Buffalo Counties.

CAVANAUGH: Machaela Cavanaugh, District 6: south-- west central Omaha.

HOWARD: OK. Also assisting the committee is our legal counsel Jennifer Carter and our committee clerk Sherry Schaffer and our committee pages Maddy and Brigita. Awesome. All right, a few notes about our policies and procedures. Please turn off or silence your cell phones. This afternoon we'll be hearing one interim study and we'll be taking, we'll be taking it in the order listed outside the room-- which is just one. On each of the tables near the doors to the hearing room you will find blue testifier sheets. And if you're planning to testify today, please fill one out and hand it to Sherry when you're coming up to testify. This will help us keep an accurate record of the hearing. Any handouts submitted by testifiers will also be included as part of the record as exhibits. We would ask if you do have any handouts that you please bring 10 copies and bring them to Sherry or the page. We do use a light system for testifying, we will be using a light system today. Each testifier will have five minutes to testify. We do have three invited testimonies for the first LR that will be-- we will not be using the light system for them. When you come up to testify, please begin by stating your name clearly into the microphone. Then please spell both your first and last name. In each interim study we'll begin with the introducer's opening statement. And because interim studies are a little bit different than a regular hearing it's just a reminder that they work a little bit differently. Testimony will not be grouped by supporters or opponents but just be taken in turn unless we have invited testimony, as we do today. If the legislative resolution is a committee resolution, which is what we have today, I will introduce it and then return to my seat to proceed with the rest of the hearing. We do have a very strict no prop policy in this committee. And with that we will begin today's hearing with LR105. And I will pass it out to Senator Arch for a moment.

ARCH: I have the tough job here.

HOWARD: All right.

ARCH: Welcome, Senator Howard.

HOWARD: Oh, thank you, Senator Arch.

ARCH: You may proceed.

HOWARD: Thank you, Vice Chairperson Arch. All right, good afternoon, Vice Chairperson Arch and members of the Health and Human Services Committee. My name is Senator Sarah Howard, H-o-w-a-r-d, and I represent District 9 in midtown Omaha. I'm here today with a resolution that was submitted by our committee to study the eligibility requirements applied to children with disabilities for coverage under the Aged and Disabled Waiver in Medicaid. As you all are well aware, early in the year our offices started hearing from distraught parents whose children with disabilities were found ineligible for the Aged and Disabled Waiver in Medicaid. These are children with a combination of medical needs, physical challenges, and very often significant cognitive issues that require them to have significant medical care and constant caregiving. The children and families on the A&D Waiver rely on the waiver to help cover the cost of expensive treatment and child care, which allows the families to continue to work to support their families and cover the remaining costs of care. We had many helpful conversations with the division of Medicaid and the Department of Health and Human Services and learned that the children who were losing coverage on the Aged and Disabled Waiver were being reevaluated under newly promulgated and more restrictive criteria than had previously been used. The purpose of the Aged and Disabled Waiver is to provide care in a community setting, community-based setting to adults and children with disabilities who would otherwise require such care in a nursing facility and who do not traditionally qualify for the Medicaid program. This is the-- eligibility for the Aged into disavored-- Aged and Disabled Waiver is determined by: One, having a disability determination by the state review team. This is foundational. If a child does not have a disability determination they are not eligible for the Aged and Disabled Waiver. If there is a disability determination, the next step in determining eligibility is to do an institutional level of, level of care assessment. A child can meet the institutional level of care in two ways. One, by having 1 of the 11 treatment needs listed on the level of care assessment tool or have 1 of the 3 listed medical conditions on the level of care assessment tool. Or two, if you don't have 1 of the 11 medical treatment needs or 3 medical conditions you can qualify if you have a certain number of ADLs, or activities of daily living, which you cannot complete, complete or a few ADLs combined with other risk factors. Very complicated eligibility for us to understand. So currently the regulations require that a child with a disability meet six out of seven activities of daily living to qualify for the Aged and Disabled Waiver or four of 7 ADLs plus 3 other conditions. The practical result is that if a child can walk even a breeze-- brief distance, see, or hear they will not be eligible for the A&D Waiver, regardless of their other significant medical issues and cognitive issues. The Department of Health and Human Services had used this same level of care assessment prior to 2015 until it was challenged in court. The Nebraska Supreme Court found that the level of care assessment was not properly promulgated and directed the department to utilize the same level of care assessment for both adults and children, which required fewer ADLs to qualify. In that case, the Supreme Court also examined the level of care assessment tool the department has been using for children-- essentially the same one used earlier this year-- and found it to be arbitrary and too restrictive, resulting in the exclusion of profoundly disabled children. The difficulty in part is that the level of care assessment tool is unable to properly account for the span of development over a child's life. It may be appropriate for a 3-year-old not to be able to bathe themselves, but that will not be developmentally appropriate for a 9-year-old. In addition, the tool does not seem to consider the significant cognitive issues that will make it unsafe for these children to be left alone to do some of the activities of daily living like eating and bathing. We appreciate the department's willingness to work on this issue. And not on the script, but the department has been very transparent with the committee. When we first heard about the issue they were willing to come and speak with us about it. They immediately hired a contractor to evaluate the tool and they worked with us to put a moratorium on revaluations. So I have nothing but praise for how the department has handled this specific issue with the committee. In April, due in part to flooding suffered in much of the state, the department put a moratorium on revaluations and contracted with Optumas to review the level of care assessment tool and explore other avenues for coverage these families, for these families and children in need. This hearing serves as a follow up as we near the end of the moratorium and an opportunity for the committee to hear directly from Optumas about their work thus far. I know we'll all appreciate hearing from family members as well who have been directly affected by the change in the assessment tool. My hope is that with the work Optumas and the department is doing, and what we learn today, we will see a path forward for finding help for these children who clearly need support and care. Thank you for your time. I'm happy to try to answer any questions, but I know the folks who are coming directly behind me have the expertise beyond mine. So are there any questions from the committee?

ARCH: Seeing none, thank you, Senator Howard.

DANNETTE R. SMITH: Good afternoon, Senator Howard and members of the Health and Human Services Committee. Thank you so much for allowing me to be here today. We're here to provide you an update regarding the children's institutional level of care criteria for Medicaid,

Medicaid's Aged and Disability Waiver and child institutional level of care criteria for children who meet the level of care necessary to, to live in a nursing home but are receiving services at home. We heard from many families, and I want to underscore that we heard from many families, and we shared their concern about the criteria and we wanted to be responsive. We agreed to hire a consultant to come in and review the current criteria to see if it's the most appropriate for Nebraska. And we've been very fortunate to have consultation by Optumas health care, particularly Mr. Steve Schramm, who is the managing director, and his team who have really worked with us to look at what the path forward would really look like. So we're working to design the most appropriate and effective institutional level of the care assessment. I have asked Courtney Miller, director for the Division of Developmental Disabilities, who is here with me today along with Mr. Schramm, to lead this effort because of her expertise and knowledge of Medicaid home and community-based services. We're looking to redesign not only the child's level of care assessment but also the adult as well. Not just looking for nursing facilities, but we're also looking at intermediate care facilities for people with developmental disabilities as well. With that, I provided an introduction for you. Courtney Miller will be up next as my division director for developmental disabilities and the voice that you hear after her will be Mr. Schramm who represents-- thank you very much. If you have any questions-- oh, I was supposed to spell my name. Dannette, D-a-n-n-e-t-t-e, middle initial R. Smith, S-m-i-t-h. Thank you.

HOWARD: Are there any questions for the CEO? Senator Williams.

WILLIAMS: Thank you, Chairperson Howard. And thank you, Director, for being here. Will someone be able to testify specifically about what you see as the path forward when we get, and also about what the department intends to do with the moratorium when that comes to an end?

DANNETTE R. SMITH: We will be able to talk about the path forward and a little bit about the moratorium. But what we wanted to capture today was what does the path forward look like. We recognize that we're not at the end part of that. To be honest, Senator Williams, we're really at the beginning and middle of that whole process. But we wanted to keep the committee informed of what our next steps would be. This process has ended up being a lot bigger than we thought. And I thought that since I was addressing issues for children I would go ahead and address issues for adults so that we make sure that we have good levels of care that can be utilized for all. And so that's what you're going to hear today.

WILLIAMS: Thank you.

HOWARD: Senator Cavanaugh.

CAVANAUGH: Thank you. Thank you, CEO Smith, for being here today and for bringing your colleagues along. Are we going to know, hear what the time line is?

DANNETTE R. SMITH: You'll hear a little bit about that today.

CAVANAUGH: OK. Because I, I'm looking behind you and I see a lot of, a lot of interested faces that are-- I want to make sure that we're going to hear, and we know that October is coming up and families are very concerned about what that-- not just what the path forward is but what the timeline for that path forward would be. And, and maybe this is something that next test fire can answer but I'm going to ask you just in case the families that were children that were kicked off earlier this year before the moratorium. Have they been allowed back on during this process or what's happening with those families?

DANNETTE R. SMITH: I'm going to let my experts talk about that more.

CAVANAUGH: OK.

DANNETTE R. SMITH: OK.

CAVANAUGH: Thank you.

DANNETTE R. SMITH: Thank you.

HOWARD: All right, seeing no other questions, thank you. Our next invited testifier is Courtney Miller, the director of the Division of Behavioral Health.

COURTNEY MILLER: Good afternoon.

HOWARD: Good afternoon.

COURTNEY MILLER: My name is Courtney Miller, C-o-u-r-t-n-e-y, Miller, M-i-l-l-e-r, and I am the director for the Division of Developmental Disabilities with Nebraska Health and Human Services. So, as you're aware, until 2015 the children were assessed for a nursing facility level of care criteria and a home-grown tool differentiating them from adult need that was established over 30 years ago. And what we're also looking at is the level of care criteria and tool for the intermediate care facilities for the developmentally disabled that appears to be around the same age. So I want to talk to you say about the overview of the project scope of work, the approach, the time line, and the anticipated extension to the overall project time line. So the reason that we chose Optumas to help us and partner with us on this project was their familiarity with our approach and project management. Also stakeholder engagement. Optumas has had several different contracts in Nebraska, currently working with the Division of Developmental Disabilities on our objective assessment process redesign, which is phase two of our rate reform. So the scope of work is to make sure

Nebraska's level of care assessment criteria and tools are the right fit and aligned with national best practice for long-term services and supports. So this project is being completed in two phases. Phase one is the nursing facility level of care for both children and adults. And phase two is for intermediate care facility for the developmentally disabled level of care. So Optumas started with reviews of all federal and state law requirements, national best practices to align where we compared to other states. They're working on both the level of care. They started with the tool itself and now moving on to criteria to have that alignment in a document for us, and then reviewing our current criteria and tools to see how they align and compare overall. And then Optumas will recommend any changes to our criteria assessment tools, adjustments to our tools, or any alternative tools for consideration as well as criteria. And then we've asked them to conduct a validation analysis of the assessment tools to identify any errors with outcome assumptions related to the tools to ensure there's an alignment with the waivers' criteria and the tools. And I think that's important to know the end result rather than the implement and wait and see model that we are not in favor of approaching anything that way. So to ensure that we had robust stakeholder engagement and communication in the process we made available and are making available many opportunities to hear from individuals and services, families, advocates, providers, and the community. The first opportunity we created a Web page specifically for this project to keep all stakeholders informed of the process. The second is, is that we convened a technical advisory group, and that group includes a group of professionals representing clinicians, policy advisors, service providers, and the University of Nebraska to provide transparency and for DHHS to receive their input throughout the project. We intended to facilitate two focus groups for each phase. One for the adult tool and one for the children's tool for that feedback from the critical voices of individuals, families, and advocates. When I put the word out for the focus groups we intended that to be a small focus group. But, due to the overwhelming response of families that wanted to participate in that focus group, we switched gears and we changed that into a larger listening session. And so in July we changed the venue to the public library so it would be more accessible in a bigger room. And I believe we had over 65 individuals attend that and it was a very, very good listening session. We are going to have another one in October. And also my personal director statewide tour, my let's talk meetings throughout the state, I have had three so far: La Vista, Beatrice, and Lincoln. And we have had families in attendance wanting to have discussions about the Aged and Disabled Waiver, the children's level tool. So happy to engage with stakeholders during that time as well. I'm just getting started. On Sunday I head up to Valentine and then I'm in Scottsbluff, Kearney, and in Omaha. There's probably a couple-- Wayne-- and a couple more in between there. But I've gone all next week on a statewide tour traveling the state. So happy to engage with families that want to come talk to me during those sessions as well. And finally, we are having a statewide Webinar at the conclusion of each phase to provide the overview of the project and then the outcome. Those will be recorded and also placed on our Web page. So as for the time line, phase one was expected to wrap up in October and that contract will be amended to be extended. Right now we're thinking an additional 60 days. The reason for that is based on the population data analytics. We do not have an integrated data system that collects information to compile that and so we are gathering information from multiple sources to determine the criteria, the children's-- well, and the adults. We're looking at diagnoses, claim utilization, and the tool itself. Many of the documents that surround the tool are in paper format and loaded into a system. And so trying to gather all that information has taken a little bit longer than expected. Also is the factor of when the tool, whether it be redesigned or it is an alternative tool that we select, the question is who will administer the tool that aligns with best practice also where it will be based? Essentially what system that it will be in to make sure that we aren't in a situation as we are today trying to compile that information and make it more user friendly in the IT system. So it will be a tool that will be deployed and trained on throughout the state with our team members. So with that information I'll take questions. Otherwise I'll turn it over to Steve Schramm with Optumas to highlight their progress on the project to date.

