

Transcript Prepared by Clerk of the Legislature Transcribers Office
Health and Human Services Committee December 3, 2021
Rough Draft

ARCH: Well, good morning. Welcome to the Health and Human Services Committee. My name is John Arch. I represent the 14th Legislative District in Sarpy County. I serve as Chair of the HHS Committee and I like to invite the members of the committee that are here presently, and we'll have at least another one joining us here, introduce themselves starting on my left with Senator Cavanaugh,

M. CAVANAUGH: Senator Machaela Cavanaugh, District 6, west central Omaha.

WILLIAMS: Matt Williams from Gothenburg, Legislative District 36.

ARCH: From Gothen-- well, Gretna, right? Is that--

WILLIAMS: It starts with a G.

ARCH: OK, starts with a-- OK. Also assisting the committee is one of our legal counsels, T.J. O'Neill, our committee clerk, Geri Williams, and our committee pages, Kate and Natalie. A few notes about our policies and procedures. Just a reminder, please turn off or silence your cell phones. This morning, we'll be hearing one interim study resolution, and we'll be taking it in the order listed, of one. The hearing, LR 239, will begin with an opening statement. And after the opening statement, we will hear from a number of invited testifiers; and I may close at the end of the hearing. For those of you who are planning to testify, you will find green testifier sheets on the table near the entrance of the hearing room. Please fill one out, hand it to one of the pages when you come up to testify, and this will help us keep an accurate record of the hearing. We use a light system for testifying. Each testifier, with the exception of Director Green, will have five minutes to testify. And when you begin, the light will be green. When the light turns yellow, that means you have one minute left. And when the light turns red, it is time to end your testimony. We'll ask you to wrap up your final thoughts, but there certainly could be questions following your testimony. 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. And there are a few reasons we wanted to hold this interim study. Last year we advanced LB376 out of committee, which would have created a family support waiver. When it came out to the floor, numerous points were brought up on Select File that made it apparent we needed to understand the population on the waiting list a bit better than we did at that time. So it is my hope that with the testifiers we have today

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we'll be given a better understanding of our current waivers, the populations affected, and what could be done to help serve Nebraskans better. Senators that will be present here are welcome to ask questions for clarify-- clarification at any time. We're going to have periodic breaks. I know Director Green is going to do his presentation as more of a-- as more of a dialogue with the senators and appreciate that flexibility. So there is no bill to consider today. Today's hearing is truly intended to educate. So with that, we invite Director Green to come up and provide his testimony first. Good morning.

TONY GREEN: Good morning, Chairperson Arch and members of the Health and Human Services Committee. My name is Tony Green, T-o-n-y G-r-e-e-n, and I am the director for the Division of Developmental Disabilities within the Department of Health and Human Services. Happy to be here today to provide testimony on LR239, which provided the interim study on the effectiveness of Medicaid waivers in Nebraska. And in order to gain a full understanding of our system, I thought it would be good to first start with an understanding of the eligibility criteria of what it takes to be eligible for the various waivers in Nebraska that are set forth in statute. Nebraska operates four separate home and community-based waivers: a traumatic brain injury waiver, an aged and disabled, developmental disability day, and a developmental disability comprehensive. So we'll first look at the traumatic brain injury waiver, and you have that on Slide 2 that the eligibility is based on being 18 to 64 years of age. A medical diagnosis of traumatic brain injury is also required, and you can see that on the definition there on the slide. Once the age requirement and medical diagnosis is present, you must then meet the level of care for nursing facility services, which I'll talk about in a moment. The second eligibility category we have for one of our waivers is the aged and disabled waiver. And for this category, you must first qualify under your age, being 65 years or over and-- or with a disability defined by Social Security or the Medicaid state review team. Once either or both of those criteria are met, you must then meet the required nursing facility level of care. So on Slide 4, as I've shared with the committee in previous annual division briefings that we do, we began using the-- a new statistically validated level of care tool, the InterRai. And so we have an InterRai HC and an InterRai PEDS. The HC is for our adults and the PEDS is for the children. Using this tool, we've been able to set the criteria for nursing home level of care. For children, you will see the criteria is set for two separate categories, those from birth to 47 months and then those from 48 months to 17 years.

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ARCH: Could I ask you a question? You might as well start the questions--

TONY GREEN: Sure,

ARCH: --right now. You use nursing home level of care. At times we've had discussions and we use the term intermediate level of care. Could you explain the difference between those two or if there is a difference?

TONY GREEN: Absolutely. So the aged and disabled waiver and the traumatic brain injury waiver are for folks who would qualify to live in a nursing home, and they have to meet that level of care. The two developmental disability waivers are for folks that would qualify to live in an intermediate care facility. And which would be-- an example of that would be the BSDC State Development Center. So the criteria and we'll kind of look at the criteria a little bit in the next few slides of what does it take to be nursing home eligible and intermediate care facility level. Nursing home, obviously, is a higher threshold involving medical conditions, nursing level type services that-- ICFs are a little bit different, but each has their own tools that are used to determine whether or not the needs qualify for that level of care.

ARCH: Thank you.

TONY GREEN: You're welcome. So on the-- on Slide 5, you'll have the adult nursing facility level of care, and you can see there that that can be met in any of four different ways that are described there on the slide. And there's variation of categories between activities of daily living, risk factors, and medical conditions. So any one of those criteria on the slide there will render you ineligible for nursing facility level of care as an adult. And then finally on Slide 6, you have the developmental disability waivers. Recipients for that waiver must meet the statutory definition having an intellectual or a developmental disability. This includes a likelihood that the disability will continue indefinitely and that it occurred prior to the age of 22 years. In addition, the waiver recipients must meet all three of the substantial functional limitations of social, practical, and conceptual that are laid out there for you. So I think that's always important to note that it's both components of the statute need to be present in order to be eligible for DD, the actual diagnosis of an intellectual or developmental disability, as well as the substantial functional limitations in all three of those areas.

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M. CAVANAUGH: Can I ask a question? So I know this is kind of going back to something that we've been dealing with for a few years now. So the A&D waiver and the DD waiver, the barrier to entry is different. The barrier to entry for the DD waiver is actually lower. Correct?

TONY GREEN: Um-hum.

M. CAVANAUGH: OK. So when we had that change in the rules for the A&D waiver and we had a lot of kiddos kicked off and then we moved them to the DD waiver, but now we have this big waitlist on the D-- for the DD waiver. Is there any possibility of changing some of the assessments for the A&D so that we can accommodate more people through that waiver? Does that question-- that was a long question.

TONY GREEN: No, that's OK. So I think you're saying could the requirements of level of care be lowered--

M. CAVANAUGH: Right.

TONY GREEN: --for the aged and disabled.

M. CAVANAUGH: For children.

TONY GREEN: So every state sets their own criteria of what qualifies to live in a nursing home. So I mean, the short answer would be the state could adopt that-- that. It becomes a question of what's the threshold that you want to have as a state to say, because these folks are eligible for the waiver, but that would also entitle them to live in a nursing home.

M. CAVANAUGH: So they--

TONY GREEN: --and so you have to balance, when do you want that--

M. CAVANAUGH: Sure.

TONY GREEN: --level of care to be met?

M. CAVANAUGH: But it previously was, and maybe I'm wrong in remembering this because it was a couple of years ago, but wasn't the level the same for adults and children? And then new rules were promulgated that created a higher threshold for children. And I'm just wondering if there's been any evaluation as to the efficacy of that move as far as it also put more to the waitlist on DD. And is there a possibility to reconsider or just adjust even the threshold?

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TONY GREEN: I think when we adopted-- so your-- your statement is accurate of what it looked like previously and then we did undergo with-- with our consultant evaluating all of the levels of cares. There was a significant amount of time that went into the validation when we switched from the old tool over to the new InterRai tools to ensure that we didn't have a new tool that would have a different level of screening criteria, meaning that it would be more restrictive or less restrictive. And so the transition of that tool went well. And we have implemented screening criterias with our registered nurses, for anybody that would be denied to take a secondary review of all denials before we would issue those on the aged and disabled waiver. And so I think the right, according to the way we've defined the criteria, the right folks are getting in and eligible for that waiver today--

M. CAVANAUGH: OK.

TONY GREEN: --that wasn't in the past.

M. CAVANAUGH: So you feel like it's working as it is.

TONY GREEN: Yes.

M. CAVANAUGH: OK, thank you.

TONY GREEN: You're welcome. OK, so then on Slide 7, just kind of then once you're eligible and this is specific for the developmental disabilities as we get into registry issues, so funding priorities for the department in Nebraska statute 83-1216 outlined the priority order in which persons who are eligible for specialized DD services are funded and there are six of those priorities. Priority one is that immediate crisis, which is defined as the category of caregiver death, homeless, or a person that poses a threat to the life and safety of themselves. Priority two are those folks that are currently in an institution, and institution is defined by CMS hospital, nursing home or intermediate care facility, who would like to transition out to community-based services. Priority three is for our kids turning 19 years of age who would be exiting the foster care system or the probation system and were unable to establish permanency or not have services or supports beyond that system. Priority four is for those youth that are transitioning out of the educational system at 21. So those are the folks that leave school at 21 and then generally transition into that day waiver. Priority five is the dependent of members of the armed forces. They still do have to meet the Nebraska

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eligibility criteria to qualify under that P5. And then all others by date of application becomes the-- the priority six. So we'll talk a little bit now about--

ARCH: Excuse me.

TONY GREEN: Oh, go ahead.

ARCH: I've got a question. So these are the-- these are the priorities. Can these priorities change with an individual? In other words, can-- can somebody move into an immediate crisis? And how would you know if somebody moved into an immediate crisis?

TONY GREEN: Absolutely. And they do move through-- within these-- these priorities. And so the notification is generally made to the service coordinator. You'll see later that there are some folks who, while they are on the registry, are also receiving active service coordination from the state, which is it is, you know, the engagement of a service coordinator every month. And so they have a connection already to the state that they would just relay that information. Our service coordinator would know that to begin the process of eligibility under P1.

