SENATOR LESSER (9TH): Good morning, everybody. I would like to call to order the March 7th, 2024 public hearing of the Human Services Committee. We have 99 people signed up to testify. So, I think we will try to keep remarks brief, but I'd like to offer the opportunity to my Co-Chair, Representative Gilchrest, for any opening remarks.

REP. GILCHREST (18TH): Thank you, Senator. No. Just good to see so many people and looking forward to listening and learning today.

SENATOR LESSER (9TH): And I would like to recognize Senator Seminara for any opening remarks.

SENATOR SEMINARA (8TH): Good morning, everybody. Wow. What a packed house we have here today and I'm very looking forward to everyone's testimony and getting further insight. So, let's begin.

SENATOR LESSER (9TH): Okay. With that, I'd like to call up the distinguished commissioner of the Department of Social Services, Commissioner Barton Reeves. Is the Commissioner -- she's not here. Oh, you are not Commissioner Barton Reeves.

DEPUTY COMMISSIONER SHANTELLE VARRS: I am not. So good morning, Senator Lesser, Representative Gilchrest, and distinguished members of the Human Services Committee. My name is Shantelle Varrs and I'm the deputy commissioner for the Department of
Social Services. Commissioner Barton Reeves had a long-standing scheduling commitment and apologizes for missing the hearing today.

I am pleased to appear before you today to offer remarks on several bills. With me are subject matter experts from DSS to help answer any questions you may have. I'll start with Senate Bill 314, AN ACT CONCERNING EMERGENCY MEDICAID COVERAGE FOR TREATMENT OF EMERGENCY MEDICAL CONDITIONS.

DSS appreciates the intent of this bill but has concerns about aspects of the proposal that do not align with federal laws that limit the state's ability to obtain federal Medicaid reimbursement for services provided to this population. Regulations provide that individuals who meet Medicaid reimbursement except immigration status will be eligible only for limited emergency medical services, required after a sudden onset of medical conditions manifesting itself by acute symptoms of sufficient severity including severe pain.

Such that absence, immediate medical attention could reasonably be expected to result in, one, placing a patient's health in serious jeopardy, serious impairment to bodily functions, and three, serious dysfunction of any bodily organ or part. Any services provided that do not comply with federal definition, would not qualify for federal Medicaid reimbursement and would require the state to cover all such costs.

Finally, the bill requires DSS to establish an administrative system for persons to apply in advance for emergency Medicaid coverage for conditions that could be treated in outpatient settings rather than in hospital emergency departments. These additional costs were not included in the Governor's recommended budget and for reasons above DSS cannot support this bill.
With respect to Senate Bill 317, AN ACT EXPANDING THE COVERED CONNECTICUT PROGRAM. This bill proposes to expand covered Connecticut by adding a second tier to the program to provide state-assisted healthcare coverage at a reduced cost to individuals with income between 200% and 300% of the federal poverty level. While DSS appreciates the intent of this bill and supports the goal of reducing uninsured rates in the state, the department cannot support the bill for the reasons outlined.

Federal approval of the current program was secured less than two years ago, and expanding the program by scope and proposed in this bill will require the department to request an amendment to the demonstration waiver. Application, review, and approval of an amended waiver for covered CT would likely take 6 to 12 months and would include updates to supporting budget neutrality reports and revisions to monitoring protocols in the evaluation design plan required of the state under the special terms and conditions of the waiver.

In addition, this proposal excludes individuals from 175% to 200% FPL, leaving a significant gap in healthcare access and lack of options for individuals that fall within that income band. Funding is not included in the Governor's budget for either administrative or programmatic costs that would be necessary to implement this bill.

The estimated cost of expansion of the program as proposed in the bill is expected to be significant. Preliminary estimates of the incremental annualized state share of the cost of the expanded eligibility for those just above 200% FPL and up to 225% FPL, with some state cost share could be upwards in the range of $32 million. It is expected that the cost for individuals above that in up to 300% FPL would be significantly higher due to lower federal subsidies available to individuals in this higher income bracket.
With respect to Senate Bill 205, AN ACT ELIMINATING INCOME AND ASSET LIMITS IN THE MED-CONNECT PROGRAM FOR EMPLOYEES WITH DISABILITIES. Senate Bill 205 proposes to eliminate income and asset limits in the Medicaid program for working persons with disabilities. Pursuant to legislation passed last session, the Department of Social Services is currently undertaking a study of the Med-Connect program and potential for expanding program eligibility.

This study is ongoing and the department believes it would be prudent to complete the study and use this information from that work to inform future decisions on that program. Thus, the overall enrollment increase is expected to be significant with annualized costs of over 7.4 million, 14.9 million after factoring in the Medicaid Federal share, projected based on a review of the experience in other states. For these reasons, and without the available appropriations, the department cannot support this bill at this time.

With respect to Senate Bill 206, AN ACT CONCERNING THE EXPANSION OF THE KATIE BECKETT WAIVER PROGRAM. Senate Bill 206 requires DSS too by July 1st of 2024 to expand the Katie Beckett Waiver in an effort to reduce the program's wait list. The Katie Beckett Waiver is a program that allows the state of Connecticut to provide Medicaid services to individuals 21 years of age and younger who have physical disability and may or may not have co-occurring developmental disability, who would normally not qualify financially for Medicaid due to family income.

There are currently 326 individuals on the Katie Beckett Waiver and the average wait time before an individual receives services is five years. There are currently 307 individuals on the wait list for this waiver. If DSS was to expand the waiver, in order to reduce the wait list for waiver services, significant costs would be incurred. For example,
adding 50 people to the waiver would cost approximately $2.6 million per year with a state share of roughly $1.3 million.

Eliminating the wait list entirely would cost approximately $16 million with a state share of $8 million. These estimates do not factor in additional administrative funding that DSS would need in case to hire case managers to account for the increase in cases and infrastructure to handle additional recipients. Because the costs are not accounted for in the Governor's budget, the department cannot support this proposal at this time.

And with respect to House Bill 5240, AN ACT CONCERNING MEDICAID COVERAGE FOR INFERTILITY TREATMENT. House Bill 5240 would require the Department of Social Services to provide Medicaid coverage for medically necessary diagnosis and treatment of infertility to the same extent such coverage is required to be covered by private insurance regulated by the state.

Currently, Medicaid provides coverage and reimbursement for family planning services including those that diagnose treat, and counsel individuals of childbearing age. In general, the state Medicaid program does not typically cover infertility services. The current federal Medicaid interpretation of family planning services benefit category includes the coverage of fertility treatments, and as a result, the fertility services only are categorized are eligible for a 90% federal match.

It should be noted however, that barring a federal update to exist in statutory language to codify the explicit inclusion of fertility treatment services as family planning, federal interpretation could be quickly amended under future federal administrations to reduce the federal match to standard Medicaid
match, which is generally 50% for most eligibility groups.

Additionally, all services that may result from coverage of fertility services, such as result in prenatal, delivery in infant services are and will continue to be eligible for the Medicaid match usually at 50%. While the department appreciates the underlying intent of this bill, the department anticipates that adding coverage for fertility treatments, both the services themselves and those that would likely result from such services would result in significant increase in Medicaid expenditures, which depending on various factors, including implementation date and utilization could result in increasing aggregate costs of about 12.1 million in state fiscal year 2025 that's including state and federal, 2.8 state share, and 58.2 million in state fiscal year 2026, which is a 22.3 million state share, and upwards of 79.1 million when fully annualized in fiscal year 2027 with a 32.5 million state share.

With the anticipated significant increase in expenditures and the lack of funding to cover expansion for fertility treatment services in the Governor's recommended budget, the department cannot support this bill.

And with respect to Senate Bill 306, AN ACT PROVIDING FOR THE PHASED-OUT ELIMINATION OF ASSET LIMITS IN THE HUSKY C PROGRAM. Senate Bill 306 requires the Department of Social Services to increase and then eliminate the asset limits for Husky C over a five-year period.

Husky C provides health coverage to Connecticut residents who are 65 years of age or older, and/or are blind and have a disability. These asset limits are currently at 1,600 for a single adult and 2,400 for married persons. For fiscal year 2025, state costs are projected to be approximately $72 million, 144 million after factoring in the federal share.
If the asset limit is increased from 1,600 to 10,000 for an unmarried person and from 2,400 to 15,000 for married persons, this estimate does not include costs related to long-term services and supports. Costs will continue to increase significantly in subsequent years as the asset limits further decrease in fiscal year 2026 through fiscal year 2028, with asset limits fully eliminated in fiscal year 2029.

The department would also incur significant administrative costs to support the increased volume in program enrollment that would result from these changes. Given the extensive costs and the fact that such costs are not included in the Governor's recommended budget, we cannot support the bill at this time.

And lastly, House Bill 5368, AN ACT CONCERNING MEDICAID COVERAGE OF DIAPERS. This bill would require the department to provide Medicaid reimbursement for diapers to any child that meets the definition of medical necessity with specific health conditions. The department currently provides coverage of diapers under Medicaid for children ages three years and older when diapers are medically necessary in the management of incontinence associated with a medical condition based on the individual needs of each member.

Additionally, to the extent required by federal law and the Social Security Act regarding early and periodic screening, diagnostic, and treatment services, the department provides coverage of diapers under Medicaid for any child under the age of 21 that meets the definition of medical necessity on a case by case basis, taken into account the particular needs of each child.

Under federal regulations, broad coverage of diapers for very young children does not meet the provisions for Medicaid state plan coverage, either under the
medical equipment, devices, and supplies benefit nor under EPSDT nor any Medicaid state plan benefit category.

Given this, the department has significant concerns that the broad coverage outlined in this bill is beyond the scope authorized under federal rules and thus is likely to not receive federal match. For example, the American Association of Pediatrics says 25% of newborns develop diaper dermatitis, otherwise known as diaper rash. A fiscal estimate of providing broad diaper coverage based on October 2023 enrollment numbers for children 0 to 3 would be a total annual gross cost of $119.9 million. Even if DSS was able to claim federal reimbursement on these costs, the resultant state share would be 59.9 million. And this concludes my testimony for today. I'm going to invite my colleagues, Deputy Commissioner, DC Hadler, and the State's Medicaid Director, Gui Woolston, to the table to help answer any questions.

SENATOR LESSER (9TH): Okay. Thank you very much, Deputy Commissioner. That is a lot. I can't say you were a ray of sunshine on all of the proposals before us, but we don't take it personally. Thank you for your testimony. First I do see a lot of people standing, there are some vacant seats, there's some back there, there's some around. Also, I think there's some in the center here.

So we're trying to get to everyone and I know there are a lot of people who are interested in testifying today. I've got some questions before I do that I maybe turn it over to my Co-Chair, Representative Gilchrest, for any opening questions.

REP. GILCHREST (18TH): Great. Thank you, Senator. Thank you, Deputy Commissioner, and the team. Good to see you again. I'm going to start with infertility coverage, so House Bill 5240. Although painful to hear, if you could go over those numbers
again and then just how you got to those numbers, would be helpful.

DEPUTY COMMISSIONER SHANTELLE VARRS: Okay. So we do have a fiscal team that does our fiscal notes for us when these bills come out. They try to get to them as quickly as possible and pull any information that we have available to us. So the numbers that I quoted for that right now with an aggregate cost for state and federal by approximately 12.1 million in state fiscal year 2025, and that doesn't realize it coming into fruition the full fiscal year.

In fiscal year 2026, we are quoting 58.2 million with a $22.3 million state cost share. In fiscal year 2027, it would be 79.1 million where it's fully annualized and that results in a $32.5 million state share. And we can provide any of the backup to these numbers for you, for your information at a later date.

REP. GILCHREST (18TH): Thank you. That first year 12.1 million state and federal, so the state wouldn't be the 12.1, it would be --

DEPUTY COMMISSIONER SHANTELLE VARRS: it would be 2.8 million, I apologize.

REP. GILCHREST (18TH): No, no, that's okay. Could you talk me through how you came to -- is this everyone who would be potentially eligible to use infertility treatment? Because I know in the past that's how fiscal notes have been done. And so, well, again, I appreciate it. Not everybody who is of a certain age would use infertility. So if you could just talk us through how you came to those numbers, that'd be helpful.

DEPUTY COMMISSIONER SHANTELLE VARRS: I'm going to turn this question over to the Medicaid Director, Gui Woolston.
MEDICAID DIRECTOR GUI WOOLSTON: Thank you. Gui Woolston, Medicare director. Nice to see you, Representative. I will answer what I can. There's some detail that I don't have right in front of me now, so we'll follow up in writing. High level, as the written testimony says, the expenses are both for the infertility coverage themselves, which we are assuming would be matched by the feds at 90%. But then there are other costs, the prenatal, the delivery, the services for treating newborns that would be matched at the standard rate, which is typically 50%.

And so the reason that the numbers that my colleagues, Deputy commissioner of ours quoted, are relatively modest in the first year and then grow over time, is the biology of it. It takes time for infertility treatment to result in a child and those costs. So, it's that full package. In terms of the uptake assumptions, we'll have to follow up and we can follow promptly with what we went in. I don't have that right with me in front of me today.

REP. GILCHREST (18TH): Thank you. That's really helpful. Then an additional question with regards to the infertility coverage, what is the process? So you mentioned how under current federal CMS guidance infertility would be included in family planning. What is the process for us to go about including that in our family planning?

DEPUTY COMMISSIONER SHANTELLE VARRS: Gui, can you take that?

MEDICAID DIRECTOR GUI WOOLSTON: Definitely. So we would do a state plan amendment SPA to include that service.

REP. GILCHREST (18TH): Great. Thank you. My next question has to do with the Katie Beckett Waiver. Could you let us know what information do you currently track for those on the Katie Beckett Waiver waiting list?
MEDICAID DIRECTOR GUI WOOLSTON: Let me take that one. Great. So I'll describe high level and then we can follow up with every single field. I don't have the full database in front of me, but high level, when people want to apply to the Katie Beckett Waiver, we do an intake to establish that they meet the financial and clinical, kind of an initial screen, then they're on the waitlist, which can take multiple years, unfortunately. And then when they're up on that waitlist, we do the screening to make sure that they're still eligible for the program, and then we provide the services when they are at the top of the list. In terms of the detail, Representative, on what exactly we collect at each stage, if you want that, we can follow up in writing on that.

REP. GILCHREST (18TH): Yeah, that'd be very helpful. Thank you. That's all I have at this point. Thank you, Senator. Thank you all.

SENATOR LESSER (9TH): Thank you. And I will actually just follow up on that question that Representative Gilchrest asked about the Katie Beckett Waiver. Do you know if we collect any specific information about acuity or the type of condition that's affected? I will just say that $8 million is a lot for a lot of us, but the actual -- if that is, in fact, the state share in terms of eliminating the waitlist, it doesn't seem like an enormous sum of money in this building, but there are lots of other fiscal pressures. Do you collect the information about the specific condition? Is that something that we could monitor?

MEDICAID DIRECTOR GUI WOOLSTON: Yeah, it's a great question, Senator. Obviously, when people are on the waiver, we have the full information because we're paying the bill, so we could give you a statistical portrait of the people who are on the waiver today, what conditions they have. For people who are on the waitlist, I'll need to follow up.
We collect a limited information. We don't collect a ton of information because we don't want to create false expectations. Like why is the state prying into all these details when they're not even in a position to offer services for several years? We do collect some, I'm not sure exactly what we do, but we can follow up with you on that. And on the cost just to talk about that a little bit.

So what we did is we looked at the average cost of serving the people who are on the waiver and just projected that for the waitlist and it's probably a pretty good assumption, and children on average are less expensive than older, even children with disabilities, so I think that's the $53,500 per person served. That's the per capita cost there.

SENATOR LESSER (9TH): Okay. And my understanding is that these other pure states don't have an analogous waitlist, does that sound correct?

MEDICAID DIRECTOR GUI WOOLSTON: It's a great question. There is a lot of variation in the use of waitlists across states for different programs. There are some states that do not, there are some that do. For Katie Beckett in particular, I don't have a good portrait. It's something we could pull if you wanted, but in general, there's just a lot of -- different states make very different choices on these waitlists.

SENATOR LESSER (9TH): Okay. My understanding is that other states in our region don't have a waitlist for an analogous program but it's something that I think we should take a look at it and figure that out. With regard to Med-Connect, I understand -- this is, I think, the first time we've gotten a firm dollar figure from DSS. So this is helpful. 7.4 million is the projected state share, but we're still waiting on the Med-Connect study. Do we know when that study is likely to reach this committee?
DEPUTY COMMISSIONER SHANTELLE VARRS: I'm going to ask my colleague, Deputy Commissioner Peter Hadler, to answer that question.

SENATOR LESSER (9TH): Sure. Thank you.

DEPUTY COMMISSIONER PETER HADLER: Thank you DC Varrs. Senator Lesser, that study is currently just getting underway right now. We anticipate that it'll probably be ready sometime in the summer. I recognize the timing of the legislative session and we couldn't quite get it done in time to be -- right now, that study is actively underway and it will be soon.

SENATOR LESSER (9TH): The summer is not soon for the context of this legislative session. That is not as helpful as you might have hoped. But the 77.4 million and that's projecting an elimination of -- that's the projected state share for eliminating income and assets test.

DEPUTY COMMISSIONER PETER HADLER: Yeah, that was based on a review of experience in other states. This is always a challenging area for us to do estimates in the unknown of who might enroll in a program that we are not certain of the entire population, but that is the estimate that we were able to pull together. Again, I think we are explicitly evaluating that very question right now in the study, so we should have additional information from the results of that study when it's complete.

SENATOR LESSER (9TH): Thank you. Now, with regards to Emergency Medicaid, I appreciate it, Deputy Commissioner, your testimony about how the bill before us might exceed what we're allowed to do under federal law. Certainly, I don't think that was the committee's intent. What we think we're hoping to do would be to, one, codify your existing practices, but also see if there are any areas where we are not going up to the limit allowable under
federal law. So, do you have guidance for us on how to do that on how to make sure that we are using the Emergency Medicaid program where we're possible to extend coverage to folks who would benefit from it? But not certainly, we don't want to exceed federal law in any respect.

DEPUTY COMMISSIONER SHANTELLE VARRS: I'm sure we do have guidance, and we can provide that to you in writing at a later date, but I will ask, Gui Woolston, if he has anything that he would like to add to that.

MEDICAID DIRECTOR GUI WOOLSTON: Yeah, I'll touch on it and Deputy Commissioner Hadler can also chime in. This is a tricky area because the federal rules, while they're clear and they're in the Deputy Commissioner's testimony, they're not entirely self-executing in terms of exactly where we could get to the line.

I think one could review what other states were doing and see what CMS has approved elsewhere. I think that would be one technique. I'll just flag, separate from the -- I guess the testimony had two concerns. One was getting up to the federal line and then the other was the money. But DC Hadler, if you have anything else you want to add on getting up to the line, I'd love to get your within as well.

DEPUTY COMMISSIONER PETER HADLER: No, I would just emphasize that it's really a case-by-case basis really. It's the emergent status of a particular condition that triggers the federal parameters for what's reimbursable. We do review those cases literally one by one to make sure that they could potentially be covered by Emergency Medicaid or not.

So I think that these recommendation, we can continue to survey other states and see if they've actually codified and gotten any feedback from CMS on particular diagnosis is whether that's a framework we could do. We could potentially also do
that outside of a statutory framework if we get that clarification. We can in turn advise our contractor who does these determinations that these are explicit types of situations that we believe would be covered.

SENATOR LESSER (9TH): And then with regard to the substantial fiscal note we heard from you about diapers. I also heard you say that you do approve diapers on a case-by-case basis where medically necessary for children under the age of three. I guess I'm confused about what you're doing currently versus what is -- as I understand it, the both the current practice therefore, and under this bill, there would be medically necessary diaper coverage for kids under the age three, again where medically necessary. How does that go from a case by case -- yeah, I guess I'm trying to figure out how does that become a $60 million fiscal?

MEDICAID DIRECTOR GUI WOOLSTON: Good question, Senator. So in terms of what we do today, the current policy, one needs a specific medical diagnosis and merely having a young child like you and I do, under current policy is not considered a medical reason for needing a diaper. So this would be the child has a medical condition that prevents her from -- there's something specific to the child, not just kind of generally all two-year-olds or all one-year-olds need a diaper.

In terms of the fiscal note, and this, I will confess, we were trying to read the statute carefully and thoroughly and it was our reading that the bill -- excuse me, the bill, not the statute, the statute was pushing for a potentially broad coverage of diapers for as broad a group as possible, and so what we did was we took that the estimate of the percent of newborns who developed diaper rash, which is 25%, took the population that we're covering, took the cost of diapers, number of days -- diapers are expensive, hence the goal of the bill, and that we cover a lot of children.
So that's the origin of that note. The extent to which the bill it was intending to have a more narrow focus, narrower than merely diaper rash, which affects one in four infants. The note would be lower, obviously, then we would be serving fewer children.

SENATOR LESSER (9TH): That is helpful. And I can't speak for the proponent of the bill, but I think she can speak for herself, but I suspect that it was intended to be narrower than covering every child with a diaper rash, but it was for more more acute conditions. But what that looks like and how we could help spell that out, I will defer to --

MEDICAID DIRECTOR GUI WOOLSTON: Needless to say, we commit to working and we have worked with Rep. Gilchrest a bit on this in the fall and we'll commit to continuing to help explore as you dial up or down the coverage, the associated costs.

SENATOR LESSER (9TH): And so with regard to the infertility, the bill, as I understand your concern that that's -- it is currently an 80% match and you're partly concerned that the federal support could change in a future administration that doesn't want to continue that. I mean, is that true of a lot of other programs that we fund through the Medicaid program?

DEPUTY COMMISSIONER SHANTELLE VARRS: So, just to clarify, it's 90% match, and so I will actually Gui take a stab at that. Thank you.

MEDICAID DIRECTOR GUI WOOLSTON: Yeah, great question. Of course, any policy could change in the future. No one has a crystal ball. There's some things that are set in federal statute. So for example, the Medicaid, the Obamacare Expansion, Husky D that statute to require an Act of Congress signed by the president override by the veto. So that feels much more secure than merely a policy
decision that CMS made it. It's not a federal rule or regulation. It's a kind of a policy memo that they've written.

So I think the point of the testimony here, Senator, was just the amount of legal or bureaucratic. It wouldn't take much for a future administration to issue a new policy memo, and we're highlighting that, that potential risk. To be clear, the fiscal note assumes the 90% coverage for the services themselves.

SENATOR LESSTER (9TH): A 90% federal match is a tough thing to turn away, but I hear that. So with regard to Husky C, those numbers were high, and so it would be really helpful, perhaps not in this forum, but if you could follow up with the committee and provide what financial analysis you used to come up with that figure, that would be helpful for us.

DEPUTY COMMISSIONER SHANTELLE VARRS: Certainly, Senator Lesser.

SENATOR LESSTER (9TH): Thank you. And then it occurs to me that doing asset verifications is probably administratively complex and difficult and expensive for the department to do. So are there savings that we could realize by doing fewer of them?

DEPUTY COMMISSIONER SHANTELLE VARRS: Thank you for that question, Senator Lesser. Can Deputy Commissioner, DC Hadler, take care of that? Thank you.

DEPUTY COMMISSIONER PETER HADLER: Thank you. You're correct, Senator Lesser. Asset verification is a complex process. I would just note that if there is any asset test that some evaluation will still need to be done, and so therefore, the administrative burden wouldn't reduce. If you eliminate them entirely, that would be a simplification that would reduce administrative burden.
SENATOR LESSER (9TH): Great. Thank you. I think that's all I have, but I bet you there are questions from members of the committee. Senator Seminara.

SENATOR SEMINARA (8TH): You asked a number of my questions, but I still have one. On the Katie Beckett Waiver, can somebody just clarify for me that is not for -- in order for someone to put in an application on that waiver, there is no financial means testing on that. Is that correct?

MEDICAID DIRECTOR GUI WOOLSTON: I can take that one. So, first of all, anyone can apply for anything they want, but to get off the waitlist and be eligible, it's a tiny bit subtle. And so if you look at me looking at my phone, I'm just pulling up the answer. So Katie Beckett covers the child, we do not look at the income or assets of the parents. We do look at the assets of the child and there is a limit of $1000 asset test for the child. Was that your question, Senator?

SENATOR SEMINARA (8TH): That was my question. Thank you so very much.

SENATOR LESSER (9TH): Thank you, Senator. Representative Dathan.

REP. DATHAN (142ND): Thank you very much, Mr. Chair, and it's nice to see everybody from DSS and your team today. Just a couple of follow up. I'm going to start with Katie Beckett Waiver because we were just talking about that. My understanding at the Katie Beckett Waiver, it is based on a disability rather than an IQ or any other measure of IDD. Is that correct?

MEDICAID DIRECTOR GUI WOOLSTON: Yes, Representative.

REP. DATHAN (142ND): Sorry. Thank you. How do you determine who is able to get on that waitlist if
there is no IQ or other? Is it based on a recommendation from a pediatrician?

MEDICAID DIRECTOR GUI WOOLSTON: Great. Good question. Yeah, so the waiver, I'm looking down to make sure I get the words exactly right, cover people who have a physical disability and may or may not have a co-occurring developmental disability. So on the physical disability side, there is a process where there is an assessment done by clinicians, and that includes a functional assessment of the child and we can get you the details of how that works, if that's useful. But high level, it's verifying that the -- obviously every child has needs, but it's verifying that the needs are, are high enough to justify to meet the standard for the waiver.

REP. DATHAN (142ND): So these are severely disabled children, you're saying. Is that right?