HOWARD: Thank you. Are there questions?

CAVANAUGH: Senator Cavanaugh. I just want to get clarification. So, as I said to CEO Smith, the families that are here today and are watching are really going to want to know when are you going to start evaluating their cases again and when can they expect the potential of being kicked off the waiver? So can you tell us when are you going to start evaluating the waiver again?

COURTNEY MILLER: So the, from my understanding, our federal-- we had federal approval to provide extensions that were scheduled to occur from early March to early September of this year. And so those, those children that were receiving services continue to receive those services during the six months. That, I believe, concluded on September 8. And so as we get those scheduled moving forward, September 9, that will occur again. The process that we've put in place is that children who initially are determined no longer to meet the level of care criteria will also be reviewed by the medical director to review those cases to see if there's additional information. We're also going to screen them and see if they are eligible for the, the DD waivers, the waivers for the-- the home and community-based waivers for the developmentally disabled. We are reviewing with CMS, our federal authority, of options to see for those that are on the waitlist for the waiver, for the DD waivers, if there is an opportunity as based on the statute with the funding criteria. Just seeing what our options are to see what's available but to also review with those families other options and programs through DHHS that are available. But we're also not just looking forward to those that or moving forward with those that are in review now, we are also doing the population health analysis of those that were no longer eligible prior to the March date when the mortuarium [SIC] came into play.

CAVANAUGH: So we don't have a new tool kit in place?

COURTNEY MILLER: Correct.

CAVANAUGH: But you are beginning evaluations now, you began evaluations last week?

COURTNEY MILLER: We started to schedule them, yes.

CAVANAUGH: You started to schedule them. And do you anticipate to have the new tool kit in place when you begin those scheduled evaluations?

COURTNEY MILLER: No. The scheduled evaluations, we got the six months delay, that mortuarium with federal approval. We do not have federal approval to move forward.

CAVANAUGH: Did you seek federal approval? Did you seek approval for additional time?

COURTNEY MILLER: No. The federal approval came with the Appendix K, which is the emergency preparedness and response, and was based on the disaster of the state, of the availability of service coordination and families to, to be able to come together for those team meetings and evaluations. And so six months was the deadline in which we-- or that's the time frame that we received from the federal government.

CAVANAUGH: And you didn't pursue the option of extending that approval?

COURTNEY MILLER: I can't speak for the division of Medicaid and long-term care, I'd have to go back and see what those conversations around. But it is not an extended or a long time frame.

CAVANAUGH: And has there been communication with the federal government on what to do in the interim since you are currently using a toolkit that was deemed not appropriate in 2015 by the Nebraska Supreme Court and children have been kicked off and you're going back to that toolkit that we've taken six months off from doing but nothing has changed basically? Once, once you-- once the kids come back, once these scheduled reviews happen you're using the same toolkit that you were using in January and February. So nothing's changed, we've just spent six months and nothing's changing. And so I would like to know, and I think the families would like to know, what they can expect. Can they expect that they're just going to get kicked off again because of the, the toolkit that you're using is the same? Or can we expect that a new toolkit will be used. And it sounds like we're using the same tool kit. So we just spent six months going through this process and I'm confused. I'd like clarification on why we took six months to go through this process if nothing is, if literally nothing has changed.

COURTNEY MILLER: So I wouldn't say that nothing has changed. We've made progress with the project.

CAVANAUGH: Well, if you're a parent.

COURTNEY MILLER: But I do understand that the regular, the current criteria and the tool are promulgated in regulation today. And by law that's what we have to follow today. And CMS has not determined that our criteria is inappropriate. It is, it has been determined appropriate. What we're looking at in this project is to determine the most appropriate and the best fit for Nebraska to see for changes.

CAVANAUGH: So the department, though, promulgates the rules. The department promulgated this rule last year and the department spent six months with the CMS and Optumas but has not promulgated anything else, and is going back to the toolkit that we all raised serious concerns about and families across the state are raising serious concerns about. So I am confused as to why six months later the department is sitting here telling us we spent six months, we need more time but the families that have been impacted by this are going to continue to be impacted exactly the same as they were impacted six months ago. That's very concerning to me. And I don't feel like I'm getting an answer to that as to why that's happening. Because the department could have done something, could they not? Could the department not promulgate different rules over the last six months?

COURTNEY MILLER: I think the question with the project is what rules do we promulgate and what, what criteria and what tool do we use.

CAVANAUGH: Well--

COURTNEY MILLER: And I think the, the assessment, the initial assessment that we've done with Optumas is that our criteria is not far off from other states. It's very similar. And so it's not more restrictive necessarily from other states. So it's been determined appropriate--

CAVANAUGH: Has there been a discussion within the department as to going back to what the, the rules were prior to this toolkit? Until the full breadth of work that you are all doing here can be resolved has there been discussion about going back to what you did before January 1?

COURTNEY MILLER: I can't speak to those discussions.

CAVANAUGH: Who can speak to them?

COURTNEY MILLER: My role in this is, is the project lead and to, to move forward.

CAVANAUGH: Who can speak to those discussions?

COURTNEY MILLER: Who can--

CAVANAUGH: Who can speak to whether or not--

COURTNEY MILLER: To the discussions?

CAVANAUGH: Yes, about promulgating the toolkit.

COURTNEY MILLER: Promulgating back to get previous regulations?

CAVANAUGH: Yes.

COURTNEY MILLER: Well, I think that would be a question that would be for Director Van Patton.

CAVANAUGH: OK. And I do not see Director Van Patton here today so--

COURTNEY MILLER: We would have to follow back up with you.

CAVANAUGH: OK, thank you.

HOWARD: Are there any other questions from the committee? Thank you.

COURTNEY MILLER: Thank you.

HOWARD: All right, our next animated testimony is Steve Schramm from Optumas.

STEVEN SCHRAMM: Chairperson Howard, members of the Health and Human Services Committee, for the record my name is Steven Schramm, S-c-h-r-a-m-m. I'm the managing director of Optumas as Director Miller said earlier. We have been consulting actuaries for the Nebraska Medicaid program under a competitively procured contract in 2012 and in 2019. We were engaged by the agency to assist in this project. I've been asked to testify about four areas. So the first thing I'm going to talk about is Optumas' role in this project to date. The second area that I'm going to talk about is our initial findings about other states' nursing facility assessment tools. The third area I'm going to testify about is the central question about whether or not the assessment tool can meet the criteria that are laid out for nursing facility level of care in Nebraska. And then the fourth area I'm going to testify about are the next steps, the additional work that Optumas will complete. And as CEO Smith and Director Miller said, I am available to answer questions through the course of the presentation. So feel free to, to interrupt. In terms of Optumas' role, so far what we have done is we facilitated that listening session that Director Miller described in June in Lincoln. We also received and reviewed written testimony from that listening session. We facilitated the first technical advisory group that Director Miller described. And we anticipate that there will be additional listening sessions, hopefully scheduled in October, as well as additional technical advisory group meetings. Again, looking for those to be scheduled in October. And, as Director Miller said, we intend to hold a Webinar at the conclusion of phase one to make certain that people understand the results of our initial work. From an internal perspective we have met with and led meetings with the DHHS staff for us to understand the tools that they use, the training that the staff has undergone relative to those tools. And we have also begun to review the criteria itself and the tool itself. Any questions about the first piece of my testimony?

HOWARD: Are there questions from the committee? Senator Walz.

WALZ: I just had a quick question. Thank you, Chairwoman Howard. When did that process start? I'm sorry, I missed that.

STEVEN SCHRAMM: So our initial kickoff meeting was at the end of April.

WALZ: OK.

HOWARD: That's it? All right.

STEVEN SCHRAMM: Chairwoman, section two. This is the initial results of our review of other states' assessments. One of the things that Director Miller talked about was the alignment of the level of care. And when we think of alignment we think of the waivers that exist within the state, the criteria that the state uses, and then the tool that it uses to gather data about individuals and whether or not they meet those criteria. So one of the things that we need to be very clear about, in this first phase we're talking about nursing facility level of care. Remember Director Miller talked about phase one and phase two. Phase two is the ICF phase, and that has to do with developmental disabled individuals. For nursing facility level of care it's very focused on health care needs. And so when you look at other states' tools you will see that the criteria that they are trying to gather information on in that tool is very much focused on health care needs. In review of other states' nursing facility level of care tools and their criteria, they are a potential mixed bag. What I mean by that is you will see some states use a single tool for both adult and children, and then you will see other states use separate tools: one for adults, one for children. The one factor that we have seen is it is almost unanimous that states, whether they use a nationally recognized tool or set of tools or their own tool that they have built themselves, they differentiate the capabilities of adults versus children. And the example that we like to use is bathing. As noted earlier, what would be appropriate for capabilities of an adult relative to bathing would not necessarily be appropriate for a child. And so that's the genesis of this idea behind using either a separate tool or a separate set of criteria of the data that comes out of the tool for adults versus children. The other piece that is important to note as part of our research of other states is that there is a clear movement in states to go away from home-grown tools and evaluate the applicability of validated, standardized tools for their nursing facility level of care. In our review, for instance, there are approximately two dozen states that use a national tool produced by InterRAI. And so that would be what we would consider to be a validated, standardized tool. It is not to say that Nebraska is alone in using a home-grown tool for its level of care. But the movement tends to be towards more validated, standardized tools. That's the second piece of my testimony. Any questions about that area?

HOWARD: Are there any questions? Senator Williams.

WILLIAMS: Thank you, Senator Howard. And thank you for being here again. Just, so is that going to lead-- is that what your recommendation is going to be then?

STEVEN SCHRAMM: Chairman Howard and Senator Williams, it is too early to say what our recommendation is. But I think it is fair that Nebraska understand that contextually other states when evaluating their homegrown tools versus national tools are tending to lean more towards national tools. The important thing to think about, though, is the tool is only one piece of what we're talking about when we say aligning the level of care. You have to consider the waivers that exist, the criteria that you use, and then the tool. The tool is literally just that. It is meant to gather data so that you can satisfy the criteria.

WILLIAMS: OK, thank you.

HOWARD: Any other questions?