ARCH: OK, so they could--

TONY GREEN: And then obviously, as they age and they hit 21, they'll move into that P4 category where before they were maybe just waiting under a P6 by date of application. So they do move depending on the dynamics of the family [INAUDIBLE].

ARCH: And so they just they let the care coordinator know that--

TONY GREEN: Yes.

ARCH: --things have changed.

TONY GREEN: Um-hum.

ARCH: OK. Thank you.

TONY GREEN: You're welcome. So on Slide 8, I'll move to the registry. If a person is determined DD eligible and the person does not qualify for funding under priorities one through five, they're maintained on a statutorily required registry by date of application. The term registry is used by the division as opposed to a waiting list as

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prescribed in statute. A registry also more accurately portrays the intent and the needs of the population, as we'll review momentarily. On Slide 9, LR239 seeks to study the individual factors of persons on the registry, including basic demographic data, so I've provided that for you there. You'll see data as of November 1. There are 2,866 persons eligible for specialized services from DHHS. Some of that breakdown includes at the center chart at the bottom there, 62 percent of those 2,800 are male; 38 percent are female. At the age chart up in the top left, you'll see if you added up all of the various age brackets that those zero to 18 years of age are 1,164 in total, which make up 41 percent of the individuals on the registry. And then 83 percent of all persons who are on the registry are Medicaid eligible and currently accessing state-funded services that I'll show you more in an upcoming slide. We do not track-- currently track income levels of persons on the registry or their parents' income if they are minor children. However, those with existing Medicaid eligibility are likely to qualify for waiver services under the income guidelines. And so that was one of the questions that you all had as far as the income within the resolution, and we do not track that, but you can make the inference in later slides that you'll see with the Medicaid status what that would break out to be.

ARCH: I may have missed this. Thanks for making this so simple. I may have missed this, but we are now talking about the developmental disability comprehensive. Correct?

TONY GREEN: Correct.

ARCH: Did-- did you talk about the developmental disability day? You mentioned there were four waivers.

TONY GREEN: Um-hum.

ARCH: There was the-- the traumatic brain injury, the aged and disabled, developmental disability day, and the developmental disability comprehensive.

TONY GREEN: Correct.

ARCH: We're talking now about the comprehensive.

TONY GREEN: This is the registry for folks for the comprehensive waiver.

ARCH: Correct.

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TONY GREEN: Yes.

ARCH: Correct. We didn't reference-- we didn't represent-- we didn't reference the date-- the day waiver. Is that a separate waiver?

TONY GREEN: It is a separate waiver, but there is only one registry for-- and everyone that's on the registry is on there, identified as wanting the comprehensive waiver.

ARCH: OK, so in that point, well, you're going to get to that I know.

TONY GREEN: Yeah.

ARCH: OK, thank you.

TONY GREEN: You're fine. So then registry, there's questions about the duration and movement of folks from the registry. Eligible applicants are placed on the registry by their date of application. Since statute identifies our six funding priority based on date of application, parents often apply early, even when services may not be needed. For example, on the registry today, there are 129 infants and toddlers aged five years and under. The youngest person currently on our registry is four months old. In current state fiscal year '22, the state adopted a budget that includes additional funding specifically for the registry. As a result of this funding, we're in the process of adding 500 slots to the DD comprehensive waiver. In state fiscal year '21 previously, DHHS made available an additional 200 slots on the DD comprehensive waiver. In August of 2020, there were 154 waiver offers made to persons on the registry; 100 of those offers were accepted; 54 were declined. So 35 percent of the folks who received a waiver offer in that first 100 slots that we were filling declined their offer for waiver services. Then in March of 2021, we had another 161 home and community-based waiver offers for folks on the DD comprehensive waiver again to fill another 100 spots. So 61 of those offers were denied, which again, that would be a 37 percent rate of folks that declined their offer for services when funding became available. So in total, filling those 200 slots on the DD comprehensive waiver reduced the registry by 315. Per 403 NAC 2-007(D) you see there, if a person is offered a DD comprehensive waiver and declines it, they are removed from the list of people waiting for the comprehensive waiver slots.

M. CAVANAUGH: So they declined because-- you said "decline" and it says "deny" here. They-- they declined to-- to take the waiver because meaning they're removed--

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TONY GREEN: They denied their offer, yeah.

M. CAVANAUGH: --and they-- because they no longer need it or--

TONY GREEN: Various reasons.

M. CAVANAUGH: OK.

TONY GREEN: So again, folks, as alluded to, come on the registry very early to get their place by date of application. And so much like situations will change that may move them in the priority status, there were other changes. So some of the folks when we reached out for funding offers had moved and they were no longer in Nebraska and just hadn't notified the department that they needed to be off of our registry. Others had gone on to be successful in the community. They had jobs. They were living at home. Parents were fine. They didn't want any services and declined the offer at that point.

M. CAVANAUGH: OK, thank you.

ARCH: Because-- because what is being declined is institutional care. Is that-- is that correct?

TONY GREEN: All of the folks on the registry, on the DD registry have met the criteria for institutional level of care.

ARCH: Right.

TONY GREEN: Or in simplistic terms, they all qualify for that level of care to receive services in an intermediate care facility. And so they are-- they have-- they are on the registry for waiver services in the community, and they declined that waiver offer.

ARCH: OK. OK. All right. Thank you.

TONY GREEN: So as far as reg--

WILLIAMS: Stupid question about that.

TONY GREEN: That's OK.

WILLIAMS: If you've got somebody that was there and they were, they did decline to take the service and then their circumstance at home changes again, where do they start back on the registry system?

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TONY GREEN: They would start back over by their new date of application.

WILLIAMS: By their new date of application.

TONY GREEN: Yes. And I can tell you, Senator, we have a-- a staff person that manages this registry as-- as their focal position responsibilities. And that is something we spend a significant amount of time explaining and making sure that people are truly making an informed choice if they're going to make that denial of the waiver offer and understand what that means. So as far as reducing the registry, as you can see on Slide 11, our applications for DD eligibility determinations have remained fairly stable since 2015. The newly eligible persons, the third column there in your chart with intellectual or developmental disabilities, averages of those numbers, they're about 480 per year. This means that there are about 480 persons entering the registry every year as new applicants. Registry reduction would require removals from the registry to exceed entries. Based on the historical figures, over 500 DD comprehensive waiver slots each year would need to be offered in order to reduce the registry population. Slide 12. I just wanted to point out as well and have a conversation that while almost all states have a registry or some-- something similar, we always need to be mindful of our obligations under the Olmstead ruling, Olmstead requires states to ensure that persons with disabilities receive services in the most integrated settings possible. Supreme Court rulings have identified that a state's compliance with the Americans with Disabilities Act integration mandate may be met by maintaining a list process that moves at a reasonable pace. Nebraska did submit its first Olmstead Plan to this body in December of 2019. An evaluation of those implementation efforts will be submitted as required by statute by December 15 of this month. Any questions on the impact of that?

M. CAVANAUGH: Looking forward to the report.

TONY GREEN: It's on its way. OK, so we'll take a look at Slide 13. So this is a-- I've tried to give you an illustration of what everyone on the registry is and show you that it truly is a registry of-- of people eligible for DD services. Moving left to right on that first blue bar, that represents individuals who are not receiving Medicaid or home and community-based services. This 500 folks does include 101 young adults, or 20.2 percent who are between the age of 19 and 21, who are in that transition age and in the process of applying for Medicaid now that they are adults. So we're really looking at 399

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folks in that 500 that do not have active Medicaid or any home and community-based services or supports.

ARCH: OK, stop there for a second.

TONY GREEN: OK.

ARCH: So is that because they do not qualify for Medicaid?

TONY GREEN: Correct.

ARCH: Is that-- is that 100 percent of that population they don't qualify for Medicaid income. And-- and if this was a child, we'd be at 200 percent of-- of FPL for qualification. So CHIP would kick in. I mean--

TONY GREEN: These are all children.

ARCH: All children.

TONY GREEN: Yes.

ARCH: OK.

TONY GREEN: Yes, I can. So all 500 of those are children and they are not eligible based, because prior to the waiver being offered, the Medicaid eligibility is contingent on the family income. And I can explain that here a little bit more. So those 399 families don't qualify. Again, there's 101 that are in process right now of getting Medicaid eligibility because they're transitioning as adults from school into the adult system. But that 399 families, they are all children under the age of 19. They do not qualify for Medicaid due to their families' exceeding the income guidelines. For example, a family of four with a ten-year-old child meeting the definition of developmentally disabled must have a Medicaid determined modified adjusted gross income, or MAGI, of less than \$2,938 per month. If the family's making more than this amount, then they would not qualify for Medicaid.

M. CAVANAUGH: Is that before or after taxes?

TONY GREEN: I don't think I know.

M. CAVANAUGH: OK.

TONY GREEN: I'm not the Medicaid eligibility expert.

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M. CAVANAUGH: And that's for a family of four.

TONY GREEN: For a family of four, yes,

TONY GREEN: They're not eligible, and that would be rounded up to 3,000 times 12.

TONY GREEN: \$2,938 would be \$35,256 annually.

M. CAVANAUGH: For a family of four to be ineligible.

TONY GREEN: Correct.

ARCH: Is that-- is that the 200 percent? Is that the CHIP level?

TONY GREEN: It is new-- new amount of-- with the expansion figures, yes.

M. CAVANAUGH: Holy smokes. Sorry.

TONY GREEN: So that's the-- the first bar is that 500 population or 399. The next column shows the number of persons in the registry who have active Medicaid as their only specialized service. This allows those 1,060 recipients to have their physical, behavioral, pharmaceutical, dental, and vision needs taken care of by Nebraska Medicaid. This group is comprised of 482 children and 578 adults. For those on Medicaid as their interim service while awaiting the DD waivers, Nebraska is spending a total of \$14,983,812 for this group here just in their Medicaid benefits. And you can see the-- the figures on the left-hand side in the yellow.

M. CAVANAUGH: Oh, sorry.

TONY GREEN: That's OK.

M. CAVANAUGH: So going back to the 339 or 399--

TONY GREEN: 90.