MEDICAID DIRECTOR GUI WOOLSTON: Yeah, I'm only hesitating. The word severe may have definition. I can maybe follow up with the exact criteria.

REP. DATHAN (142ND): The criteria. Okay.

MEDICAID DIRECTOR GUI WOOLSTON: Yeah.

REP. DATHAN (142ND): Because this is not a means test, would any of these children who potentially have an IQ below 69 be on two waiting lists? The Katie Beckett as well as another waiting list.

MEDICAID DIRECTOR GUI WOOLSTON: Yes.

REP. DATHAN (142ND): So that is a possibility.

MEDICAID DIRECTOR GUI WOOLSTON: It is. Yeah.

REP. DATHAN (142ND): Okay. And then also along those lines, if a child who is on the waiting list of those 307 children, if there is someone who is
end of life, they're not sure the ability of that child living for long time may not -- they may never get on to receive it. Is there any sort of account taken for children that might be needing that extra care for the last pushing their life rather than sitting on that waitlist and never getting services?

MEDICAID DIRECTOR GUI WOOLSTON: It's a great question and obviously really tough situation for the child and the family. So the waitlist is if you meet the criteria, the financial and the clinical, you're on the waitlist and there's not a tier based on high need and extra high need.

REP. DATHAN (142ND): So it's about $53,000 per child per year, is the estimate?

MEDICAID DIRECTOR GUI WOOLSTON: Yeah.

REP. DATHAN (142ND): And what kind of services do those entail?

MEDICAID DIRECTOR GUI WOOLSTON: So it's case management provided by a home health agency, and then the full range of Medicaid coverage services; so, inpatient, physician, outpatient, prescription, drugs, non-emergency medical transportation, dental, whole package you get if you're on the program.

REP. DATHAN (142ND): Because there's no means testing, and if a child is insured with an outside insured through a parent's plan, is there any sort of offset? Does this help supplement where you may have lower costs per child per year if it's an additional benefit?

MEDICAID DIRECTOR GUI WOOLSTON: Yeah, great question. And just reminder, there is that asset test for the child, so there's a little bit of means testing. But the answer to your question is yes, the extent to which a child has private coverage that does reduce our costs. We have a third-party liability team that helps make sure that Medicaid is
the last payer, so whether someone has -- not in this case, but if someone has Medicare or commercial insurance, Medicaid pays last. I'll just flag, for your Representative, that that's baked in -- our estimated cost of 53-and-a-half thousand dollars that reflects the cost both for people who only have Medicaid and for people who have Medicaid and commercial.

REP. DATHAN (142ND): Okay. That's helpful and it's shocking to see that we're one of the only states in the country that do have this. It's with not a huge price tag. I do think it's something that we should consider. Kind of shifting gears if I may to talk about the differences between the Med-Connect and Husky C. In terms of the Med-Connect program we have, I understand there is a study going on, but we do have asset limits that are comparable to our neighboring states that would receive full Medicaid coverage. Is that correct?

DEPUTY COMMISSIONER PETER HADLER: I don't have that comparison at hand right now to say that we are right in line with other states, but my general recollection is that yes, we are in line with Med-Connect asset limits with other states. But I can give you that more specifically --

REP. DATHAN (142ND): And just to clarify, Med-Connect is for adults under the age of 65. Is that right? Or is it for any sort of working adult? Is there any age limitations?

DEPUTY COMMISSIONER PETER HADLER: I don't have the answer to that off the top of my head. I can also get that back to you.

REP. DATHAN (142ND): That's all right. What would be helpful is if we could have an understanding, things like -- I think we saw something in MAPOC that was an analysis of what's covered under Med-Connect. And I'd like to get an understanding because I'm looking at SB 205 and then also SB 306
and looking at those in together on how we are able to phase out or get more in line with other states for our Husky C program and also how we can look at our asset limits under the Med-Connect program so that we can expand those two together and just get a better understanding of what other states are doing in comparison. I think you did something for MAPOC on this. Maybe I'm conflating items, but I'm trying to remember. It would be great if the agency could let us know a little bit so we can kind of look at those two items together. Does that make sense?

DEPUTY COMMISSIONER PETER HADLER: It does. I do want to note right that the study is ongoing with Med-Connect and it will have answers to these questions that you've just posed like the state comparisons and the information around Med-Connect and the potential for making changes and what that would look like projected -- changes in enrollment and associated costs for that.

REP. DATHAN (142ND): Okay. And when's that study? Can you remind me when that's going to be released?

DEPUTY COMMISSIONER PETER HADLER: We're anticipating it'll be probably June or July.

REP. DATHAN (142ND): June and July. Okay. That's helpful. I did have one question for the infertility treatment. You talk about bringing it in parity with our insurance. Could you just explain to all the watchers at home what that means in terms of what services are covered and how folks get to qualify to receive those services?

DEPUTY COMMISSIONER SHANTELLE VARRS: Gui, can you answer that, please?

MEDICAID DIRECTOR GUI WOOLSTON: Sure. Happy to at least try. And I know there's a separate proposal to change what is covered by commercial insurance and the fertility space that is before the legislature. But high level, and repeat and tell me
if I'm not answering the question, this would be including things like coverage for IDF, the extraction, the implantation. Those would be examples of services that are covered by a commercial plan that are not covered today by Medicaid. Is that where you're going or did I not understand the question?

REP. DATHAN (142ND): Similar. I was trying to understand, folks in order to receive treatment, do they have to say that they've tried for several cycles or is there any sort of indication that you could say because of somebody's situation that fertility just cannot happen for one reason or another?

MEDICAID DIRECTOR GUI WOOLSTON: Right. Good question. I am not an expert on what the commercial plans are required to cover today. I know our team and we are making the fiscal note research that, so let me -- in the more general follow up on the fiscal note on this, let us include the mandates for the coverage on the commercial side as part of our answer.

REP. DATHAN (142ND): Great. Thank you so much. I think that's it. Thank you, Mr. Chairman.

SENATOR LESSER (9TH): Thank you, Representative. Representative Hughes.

REP. HUGHES (135TH): Thank you, Mr. Chair. Going back to a couple of these areas in the high costs that are estimated. I've heard all the comments about the asset limits for SB 306 and SB 205. Would the department be amenable to again beginning that phase out as part of our policy planning where we can actually bring those actual costs in line? Because those projected costs seem ridiculously high for people that are already working.

Again, we're not talking about necessarily a whole bunch of new folks coming in but really relieving
that anxiety of those folks that testified for hours and hours last year and I'm sure we'll testify this year that we are limiting their scope of economic security, professional practice, all those kinds of things with these ridiculously low assets and income limits that haven't been updated in decades.

DEPUTY COMMISSIONER SHANTELLE VARRS:  Representative Hughes, is this in response to Senate Bill 205?

REP. HUGHES (135TH):  Yes.

DEPUTY COMMISSIONER SHANTELLE VARRS:  Okay. Deputy Commissioner Hadler, can you please answer that question?

DEPUTY COMMISSIONER PETER HADLER:  Yes, I can [inaudible 00:45:23] Thank you, Representative Hughes. I think that we do have concerns with making the changes without having a more firm understanding of what the potential costs would be. We recognize that there definitely would be costs every time you adjust eligibility to expand coverage, it increases enrollment and there are corresponding costs with that. I do think that the study that we're doing for Med-Connect will help to inform that conversation and give us a better sense of what certain changes to the eligibility of the program, what kind of enrollment and corresponding costs we can expect from that.

REP. HUGHES (135TH):  Okay. I don't want to speak for the proponent of the bill. Switching gears to the Medicaid reimbursement for young children, medically necessary. We're really talking about those Medicaid eligible children that are coming out of Children's Hospital neonics with severe compromised medical conditions and the family is under severe stress.

They're Medicaid eligible and they're taking care of new baby and maybe not for forever, but we want those diapers could be reimbursed as one way of,
again, relieving the stress, focusing on the care of that baby at home, and often there are other children. So this is very, very compromised baby that we want to help. It doesn't seem like this cost estimate was really focused on how many are discharged from Children's Hospitals and that kind of thing. Can you tell me about how you got to that cost estimate, 59 million?

DEPUTY COMMISSIONER SHANTELLE VARRS: Representative Hughes, that is correct. It was a broad estimate and I will turn over to Gui Woolston to add any additional information.

MEDICAID DIRECTOR GUI WOOLSTON: Yeah, Representative, you got it right. And I just want to say again, we are very excited to work with you all to help size. Your different proposals will obviously have different costs and will help different amounts of people. We were trying to read the words as written in a bill. If we read them wrong or if you know the different legislative intent, would look forward to working with you all.

Needless to say, a narrow reading would result in a much lower fiscal note. I think from our perspective, what we want to do is help you all think through -- given your intent and the coverage that you're looking to support, thinking through the cost when you're deciding on the budget and others, you can make good choices and so look forward to working with you on that. Thanks.

SENATOR LESSER (9TH): Are you all done, Representative Hughes? Okay. She's not here.

MEDICAID DIRECTOR GUI WOOLSTON: So hopefully nothing I said.

SENATOR LESSER (9TH): Don't take it personally. Representative Gilchrest.
REP. GILCHREST (18TH): Great. Thank you. Just one follow-up question with regards to the conversation on infertility, which I so appreciate. As you're getting us follow-up information, was hoping you could also get us follow-up information on those -- so not the 12.1 million for this first year, but those two out years, where you -- correct me if I'm wrong, but you included the prenatal and the labor costs.

DEPUTY COMMISSIONER SHANTELLE VARRS: Correct.

REP. GILCHREST (18TH): Any additional cost or it was just those two pieces, the prenatal and the labor?

DEPUTY COMMISSIONER SHANTELLE VARRS: I'm going to ask our CFO Nick Venditto to answer this question.

CFO NICHOLAS VENDITTO: Hi. Thank you. Nick Venditto, Chief Financial Officer at DSS. So really the estimate included three parts, the infertility services, which we talked about the estimate assumed a 90% federal match on those, and then the two real large parts that compound as the program would advance are; the prenatal delivery and postpartum coverage. But also we included the additional births and the additional children being covered under Husky A at a regular 50% match.

And as you have more births onto the Medicaid program, those costs compound in the out years of the estimate matched at 50% like a normal standard Husky A child would be today. And the average PMPM for a Husky A child ranges from 300 to $320 per member per month. So that's why you start to see those higher costs in the out years of the estimate once things start to fully annualize and you pick up the additional coverage of the additional children.

REP. GILCHREST (18TH): Thank you. So it's the infertility coverage, it's the prenatal and delivery
-- no, prenatal -- delivery and postpartum, and then there also is a cost in there for the Husky A child.

CFO NICHOLAS VENDITTO: Right. The resulting births that we're assuming a portion of them or the majority of them would stay on Medicaid under Husky A going forward.

REP. GILCHREST (18TH): So some might and maybe a large majority, but we don't know how many would, and we also don't know how many of the adults would stand for the postpartum. So I guess instead of getting into those weeds, could you when you follow up break out that fiscal note into those? So I'd like to be able to see the infertility treatment cost, the prenatal delivery and postpartum cost, and the Husky A child cost for those two out years, would be fantastic in that follow-up.

DEPUTY COMMISSIONER SHANTELLE VARRS: Certainly, Representative Gilchrest.

REP. GILCHREST (18TH): Thank you very much.

SENATOR LESSER (9TH): Thank you. Any other questions for members of the committee? Seeing none, thank you for being here today and we've got some follow-up conversations that we're going to have to have.

DEPUTY COMMISSIONER SHANTELLE VARRS: Thank you. Have a good one.

SENATOR LESSER (9TH): Next up, I believe just under the first-hour wire, we have Commissioner -- is Commissioner Porter here? Oh, hi Commissioner Porter. Good to see you. From the Department of Aging Disability Services.

SENATOR SEMINARA (8TH): Chair, may I have a point of personal privilege for one second?

SENATOR LESSER (9TH): You may, Senator.
SENATOR SEMINARA (8TH): Thank you. Excuse me. I just wanted to say that I am so happy to have sign interpreters in this room today and that I am hopeful that in the future we might be -- I know they're here specifically for a bill that we're hearing, but I'm hoping in the future that we may provide that service on an ongoing basis, so for those who are impaired, are able to follow our testimony and our committee process in the future. So, thank you so much.

SENATOR LESSER (9TH): Completely agree, Senator Seminara. Thank you. We've got broad agreement on that in this room as well, it looks like. And with that, Commissioner Porter, the floor is yours. Good to see you.

CMMR. AMY PORTER: Thank you. Senator Lesser, Representative Gilchrest, Senator Seminara, Representative Case, and distinguished members of the Human Services Committee, my name is Amy Porter and I'm the Commissioner for the Department of Aging and Disability Services. And today I'm here to testify on House Bill 5241, AN ACT ESTABLISHING A BUREAU COORDINATING SERVICES FOR DEAF, HARD OF HEARING OR DEAFBLIND PERSONS.

We appreciate the committee's focus on access, particularly for this population and we share the concerns about access. For those of you who may not be familiar with our agency, we have four major program areas. We have the Bureau of Disability Determination Services, the Bureau of Aging Services, which houses both our State Unit on Aging and our Long Term Care Ombudsman Program, we have the Bureau of Education and Services for the Blind, and the Bureau of Rehabilitation Services.

This bill proposes adding a fifth bureau within ADS and directs me to hire an executive director and an administrative assistant. We do have some concerns that this structure might be incongruous with our
existing bureaus in size and scope and might raise some parity issues in terms of compensation and workloads with our existing bureau leadership, but we welcome working with the committee to evaluate different structures that would accomplish the goals of this bill.

It might be helpful also to understand some of the work that we're already doing specific to the duties outlined in the bill. The good news is we are providing information and referral services, including a website. We are doing the interpreter registration and issuing ID cards and responding to various consumer concerns and assistance requests. Specifically, within our community living division in the Bureau of Rehab Services, we do have a deaf services unit comprised of a full-time counselor and a full-time human services advocate supported by a part-time interpreter.

Our counselor provides counseling related to special language, communication, and socio-economic problems that may be specific to individuals who are deaf or hard of hearing and their families. This position is funded through our social services block grant, and it's limited to working with individuals who are experiencing two or more barriers to self-sufficiency and with household incomes at or below 150% of the federal poverty level.

Our human services advocate covers a diverse range of activities, including educational support, legal advocacy, housing assistance, and collaboration with various professionals and organizations to ensure accessibility and inclusion. And within our Bureau of Education and Services for the Blind, we have a full-time social worker who specifically supports individuals who are deaf-blind. We also have staff sprinkled throughout our other programs within the bureau that serve sort of cross agency. So our vocational rehabilitation programs, our children's services program through BESB, our Connecticut Tech Act program, all of them work to make sure that we
provide accessible services and do include individuals who are deaf, hard of hearing and deaf-blind on their caseloads.

We also do have a number of contracts that we manage. So we have contracts with each of the five centers for independent living and part of the budget to them is funding to increase access, interpreter access in particular, to core services that they provide. We do have community inclusion contracts for adults who are deaf-blind. And I know one of the things in the list of proposed duties is a public awareness campaign. So we are working with the American School for the Deaf on their campaign.

The bill requires the new director to consult with the advisory board for persons who are deaf, hard of hearing, and deaf-blind. Many of whom are here in the room today and I am a member of that board. We work very actively. They're a great group, really designed to address policy changes that might be necessary to better support the community and we're committed to continuing that work with them.

So all of those services we're able to support. There are a couple of areas that we don't currently provide and I'd like to share some concerns related to those areas. One would be the new director. It would be asked to coordinate education and training initiatives in two major areas. So the first is sharing best practices with public safety and health officials, first responders, this is a very broad requirement, and it's a pretty extensive scope there, spanning public health and safety sectors. So that may be unachievable for a single leadership position.

The second area is training for interpreters to maintain or enhance their skills. There's a national shortage of interpreters, that individuals in this room are affected by every day, and this does create many access. We agree that training is
critical, mentoring, internships, all of those components.

We're just not sure where the best place to offer the training and the mentoring and the internships because we don’t have that interpreting experience. So there is the Connecticut Registry of Interpreters for the Deaf and we can work with the advisory board to try to better understand that piece, but we're just not sure that's the best role and function for ADS.

And then Section 2 of the bill requires us to convene a working group on access to health care by persons who are deaf, hard of hearing, or deaf-blind. So to avoid any unnecessary duplication, we wanted to note that our department has used ARPA dollars. We did a million-dollar investment with the American School for the Deaf to identify communication, access challenges, and to develop solutions. So, Phase 1, they gathered information, they finished a needs assessment, and they concluded that last month.

They're starting Phase 2 now, which involves addressing some of those needs, including significant challenges in emergency, medical, and hospital settings. Additionally, our human service advocate has been part of an active workgroup with again, many of the folks here in this room today who are are very strong advocates and working with the Connecticut Hospital Association on this issue. So we don't want to duplicate, create a new working group when there are already effective groups out there that we would be happy to work with.

And finally, I would like to note that the bill does have unbudgeted costs, so any additional staffing or other requirements would need to be addressed in the final budget adjustment for fiscal year '25. I want to thank you for your coordination of and your support for the needs of individuals who are deaf,
hard of hearing, and deaf-blind, and I'd be happy to answer any questions.

SENATOR LESSER (9TH): Thank you, Commissioner, for your testimony. And certainly, we would like to work with you on understanding the fiscal note and figuring out how we can address the cost anticipated in this bill. But broadly speaking, and I think we're going to hear from a lot of people today about this topic, I think there's a sense that over the last few years due to a series of budget cuts, there's been a drop in services that have been available to the deaf, deaf-blind, and hard of hearing communities.

And can you just speak to -- that is and so far as you can speak to the Department of Aging Disability Services, just what had been offered and how the department is trying to make do with less because I think this bill is intended to in part respond to that and to make sure that we're expanding services.

CMMR. AMY PORTER: Great Thank you for the question. And then I will do my best to answer that. So, there's probably two points in time that are relevant to answer that question. One is the creation of our agency which happened back in 2011. There was a Commission on Deaf and Hearing Impaired at the time, and they were brought into our agency. Our agency was created with multiple programs coming together at that point.

So there was an independent commission at that point, and then as of July 2011, they became part of our structure and there was an executive director position and an executive secretary position that were eliminated as part of that merger. And then in 2016, there was an interpreting unit that because of budget cuts, because of changes in policy, there was a change to privatize interpreter services in the state. And those services are now provided through a host of private providers available to individuals
in the community and to organizations who have to provide those services.

SENATOR LESSER (9TH): Thank you. Are there questions for members of the committee? Yes, Representative Cook.

REP. COOK (65TH): Thank you very much. Nice to see you, Commissioner, and great to see all of you that are out today. My question adds to the services for interpreters. As we know that it did privatize for a variety of reasons, whether we may or may not have supported that. Because we do know that there is a shortage, do you know now how many interpreters are in the state of Connecticut that are available for us for hire off the top of your head or an approximate?

CMMR. AMY PORTER: I don't have the exact number and it's complicated by the fact that there are interpreters who are available in state and there are interpreters who might work for an out of state company who are available remotely. And so in order to provide those services remotely, they still have to be on our registry. We know the number of individuals on our registry, which I believe is about 200 interpreters, but they're not all available here in Connecticut.

REP. COOK (65TH): So I think that to the good Senator's point about having interpreters during our public hearings, the shortage creates a hurdle for that. Would that be correct?

CMMR. AMY PORTER: Yes.

REP. COOK (65TH): And then budgetary?

CMMR. AMY PORTER: Yes, I think there are both elements to that being able to find enough interpreters to be available for any public meeting that you might be interested in providing access for and then there's a budgetary component to that.
REP. COOK (65TH): So then my question would be if folks that needed the service and were able to interpret or know somebody that was able to interpret, would that be legal upon our laws?

CMMR. AMY PORTER: I'm not sure I understand the question.

REP. COOK (65TH): So if I take Harvey and Harvey was able to interpret for us, would we be able to allow him or does he have to go through all of the certifications for that?

CMMR. AMY PORTER: An individual has to be a registered interpreter and meet certain qualifications before they can interpret, except for settings like church settings. There are a few small community exemptions, but for the most part, it has to be an individual who is qualified and has registered with the state of Connecticut.

REP. COOK (65TH): So as we're trying to bridge the gap and I hear you not pushing back, but with concerns about a different branch or a different addition to your department. And listening to some of the things that you say that are already encompassed in what you do. Is there room for growth? Is there room for bettering those services and offering better service to the folks that need what they might feel are being missed?

CMMR. AMY PORTER: Yeah. I think we are very interested in trying to find ways to increase access for our entire population and individuals who are deaf, hard of hearing, and deaf-blind face significant challenges for the variety of reasons that we've talked about. The shortage of interpreters, the lack of understanding, the access on television.

That's one of the things that's proposed in the bill, making sure -- for those of you who can see
the screen behind me, there is an interpreter, a picture in picture, which is fabulous, but that's not always the case. So being able to continue to educate, work with the advisory board to help improve access that is the right of this population.

REP. COOK (65TH): So, in full disclosure, I'm honored to sit on their board and I think that the simple thing that they asked for, which seems to be the most complicated is equality, so I would hope that whatever we can do, we make sure that that happens. So, thank you.

CMMR. AMY PORTER: All right. Thank you.

SENATOR LESSER (9TH): Thank you, Representative. Representative Gilchrest.

REP. GILCHREST (18TH): Great. Thank you, Senator. Good to see you.

CMMR. AMY PORTER: Good to see you.

REP. GILCHREST (18TH): My question also has to do with this bill, and I'm sure we will -- I know we are going to hear testimony from folks and I've already had the opportunity to speak with many who have been impacted by our lack of interpreter services.

And so I want to take one example and would love you to talk us through what it would have looked like prior to 2016, and now what I'm being told it looks or maybe you could explain what it looks like. So, when someone is in the hospital and needs interpreter services, what did it look like prior to 2016 when you had an interpreter unit versus today? What would the hospital do?

CMMR. AMY PORTER: Yeah. Great question. There were two primary interpreting agencies prior to 2016, there was the commission which then became part of our agency, which has changed names often.
So I don't want to use our agency name for that particular time period, but there was Life Bridge, which was a community provider and the state-run interpreting unit. If an individual were in the emergency room during the day, during regular work hours, they could call one of those two entities and the two entities worked with one another to -- when they weren't able to provide services, they could contact the other service.

The hospital might have used video remote interpreting. They might have done that on their own. If it was after hours, there was an afterhours program, but it was not strong. There were not a lot of individuals available to provide. There were some interpreters who tried to make themselves available as much as they could, but the afterhours program was not strong.

REP. GILCHREST (18TH): Thank you. And so today, what does it look like?

CMMR. AMY PORTER: Today, there's no state run interpreting unit, so the interpreting companies are all listed on 211. If you call or on their website and people can access the interpreters through those organizations. So, some interpreters work for multiple agencies, some work for just one agency, but it's going through the private entity who manages the interpreting services, is the process now.

REP. GILCHREST (18TH): Great. Thank you. And I'm sure we'll hear today from folks on their goals with this bill of what that would look like going forward. As you read it, what do you see the role your agency being with regards to interpretation services?

CMMR. AMY PORTER: So I didn't see anything in the bill about interpreting services other than the piece where it's coordinating education and training around interpreters and making available
internships, mentorships, things like that. I did not see anything specific to interpreter services.

CMMR. AMY PORTER: Okay, thank you.

SENATOR LESSER (9TH): Thank you. Other questions from members of the committee? If not, thank you very much for your testimony today.

CMMR. AMY PORTER: Thank you.

SENATOR LESSER (9TH): Next, we're going to hear from Harvey Corson, followed by Senator Cohen. Good afternoon.

DR. HARVEY CORSON: Good day. I'm Dr. Harvey Corson and I am here this morning to testify on the Raised Bill HB 5241. I'd like to begin by talk about how this all happened and give you a little bit of background. The state advisory board for persons who are deaf, hard of hearing, and deaf-blind, established task force to study the needs and there was a de needs assessment done for people who are deaf, deaf-blind, hard of hearing in April of 2023.

There were two functions. The first was the study the results of the Connecticut statewide needs assessment report done in February of 2022 by any of these strategies, and the research report done by our own state agency here serving people who are deaf, deaf-blind, and hard of hearing.

That report is called the report of state agencies and that was done in September of 2021, and that research was provided by Mary Fitzpatrick, who is the principal analyst here at the Connecticut General Assembly. Okay. So that's where we stand. That's where we got the information so that we could then make these recommendations.

Now, the second purpose of the task force was to develop and recommend potential legislation. In summary, the findings indicated that deaf, deaf-
blind, and hard of hearing people here in Connecticut are not satisfied with the current services.

Also, there is not much accessible information and the resources to provide the information that is comparable to the information and resources that are available to the general population for their everyday lives. This was especially notable during the COVID pandemic.

During the fiscal year 2021-2022, Governor Lamont recognized the difficulties experienced by thousands of people in our state during this pandemic. He remarked that the deaf community was "hit particularly hard during the pandemic". Therefore, we are seeing many different things happening because of the lack of funding support from the federal and state agencies to make things happen.

One of the things happened was this wonderful report that was done from interview strategies that was able to then help us establish this and proposed legislation and for setting up this bureau under the Aging and Disability Services. They do have other bureaus, as was mentioned, in their programs. They have leaders that Commissioner Porter spoke to, but currently we have nothing that exists in Connecticut on that level for our population.

You may have a couple of people here, a couple of people there, but they are separated out and there is no cohesive group providing this information in that agency and so forth, that needs to be focused on the needs of individuals who are deaf, deaf-blind, and hard of hearing. And that's why we have all these people here to share their experience and their stories as to what has happened. And that is why we members of this task force wanted to be able to be forward-looking, that is the point of this proposal because we want to improve communication access with program leadership in that agency.
That's in a nutshell of what we're talking about here. And I thank you.