STEVEN SCHRAMM: The third area I'm going to talk about is the essential question of the scope, and that is does the nursing facility lever-- level of care tool provide the data necessary to meet your current nursing facility criteria? And I want to be very clear about this. Our initial assessment is that the tool that you use is adequate to satisfy the data that are necessary for your current nursing facility criteria for adults. But I want to clarify. Director Miller very specifically said there are really two questions to be answered here. First is, is the current tool appropriate for the current criteria? And then as part of the analysis, do you utilize the most appropriate criteria for nursing facility level of care? And I want to be clear, I am not opining at this point about the determination as to whether you have the most appropriate criteria at this point. The other thing that is very important to note, and Director Miller already gave you some perspective on this is, as part of our review of the level of care criteria for nursing facility and the level of care tool one of the things that we wanted to do was see if we could validate the documentation that was being used in the level of care determination. And it was very challenging for us to do that because, as Director Miller said, there is not a single integrated data system. So we actually had to go to multiple data sets and use that information to build a comprehensive data set for us to do our analysis. And so from a peer review of the level of care determinations it is time-consuming to gather all of that information and there are a number of things that stick out in that. One of those is that there are several steps that are manual. And so, as we talk about this idea of the absence of an integrated data set, that represents significant challenges to DHHS to go back and review and verify the documentation as well as the results of the determination. That's the third area that I will testify on. Any questions on that area?

HOWARD: Are there any questions? Senator Cavanaugh.

CAVANAUGH: So I'm looking for a little bit of clarification here. You are evaluating the tool for the current criteria. And the data collection that you are able to get using the current tool is appropriate for the current criteria?

STEVEN SCHRAMM: Chairwoman, Senator, that is correct.

CAVANAUGH: OK. But you aren't making a judgment or a recommendation at this point as to whether or not the current criteria are appropriate for the children.

STEVEN SCHRAMM: Chairwoman, Senator, that is correct.

CAVANAUGH: Do you have a time line of when you will have that recommendation?

STEVEN SCHRAMM: Chairwoman, Senator, we have worked with Director Miller and we have committed to within that 60-day window that Director Miller committed to completing phase one, providing a recommendation about the most appropriate criteria and tool.

CAVANAUGH: Have you-- has your company, your organization worked with other states on this type of evaluation?

STEVEN SCHRAMM: Chairwoman Howard and Senator Cavanaugh, we have worked in other states and looking at their nursing facility level of care.

CAVANAUGH: And typically is that done after they have promulgated changes or is that typically done in preparation for promulgating changes?

STEVEN SCHRAMM: So, Chairwoman Howard, Senator, I cannot say what's the typical approach. We have been engaged by states to review their processes before they promulgate new rules and we have been engaged to review processes after they have promulgated rules.

CAVANAUGH: OK. So the absence of integrated data system has been problematic, a challenge. Sorry. Thank you.

HOWARD: All right, any other questions? Continue.

STEVEN SCHRAMM: Chairwoman, I'm going to hit the last of my four categories for testimony, and that is the next steps. To give you all an understanding. So at this point we have done an initial review of other states' alignment of their waivers, criteria, and tools. The next step is really to do a much more comprehensive and in-depth review. And so when we talk about that we will look at the waivers that they have available, their criteria that they utilize. We will distinguish between whether or not they utilize adult versus children criteria and then we will look at whether or not they utilize a single tool or if they use multiple tools. In addition, we will do an internal set of facilitated meetings working with the DHHS staff to determine what the most appropriate alignment of waivers, criteria, and tools, again, similar to the other states reviewed distinguishing between adults and children, would be for the state of Nebraska. The third area that we will continue to work on is the area that director Miller spoke about and that is the population health analytics. We are committed to understanding which are the children, the children who have lost eligibility as a result of the level of care criteria. We want to understand what their diagnoses are, we want to understand what services they are. We want to distinguish between whether those are waiver services or state plan services and we want to be in a position where we can talk about the level and type of utilization associated with those children, because that is essential to designing a solution that will address those children's needs. In addition, we will continue the stakeholder engagement that we have already begun. And so, as I mentioned, there will be additional listening sessions, there will be additional tag meetings and Webinars in order to receive feedback as well as disseminate information. With that, Chairwoman Howard, that concludes my testimony. I'm open to additional questions.

HOWARD: All right, are there questions from the committee? Senator Hansen.

B. HANSEN: Just a kind of simple question. I think Senator Cavanaugh was trying to allude to this a little bit with that, and you kind of talked about in your last step, how long will that last step take?

STEVEN SCHRAMM: So, Chairwoman Howard, Senator, the data analysis if there were an integrated data set would have typically taken two weeks or less. We have been engaged in the data analysis for materially longer than that and we are hopeful that we can complete that data analysis within the next two to three weeks.

B. HANSEN: OK, thank you.

HOWARD: Other questions? Senator Williams.

WILLIAMS: Thank you, Senator Howard. And thank you for being here. And this, this question may not be for you but, but I think-- I don't know if anybody else is sitting here finally just getting frustrated. Not having an answer to what we want to know is-- we've got a problem that was created by a change in how these issues were looked at. There's been a lot of work going into trying to find what is a solution. And we're not hearing from a business perspective what is the answer to that and when are we going to have an answer to it so these parents out here can have some comfort in knowing where they're going to go with their children. Where are the adults that are affected by this, both in and out of the nursing home, are going to know. And I don't know that, that may not be a fair question for you, Mr. Schramm, from Optumas, but I think that's ultimately the question that we are, we are all seeking here. Do you have any comments on that?

STEVEN SCHRAMM: Chairwoman Howard and Senator Williams, what I can say is we have been directed quite forcefully by CEO Smith and by director Miller to provide our recommendations within the next 60 days. We are working overtime on the data analysis issue that Senator Hansen asked about. I think I would defer to Director Miller and CEO Smith to address your other comments.

WILLIAMS: Thank you.

HOWARD: Are there any other questions from the committee? Just for point of clarity for me. So you were originally contracted to begin this work when?

STEVEN SCHRAMM: Chairwoman Howard, we did the original kickoff meeting at the end of April of this year.

HOWARD: At the end of April, OK. And then throughout the course of the summer then you have facilitated several conversations both internally and externally?

STEVEN SCHRAMM: Chairwoman, that is correct.

HOWARD: And then we can anticipate sort of a report from you in two to three weeks?

STEVEN SCHRAMM: Chairwoman, as part of our contract we have a set of deliverables, and one of those deliverables is a report with our findings.

HOWARD: And I'm sure the department will be willing to share that report with us. When you are considering your recommendations, do your recommendations give us-- should we do a single tool or multiple tools and then do they recommend what type of tools? Or is it just one or the other? Is it, is it vague or is it specific?

STEVEN SCHRAMM: So, Chairwoman Howard, the request from DHHS was that we give a specific recommendation for a tool and also talk about the implementation of that. So that would describe whether or not there would be a single tool, whether it would be applicable to adults or adults and children, and it would talk about the alignment of that tool with the criteria as well as the waivers that exist in Nebraska.

HOWARD: Senator Arch.

ARCH: Thank you. The issue of data has come up repeatedly in the presentation and discussion. And could you amplify and help us understand a little bit some of the issues that would have caused a delay in your ability to analyze? You obviously spent a lot of time gathering the data.

STEVEN SCHRAMM: Absolutely, Senator. Chairwoman Howard and Senator Arch, so as a strategy and actuarial firm we are actually intimately familiar with the state of Nebraska's data. We have manipulated it for the last seven years. And so what has happened in other areas is we receive data files quite quickly that we are able to immediately import and validate and then begin our analysis on. In this particular project, when we would ask for a data set, we needed to go through a several-step process to clarify who would be the most appropriate individual to provide that to us, what that data set would contain. And then one of the major challenges was several of the data sets don't easily talk to each other because they are developed on a database level using different keys. So we needed to take information and crosswalk it, which can be time-consuming when you don't have the same key between databases. For instance, the ID of the individual. And so it becomes a challenge for you to go and have these multiple datasets talk. The other challenge is there still remain several manual steps within the process that we have discussed with DHHS. And we will make those steps known as part of our report.

ARCH: Thank you.

HOWARD: Any other questions. Senator Cavanaugh.

CAVANAUGH: I just wanted to continue the clarification on time line here. So the department received a six-month delay from the federal government that they could hold off on evaluating these waivers in March. You began working with the department at the end of April? Is-- that's correct?

STEVEN SCHRAMM: Chairwoman Howard, Senator, that is correct.

CAVANAUGH: And then when you began in your scope of work they knew that they were a month in so they had five months left. Was it communicated to you that there was this deadline with the federal government on needing to go back to evaluating the waivers?

STEVEN SCHRAMM: Chairwoman Howard, Senator, we did know that the moratorium existed. And we, as part of our scoping process, were directed by CEO Smith and Director Miller if possible to provide recommendations before that process. Excuse me, before that moratorium expired.

CAVANAUGH: And at what point did you communicate to the department that you would not be able to give them those recommendations before the expiration date?

STEVEN SCHRAMM: Chairperson, Chairwoman Howard, Senator Cavanaugh, I can go back and look at the communications that we've had with the state. I cannot give you a specific date at this time.

CAVANAUGH: Can you give me a month?

STEVEN SCHRAMM: I would say we-- excuse me, Chairwoman Howard, Senator, we communicated, if this is the middle of September. We have communicated within the last two to three weeks that we were unable to meet those deadlines.

CAVANAUGH: And when did it come to your attention that you would be unable to meet those deadlines?

STEVEN SCHRAMM: We communicated, Chairwoman Howard, Senator Cavanaugh, we communicated that to the state as soon as we realized it would not be possible.

CAVANAUGH: And you only realized that two or three weeks ago?

STEVEN SCHRAMM: Chairwoman Howard and Senator Cavanaugh, when we were going through the data analysis we had an expectation that we would be able to complete that quite quickly. And through each step and iteration of the data that we were provided our expectation was that we would be able to complete it quite quickly. We did, though, have to receive multiple feeds of the data. And so it was only after we had received multiple data feeds that we determined we would not have sufficient time to complete the data analysis.

CAVANAUGH: And so you weren't receiving the data until two to three weeks ago?

STEVEN SCHRAMM: Chairwoman Howard, Senator Cavanaugh, that is not accurate. We have been receiving data throughout the entire process. The challenge has been that as we've received the data it has not always been in a format that we could utilize at that time.

CAVANAUGH: OK. So you said that you worked in Nebraska often and you're familiar with our process. And I don't think that it is a secret that we don't have an integrated data system and that this is a challenge for us as a state and infrastructurally. So it would have been my anticipation that you would have known that from the outset. And I guess I'm concerned that your company wasn't aware sooner than two to three weeks ago to notify the department that you wouldn't be able to meet this deadline. Because we're talking about children and their health. And so I, I guess I'm just kind of disheartened by this answer that you wouldn't have known that sooner in the process. Thank you.

HOWARD: Are there any other-- Senator Walz.

WALZ: Another quick. Thank you, Chairman. So how long is the contract? Like how long does the contract go?

STEVEN SCHRAMM: Chairwoman Howard, Senator, the contract has two phases to it. The original phase was intended to be through October. The extension that Director Miller talked about would add 60 days to that for this particular phase.

WALZ: That, I guess I would-- I have another question then. So why, why is there an additional 60 days? Where did that come from, how did that come up?

STEVEN SCHRAMM: Chairwoman Howard, Senator, we had informed the DHHS team that because of our inability to complete the data analysis that we would need additional time to finalize a report.

WALZ: OK, it came from you. OK.

HOWARD: Any other questions? All right, seeing none, thank you for your testimony today.

STEVEN SCHRAMM: Thank you very much.

HOWARD: All right, that concludes our invited testimony for today. We'll now open the floor to the public, our first testifier for LR105. And we will be using the light system but we'll obviously do an ADA accommodation if folks need it.

JENNIFER HENNING: Hi.

HOWARD: Good afternoon.