M. CAVANAUGH: --is that determined, that income eligibility determined at a federal level or a state level?

TONY GREEN: Again, I-- that would be Medicaid eligibility questions that--

M. CAVANAUGH: OK, I'm just--

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TONY GREEN: I'm not able to answer that for sure, but I can get that answer.

M. CAVANAUGH: I'm curious if we were to, if at the state level, if we were able to raise it so that the income eligibility was higher but not a million dollars, not just anyone, then that would be an interesting opportunity for us so.

TONY GREEN: Any questions on the Medicaid eligible of the 1,060? OK.

ARCH: I-- I guess I have a question. We were just looking up the CHIP eligibility, so, you know, above regular Medicaid, 213 percent FPL family of four, our numbers show \$4,700 per month. So maybe that's something we can have a discussion later for-- for the qualification of Medicaid eligibility.

TONY GREEN: Yeah, I think these figures are based on just regular Medicaid, not looking at the CHIP program.

ARCH: OK.

TONY GREEN: So this was just taking a standard MAGI family of four.

ARCH: OK. OK, that-- OK, yeah, that helps me understand that. All right. Thank you.

TONY GREEN: Um-hum. So moving then to the right of those getting Medicaid, then this third column shows those groups on the registry who are not only receiving Medicaid coverage but also receiving the benefits of service coordination from the state. This is also known as the targeted case management option in the Medicaid state plan. This group has the same benefits for their health needs via Medicaid as those in the second column. Additionally, they have a dedicated service coordinator to help identify needs, develop plans, navigate systems, and serve as a patient advocate on their behalf. This population of 372 persons receiving Medicaid and service coordination as their interim service costs \$6,798,178 to provide their Medicaid and their service coordination while they're on the registry.

ARCH: OK, so question.

TONY GREEN: Um-hum.

ARCH: The-- the bar-- the bar chart you have here, so-- so once you if you are receiving Medicaid services and-- and you move to the Medicaid

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end service, all of these are cumulative as far as services, correct? In other words, people that are receiving Medicaid and service coordination are receiving Medicaid. And as you move to-- as you move to your right here, all-- it's-- it's-- it's those services plus.

TONY GREEN: Absolutely correct.

ARCH: All right.

TONY GREEN: Correct.

ARCH: OK.

TONY GREEN: Your 1,060--

ARCH: Hope that [INAUDIBLE]

TONY GREEN: Yep, that's perfect. The 1,060 is Medicaid onl.,

ARCH: Right.

TONY GREEN: And the column we just went through, they-- they have the Medicaid and the service coordination. And now we'll move into the-- the next column to the right, which is the Medicaid service coordination and the aged and disabled waiver. Or excuse me, this is the, yeah, aged and disabled waiver. So this shows this is a group of-- of folks that are on the DD comprehensive waiver with a nursing facility level of care because of age or physical disability, who also qualify for that comprehensive DD waiver. So it is possible to be eligible for the aged and disabled waiver under that criteria we went through earlier of aged or disabled and that disability might also qualify you under the DD waivers with an intellectual or developmental disability. So this group is receiving Medicaid service coordination and the aged and disabled waiver services. So similar to the previous columns, their healthcare needs are met via Medicaid service coordination, but also receive the A&D waiver. The services available to those participants in the waiver are listed above the column. As you can see, this group has services and support, such as assistive technology, respite, transportation, personal care, in-home meals, home/vehicle modifications, extra care for children or specialized daycare. Nebraska is currently spending \$9,276,285 for this population of 339 participants as their interim service package. And then finally, your last column on that chart, the fifth column are those individuals who are on the DD registry also receiving the day waiver, the DD day waiver. This is the waiver that students traditionally get

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when they're transitioning out of that educational system at 21 years of age. Through current statute, Nebraska has committed to giving every person turning 21 years of age the DD day waiver. Currently, there are 595 persons of the DD-- on the DD day waiver at an annual cost of-- of \$20,496,365. This group also receives Medicaid service coordination and then the list of services that are noted on your chart, which does include some residential supports such as independent living and respite. The cost of Medicaid vary in the eligibility categories widely. So to estimate the Medicaid cost per person in here, we used an average Medicaid expenditure for this population, with the total annual cost to Medicaid for DD being \$33,445,000. The average expenditure among those 2,366 folks that are accessing the Medicaid service is how we derive at the \$14,136 per person. So as you can see there then on the column on the left, as we look at our state's total investment into those who are on the registry for-- for additional waiver services, you can see that annually we spend \$51.5 million. This amounts to \$21,790 annually per person. And I'll stop there for questions because I'm sure there are many.

M. CAVANAUGH: So Medicaid, the cost of Medicaid, the \$14,136, if they don't qualify for Medicaid, is that the assumption that that's the same cost to the families to get those same services? Like, if--

TONY GREEN: I'm not not sure I understand.

M. CAVANAUGH: So the family makes over \$45,000 a year and so they don't qualify for Medicaid. Are we assuming then that their costs for that child is \$14,136?

TONY GREEN: I-- I could not make that assumption. I mean, the assumption I can make is that if those 399 out of that 500 are not qualifying due to income and we don't track, you know, some of the-- we don't track the income. So I don't know if those children are being covered under private health insurance or what the cost would be for those kids. So I'm unable to answer that.

M. CAVANAUGH: I'm just-- I'm asking because I'm looking at these numbers, annual cost, per person cost seems like it's more than the salary that threshold that kicks you out of eligibility. So I'm just curious about how we calculate all of that.

TONY GREEN: Yeah. I think in the written testimony, you can see there how we kind of derived that \$14,000 because it is--

M. CAVANAUGH: Right.

TONY GREEN: --every person on here, as you know, there are multiple eligibility categories within Medicaid, and the cost then vary depending on which category of Medicaid you're in.

M. CAVANAUGH: Sure.

TONY GREEN: And so we just used an overall cost of all the 2,300 folks that were on the registry pulling data specifically to those folks. And this is how we came up with that average.

M. CAVANAUGH: And I could be understanding this incorrectly, but I think my understanding has been that families might actually have their own employer-sponsored health insurance, but they max out on that right away with their kids. And so even if they have that, the Medicaid services is where that comes in to help. So that's why I was kind of asking that.

ARCH: Can I go back and clarify one thing I missed? I missed something. When you were talking about the 500 that had no Medicaid services or home-- home and community-based, you said it's not that entire population. Could you go back and remind me what you said there? It's actually 399. How did-- how do we get to that number?

TONY GREEN: Absolutely. So that the 500 who do not have Medicaid services, currently within that 500, there's 101 young adults, students who are now adults 19 to 21 still in school, but they're technically adults and eligible for Medicaid on their own right, not taking into factor parental income anymore because they're their own person. So 101 of those 500 are currently in process now that they are adults they're applying for Medicaid as a family of one.

ARCH: Thank you.

TONY GREEN: Ready to move to active participants? On Slide 14, I kind of put the same visual format for you to examine all the active waiver participants that are currently receiving one of our four home and community-based waivers and their services. On the left-hand side, you will see the average cost for the various components of service delivery. As noted from the previous slide, some people receiving these waivers are also on the registry to obtain other services. Want me to explain that?

ARCH: Yeah, I want to see that one more time.

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TONY GREEN: So there are-- there are folks actively on these waivers who are also on your previous slide on the registry. So an example would be there are folks who are currently captured in this 5,894 column for aged and disabled waiver who are on the registry for the DD comprehensive waiver.

M. CAVANAUGH: So there, and I know we've discussed this previously, so they are receiving services. Just because they're on the DD waitlist doesn't mean that they aren't receiving services, is what you're saying.

TONY GREEN: Yes. I'm just trying to make the correlation or transition that these folks are getting-- some of the folks on your registry are getting waiver services, so they will be captured in here as well as active waiver participants because they're getting services.

M. CAVANAUGH: And so if they're on the waitlist for the registry, I'm sorry, if they're on the registry, what are the additional services that they are needing that they're not getting on the A&D?

TONY GREEN: Say that again, Senator, I'm sorry. If they're on--

M. CAVANAUGH: If they are currently on the A&D waiver--

TONY GREEN: OK.

M. CAVANAUGH: --and they're on the DD registry, what are the serv-- where's the gap there for those individuals?

TONY GREEN: So and I'll talk about this a little bit, but the comprehensive waiver, really, the service that's not in any of the waivers that is unique to the comprehensive waiver is the 24-hour out-of-home residential care. In-- in a residential habilitation service, which-- which most people will call the group home or the traditional 24-hour shift staff home with an agency or the other most utilized service would be the shared living provider, the subcontracted family or individual of the agency provider that the participant lives with. So that 24-hour residential habilitation is-- is the service that makes many of these waivers different, but certainly between the day waiver of DD and the comprehensive waiver of DD, that's one of the major differences. AD is a little bit different because it has a different service package for the continuum of folks on that waiver. So obviously on the aged and disabled waiver, there is a-- there is a 24-hour out-of-home care of assisted living, but that's for our aged population, not our younger population.

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M. CAVANAUGH: So the shared living provider piece of that is that like they could live with their parent and their parent would be compensated to take care of them?

TONY GREEN: As long as they are not legally responsible as the guardian, that-- that is allowable.

M. CAVANAUGH: So they would have to give up their rights as a parent?

TONY GREEN: If somebody wanted to be-- if a parent-- if a parent who is also a guardian of their adult person--

M. CAVANAUGH: OK, an adult child.

TONY GREEN: Yeah, I'm thinking of an adult.

M. CAVANAUGH: OK.

TONY GREEN: They could not be-- and you couldn't do it as a parent either, because you're then the legal of a minor. So parents of minor children or parents who have obtained court-appointed guardianship of an adult, they cannot be a shared living provider.

M. CAVANAUGH: So then who would be a shared living provider?

TONY GREEN: Most of our folks are in shared living, either with relatives or folks that are somehow perhaps known to them. Maybe former staff have now become shared living providers.

M. CAVANAUGH: But not-- but they can't be their legal guardian.

TONY GREEN: It can't be the legal guardian. But we do have parents who are not the legal guardian who are providing services for their adult persons.

M. CAVANAUGH: OK. Thanks.

TONY GREEN: You're welcome.