SENATOR LESSER (9TH): Thank you for your testimony this afternoon and thank you, Doctor. It is very helpful. So, one question is that we always have is on the alternatives we have, we can focus on direct services or we can improve coordinations. And can you help us figure out why -- walk us through the choices that we have about improving services to the community?

DR. HARVEY CORSON: Wow. A lot of possible choices that occurred in the past and we're not going to talk about what is the best, but I think what was the problem is there was just an issue of them cutting services without looking at what was the best benefit. I was a former director of Schools for the Deaf in four different states including here in Connecticut and I had to deal with budgets and budget cuts. It's not a pleasant experience.

I think the state itself and the agency that was involved made some decisions that had severe negative impacts on our community here, and we are trying to live through them. We are surviving, but many people -- it was not a very good experience. And so those decisions that were made, whether they were right or wrong, they were made and we've had to accept them because we are part of a democratic society.

I am telling you that the stories that I think you're going to hear today are experiences that these people had. We are a very small minority in terms of population and we are considered "a low incidence population" and we don't have a voice and we haven't had one for many years. We have people telling us they're going to take care of us and do things for us, but we have learned from a very expensive experience over these past few years that this has not worked and it's going to take time.
We need time to educate people. We need to educate people about what our needs are and how we can provide better services. So basically, to answer your question, there are some things that need to be done with direct service, but there are other things to avoid crazy outrageous costs that could be coordinate depending on what priorities are established.

SENATOR LESSER (9TH): Thank you for that answer. I see my Co-Chair Representative Gilchrest has a question.

REP. GILCHREST (18TH): Hello, Doctor. So good to see you. Thank you for being here today. Since you said and shared your years of experience, I want to ask you again about this state run interpretation services versus the when it became privatized. Do you think that the bill before us will help address the concerns that have come from it being a privatized service in the state?

DR. HARVEY CORSON: I am sure by hiring a new program director, as we have mentioned, an executive director for that bureau, that program director can then help to do an assessment with the core group of experts within their agencies and elsewhere to get a better idea of what is -- first of all, I am a professional, I understand what the pros and cons are. Let me tell you from my own experience.

When we had the former commission on the Deaf and Hearing Impaired, we used to say hearing impaired, we don't say hearing impaired any longer, we now say hard of hearing, however, but what was missing is at that point, we did not focus enough on the deaf-blind community and now we have incorporated them within our community and to make sure that their needs are also being met. So that's why we are saying deaf, deaf-blind, and hard of hearing because all three groups need to be given access. And the one thing that we all have in common is some form of hearing loss to varying degrees.
Now, deaf-blind individuals are also a part of our community. We use the same form of language. Now, they may need to depend on a more tactical way of accessing the language while we're using a visual access. All right. So you may be seeing that because they can't see.

So, it's an amazing thing that they can do and it's wonderful how people can be creative in being able to survive. But the reason I'm saying this is because at that time, I believe it was 2012, we had at least 40 people in the interpreting unit. Two of them were coordinators and the others were interpreters and they took care of the interpreting needs for the state with the scheduling that would happen when calls were received.

Now, I was not involved in that day-to-day operation. I, at that time, was working at the American School for the Deaf, and then after I retired in 2006, I pretty much have been focused on doing advocacy since that time. I am aware of some of the things that had happened over the years but anyway, to get back to the point in 2016, I temporarily relocated back into Pennsylvania and stayed in the Philadelphia area and provided services like an executive director would do for the Pennsylvania School for the deaf.

I was a full-time advocate for them, working with the state legislature and so on and so forth and it was an 18 month contract. That was a way for me and my wife to be able to give back to our home state of Pennsylvania. We then moved back here to Connecticut in the fall of 2017. And while I was gone, that's when I learned the news of what had happened and that the interpreting unit from the state had been cut and I was in shock because we thought we had this wonderful reputation and things were working -- we had this wonderful group of interpreters who were professional. They were the top in their field in this country.
When I got back here to Connecticut, I was learning about the different issues and the different problems with access, and they have continued from day one. I'm not here to say what is bad or good. I was not here at that time to comment on that decision, but I'm looking at an overall perspective from 2016 to what I'm seeing right now and we are seeing numerous complaints that have increased and they're not getting services.

So for example, private agencies. These private agencies do not have any kind of coordination as before they could contact the state. It was a one place that they had to contact. Now, you're talking about a lot of different agencies. Some are located in Connecticut, some of them are outside of Connecticut, but there is no coordination. There's no transfer when the needs are expressed, many people don't even know who the interpreting agencies are. They say there's a list but we don't know who these people are.

I've been working with our president of the Connecticut Association of the Deaf, Luisa Gasco-Soboleski, and she is developing on her own these lists of who these vendors are and trying to get this information out to all of the necessary individuals. We are a volunteer organization, we shouldn't be doing this. This should be done by a state agency. The observation that I am making is that there -- why is it that we have to do this on our own?

I was president of the Connecticut Association of the Deaf. I received many calls that I knew should have been going to certain state agencies and I was having to provide that information referral. I talked with Luisa and she's doing the exact same thing now. Why should we be doing this? Why isn't the state agency doing this? We are volunteers. We're wearing out. We're not going to live forever. So who is going to take our place? I'm trying to
bring a sense of realism to you as to what we are experiencing. I'm want to be positive. I want to be honest, but I need to be realistic and the picture is not necessarily that good.

REP. GILCHREST (18TH): Thank you very much.

SENATOR LESSER (9TH): Thank you, Representative. Representative Cook.

REP. COOK (65TH): Harvey? Harvey.

SENATOR LESSER (9TH): No, we're not done with you. Unfortunately, for your plans this afternoon, you got a lot of people who want to ask you questions.

REP. COOK (65TH): Okay. Harvey, you can't sneak away that fast. Hello. First, thank you so much for your dedication to what you know is the right direction for the population that needs the services and for our state. Second, I think it warrants noting as well as we had a conversation the other day that not only have they lost services at the state level in the agencies, but also at the community and state college systems.

So for our students that look to advance their education, they also have little to no guidance on our college campuses either and we are failing them. So the one place that they would be able to go if those services were removed would be to a state agency and they don't have that option as well. So, my question Harvey is, do you see a way to put both of those components, the higher education side and the state side under that one umbrella, or do you believe that they need both umbrellas like we used to have before?

DR. HARVEY CORSON: Okay. That's a very complicated question, and the reason is unfortunately, I've been watching the news very closely, what's happening here in Connecticut and the Community Colleges and the University of Connecticut System, are currently
experiencing serious deficits. The state itself has improved considerably with considering tax revenues and setting up guard rails to make sure that spending doesn't get out of control. I understand that.

I guess my response would be we need to see an increased level of working together, a cooperation of this bureau that we're talking about and the colleges and universities and between the two of them coordinate. Secondly, a better working relationship with some sort of a training to provide interpreters in the future. I know that's critical. I know that at the Community College, historically, it was in Northwestern Connecticut Community College, we had an interpreter training program since 1974 that produced many quality interpreters over the years and you're seeing many of those products here. It was a wonderful program.

Now, the National Professional Interpreting Body called the National Registry of Interpreters for the Deaf recommended a bachelor's degree as part of that requirement in order to get interpreting certification. Now, I know you and I have both worked very closely on that advisory board and they recommended that we look at some sort of a consent or a way of working between -- an agreement between the Northwestern and University of Connecticut because they could get their bachelor's degree at another college. I don't know what the status is currently because the new system, with the college system and the community college system, has changed compared to what I was used to, but I think we need to take a look at that.

And I do believe University of Connecticut does have sign language classes. I believe they have over 500 students taking these classes and they have faculty teaching these classes. They have, I believe a new major, they announced a year or two ago called the American sign language studies major and you can get
a degree in that, but they do not provide a formal interpreter training program.

Now, of those 500, I know that at Northwestern Community College, I believe they have a good number of students that are currently taking sign language classes there. I think they have between 50 and 100. But it doesn't necessarily mean that just because you're taking sign language, you're going to become an interpreter, but it's important to learn what it's all about and see what the field is like.

Now, our advisory board did recommend to the board of regions through the President of Northwestern Connecticut Community College that we needed to make some changes because of the changes in the community college system itself. And so we recommended that we move the program to Naugatuck Valley because Naugatuck Valley would have a VOC ed and an academic. Oh, excuse me, a VOC tech and an academic program. And we thought that would be better suited to our students and it was a more urban area, easier access, related to transportation and so on and so forth, and also for housing access.

If that is the recommendation that we made back in 2020 and currently it is still not happening, it has not been implemented. I think we are a very patient group of people. I'm not sure how long we're going to stay patient because this has been quite a while that we've been waiting and struggling. If we were to go ahead with that move, we could then talk about working with University of Connecticut. And could we jump start an interpreter training program here in Connecticut if we have access to that many students taking classes? We have the chair of that advisory board actually here with us. She's right -- where is she? I see her. Oh, Paul. I'm sorry, it's Paul. Yeah, he's the chair of the advisory board so he could answer that question for you.

REP. COOK (65TH): Thank you. And I think it also warrants noting that sign language is now offered to
university students instead of a foreign language as a world language. My son who has dyslexia took two years of sign language to complete his world language credits because a foreign language was difficult for him. But we as a state are not recognizing that any other level, and I think that we really need to continue to move forward. For folks like Harvey and everybody in this room, they deserve better and we can do better. So thank you. Thank you, Harvey, for everything you do.

REP. GILCHREST (18TH): Thank you, Representative. And I was telling the good Senator next to me that in my children's high school, they are offering sign language in lieu of the foreign language, but we would be great to see us get that across the state. With that, Senator Seminara.

SENATOR SEMINARA (8TH): Thank you, Madam Chair. Harvey, I do agree with you that I feel that we've failed this population which often is the case with those with disabilities in the state of Connecticut. Please know that we're working on it and we're trying to address it. My question is, it seems to me that over the course of time, there is a lack of interpreters. What do you think contributes to the lack of interpreters?

DR. HARVEY CORSON: Well, I would say that there are many factors at play. Part of is just, it's a change in interest of the individual that works in the field. I think because of the pandemic and what we experienced there, a lot of interpreters prefer to stay home and do remote interpreting work. And that's something new. That's a new twist that comes into play just because of life that we have to now deal with.

A lot of our interpreters don't have the interest in working with deaf-blind individuals in our community because it's hand over hand, it's tactile. They can't use video remote interpreting, they can't use remote computer screens to see an interpreter. It
doesn't work. It has to be tactile. In fact, I saw something recently where a deaf-blind person asked for an interpreter as they were going to the hospital and the interpreting agency, one of the agencies of today said, fine, but we're not going to send an interpreter, just use VRI.

And then another example is related to the idea of a female deaf individual asking for an interpreter to go to her doctors and they will send a male to interpret that appointment. So there are a lot of just common sense errors, just common sense that isn't happening within the interpreting field. And many of our interpreters as stated earlier are from out of state. And I think they're contracted out, that's where the loss comes into play for our population. These interpreters were contracted out before it was in-house, meaning the state agency.

Everything is expensive nowadays. We have to remind ourselves of that. But there are some services that existed in the past, if I remember correctly, some of those services provided by the state that were reimbursable via different agencies, hospital systems, whatever the case may be. So it wasn't connected to their mission of services for the deaf, they would be reimbursed. I think if you were to provide healthcare services, that's reimbursable, just like any other business industry field. It's not a complete loss for the state if you follow what I'm talking about. Does that make sense?

SENATOR SEMINARA (8TH): Yes. I have another question. I recognize that there's a special expertise in becoming an interpreter and I'm not minimizing that in any way, shape or form. My question is, do you think if we made the requirements to be an interpreter a little less stringent, do you think there would be more available? And do you think they would be capable of doing what is necessary for this population?
DR. HARVEY CORSON: Okay. My way to answer your wonderful question is -- well, okay, let's see. Here's a good way to answer this question. In the past, interpreters would not need a bachelor's degree to become an interpreter. They would go interpret in the K12 setting at a kindergarten level, you wouldn't need that bachelor's degree. You would just need the expertise in interpreting.

So I'm not talking about degrees, but in childhood, it's different. With adults, we all need those -- children, I'm sorry. Excuse the interpreter. Children need that adult language model. So therefore, children are able to then learn to just absorb that language and really integrate that in their use so that they will then become competent speakers, language users.

So all children in public schools have teachers that can speak to their students, and that teacher is the adult language model. Why should deaf children be different? Why should we not have access to that first language, adult language model? So, deaf children need to have those language models themselves in order to learn their own language.

So, in terms of restricting interpreter qualifications, I would just say that that's my answer, that example in itself. Now, if I am going over to a friend's house or I'm going out to a restaurant and we happen to have a hearing friend and I do, I have several hearing friends. My friends do not have certification for interpreting. They do not go to the restaurant as my interpreter, but sometimes I can handle communication all on my own with the waiters. It could be an off-day for me or an off-day for the server and so I end up just riding back and forth on their pad that they have and I always have note cards with me. You see me carrying them around all the time. It's a lifelong habit of mine. It's survival skills, right? Communication access survivor skills.
So, if I feel like I can't adequately communicate with that hearing person, then I have my note cards, but if I'm with a hearing person that can sign and if they may volunteer to interpret very briefly what may be needed, that wouldn't require any type of formal certification, but they're not necessarily speaking for me or I've given them that permission. But interpreting in health care settings are in other type of professional settings, that's life and death for the deaf individual and so certification is absolutely required. So I hope I answered your question as best I could.

SENATOR SEMINARA (8TH): You did it a way. My question was more around -- I'm trying to look at a solution in maybe how we can have more interpreters available. In no way, shape, or form, do I want to minimize the need of a child having a professional teach them the language and work with them nor do I want to minimize your or anyone else with impairment having a professional with them in a setting that is necessary. I'm trying to look at is what we require of someone to get an interpreting degree over cumbersome and can we simplify it in any way, shape, or form?

DR. HARVEY CORSON: Okay. I am actually going to choose to defer to the professional interpreters that you will see here today in the room, the interpreters that are being utilized today as well as those that will provide testimony. I think maybe one good thing to keep in mind long-term is encouraging public schools as mentioned earlier to have ASL classes in their schools, starting at elementary secondary. That may have been an overlooked option in the past, but there is interest out there.

I would say let's get that interest started young, and then that way as they become on the track for interpreting, they have that experience, they have that under their belt, and they are more professional by the time they exit their
interpreting program and what we can see them do after college.

SENATOR SEMINARA (8TH): Agreed. I think you shifting my question to one of the interpreters is a good answer because they could probably answer that question better than you. But thank you for your patience.

REP. GILCHREST (18TH): Thank you, Senator. Representative Dathan.

REP. DATAN (142ND): Thank you very much, Madam Chair, and thank you to be for coming today and thank you to all the interpreters. This is so important that we invest in this properly in our state, but one of the questions I had is we talked a lot about ways that we can help local officials, emergency responders, and others with some of the reductions in the educational space to the American school to death, even though they are getting some ARPA funding and there is some support that is also coming to community supports. What about ways that this bureau could work with our educational institutions both in primary education, as well as secondary education, and Birth to Three programs even?

DR. HARVEY CORSON: You're speaking of the bureau that we are asking to be established?

REP. DATAN (142ND): Absolutely. Yes.

DR. HARVEY CORSON: I think again, it's providing that education and the resources for referral services. So, programs throughout the state, the Department of Education, giving them the option, the accessibility by educating them to improve the services that they provide. So I believe that the bureau can establish a collective, whether that be in the public school setting, other schools out there, private schools, whatever would be able to contact the bureau and have that high quality
information, accurate information, about how to best serve the student population in their schools.

REP. DATHAN (142ND): And possibly working within either SDE or OPM like we have done with the autism and the IDD services kind of like an ombudsman almost in that organization. So it's really works pan agency, not just within ADS.

DR. HARVEY CORSON: Yes. I would say a very similar concept, also statewide efforts. Having that program leader that can assist in making things happen, right? Speaking with other program leaders of various programs within or even outside of the state, so global efforts.

REP. DATHAN (142ND): Wonderful. Thank you so much. And the last thing I just want to say is, we do some state investment 78,000 into the theater for the deaf and I think in light of COVID and in light of the social isolation that folks have had, this is money very well spent and I would hope that this bureau would work with theaters to make it more accessible for people who need translation services. So, thank you so much for your advocacy. This is so important. I know we've looked at this in the past, but we need to keep advocating and your group being here today is very important to us. Thank you so much. Thank you, Madam Chair.

SENATOR LESSER (9TH): Thank you, Representative Dathan.

DR. HARVEY CORSON: [inaudible 00:45:25]

SENATOR LESSER (9TH): It's okay.

DR. HARVEY CORSON: You suck in.

SENATOR LESSER (9TH): It's okay. On the Zoom, we have Representative Comey.
REP. COMEY (102ND): Hello. Thank you. Hi, Dr. Corson. Good to see you.

DR. HARVEY CORSON: Hello.

REP. COMEY (102ND): So, a few years ago, I suppose that was during the pandemic, we had a group that I worked with Representative Abercrombie where we were talking about -- we had broken down to a bunch of different important issues that we're facing the community and one of the subcommittees that we had was workforce development and we did meet with UConn and we could not find any other existing programs within the state for higher education.

And I know that some of these issues are coming up -- questions among committee members are that part of -- it's kind of like the chicken and the egg in the sense that we didn't have enough students to fund teachers and didn't have enough teachers to be able to stop classrooms if you grew the program. So the program itself at UConn we learned was underfunded, but it was also under attended.

And so I would be supportive of this office having a broad scope of practice and authority. And I have been working with several constituents that are also deaf and hard of hearing, and they were having so much difficulty during the pandemic as far as accessing the health care community, everything from going to CVS, going to the pharmacy and the whole mask wearing, and how that became really untenable to the community, especially for those who depend on lip reading.

So I just wanted to thank you, but I did want to mention that, just for the committee's information too is that it is a chicken and the egg thing and perhaps focusing on growing interest at within our K to 12 schools could provide some feeder students.

DR. HARVEY CORSON: Thank you.
SENATOR LESHER (9TH): Thank you very much and I think that concludes the questions we have from members of the committee. Thank you so much. It's been great to have you here this afternoon.

DR. HARVEY CORSON: Of course. And thank you committee members and our Co-Chairs. Thank you very much for asking such great questions today.

SENATOR LESHER (9TH): Thank you. Okay. Next, we have a Senator Christine Cohen.

SENATOR CHRISTINE COHEN: Good afternoon, Senator Lesser, Representative Gilchrest, Senator Seminara, and members of the Human Services Committee. I am here today to testify on SB 206. I would just point the committee to my testimony, but it is my privilege and honor to introduce to you the Negron family. Sitting next to me is David. He is here joined in the room by other family members, particularly his wife, Rennie, and beautiful daughter Chloe. But I will yield my time to Mr. Negron and allow him to share his story also in favor of SB 206.

MR. DAVID NEGRON: Thank you, Senator Cohen. I'm going to start by reading and then I'll speak freely. So my name is David Negron. I'm a Guildford resident and father of two daughters. I'm here today to raise awareness for terminally ill children on a five-year plus waitlist for their Katie Beckett Waiver program, excuse me, and to ask for your support for Bill 206.

I will start by sharing about my daughter Chloe Negron who's in the rear of the room and five years old. As a baby, she met all of her developmental milestones and was a healthy child. She would laugh and play with her friends. She would go to daycare, she would play in slides and everything that we would expect of a young healthy child. She would speak and tell jokes and just have a great relationship with her older sister. She would also
say I love you. She can't do any of those things anymore.

In November 2022 she was one of four children diagnosed with a terminal disease called Juvenile Tay Sachs disease. It's a rare neurodegenerative disease. And according to her, geneticist, it will likely lead to her passing in the next 2 to 3 years and that was a year ago, so next year or two.

Her illness will take away her ability to talk, walk, eat, and see and live. She has already lost her ability to communicate with us. She now can only walk with assistance and it's being fitted for a wheelchair. We were unaware, like many probably people in this room, of the existence of the Katie Beckett program, and it being the only support that is offered to middle-income families as it is a non-income bearing program.

We were also unaware when we got our daughter's diagnosis that there was a massive waitlist as we talked to other people in the Tay Sachs community around the country that were already being supported by Katie Beckett in other states. Connecticut is the only state, I repeat, the only state in New England with a cap on the number of qualified accepted youth within the Katie Beckett program. And I asked the committee like, how is it possible that Massachusetts, New Hampshire, Maine, Vermont, Rhode Island could all have Katie Beckett programs that would support my daughter tomorrow? But I am on a waitlist. My daughter is on a waitlist that is longer than she will live.

The Katie Beckett program was created in order to support at home care and create support so our children would be able to die with dignity or be supported with dignity because other folks don't have terminal diseases but are on the list as well. This would include things like night nurse support to manage end of life care, reduce hospitalization. And as we know, hospitalizations are a huge burden.
to our society and economic cost. It would also increase therapies to maintain her strength so she can live out her life to be a happy kid as long as she can, and it would give us access to medical equipment that we can and we cannot afford.

I am someone who has always lived below my means and that has allowed us to spend tens of thousands of dollars just to cover the constant medical bills that we get every day in the mail, but we cannot sustain her upcoming medical care. We cannot sustain the hospice care that will be forced to be upon us. We've heard stories from other families that have had to been forced to put their child in nursing homes that are not designed to support kids because there is nothing in place for terminally ill children in this state.

You will hear later today, I believe from another family I connected with this week that also has a terminally ill child that has been on the Katie Beckett waitlist for four years. You will also hear testimony from others who will share stories about individuals getting access to the Katie Beckett waiver being told three weeks after their child passed.

I asked that the committee come together and allocate the $8 million, which is a drop in the bucket in comparative to the larger economy and budget of Connecticut to clear the waitlist. And if for some reason that is not possible, which would baffle me, I ask that you dedicate and change the language to make sure that terminally ill children do not sit on a waitlist that is longer than their life expectancy. Thank you.

SENATOR LESSER (9TH): Thank you, David. Thank you, Senator Cohen for being here. And I think all of the legislators who are up here are our parents and I don't know what to say other than if it were any of our families, we would say that no amount of money to support a program like this would be too
high to provide support for families in your position. And so, our hearts are with you and with Chloe, and this is enough to wrestle with on its own without also having to lobby the legislature in your spare time.

So with that being said, I hear that. I was frankly flabbergasted that we hear about all these long expensive waiting lists, but $8 million is, as you mentioned, not a ton of money in the context of the state budget. We have a state budget of over $20 billion a year, well over that now, and so this is not an enormous amount of money for the state.

We do have fiscal constraints and other things that we have to work up against, but it is not a huge amount of money and five-year wait list is way too long. And I'm also hoping that we can get some data from the Department of Social Services about how they administer the program.

Perhaps there are better ways to administer it so we can better target it to -- I'm sure all of the kids who are on the waitlist deserve care and deserve it quickly. But perhaps we can get some more information about how the program is administered to see if we can tweak it to best prioritize. Although I hate to say that because every kid who's on that waitlist deserves it. I don't know that I have questions. Representative Gilchrest though does.

REP. GILCHREST (18TH): Thank you, Senator. Thank you for being here today and I echo what my good Co-Chair said, I'm sorry for what your family is going through, but truly appreciate you sharing that experience so that we can both help your family but help other families here in the state. I do have a question. Just to go back in your testimony, did you say Connecticut is the only state in New England that has a cap for children?

MR. DAVID NEGRON: Cap for eligible children for the Katie Beckett program. That is correct. So all
other states have structured it without a cap. There are other states such as Tennessee that is outside of New England that was the last state to sign up for the Katie Beckett program, but they started at a much larger proportional list. So they started at 2,500 kids.

I recognize that they have doubled the population, but that is not proportional and they're in the process of adding 1,200 more seats, so they will have 10 times the number of seats that we have with only double the population. So, it's depending on the how the state structure it, but in New England specifically, we are the only state that caps the number of medically fragile qualified children that get this dire support.

REP. GILCHREST (18TH): Thank you. And as you mentioned, you said your daughter was one of four in the whole country.

MR. DAVID NEGRON: Correct.

REP. GILCHREST (18TH): I guess to me the role of government -- like this could happen to anyone.

MR. DAVID NEGRON: Correct.

REP. GILCHREST (18TH): You weren't expecting this to happen to you, and so we should all work together to support one another. So, thank you again for being here.

MR. DAVID NEGRON: I really appreciate it. That's the thing. Our family is healthy, never would have thought this was possible and I think it really can happen to anyone.

SENATOR LESSER (9TH): I'll just add Representative Rader, I think we'd hear from in a little bit and Senator Cohen have been working very thoughtfully and diligently behind the scenes to try to work with us to figure out what we can do here because it's a
heartbreaking situation and we want to be helpful. Are there questions or comments from members of the committee? Thank you very much. Thanks for being here.

MR. DAVID NEGRON: I appreciate your time next.

SENATOR LESSER (9TH): We are going to hear from Luisa Gasco-Soboleski.

INTERPRETER FOR LUISA GASCO-SOBOLESKI: Good afternoon, Senator Lesser, Representative Jillian Gilchrest and Co-Chairs and members of this Human Services Committee. I am Luisa Gasco-Soboleski and I'm here to thank you for giving me this opportunity to speak with you today on behalf of our deaf, deafblind, and hard of hearing community. I am the President of the Connecticut Association of the Deaf. I'm a board member of Disability Rights, Connecticut.

I'm also the co-chair of the State Advisory Board for persons who are deaf, deafblind, and hard of hearing. And I'm also a retired principal from the American School for the Deaf. I live in Southington, and I am a third generation deaf person. I have two deaf children, and three of my grandchildren are deaf. So the deaf community is critical to me.