JENNIFER HENNING: Good afternoon. My name is Jennifer Henning, J-e-n-n-i-f-e-r H-e-n-n-i-n-g. First and foremost I want to say thank you, Senator Cavanaugh. I feel very thankful that you seem to be feeling the frustration that families like mine and advocates like me are feeling today and that we have felt like for a very long time. So I had a-- my son's kind of story all written out, but while I'm listening to this testimony I'm feeling concerned that there's a significant lack of transparency. So these change, these changes were implemented in January, OK? These came down the line and families like mine, with a little boy with a brain injury, were told because your son is mobile, because he can walk, you're going to lose waiver. We're a two-income household, we don't depend on government assistance. We work. My husband works for a Fortune 500 company, we have pretty good salaries. But the reality is, even with one of the best insurance company's policies in the state, it excludes home health nursing, it excludes formula. The reality is our son needs home help nursing. He suffered a brain injury. So that caused panic, that caused a significant crisis for our family. So when we heard about this coming down the road, all families like these, like me and myself and all these people behind us we were shocked we were appalled. The excuse from DHHS we were getting was it was CMS's fault. CMS made these guidelines, they made these changes. So here I go as a mother, as an advocate for special needs kiddos. I call CMS. I'm desperate to find the answers, I'm desperate to be able to work and provide for my family. I don't want to be dependent on the system. I want to work. I want to make sure my kids have a good example. So here I go calling CMS because that's the excuse Nate Watson and your staff were giving me. So this is an email directly from CMS. This is Barb Cotterman from CMS: Dear Jennifer, thank you for contacting us. We of course are willing to investigate and determine what CMS policy would be at the root of why, as you said, thousands of children are losing access to the Aged and Disabled Waiver in Nebraska. Please send me any additional information you have that the state agency has shared with you and the parents. She goes on to ask that I keep her contact information confidential. She doesn't, she's not aware of any of this. She's shocked and she appears appalled. So that was February 2, OK? I'm sure all of your legislative aides have heard my name a million times because I've been calling every single one of you. Timoree is probably like, oh, my gosh, this lady. I am desperate. My child, we didn't ask for this. I'm sick because of the lack of transparency and the excuses. It's all talk. It's like talking to a brick wall. If you guys are getting that impression just sitting here from the testimony, imagine you're the mother or father of a special needs child. Your life is already extremely hard, OK? There's zero communication. It's all excuses. It's all, oh, we need an extension. You know what, why do they get an extension, why do they get 60 days? What about my family? I don't even know if I'm going to be able to work tomorrow when they do the reassessment because I don't know if I'm going to have nursing care for my son. I don't know if I'm going to be able to feed my son his formula. You know why? Because they're taking it away. So they can ask for 60 days. But me as a mother, who my son's life depends on this, can't ask for an extension. It's sick to say thank God for a flood because that's just, it's disgusting. But thank God for that flood for families like mine. There was so much devastation. But, you know, I feel devastation every day for my son and what happened to him and the life that he has to live. I feel very concerned that Optumas is being hired and paid for and is answering to DHHS. When you have Courtney Miller stating in quotes there's an overwhelming response. These children, these families, we're in crisis. When you have Mr. Schramm in quotes saying manipulated data. I don't care about your data. You know what I care about? We are Nebraska. We fight for our children and our families. These children didn't choose this lifestyle. We are not asking for handouts. What we are asking for is assistance with our children so we can work, so we can provide. If you don't allow us that ability to work and provide you are going to be the burden of my entire family. So instead of taking the burden, a small financial burden to keep him living in his house, you know what's going to happen? My family's either going to be forced to divorce, my son's going to go into an institution, my husband and I have to quit working, and then you take on our whole family with government assistance and you take us on, our whole family, for Medicaid. And right now you've got Union Pacific Railroad footing the bill for a lot of the private insurance bill for my son. Medicaid is paying a very small amount of money. Other concerns I have. When we're discussing claims utilizations, what about the families who have been kicked off the waiver? How can you talk about claims utilizations, they don't have any claims? They're in crisis, they've lost the waiver. They don't have any other options. We're talking about a time line that's been extended. We're giving the excuse of, oh, they can go on DD waiver. Do you know that the waitlist for DD waiver? My son is only three years old. He's been on the waiver for two years. He still has at least six years before he can even be up to the top of that waiver list. When we're looking at other states, other states have other waivers. We have an autism waiver in this state but, yet, it has no funding. We are not representing the people in this state. Our voices need to be heard. You guys need to help us because DHHS, they're not helping us. They're ignoring us, they're giving us excuses, and pushing us away. They're sitting here testifying to giving you excuses. If they were in our shoes, they would be fighting. They would be crying, they were pleading, they would be like Timoree, like Senator Wayne, like Senator Cavanaugh, and they would be appalled. You all should be appalled because these families were hurting. And these excuses, frankly they're unacceptable. They're unacceptable. This is not fair.

HOWARD: Let's see if there are any questions. Your children are incredibly lucky to have you as their mom.

JENNIFER HENNING: We didn't have a choice in this.

HOWARD: Yeah, I know. OK, let's see if there are any questions. Thank you. Senator Cavanaugh.

CAVANAUGH: Thank you. Thank you for being here today. I'm sure it's not easy to get away and be an advocate in this forum for your family, so thank you so much. And you, you passed out photos of your fam-- you have a beautiful family, two beautiful children. And I think I can, perhaps, speak for the whole committee that we want to see your children thrive.

JENNIFER HENNING: Thank you.

CAVANAUGH: And we have been hearing from families and, and, and talking to everyone, and there is a great deal of concern for this. So

I just want to thank you for sharing your story. And if, if there was any last remarks that you wanted to share with us as a committee.

JENNIFER HENNING: I would hope each and every single one of you would create a bill to fix this, because families can't wait 60 days. They can't wait for these extensions, they can't wait for Optumas to make these determinations, they can't wait for DHHS to just keep putting this off. If Senator Arch, Senator Howard, Senator Williams, we need you to create a bill to help our families. If it's not for the Aged and Disabled Waiver, it's the waitlist on the DD waiver, it's to fund the autism waiver. We need to have an outlet to help take care of these kids because if we don't take care of them here, right now, they are going to be in prison, and you guys are already struggling with our prison system here. We need help. We need you to take control now because it's going to be more cost-effective right now than it will be down the line. We're already in a crisis in a lot of areas in the state. Don't make our children and families suffer as well.

HOWARD: Thank you. Are there any other questions? Seeing none, thank you for your testimony today.

JENNIFER HENNING: Thank you.

HOWARD: Our next testifier? Good afternoon.

EDISON McDONALD: Hi, my name is Edison McDonald, E-d-i-s-o-n M-c-D-o-n-a-l-d, I'm the executive director for the Arc of Nebraska.

Thank you very much for being willing to hold this hearing today, Chairman Howard, and to the rest of the committee. We've heard from families over and over again that these issues are creating unbearable pressure. In response to these issues, the Arc has been working with families, advocates, professionals, legislatures, the department, and really trying to figure out how we can go and dig into this. I think, you know, that I want to take a step back. I think the way that we've been approaching this is really digging in and looking just solely at the tool. I think instead we need to talk about some of the tools that aren't in our toolbelt. So the Arc went and got a group together and we created this study that we have handed out to go and say let's take a larger look at these issues. And along with this we didn't just say it's the Aged and Disabled Waiver. As you heard from Ms. Henning, I think that overlap with the DD waiver and then, you know, issues with our VR waitlist all kind of crossover a great many ways. So we said let's, let's look at this a little bit more holistically. So we went and produced this study to really start to dig in to some of these issues and try and find some potential solutions. Ultimately the loss of the Aged and Disabled Waiver exposed many of the gaps in systems delivery in Nebraska. For example, when children with autism had access to the Aged and Disabled Waiver they were receiving Medicaid coverage, thereby able to access applied behavioral analysis and other early intervention services. Children with high medical needs who may not necessarily meet a nursing home level of care were able to access

Medicaid coverage to help pay for prescription benefits, copays, and durable medical equipment, things that many private insurance companies don't pay for or don't cover adequately. Finally, there truly are limited programs available to support children with disabilities and their families in Nebraska. The Aged and Disabled Waiver was the one program that allowed working families in Nebraska to access Medicaid and other supportive services such as specialized child care. So as we were going and starting to hear these cases we started to see some trends. In particular, we saw a lot of kids who were also on the DD waiting list or who, you know, although we'd have a different interpretation, the department told us really fit better on the DD waiver. We also saw a lot of kids with autism. And then kind of a third big category were kids who didn't neatly fit into the check box, who, you know, trying to go and really concretely develop a tool for I think is difficult. But obviously, you know, you can tell from a human perspective needed care, but if you're just looking at a form you're going to have a hard time. And that's really hard to legislate. But we tried to kind of take that larger approach and take a step back. So some of the things that we'd really suggest taking a look at: Number one, utilizing language that would open up a broader range of coverage. For example, utilizing language such as "children at risk of institutional placement." So like a nursing home or a hospital would require the state to consider the child's outcome without access to the waiver. Number two, requiring the state to use an assessment tool that considers children's growth and development and their achievement of key developmental milestones. Number three, ensuring that the Aged and Disabled Waiver, and really any waiver, doesn't punish family for improvements. One of the most touching moments of the Optumas hearing was a mom who said, I'm afraid for my kid to get better. And, you know, that was just so striking that they're afraid for their child to improve. Number four, making sure to implement the Family Opportunity Act. States like Iowa, Oklahoma, and Ohio offer the Family Opportunity Act. This program only considers the income and assets of the child with disability, special needs because of their family income disqualifies them for Medicaid eligibility. So this allows their families to continue to be in the work force and children to continue to be able to improve. Number five, implementing a family support waiver like Tennessee, Pennsylvania, Maryland, because it takes individuals off of state waiting lists, help support family caregivers by providing coverage for specialized care, respite, independent living skills, and training, etcetera. And then the last thing is identifying programming to support children with autism, intellectual disabilities, and those with more challenging behaviors. Ultimately, Medicaid nationally was designed to be a program that much more goes and covers children in terms of a scope of not only age but also of disability. And I think that that's really important. Thank you, again, for holding this hearing. I hope you will look in great detail into this report because I'll be talking about it many times throughout the upcoming year. Any questions?

HOWARD: Thank you. Are there questions? Senator Cavanaugh.

CAVANAUGH: Thank you, Chairwoman Howard. Thank you for being here today. So you said that some of the families that you've spoken with they've been directed that they be a better fit for the DD waiver. And I'm just looking at page 15 of your report from my colleagues. At the bottom that the state acknowledges that the DD waiver doesn't have funding to get everyone off of the waiting list or that it would be a large lift. Have they communicated, has the department communicated to you or to the families-- and ask this of you because, I'd also ask this of the department, I'm sorry to the department, I didn't think to ask this earlier. But what spurred this change, because the DD waiver has existed for a long time and it has a known waiting list. So what spurred the change in rules or the toolkit that they promulgated in January?

EDISON McDONALD: So the tool kit was really changed based upon that Brayden O. court case in the Supreme Court we were talking about earlier. The waiting list has been kind of consistently growing for the last like 20 or 30 years. So I think that's, you know, in that regard it is separate. Ultimately, though, I think what happened was I believe that some well-intentioned service coordinators started to go and say, well, your kid is on the DD wait list but they could go and get access to the A&D Waiver right now. And because that's the only other significant tool that we have in this state that's where they sent them to.

CAVANAUGH: And is it your understanding that the state could seek the additional funds from the federal government to fully fund the DD waiver?

EDISON McDONALD: Yes. To go and fund the DD waiting list we would have to increase, you know, the amount that the state is providing too. But then the feds do help to match those. I think also if you look into the waiting lists section one of the things that you'll see is especially some of those higher criteria levels have significantly higher costs. So like those who are on DD Court-Ordered Custody Act or in an emergency setting, as many of these families may go into, the average costs for those individuals would end up being about $130,000. Whereas the individuals in, say, coming in transition, so out of high school, when families have the ability to plan, you know, conservatively go and set a budget and think things through, that's only about $19,000 per individual. So the savings to the state ultimately by, you know, taking a little more thoughtful approach on this could be huge. Or like a family support waiver, the average cost in, in other states is about $12 to $15,000 in comparison to, you know, even $90,000 for the foster care system placements.

CAVANAUGH: Thank you.

HOWARD: Any other questions? Senator Walz.

WALZ: I have a question. Thank you, Chairman Howard. And thanks for being here today, Edison. The recommendations that you talked about, are they on-- are they the recommendations found on page 16?