ARCH: OK, so the-- the active participants on the human-- on the home and community-based services, you're saying that there are people receiving home and community-based services that are not on the registry because this number is larger than those on the registry. So they're-- they're receiving services and they are not on the registry.

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TONY GREEN: Correct. So absolutely for sure the far right-hand column, 4,385--

ARCH: Right.

TONY GREEN: --who are getting the comprehensive waiver, they are not on the registry--

ARCH: Oh, they're receiving--

TONY GREEN: --because that's what the registry is for is that that far end waiver?

ARCH: OK.

TONY GREEN: So none of them are on the registry. But there are some folks in that aged and disabled bar as well as the adult DD or the day waiver for DD--

ARCH: Right.

TONY GREEN: --who are back on the other slide on the registry because they're waiting to move over to that comprehensive waiver on the right side.

ARCH: But some decline moving to that comprehensive waiver, and perhaps they're receiving adequate services from their-- their determination.

TONY GREEN: Um-hum. So I walked through those just to make sure we don't have any questions. So kind of moving left to right, the first column are those that are active on the traumatic brain injury waiver. There are currently 17 participants. Currently, this waiver is for services in a specialized assisted living facility, and our only provider is Quality Living, Inc., in Omaha. And you can see there the number of participants and the cost for the Medicaid service coordination and the TBI waiver. The next column becomes those that are actively on the developmental disability adult day waiver. Currently, there are 673 participants receiving Medicaid service coordination and the array of services that are-- that are noted there on your slide for the day waiver. Again, that has an average of \$23,183,229 being expended annually for this waiver population. And then moving into those that are active on the aged and disabled waiver, currently we have 5,894 participants receiving this waiver in addition to their Medicaid and their service coordination benefits. So

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the expenditures that the department is-- HHS is expending on-- on this population is \$161,278,000. And then finally, the comprehensive waiver there are currently 4,385 participants in this waiver. This waiver offers many of the same services in the DD day waiver with that primary distinction or difference of being that residential 24-hour out-of-home care. The average total state expenditure for this waiver, including the Medicaid service coordination and the waiver costs is \$420,681,000. In total, all four or for all four of the home and community-based waivers, we're expending around \$600 million annually in Medicaid service coordination and then whatever service array they might be accessing.

M. CAVANAUGH: And that's directly from the state budget, not-- that doesn't include any federal matching dollars.

TONY GREEN: Yes, and that's-- and it's a mixture of budgets. So that's not just the DD budget [INAUDIBLE]

M. CAVANAUGH: Right. But it's coming from state dollars. We're not talking about a mix of state and federal.

TONY GREEN: Yes.

M. CAVANAUGH: OK.

TONY GREEN: So I tried, hopefully, in those two slides to give you a-- a good picture of what all of the folks on the registry look like and then what does that look like for folks that are currently in the system accessing one of the four approved home and community-based waivers. One of the other questions that you had posed in the LR was what-- what did service utilization look like? And so I've given you a couple of slides here. On Slide 15, we look at the waiver service utilization that's most utilized amongst the three waivers. I did not include the traumatic brain injury waivers. That's just one service, the specialized assisted living. So if you look at the top five utilized services on both the comprehensive and the D-- day waiver for DD, habilitative community inclusion is the top utilized service. This was a service we added a couple of years ago that is more community focused as opposed to participating in facility-based day services. As a newer service offering, I'm glad to see such high utilization. On the aged and disabled waiver, in the bottom chart there you will see that our most utilized service is the chore service, which includes services such as light housekeeping, essential shopping, and then you

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can see the-- the rest of the services as they're ranked there by order.

M. CAVANAUGH: Could you--

TONY GREEN: Go ahead.

M. CAVANAUGH: Oh, sorry, I guess I don't understand exactly what the habilitative community inclusion is.

TONY GREEN: OK, so habilitative community inclusion is-- is a service that folks get out in the community. And so as opposed to what would be more of the traditional service next to it, you see there habilitative workshop. Habilitative workshop would be what some folks would traditionally call where somebody goes to a day center at a provider-owned or operated building with peers of folks with developmental disabilities and receive services there during the day. Hab community inclusion was created as a way to have a higher payment rate and a new service that incentivized folks for being out in the community. Both are still available options for service, but more people are choosing that community-based approach as opposed to the hab workshop facility-based approach is what that's showing you there.

M. CAVANAUGH: Are the--

TONY GREEN: Did that explain the--

M. CAVANAUGH: It did.

TONY GREEN: OK.

M. CAVANAUGH: But are the people that are choosing one versus the other, is that the individual or is that the provider?

TONY GREEN: The individual. So through the team process to include the participant, the family, provider, service coordination, they would decide based on needs which service they want to purchase.

M. CAVANAUGH: And now that you've explained the habilitative community inclusion, it brings to mind some concerns that people have expressed. Are there, I don't know requirements for what that actually looks like because I'm thinking about stories about people just putting them on a bus, driving them around and taking them back. I'm not saying that that's what's happening. That's just what I'm thinking back on.

TONY GREEN: Yeah. So we have modified this service a little bit since its inception a few years ago. So it started out with kind of a hard and fast rule within the service definition of the amount of time that needed to be spent in the community in order to be reimbursed at that higher rate. And it really ended up creating some unintended consequences, right? I think to some of the concerns that you're likely hearing of folks needing to go out in the community, perhaps not wanting to go out in the community to perhaps have a higher rate. So we've restructured the service definition in a way that the hard and fast you must be out in the community 51 percent of the time during that week in order to bill that service, it's more relaxed and it's more person centered now. I think we had in the waiver after that, we went to a majority of the time and I think in our current plan, it's-- it's more directed from the person level to decide how much you want to be in the community versus how much you would want to be in the other service.

M. CAVANAUGH: Thank you.

MURMAN: Yeah, I've-- I've got a question on that. And with the habilitative workshop in Greater Nebraska, you know, there's a large number that do the habilitative workshop in the state. But in Greater Nebraska, it's pretty limited and not a lot of providers. And the providers are having difficulty staying open because I guess to me, it's being forced, but incentivized to be out in the community more. It's much more difficult for the providers, especially for the people that have direct supervision of the most profound, probably the more profoundly disabled people in wheelchairs and all that kind of thing and need special toileting and all the difficult things that are-- that are hard to do out in the community, you know, considering the weather and everything in Nebraska. I'm concerned that a lot of those habilitative workshops that are now open will be almost forced to close because they can't do that by-- can't-- can't provide that workshop yet with-- with all of the incentives or the forcing of the clients to be out in the community more. That's a big concern of mine. I mean, I was out in McCook yesterday and-- and I'm not sure they even have a habilitative workshop there. At least they don't have one from the provider that I'm familiar with in Hastings. So what-- how-- how can that be addressed? I mean, and I know you say it's individual; but, you know, but the families have the individual or the client have the individual choice of whether they want to be out in the community more or not. But it seems like it's almost being forced yet. I know you say you've modified it.

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TONY GREEN: Um-hum.

MURMAN: The big question.

TONY GREEN: Yeah. And I know you and I have talked a few times, Senator, on this.

MURMAN: Yeah.

TONY GREEN: It is-- it is a moving target and it's difficult to explain. But the short answer is it is a service still available today. It's a service I think that will always need to have the-- the reimbursement structure evaluated as we do rate rebases in the future. And then, as you know, the-- the-- the larger movement is to move away from, at a federal level, that states are needing to implement locally is to move people away from that congregate care and some of the activities that historically had gone on in more congregate care of subminimum wage certificates and those types of activities. They're all being faded out at the federal level. But it is still a service that's available, a service that we can continue to tweak and figure out. I think in the current waivers, we've even switched now we don't call it habilitative workshop anymore. It has more of adult day type definition to-- to be more person centered of what you want to do during the day. And it doesn't give the implication that you're in a workshop and try to be a little more flexible with the definition. So I think through continued amendments and revisions that we do, we'll continue to work on that definition. But you are absolutely right, Senator, that the continuum of care has to be there for all. And what that will look like, whether folks want to be in the community, want to be in their home during the day, or they want to be out competitively employed 40 hours a week. I mean, there's a large continuum that we have to be able to provide within that waiver to meet everyone's needs.

MURMAN: Yeah, I'd just like to emphasize from the federal level, you said-- it's said-- and I realize it is being directed from the federal level, but that's pretty idealistic. And-- and I want to emphasize that it should be individual choice, like you said and those-- what it used to be called habilitative workshops. I guess I don't know what the name is now, but that those services are-- continue to be available, especially in Greater Nebraska, where there's less numbers--

TONY GREEN: Right.

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MURMAN: --of clients. Thank you.

TONY GREEN: You're welcome. So those are our most utilized services amongst those three waivers. And if you flip then to Slide 16, you'll see the least utilized services among the three waivers. The top two charts for the DD waivers showed the least utilized services tend to be more for intermittent or time-limited services. So, for example, prevocational is a service that's limited to 12 months to prepare folks for supported employment. The medical and behavioral in-home are short-term day services in the home for specific temporary durations. On the aged and disabled waiver at the bottom, excuse me, in the center chart there, although respite and disability-related childcare in the top four least utilized, they are generally utilized by children more than adults, which narrows that population of utilization. So when I pulled the data, I pulled it for the entire waivers utilization. I didn't separate it out by children or adults; certainly could do that if it's something you're interested in. But as a whole, for the entire population of folks on the aged and disabled waiver, these would be the least utilized services within that waiver.

M. CAVANAUGH: I'm a little surprised that respite care wouldn't be utilized more. Is that-- do you have any thoughts on why that would be?

TONY GREEN: Yeah, I think it's interesting. I think it's the two different kinds of respite, Senator. If you look at the most utilized chart prior to that, respite in home is in the top five.

M. CAVANAUGH: OK.

TONY GREEN: This category of respite is more out or facility-based respite. It's just by title iIt doesn't [INAUDIBLE].

M. CAVANAUGH: Yeah, that--

TONY GREEN: It's--

M. CAVANAUGH: --I was like, whoa, maybe people need to know about this.

TONY GREEN: Yeah. So it's a different kind of respite because respite in home is-- is in the top five of AD services.