I want to say that we need to support this Raised Bill HB 5241. And I want to thank you for your dedication and time working on this. As an advocate within the deaf community, I receive many calls regarding issues related to interpreters.

It's always related to interpreters. It's primarily in medical settings throughout the State. Many of our community members have so many frustrations in getting information, and primarily because there is no hub where they can get referrals and access to resources. Accessibility was not well received by most of our community members. Again, as I have
mentioned in my conversations through media, I want to clarify that 90% of deaf individuals have parents who can hear, which means they are not getting access naturally to language right away.

10% of our deaf people, myself and my dear Harvey Carson are in that group where we had deaf parents and we had access to language from day one. This 90% of individuals very often those hearing parents when the child is born, they do not have opportunities to provide them with natural language access, which leads to language deprivation. Birth to Five Program talks about how important language access is. It is a critical way to learn our language. This language deprivation means that they are not getting proper communication access. We need to provide it as soon as possible.

I want to go back in history briefly. Connecticut was the first State to have a Commission on the Deaf. And then in 2011, the unit merged with DOORs, and then it ceased to exist in 2016. When we had the unit, we had a community liaison who gave trainings to medical providers, to police, and Fire Departments. Since 2016, no such trainings have occurred. We are seeing many more issues as a result of this. We were also role models for other States. Today, we have about 38 States with similar services, while we do not. This Bill will develop the proper mechanism to foster greater communication access within our State.

The main issues that we see are that the hospitals and healthcare facilities do not understand the needs of our community. VRI, video remote interpreting does not work for everyone. And individuals who are deafblind cannot use VRI. There are many issues such as the Wi-Fi not working properly, interpreters not being from Connecticut, and therefore, having issues with the sign language. They may not even know what the town's name is. We don't spell out the name of the town, we have a sign, this is Hartford.
Well, somebody from Utah doesn't know what this means. The issues have repeatedly continued for the members of our Deaf, DeafBlind, and Hard of Hearing Community, and we are very frustrated. I still receive calls from many of our community members continuing to express concerns about the lack of language accessibility in health care sites. This needs to be heard and we need to improve the situation. We need a bureau to be this hub. By having a bureau, we can improve services primarily by giving trainings on how to provide proper communication access.

In the end, we need your support, and of course, we will be happy to work with you to make this possible for our Deaf, DeafBlind, and Hard of Hearing Community. It's a long overdue need that our community is asking for. We need to be recognized and heard. And I want to thank you for taking the time to listen.

SENATOR LESSER (9TH): Thank you so much for being here today, and for everyone who's here today. Are there questions from Members of the Committee? You got off easy this afternoon. Thank you so much.

INTERPRETER FOR LUISA GASCO-SOBOLESKI: I know Harvey probably answered all of your questions. We worked very closely together. We've been working for many, many years, and we are both from Pennsylvania. We actually grew up together, and then have been lifelong best friends. His parents and my parents were best friends. So it's so nice to have him here in Connecticut with us and have all that support. I just want you to also know that Chris Poulos is my Representative, and he has been a wonderful supporter, and I am very grateful for his time and his support. And so thanks to all of you, and thanks to the members of our community.

SENATOR LESSER (9TH): Thank you. Stay right there though. We do have a question for you, but I will
also say that it's always great to see
Pennsylvanians here. My wife is a Pennsylvanian,
and so we're all trying to bring the all State over.
Representative Cook.

REP. COOK (65TH): Thank you, Mr. Chairman. And
it's great to see you. Something totally unrelated,
but I think we would all be interested in some good
Harvey stories.

INTERPRETER FOR LUISA GASCO-SOBOLESKI: Well,
Harvey, what can I talk about? I'll give you a short
story. I'll give you one short story.

SENATOR LESSER (9TH): We have 99 people signed up
to testify today, Representative Cook.

REP. COOK (65TH): We'll take it offline.

INTERPRETER FOR LUISA GASCO-SOBOLESKI: Well, this
is real-- Oh, well, never mind. Okay. Just to let
you know, he wanted to be the Deaf Executive
Director, and he asked me what I wanted to do. And
I said I wanted to be a teacher. But then years
later, I be-- No, I'm sorry. He wanted me to be the
principal under his tenure. Years later, I became a
principal. And when he moved to Connecticut a few
months later, he came in as our Executive Director
at the American School for the Deaf. So we looked
at each other and said, wow, both of our dreams came
true.

SENATOR LESSER (9TH): Great story.

INTERPRETER FOR LUISA GASCO-SOBOLESKI: Thank you.

SENATOR LESSER (9TH): Thank you. Okay. Next, we
have Representative Rader. Good afternoon.

REP. RADER (98TH): Good morning, everybody. Good
afternoon, everyone. Honorable Co-Chair, Lesser and
Gilchrest, Ranking Members, Seminara and Case, Vice
Chairs, Gaston and Dathan, and esteemed Members of
the Human Services Committee. I'm going to submit this. I've submitted written testimony that you will be able to see, but I'm just going to also read it here today. I submit this written testimony to express my strong support for SB 206, AN ACT CONCERNING THE EXPANSION OF THE

REP. RADER (98TH): KATIE BECKETT WAIVER PROGRAM. As a legislator, many of our most important Bill proposals are grown out of the needs and outreach of our constituents.

In my case, this Bill is wholly born out of the incredible advocacy and bravery of the Negron family. Chloe Negron is a beautiful, precious five-year-old girl who I am blessed to have living in my hometown of Guilford. Just a little over a year ago, Chloe was diagnosed with Tay-Sachs, a rare neurodegenerative terminal illness. For her parents, David and Rennie, it took almost 18 months from Chloe's first signs of symptoms to a definitive diagnosis. As a parent myself of four children, I can only imagine the devastation felt by Chloe's family. Yet they were able to muster the strength and determination to reach out to both myself and my colleague, Senator Cohen, to see how we might be able to help Chloe and other children like her receive the services so desperately needed.

The Katie Beckett Waiver Program has been a lifeline for many families in our State, giving children with severe disabilities and illnesses access to the medical care and supportive services they need while remaining at home with their loved ones. However, the current program has fallen terribly short in serving every qualified child. Per current data, the Katie Beckett Waiver waitlist in Connecticut is well over 300 and counting. Sadly, the urgent needs of many of those awaiting services may very well come too late for the most fragile and terminal children, children like Chloe Negron.
As you've heard, Connecticut is the only State in New England with a cap on the number of qualified children accepted into the Katie Beckett Waiver Program. This program offers Medicaid waivers to allow for coverage of medical expenses and supports that are essential to a short quality of life, including therapies, equipment, or nursing end-of-life care, not always covered under private insurance for families with children who wouldn't normally qualify for Medicaid. As you've heard, as Chloe's disease progresses, so do her needs, yet those services and associated costs are fully borne by her family as they wait her progression on a 300-plus patient waitlist.

Her family is navigating mounting medical costs while managing the uncertainty of closed complex and urgent needs. I urge this Committee to include a provision in SB 206 to give priority on the waiver of programs waitlist to children with terminal diseases and illnesses. These vulnerable children and their families are in desperate need of services, and it is honestly unconscionable to make them wait when their time together with us is so very short and precious. And I'm happy to answer any questions you might have regarding this Bill.

SENATOR LESHER (9TH): Thank you, Representative, for your testimony and your advocacy on behalf of the Negron family. And as I said to Senator Cohen and to David, there's not enough that we can do to support a family in that situation. And so I'm sure that they appreciate your advocacy. Just in terms of, if we were not to do this, what are the options available to parents? Because I think there probably are costs that are born by the State if we don't expand the waiver. There's a cost to expanding it, but there's also cost to not expanding it.

REP. RADER (98TH): Well, this is how we have to look at it. Right? If we don't expand the waitlist, these families are incurring extensive medical costs. They may not be able to pay those costs.
There are services that they're going to have to incur themselves. They may very well have private insurance, but very often the private insurance doesn't cover them, or it was shared with me, Chloe's grandfather is here in the audience, Michael. And a few months ago, she suddenly needed assistance walking. It just happens like that.

And so they had to quickly expedite finding a specialized walker for her, they found a nonprofit in Hartford who then connected them with a grant. They couldn't wait on insurance to help them with those services, and they'll probably have to chase down insurance to cover that. But this is what families like this are dealing with. They have to take care of their child in the moment. So very often, those costs just fall back to these families. Many of these families are who we could identify as United Way does as ALICE families. They're really just making ends meet, but yet the Medicaid requirement is so low in terms of income.

We see a lot of families that could be made bankrupt by this. But like all of us here are parents, you would do anything. You'd sell your car, you'd sell your house, you would do everything. We shouldn't be putting families who are literally losing their children through that. So, if we can't expand the waiver in terms of the fiscal note, that's why I added, I would like to see hopefully that we could find a spot for those children who are identified as terminally ill. They don't have the benefit to wait four or five years.

They need the services now, their families need it now. I don't think any of us argue that that's not the right thing to do. I would never want it to come at the detriment of other families waiting on that list, but if we could at least have DSS identify those families, provide that data so that we could create an opening for this specific group of families now. But obviously, the bigger end goal
is to eradicate the waitlist if we could ever do that.

SENATOR LESSER (9TH): Well, I'd like to think we can. But meanwhile, I think you probably heard my colloquy with the department earlier, we are trying to find out what data is getting, see if we can get access to that data, and then see if we need to ask them to collect additional data as well to help inform this case.

REP. RADER (98TH): Yeah, I think it's really critical. I think the data will substantiate what we're seeing, and if they're not collecting it, we really should be. Not that we don't have a tiered system right now, but that data could help us understand how to prioritize applicants. But again, the end goal someday, the dream is that we don't have a waitlist. But for the here and now, those are the things that we should be asking for.

SENATOR LESSER (9TH): Thank you, Representative. Questions from Members of the Committee? No. Thank you very much for you very much, Representative.

REP. RADER (98TH): Thank you.

SENATOR LESSER (9TH): Okay. Next, we have Cheri Byrnes. I think I actually went -- We'll hear from Cheri, and then I made a mistake. So we're going to go back to Barbara Cassin. Sorry about that. Actually, after Cheri, we will hear from Representative Turco, and then Miss Cassin.

INTERPRETER FOR MS. CHERI BYRNES: I apologize. One quick moment while I get my visual accommodation set up. Okay, I apologize. Thank you very much for your patience. Hello, everyone. I am here to show support for House Bill 5241. I am Cheri. I am a deafblind individual. Thank you. Perfect. I apologize. I do have sensitive eyes, and so sometimes the lighting in here can be harsh with the reflection. So I do appreciate your continued
patience. I have come here today to share my experience and how hard it was for all of the different issues I've experienced in getting an interpreter in the State.

There have been a lot of different situations that have been a struggle for me. So I was struggling to get an interpreter through any State area, any area of this State for quite a long time. What has happened is they have kept canceling my appointments so many times and at the last minute. I've become exhausted and very frustrated. My health issues were growing worse. They would keep postponing or rescheduling to new dates several times. It is not right. I do have my right to depend on a tactile interpreter in any area because I am deafblind. The agencies are seriously lacking in communication in the midst of a lot of confusion. There's not a lot of assistance or help, and it is continuing to be confusing and frustrating.

I want to be independent, and I want to make decisions on my own and not solely depend on others and family members. It is my right to choose a live in-person tactile interpreter because I cannot depend on video remote interpreting. How can I communicate as a deafblind with a remote interpreter? I do require to have tactile interpretation at all times. Now, communication access is critical and important to me. I would like to request that Deaf, DeafBlind and Hard of Hearing Services have an opportunity to have a centralized space for resources and support.

Thank you for your time and in consideration of passing House Bill 5241. Phyllis is my mom, and she would like to say something. She's asked me to read. I am the mom of an adult deafblind daughter. And I learned there was a Bill going to the Legislators on March 7th, House Bill 5241, which States to establish a bureau of services for persons who are deaf, hard of hearing, or deafblind, which should be within the Department of Aging and
Disability Services. In reading the Bill, I felt more and more excited at the possibilities of having a service for these people to go to when help is needed. Here are some possibilities for this new Bill in order to help deafblind individuals.

This will provide them with the assistance to be independent, make their own decisions. I apologize again. The reflection on this is impeding. So this will help them know what's going on in the world and communicate. Getting updates that are clear and not fractured, they need in-person interpreters as of now. The deafblind does not always have family that can help them.

In the 80s, when I'm in my 80s, I am not going to be able to have a family member to rely on. I would like to be independent and have the services and support I need. My hope is that this Bureau of Service will pass, and the Deaf, DeafBlind, Hard of Hearing will be under one umbrella to have the services they so desperately need. Thank you so much for your time and patience as I was getting situated up here.

SENATOR LESSER (9TH): Thank you so much for your testimony. And let me first start out by apologizing for the harsh lighting. We were trying to fix that, but it is apparently more complicated than I realized to do that. So, I apologize for the harsh lighting in this room.

INTERPRETER FOR MS. CHERI BYRNES: Oh, thank you so much. And I do accept that apology. Of course, it's not up to you, but I think maybe next time, we'll see what we can do for accommodation so that the deafblind can see better. I may also try to switch up my iPad just to make it so that the reflection is not as harsh. But thank you.

SENATOR LESSER (9TH): Yeah. And just as we were trying to understand the history of services for all the communities represented here, but certainly for
the deafblind community. Was there a point in the past where there were more services available than there are today?

INTERPRETER FOR MS. CHERI BYRNES: I would say that a long time ago, it was more not as common to be identified as deafblind. You would have those individuals that you knew were Usher syndrome. So they were born deaf and would lose vision over their childhood and over their adult life. But now we as deafblind individuals have more of a say and are more incorporated in our community, so that's why I am here today to speak out to this Bill.

SENATOR LESSER (9TH): Well, wonderful. Thank you so much for your incredible advocacy. And we really appreciate you being here, and hopefully, this will result in improved services.

INTERPRETER FOR MS. CHERI BYRNES: Yes, I do hope so, and I do appreciate your time. Thank you so much. We hope that you follow up with the support of 5241.

SENATOR LESSER (9TH): Thank you. Okay. And next, we have Representative Turco. And after Representative Turco, we will have Barbara Cassin.

REP. TURCO (27TH): We're going to combine our testimonies.

SENATOR LESSER (9TH): Okay.

REP. TURCO (27TH): Gary Turco, State Representative for the 27th District, Newington and New Britain.

MS. PATRICIA REHMER: And I'm Pat Rehmer. I am former Commissioner of the Department of Mental Health and Addiction Services, a Board Member of the Root Center for Advocacy and Recovery. And I live in 26.
REP. TURCO (27TH): Perfect. Senator Lesser, thank you so much for being here, and the rest of your esteemed colleagues on the Committee that may be watching on Zoom. I really appreciate you raising House Bill number 5370, AN ACT CONCERNING MEDICAID COVERAGE FOR ROOM AND BOARD COSTS FOR SUBSTANCE ABUSE TREATMENT IN A RESIDENTIAL SETTING. We are testifying in support of this legislation today. We believe this is important legislation to help us with the battle with the opioid epidemic. And I'm going to turn it over to Pat, who's the expert from Roots on this legislation.

MS. PATRICIA REHMER: Thank you. Good afternoon, Senator Lesser, and Members of the Human Services Committee. As Representative Turco said, I am Board Member of the Roots Center, which is the largest provider, as you know, of methadone maintenance in the State of Connecticut. They've been treating clients for addiction since 1970, and have 11 locations across the State, treating over 6,000 patients a day. They are currently in the process of opening a residential treatment center in New Britain, Connecticut.

And as you're aware, the DSS budget contemplates cutting room and board for anybody that is not in the current SUD waiver. I would say I was around during, I think I was the Tried Chair of the Behavioral Health Oversight Committee during SUD waiver development. And I don't think that there was any contemplation that it would exclude providers who wanted to open these beds, I suspect, at the time. We thought no other providers would want to open these beds because they lose money. But in fact, we know that we need more beds in the State of Connecticut.

We are still in a major opioid crisis. And also let me remind people that alcohol is still the number one cause of death in substance abuse disorders. The opioid epidemic is very, very impactful on young adults and middle aged adults, and actually older
adults as we go along. But these beds are for treatment of all substance use disorders. And the other thing— you have my written testimony. So the other thing I wanted to mention is I was listening was the issue of parity. We would not say to somebody who was in a general hospital and just had wrist surgery, for example, that they could go to rehab, but DSS wasn't going to pay for the room and board for that. But we are saying that for substance use disorders.

And as you know, my legacy is that this is discriminatory, and I would say that that certainly is the case as we move forward. I also think that there's a possibility to just amend the waiver. I don't remember the details of whether amending the waiver or paying people outside the waiver, but also to mention that the cost is very, very low. I believe it's about $43 a day. And given that at this point, there are only two providers that I believe are not covered under the waiver, that's a very, very small amount of money well under probably half a million dollars. And I'd be glad to answer any questions.

SENATOR LESSER (9TH): Well, thank you. Thank you, Representative Turco, and Pat, for your testimony. And yeah, we've seen some very large numbers here today and some very small numbers. So yes, that sounds like a very small number. If we were not to move this forward, would you assume, and we were to accept the Governor's recommendations, would that mean that the Root Center would likely not be able to offer that residential option?

MS. PATRICIA REHMER: No. The Root Center is extremely fortunate in that they are, number one, very mission driven, and number two, financially in a much better shape than most of the PNPs, unless something has changed drastically in the two years. So they're doing it based on their mission, which I absolutely applaud, but I don't believe that there's a lot of other providers that could afford to do
that. And even though it's a small amount of money, as we know, the Medicaid rates for the payment of behavioral health are already very low. So paying for the clinical services without the room and board is really going to be a nonstarter for most providers.

SENATOR LESSER (9TH): And if we see a shortage there, right, if we don't have the beds available, what happens to patients who need those services? Are they--

MS. PATRICIA REHMER: They are typically discharged. I mean, occasionally, a facility that provides detox, if they know a bed is available in 24 hours, for example, may extend a stay. It's not likely insurance is going to pay for that. And so sometimes people are discharged waiting to go into a bed. And I can tell you that probably in about 50% to 70% of those cases, that individual is going to relapse. It's just too tenuous. If we're saying they need that level of care, because not everybody after detox does, but if we're saying they need it, there's a reason for that. And if we can't get them into a bed, it's likely they will fail.

SENATOR LESSER (9TH): Thank you for your testimony. I don't have any more questions, but thank you for your work and for your service to the State of Connecticut as well.

MS. PATRICIA REHMER: Thank you.

REP. TURCO (27TH): Thank you.

SENATOR LESSER (9TH): Next, we will hear from Barbara Cassin, followed by Representative Poulos. And Miss Cassin, apologies for skipping you earlier.

INTERPRETER FOR BARBARA CASSIN: No, that's okay. All right. Good afternoon, Representative Gilchrest and Senator Lesser. I am Barbara Cassin, and I am here to speak in support of Raised Bill 5241. In
2021, with monies from ARPA funding, the Connecticut Association of the Deaf was able to hire Innova's strategies to do a survey with a broad section of our community to identify areas of need. After reviewing this report, the Advisory Board created a Task Force to address those needs. The Task Force worked to develop the proposal, and presented it to the Advisory Board, gaining the endorsement.

In this proposal, we are asking for a bureau to be established under Aging and Disability Services. While ADS has a bureau dedicated to individuals who are blind and a Bureau for Rehabilitation Services for people who have disabilities, there is nothing that currently exists to address the needs of those of us who are deaf, deafblind, and hard of hearing. Our goal is for this bureau to provide a centralized resource center, one place where people could contact to get information about what are the available resources and supports for those who are deaf, deafblind, and hard of hearing.

It might be a parent looking for accessible educational and recreational opportunities, or an agency, or an employer with questions about how to secure qualified interpreting services. As identified in Innova's Report, the scope of needs is broad. We envision this bureau providing training for agencies and entities such as Police and Fire Departments to provide appropriate communication access. When we are experiencing weather related emergencies such as hurricanes, blizzards, flooding, the director from this bureau could have already worked with the Governor's Office, the Mayor's Offices, the First Selectman's Office, to be sure that the communication access is provided when such announcements are being made on TV.

This is a proactive educational approach that would address the needs of making sure that the interpreter is always visible on the TV screen, and the captioning is provided. Often, the interpreters may be present but they're not visible on the
screen. Instead, the camera pans over to a map or something else. Here, CTN has PIP, Picture-in-Picture, which is perfect. This is just a couple of ideas that we envision that would be some of the tasks and responsibilities of this bureau. I assure you, we are eager to work with you and to talk with you to build back access for services for our members of our community and those who work with them. I respectfully ask you to support House Bill 5241 to address these needs. Thank you so much for your time.

SENATOR LESSER (9TH): Thank you so much for your testimony. Are there questions from Members of the Committee? Seeing none. Thank you so much for being here this afternoon.

INTERPRETER FOR BARBARA CASSIN: Thank you.

SENATOR LESSER (9TH): Next, we have Representative Poulos. Representative Poulos, could you wait a second? I think it looks like we have some technical difficulties here. Oh, we're back on CTN.

UNIDENTIFIED SPEAKER: Never left.

SENATOR LESSER (9TH): Never left. Okay.

CLERK: It's just the screen unplugged.

SENATOR LESSER (9TH): Representative Poulos, good afternoon. Good to see you.

REP. Poulos (81ST): Hi, good afternoon. And this has been great turnout today. Okay. Good afternoon, Members of the Human Services Committee, Chair Gilchrest, Chair Lesser, Ranking Members, Representative Case and Senator Seminara, and Vice Chairs, Representative Dathan and Senator Gaston. I am here representing the 81st District, encompassing the Town of Southington, and to voice my support of House Bill 5241, an Act Establishing a Bureau
Coordinating Services for the Deaf, Deafblind, and Hard of Hearing Persons.

The current State of Deaf Services in Connecticut is lacking. In 2016, the Commission for the Deaf and Hard of Hearing disbanded due to a lack of State funding, resulting in a decentralization of services and care for the Deaf, Deafblind, and Hard of Hearing Community. I will admit, I previously did not know much about the issues facing these residents, but Southington is fortunate to be home of Luisa Gasco-Soboleski, President of the Connecticut Association of the Deaf. Through Luisa's leadership and our numerous interactions, I've learned a great deal about the many issues impacting the deaf, deafblind, and hard of hearing.

And I recognize the tremendous disservice the elimination of the commission has done to this community. Currently, the Governor's Advisory Board for the Deaf, Deafblind, and Hard of Hearing meets quarterly to discuss the State of services for Connecticut's deaf community. At these meetings, the challenges confronting this community of Connecticut residents are evident. Among their concerns, Members of the Board report inconsistent interpreting practices, barriers to legal representation, and lapses in medical care due to their interpretation needs.

At their November 2023 meeting, this Board reviewed the results of the Innova Report on the State of Deaf Services in Connecticut, which not only substantiated the Advisory Board's concerns, but unearthed new ones. Due to the lack of a database of documented State services, the report could not determine the quality of care available to Spanish sign language users, the usage of certified deaf interpreters at healthcare offices, and the experiences of late deaf and aging populations. Importantly, there were little to no data for medical professionals and specialists who treat this
community, and no mention of the effectiveness of the ADA accommodations.

Amidst all these needs, in the absence of a dedicated government bureau, the Board was forced to pick just one category among many for the possibility of future study. The current decentralized structure of the Deaf Services in Connecticut has been unsuccessful, is inefficient and unsustainable, and provides little, if any, benefit to our State's Deaf, DeafBlind, and Hard of Hearing Community. We must do better for those who need additional support. And the most immediate course of action would be the passage of HB 5241.

The proposed bureau would appoint an Executive Director to oversee the available resources for deaf, deafblind, and hard of hearing persons, increase interpreter oversight, address consumer concerns, provide education and training initiatives, partner with community organizations, and increase accessibility of television broadcasts, among other tasks. Working in consultation with the Department of Aging and Disability Services, this newly formed bureau would fill a gap in needed services. I strongly urge you to pass HB 5241 in support of the Deaf, DeafBlind, and Hard of Hearing Community. Thank you.

SENATOR LESSER (9TH): Thank you, Representative Poulos. And yes, we did hear some impassioned testimony from Luisa earlier. So thank you for working with her and the whole community. I know that a lot of folks were appreciative that we seem to be moving forward on this this year. Representative Gilchrest.

REP. GILCHREST (18TH): Hi, Representative Poulos. I just want to thank you for your advocacy and for being such a champion for this issue, and look forward to our continued work together.
REP. POULOS (81ST): You're very welcome. I'm proud to do it.

SENATOR LESSER (9TH): Thank you for being here this afternoon.

REP. POULOS (81ST): Thank you.

SENATOR LESSER (9TH): You've got some fans here, Representative. Okay. Next, we're going to hear from Susan Pedersen. Good timing.

INTERPRETER FOR SUSAN PEDERSEN: Well, good day for Senator Lesser, Representative Gilchrest, and the Human Services Committee members. My name is Susan V. Pedersen, and I am of West Hartford, Connecticut. I am asking you to vote in favor of House Bill 5241. I'm a deaf retiree of State Commission on Deaf and Hearing Impaired, CDHI, which was founded under previous legislation back in 1974. I am one of the remaining staff members that witnessed the unfortunate conclusion and events that happened, and I put down 2017, that's an error, 2016.

I witnessed what happened to the very first model of an agency throughout this nation, serving the Deaf, DeafBlind, and Hard of Hearing communities. I worked there for 26 years, and I was thrilled to see so many deaf community members leaving our office with sighs of relief and excitement that they were able to move on and move forward with less communication barriers in place using sign language interpreters. I do want to say that that office was their second home. These were a group of people that were led by Barbara Brasel and the Deputy Director, Richard Schreiber.