EDISON McDONALD: So if you go into the Aged and Disabled Waiver section, let's see-- so the, the recommendations I was going off of is on page 11 and 12. And those are specifically around the Aged and Disabled Waiver. We tried to sectionalize and compartmentalize at least pieces of this, as kind of the key priority areas. But then in the back of this you'll see number one, kind of a larger set of policy recommendations that's a little bit more in-depth. And then number two, if you don't hear enough stories today, we've got more say in the appendices for you.

WALZ: And then I have another question for you. Where did you get the data? How did you gather your data that you have?

EDISON McDONALD: Which--

WALZ: Just, I guess, the report itself.

EDISON McDONALD: Yeah. So I had a fantastic team of parents and professionals and advocates who helped me and, you know, did a variety of research. You know, kind of going and pulling that from a couple different state resource guides. And we have sources like the Kaiser Institute on Health. And we kind of pulled all of that together.

WALZ: OK-- this is just--

EDISON McDONALD: This is just published by the Arc of Nebraska.

WALZ: In the fall?

EDISON McDONALD: Yeah, last week.

WALZ: Last week? OK. All right, thank you.

HOWARD: Any other questions? Seeing none, thank you for your testimony today.

EDISON McDONALD: Thank you.

HOWARD: Our next testifier? Good afternoon.

JULIA KEOWN: Good afternoon. My name is Julia Keown. Thank you for the opportunity.

HOWARD: Will you spell your name for me?

JULIA KEOWN: Yes.

HOWARD: Thank you.

JULIA KEOWN: J-u-l-i-a K-e-o-w-n. Thank you, again, for the opportunity to speak today. Like many of us here I was born in Nebraska, was raised in Nebraska, and have chosen to raise my own family in Nebraska. I am a mother of a medically complex child and I am actually a health care professional in the Lincoln area as well. So I have a little bit of experience in both. When Simon and I, my partner, decided to have kids we had no idea what kind of roller coaster ride we were in for. We had a set of boy-girl twins, they were five weeks premature. Gavan spent the first weeks of his life in the intensive care unit recovering from ostensibly nearly starving to death in utero due to pregnancy complications. So it's kind of our first go around with this. Once we got home Gavan did OK with growth and development until just before he turned 1. He began vomiting during each feeding and couldn't keep anything down. He lost weight and no one could tell us why. We went to countless specialist appointments and no one could give us a firm diagnosis or treatment for what was happening. When Gavan was 15 months old he was hospitalized with a virus that would cause a cold in a typical child. Due to his malnutrition and compromised immune system at the time we nearly lost him while he was in the intensive care unit at Children's Hospital. So that was his second brush with death in his short life. It was while we were in the hospital there that we were informed that

Gavan's conditions, both congenital and acquired, would allow him eligibility for medical and therapy assistance. We signed up in the hope of finally getting answers and treatments for his various conditions. Having Medicaid and the Aged and Disabled Waiver as a working-class family with two working parents meant that we now had access to a community of expert caseworkers, specialists, therapists, genetic counselors. It has been nothing short of a life-changing situation for us and our family. At this point, around one and a half years of age, Gavan was below the lowest percentile on the growth charts, which he wasn't even on the growth charts. He would have been like negative 10 percent. He had a cognitive delay, he was not talking and was not making progress toward walking. The vomiting had worsened and we still had no answers, so a permanent feeding tube was surgically placed in his stomach. This meant that we could focus on therapies for Gavan's conditions while not having to worry that he would starve himself to death. Having the waiver and resources available have allowed his malnourished body to grow sufficiently that he is now walking, talking, and his kidneys are fully functioning. Gavan's intellectual delay is no longer an issue and he is now at or above the appropriate educational abilities for his age. He's obsessed with physics, entomology, and paleontology, and tells me on a daily basis new and disgusting factoids about bugs that no one ever wanted to know but now you do. Also at this time Gavan began occupational therapy and physical therapy for his motor delays and oral feeding issues. These continue to be his main areas of deficit. We are making slow but steady progress in these areas due to the nature of their ideologies. All of the therapies and medical treatments have led us to the point where we are now. Gavan is sufficiently stable to where he has not had to be hospitalized for over three years. Due to the skills and treatments that we have available to him at home by our medical and therapeutic teams we are able to deal with most of his issues at home. This is not because his issues have gone away, it's due to the fact that the waiver services are doing exactly what they are meant to do, which is keeping kids at home and out of medical institutions. The Aged and Disabled Waiver program is successful and keeping kids at home by ensuring that disabled children have access to preventive medicine and therapies. Utilizing preventive medicine, rather than having to play quote unquote catch up after a hospital-- hospitalizations. This is what we refer to as a disease or treatment model. It's, the preventive medicine is not only evidence-based to be best practice for kids' health, but it's also fiscally responsible. Gavan's medical bills the year prior to him being determined eligible for the waiver program were in the hundreds of thousands of dollars. Because waiver services have allowed us to keep him out of the hospital and at home his bills now add up to approximately $30,000 per year when he is medically stable, so it's really quite a significant difference. I would emphasize that even if one doesn't find the idea of stripping disabled children of their health care and therapies morally and ethically repugnant, it should at least strike a person as odd that this decision is being made despite the fact that it does not obviously stir-- serve the state well financially. Nebraskans take care of each other and we are smart with our money. It is going to cost considerably more dollars to pay for hospitalization and institutionalization bills for disabled kids than it is to pay for therapies and preventive medicine. Waiver eligibility needs to be returned to its former state so that we can properly care for disabled children and save the state money. Because what's good for one of us is inevitably good for all of us.

HOWARD: Thank you. Are there questions? Seeing none, thank you for your testimony.

JULIA KEOWN: Thank you.

HOWARD: Our next testifier? Good afternoon.

PAULA McDONALD: My name is Paula McDonald, P-a-u-l-a M-c-D-o-n-a-l-d. I'm a little nervous, so I'll probably just read most of this. I'm from District 18 in Omaha, represented by Brent Lindstrom. And Aaron's family, who I'm going to talk about, that's my grandson, is from District 49 in Millard, represented by Andrew La Grone. I have a master's plus 30 in special education, I'm a retired special education teacher from OPS. And I'm his fraternal grandmother and caregiver, one of the caregivers for Aaron McDonald. God made Aaron, and I am his grandmother, and I love him. I'm here to give a background of how Aaron developed his special needs and what his family is doing to help him and how Munroe-Meyer is assisting us in this loving but endeavor-- challenging endeavor and why it is imperative that you continue to vote for funding of this invaluable money-saving resource. Aaron is nine and a half years old. At six weeks of age Aaron had a 12-hour brain surgery, a functional hemispherectomy. They cut his brain in half to stop seizures that would have killed him. From the surgery he became visually impaired and is unable to use the right side of his body, as well as he does better on his left. As a result he had cortical visual blindness that makes it harder for him to see letters and numbers on the page, orthopedic needs for braces on both legs, and the right hand and arm is weaker than the left. This surgery did save his life because he would have died at probably around two. It left him verbally impaired with orthopedic needs and autistic-like behavior. Aaron's-- although he's not autistic. Aaron's autistic behavior shows up in aggressive and injurious behaviors to himself. Being nonverbal, he has trouble understanding and communicating in his world. He bites and pinches himself. He has to be locked into his car seat because he tries to unlock his door while we're driving. And that's pretty thrilling, I could tell you, because I drive him. His dad, my son, has to sleep with him until he falls asleep to make sure he's safe and then stay alert during the night to make sure that he's not wandering. This summer his behaviors became a crisis at our house.

I babysat for him. I had to remove all the lamps and pictures in our front room. Flower pots were thrown outside, many toys were removed since he would throw them hitting one of us, and he broke two TV screens. Typically as a family we get stared at when Aaron is with us. Honestly, he is adorable and that's true. OK, I'm-- maybe I'm biased. I'm allowed to be biased. But he also screams and throws things. I had a neighbor suggest that I explain to people who look at Aaron that he has special needs. God made Aaron, and I'm his grandmother, and I love him. Aaron's parents are doing an amazing job at raising their two boys. They are hardworking, loving, intelligent people. Both parents have master's degrees from UNO, Dan's is in IT and Breanne's is in business administration. Aaron has a twin brother Connor. He is an intelligent young man who started to play chess at second grade. Both parents served in the Iraq War. Both were Army staff sergeants, Breanne was a gunner and Dan drove trucks. They used to go to church here in Omaha until it became too difficult to take Aaron. But they do try to get Connor to church with the other relatives. Dan and Breanne were lucky to get Aaron into Munroe-Meyer, although there are lots of other institutions, too, that help with behavior. Munroe-Meyer Institute for Severe Behavior started June-- he started there in June, 2019. As is usual it's-- there's an 8 to 12-month waitlist. His therapy is called applied behavior analysis. It's evidence-based best practice treatment approved by the U.S. Surgeon General and by the American Psychological Association. It's tailored to meet the child's needs. Research-based for 20 years students find success with autistic behaviors or behaviors that are like autism. I observe Aaron in his therapy and take him from Munroe-Meyer to school and his other ther-- therapies at Tree Top. And I've been assisting them whenever possible doing child care while his mother has a part-time job. God made Aaron, I'm his grandmother, and I love him. Aaron attends the institute five days a week, three hours a day at a cost of $750, the insurance company through Medicaid. He also goes to speech therapy, occupational therapy once a week at Tree Top in Gretna. They all cost $135 for each therapist for a half-an-hour visit. And I hear ortho visits with children are $300 and that does not include his braces. The car seat costs between $2,000 to $3,000. All these therapies help. He's using total communication with iPad Proloquo2Go, PICS, and sign. He is learning how to get his needs and wants met. Munroe-Meyer is working on his behaviors of self-injury; flopping, which is melting to the ground and refusing to move, and also on the emergency two-person transport; eloping and running away; and education tests of letter recognition, functional play. They're training us to use the 1, 2, 3 method for us to tell them what you want to do, and next you-- the model and finally you use overhand guidance. We are trained to be positive, ignore the bad behaviors. The team of the three psychology students, some with master's degrees, one working on her Ph.D., and a doctor of psychology do data analysis on preferred toys, sensory motor issues, and functional communication. They film it, graph it, and do research. I said to myself, wow, this must cost a lot of money. Why would the state want to pay for all this? Especially when I found out that it costs $750 for a half-day, three hours, five days a week. If you're more severe, it goes to $1,500, five days a week for six hours a day. So I did a little research on the Internet or Google. People with autistic behaviors are three times--

HOWARD: Ms. McDonald, I hate to interrupt.

PAULA McDONALD: OK.

HOWARD: But you've got the red light, and I want to make sure that if the committee has questions we have time for them.

PAULA McDONALD: OK.

HOWARD: Would you just want to wrap up very briefly?

PAULA McDONALD: Well, the rest of the, this one paragraph, it states that kids that go into the hospital because they have executive, impaired executive function are not able to make good choices. And so if, they're three times as likely to go into the hospital. So if you take care of learning about their needs and wants and they can tell you about that then it reduces the need to go into the hospital. And also it reduces the need later on when they're older. So, and I guess you can read the late-- you can read the last so.

HOWARD: Let's see if there are questions. Are there questions from the committee? OK. All right, seeing none, thank you for your testimony today. Our next testifier? Good afternoon.