M. CAVANAUGH: Thank you.

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TONY GREEN: You're welcome. OK, so moving to Slide 17 and looking at how we ensure that the services within the waivers meet needs. Examining-- examining utilization and obtaining stakeholder feedback are critical steps to ensuring that each waiver has the necessary supports for participants. The division has ensured that participants, staff, families, providers and stakeholders provide input into the service arrays within the existing waivers. CMS actually requires a public comment period for every single waiver, renewal, or amendment, and I believe the division has gone above and beyond this requirement by forming stakeholder committees, holding WebEx meetings, listening session-- sessions, and by garnering information from surveys such as National Core Indicators. So to answer one of the questions within the LR of how do we-- how do we get to the services and the waiver, we try to do that as much through public input from folks of what's working, what's not working. And so a good example would be the previous conversation we had about have community inclusion that it started out kind of as this. We realized it had unintended consequences of people accessing community, perhaps when they didn't want to. And so we relaxed those restrictions and made it more person centered. On Slides 18 and 19, we will go into the fee schedules, so for both of the developmental disability waivers, a fee schedule has been created, adopted, and approved by CMS. I've included a copy of the current fee schedule that went into effect October 1 as a-- as a separate handout there for you all. These rates were determined or implemented, I should say, in 2019 after an 18-month process where DHHS as contractor, Optimus, and their subcontractor, Alvarez and Marsal, worked with DD providers to examine their cost of delivering services. That study showed that Nebraska needed to invest an additional 6.6 percent in rates. LB294 and LB1008 in 2019 and 2020, respectively, appropriated those needed funds to get to 100 percent of those-- of the modeled rates at the time. Rates are required to be rebased and reevaluated at a minimum every five years. In 2021, DHHS developed regulations that required providers to annually submit cost reports. This will allow the division to evaluate cost on an annual basis and determine if a rebase is needed prior to the required five-year benchmark. And then on the second slide staying on fee schedules, you'll see the aged and disabled and the traumatic brain injury waiver rates are-- their waiver is more of a combination of fee schedules, posted rates, and negotiated rates, and you'll see some of those there on-- on Slide 19.

M. CAVANAUGH: Yes.

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ARCH: I have a question and this may be for a later testifier as well. Obviously, we're seeing a lot of pressure on wage inflation and difficulty in recruiting. How's that-- how's that impacting services from your perspective?

TONY GREEN: It is impacting services. We have folks and I'll talk-- speak to people active on-- on the waivers and specifically all four with the exception of the traumatic brain injury waiver. We have folks who are not currently able to access all of the hours maybe that they were previously. We have had folks that have had to change providers because one provider was unable to hire and deliver services at the needed level in-- in that provider and they chose-- had to terminate and go to another provider. And we have had a couple of providers actually close since January. Small providers, we had one in northeast Nebraska that served about 48 folks and then two, one not serving anybody and one only serving a couple of people. But--

ARCH: And-- and that's for-- for current and for-- for people new to the services as well. Are-- are you-- are you seeing difficulty in when you refer a new-- a new individual for services that the providers are not able to to pick those up?

TONY GREEN: Good question. So the-- earlier when I mentioned that in this current fiscal year '22, we had funding in our budget to bring in an additional 500 folks on to the developmental disability comprehensive waiver. That has been a very slow process that has a couple of things at play. It required the state to have the service coordinators in place to be able to provide the case management and deliver the-- the-- the case planning component. But more significantly, it was the provider capacity is just not there today to be able to-- to bring in that many folks like we normally could pre-COVID. Pre-COVID, we would go when we would receive funding for-- for waiver slots and we generally would be able to put all 500 out and have them in services within a matter of months in cooperation with our providers. Today, we have had to slow-- slow those down quite a bit. I think today we started in July and I think we're at about 132 that have been made since July towards that 500. So we're-- we're going much slower and a lot of it is the capacity of the providers and their staffing levels just aren't there. And so we're being purposeful and working together with the providers to kind of do that slowly so that we weren't making offers to families to come off of the comprehensive waiver, only to be told, but now you have to wait again because we have to hire and train staff. And so we're trying to work

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with them. As things get better in a certain area, we're able to perhaps bring folks in. But our goal is still we'll get all 500 in.

ARCH: Thank you.

M. CAVANAUGH: So when it comes to the staffing issue and providers closing, why are the providers closing?

TONY GREEN: Well, I have had two close. And so the two had-- had issues not related to anything COVID. One was disciplinary issues that they didn't want to follow through on and decided to just terminate their status as a certified provider. The other one wasn't serving participants from the DD waiver and decided to work more with voc rehab and do just supported employment. The one in northeast Nebraska that did close their doors that was serving the 40, 48 folks, it was a combination of things, but primarily a lack of being able to get staff.

M. CAVANAUGH: And is that because of the pay?

TONY GREEN: I don't know that I could answer for that director. I mean, you could probably assume it's a multitude of factors that went into that decision.

M. CAVANAUGH: Do you know what the average hourly rate is for employees at that facility?

TONY GREEN: I do not at that facility.

M. CAVANAUGH: Or just--

TONY GREEN: I just know in our-- in our public data from National Core Indicators that the providers fill out the staff stability survey. It was averaging for Nebraska, I believe, at \$13-something an hour.

M. CAVANAUGH: So that's I mean--

TONY GREEN: And that was our 2019 data, so it lags behind, but I would imagine it's not too far off from that.

M. CAVANAUGH: Yeah, because my grocery store yesterday is advertising they're hiring for \$14.50. So it sounds like that might be part of the problem. I do have questions about the ARPA dollars, but I don't know if maybe that's something--

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ARCH: We'll hold-- we'll hold those till the end.

M. CAVANAUGH: OK.

ARCH: Yeah, go ahead.

TONY GREEN: OK. So then the next two slides, I'll walk through kind of the various types of waivers that CMS has available under the-- the home and community-based services. This was one of the questions of what-- are there other types of waivers that Nebraska could explore? And as you can see there on the chart that I provided, there are various waivers for home and community-based services. We have the 1915(c) authorities. Those are the actual waivers we're administering here in Nebraska to support our populations needing long-term services and supports. You have information there on 1915(i) waivers. Those allow the states to provide services for people with income lower than 150 percent of the poverty level, and they don't need to live in a facility to receive care, which is a little different than the (c)s. 1915(j), these waivers are specifically self-directed personal assistance services. 1915(k), these are called Community First Choice waivers. They allow a state to provide home and community-based attendant services and supports to eligible Medicaid enrollees. And then your second slide is another type of waiver on-- on Slide 21 that is an option called the 1115 Waiver Demonstrations. These can be applied for to demonstrate and evaluate a state-specific policy approach to better serve Medicaid populations. These waivers must be budget neutral to the federal government. So I just tried to outline for you all of the different types of authorities that are available to states and give you the electronic links if you wanted to look at any of those, but those would be the different types of waivers available.

ARCH: What category does-- do our present waivers fall into?

TONY GREEN: In the first box of the 1915(c).

ARCH: Those are our present waivers.

TONY GREEN: Those are all four of the current waivers are coded as 1915(c) waivers. Correct.

ARCH: Could I take you back to the-- the rates on page 19? You-- you-- you mentioned CMS. You mentioned DHHS. Who sets rates? Does C-- are these CMS rates?

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TONY GREEN: They are-- no. They're-- rates are set by the state.

ARCH: But does CMS set a maximum rate? Do they have anything to do with rates?

TONY GREEN: within the waivers?

ARCH: Yes.

TONY GREEN: No. We are required under the waivers to set rates that are adequate to ensure capacity for services.

ARCH: OK. OK.

TONY GREEN: And then your rates have to be submitted to CMS within the waiver for approval. And the-- the overarching requirement is that your waivers cannot cost more than the replacement they're replacing. So on the DD waivers, we're replacing intermediate care facility services in aged and disabled; and TBI, we're replacing nursing home services. So you have to be less than what it costs the state to provide those services under a waiver. And you can do-- you have two options to do that at an individual level or an aggregate level. And we do ours at an aggregate.

M. CAVANAUGH: And the state sets the reimbursement rate for long-term care and the facilities that you were just discussing that you have to be the same or less than, the state also sets those rates.

TONY GREEN: Correct.

M. CAVANAUGH: OK. So you said adequate, the rate has to be adequate to ensure capacity for services.

TONY GREEN: Capacity and access to services, yes.

M. CAVANAUGH: And access to services.

TONY GREEN: Yes.

M. CAVANAUGH: So what conversations are happening around the fact that that's not happening? Our rates clearly are not adequate for capacity of services, both for what we're talking about here today. And if they have to be less than the services they're replacing that are set by the state, and we know that those long-term care facilities' rates are not adequate because they're closing as well. So what conversations

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are happening or what do we-- how can we partner together to address that? Is that something that DHHS is looking to increase the rates, or is that something that you need us to do? How do we how-- do we fix this is I guess what I'm asking?

TONY GREEN: Probably a much broader topic than I have for the resolution that we were-- that I'm coming forward with. But I can say yes, things are being-- so one of the examples that I was giving you earlier that we-- we put a regulation into place last year that said, we want cost reports on a regular basis. Let's not wait for five years was a direct attempt by the department or the division to-- to get that data so that we can have conversations with our providers every year when those come in. Now, unfortunately, that-- that regulation went into effect for this last fiscal year, which just ended in June. And the requirement is the providers have six months to submit those to get their books closed down. So we don't even have the first cost report yet. We'll see those at the end of December, first of January as far as where things might be at. Now I'm sure they will give you enough information and detail to tell you where they're at, but we know that the staffing issue is a concern right now, just in the vacancies that we're seeing.

MURMAN: I'd just like to comment on that. The complaints I hear about hiring and retaining staff, the rates is part of it, but also the Olmstead part of it being forced to be out in the community more, it's more difficult to staff, for staff to do that. And that's one complaint that I've been hearing.

TONY GREEN: So then I just, the last slide there is [INAUDIBLE] You have my contact information. I'm hopeful that this was information to give you a more clearer picture and hit some of the points that you were hoping to achieve from LR239. I'd be happy to answer any final questions you might have.