Now, they could hear, but they were also sign language users. Now, if they were still alive, they would be here in support of asking you to pass this Bill 5241. Other individuals have retired from CDHI, from the American School for the Deaf. All of
us within the deaf community are serving the deaf community. We have Connecticut Association of the Deaf, Communication Advocacy Network, Council of Organizations Serving the Deaf, Deaf, DeafBlind, and Hard of Hearing. All of these agencies are here to support consumers' emotional, human mental, and personal needs.

Now, this bureau would help all of these individuals to live independently, being able to refer them to any other members in order to ask for that assistance that is needed. The bureau could be the ideal resolution to asking for all types of support and help for those that are hearing, sighted, nondisabled, and those that are a part of our community. We all need help. And we all need help from the State government at times. Allow us, allow these volunteers that are currently doing this on their shoulders to have a retirement frame, allow us to take that time to enjoy our lives and have this workload under the bureau.

We hope that with these types of services that the bureau will offer, we can get that back into the State of Connecticut and become that model again. We are asking that you support Bill 5241. And I'm going to quote Rosa Parks. "I have learned that in order to bring about change, you must not be afraid to take that first step. We will fail when we fail to try. Each and every one of us can make a difference." Now, let us re-establish the State Agency together. Thank you so much for providing ASL interpreters for both parties, the legislators and the deaf community that are present here today. This is a wonderful example of communication access in this room. Thank you again.

SENATOR LESSER (9TH): Thank you. No, no, no, you got us. You can't get up. You have to stay here for one second. We may have questions. First of all, thank you so much for being with us here today and for coming back. We're recognizing, we're trying to rebuild what we used to have, and then
perhaps provide some additional services on top of that. So your history, your expertise is really important, but don't stay here too long. We might enlist you personally and put you back to work. But I do think we have a question though from Representative Gilchrest.

REP. GILCHREST (18TH): Thank you, Miss Pedersen. I just want to thank you for giving us that historical knowledge. And as you're all mentioning that year, I was employed at the Permanent Commission on the Status of Women, which I sadly make the joke is no longer permanent. But that too was part of those 2016 cuts. And so it is my hope that we can get back to a place where these vital services are reinstated. Thank you.

SENATOR LESSER (9TH): Thank you so much for being here this afternoon.

INTERPRETER FOR SUSAN PEDERSEN: Thank you. Thank you so much for your support and your time.

SENATOR LESSER (9TH): Okay. Next, we have Lisa Flaherty-Vaughn, followed by Liza Alers.

INTERPRETER FOR LISA FLAHERTY-VAUGHN: So I do, before I begin, want to explain to you a new language use which is called Protactile. This person to the side of me is a Protactile interpreter, allowing me to understand what the reactions are and the happenings around the room. Good morning, Co-Chairs, Senator Matt Lesser and Representative Jillian Gilchrest, and the Human Services Committee. Thank you for letting me share my story. My name is Lisa Flaherty-Vaughn, and I am deafblind. I have resided in Enfield for almost 24 years.

I have worked as a volunteer and advocate for the very diverse Deaf, Hard of Hearing, and DeafBlind Communities of Connecticut. I provide auxiliary support and advocate for our civil rights for now
and for future generations. Every day, I face barriers, but there are two unpleasant experiences that I want to share with you today. In 2017, I went to the emergency room and stayed at the hospital for a few days during the Thanksgiving holiday. I was not well and I was very sick. And I had even more of a difficult time with communication because of my vision. I did request a translator many times so that I could see the close and touch the tactile signing.

My family and myself tried to explain my situation to the hospital staff many times, but the hospital said they rely on video remote interpreting for people who need ASL. But getting an ASL interpreter was incredibly difficult because this hospital surgical team delayed the surgery I needed because they did not have appropriate interpreters present for me to consent to them my surgery. VRI is not a great tool for the deaf community and not always appropriate to use, such as situations with high turn-taking, exchanging complex dialogue, or involving individuals with visual impairment, high risk medical situations or mental health settings. VRI is not friendly to the deafblind community.

The deafblind community needs touch tactile signing as a method of communicating, using touch that is used by children and adults who have hearing loss and sight impairment. I lost my job because my former boss was so upset with me after I tried to contact the Department of Aging and Disability Services. I contacted ADS to request someone to come educate and support me in use of communication access and accommodation access. Trying to explain to my employer, my former boss was hearing and didn't speak or use American sign language very well. They depended on one of my deaf coworkers to interpret for me frequently.

I felt it was not right for me or to my coworker. My coworker was not responsible for interpreting. They were not a certified deaf interpreter. It was
a conflict of interest. I felt that there are so many barriers and those barriers cause confusion for Deaf, Hard of Hearing, and DeafBlind Services, and many State division offices. It causes a lot of problems and struggles. For instance, service providers may not have experience working with deaf, hard of hearing, or deafblind people.

They might have exposure to some people that are deaf, hard of hearing, or deafblind, but not understand the culture. I do believe that we can break down barriers with a bureau for coordinating services for Deaf, Hard of Hearing, and DeafBlind. It'll provide full resource and support, education and job access to operate and serve Connecticut. Thank you for your consideration.

SENATOR LESSER (9TH): Thank you for your testimony this afternoon, and for educating us. Next up, we have Liza Alers, followed by Julia Silvestri. Liza is not here? Liza is not here, so we're going to go to Julia Silvestri. There's Julia here.

UNIDENTIFIED SPEAKER: Let me go get her. She's here. Let me go get her.

CLERK: Oh, she was the young lady with the infant. So I think she just went outs.

SENATOR LESSER (9TH): We'll come back to Julia. Is Alexandra McGee here? Oh, Julia is coming right now.

INTERPRETER FOR JULIA SILVESTRI: Okay. Good afternoon. My name is Dr. Julia Silvestri, and I'm a teacher of American Sign Language, and Coordinator of the ASL Program at Yale University. I also work as a professor in coordination with an Education Program at the College of Columbia University. Before, I was a teacher of the deaf at a deaf school, as well as in public schools here in the State of Connecticut. Today, I am here to represent myself as a deaf individual here with my community to support House Bill 5241, to establish a bureau
for coordinated services for the Deaf, DeafBlind, and Hard of Hearing Community.

I grew up here in Connecticut, and I was very fortunate, I was able to attend public school, but there were a lot of services, resources, and supports, such as ASL Interpreters Advocates. And I was very lucky to have that Commission in place that supported the individuals such as myself to have role models and language models in the school. I loved school. But in the year of 2016, I graduated with my PhD in Deaf Education. A month later, I found myself here in Hartford on the street, protesting along with my fellow deaf community members, greatly upset because of the elimination of the services. And that was a traumatic event for us.

Since that day, I have seen our strong serving system crumble down to the ground. And it impacted me greatly five months ago with the birth of my son. In the hospital, during that labor and delivery, it was tough. It was scary, overwhelming. I was needing an interpreter. My family and friends had to fight that battle just to provide an interpreter. Now, the worst part of that experience was that I know that what was happening to me has happened to almost everyone in this community, and people may not have a way to protect themselves.

So today, we are asking you to give us a way to protect ourselves, to have the services, to educate and promote awareness of what our community is and our needs, someone that can oversee and coordinate all of the services. Deaf people here in the State of Connecticut have suffered enough. It is time that we thrive again. Let's stand as a State with such beautiful history. Thank you to the Human Services Committee for listening to my testimony today.

SENATOR LESSER (9TH): Thank you, Dr. Silvestri, for being here and for your work and your advocacy. And
it's striking-- first of all, congratulations on the birth of your son. And it is striking to me that if you, as a professor at Ivy League institutions, were struggling to get the services you need, what hope do the rest of us have?

So thank you for sharing your experience, and hopefully we can translate that into some real change. Any questions from members of the committee? If not, thank you very much.

INTERPRETER FOR JULIA SILVESTRI: Thank you. I appreciate your time.

SENATOR LESSER (9TH): Next, Alexandra McGee.

INTERPRETER FOR ALEXANDRA MCGEE: Hi, members of the Human Services Committee, I am Alexandra McGee, and I live in Burnham, Connecticut. And I want to ask you to support House Bill 5241. In the past, we had a one stop center where all the services were located in one place that served deaf, deaf-blind, and hard of hearing people. Since the Commission For The Deaf closed, we have struggled. There have been a lack of training and a lack of resources.

I'm asking you to support Bill 5241 to establish this Bureau under the Aging and Disability Services. Our goal is for the Bureau to work with police departments, fire departments, EMS, provide necessary training on how to access interpreters and how to communicate and improve communication statewide. My primary concern is safety. Again, I'm going to ask you, please support Bill 5241. Thank you.

SENATOR LESSER (9TH): Thank you for your testimony. Any questions from members of the committee? Next, we're going to hear from Mary Silvestri.

INTERPRETER FOR MARY SILVESTRI: Hi. Co-chair, Representative Gilchrest, Co-chair, Senator Matthew Lesser, and other members of the Committee for Human
Services. Thank you for giving me this opportunity
to testify in support of Raised Bill 5241, an act
establishing a Bureau coordinating services for the
deaf, hard of hearing and deaf blind persons.

Excuse me. My name is Mary Silvestri. I'm from
Danbury. I have lived there for more than 40 years.
I am deaf and I have three adult deaf children, and
one of them you just heard from. I worked as a
teacher of the deaf and hard of hearing in the
Danbury Public Schools for 39 years, I am now
retired.

In 1979, I moved here to Connecticut from Ohio, not
Pennsylvania, to start my teaching career. The
former Commission on the Deaf and Hearing Impaired
was always there to provide me with a great deal of
support as a solitary deaf professional in the
public school system. I didn't hesitate to join
CDHI as a board member when I was asked in 2002,
because I felt it was an opportunity for me to give
back.

I continued to serve as a board member for many more
years, and I left primarily for family reasons.
Years later, not only was I disappointed to learn
that the commission had been discontinued, but I
also personally experienced the significant decline
of quality interpreting services in my two hospital
visits. Time does not permit me to recount the
impact of the untrained medical professionals and
interpreters, except to say that my family and I
were greatly underserved and potentially harmed.

I had been so used to the commission educating
hospitals on meeting our communication needs, such
as individuals like me or others, that I hadn't been
initially concerned at first. Fortunately, I
survived this harrowing experience, and hopefully
this bill which has been proposed will result in a
critically needed bureau to coordinate services for
individuals who are deaf, hard of hearing and deaf-
blind. Thank you.
SENATOR LESSER (9TH): Thank you so much for your testimony this afternoon. Any questions? Next, LeRoy Terrio. Good afternoon.

INTERPRETER FOR LEROY TERRIO: Good afternoon, Senator Lesser, Representative Gilchrest, and the Human Services Committee. My name is LeRoy Terrio. I live in Ridgefield, Connecticut, with my wife Suzanne, who is a nationally certified interpreter. In 1979, I moved to Connecticut as an accountant in a corporate headquarters of GTE. They supported achieving my MBA in finance at Pace University.

My wife and I married in 1986, she gave birth to two children, and we have paid Connecticut state income taxes and we are in our third house now in Ridgefield, and we continue to pay property taxes to this day. I am now 70 years old. I walk three miles a day, I eat my wife's very healthy Italian cooking, and I volunteer as a board representative for both the Connecticut Communication Advocacy Network and the Connecticut Association for the Deaf.

Despite my best health practices, hospitalization, doctor's visits, medical consultants, will most probably be inevitable going forward, and I am concerned. We have a population of long time deaf senior friends who are aging along with me, some more than I, require extensive patient centered care. Patient centered means we need two way communication to make life and death decisions.

These may involve medications, surgeries, or treatment. Two way communication requires that we have skilled interpreters who can be available in emergencies as well as for planned visits within the health care system. It means providing incentives, recruiting and training deaf and non deaf on what is known—Oh, excuse me, interpreter error. —for deaf and non deaf interpreters, this is usually
referred to as hearing interpreters, on call within a unified health care system.

The coordination and logistics of providing this unified approach to compliance of the federally mandated Americans With Disabilities Act is daunting. Let us make the such compliance streamlined by having services that are managed by a bureau to serve deaf, deaf-blind and hard of hearing people, who the members of this Bureau can communicate using sign language with those who they will serve.

Medical personnel are unable to do their job of healing and serving deaf patients without instant communication access. Interpreters are as much for them as they are for the deaf person in need of those services. Since moving to Ridgefield in 1985, many of the long standing interpreters that we used to have have retired, they've moved away, or they're inactive.

I commend Connecticut for this proposed Bill 5241, in establishing a consistent approach towards meeting the needs of our hospital system to provide communication with deaf, deaf-blind, hard of hearing consumers and their service providers. I thank you for your consideration of Bill 5241, which reinforces why I choose to continue to contribute my resources to this beautiful state. My vote supports the people who work for the health care system and the people that they serve. Let us work together. Thank you.

SENATOR LESSER (9TH): Thank you for your testimony. Have a good afternoon. Next up we have Terri Ditimi, followed by John Silva.

INTERPRETER FOR TERRI DITIMI: Oh, that's okay. We seem to have-- Okay. Good afternoon, Senator Lesser and Representative Gilchrest, and our co-chairs here for the Human Service committee here in Hartford. To all of my dear members of this committee, my name
is Terri, my husband who is not with me is Paul. We are deaf and we are members of the Connecticut Association of the Deaf.

I work for the deaf black community here in Connecticut, and I am requesting your support for House Bill 5241, which aims to provide as a resource hub for our deaf community here in the State of Connecticut. The closure of the former Commission on the Deaf has made it challenging for me and other deaf individuals to communicate with those who provide essential services such as hospitals, the police, fire departments, health offices like doctors, and legal services.

Some deaf individuals have lost interest in participating in our community. I am personally appealing for support of this House Bill 5241, here at the legislature on this day. But I have work commitments with my students at the university, that's my husband saying that. Okay, that's his contribution.

My husband and I have faced difficulties in our experiences at Stamford Hospital numerous times, having to spend days in the emergency room dealing with COVID 19 without an in person interpreter. Despite the staff providing VRI, video relay interpreting, many could not troubleshoot the technical issues they needed to be able to use the VRI, leading to communication breakdown and medical misunderstandings.

We experienced adverse side effects from numerous medications that was prescribed without a proper explanation. However, when stopping some medications, then the health improved significantly. It is critical that we have clear communication via qualified interpreters.

It is crucial in health care settings, especially for deaf individuals like us. I support House Bill 5241. I urge your assistance in enhancing the
services for deaf individuals by establishing this new bureau which will be a deaf center to help with interpreter service coordination in Connecticut. I thank you for your attention and your support.

SENNATOR LESSER (9TH): Thank you for your testimony this afternoon. Next, we have John Silva, followed by Kim Silva.

MR. JOHN SILVA: [inaudible 00:17:09] All right. Thank you. Okay. To Representative Gilchrest and Senator Lesser, my name is John Silva, and I'm a retired teacher at the American School for the Deaf. My wife Kim and I will offer a testimony in support of Bill 5241, for the Bureau of the Deaf. Our family started to complain against hospital bill.

And I went after contrast, a dark contrast to what happened to me in 03, in 2003, when I had a heart attack and we got into the emergency room and we had interpreters. We had interpreters there. And also during my procedure, I had an interpreter during my surgery. Okay. And then fast forward to September 13th, 2022, I woke up with a kind of a stop, and my wife and I rushed to Harford Hospital emergency room. When we entered, I explained we were both deaf and immediately asked for interpreters in person, and, or VRI, the video relay interpreter.

The staff didn't know what the VRI was, and so the staff person described it as a language program with a tablet on a stick, but they didn't know about what it was. So, meanwhile, I returned from CT scan on [inaudible 00:19:28] and told my wife about what had happened. The nurse had tried to hook up the VRI interpreter to her phone for me to read, but that was too small and I was forced to [inaudible 00:19:47] instructions.

I was upset and became worried that the CT may not have been done properly. And then [inaudible 00:20:01] the staff met with us to tell us the results of the test. My wife was anxious and
worried because the stroke is life threatening and can cause of permanent disability. And Kim did her best to interpret it, and we waited all day before the staff found the VRI.

But then one hour later they took it away saying they need it for another person. I stayed overnight for the MRI and had the VRI, and that worked fine. In the morning, I was evaluated and met with two doctors and I used my phone with a speech [inaudible 00:20:58] app to try to understand the doctors. And then I was discharged without my family being included.

The app wasn't perfect and did not translate that well. It was not my mode of communication, anyway. I got mad because the doctors couldn't understand my speech. So I want to emphasize we need the Bureau of the Deaf, Deaf-Blind and Hard of Hearing, so we can ensure that the deaf people's rights are overseen and enforced. So thank you for your time consideration. Okay.

MS. KIM SILVA: Right in the middle. Okay. Can you see me on the screen? Okay. All right. My name is Kim A. Silva. My husband, after his experience in the emergency room, I contacted Patient Advocacy, and I want to begin with a quote first by Abraham Berg's, "One shouldn't just hope to be treated well, one must insist upon it." So I contacted Patient Advocacy and hospital staff met about our complaint. We received a letter stating that the hospital had offered us an interpreter in person and VRI, but we had turned it down stating that we preferred to lip read.

So I contacted the Patient Advocacy and I said, "This is a blatant lie." "Well, your grievance is closed." So, several months later we went for a doctor appointment and Hartford healthcare had ADA posters, so I contacted the ADA person and we set up a meeting with CAD President, Luisa Soboleski, and also Connecticut Disability Rights rep, Dana
O'Leary, and ourselves, to meet with ADA and train them on the errors that they did and also hope to prevent other deaf from facing these problems.

So, ADA rep apologized profusely, President Louisa explains thoroughly all kinds of training equipment services needed so that the hospital would be able to meet the requirements of ADA. I said I want a follow up meeting so that I'm at a list of what you have done according to the recommendations made by Louisa. Three weeks later, I emailed and I got the following response, "Dear Mrs. Silva, our hospital is committed to serving the needs of deaf, deaf-blind and hard of hearing. What are your goals?" Apparently, they threw the notes away.

So this year, well, last year, October 2023, I found that I needed surgery. And in the past, I've had surgery in Hartford Hospital for almost 40 years now with the commission, I was not expecting to have any problems, especially since we tried so hard to educate ADA, right? So, I was going to need surgery and then I went for my pre op, and the nurse explained to me that hemorrhoidectomy is different than colonoscopy. I will be face down on the operating table, VRI will not work for me, I will need a person to interpret.

So I said, October 20th, I am formally requesting an interpreter for this surgery. Then I called the hospital and we played phone tag and I got my date, November 8th, and I said I need a person to interpret for me, I can't use VRI, and I explained why. So the night before my surgery, it almost is like a colonoscopy prep for any of those of you fortunate enough to have that surgery.

So I thought, "Oh, I'm going to check my chart and see. Oh, I got my interp." Right? No, they never called for an interpreter for me. Never. I showed up and we had VRI, which was a metal stand with wheels and a screen. When I get into the operating room, I strip, I have the IV in my hand, my wrist,
and it's restrained, which is okay because I don't want to hurt myself or tear it out.

But now that I'm on the bed, the VRI is up here, I can't see it. The doctor tells you you might die, and so I want to make sure I'm following what I'm supposed to do. I can't see. Then they restrained this hand. So I am looking up, what am I supposed to do? Then the medical staff pushes my shoulders down and pushes my head down on the operating table. I felt like rape. So I contacted Patient Advocacy again. I got two letters saying we need more time. The third letter said, 'You asked for an interpreter, November 7th,' the night before.

I am not deaf and dumb, I know how to arrange for an interpreter with plenty of time, and I did. Then they said the operating staff adjusted the VRI for you. It doesn't go up and down. So we met with the DOJ courtesy of President Luisa Soboleski. So I am asking that we have a bureau of the Deaf, Deaf-Blind and Hard of Hearing to ensure that deaf people's rights are overseen and enforced.

We were the first state to have a Commission on the Deaf and we were so proud of that. Both political parties contributed to the folding of CDHI, why us? We still have [inaudible 00:27:54], we have BSB, we have other agencies for disabilities. Without oversight, the needs of the deaf will continue to be ignored and dismissed. Deaf people will die, will experience needless trauma, lack of care and access. Thank you for your time and consideration.

SENATOR LESSER (9TH): Thank you both. And let me say that the stories we just heard are absolutely infuriating and intolerable. And I don't see anybody, any representatives of Hartford Hospital in the room, but I hope they are watching. I think they're in the building actually here today, and I think they can do an awful lot better.
Representative Gilchrest.
MS. KIM SILVA: We contacted our reps. [inaudible 00:28:45] Yeah, I did tell him to contact them. We contacted DOJ with Luisa. But yes, I did contact, when we had the breakfast, I contacted our rep, Billy Sanchez, I think.

SENATOR LESSER (9TH): Okay.

MS. KIM SILVA: Okay.

SENATOR LESSER (9TH): State Representative Gilchrest has a question or a comment.

REP. GILCHREST (18TH): Just a comment. I too want to thank you for being here and apologize for what you have experienced in the State of Connecticut. But truly thank you for sharing your experience so we can ideally help others not to have to go through that. Thank you.

MR. JOHN SILVA: Mm-hmm. Okay. Okay, thank you.

MS. KIM SILVA: Thank you.

SENATOR LESSER (9TH): Next we have Wade Terry followed by Maria Bermudez.

CLERK: Maria is not here.

SENATOR LESSER (9TH): Okay. Good afternoon.

INTERPRETER FOR WADE TERRY: Hi there. Good afternoon, Senator Lesser and Representative Gilchrest, and to all the members of our Human Services Committee. My name is Wade Terry, I live in West Hartford, you're in Connecticut. I am a retired counselor from the former commission on the deaf and hearing impaired.

I am so happy to hear where we are with this bill being introduced, because we have so many needs here in the State of Connecticut. When I worked for the Commission on the Deaf, at that time, we provided so
many services, counseling, job placement, informational referring and sharing, interpreting services, and we worked collaboratively with all of our other sister agencies. And we worked with hospitals, police departments, we provided training for them annually.

We wanted to make sure that they were kept informed and up to date on how they could work with the members of our community. This is why we need to establish this bureau for the Deaf, Deaf-Blind and Hard of Hearing. It is a huge need. I recall, I believe it was about 210,000 deaf and hard of hearing residents lived in Connecticut, and we had 17,000 of them that were profoundly deaf.

I don't know what the numbers are today, but I know that there are a lot of us, deaf, deaf-blind, and hard of hearing people who need these services. Currently, we have no commission, there is nowhere for people to go for that support, there is no stand alone existing service, the services that exist have limited access, and very often these agencies need to try to get interpreters to communicate with them. We didn't have to worry about that, the commission.

We provided direct service to our community. Instead, the current system requires third party service. It's okay, better than nothing. But I am hopeful that Connecticut in re establishing this new bureau, will be able to meet these great needs that we have here in Connecticut. We were the first to have a commission on the deaf and many other states look to us as the role model. We were the model for many to come. I am asking for your support for this bill and I thank you for your time.

SENATOR LESSER (9TH): Thank you very much. And it's great to have the experience of lots of people who've gone through the ringer on this one. Thank you very much. Next, we have Richard Golebiewski.

CLERK: Richard Golebiewski.
SENATOR LESSER (9TH): Richard Golebiewski, followed by Marc Anthony Gallucci.

INTERPRETER FOR RICHARD GOLEBIEWSKI: I'm here to speak on raised Bill 5241. My name is Richard Golebiewski, and I live in Meriden, Connecticut. I was born in New Haven, I have lived in Connecticut my entire life. I am currently 76 years old and I still work part time at different jobs. I worked for the US Army Engineering Department, then later I became a teacher at the American School for the Deaf and then retired. However, I still sub at the school a few days a week. I also volunteer at Beautiful Life, Deaf adult Day, Homecare Center.

I was so proud back in 1974 when our legislature at that time created the Commission on the Deaf. Being the first state to have such an agency and to see other states follow. It was so wonderful to see the advocacy and the beginning of so many wonderful programs that helped deaf individuals get jobs, provided mental health services and so many more.

In 2016, due to budget cuts, they closed all of these services, leaving us lost, scared, confused and not knowing where to go. There was no transition plan, we did not know where to go for any referrals or assistance. When we tried to ask for help, we were told, oh, go here or go here. It was always the wrong place and they could not help us. Some even refused access because they didn't want to pay for interpreters.

Many service providers are not aware of the Americans with Disability Act about the need for accessibility and interpreters for deaf individuals. The essential training of how to communicate with those of us who are deaf, deaf-blind, and hard of hearing, was formally given to these entities, the firefighters, the police, the health care providers, educational systems, and all of that stopped.
It has been a very sad and frustrating time of being neglected and ignored. People telling us they can't serve us, forcing us to feel helpless, many refusing to provide any services, especially if we ask for interpreters. We must have this bureau that will coordinate this information of services available to deaf, hard of hearing and deaf-blind individuals.

We need a place that we can reach out to to get referrals or assistance from various providers who have some experience working with members of our population. We need someone to provide training as they did back in those days. Many of us were unaware that the deaf unit that is currently under the Department of Aging Disability Services actually existed. Apparently they have some staff there to assist in their caseload, but apparently they are overloaded and unable to serve the many requests that they receive. We are then often left waiting for weeks or months while attention is given to more serious cases.

I am asking all of you to please address the importance of this very crucial Bill 5241, to provide the funding, to get the executive director, and perform the 10 essential tasks that are needed for our community. I thank you for your time and listening and allowing me to speak with you today.