MELANIE KIRK: Thank you. My name is Melanie Kirk, K-i-r-k, and I'm a parent of a medically fragile child. Actually, two medically fragile children. We'll be adopting our second medically fragile child in November on adoption day. I wanted to give you some information about what it's like to be a parent with a medically fragile child. Before I became-- currently I'm an attorney. But before I became a lawyer, before I attended law school, before I even finished my undergrad I became the parent to a medically fragile child. Logan [PHONETIC] was born at 28 weeks weighing 2 pounds, 2.3 ounces. He stayed 101 days in the NICU at St. Elizabeth. When we were able to bring him home he came home on oxygen and monitors, and the doctors told us that he would start to get better soon and we would be able to wean him off oxygen. Logan didn't get better, he continued to get worse. And eventually this took us to multiple doctors in Omaha, eventually to Iowa, as well as Cincinnati. And then we had to do a lung, lung biopsy when he was about three years old, and what we found out is that Logan was diagnosed with a rare lung disease called Childhood Interstitial Lung Disease. That's a section of about 15 rare lung diseases in children. Logan's is so rare that there's not a name for his type. We don't know what the outlook is going to be and we don't know what will happen down the road. We know that he requires oxygen 24 hours a day. We have to monitor him consistently to make sure that his oxygen needs are met. We later found out when he was about 7 that he had additional medical needs that we were either overlooking or we weren't aware of previously. Logan was eventually diagnosed with optic nerve hypoplasia septo-optic dysplasia, and that led to growth hormone deficiencies. Logan now gets a growth hormone shot every day. These shots, even though they've been around since the 1970s, are incredibly expensive. Each individual insurance has a preferred drug, they have a preferred pharmacy that provides that drug, and coordinating care between two pharmacies takes the better part of my day at least once a year. In addition to the growth hormone deficiency and to give you an idea, the cost varies between $5,000 to $60,000 a shot daily. Logan also has a diagnosis of an adrenal insufficiency which is similar to Addison's disease, that was just diagnosed in the past two years. In the past year, in the past like nine months, Logan has had in an adrenal crisis three times. That is a life-threatening condition that we need to recognize. We have to give him an intramuscular injection immediately and then take him to the hospital where we have a pass to go through triage so that we don't wait in the waiting room because Logan could die. When we're there they start giving him a specific set of criteria medications and steroids in order for him to manage and his body to start kicking in. His body doesn't produce cortisol which is a stress hormone that is necessary for life. In addition to this, Logan has been diagnosed with periventricular leukomalacia, which is scarring in the brain. And as an attorney I should never have to know those words, but I do because he's my son and I need to fight for him. Logan's on medications through two different durable medical providers and three pharmacies. Two specialty pharmacies, one out of state. We are experts on our children. All of these parents in here become experts on things that we never thought we would need to become experts in. But I wanted to give you an idea of how we are supported by the Medicaid waiver. Medicaid is the primary resource that we have access to under the waiver. And this, Medicaid is often secondary to a primary insurance. Many parents here have a primary insurance, but that primary insurance doesn't always pay for all of the services and needs that our children have. The cost to care for our children is astronomical. Bill Gates couldn't afford my son out of pocket, I assure you. We're not nervous about a $10 copay. When we say we're going to lose Medicaid we're talking about out-of-pocket costs for one medication that outstrip our annual income every single month. I'm an attorney, and I don't make a little amount of money. But I'm also not wealthy enough to afford Logan. We fight for the care for our kids and when a diagnosis is rare we have to keep fighting. It took a very long time to find all the diagnoses and just now we're beginning to see how those two different diagnoses interact with one another. Services. Often private insurance won't pay for OT feeding therapy. Logan also has a feeding tube that helped get him on the growth hormone, or the growth charts when he was about 10. He's 13 now and he attends Lefler Middle School here in Lincoln with his service dog Draco, who carries his oxygen for him. I want you to consider this. If parents are worried that if their children drops below a certain percentage of tube feeding that, because the child will lose waiver and then the child will lose Medicaid coverage, you're incentivizing parents to not provide the care that their children need. And that doesn't make any sense. It doesn't make sense in Nebraska. In addition, the waiver provides respite and child care to families who care for their medically fragile child. I can't drop Logan off at daycare, I can't drop him off at the Y. I need somebody who's a nurse, who is trained to recognize the symptoms and signs of his diagnosis so that we don't lose him. This is literally life or death. Parents-- that respite and child care also provides care for me to be able to work, for my husband be able to work. It is beneficial to the state for us to work because private insurance is primary over Medicaid. In addition, you want people who are medically fragile children's parents to work in your state. We are resourceful, we are determined, and we do not take no for an answer because our children's lives depend on it. And you want those people in your work force. We are expert task managers, we get things done. And we're not talking about juggling beanbags, we're talking about the flaming swords that we're throwing high up in the air and managing to balance. Our kids are incredible, and the better our kids do today the reality is, is that some of our kids aren't going to get better. And we know that. But we're going to give them the best life that we can for as long as we can because we're not guaranteed any additional time with them. And because of that I ask you to consider that the care that we give our children today will decrease the level of their needs later. And it will cost the state less later when they turn 19. And one more thing, I know that the red light is on. This is this is sort of like a carefully balanced Jenga game for parents. And when you take away the waiver program you're not removing one brick, you're not moving one little block, you're moving the table on which we are balancing our children's health. And I ask you to please find a way to help us to be good parents to our children because Nebraska needs kids like ours.

HOWARD: Thank you. Are there questions? Senator Cavanaugh.

CAVANAUGH: Thank you for being here and for sharing Logan's story with us. Did I hear you correctly that the daily injection costs $50,000 to $60,000 a day?

MELANIE KIRK: So the way that this works, it depends on the month. When we get our statement from our primary insurance the same medication can be listed as costing between $50,000 a day down to $5,000 a day. There is no rhyme or reason to it. But what it generally comes out to is about $3 million a year if we didn't have insurance.

CAVANAUGH: OK. And what would happen to Logan if he couldn't receive that?

MELANIE KIRK: So Logan would stop growing without this medication. And growth is not just height, we're talking about lung progress as well. And without that lung progress and new tissue Logan will struggle and Logan will eventually die.

CAVANAUGH: Thank you very much.

HOWARD: Any other questions? Seeing none, thank you for your testimony today. Our next testifier? Good afternoon.

BRIDGET ASCHOFF: Good afternoon. My name is Bridget Aschoff, B-r-i-d-g-e-t A-s-c-h-o-f-f. Thank you so much for the opportunity to share with you today. My name is Bridget Aschoff and I'm already crying.

HOWARD: That's what they're there for.

BRIDGET ASCHOFF: I am a mother of three children, one who was born with a neurological and developmental disability and is medically complex. Our daughter Claire was born with a neurological disability, agenesis of the corpus callosum or ACC. From the day we found out about Claire's disability her medical needs and costs have caused our family significant financial strain. Her first year of life was mostly doctors' appointments, specialists, and having therapy after therapy for her. We still revolve a lot of our schedule around Claire's appointments. I had previously been a teacher but ended up having to leave the profession and find a different career that allowed me more flexibility so I could better meet Claire's medical needs. We had applied for Medicaid twice when Claire was an infant but were denied due to income. In December of 2017 she was diagnosed with Dandy-Walker syndrome. Her medical team was floored that she wasn't already receiving services through Medicaid and encouraged us to reapply for the A&D Waiver since she was getting older. So we did. Initially we were denied, but after threatening to appeal she was approved and we began receiving assistance in March of 2018. Being on the A&D Waiver had a tremendous positive impact on our family. For the first time in three and a half years we could finally breathe. Not having medical bills piling up one after the other on our kitchen table as we tried to figure out which ones to pay for and still have enough money budgeted for child care, groceries, utilities, and other daily needs. I vividly remember the time our oven broke and we waited six months to buy a new one so that we could continue to pay for Claire's medical expenses and slowly put away to purchase a new oven. With the supports from the waiver Claire was able to attend weekly PTOT and speech which her medical team deemed necessary and critical for her growth and development. Because of the waiver we didn't have to worry about our financial limitations or limitations on the number of visits enforced by our primary insurance. Over the past year we have seen tremendous growth in Claire due to her consistent work and therapy. Her biggest accomplishment this last year was learning how to walk. Ironically enough this was the same skill that was used against her in requalifying for A&D Waiver services with the new eligibility criteria. The waiver provided respite services so that my husband and I could get some reprieve from the taxing day in and day out demands of caring for a child with a disability. This time away has strengthened and revived our marriage. Another huge impact the waiver had on our family is Claire was able to have repeat brain MRI and genetic testing done. We would not have been able to afford this on our own. Her genetic testing found that she has a gene mutation on the TEAD1 gene which they suspect caused her ACC. Her gene mutation is so rare that it is the second person in the world to have this diagnosis. Not having the waiver is devastating for Claire and our family. Claire is funny, sassy, and has a way of captivating the hearts of everyone she meets. She loves to watch cartoons, build with blocks, and play with puzzles. Her disability does not define her but it certainly has a huge impact on her life. Her disability affects her ability to walk and talk. It affects her stamina, balance, and endurance. She cannot dress herself, take her shoes off or on, or use the toilet. She's mostly nonverbal, only being capable of expressing one word commands from a handful of words she knows. Her disability affects her brain's ability to process, understand emotion, and without the verbal ability to communicate she's often frustrated and this frustration turns into self-harming behaviors and harming others as well. While Claire is well behind her typically developing peers right now it doesn't mean she can't obtain the skills to achieve those milestones. But these are only attainable for her through the intense and consistent therapies and routine visits with her medical team. Without the support from the waiver there is nowhere else for our family to turn for help from the state. We have looked into every other option the state provides and Claire does not qualify for any of them. Our only other option is the DD waiver whose waitlist is six to seven years. Those are critical development years for Claire. She cannot afford to go without help for almost a decade. Without the waiver Claire will fall farther behind her peers making the gap between what she can achieve and what she will achieve shrinking at an alarming rate. We're now back to where we were nearly five years ago, uncertain of what the future holds for our daughter and under great financial strain as we try to provide the best life for Claire and her siblings. Many in our community who live with disabilities whether physical, neurological, or behavioral are slipping through the cracks because they don't fit perfectly into the set of criteria our state has created. They're being stripped of their dignity and the ability to achieve their full potential by being denied access to state support. Studies show that early intervention is critical in setting children up for success later in life. Our children with disabilities deserve access to those supports so they can gain skills that will help them obtain jobs, live independently, and lead full, happy lives. With all of the things that our state can afford and chooses to spend money on our children, all children should be a top priority.

HOWARD: Thank you. Are there questions? Senator Walz.

WALZ: I just wanted to make sure I heard this right. Ironically enough this was the same skull that was used against her in requalifying for-- OK. And it looks to me she was not walking independently though.

BRIDGET ASCHOFF: So she started walking end of December and she had her reevaluation at the beginning of January and she could take a few independent steps.

WALZ: Thank you. Thanks for coming today. Thanks for your story.

HOWARD: Senator Cavanaugh.

CAVANAUGH: Thank you so much for coming today. How many steps is a few independent steps?

BRIDGET ASCHOFF: I think at the time she could do between like five to seven.

CAVANAUGH: Because my 14-month-old is doing about that.

BRIDGET ASCHOFF: Yes, she worked very hard.

CAVANAUGH: Yeah.

BRIDGET ASCHOFF: Three and a half is a long time to wait to learn that skill.

CAVANAUGH: And I think what Senator Walz was saying in this picture it looks like she has sort of a little walker.

BRIDGET ASCHOFF: Yes, yes. That's what she used when she was starting to get more stable to, to help her legs learn and her brain without, you know, having some of that stability.

CAVANAUGH: Thank you for sharing Claire's story.

BRIDGET ASCHOFF: Yes.

CAVANAUGH: Thank you.

HOWARD: Any other questions? Seeing none, thank you for your testimony.

BRIDGET ASCHOFF: Thank you.

HOWARD: Our next testifier?