ARCH: This has been very helpful. Appreciate it very much. You've done a tremendous amount of work in the analysis and trying to make something very complex, understandable. And so I appreciate that.

TONY GREEN: You're welcome.

ARCH: Senator Cavanaugh, do you have some questions on ARPA-- ARPA funds?

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M. CAVANAUGH: The ARPA funds. So has the department done anything to utilize ARPA funds to help fill the stopgap? Or are there plans for the upcoming budgetary request? And what-- what is it looking like for utilization? Because I know that there's opportunities with those funds to help with some of these concerns. I know that our, like our childcare facilities across the state have been able to apply for funds that have allowed them to give bonuses to employees or just help pay for, you know, stopgap in loss of revenue. So is that something that's also being done for providers?

TONY GREEN: Yes.

M. CAVANAUGH: OK. Is it something we can do more of? Are there plans to increase it? Because I'm really concerned with the fact that you said a provider out west that serviced 40 people shut down.

TONY GREEN: Northeast.

M. CAVANAUGH: Northeast. I'm sorry. Northeast. Wrong direction, that they shut down. And-- and what-- do we have an opportunity to help providers like that with these funds?

TONY GREEN: So I would not be able to speak to larger just ARPA dollars in general, specific to the specific funding that was done for home and community-based services, you have seen the spending plan that Director Bagley with Medicaid Long-Term Care and I and our teams have put together for that specific population of money that's just or, excuse me, pot of money that's just for this population of home and community-based services. So there's an initial spending plan that is up on the public website that had some initiatives in there. There were also placeholders that were put into that plan that indicated we wanted to also in future updates, because we're required to update that plan every quarter with CMS for this specific funding. There is a-- is a placeholder in that document that talks about wanting to put in a request for staffing issues at provider levels and whether that would be something in the hiring, the retention phase, but something around direct care and-- and we continue to-- to work on that.

M. CAVANAUGH: Is there any consideration of looking to do some sort of pilot program of a waiver or piloting doing an increase salaries or things like that? I know that that gives you a little bit more flexibility with the funds.

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TONY GREEN: I can, no, I have not looked at piloting a new waiver, as that's a significant amount of work to go through--

M. CAVANAUGH: Sure, yeah.

TONY GREEN: --submitting a new waiver.

M. CAVANAUGH: I'm just throwing out all options.

TONY GREEN: I understand, Senator. The monitoring and oversight of just doing a whole new waiver under one of the authorities that you're looking, there may be a task that would take us well into the future before that would even be approved or--

M. CAVANAUGH: Sure.

TONY GREEN: --done by CMS. But to the immediate need, yes, there-- there are plans underway within the larger HHS system and specifically with Medicaid and Developmental Disabilities on trying to get money into the hands of providers through that CMS spending plan that we've created.

ARCH: I think we know the ARPA funds themselves will be a large topic of conversation beginning in January.

M. CAVANAUGH: Yeah, they will. I, just one more question. So we have these waitlists and-- or registries. I'm sorry. I'm trying to use the right terminology, these registries. We have a registry. We-- this committee moved out and prioritized the family support waiver. What is the answer to fixing the lack of access for some that need it? How do we do that? Is it that we increase the income eligibility for families to get Medicaid so that they can at least get those services? What-- what are the things that we can do that we can partner with you to do to create more access and eliminate barriers for individuals that need these services?

TONY GREEN: Yeah, I think and that was one of the the topics in the LR that I think Senator Arch even had a conversation of difficult for me to answer in that-- that box of folks of what might they need, who aren't accessing the services today because they're not really involved at this point with the department in any way. And so getting at what those needs are would-- would probably need to be done so that we know what that might look like. The other folks on that chart with the one that shows the-- the registry folks, we know where all of them

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are and what they're getting and what their needs are, except that 500 or 399.

M. CAVANAUGH: So how do we fix that?

TONY GREEN: I don't know that I have an answer for how to fix that. I mean, obviously there-- you-- there could be ways to reach out to those folks, but they are currently just, again, the-- the numbers that I was sharing with you that the families who are applying to be on the registry, the youngest being four months old. So they're contacting the department, letting us know that they-- they're making application for eligibility, letting us know that they're fine, they're not needing services, but they just want on the registry with their date of application. And so they're not requesting service coordination to meet with them every month because service coordination is an option for folks on the registry, but they're not choosing to have that service available. So--

M. CAVANAUGH: Do they know that that's an option?

TONY GREEN: Yes.

M. CAVANAUGH: OK, so the 399 that I guess they're kind of like not system involved, is that?

TONY GREEN: Correct. They're not receiving Medicaid and they're not receiving any home and community-based services to include our service coordination.

M. CAVANAUGH: Is outreach to that population something that DHHS can do without the Legislature getting involved?

TONY GREEN: It would be something we'd have to assess as a resource issue of what that would look like.

M. CAVANAUGH: OK.

ARCH: I think-- I think the one conclusion which has been very helpful is-- is a better understanding that there are times when we have talked about the waitlist or the registry as though it was a homogeneous population. It was all in need of the same things at the same time and they're waiting. And that has been a misunderstanding by the-- by the-- by us, by the Legislature. And I think this has been very helpful. I would assume we would have similar situation with those 399 individuals that are on the registry, not receiving

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services. It-- it really is very individualized the need of the families, the-- the desires of the families, which then of course, also could change over time.

TONY GREEN: Yes.

ARCH: And so I, you know, appreciate the work of the department in-- in trying to stay in touch with these families and assess what those needs are. And-- and we'll continue to have those discussions as a committee and with you. Again, really appreciate your time.

TONY GREEN: You're welcome. Thank you.

ARCH: We'll move to the next testifier and that will be Alana Schriver. Welcome.

ALANA SCHRIVER: Short. Good morning, Chairman Arch.

ARCH: Those don't adjust. It doesn't adjust.

ALANA SCHRIVER: I know. Good morning, Chairman Arch and members of the committee. My name is Alana Schriver, A-l-a-n-a S-c-h-r-i-v-e-r, and I'm the executive director of the Nebraska Association of Service Providers, representing both urban and rural, large and small providers. So I want to thank you for the opportunity to speak this morning on behalf of the people we serve and employ. In order to address the issue of provider capacity, please understand that DD services differ from other healthcare professions in that capacity isn't determined by specific staff-to-patient ratios or numbers of beds or anything like that. Some individuals we serve require one-to-one staffing. Many do not. So the number of people who can be served by one staff member differs depending on the situation and location. Essentially, our product is habilitative hours. In other words, a real-life person or persons needs to be available every hour to provide individualized care. On the average, DD providers are 30 percent short of the direct care workforce needed to provide essential services. Without staff to fill those habilitative hours, we have no product to offer, regardless of physical space or number of agencies. Like Dr. Green said, funding was made available to bring 500 Nebraskans off the waitlist this year. And while 132 referrals have been made, just because someone is accepted doesn't mean they're receiving services yet. In fact, many providers are being forced to send notice to people already in services that their needs can no longer be safely met, let alone accept new referrals. Nationwide, 77

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percent of providers are turning away new referrals and 58 percent are discontinuing programs and services due to the staffing crisis. So while the program problem is not unique to Nebraska, it's exacerbated by our historically low unemployment rate here. The pandemic is not over, far from it. We're in a worse position today than at this same time last year, and at that time, the pandemic was being acknowledged and addressed by Appendix K. Not only are we dealing with high numbers of positive cases and quarantines, but there's less staff now to cover those shifts. Holiday gatherings are likely to increase the number of positive cases and quarantines on top of being a hiring desert. Unlike other industries that can adjust their hours or pricing to mitigate staff shortages and rising costs, DD services cannot. While it's true new providers have opened this year, it's not a barometer by which to measure the health of the DD system. The differences between newer and more established providers is stark. Many of the new providers are very small or only offered shared living. Being a shared living provider doesn't compare to the challenges larger providers face, who offer a wider range of supports to people with disabilities, as well as benefits to their employees. You understand the workforce crisis well. Childcare, schools, your own state employees have all brought the issue to the forefront. State employee wages needed a drastic and permanent rate increase in order to attract and retain essential workers for the same reasons we do. Typically, our direct care workforce mirrors the wages at Beatrice State Development Center and those BSDC techs recently received a permanent 30 percent wage increase plus shift differentials. We need the same in order to remain competitive. Without an equivalent rate increase, DD services will continue losing staffing to other industries that can pay more. Without staff, provider capacity will continue dropping and the waitlist will continue rising. Raising wages works. Correction officers in Nebraska recently received a permanent 33 to 40 percent bump in wages and had 70 new applications in a week. Without intervention from the state to address the staffing crisis in DD services, this committee will have to decide whether your goal is to serve the people with the highest needs or serve a higher number of people with lesser needs. It's not a comfortable question, and ideally this shouldn't be a question. We should be able to serve everyone. Unfortunately, providers are being forced to ask themselves this question every day. For every person with complex needs requiring one-to-one staffing, they could serve five or six people with less intensive needs. It's an unwanted position to be in, but more importantly, it's unfair to the people in need of services and their families. As a parent of a child on the waitlist myself, it's

heartbreaking. Providers would love nothing more than to accept and successfully support every Nebraskan on the waitlist. It's mutually beneficial to do so. Every provider wants to grow, but we have to recover before we can grow. On average, providers have experienced a 12 percent margin loss since the start of the pandemic, meaning providers have gone from being reimbursed roughly 2 percent above their costs to losing 10 percent on the services they provide because the current reimbursement rate does not reflect the recent significant increase in cost to provide-- to provide care. Overtime, paying salaried employees to provide direct care, increased job advertising, and cost of inflation have all contributed to these financial losses. Our emergency deficit request to increase rates 30 percent would enable providers to mirror the state employee rate-- wage increase and address this margin loss, bringing us back to the starting line where growth and innovation hopefully becomes an option again. In summary, providers are operating at 70 percent prepandemic capacity due to historic staff shortages. Without sufficient staff, providers cannot maintain prepandemic levels of care, let alone serve new referrals from the waitlist. Staff are leaving for higher paying jobs, including BSDC. Providers cannot increase wages to attract and retain high-quality staff without a permanent rate increase from the state. If you want to get Nebraskans off the waitlist and into DD services, the state must increase provider rates. In the packet since the cost reports haven't been submitted yet, there is a chart where we had five of the providers who represent about 45 percent of the people in services is how we got that margin loss average. I've also submitted 35 testimonies from those front-line workers, so you can get an idea of what it's like on a weekend when five people call in or are in quarantine or how you address that problem in the moment. So thank you for your time and I'm available for questions.