SENATOR LESSER (9TH): Thank you for being here this afternoon. Any questions or comments from members of the committee? If not, thank you very much for your testimony. Next, we have, I believe on Zoom, Marc Anthony Gallucci.

MR. MARC ANTHONY GALLUCCI: Hello. Can you hear me?

SENATOR LESSER (9TH): We can.

MR. MARC ANTHONY GALLUCCI: Yes, but I don't see my—Okay, got it. All right. Thank you for having me, distinguished members of the Human Service Committee today. I'm testifying on HB 5241, Senate
Bill 205 and Senate Bill 306. I just want to briefly not rehash what everyone has said about 5241, but I am a person who's deaf, I do use my voice, I'm an expert lip leader.

And as many of you know, I'm a fierce professional advocate, but I can spend the whole afternoon sharing with you my own nightmare stories when I try to have access for medical services in the hospitals and stuff, it's just absolutely infuriating. And this could really be a good function for the new bureau to be able to be a central focus point that can work with the Department of Public Health and other entities to make sure that our medical services are compliant.

Well, that's as much as I'm going to say about that. I like to spend the rest of my time talking about income and asset limits. As you know, the husky, my Medicaid asset limit of $1600 was set in 1973 and it's never gone up, it is by far the lowest in the nation. 1973 is a long time ago, Richard Nixon was president, a package of Oreos was 59 cents, the average rent was $175 a month, and the average annual income was on the 12,000 range. This is not the seventies anymore, we need to increase that asset limit.

And also for Med-Connect, the asset and income limits were set more than 20 years ago when that was instituted, and they've never grown up as well, and they need to be looked at and increased also to keep up with inflation and possibly even eliminated as many other states have done.

I want to share one story. Most of the people we work with at the Center for Disability Rights, we transition under many files per person. We find usually about 150 to $300 over income, and because of this, we're not eligible for many files per person and for Medicaid in the community, even though the state gladly pays for the Medicaid in the nursing home.
And so what happens is, these folks because of a $1600 asset limit, often don't even have the resources to set up a trust for PLAN of Connecticut, so they can't take advantage of that. People who have resources, they have lawyers, have accountants, they have trust, have all kinds of things.

Some of these people are wealthy and they somehow get on Medicaid. But the people who are suffering are the working poor or the people who have very, very few assets. And so I think you need to look at that. I can tell you a story. I have one person, for example, who had no income. She'd been in a nursing home for 10 years, she had no monthly income, no social security. All she had was $8000 to her name.

And they said, "Sorry, we can't help you move out of the nursing home because you're too rich, you have to get rid of your $8000." And she said, "But that's the only thing I have in the whole world when I go out in the community, I don't even have an income at this point." And so I think we really need to be realistic and understand what we're doing here. These asset income limits are way too low and they need to be trained. It's not the seventies anymore. Thank you.

SENATOR LESSER (9TH): Thank you, Marc Anthony. And, agreed, it is not the seventies anymore, but appreciate your testimony and your zealous advocacy for people with disabilities. We have to work on the fiscal note, but I'm hoping we can make some progress this year.

MR. MARC ANTHONY GALLUCCI: Thank you.

SENATOR LESSER (9TH): Any questions from members of the committee? If not, thank you very much. Next, we have Paul Atkinson followed by Maura McGuire. Good afternoon.
INTERPRETER FOR PAUL ATKINSON: Good afternoon, Senators and Representatives. My name is Paul Atkinson, and I am from Norfolk. I am the chairperson of the advisory board for three programs in Connecticut, Connecticut State Community College, The Program for the Deaf and Hard of Hearing and Deaf-Blind.

Secondly, the Deaf Studies Certification Program and the Interpreter Training Program. I also serve on the board for the Connecticut Registry of Interpreters for the Deaf. For 34 years, I worked as an educator for Northwestern Community College, teaching English and Math, various other courses.

Also, up until present day, I have been a professional certified interpreter for over 52 years. It may surprise you, but there are many deaf individuals that do not see themselves as disabled. It is just a communication mode variance. They are able to socialize with the world in a different way, a different language that is not a spoken or auditory language, but a visual manual language.

And what do deaf people need to be equitable with their hearing peers is simply access for communication, using their native language, and also for hearing people to understand that there is a unique way of socializing with the world. I would like to pull a quote from the first deaf president at Gallaudet University. Gallaudet University was the only university in the world for the deaf, and the president that I am quoting is I. King Jordan, who has stated, "Deaf people can do anything," except here. I moved here to Connecticut from Canada back in 1985.

At that time, the Commission for the Deaf was well underway with a great reputation. A lot of other states looked to the Connecticut Commission for the Deaf wanting to imitate. The commission had a full staff, they had an executive director, interpreters and interpreter coordinator, counselors, as you've
heard from Wade. I would say toward the end of the nineties, close to the 2000s, we saw the commission slowly start to diminish, my program in the colleges were also cutting back.

People were retiring, people were leaving for other opportunities and they weren't being replaced. So the staff were dwindling in numbers and they were not able to provide the consistent level of services as before. With the decrease of services, it finally got to the point where there was nothing left.

Some of these deaf individuals were not able to access programs of education or services, they would have to settle for a low paying job or settle for simply drawing on social security income. I strongly encourage the support of the Bill 5241, which establishes the foundation for a similar concept of commission again. The keyword here is going to be the foundation, this is the beginning step.

The Bureau would make it possible for deaf people to access their world of employment, government services, post secondary education and health care, better than what they are experiencing now. So many other people, maybe that have not mentioned that the economy really does play a part in this. The deaf professionals and hearing professionals, those that have their doctorates, their masters, trying to draw in other individuals to come to Connecticut for work with raising families in the state, contributing to your community and our economy.

Deaf students that have just recently graduated from high school, they may decide to stay in Connecticut and go to Connecticut State Community College or a state college. And then when they're done with that program, continuing on in Connecticut by finding employment here, paying those taxes and contributing to our economy. The return on state investment seems to be very positive.
So again, I encourage you to vote in favor of House Bill 5241, and get it out to the larger vote in order to pass this bill in entirety. Thank you for seeing the comments, listening to the voices of the deaf community today. Thank you.

REP. GILCHREST (18TH): Thank you Mr. Atkinson, for your testimony and for being here today. Next we'll hear from Maura McGuire.

MS. MAURA MCGUIRE: I'm going to be brief. Senator Lesser, Representative Gilchrest and esteemed members of the Human Services Committee, thank you for the opportunity to share my thoughts in support of Raised Bill 5241, an act establishing the bureau of coordinating services for deaf, hard of hearing and deaf-blind individuals.

My name is Maura McGuire, and I've supported children who are deaf and hard of hearing, deaf-blind and their families in Connecticut as an educator for almost 40 years as part of CREC Soundbridge and various community boards with Harvey, Luisa, Paul and others. During my tenure as an educator, I've seen our state move from the forefront to the rear in providing services for the deaf, hard of hearing and deaf-blind.

Raising Bill 5241, is a step towards rectifying that. Others have noted the recent research that's been done, I'm just going to summarize and say that it is well known that although we have the Connecticut State Department of Aging and Disability Services, and the commission was absorbed into that, those services are hard to find or non existent.

And creating the bureau would help to address the needs stated in the research reports and the Connecticut statewide needs assessment that have been mentioned before. It would create a centralized place to dispense information and resources as well as support the specialized
services for those who are deaf, hard of hearing or are deaf-blind, provide training to local and state agencies as well as health care facilities, empower those who are deaf, hard of hearing and deaf-blind as well as their families by providing education services and support so that they can navigate the unique challenges that are presented to those with deafness in accessing their world and advocating.

Creating the Bureau of Deaf Blind Services would empower, educate and support access and independence for citizens who are deaf, hard of hearing and deaf-blind. And I wholeheartedly support it. Thank you.

REP. GILCHREST (18TH): Thank you so much for being here today and for your testimony. Next, we'll hear from Nicholas Dionne.

MR. NICHOLAS DIONNE: Hello and good afternoon. I want to thank you all very much for your time and attention today, and thank everyone in this room from this wonderful community for all the incredible testimonies that they've given as well as the ones that are to come.

My name is Nick Dionne, I am a board member of the Connecticut Registry of Interpreters for the Deaf, a nationally certified ASL interpreter who works here in the State of Connecticut, and I've been a resident here in Connecticut for the majority of my life. Today, I and so many of us have taken time off of work for a very important reason, to urge your support of this very essential Connecticut House Bill 5241.

I could give this testimony in American sign language fully in ASL, but today I believe it's important to accommodate you, the legislation, and speak to you directly in your primary language. This is something that deaf, deaf-blind and hard of hearing people are forced to do every day of their lives.
They're constantly placed in situations where they have to accommodate the majority of people in the world who do not know their language or who do not understand how much they are actually capable of, but they rarely get to experience when we the majority reciprocate.

How privileged are we that we have the power to make so many choices and decisions for other people, when so many in this room and around our state are not afforded the same luxury to do so. If you don't feel humbled by this sobering reality, then you're not paying attention or you don't care. I do not believe this to be true of any of you.

I always like to think the best in people and believe that all people are just trying to do the best they can every single day. The thing is though, there comes a point when we all have to stop and think to ourselves. Are we though? Are we really doing all that we can do?

I want to acknowledge that I'm glad to see that Commissioner Porter had mentioned all of these other vital services that exist within our state and the great work that those services do. But the challenge and the elephant in the room is that they are all so separated and divided that there is no one central coordination for all of these services.

By establishing this bureau and appointing somebody of the community, that this bill is about, they will be able to, there is so much potential to coordinate these services. And what often happens in this state is, when something like a entire commission of the deaf is closed, all of the services are lost, and when the pieces are picked up, they're handed to people who are working in the state who have not worked with this population for their entire careers.

And to ask someone to handle that and to pick it up and to learn about all of this and to be able to
competently handle it, is a big ask. So I ask, why are we not looking to the community that this bill as well as the entire community around the state is about, why are we not talking to the people who have dedicated their entire lives, their education, their careers and putting them into the position to take it and run with it?

We are among so many intelligent, dedicated adults that came here directly from the community of which this House Bill will affect, and this legislature has cast them aside for almost a decade. Connecticut is the birthplace of American Sign Language and the entire American deaf community right here in Hartford. But in just eight years, we have become a state that struggles to support their very existence.

You have all heard their testimonies, you have felt the sting of their frustration, the frustration that they feel when they describe so many avoidable incidences here in our state that have all happened to them and their loved ones, and you will also continue to hear more today after I am done. And you know in your gut that change needs to happen now, it cannot wait, and it starts with your support of this crucial bill.

You have a great opportunity in front of you, not only to ensure the people in this room that they will always have a place here in Connecticut, but also to show our entire state that policy decisions can and should be made with the people who will be affected by them. Deaf, deaf-blind and hard of hearing people are the ones who know best about their own lives, their culture and their natural language.

Simply making a seat at the table for them is not enough unless you actually hear them. It's time to stop looking away, and it's time to start recognizing the value of their contributions in our
State. It's not too late to pave the way and extend an olive branch. Thank you.

REP. GILCHREST (18TH): Thank you, Mr. Dionne. Can I ask you to explain briefly what is the Connecticut Registry? And how would that work with this new Bureau?

MR. NICHOLAS DIONNE: So similar to many of the other organizations that are here representing the Connecticut Registry of Interpreters for the Deaf, is a nonprofit organization comprised of a board of directors, all of which are volunteering our time for various things that, I won't go into now, but a lot of it has to come down to advocacy, effort, providing resources. Sometimes we're contacted, asking for interpreting services, which people don't realize that there are proper avenues and we don't provide those services. We try to refer them to, for pay agencies and things like that.

REP. GILCHREST (18TH): Thank you very much.

SENATOR SEMINARA (8TH): Thank you Madam Chair. I don't know if you were here earlier, when I had asked the question, you are an interpreter, correct?

MR. NICHOLAS DIONNE: Correct, yes.

SENATOR SEMINARA (8TH): So, and this may have been answered, I'm sorry, I had to leave the room but I had asked a question earlier wondering how people felt about the certification process of becoming an interpreter. And I'm wondering, what is your opinion on that? Is it laboriously unnecessary or do you feel that, everything that you had to go through to become certified was necessary and in order to be effective?

MR. NICHOLAS DIONNE: Thank you, Senator, I do recall this question being asked and I think the context of that was, is there a potential to lessen the requirements, to in turn increase the pool here
in Connecticut? It's a valid question, however, there's an irony to it because originally when the State statute was established, as well as in general, National Certification for interpreters, there was very little requirements and not only did the whole nation, but especially Connecticut fought to increase these requirements because we had recognized the difficulties and the unique skill set that is required to be qualified enough to do this job, and the danger it is to put people in there who are not qualified and trained to do it.

So while it is a valid question, there is no way to go backwards from it. The amount of training is extensive and necessary and having a board that is able to provide education to the community, not specifically to interpreters will help educate the entire State that this training is what we interpreters have to go through now. And the importance of it and why they need to be very conscious about screening those folks going into their establishments and the people that they're hiring.

SENATOR SEMINARA (8TH): Terrific. Thank you so much for answering that question and providing that clarity. Thank you, Madam Chair.

REP. GILCHREST (18TH): Thank you. Thank you, Mr. Dionne.

MR. NICHOLAS DIONNE: Thank you.

REP. GILCHREST (18TH): Next, we will hear from Keith Vinci.

MR. KEITH VINCI: Two chairs to choose from. Okay. I'd to thank the Human Services Committee for hosting this event. I also want to thank the interpreters who are working it because they're working very diligently. What you're seeing is our professional interpreters who have certification from somewhere nationally, mostly RID, and who have
registered with the State of Connecticut, so that's the requirement that they have.

My name is Keith Vinci. Currently, I'm the President of the Connecticut Registry of Interpreters for the Deaf. I am a CODA, which is a Child Of Deaf Adults. I'm a 70 year old child, and a lot of people here know that I act like one sometimes. I don't want to rehash all the stuff that you've already had, you've been here since 11 o'clock.

I just want to reiterate about, I just want to say something about ASL, it's an American Sign Language, is a different language. So when you get documents or you get a piece of information that you look at, you have to revise it in some way in your mind to make sure that the ASL person can understand what's going on. And what happens, I'm going to give you a little example. I'm not going to really go into all of the, everybody knows what we want. We want this Bureau, we need this Bureau. I worked for the commission on the deaf and hearing period for 29 years. I ran a vocationally, the job development replacement unit and also I was an interpreter coordinator.

So I'm pretty much aware of all the issues that we're talking about right now. But I'm going to give you a little bit of an example. Imagine you're a person who has no concept of English or has a difficult time with English, and you're really dependent on your vision. Unfortunately, this doesn't apply to the deaf, blind as much. But imagine that, this is a true story and I'm going to sign, I'm going to act it out a little bit so that the interpreters will give, I'll make it work a little harder now. So okay, so this is what happens.

INTERPRETER FOR KEITH VINCI: I got home and there's this piece of paper in the mail, in this envelope. It was red, white and blue and I opened it. I don't
know, I don't understand what it said. It used all these big words, formal language. And, so I asked somebody to look at it and could they tell me what it said? And I asked somebody else, and nobody could tell me and I didn't know what to do. I didn't know where to go. I didn't know who to talk to. Maybe I could call Luisa, or Harvey, or somebody. Because I didn't understand what this piece of mail was, but it looked very official.

MR. KEITH VINCI: It happened at my house, my mother got a letter when I was growing up, had all this fancy writing on it. She ended up donating money because she thought it was something that she had to pay for. This is why we need to have a Bureau. We really do need to have something that we can rely on, the commission on the deaf is dead. Sadly, I work with Wade, I work with Sue. Well, I think Shatney, over there too, your hair colors changed. [background noise] but I don't care what you do. And I was hoping that Matt Lesser would be here because I live in Middletown.

So I thought that would be good. But, my testimony is on file so you can see what I really talked about, but I just thought that you needed to hear that. Oh, and also one more thing, lip reading, you only see 30% on the lips. That means you got to piece everything together from the air, and it's very often you get wrong mixed messages. Okay.

REP. GILCHREST (18TH): Thank you so much for being here. It was very helpful. Thank you. Next, we'll hear from Marsha Wetzel.

INTERPRETER FOR MARSHA WETZEL: Oh, I shut it off again. Okay. No, I'll get it. Can you back up the Chair? Because the [inaudible]. Hello everyone. Members of the Committee, House Representative Gilchrest, Senators. My name is Marsha Wetzel. I am a deaf individual born to deaf parents. So therefore, I am also a CODA, a Child Of a Deaf Adult. I do have one sister who is deaf, autistic,
and developmentally delayed. She currently lives in a group home.

I am a Certified Deaf Interpreter, which is known as a CDI, I’ve gone through legal interpreting training, medical interpreter training, and educational settings. I remember back in the day, I was born here in Connecticut in Newington. When I was a little girl, growing up in the seventies, we had the Commission for the Deaf, and it was an amazing service that the State provided with interpreting, counseling, supports, resources, everything my parents and my family and I needed.

I moved away. And in 2020 I moved back to Connecticut after my mom had passed away in order to take care of my aging father. Over the course of these past four years, I have already been through 10 different instances of disruption, and barriers in my medical health care setting experiences. Now, the 10 cases, relate to discrimination, not providing accommodations for access, access to services and communications such as providing an interpreter, which could be classified as language deprivation in the moment. I am an American taxpayer. I pay my taxes, but my rights seem to be violated, quite frequently. During my testimony. I am not going to explain all 10 situations I've been through, but let me hit two of them.

At Hartford Hospital, I was going in for two separate procedures that required anesthesia. Now, I've always wanted a live interpreter in these types of situations and I asked for that well in advance, of the procedure dates, it was not provided, and they rolled in the VRI which of course elevates the anxiety, the nerves because you're about to put me to sleep and operate on me. And yet you expect me to gather all information from a two dimensional small screen. The doctor said, well, we could reschedule. I had already waited for this appointment and the procedure for months on end. So I of course, did not want to reschedule and decided
to move forward with the procedure feeling I had no other choice.

The second instance was at Yukon Health Center, which happened just a mere three weeks ago. I was drastically ill and I decided to go to the emergency department. When I arrived, I asked for a live interpreter to be called, to come on site. It seemed like, I had waited for a while and nothing was happening. The triage nurse, called me into her area and said, oh, I'm sorry, we can't find a live interpreter. They rolled in the VRI, and again, the technology struggled and did not work. We ended up resorting to writing back and forth on napkins.

Ladies and gentlemen of the Committee, I brought them in as visual evidence. We had to take the paper towels from the dispenser in the room and write back and forth. How offensive is that to me as a highly educated deaf individual, that has the capability to communicate with this person. I am in there because I have had recently an injury for my elbow and my left wrist and hand. So I struggle with, writing back and forth, didn't have an interpreter during triage, didn't have an interpreter during the whole pre-check. We've had doctors and nurses coming into the room. VRI never worked until maybe three or four hours later. And we finally had the 2D experience. This was all very traumatic.

Also, I am a user of glasses. So even looking at an iPad or a small screen for VRI video remote interpreting, is not effective. It's nice to have a live interpreter who is actually three dimensional with the visual modality and cues, that I can see very clearly. It is dangerous to rely so heavily on VRI. A lot of misunderstandings and miscommunications can happen, and frequently do. Misdiagnosis because the VRI interpreter is not able to see the entirety of the room. They do not have a 360 degree view, but a live interpreter is there, in the environment can see everything that's going on.
So I just want to emphasize again, establishing a Bureau is going to be vital, having an executive director that is well aware and knowledgeable of deaf community and culture, ASL, language use, deaf blind, all of the nuances of the deaf community, and that person being deaf themselves would be ideal.

Interpreting services, access to those types of accommodations, it is important, especially important from birth to 18. They need to have what's called the certified deaf interpreter because their first language, their [herited?] language is going to be ASL. That's something that's already ingrained in the certified deaf interpreter. They are able to be the role model and clarify all communication. Out in the community, you have a wide range of communication modalities, when you have a deaf individual that we call grass roots, meaning they use that native heritage language. That's when a certified deaf interpreter comes in and provides that accessibility.

Right now, deaf members, deaf community do not know where to go to find resources to get the support. There's no place to go, not even to download information. But if there is a Bureau established, that's when there will be a centralized hub, and deaf individuals will be able to have that access and utilize it well. Also expanding, interpreting services provided throughout the State. Again, we've mentioned that those have diminished, dwindled. So providing the training to the interpreters, educating those on the importance of using an interpreter and the importance of using a qualified interpreter. How do we prepare these interpreters for the professional settings, medical settings, legal settings, law enforcement and emergency. How do we prepare those, in those settings to communicate with deaf individuals, if an interpreter is not present? That's what the Bureau can do.
Now, for example, I've already mentioned my parents are deaf. We talked about the concerns. We've talked about where they will go in the future when they do become ill, when they are needing to be placed in a assisted living facility or a nursing home. But my parents have stated, they don't want that because interpreting services are not provided in those environments. VRI is not available, CDI's are not really available, and communication access among peers and staff members at these facilities are nonexistent. They are unaware of any type of cultural sensitivity background. There's no training for the staff members, working with deaf individuals. They may have never met or even seen a deaf person before and yet are expected to adequately provide and support this person.

So I think having the Bureau in the State, will have a well-established potential for creating a facility for deaf, deaf blind, and hard of hearing, senior citizens and those with special needs. Having that be a State provided resource is wonderful because otherwise they look for money, they have to look for funding, and they struggle to find that. And so the dream is always put on pause because it seems unachievable. But with House Bill 5241 in its passage, then setting up that Bureau, they could take the first step in just looking at researching how this could come to fruition. Right now, everyone is siloed and working as an individual across the State. But that's not how we want people to end their lives. We don't want isolated deaf members to experience only isolation. We want to provide them the opportunity to experience life with access and communication, short term, long term rehab, being in a part of all of this.

As a certified deaf interpreter. I used to live in Rochester, New York, well, for 20 years and I worked in the medical field in the hospitals there, as an on call CDI and I just have to say, that they provided interpreting services 24/7. Interpreters were on call, interpreters were on site, during
hours of the day. And that is something that I think the State of Connecticut once establishing a Bureau can look at and take into consideration, pulling parts of their structure that we can use here in Connecticut to provide 24/7 access to the health care setting.

For those of us in the deaf, deaf blind, hard of hearing community, we deserve equitable quality of life. And right now, it is drastically skewed. Establishing this Bureau is a step in the right direction to providing equity in our access. Hearing individuals can hear anything that they want throughout any time in the world in their daily lives. And we do not have that same experience. Providing an equitable access to communication is what's needed, whether that be in the legal, educational, medical, mental health, setting, all of these systems need someone to be able to just keep their eye on what can be done within those fields, and having high quality services being provided. Interpreter certification, sometimes it is not even required because of just liability and they don't want any skewed messages from that clarification from the interpreter.

SENATOR LESSER (9TH): Can you please summarize?

INTERPRETER FOR MARSHA WETZEL: Hold on. Okay. Yes. So clarification from the interpreter is certification is needed because it is such a high demand in life or death for many deaf individuals. So I think the frustration, the problems that are happening in today's deaf community barriers can be reduced and hopefully eliminated with this Bureau with providing live interpreters, with providing certified deaf interpreters. Our deaf constituents will become more knowledgeable, more aware and more productive members of their societies. Thank you so much for your time today and for listening, please support House Bill 5241.
SENATOR LESSER (9TH): Thank you so much, Marsha. It's good to see you again. Thank you for your advocacy and for meeting with me and Representative Farrar way back when, and okay, thank you so much.

SENATOR SEMINARA (8TH): I have a question.

SENATOR LESSER (9TH): I'm sorry, Senator Seminara has a question.

SENATOR SEMINARA (8TH): Hi, Marsha. Good to see you again. And I'm very sorry to hear of your experience in the hospital. I can only imagine what someone in the deaf community, or deaf blind community, or hard appearing community, goes through when their injuries may be more serious and you're unable to write on a scrap of paper. I can only imagine that, that is completely overwhelming, and frightening, and lonesome. Having said that, I do have one question, from an assistive technology standpoint, is there anything out there other than the VRI that might be helpful to those in your community or those in the deaf, deaf blind, hard of hearing community?

INTERPRETER FOR MARSHA WETZEL: Being forthright, the deaf, deaf blind, hard of hearing community, first language is always going to be ASL right. As stated several times, ASL the visual manual modality. So the interpreter is always going to be the best primary fit. Now, you could add things such as captioning. Captioning is always going to be an assistive technology that you can use. But again, it's going to be in English, so not the first language, the second language, but captioning is a provision. VRI captioning, interpreter.

SENATOR SEMINARA (8TH): Okay. Thank you very much. I just didn't know if there was another piece of equipment out there that would be helpful in certain situations.
INTERPRETER FOR MARSHA WETZEL: I will say that, nowadays with smart phones, there is that speech to text, right. So again, that does come out in text format which is English, not the first language. So I wouldn't say that, that should ever be the first option, but it's a potential aid. Hearing person can speech to text for the deaf individual. But how would the deaf individual then respond? They would have to type in English, not their first language. Again, interpreter is going to be the communication access ideal and a time saver.

SENATOR SEMINARA (8TH): Thank you. Thank you very much. Thank you, Mr. Chair.

SENATOR LESSER (9TH): Thank you, Senator. Other questions, if not, thank you. Next Richard Famiglietti on Zoom, followed by Rosa Ferraro.

MR. RICHARD FAMIGLIETTI: Good afternoon, everybody, Human Services Committee. My name is Rick Famiglietti, and I'm here to speak today in support of the elimination of the asset limits, for the HUSKY C Medicaid programs, for both the working disabled, and the unable to work disabled people. This would be one step closer to ending the discrimination against persons with disabilities by allowing unlimited assets, just like the HUSKY programs for the healthy able bodied people.