SUSAN SAMUELSON: Thank you. My name is Susan Samuelson, S-u-s-a-n S-a-m-u-e-l-s-o-n. I'll try to make this through without crying also. I represent children in Nebraska with Duchenne muscular dystrophy. I am affiliated with an organization called Parent Project Muscular Dystrophy. My grandson has Duchenne. My grandson is not on the waiver, he's been denied the waiver even with the initial assessments. And now it would be even more difficult. However, there are a number of children currently who are, have been threatened to be taken off of the waiver now who also have Duchenne. And I think we are a state that deserves to give our children better and more. We call ourselves the "good life," "Nebraska strong," "Nebraska knife-- nice." We say "it's not for everybody." I've lived here all my life, I've paid my taxes. My children, Hunter's parents, pay their taxes. My husband has lived here, paid his taxes. We never in a million years thought we would be asking for any type of financial assistance. Quite frankly, we've educated and told our children be independent and don't expect help. And we're in a dire situation along with the other families with Duchenne now, because Duchenne is a progressive degenerative muscle disease. It is life ending. Parents, and if any of you are familiar, can remember when Jerry Lewis did the telethon, these are the boys. These are the boys we're talking about. So I guess what I would just simply say to you as a state and as a health and human services organization and representatives of the people of Nebraska, nobody here came here wanting to ask for help. None of us want to have to get help. But when you are dealing with these types of medical issues there is just no help, as everybody else has already explained. My daughter and her husband have a $6,000 deductible, a $12,000 out of pocket and, although theirs would be the primary and Medicaid secondary, my husband and I have taken to doing a fireworks stand to raise money to keep them out of bankruptcy because they're so busy caring for their son. As they should be. So I just very simply want to say to you: Take care of the children, take care of the people of the state. We love the state, we want to be here. It's not something we can just pick up and move from. But please take care of these children. And you are the only ones who can do this. You're the only ones who can impact and make the change. We can vote but that's all we get. You are the ones right here that can make the change for these families and children. We're desperate. That's all I have.

HOWARD: Thank you. Are there questions? Seeing none, how, how many other people are wishing to testify? A show of hands. OK. We're going to take a five-minute break and then we'll come back, OK?

[BREAK]

HOWARD: --reconvene. We would welcome our next testifier. Good afternoon. Thank you for waiting for our break.

PEGGY STONE: Sure. Are we ready to roll?

HOWARD: Sherry, are we ready to roll? OK, yes we are. And we would ask that any private conversations take them outside so that we can hear the testifier.

WILLIAMS: Folks, we're having trouble hearing up here. Can we have everybody take your seats and be quiet so the Chairman can start our hearing?

HOWARD: Go ahead.

PEGGY STONE: Hi. My name is Peggy stone, P-e-g-g-y S-t-o-n-e. And I, too, am originally from Nebraska, although my husband is from Illinois. We are a family of four. We have two children, a typically developing 11-year-old daughter and a son who is 8. Our son Paul had many medical, physical, and mental difficulties since birth. He was diagnosed at 18 months with autism and we began early intervention therapies almost immediately. He attended Munroe-Meyer's behavioral intervention program at 24 months old. He then transition to ABA therapy with them for three years. He attended stones were stepping speech program and learned some basic baby sign language. Through these therapies my son learned how to communicate. He also learned how to use his memory to recite single words when asked important questions. He is still considered nonverbal even though he can provide consistent answers to questions like: What is your name? What is your last name? Where do you live? Questions like how old are you need to be relearned and retrained every single year. He just turned 8 in June and we are still working on this. He also does not know how to answer open-ended questions or even multiple choice. If there are choices in the question, in the question then he will respond with whatever word was said last. For example, would you like peas or corn? His response: corn. You rephrase that, you say would you like corn or peas? Peas. This often happens with yes or no questions as well. He doesn't always mean what he says. He tends to hold onto the last spoken word. With medical professionals we tell them to avoid saying negative phrases like: This doesn't hurt? Because Paul will only focus on the word hurt. Paul needs assistance with every aspect of living. If left to his own devices he would jeopardize his own safety. He needs constant supervision and/or a controlled environment. Essentially our home is still baby-proofed. He is 8. We require alarms on our home because he has eloped, and we can't risk that happening again. He does not have the intellectual capacity to know to watch for cars or not to cross a busy street or not to go with strangers or how to speak up if he gets lost or how to get home if he has wandered off. We continue to hear, hearing from every speech pathologist and all of his therapists that although Paul was autistic he was unlike any other child they had worked with before. Which led us to believe that there is still more medically going on with our son. We confirmed our suspicions with our school district psychologist who diagnosed Paul with an intellectual disability at age 6. We also sought out genetic testing, which we would not have been able to do without the Aged and Disabled Waiver Medicaid supplement. Genetics has since recommended to get further testing with neurology based on an LAMB1 gene mutation which affects the brain and can lead to many other debilitating disorders. We need an avenue to Medicaid to get these tests complete. We need therapies and medical rehabilitation to treat what we find. We had Paul on a waitlist for Radical Minds for more ABA therapy when in January of

2019 he was eliminated from the Aged and Disabled Waiver program. Not more than a week from being eliminated we received a phone call that placement had become available. We had to decline the opportunity for services. We have a child who has a disability within his brain. And just because this organ is not visible does not mean that there is not a problem with it. Children suffering from heart, lung, or kidney problems do not face this type of scrutiny. Since when was it more of a disability to have a problem with these organs versus the brain, which essentially controls the entire body? We are interested in finding the guidelines that determine the inability to hear is worse than the inability to speak. These are issues with the regulation criteria. Determine-- determinations are made based on incomplete understanding and on a set of rules which do not apply. My son is disabled. My son has never communicated a spontaneous thought or had a meaningful verbal conversation with anyone. And he is 8. Here's where it gets hard, sorry. My son doesn't understand that in July his dad was diagnosed with cancer. We are not immune to other life's problems. My husband has been in the hospital for 44 days. My son has not seen his dad in that amount of time because it is too much of a risk to bring my 8-year-old to the hospital to see his dad. My husband is our sole income provider who is now fighting for his life and I am still here fighting for my son. We need respite services now more than ever the past two months and they were removed with the A&D Waiver in January. We could use the option of having reliable child care now, with the possibility of me having to return to a full-time career. I have been a stay-at-home mom and only began working part-time for the school the past two years so that I could care for Paul before and after school and on all school breaks including summer. Now that our financial outlook is much different, we need to consider all options. Should my husband be permanently disabled or die as a result of his disease I will be left caring for a teenage son who most certainly will outgrow me and outpower me. These are the scenarios that play out in my mind where I begin to wonder what great institutions might be available. I just want to reiterate that the Aged and Disabled program means a world of differences to families like mine. With it we can make progress on so many levels. I want to raise my son. However, he needs help, and that is why I am here. In order to achieve these goals the Aged and Disabled Waiver regulations must become less restrictive and they need to be nondiscriminatory based on age or disability. Thank you for considering the changes in order to help children like Paul.

HOWARD: Thank you. Are there questions? Seeing none, thank you for your testimony today.

PEGGY STONE: Thank you.

HOWARD: Our next testifier? Maddy, do you want to move the chair?

LISA O'CONNELL: Lisa O'Connell, L-i-s-a O-'-C-o-n-n-e-l-l. I'm from Fremont. I am a volunteer who has been at Unique Disability Support for like three years. I am a tremendous help with the community. Everybody comes to me for a lot of support. I do have two kids that are disabled. They have ADHD, they're autistic. My oldest son is reverting backwards now instead of moving forward. He is in the transition program now because he's 22. My youngest son, he almost didn't make it when he was born. He ended up having to have chest tubes and he was having seizures and everything. And he had to go and learn how to feed again, he had to, he had to learn all these milestones. And I agree with every parent that's been up here. And I would say this, basically like this, the system is broken on almost everything. I have somebody that I'm working with right now, she has a little girl that has a chromosome that has been missing when she was born. It was only two cases, hers and another one, in the world and the other one passed away. She is the only one that's living. She wasn't supposed to survive. She's 11, but she is nonverbal, she has got a feeding tube. And she, the mom, was an RN working really great jobs. She cannot work anymore, there's no support from her. She's a single parent. The respite care system stinks. It is nothing like when my kids were having respite care. I got 734 hours for each kid. Now it's like you get $190-something and you have to call out like three hours away just to be able to contact to get respite care. And for the waivers I would say, like, even the chore services it is horrible when somebody else is in the home taking care of this person but can't apply to be a caregiver and get paid because they live in the same household. I have even went through that. I have somebody that lives with me and they're my kid, they've been helping me out, can't get paid because we're in the same household. So something needs to be done with this. There's so many people falling through the cracks. I mean, take an example like for me with when I have my two kids with social security and everything. Yeah, because they had to pay a portion to the rent and the whole nine yards. Now I am, just my income alone, I am in the poverty level, way under. So just trying to, I mean, I have-- just navigating the system and everything is horrendous. I have so many people come in and they're like at their wits end. Like my younger son, he has type 1 diabetes. I went for a whole year without insurance going through a divorce and then they were going to take away my, I mean, his insurance and stuff. And I went to DHHS, the other lady that was sitting beside her, I asked for her to get stuff going because that's how I am. I said the workers, I'm like-- they couldn't understand stuff. And that's one of the other big complaints, there needs to be more training with these workers in DHHS that make-- you call somebody up, they don't-- one gives you one answer, somebody will give you a totally different answer. Nobody knows the right answers. There may be a few good ones. The one that I worked with when I asked for a supervisor she said to me: I am so glad you asked for one because it was getting too difficult for me to even understand. So, I mean, I am one that I do. I fight, I push, I have with the school systems. Fremont, I was fighting at the end of the school year for my older one to go into the transitional program. What they did is like, oh, he can make a hot dog, he can live on his own. I said uh-uh. I said let's reverse the roles. And I don't know how many that know or experience any family members or anything with disabilities, but I think everybody needs to get some training to really understand. If you don't live the role, you really don't know what you're talking about. If you're trying to understand stuff, you need to get training and listen to people that actually have kids and all these different diagnosis. Go get some background information on it. Try to get like, you know, I got a hereditary bone condition that my kids got, and it's very rare too. And it should have skipped generations but it didn't, and that's where they get the autism and all this stuff on it. So, I mean, it's like anybody ask me questions on it, I'm fine of educating people. So but within the agency I do support groups, I teach parenting, I'm a board member. So I'm just a go-getter I guess.

HOWARD: That's wonderful. All right, are there any questions from the committee? Seeing none, thanks for all you do.

LISA O'CONNELL: Thank you. Yeah.

HOWARD: All right, our next testifier? Good afternoon.

SHONDA KNOP: Good afternoon, senators. My name is Shonda, S-h-o-n-d-a, last name is K-n-o-p. I am a constituent from Fremont. I see Doctor-- or Senator Walz. My son Jacoby is known around Fremont. He has these big brown eyes and he's in a wheelchair and he's funny and he loves pizza. Now he's 12 so we're talking about don't smile for girls, that whole thing. It's kind of mind-blowing to me, I just have to say this, that people are getting kicked off the waiver for their kids walking, but my kid is wheelchair-bound and can't be on the waiver. Like can we-- just a little strange. I'm just pointing it out. We found out Jacoby was going to have spina bifida at 20 weeks gestation. We were given the options and we decided he's worth everything, and he still is. He reminds us every day about great love and just having a good life. He every day is a blessing. He was born with his spinal cord outside of his back, was born at 35 weeks. Spent two weeks in the NICU and, honestly, he has been doing great. He's wheelchair-bound but he loves to play basketball, he likes Pokemon cards. It doesn't let that-- it doesn't stop him from being a normal kid. My husband and I work full-time jobs. We're bachelor's prepared. I'm in grad school and I actually work a second part-time job. So we are all in 100 percent working parents, middle class, have two other kids that we have to think about as well. Jacoby has spina bifida, which I say is like the turkey of Thanksgiving dinner and then he has all these diagnoses. So in that pamphlet you get there is our cost of his cast supplies monthly costs, as well as all of his medical diagnoses. You look at that kid and you think, he's funny, he's great. But he is medically complex and medically expensive. We pay $1,000 a month for his trileptal which is his epilepsy medication. We pay three grand a month to keep his kidneys going, to keep him off of dialysis, to keep him from having to get a kidney transplant. And there is-- if he, because of his complex medical condition, if he would ever need to get a kidney transplant, depending on who we could find as donors he might, he would not be able to go on the donor list because he would be at risk for multiple. In his 12 years of life he's overcome so much and he finds joy every day. When we talk about his long-term goals, as parents we aspire and we hope that he's going to be happy and healthy. And I think anyone who has a kid thinks the same thing. But to say that we sit here and we work and that we have to pay for our kid to go to the bathroom, $3,000 a month for my kids to go to the bathroom and everyone else's kid can just go. And if he doesn't go, he gets renal failure. If he gets renal failure, he goes on dialysis. He can't go to class, he can't go to school. Nothing. It could mean death for him. We have primary insurance that covers it, but what the A&D Waiver program does help pick up means that, yes, we'll meet our deductible by May because of all of his medications and doctor's appointments and braces and wheelchairs, but we're not having to decide between pain his catheter supplies to keep him alive, to divorce-- which we've honestly talked about. This is an option for us. If I could divorce my husband we could make an agreement and I would be able to get assistance for my kid. And it's really putting us in a tough situation. As parents, we should all aspire for our kids to be the best. But in order to do that for some of us it's harder than others. It's not just going over homework at night, it's "cathing," it's medical equipment, it's PT, it's OT, it's speech, it's seeing neurologists, it's going to counseling. Jacoby was in the hospital for 150 days already this year. I was a single mom at the med center with him and my husband was taking care of two kids at home. And when that first EOP hit and we saw that his stem cells that he needed were $12,000 for a minute of getting them infused-- $12,000 a minute and had to have four treatments-- that's not something that I don't think any of us could say we could just afford. And then when the total cost is over a million dollars, take my house, take my cars. Luckily we don't have to do that because the A&D Waiver program. But it puts the fear in us what happens next time. What happens? Do we sell our house, do we give everything up? You're putting, you're putting us on rocky ground. I think what is happening is minimizing disability, and that's atrocious. So you have kids who can walk but can't eat on their own, but that's not disabled enough. You have a kid who can't go to the bathroom on his own. Can't walk, has never walked, has never felt the grass underneath his feet. And we worry about him having a seizure at night and passing away in his sleep, but he's not disabled enough either. Our caseworker has been very honest, he's not a number six on this stupid scale that they use. How can you give a kid a number?