ARCH: Thank you. Questions? Senator Cavanaugh.

M. CAVANAUGH: Thank you. Thank you so much. This is very informative. I was-- my question, and then I see at the bottom here you have some information about Appendix K. And you have stated that Appendix K was, I guess, helpful. Could you maybe just explain a little bit more of what that did for providers?

ALANA SCHRIVER: Yeah. So Appendix K was a temporary increase in rates and also allowed for a change in the way services were provided due to the pandemic, since people with DD are at a much higher risk of COVID complications. So it allowed for virtual services, other things that were just safer. While-- while even though the pandemic is still going

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on and a lot of those accommodations are still needed, those did expire this summer.

M. CAVANAUGH: And the virtual services, are those things that were working well? I know sometimes [INAUDIBLE] is that something that we should consider?

ALANA SCHRIVER: Particularly in the rural areas, because a lot of times those direct care workers don't get paid for drive time. So if you have to drive 30 minutes to a visit and then 30 minutes back home, you've just lost an hour that you're not paid for. So it is helpful not only just for quarantine, but also for logistics when you live way out in the middle of nowhere.

ARCH: I have a question, a follow-up question on virtual services. And that is that when in the middle of the pandemic, the state waived certain requirements. Does CMS-- did CMS waive requirements for virtual services for developmental disabilities, as they did for other services? And in other words, do they allow virtual services and to bill for virtual services?

ALANA SCHRIVER: I don't personally know that answer. I'm fairly new to my role, but I can get to that answer later today.

ARCH: OK because it was-- that was part of the discussion was, you know, in some cases, CMS says you can't. You can't do that. In other cases, it was up to the state whether you could or couldn't.

ALANA SCHRIVER: I can get you that answer. Yeah,

ARCH: I'm sorry.

M. CAVANAUGH: No, that's OK. And my only other question was, you said there was a rate increase under Appendix K and what was the rate?

ALANA SCHRIVER: Five percent across the board. And I was going to I want to turn to Justin because I don't--

JUSTIN _____: It was 15 percent from [INAUDIBLE] pandemic to October and then step down to 10, 10 and 5 [INAUDIBLE] It was a stairstep approach from 15 percent to about 5 percent [INAUDIBLE] January or December, and then the state came back with another 5 percent [INAUDIBLE]

ARCH: OK if you could restate--

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ALANA SCHRIVER: I came into my role this summer so.

ARCH: If you could please restate because you're-- you're the testifier.

ALANA SCHRIVER: Sure.

ARCH: And so for people that are transcribing.

ALANA SCHRIVER: It started out at 15, yeah, 15 percent and then stepped down to the last reimbursement was 5 percent from January to June of this year.

ARCH: Thank you.

M. CAVANAUGH: Thank you.

ARCH: Any other questions? Well, thank you very much. Thanks for your test-- oh, one other question.

ALANA SCHRIVER: Sure.

ARCH: And that has-- does-- do you-- do you provide mostly services to adults, children? What?

ALANA SCHRIVER: NASP represents adult service providers.

ARCH: OK, so that doesn't include-- OK, service to children. Because when I saw this, I saw the statement and I don't know what-- what shared living services are. Could you explain that?

ALANA SCHRIVER: Sure, that's what Director Green was talking about when perhaps a relative or someone known to that person gets paid to live with them and make sure their needs are being met in the home.

ARCH: OK. OK. All right. Thank you very much for your testimony.

ALANA SCHRIVER: Thank you.

ARCH: Our next testifier is Sarah Swanson from Munroe-Meyer. Welcome.

SARAH SWANSON: Thank you very much. Should I start?

ARCH: Please.

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SARAH SWANSON: OK. Good morning, Senator Arch and members of the Health and Human Services Committee. My name is Sarah Swanson and that is spelled S-a-r-a-h S-w-a-n-s-o-n. I am an assistant professor at the University of Nebraska Medical Center's Munroe-Meyer Institute and work under the state's federally funded University Center for Excellence in Developmental Disabilities or UCEDD grants. As the state's designated UCEDD, we are part of a federal network of UCEDDs asked to provide training, technical assistance, and services to improve systems for individuals with their dis-- with disabilities and their families. My testimony today does not reflect the views of the university system, UNMC, or the Munroe-Meyer Institute. I have been asked to describe innovations that are occurring across states to better support individuals with developmental disabilities and their families. So just a little bit of background. Developmental disabilities are a group of conditions due to an impairment in physical learning, language, or behavior areas. Most individuals with developmental disabilities are identified as children and will need lifelong supports. It's important to note that Medicaid is the largest funder of long-term services and supports, but family caregivers are the backbone of long-term services and supports in the United States. Children with developmental delays need early intervention to gain the skills that their typically developing peers naturally acquire. High-quality early intervention services can change a child's developmental trajectory and improve outcomes for children, families, and communities, and decrease the need for special education and public expenditures later in life. Unfortunately, providing early intervention and/or medically based services are typically at a significant cost to families. While most families have access to some health insurance, many plans are inadequate to cover the medical and related health services that a child needs, often impacting a family's financial health, putting the entire family at risk of financial hardship, medical debt, and poverty. According to the National Survey for Children and Youth with Special Healthcare Needs, 37 percent of Nebraska families indicated their health insurance was insufficient to cover their child's healthcare needs. Even though children with special healthcare needs covered by Medicaid or CHIP-only have greater healthcare needs, they are more likely than those with private insurance alone to report that their benefits are always adequate to meet their needs, reflecting Medicaid's robust benefit package, especially for children. Many states offer pathways for working families to gain Medicaid access for their disabled child, not the entire family, but only the child having the disability. Without a specific pathway for the child with a disability to have access to

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Medicaid, the child will frequently be found ineligible because of the income and resources of the working parents, which is often a disincentive for both parents to remain working. Medicaid waivers or amendments to the Medicaid state plan are pathways states can take to offer long-term services and supports for individuals with disabilities to help achieve independence in home and community-based settings, rather than an institutional setting like BSDC. These are an optional Medicaid service. Medicaid pathways for children's eligibility and types of waivers are further defined in the appendix. A relatively new model that is being used by states to support individuals with developmental disabilities is a Support Waiver. These provide limited services but offer budget predictability for states as they're a set budget and is-- also a set number of slots. States that have started to use Support Waivers are doing so to complement other waivers, help to provide more limited services to help avoid crisis placements or more costly interventions, and embed them in the DD delivery services system. They complement the natural supports of families and offer family caregivers support. Of the estimated 6.2 million people in the United States with intellectual or developmental disabilities, most reside with their families. Recent studies from the University of Minnesota estimate that less than one fifth of individuals with IDD are known by state IDD agencies, and-- and less than 17 percent are actually being served by a state DD agency. To help support family caregivers, five states allow legally responsible representatives, such as a spouse or parent, to be paid providers. In conclusion, I would be happy to provide additional information as I did my capstone project for my master's in public health on "Innovations and best practices in Medicaid Managed Long-Term Services and Supports" so this is an area of interest for me.

ARCH: Thank you.

SARAH SWANSON: Yes.

ARCH: Questions? I-- I have a question.

SARAH SWANSON: Yes.

ARCH: I-- I actually met with Dr. Mirnics--

SARAH SWANSON: Yes.

ARCH: --a while back.

SARAH SWANSON: Yeah.

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ARCH: And he was talking about some remote-- remote services being provided through Munroe-Meyer. Are you familiar-- are you familiar with those and what's happening?

SARAH SWANSON: Sure, sure. So during COVID, many medical providers could not see patients face to face. And so I want to say, and I'd have to go back to Dr. Mirnics, but I think about 75 percent of our services changed to be virtual. So through UNMC, there is a platform called Zoom, which is HIPAA compliance, that families can access.

ARCH: OK.

SARAH SWANSON: And like, we have psychologists that can do virtual sessions all across the state. And it's my understanding that because of COVID, some of the reimbursement issues that had been problems in the past were restricted. I mean, those restrictions were lifted.

ARCH: Yeah. Good. OK. Senator Cavanaugh.

M. CAVANAUGH: Thank you. Thanks for your testimony.

SARAH SWANSON: Yeah.

M. CAVANAUGH: You mentioned something and I had spoken about this with Director Green about the health insurance, the Medicaid/CHIP.

SARAH SWANSON: Um-hum.

M. CAVANAUGH: So is it-- am I understanding correctly that families that don't have Medicaid, their personal health insurance is not comprehensive enough?

SARAH SWANSON: Correct.

M. CAVANAUGH: OK.

SARAH SWANSON: So as you think about what's happening to health insurance in general, more and more people have high deductible health savings plans that are like \$5,000 or \$10,000. So if you think about the chronic needs of a child that has a disability or a special healthcare need, unlike a child that doesn't have that chronic need, that family is going to have to spend that amount of money each and every single year. They're never going to get caught up. So one of the things that the state of Nebraska could consider doing is offering Medicaid, not CHIP, but Medicaid as a payor of second only for that

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disabled child. So when you step back and you think about that cost, that-- that is from a holistic perspective, right? It really helps encourage working families to stay in the workplace so they're contributing to, you know, the state system. But they also are doing so at a less expensive rate because that family will probably have their own individualized health insurance, which will always be a payor of first and Medicaid would be a payor of seconds.

M. CAVANAUGH: You-- this is probably not-- you're probably not the right person to ask this question, but I'm going to keep asking until somebody knows the answer.