I'm in support of Senate Bill 205 and Senate Bill 306. In October 2000, the Medicaid for the employed disabled, then called the Medicaid for the employed disabled. So five program was implemented. I began working at the Center for disability rights. This program allows persons with disabilities to buy into Medicaid as a health care premium, only while they are working, and enjoy a higher income and asset limits.

However, limiting income and assets prevents persons with disabilities to climb the social class ladder and keeping persons with disabilities in poverty, so
not to lose their health and home care service they need, under HUSKY C or to avoid going to a nursing home. The current income and asset limits for the med MED-Connect, may seem to you, able bodied people, okay. But with an asset limit of 10,000, is that really enough for emergencies like, replacing a furnace, leaky roofs, car repairs or temporary loss of employment when you have to pay for a mortgage? No, it's not.

Not only that, but it's discriminatory because the able bodied HUSKY programs do not have an asset limit. And I know you've heard us say this many, many times. So if Senate Bill 205 is passed, it will also encourage more people with disabilities to work and there's no need for a study for that. The current limits, only limits persons with disabilities potential.

Senate Bill 306, providing for the phase out elimination of asset limits in the HUSKY C program. This is for people on HUSKY C who do not work. I support this Bill. However, I respectfully request that the language be changed and take out the phase out elimination and eliminate it immediately. This will, and two kinds of discrimination.

One type of this discrimination is those who can work in spite of their disability and those who are unable to work. The discrimination is against persons with disabilities, unable to work as they are subjected to lower income, and asset limits than person with disabilities who are working in spite of their disabilities. The second discrimination is that again, able-bodied people have higher income limits and no asset limits for the same HUSKY programs. And that's not fair. I'm in support of--

SENATOR LESSER (9TH): I'm sorry, can you please summarize?

MR. RICHARD FAMIGLIETTI: Summarize, uhm. I pay the same taxes as able bodied working people and you
know what? I can't get to the top of sleeping giant. Okay. I pay taxes and can't access many of the things that able bodied people can access. So this needs to be corrected. Eliminate all this discrimination, the same HUSKY programs need to be having the same access with the same income and asset limits as able bodied people. Thank you.

SENATOR LESSER (9TH): Thank you. We hear you, and thank you for being a zealous advocate. Any questions from members of the Committee? If not? Thank you. Next, we have Rosana Ferraro followed by, oh, we already had Pat Rehmer, followed by Werner Oyanadel.

MS. ROSANA FERRARO: I'm here instead of on Zoom.

SENATOR LESSER (9TH): That's great.

MS. ROSANA FERRARO: Senator Lesser, Representative Gilchrest, and members of the Human Services Committee. Thank you for the opportunity to speak to you today. I just want to take a few moments to elevate Universal's position on four Bills today. SB 314, HB 5240.

SENATOR LESSER (9TH): I know who you are. But can you just state your name for the record, please?

MS. ROSANA FERRARO: I just realized I left that part out. I'm so sorry, I'm Rosanna Garcia Ferraro. I'm Program Lead at Universal Health Care Foundation of Connecticut for Health Justice Policy Advocacy. And so I'm just going to talk about SB 314, 5240, 305 and 309. There will be other folks that will get into sort of deeper detail on these, but we just wanted to elevate that, for us at Universal Health Justice means that everyone has a fair and equitable opportunity to be as healthy as possible.

And we feel that each of these Bills addresses a health justice issue. There will be more detail in written testimony, but I just briefly, we support
314 because it's critical for uninsured patients. It's just make sure that we're leveraging Federal matching funds to cover emergency medical care to the fullest extent and broadest definition within Federal law.

And we absolutely support folks being able to enroll before an emergency so that they have the safety and security of knowing they are covered in the event that they do have to go to the emergency room. We support HB 5240, because it ensures that infertility treatment is covered by HUSKY. We see reproductive justice as a health justice issue, which is why we support everyone's right to access the care they need to have children, regardless of how much they make. Our HUSKY program has always been comprehensive and infertility treatment is health care, with this 90% Federal match that we would be able to access, we can afford to continue to hold the standard of comprehensive coverage.

Rick just said my piece about SB 306 and he has lived experience, but we also support it with the caveat that we should eliminate the asset limit now rather than phase it out because, one again, no other HUSKY program has it. And earlier today, I was watching Testimony and Deputy Commissioner Hadler did say that without an asset limit that would, that would actually save the department some money as well as administrative burden. And just to wrap it up, SB 309 would study medical assistance for certain legally present, older noncitizen. We see that any way that we can expand access to care regardless of who people are, we are supportive. So, thank you for your time today.

SENATOR LESSER (9TH): Thank you for your testimony and thanks for joining us in person. Any questions for members of the Committee? Seeing none. Thank you for being here this afternoon. Next up, Werner Oyanadel followed by Jonathan Aidukonis.
MR. WERNER OYANADEL: Good afternoon, members of the Human Services Committee. My name is Werner Oyanadel. I work for the Commission on women, children, seniors, equity and opportunity. But today I'm actually going to be speaking as Vice President of the Connecticut Immigrant and Refugee Coalition.

We are here to speak in support of HB 5371 which proposes the creation of a working group to study the expansion of HUSKY health benefits to all uninsured residents under the age of 19, regardless of immigration status. Connecticut has already made significant progress by extending HUSKY health coverage to our youngest residents, including undocumented children and pregnant women. This expansion is a beacon of hope and a critical step towards ensuring a healthier future for our State.

However, the urgency of this situation requires more immediate action than just the initiative of creating a study group. The need for comprehensive healthcare access for uninsured children in our communities is urgent and their wellbeing cannot be postponed. While we recognize the value of a detailed study to explore the benefits and costs associated with expanding HUSKY health benefits. We urge the legislature to consider the immediate implementation of these changes ensuring healthcare access for all children under 19 regardless again, of immigration status, not only supports in our opinion, the wellbeing of our most vulnerable, but also constitutes a sound investment in the future of Connecticut.

An important economic benefit of expanding HUSKY health coverage includes significant financial relief for hospitals by extending coverage, hospitals would see a decrease in uncompensated care costs as more patients gain access to preventative and ongoing health care. This reduction in uncompensated care not only alleviates financial pressure on hospitals but also contributes to a more
sustainable healthcare system. Statewide, Connecticut already provides coverage to children up to the age 15. We encounter situations where siblings within the same family receive an equal access to health care based on their age. So expanding coverage to include all children under the age of 19 addresses this issue of fairness and equality.

Furthermore, we recognize the solution to these challenges could be significantly advanced by the enactment of comprehensive immigration reform at the Federal level. Such reforms would alleviate the burden on States like, Connecticut in addressing these health care disparities. CIRC is supportive of this Federal efforts and beliefs that our elected officials at the national level, play a crucial role in this endeavor. Expanding HUSKY health benefits is more than a policy adjustment, in our opinion, it is a commitment to the values of compassion, equity and inclusion that defines Connecticut. It’s an investment in our collective future, ensuring that every child has the opportunity to thrive, contribute and become a vibrant part of our community. Thank you.

SENATOR LESSER (9TH): Thank you for your testimony. Questions from members of the Committee. If not, thank you for being here this afternoon.

MR. WERNER OYANADEL: Thank you.

SENATOR LESSER (9TH): Good to see you. Next, we have Jonathan Aidukonis followed by James Lawrence.

MR. JOHN AIDUKONIS: Hello, I'm John Aidukonis, from Hartford, Connecticut and I appreciate the time with the Committee today. I'm here to talk about Bill 5364 about preserving the assets of former patients of State Humane institutions. And the story, I'm here to talk about today, there's a full written testimony submitted, but I wanted to give a little bit of personal color. It's a personal story, but I
think it reflects some broader issues that require some attention and change.

My mother died in November of 2022. Her death was unexpected and that shouldn't be a total surprise because most of her life was full of unexpected moments and I described as two chapters. One that had a lot of abuse, a lot of decisions made to survive trauma, and then eventually a long term battle with addiction. And one that was born out of recovery where she really became a beacon of hope for a lot of people and taught the importance of second chances.

Her resilience and dignity I think is something that taught me a lot about grace and fortitude, especially in the wake of her loss. About three months after her death, I was forced to go back to that first chapter. I received a letter from the Department of Administrative Services, one that the Probates Court in Connecticut, whimsically called the maybe letter that said there might be a claim due to a statute around Human Services that we might or might not owe that required a lot of information or I should say requested a lot of information to be sent with no real detail or follow up. About six or seven phone calls and emails later, we were able to finally get a claim presented to the State. I was serving as our executor. So it was sent to me in that capacity, where it asked for a pretty large sum of money regarding rehab services that happened about 50 years ago, up until the time I was conceived.

So the question there started to become as any debt, can you prove it a little bit because it came up, frankly out of left field. and I understand that those laws are in place to protect taxpayer assets and things like that, but it felt a little old and because we do have some record, retention limits, there were no actual records to talk about the services rendered or any specificity.
Furthermore, I grew up in an Italian immigrant household, where you were taught to save everything during the depression, including every letter, receipt, or bank statement you ever had. So I was armed after cleaning out a house with a lot of documents over the same times, dates and spans that would have created a pretty reasonable doubt that she was in countries like, Germany or at one point even, in other State institutions that couldn't have been two at the same time. Eventually after, disputing this with the Attorney General's office, we were able to settle and close the financial part, but it begged a bigger question to me.

I, by no means a lawyer, I review a lot of contracts in my job. I feel comfortable pushing back and I understand the legal jargon, but I started to think about the population of people who mostly go through this. And when you think about the Americans who struggle with addiction in the families. There's a big parody with socio and economic circles who probably don't feel that comfortable or confident. It becomes a little bit more disconcerting when you start to think about the definition of the statute that is reimbursement for the care received, and not to be totally lost, but if the dates were remotely right, I would have been conceived while she was in the care of the State, which starts to say, in best case, that's neglect and worst case something else.

I think as we consider the implications of this Bill, it's not just about me grieving my mother and I'm not seeking financial restitution on this, but I think more than anything, it starts to talk a little bit about putting the human first and honoring people's legacies and not thinking of what they leave behind as, simply financial assets. I don't think the intent of the law was to take the human out of the story. And I'm just asking us to make some changes that I think better reflects our values as a State and the one that takes care of our people, and probably sets a generation that's starting with a couple of raw deals up for success,
rather than a point of taking more away in a moment of extreme loss. So I appreciate the time, and thank you.

SENATOR LESSER (9TH): Thank you for being here. I'm sorry for your loss.

MR. JOHN AIDUKONIS: Thank you.

SENATOR LESSER (9TH): And thanks for telling your story, to hopefully make sure that doesn't happen to other people.

MR. JOHN AIDUKONIS: I appreciate it.

SENATOR LESSER (9TH): Are there questions from members of the Committee? Representative Hughes has her hand up online.

MR. JOHN AIDUKONIS: Hello.

REP. HUGHES (135TH): Thank you so much, Mr. Chair. And I just really thank you and commend you for coming forth and really illustrating the lived experience of why this law is so draconian and that it needs to be repealed. That's very outdated and puts undue burden like you say on families that have suffered enough and quite frankly on the State to administer this onerous, claw back if you will and I'm really happy that we're moving this forward to get rid of it.

MR. JOHN AIDUKONIS: Well, thank you.

REP. HUGHES (135TH): Get rid of it. And I'm sorry for your loss in this undue burden.

MR. JOHN AIDUKONIS: I appreciate it. Thank you.

SENATOR LESSER (9TH): Thank you, Representative, seeing no other questions. Thank you for being here this afternoon.
MR. JOHN AIDUKONIS: Thank you.


MR. JAMES LAWRENCE: Good afternoon. Esteemed members of the Human Services Committee, thank you for the opportunity to speak today. I come for you today in support of HB 5241. My name is James Lawrence. I'm a current candidate for master of public health and health policy at the Yale School of Public Health, an incoming medical student at Harvard Medical School. But most importantly, I am CODA, the son of two deaf parents.

I've had the pleasure of working with health equity experts from Gallaudet University, who championed disability rights within the health care sector where I learned not only about the shortfalls of the health care system, but how under equipped social services failed people like my mother and father, from the perspective of someone who spent the better part of my childhood, helping to make up for the shortcomings of an ill-fitting social services system.

Establishing a Bureau for the deaf, deaf blind, and hard of hearing, would foster the wellbeing of not just those who are most convenient to care for but all who seek it. I'd to highlight data from a needs assessment conducted by the American School for the deaf in which the following points were made. More than 40% of deaf, hard of hearing, and deaf blind participants said they prefer in person ASL interpreting services as their primary means of communicating with their health care provider. These patients however, are instead provided with video relay interpreting, paper and pen writing, lip reading and gesturing. Not the same thing.

Only 11% of participants always receive the accommodations they requested while over 60% never
or only sometimes do. As one individual stated, I gave birth in 2013, they forced me to use a TTY to communicate rather than provide an interpreter. That was the second time this happened. As a prospective medical student who has worked in the field of disability advocacy over the last few years, during my time at Yale, I was not shocked to learn that medical education on the rights and needs of disabled patients is abysmally short, often no more than a two hour seminar or a week long elective, before medical students are transitioned to their clinical training. Never to be touched again.

As a CODA, I witnessed the effects of this educational negligence, firsthand, my entire life, I often served as my parents interpreter when health care providers failed to accommodate this basic right. I often think back to my childhood when I wasn't more than 10 or 12 years old, when doctors spoke to me, not my parents, their patients, even the most basic of respect was not paid. I witnessed my deaf mother's mental health deteriorate, after years of being unable to find a job because of language discrimination.

Unable to receive mental health care from providers who specialize in deaf health but wouldn't take public insurance. At 17, I watched helplessly as she was placed in a psychiatric hold, her beautiful face marred by years of hopelessness and her hands telling me that she wanted to take her life. By targeting this shortcoming through the provisions outlined in section 1.4, 1.6 in section two, I remain hopeful that this Bureau may have an impact not only on current practices but also on positively shaping the future of health care providers who choose to do their training in the State of Connecticut. Thank you for your time.

SENATOR LESSER (9TH): Thank you, James for your testimony and for being here and I think we all wish
you best of luck in your studies. And I think Representative Gilchrest has a comment.

REP. GILCHREST (18TH): Yes. Thank you. Did you testify yesterday in public health as well?

MR. JAMES LAWRENCE: Mhm.

REP. GILCHREST (18TH): I was on Zoom and couldn't get to the button quick enough, but just thank you for being here yesterday and today and for your advocacy.

MR. JAMES LAWRENCE: Absolutely.

REP. GILCHREST (18TH): Thank you.

MR. JAMES LAWRENCE: Thank you for your time.

SENATOR LESSER (9TH): Any questions? Representative Dathan.

REP. DATHAN (142ND): Thank you so much and I'm so heartened to hear about your future plans on how you are going to medical school and really aware of these challenges. The Connecticut Council on Developmental Disabilities had a great program in the off session this year. One of the key topics we talked about was the ability for people who are disabled in one fashion or another to be able to get the equal services from medical providers.

And I'm really hoping that as part of your studies, this is something that your medical school will look at and make sure that we can provide equal rights to everyone, whatever their disability might be. And the story that you said about professionals would talk to you rather than your parents was one that we heard over, and over, and over, again and hearing the stories of people who didn't have adaptive equipment at their medical appointments, whether it was an MRI machine or even getting a mammogram. So I do have very much hope that your generation of
upcoming doctors will be addressing this and ensuring that all people, of all abilities in our State are able to access proper health care. So, thank you very much. Thank you Madam Chair, Mr. Chairman. Sorry.

SENATOR LESSER (9TH): You've done that now twice. Thank you. Thank you, Representative. Anybody else? Yes, Representative Cook.

REP. COOK (65TH): Thank you Mr. Chairman. Thank you for being here and for yesterday. So I've seen you twice now and I have so much hope for the generations that are to come, because you're not afraid to speak up and you're not afraid to advocate. And you're honest about your story and your truth.

So with that, I have a question and it might be a hard one. As you were growing up and you were in essence responsible for your parents, and the communication and the care. I don't want to use the word burden because I don't feel that, that's an appropriate word. But as you were growing up, were you able to continue with your traditional childhood activities or did you find yourself rerouted often because of what you were doing to help with your parents.

MR. JAMES LAWRENCE: That's a good question. I think about that a lot, and it wasn't something I realized until I got a lot older, yeah, that did happen a lot. I mean, something as simple as, going through the drive through at McDonald's is punt over to your son, your daughter. I don't think that children should have to accompany their parents to colonoscopy appointments.

I don't think that, that's very appropriate. No, kids should have to, I don't know if you guys have seen the movie CODA, but talk about their parents' STD's for them. There's a time and place and those hard conversations shouldn't have to happen. But I
think a lot of the time they do. My parents paid taxes, my parents worked their best.

They went to college, it took them a little bit longer because the education system truly failed them and did not provide them with the interpreting services they needed and they still struggle to find jobs, they still struggle to support our family. I think burden is the right word because it is tough. And to both the Representatives earlier points about having hope for the future generation, I really appreciate that comment, but I'm here today because I'm hoping that, that change doesn't have to come 10 or 15 years from now when we all finished our training, I'm hoping it can happen tomorrow.

So thank you for your time and thank you for listening.

REP. COOK (65TH): And thank you. And I think that I could speak for all of us that are sitting here that if we could fix that tomorrow, we would. And if we were the only decision makers, there's easy decisions to make, but there's also so many more of us, but I would request that when you tell your story, you tell your whole truth. And don't be ashamed of your truth, because I think that the shoes that you've walked in and the life that you've lived, has brought you to be an incredible young man. So good luck to you and thank you so much for being with us.

MR. JAMES LAWRENCE: Thank you.

SENATOR LESSER (9TH): Thank you for your testimony. We're going to actually scratch the order that I had announced previously, we're going to get to Claire. But before Claire, we're actually going to jump to number 74 on the list. Sue Shatney. Sue. Are you here? Right. Sorry for calling an audible.

MS. SUE SHATNEY: And I'm also, the counselor for the deaf not dead.
SENATOR LESSER (9TH): We figured.

MS. SUE SHATNEY: That's an entirely different testimony.

SENATOR LESSER (9TH): The Séance is next week.

MS. SUE SHATNEY: Okay. Sorry, you had to brief me. Good afternoon, Senator Lesser, Representative Gilchrest, ranking members and members of the Human Services Committee. My name is Sue Shatney and I'm a counselor for the Deaf with the Department of Aging and Disability Services as well as [inaudible] Council for local 2663. I'm grateful for the opportunity to testify before the Committee today regarding the importance of increasing services for the deaf community. While I acknowledge the well intentioned goals of the Bill 5241 as the sole State employee holding the original position title from the old commission on the deaf and hearing impaired, I find myself compelled to voice the opposition to the creation of this new Bureau as it's currently written. I strongly agree that the services are greatly needed, as I am the only State employee providing services Statewide to a specific socio-economic disenfranchised population where services, resources, education and communication, access are gravely inaccessible. Each day. I'm working with a person and I'm struggling alongside them. I need the community. I need help and the community deserves more, and adding an interpreter doesn't necessarily meet the standards of quality nor equity. Rather than proposing increased levels of management for employees,

I urge the Committee to focus on enhancing the services that directly impact members of the deaf community, through the use of case managers, legislative liaisons, counselors, educational advocates, et cetera, who understand the cultural and linguistic nuances attributed to the community
by doing so, not only can we address the immediate needs but also streamline the service delivery process. We must ensure these services are accessible, efficient and tailored to meet specific needs of the deaf individuals. My concern also lies in the potential diversion of resources to administrative overhead rather than directing them to the front line services where they are urgently needed.

House Bill 5241 suggests appointing an executive director and an administrative assistant which could further the burden of our already restrained resources. Rather than creating a new Bureaucratic structure. I propose that we first address the deficiencies, sorry, in the existing system to ensure the current employees have the necessary support to fulfill our responsibilities. The reporting chain of command outlined in legislation directly leads to the Commissioner who as indicated earlier in testimony doesn't adequately support the needs of our current employees. Placing the responsibility on an unsupportive Commissioner to oversee a new Bureau risks further disconnect between the goals of the legislation, and the actual support provided to the deaf and hard of hearing community.

Instead of creating a new Bureau. I recommend that we focus on enhancing the current infrastructure, providing the necessary resources and addressing the challenges faced by the current employees. By doing so, we can ensure that the deaf and hard of hearing community receives the support they deserve without introducing layers of management. I appreciate your consideration of my viewpoint on this issue. Should you have any questions or require further information, please feel free to reach out. Additionally, I'm available to discuss any ideas on how to effectively achieve the goals in the proposed Bill, particularly in terms of expanding services.
SENATOR LESSER (9TH): Thank you for your testimony and for being here. Your testimony sort of speaks to a question, I asked a few hours ago with Doctor Corson about, the choices that we have about expanding direct services versus, because he can do what I think the Bill is trying to do, which is to coordinate the existing services better. Do you see any value to the latter to trying to court, or is it really, you think we just need to add positions?

MS. SUE SHATNEY: We need to add positions. I'm the only person, the population is 150% below poverty line. They can't get to Hartford, they can't get to a one stop shop, they can't get there. I have to go to them, and I'm doing that on my own, in my car hoping for mileage reimbursements, when they come. It's difficult but that's where my heart is in social justice and it's not there. So that's why I'm--.

SENATOR LESSER (9TH): Now we've heard some specific concerns from the deaf blind community and I didn't know if that community had specific needs, that should be addressed separately and in that respect, so, I think saw it's particular value in the Bill, the folks who testified, we also heard the concerns about care received in hospitals, and I don't know if you have any advice for us on how we could improve both of either of those things or both of them.

MS. SUE SHATNEY: For the first question, I didn't mention deaf blind, because I have a counterpart that works under the Bureau of Education Services for the deaf. She's a social worker for the Deaf Blind Community. So that's why I specifically just talked about the population that I serve, because she takes care of that part of it. But the needs and the resources look very different. They're not your typical as you saw today, we had multiple interpreters. We had different levels of interpreting for deaf blindness. We had tactile, we
had close vision, sometimes we need far vision because of the acuity of the vision loss.

So it looks very different. But we do have another counterpart, another colleague that we all work very well together. The other person who I work with the Human Service Advocate, we really try to collaborate together and not duplicate services, but we also banter ideas off, of each other, but we're so limited for Statewide services. Your second question was--

SENATOR LESSER (9TH): The hospital issue.

MS. SUE SHATNEY: The hospital issues. I'm actually the person going and helping them fill out the complaints with CHR over the Department of Justice. I'm the person because English is a second language. It's not native, so a lot of people won't go and fill out a complaint because, is the person going to understand what I mean? So I'm working together with them to help them navigate all of what they're trying to say. So that it's an actual formal complaint.

SENATOR LESSER (9TH): Thank you. Senator Seminara has a question.

SENATOR SEMINARA (8TH): Thank you, Mr. Chair. You just mentioned that you have a counterpart that works with the deafblind, correct?

MS. SUE SHATNEY: Through BESB. Yes.

SENATOR SEMINARA (8TH): Is that person able to assist you in any way? Or that she or he is kept completely separate and can only work with the deafblind population?

MS. SUE SHATNEY: She's only with the deafblind because of how the funding sources streamed in. So they're there. They're with BESB, they've always been with BESB. I've always been with, well, CDHI.
I started there. I was one of the impacted interpreters when we got laid off, and now I'm back. And VRI has always been traditionally separate. The only caveat was back in the day with CDHI, we did have a Vocational Counselor, and he functioned in employment area when BRS Vocational Services had an order of selection system.

So he captured all of those people that couldn't access the order of selection. So we are separate, but we do collaborate so that we can make sure that those services are going. And because there's only three of us, we coordinate amongst ourselves, which is why I'm trying to get more people, not necessarily more layers of management.

SENATOR SEMINARA (8TH): Okay. Thank you so much for that clarity.

MS. SUE SHATNEY: Thank you.

SENATOR SEMINARA (8TH): Thank you, Mr. Chair.

SENATOR LESSER (9TH): Thank you, Senator. Other questions from Members of the Committee? If not, thank you for being here this afternoon.

MS. SUE SHATNEY: Thank you.

SENATOR LESSER (9TH): Next-- Yes, we're going back to where we were. We're going to go back to Claire. Claire's on the Zoom, I believe.

MS. CLAIRE SURKIS: Good afternoon, Senator Lesser, Representative Gilchrest, and distinguished Members of the Human Services Committee. My name is Claire Surkis, and I am a second year medical student from Farmington, and currently attend UConn School of Medicine. I'm testifying in support of Raised House Bill 5240, AN ACT CONCERNING MEDICAID COVERAGE FOR INFERTILITY TREATMENT. This Bill would expand access to fertility care for people who have HUSKY Health insurance, who have historically been
excluded from accessing fertility care due to the high cost of care.

This Bill has a companion Bill in the insurance Real Estate Committee, which will align fertility healthcare insurance coverage with the medical standard of care, which clearly includes LGBTQ+ and single people, among others. As a medical student, and in my time working at Planned Parenthood prior to medical school, I've seen just how much of a difference Medicaid coverage for reproductive healthcare makes for those trying now. I will never forget this one patient who came in for an IUD removal. She seemed nervous at the very start of her visit.

Her foot never stopped tapping and her hands were seemingly tying one another into knots. Her gaze never quite met mine. I soon learned that she reluctantly came in to get her IUD four years past when it was due to be removed because she was absolutely terrified of the cost that would come with it. I did some digging and realized that she qualified for Medicaid. And due to an awesome partnership between the clinic and HUSKY, we were able to register that day. I will never forget the pure and utter look of relief that came across her face when I told her, not only that she qualified but that the services were covered by it. She started crying heavy tears, of course.