That's their value? They're a three so they're not worth it? But, hey, you're six, you're worth it. I am sitting here begging you as a mom, as a nurse, and as a human to please help our families. Please support families with kids that are amazing and we're just working hard to give them everything you'd want your kids: health and happiness. And ask your fellow senators who are against changing this and helping these programs, ask the Department of Health and Human Services how much are your kids' legs worth? How much are their kidneys? How much is it for them to go to school versus being hooked up to a dialysis machine? Because that value is what we see in our kids. Our kids are worth everything, the same as your kids. But we are asking and pleading for help so that we can continue to give this to them.

HOWARD: Thank you. Are there questions? Seeing none, thank you for your testimony today.

SHONDA KNOP: Thank you for your time.

HOWARD: Our next testifier? Good afternoon.

JENNIFER HANSEN: Good afternoon. Jennifer Hansen, J-e-n-n-i-f-e-r, Hansen, H-a-n-s-e-n. Hello, my name is Jennifer Hansen, and I am here to implore you to take action on this calculated lack of supports for families of children with disabilities in Nebraska due in part to the changes in the criteria to the Aged and Disabled Waiver program. I am the mother of three children, my middle daughter has a rare genetic syndrome. My unique, beautiful, and loving 9-year-old daughter has a killer sense of humor but this syndrome has resulted in significant impacts for my daughter and my family. I could get up here and tell you about the impact this has had on her, about how she has endured and her nine years more testing and biopsies and hours of therapy and scopes than most of us adults can even imagine. How she just started walking at the age of seven and still is unable to do it independently. How she wasn't able to go with her class on their first three field trips because of her physical limitations and her behaviors. I could tell you about how extensive her needs are and how there have been times recently when I thought to myself: I don't know how much longer I can do this physically. I can tell you how she is still wearing a diaper that costs over $350 a month and is only available through a pharmacy. How she's able to crawl up and down-- up the stairs but she's unable to go down, so I am left carrying my 70-pound 9-year-old daughter down the two flights of stairs in our home several times a day. About how she requires total dependence on caregivers for these tasks as well as most other activities of daily living. I could talk to you about the impact on our family, how quickly the other two children had to grow up and deal with things that most adults couldn't handle. How my 5-year-old has grown into the role of a caretaker to his 9-year-old sister, about how our 12-year-old has matured far beyond her years by seeing our daughter go through very hard situations. About how we have left her extended family to move to enough hours away to move closer to the services that our daughter needed for a better quality of life. About how that move meant that we were in a situation with no family around and no support systems. About how my husband now has to commute to work two and a half hours one way every day. How this means my husband goes days without seeing his children and his children going days wondering if daddy will be home today, because he leaves for work at 3:00 a.m. and returns after bedtime in order for our daughter to have access to the things that she needs. I could share a story about how prior to our daughter qualifying for the A&D Waiver we were struggling financially with the costs of all the doctors' appointments. And how it became apparent very early on in my daughter's life that I would not be able to continue to work full-time due to our inability to acquire adequate child care and juggle my work schedule with her appointments. How the mounting medical bills, coupled with the decrease in my income, put us in a spot where we had to make decisions to sell our home, to downsize, to sell our vehicle, to downgrade in order to continue to provide for our daughter. And we were one of the lucky ones with good health insurance. I could talk for hours about how disability has affected my life and my children and my marriage. However, if you take anything away from my testimony please let it be that this is not just my family's story. This is the experience of hundreds of Nebraska families. This system has failed and we are now responsible for changing the way disability is addressed in our state.

We cannot support a department that knowingly pulls the rug out from all of these families found ineligible for supports and services that they depend on. We cannot stand silently by any longer while the systems are purposefully setup in a way to restrict access to the lifelines for Nebraska families. Thank you.

HOWARD: Thank you. Are there questions? Seeing none, thank you for your testimony today. Our next testifier?

MANDI REINDERS: Hi, thank you. My name is Mandi Reinders, M-a-n-d-i, Reinders, R-e-i-n-d-e-r-s. I just want to tell my son's story. Despite everything that he's been through, I consider Jojo the luckiest kid alive. He was born extremely early, under a pound. We were told he was incompatible with life. Our family planned his funeral. Hours and days passed. He persisted, so we persisted. On the day we were told he may see home, but most likely would not walk or talk or have a quality of life, that was the day I looked at the doctor and determined that was my child. He is not a number, he is not a statistic. From that point on we had a mission. We had a dream, we had goals. And our family has always prided itself on being self-sufficient. However, to achieve these goals it takes much more than our family can provide on its own. Private insurance is not the solution for our kids. Most private insurance have high deductibles, restrictive caps on therapies, refuses to cover formula and other specialized care needed by children with disabilities. We have decent private health insurance but it does not cover everything that Jojo needs to stay-- sustain life and grow intellectually. At times my son has had five separate therapies a week between feeding therapy, speech therapy, occupational therapy, physical therapy, and behavioral therapy. He can, he currently still consumes up to five cans of formula a day to maintain his weight and survive. He has spent five years at a specialized daycare paid by the A&D Waiver as there is no other daycares equipped to handle his need and medical issues. Children with special needs are not only financially expensive but they can cause a large emotional stress that no family expects. Let me clarify. Without the, without Medicaid Jojo's formula is about $700, $700 a month. Specialized daycare up to $1,400 a month. The 140 visits a year that is not covered by private insurance at $200 apiece. Other medical equipment and medicine that equals about $300 a month. That does not count all the money spent on baby gates, locks for every door and cabinet, the endless amounts of special lunchboxes, weighted vests, noise-canceling headphones not covered by any Medicaid or insurance. For safety he can't be left alone for even a moment. Without respite through the waiver I would never be able to turn my other children's activities. And the burnout of parenting special needs children is a very real thing that all families feel. Without the waiver our family has very few options to push Jojo to his true potential. One parent would be forced to quit their job to provide care for him, causing the whole family to become dependent on food stamps, Medicaid assistance, putting the burden on the state and taxpayers. The second option would be move to Iowa where we can pay $40 a month for all four of my children to receive Medicaid. That's not a choice a family should be put into. For this child that we once planned a funeral he has now started kindergarten this year. He's doing amazing. My beautiful son that was nonverbal at two and a half has graduated speech therapy. A child that wasn't supposed to run now plays soccer. He would never have reached these things without supports and services. To clarify, my son did qualify again this year because he lost weight and had multiple infections last year. But he will not meet-- and we had a great service coordinator, I should add that. Because our service coordinator was one of the few amazing people that we met through DHHS. He will not meet again in January if, because he's doing well medically. But his future should not hinge on hospitalizations or have to watch my son fail in order to get him services so he can succeed in the long run. He's incredibly lucky to overcome everything he has and seen the-- and see the amazing progress he has seen. But I also know that without Medicaid he would never have had these gains. And Medicaid covers therapies beyond what our major medical insurance will not cover along with copays, assistance with high deductibles. I'm kind of appalled that these changes were made without a plan to help families-- without a plan to help in place for these kids. By changing the qualifications for assistance which covers amounts that exceed major medical and high deductibles both parents could continue to work, provide for their special family, lessening the burden on the state and taxpayer, taxpayers. But thank you for listening and hearing Jojo's story.

HOWARD: Thank you. Are there questions? Seeing none, thank you for your testimony today. Our next testifier?

SIMON WOOD: Good afternoon. Simon Wood, S-i-m-o-n W-o-o-d. Appreciate the opportunity. By this point in the afternoon most of what I would say has been more than adequately covered by what other people have said. But I'll just make a few brief comments. I'm the father of Gavan Keown-Wood, five, one of the children from whom support has been removed. His eligibility renewal came up after the new eligibility promulgation requirements. As it happens, shortly after that his BMI was measured and it was low enough that he would have qualified for disability on the basis of his BMI alone. So that was a little ironic. And I should have added also that he, as well as losing Medicaid, he was stripped of his disability status. He can't eat. He's dependent on a feeding tube which provides him with the vast, vast majority of his food. If I had to guess, I would say 98, 99 percent. He's 5 years old and he doesn't eat candy? Right. Show me a 5-year-old, healthy 5-year-old who doesn't eat candy. That's a disability. Would anyone here think that being unable to eat is not a disability? That's a rhetorical question. Before Gavan had a feeding tube he was malnourished. Moderately to severely malnourished, the medical terminology, and at 18 months was the size of a child several months younger. He was literally not on the curve, not on the growth curve, those little things that you get at the doctor's office. Now, his mother has already related the story of his hospitalization, so I won't repeat that. I saw in the instructions not to repeat previous testimony. The point in relating these details is to emphasize that Gavan is disabled. He cannot live in any kind of normal way without a feeding tube and our pitch is really pretty straightforward. As a disabled person he is and should be eligible for whatever services the state supplies, provides to disabled people. So our question is not why should the state provide support, but why shouldn't it? Supporting disabled children, to our understanding, is a function of the state. That's part of what states do if they're good states. And I very much appreciate, it's clear to me from the line of questioning I've heard from your panel that you appreciate that and you're taking it seriously and you're, you're working hard to achieve that. And I think we appreciate the accountability that's being shown. But I would want to add to that also that parents are accountable and accountability applies to me it seems to state bureaucracy, state officials as much as it applies to state representatives. If you work for the state of Nebraska, who do you work for? Now we're asking how does it benefit the people in the state that represents them to remove support from Gavan and other disabled children? We have not seen the people who have implemented or defended the change that has adversely affected our children offering a persuasive or consistent explanation for why that change happened. One official has said on record it was done to save money, and has said also on record that the change had nothing to do with saving money. So I think that puts the question fair enough for us to ask so, so which is it? If the change was made to save money, I think it's more than evident from everything that's being said today that that's not the case. Events have shown that whatever savings accrued from that change have not been worth it. If the change was made for some other reason, we haven't heard what it is. Whatever benefit of that change is it's more than outweighed, we're suggesting, by the costs and harm to our children. So far as I understand you in the Legislature have the ability to do something about that change that happened and take action to ensure that our children receive the support that they need. That's my testimony.

HOWARD: Are there questions? Seeing none, thank you for your testimony today. Is anyone else wishing to testify for LR105? Seeing none, I will waive closing, and this will close the hearing for LR105 and conclude our hearings for the day.