SARAH SWANSON: OK, I'll let you know if it's--

M. CAVANAUGH: Do you know if Medicaid income eligibility is based on pretax income?

SARAH SWANSON: I-- I want to say that it is the gross, but I would need to go back and confirm that for certain.

M. CAVANAUGH: I'm seeing some nodding of heads.

SARAH SWANSON: OK, yes.

M. CAVANAUGH: Thank you.

SARAH SWANSON: And I also think it's important to note that CHIP, while it has a higher eligibility, if a child has access to insurance, they're not eligible for CHIP, so it can't be a payor of second like Medicaid could be. And those guidelines are established by the state in partnership with the federal government. In--

ARCH: So let me pause you there for a second.

SARAH SWANSON: Sure.

ARCH: So your-- your concern is really regarding the maximum out-of-pocket that-- that a family would need to pay. In other words, it isn't-- it isn't inadequate insurance. It is-- it is that maximum, you say, a higher deductible or a maximum out-of-pocket. It is those dollars that you're-- that you're concerned about.

SARAH SWANSON: That's one of the things that I'm concerned about. But Medicaid in general, just because of what Medicaid is intended to do, has a very, very robust benefit package--

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ARCH: Yes, it does.

SARAH SWANSON: --called EPSDT, which is early periodic screening, diagnosis, and treatment, which means that its benefit package for children specifically is almost always more robust than a private health insurance plan because that when it was established by Congress, there's a recognition that in child's development, there's key or sensitive periods of their development that when we provide intensive services, we can change that trajectory. So the states, when they offer Medicaid, is obligated to EP, early periodic-- they're obligated to screen, diagnose, and treat any condition that that child has in order to help ameliorate that condition.

ARCH: OK, thank you.

SARAH SWANSON: Yes.

ARCH: Thank you. Other questions?

SARAH SWANSON: Can I clarify one more thing?

ARCH: Sure.

SARAH SWANSON: You asked me about the maximum out-of-pocket costs--

ARCH: Yes.

SARAH SWANSON: --if that was my only concern. That is not my only concern. I think it's important to note that when we think about Medicaid and Medicaid waivers, they have two different functions. Medicaid specifically offers medical reimbursements where waivers and some of the Medicaid state plan options to offer long-term services and supports offer those long-term services and supports that are not medically based. So when I think about families that have needs, a lot of them need a break. They need respite or they need to pay a childcare provider a higher rate. That's not medically based. That's-- that's a long-term service and support. Or if they need a home modification as an example, a waiver will help them pay for that. So it really helps that family provide care in their own home rather than having to go somewhere else and not have their child live with them.

ARCH: Thank you for that clarification.

SARAH SWANSON: You're welcome. And I have to apologize. As I'm looking at this, all of my references are not in this. When I printed it, it's

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not there. So I will reach out and make sure that you get the proper copy with all of the references I cite.

ARCH: Thank you.

SARAH SWANSON: Yes. Thank you.

ARCH: Thank you for your testimony.

SARAH SWANSON: Yes.

ARCH: Our next testifier, the last scheduled testifier is Bridget Aschoff. Good morning.

BRIDGET ASCHOFF: Good morning. Are you starting my time yet, because I was going to make a joke. You know that song, just came to me yesterday, Hello darkness, my old friend, it's nice to talk with you again, I thought about addressing you guys [INAUDIBLE]. Hello, HHS Committee, my old friend.

ARCH: Good morning.

BRIDGET ASCHOFF: Nice to talk with you again. It is a pleasure to be here. All right, so my name is Bridget Aschoff, B-r-i-d-g-e-t A-s-c-h-o-f-f. And good morning. It is an absolute pleasure to be speaking with you again today, lots of familiar faces. So what I would like to do today is spend some time updating you on the current waiver situation that we're experiencing with Claire and to be the voice for other families in Nebraska who want to bring their concerns forward regarding our waiver systems. Claire is now six, has been diagnosed with ACC, Dandy-Walker Syndrome, and a rare gene mutation. And while we don't know the full extent of what she'll be capable of for many years, we do know that early intervention is critical for her achieving her full potential, which is why having accessible supports and services for our disabled children is vital. Claire was kicked off the AD waiver in January of 2019, when the criteria for children changed. In October 2019, DHHS decided to do a waiver-to-waiver transfer to help families like mine. Claire was switched from AD waiver to DD waiver, and we are so grateful for DD waiver because it allows us access to Medicaid for Claire. But it has also exposed the many gaps that exist for our disabled children in Nebraska. Switching from AD to DD didn't fix anything for families like mine. It is a Band-Aid to get us by, but it does not solve the systematic issues in our waivers. What we really need are solid policy and procedure changes. So before I dive into what's missing, I do want to share with

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you what's going really well. When I asked parents who are currently on waivers what is going well, their overwhelming gratitude for the access to Medicaid for their families was huge. Families like mine spend anywhere from \$2,000 to \$5,000 a month on basic medical needs for their children. So medical care for complex children is unsustainable for working families, so having access to Medicaid makes it doable for us. So let's dive into some of the gaps. The first hurdle families has-- have to cross is getting approved for the waiver. The requirements for AD are so restrictive now it is nearly impossible for a child to qualify. So one mom shared with me, I'm a single mom. My daughter's five and recently found ineligible for A&D and DD. She is not officially diagnosed. But her neurologist/genetics/rare disease specialist and neuromuscular doctor believes she has a neuromuscular condition. So let's stop there for a second. I don't know how many typically developing children have that many doctors. I know mine don't. Her daughter's on 15 meds a day. One's a Class A drug. She wears smo braces, has a-- has a manual wheelchair for long distances, uses e stim on her feet for neuropathy, and has a feeding tube to receive well over 50 percent of her hydration needs a day. Another mom shared, My son is nine and has autism. He is ineligible for A&D and has been on the DD waitlist for five years. He regularly meets his insurance out-of-pocket max by March or April. He's an alternative curriculum placement in schools, miles behind his peers. We would like to be a two-income family, but my son cannot go to any after-school program without adequate support and supervision. Childcare at any centers for children with disabilities is unaffordable for us without a Medicaid waiver. Like many Nebraskans, we are stuck on the waitlist, desperate for more support. And this is not a new story. Here is a story of a mom with a teen. My son has Phelan-McDermid syndrome and cannot perform any ADLs on his own. We applied for all waivers when he was four. His AD application was never actually processed. Then we found out when he was 11, he had been removed from the DD waitlist. We had to reapply in 2014 and he's currently on that waitlist. It wasn't until he was hospitalized in 2020 that the hospital helped us get him approved for the AD waiver. He should have been on the waiver 14 years ago, but the flawed system failed us. So problem number one is even qualifying for a waiver. Once kids are on waiver, we have found there aren't many services geared towards their needs. So, for example, Claire is technically receiving services because she is on DD waiver. But what services is she really receiving? I've included a supplemental page that lists all the services available for the DD waiver. If you look closely at the requirements, you can see that the services are

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directed more for people ages 21 and over. So because of her age, she can only access 2 of the 23 services. One mom told me, My twins are 16 and have a rare genetic disorder. The only medicine is therapy to keep their limbs and muscle memory at a functioning level. They lost services on the AD waiver in 2019 and were transferred to the DD waiver. We looked at all available services for the twins and the only thing available was respite care. There needs to be a middle ground for these kids that don't fit the mold. We aren't providing adequate supports for children during their most critical developmental years, which means we end up spending more money down the road because these lifelong skills were never nurtured. What we need is access to services that will help the chil-- the child long term. For children in Nebraska, CRCC in Omaha is really the only agency that can provide services for children. This is a major issue and concern for families like mine because Omaha isn't accessible for everyone. We need more reliable agency options to provide services for our kids. There are surrounding states that are getting it right. Some suggestions for services would be behavioral therapy, specialized childcare, movement therapy, HIPPO therapy, adaptive recreational equipment and fees, parent education, and home adaptations. You can see an explanation of these services on the supplemental page as well. There are so many opportunities for us to improve services for our disabled children in Nebraska. The Legislature has had a number of studies for our waiver systems in the past, but our families are still waiting for answers. If other states can do this for their children, so can we. If we strive for Nebraska to be a place people want to live and work, then we need to make it a place where all Nebraskans can live and work. Thank you.

ARCH: Thank you. Questions? Senator Cavanaugh.

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

BRIDGET ASCHOFF: My pleasure.

M. CAVANAUGH: Thank you for the update on Claire.

BRIDGET ASCHOFF: Yes.

M. CAVANAUGH: It's nice to know how she's progressing. I actually was going to ask this question and then your second to last paragraph talks about some of the services.

BRIDGET ASCHOFF: Um-hum.

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M. CAVANAUGH: Are you aware of any waiver that the state could do that would--

BRIDGET ASCHOFF: We do not currently have one that would do this. If a waiver like the family support waiver could have been adopted like was in the Legislature last session, this would have been something that could have--

M. CAVANAUGH: So with these services would be--

BRIDGET ASCHOFF: --could have been an option. If they were chosen, could have been an option to be put on a waiver like that.

M. CAVANAUGH: OK, that's very helpful. Thank you.

BRIDGET ASCHOFF: Yes.

ARCH: Other questions? Well, thank you for coming.

BRIDGET ASCHOFF: Absolutely my pleasure, thank you for having me.

ARCH: Feel free to keep coming back. We appreciate your input because you bring-- you bring the voice of the parents.

BRIDGET ASCHOFF: Yes.

ARCH: And we can talk about numbers and we can talk about dollars. But you-- you bring the voice of the parents.

BRIDGET ASCHOFF: I'm happy to do that.

ARCH: Appreciate that.

BRIDGET ASCHOFF: And there's lots of us throughout the state, so it's been very eye-opening, you know, these last three years to be connecting with these families and hearing these struggles. And when I was messaging with that mom of that little five-year-old girl this week, I'm not kidding you. I was fighting back tears like, how does this little girl not? I mean, I'm looking at all of those needs that she has as a single mom, and I don't know how she's doing it and how we are failing these children that need this help and these parents that need that support. So I appreciate you listening.

ARCH: Thank you. And that would be the last invited testifier for the day, and for that, we will conclude LR239. Thank you for coming.