Medicaid coverage of reproductive health services made such a huge difference for this patient and so many others who are simply trying to exert reproductive autonomy over the lives and their bodies. However, I strongly believe that this coverage should encompass the full spectrum of reproductive healthcare and reproductive justice, which includes not only the right to bodily autonomy and the right to not have children, but the right to have children and raise those children in safe and sustainable communities.
HB 5378 proposes amending language to ensure that insurance coverage of fertility care is accessible to all deserving individuals and couples in Connecticut, including LGBTQ+ couples and single people as is defined as the standard of care by the American Society of Reproductive Medicine. I am strongly in favor of this as I believe that the right to start a family should not depend on your sexual orientation, relationship status, or medical history.

However, I strongly believe that it needs to go further, which is why this particular Bill is so important. The right to start a family should not depend on insurance status either. People with HUSKY insurance have historically been excluded from accessing fertility care as stated due to the high cost. That's anyone on HUSKY insurance who wants to start a family, but are unable to without assistance or stuck. Reproductive justice doesn't and the right to start a family doesn't apply to them.

This is not only an issue of reproductive but economic justice. HUSKY insurance primarily covers low income individuals and families, a large portion of which are minorities who have historically been marginalized, disproportionately experience health disparity, and have been the target of inhumane and unjust reproductive coercion campaigns throughout the 20th century and beyond. Reproductive justice is acknowledging that dark history and ensuring equity for this population in every way that we can moving forward. That starts with passing this Bill. Thank you so much.

REP. GILCHREST (18TH): Thank you, Miss Surkis, for your testimony and for being here today. I don't see any hands? Thank you. Next, we'll hear from Alexandra McClellan.

MS. ALEXANDRA MCCLELLAN: Good afternoon, Representative Gilchrest, Senator Seminara, and distinguished Members of the Human Services
Committee. My name is Alex McClellan. I am a Licensed and Certified Genetic Counselor and a Clinical Research Project Manager at the Jackson Laboratory for Genomic Medicine in Farmington, Connecticut. It is my pleasure to be here with you today to provide expertise and information about rapid whole-genome sequencing, as it pertains to Raised Bill No. 5367. I provided details about this testing through my written testimony.

So today, I would like to share the story of a baby boy named Maverick. Just six days after Maverick was born, he mysteriously stops eating. He starts spitting up blood, having seizures. He's urgently admitted to the neonatal intensive care unit, undergoes over two dozen examinations, tests, blood draws, imaging, monitoring, medications, but still, no diagnosis or treatment. The doctors are worried that Maverick may soon have permanent brain damage. His kidneys start to shut down. His parents are helplessly standing by as the medical team is running out of options.

You and I are born with our own unique genetic code or genome. When it comes to critically ill infants like Maverick, the genome can provide the crucial answers we need to guide life-saving treatment. And just 39 hours after Maverick, doctors ordered rapid whole-genome sequencing. His family found their answer. Maverick was born with a rare life threatening genetic disease called pyridoxine-dependent epilepsy. This previously elusive diagnosis now allowed Maverick's medical team to pinpoint exactly how to save his life.

Maverick's story exemplifies both the simplicity and the power of rapid whole-genome sequencing. Although individually rare, there are more than 6,200 single gene diseases, like Mavericks, that could cause a child to end up in the intensive care unit. When the reason for why an infant is critically ill is unknown, waiting for the results of test after test is agonizing for families, and an
inefficient use of our healthcare resources, because rapid whole-genome sequencing can expedite diagnoses to five days or fewer, therefore, avoiding unnecessary treatments, reducing the length of hospital stays.

Investing in this initial treatment has actually been shown to be cost efficient. Rapid whole-genome sequencing may sound like science fiction, but its impact on patients, their families, and our healthcare systems is very real. There are already 10 states that provide Medicaid coverage for this testing, recognizing that it consistently shows improved health outcomes and overall cost savings. For patients like maverick, access to rapid whole-genome sequencing has certainly made a world of a difference. Thank you all for your time and attention today. I'm happy to answer any questions you may have.

REP. GILCHREST (18TH): Thank you so much, Alexandra, for being here and for your testimony and the work you do.

MS. ALEXANDRA MCCLELLAN: Thank you.

REP. GILCHREST (18TH): Any questions? Yeah, go ahead.

SENATOR SEMINARA (8TH): Thank you, Madam Chair, and Thank you, Alexandra, for coming and giving us a live example of why this treatment or this testing is so vital. I've shared this story more than once, but my child was a preemie and was born at 1 pound 14 ounces when she was born. She was relatively healthy and didn't require any extensive medical treatment, just some time to grow. But I lived in the NICU for six weeks, slept there in a chair by her side, and recognize what it's like for a parent to not have an answer. I had my answers, but I was surrounded by other parents who had very, very sick children, and didn't have any course, recourse of how to find out what was wrong with their kids.
And unfortunately, I watched children pass away because we didn't have this type of testing. So I very much appreciate you coming and advocating for it, and I will continue to advocate it, advocate for it because any parent, whether you have a sick child or not, if you have a sick child, you want any answer that can possibly be given to you, you want to know what's wrong with your child. And to sit there and not have that answer because of a financial, and I often think it comes down to a financial picture, is gut-wrenching. So I really very much appreciate you coming and very much appreciate the work you're doing. You're saving lives and you're saving parents a lot of grief and pain. So, thank you.

MS. ALEXANDRA MCCLELLAN: Thank you for sharing your story, Senator Seminara.

SENATOR SEMINARA (8TH): Thank you.

REP. GILCHREST (18TH): Thank you. And thank you so much for your testimony.

MS. ALEXANDRA MCCLELLAN: Thank you.

REP. GILCHREST (18TH): Next, we'll hear from Kathy Flaherty, followed by Peaches Quinn. And Kathy's on Zoom.

MS. KATHY FLAHERTY: Thank you so much, Representative Gilchrest, and Members of the Human Services Committee. My name is Kathy Flaherty. I'm the Executive Director of Connecticut Legal Rights Project, and I'm here to testify in favor of three Bills this afternoon, Senate Bill 306, Senate Bill 205, and House Bill 5364. You've heard from my colleagues about the need to end the discrimination in the HUSKY programs for people with disabilities. Both Med-Connect and HUSKY C are the only programs with asset limits, and that is just straight up. We've heard a lot about discrimination against
people with disabilities today, but we have embedded that discrimination in our current laws and policies with regard to these two programs.

People who are able-bodied have higher income limits and don't have to deal with an asset limit at all. And when you have asset limits, while we appreciate Bill that would phase out the asset limits for HUSKY C, I asked why are we waiting for years to end discrimination when we do have the possibility of ending it now? I appreciate the questions that you pose to the Commissioner of DSS and her staff regarding the fiscal notes that DSS is placing on them, because I just want to point out and you'll probably hear more about this from one of my other colleagues a little later, but California got rid of its asset limits in its similar program.

And they had projected the cost at $116 million. And they have a population 11 times the size of the State of Connecticut. So if you actually just divide their number by 11, you get about $10 million for the cost and not somewhere in the 70s. So I appreciate follow up questions with the department over what the true cost of ending this discrimination would be, and then deciding what kind of price are we willing to pay to continue to perpetuate that. Jonathan really told a story of lived experience of 5364 which would be preserving the assets of State Humane Institution residents.

Our clients at Connecticut Legal Rights Project who are inpatient at DMHAS facilities are residents of State institutions. And those folks do recover, and they go on to have a life. And when they pass away, for the State to claw back things literally decades later in some cases really hurts the families that have been left behind. So I am very glad to see the Committee raise this Bill, and I encourage you to move it forward. Thank you so much for your time.

REP. GILCHREST (18TH): Thank you, Ms. Flaherty, for being here today and for your continued
advocacy. I don't see any questions. Peaches Quinn. Is Peaches with us? Okay, on Zoom. Peaches, you just have to unmute.

MS. PEACHES QUINN: Yes, can you hear me?

REP. GILCHREST (18TH): We can hear you now. Yes, go right ahead.

MS. PEACHES QUINN: Okay, great. Thank you for the opportunity of being here today. Good afternoon, Senator Lesser, Representative Gilchrest, Senator Seminara, Representative Case, and all of you dedicated Members of the Human Services Committee. My name is Peaches Quinn, and I am President of the Connecticut Coalition on Aging. We are a 50-year-old statewide volunteer organization that delivers public education and advocacy on issues of importance to Connecticut's older citizens. The testimony today and the Bills that are before you this afternoon and before us, almost every one of them touch on issues affecting older adults.

You've heard from my colleagues, and you will hear more testimony on the fiscal notes, but I wanted to make a couple of points that maybe haven't been made quite as much. First of all, older adults and persons with disabilities are not two distinct groups. And often, they're represented that way. 18% of Connecticut's 65 and older population report a disability. That's 57,000 people, and the number is growing all the time. The intersection of older age and disability is as clear as the blatant discrimination cast upon these persons under the State's HUSKY C Medicaid program.

We've talked about what HUSKY C is, and certainly since the inception of this program 50 years ago, but 50 years ago, the asset limit of 1,600 for a single person and 2,400 for a married couple has not changed 50 years. It's mind-boggling. The Center for Law and Social Policy published a policy brief in 2018 on the need to eliminate asset limits, which
is another point, second point that I want to make. They wrote, these limits were intended to ensure that only the truly needy families without significant savings or assets received public help.

However, such limits run counter to the goals of programs intended to support recipients' economic advancement. Why do we want to hold people down? Why? We don't want to discourage people from saving. Temporary setbacks happen almost every day of the week lately, and this can result in a terrifically dramatic downward spiral.

REP. GILCHREST (18TH): Miss Quinn, your time has expired. Can you please summarize?

MS. PEACHES QUINN: I will. Thank you. So in conclusion, it's unthinkable and inhumane really that persons with disability and older adults share need to have ongoing resources, and they should not be held in poverty to demonstrate qualifying for vital medical care. Please support Bill 306.

REP. GILCHREST (18TH): Thank you, Miss Quinn, for your testimony. I don't see any--

MS. PEACHES QUINN: Thank you.

REP. GILCHREST (18TH): Have a great evening.

MS. PEACHES QUINN: Thank you. You as well.

REP. GILCHREST (18TH): Thank you. Next, we'll hear from Josephine Shamaly.

MS. JOSEPHINE SHAMALY: Good afternoon. Can you hear me?

REP. GILCHREST (18TH): Yes, we can. Go right ahead.

MS. JOSEPHINE SHAMALY: Thank you. My name is Josephine Shamaly, and I am here speaking on behalf
of my daughter, Elizabeth, that we affectionately call Ellie. Ellie is nine years old. She was born healthy, but at age two, she started showing some developmental delays. And at 2.5, she received a terminal diagnosis of Sanfilippo Syndrome. Our family has been waiting for over four years from the Katie Beckett Waiver for the Katie Beckett Waiver. When we applied, there was 247 children ahead of her. The Katie Beckett Waiver does not consider her diagnosis, and with children that have a terminal illness, the weight may exceed their life expectancy, and this is tragic.

Since my daughter was diagnosed in 2017, we have entered a realm we did not know existed. Our insurance does not cover monthly supplies, therapy, equipment, and many other things my daughter requires because of her diagnosis. The Katie Beckett Waiver could bridge that gap, but it is both inaccessible due to its limited number of spots and long wait. As my daughter's disease progresses, we worry that we may not be able to give her the care that she will need at home.

I wish my family's story was unique, but I know it's not. As you've heard from other families today, there are many families like mine carrying a burden of a terminal diagnosis for their child that can benefit immensely from the expansion of the Katie Beckett Weaver. My family, my daughter, we do not have time to wait. I support Bill 206 strongly, and I hope that you could take my family story into consideration when you make a decision on this. Thank you very much for your time.

REP. GILCHREST (18TH): Thank you, Miss Shamaly. We most certainly will take your family story into consideration. Thank you for being here and for sharing that with us. And as we discussed earlier, this could happen to anyone. It has happened to you and your family, and I'm sorry for what you're going through, but truly appreciate you being here to share your experience with us. I don't see any
questions. Have a great evening. Thank you. Next, we'll hear from Tonishia Signore. Is she with us?

MS. TONISHIA SIGNORE: Everybody, can you hear me okay?

REP. GILCHREST (18TH): Yes, we can. Go right ahead.

MS. TONISHIA SIGNORE: Oh, great. Okay. My name is Tonishia Signore. I'm here today to testify in favor of HB 5240 and HB 5368. I am the Policy Director for She Leads Justice, formerly known as CWEALF. We're a statewide nonprofit that uses a justice and equity lens to advocate for under-resourced and marginalized women and girls in Connecticut. As an individual organization and a coalition partner of Planned Parenthood, we support Raised House Bill 5240 and HB 5368. HB 5240 would improve access to infertility treatment to individuals with HUSKY Health insurance who in the past have been excluded because of the high cost of treatment.

This Bill has a companion Bill in the Insurance and Real Estate Committee that will align fertility healthcare insurance coverage with the medical standard of care. The intention of this Bill will allow for LGBTQIA and single people to finally be included for the coverage of infertility treatment by insurances. If both of these Bills are passed, all people in our State, regardless of gender, identity and sexual identity, insuror status, or economic circumstances will have the opportunity to grow their family. As an advocate for marginalized and under-resourced women and girls in Connecticut, She Leads Justice believes it is imperative to create policies which aim to address systemic inequities in our State.

Access to family building care, healthcare such as IVF is essential health care for many people. We urge the Committee to vote favorably and improve
fertility care coverage so everyone in Connecticut can actualize their dreams of building up a family. And in addition to HB 5240, we would like to voice our extreme support of HB 5368, AN ACT CONCERNING MEDICAID COVERAGE OF DIAPERS. In the United States, one in two families have issues affording clean diapers for their babies. In Connecticut, where income inequality is extreme and rampant, 36% of births that occur are covered by Medicaid.

Passing this Bill would be a proactive and impactful action, which would greatly help low income parents in Connecticut. Diapers are an essential item for families and babies, and it is critical that our State make policies which work to provide services and resources to hard working families who are in the most need. We urge the Committee to vote favorably on both these Bills. And I'm sorry for being off the camera. I'm actually at the OB-GYN right now. I'm actually at the OB-GYN right now. I'm actually at the OB-GYN right now. I'm 7.5 months pregnant. So thank you for being patient with me, and I'm sorry for being off camera.

REP. GILCHREST (18TH): Oh, the irony. Thank you for being here. And good luck--

MS. TONISHIA SIGNORE: Yes.

REP. GILCHREST (18TH): --with the appointment. I don't see any questions. So thank you for being here today.

MS. TONISHIA SIGNORE: Thank you, guys.


MR. JACOB D'ADDARIO: D'Addario, yes.

REP. GILCHREST (18TH): Oh, all right.
MR. JACOB D'ADDARIO: And I guess an appropriate question for the last speaker could have been, is it a boy or a girl?

REP. GILCHREST (18TH): Yeah.

MR. JACOB D'ADDARIO: Thank you, Committee. My, my name is Jacob D'Addario. I live in Rocky Hill. So thank you, Mr. Lesser. And I hope that you know my good friend, Miss Kerry Wood. We went to school together. So the reason why I wanted to speak to the Committee today deals mostly with substance use disorder. As we know, the opiate epidemic is still alive and well. Pat Rehmer, who is probably one of the best advocates and person to put her foot forward, I heard speak earlier.

It's very important that people in the first year of their recovery have access to Medicaid Assistant treatment and treatment in general, especially due to the ACM guidelines and the criteria shrinking time of folks inpatient, which is a very scary proposition. Addiction is a brain disorder, and in order for folks to recover, they need that neuroplasticity time in order to be productive members of our society and be taxpayers and pay back into the system. And that's part of my experience. And I've heard a few other people talk about other things I've experienced with HUSKY Medicaid.

I'm grateful that it has been in process. I've been someone who's utilized it, but I've also been denied it being in the working poor. And to go backwards on any of the threshold amounts, as one speaker said, it's not the '70s, well, it's not the '90s, and how it's the 2024s. And going backwards to a draconian amount of the poverty level that's really established through research that's clearly outdated with the rising housing costs, I think it's imperative that the Committee through avocation ask the rest of your constituents to raise that level. Not just lower it, not just keep it the same, raise it.
For example, I'm currently on unemployment at the max amount, which would give me $17,500 for half a year if I were to maintain being on unemployment that whole time. I'm grateful I got a subsidy for a program through the open market, but I did not qualify for HUSKY Medicaid, and my out-of-pocket expense for that insurance would be $8,700. So if you do the quick math, that's 50% of my gross would be going towards medical care. Now, most people are paying 25%. That's just a normal a number that people cannot overcome, especially those in early recovery and some of the other populations who spoke today. I am also glad that the Bill is up for rescinding the recapture money for when people pass away.

REP. GILCHREST (18TH): Mr. D'Addario, your time has expired. Could you summarize, please?

MR. JACOB D'ADDARIO: Yes. In that Bill that I hope gets rescinded, I did have to pay back money to having a mother who was an active substance user. So I do identify with a lot of the populations that people who spoke. The substance uses disorder population, mental health, and many other of the smaller marginalized people who spoke today make up 10% of the population. Please raise, not lower the threshold for the ability to have HUSKY Medicaid.

REP. GILCHREST (18TH): Thank you so much for being here today and sharing your experience and your testimony. I don't see any hands. Have a great evening.

MR. JACOB D'ADDARIO: Thank you.

REP. GILCHREST (18TH): Next, we'll hear from Janet Stolfi Alfano.

MS. JANET STOLFI ALFANO: Good afternoon. Good afternoon, Senator Lesser, Representative Gilchrest, Senator Seminara, Rep Dathan, and Representative
Case, and the Members of the Human Services Committee. My name is Janet Stolfi Alfano, and I'm the Chief Executive Officer of The Diaper Bank of Connecticut. I appreciate the opportunity to testify before you today in support of HB 5368, AN ACT CONCERNING MEDICAID COVERAGE OF DIAPERS.

This Bill would extend Medicaid coverage for diapers to children from birth to age three, deemed to have a medical necessity for diapers under certain specific health conditions, including diaper dermatitis, urinary tract infections, and other diseases of the skin related to inadequate diaper hygiene or another condition such as a developmental psychiatric or neurological one that results in an unusual need to avoid or delayed developmentally appropriate toileting behavior. This would need to be determined by a doctor, physician, or an APRN.

The intent of this Bill is to focus on the children who are suffering the most significant health impacts from not having access to an adequate supply of diapers. Since 2004, The Diaper Bank of Connecticut has been helping families meet this basic need, and we've provided over 40 million diapers to Connecticut children since we started 20 years ago. And we're a well-established leader in one of The Diaper Banks in the country, largest Diaper Banks in the country, but we're only meeting a fraction of the overall need in our State. We're serving over 6,000 infants and toddlers each month, and we know the need is about 80,000 infants and toddlers overall.

This Bill is not focused on the 80,000 children. This is focused on a specific subset of children whose diaper dermatitis, UTI, or other health condition are severe enough to warrant a doctor to determine that they need diapers in order to ameliorate the health conditions and impacts from not having an adequate supply. Extended periods in a soiled diaper or even a reuse of a previously soiled ones can increase the risk of these conditions.
conditions, UTIs, even hepatitis, eczema, and really severe diaper rash, which if those conditions which cause that don't change, then there are more harmful impacts to children and more costly interventions that will follow down the road.

This Bill focuses on those infants and toddlers again, having the most significant health consequences as a result of lack of access to diapers, providing a medically necessary supply to ameliorate these negative health outcomes and potentially prevent future ones. I urge your support of HB 5368. Thank you.

SENATOR LESSER (9TH): Thank you for your testimony. We heard a very large fiscal note earlier today. Partly, it was a generous interpretation of what is imagined under the medically necessary definition. If we had to narrow it in statute to limit the fiscal note, do you have a suggested way of doing that?

MS. JANET STOLFI ALFANO: That's a great question. And we heard a little bit of that testimony early this morning. I think we could certainly think about narrowing the focus even further. That is the intention is to really narrow the focus to those that are most severely impact on health outcomes with really severe diaper dermatitis or whatnot. That would really need to be determined by a doctor. So certainly, there can be medical layers that we can add to this Bill to make it more narrowly focused.

SENATOR LESSER (9TH): Thank you. Representative Gilchrest.

REP. GILCHREST (18TH): Thank you, Senator. Thank you, Janet, for being here and for the work that The Diaper Bank does. Also, earlier today, the Department of Social Services mentioned that I believe the stat was 25% of children experience
diaper rash. Is that the same as diaper dermatitis? Or is diaper dermatitis a more extreme form?

MS. JANET STOLFI ALFANO: Well, I'm not a doctor. I think the intent of this isn't to cover babies who have a little bit of diaper rash, an incidence of diaper rash, a one-off. This is really to treat those who, because they don't have a supply, continue to have diaper rash, which in turn then becomes worse and worse for the health of the child. And that need to be seen by a physician or medical professional, as indicated in the Bill, to actually help determine like this is really severe, we really need to get you a supply of diapers so that we can ensure that this baby is clean, dry, and healthy.

REP. GILCHREST (18TH): Thank you. And then my final question, there's been some what I would see as confusion from members of this Committee and the Legislature in the past on your role in advocating for this policy. Having come from the world of advocacy, I recognize that there are entities that can both be a service provider and an advocate for policies that positively impact the communities they serve. Could you explain kind of that distinction on that you, yes, do provide services?

MS. JANET STOLFI ALFANO: Right.

REP. GILCHREST (18TH): Yeah.

MS. JANET STOLFI ALFANO: Right. So, thank you. That is a great question, and we're certainly happy to explain that. While we provide services, and in part of my testimony, I talked about the overarching need of 80,000 children who could potentially use our services. And we offer our support through the generous contribution of the State of Connecticut, philanthropic support, grants. And that serves about 6,100. Again, we know that this is meeting a very specific medical need, and that the way Medicaid works to support this issue in other populations such as adults who have incontinence
needs or children with special health care needs, that infrastructure exists already. There is a process in place. That same thing could hold true for infants and toddlers who are experiencing medical issues around not having and a lack of access to diapers.

REP. GILCHREST (18TH): Great. Thank you so much.

MS. JANET STOLFI ALFANO: Thank you.

REP. GILCHREST (18TH): Thank you, Mr. Chair.

SENATOR LESSER (9TH): Thank you, Representative. Representative Dathan.

REP. DATHAN (142ND): Thank you very much, Mr. Chairman. I just wanted to highlight that I appreciate your testimony. One of my children had severe diaper rash. We had plenty of access to diapers. It wasn't an issue that we weren't changing that child enough, it just happened. Our pediatrician prescribed some medication, and that did help. So in most of the situations, I think that there are different types of medication that can help the children, and that additional diapers isn't the solution to it. So that's where I was a bit confused about their testimony. One of the things that we brought up and we've talked about with my appropriations hat on is the funding the State gives you. It's about $700,000. Can you let the public know how far that goes and how many families you're able to serve with that money?

MS. JANET STOLFI ALFANO: Sure. So with support from the State, and again, philanthropic dollars, we're able to support around 6,100 children. That's nonduplicated each month. So that number can range over the course of the year to much higher than that. Again, there's 80,000 potential children who may need our services based on their economic status and their Medicaid enrolled nature. We know not all of those are going to have a significant issue with
diaper dermatitis or other medical need. And so this is really focused on those who have the most extreme health consequences as the result of it.

REP. DATHAN (142ND): That was going to be actually my next question. So thank you for highlighting that. Do you give any preferential supplies to folks that have medical needs who are not being met through this potential Medicaid sort of on a case-by-case basis? I just wonder if there's any sort of ability for you guys to focus on that, or if there is just, it's however the allocation happens.

MS. JANET STOLFI ALFANO: Sure. So the determination is income-based at 200% or below depending on the funding source, but with the State dollars, that's what it is. And we work with partners across the State of Connecticut who are working already with families with young children who have low income. And so that's really the deciding factor on it. In terms of prioritization, we do have a program through the Connecticut Hospital Association that's called Diaper Connections that's separately funded through Emergency funding through COVID.

And there is a screening done, which is really the program itself is the first of its kind in the country that coordinates diaper distribution with hospitals and health related outcome data. So that is something that we are certainly thinking about and looking for, but we don't have a direct medical threshold for our services. It's income-based.

REP. DATHAN (142ND): Got it. So this would be purely a medical need-based plan. So, something totally separate.

MS. JANET STOLFI ALFANO: Correct.

REP. DATHAN (142ND): But I appreciate all the work you do. It's so important. So thank you for testifying. Thank you, Mr. Chair.
MS. JANET STOLFI ALFANO: Thank you.

SENATOR LESSER (9TH): Thank you, Representative. Any other questions? No? Thank you very much for being here.

MS. JANET STOLFI ALFANO: Thank you.

SENATOR LESSER (9TH): Next, we have Lesley Bennett, followed by Megan Scharrer.

MS. LESLEY BENNETT: Thank you. I don't know that I should say good evening, but we are getting there.

SENATOR LESSER (9TH): It's only 4:40.

MS. LESLEY BENNETT: I know we're not quite there yet, right? Senator Lesser, Representative Gilchrest, and esteemed Members of the Public Health Committee, thank you for letting me speak to you today about House Bills 5367 and Senate Bill 206. My name is Lesley Bennett. I am a Branford resident. I've just moved to Branford. And for the last 30 years, I have been advocating for children or patients, mostly children, with rare diseases and disabilities. Currently, I also serve on the Rare Disease Advisory Council. This was enacted and established by Public Act 2258.

We're currently meeting. Most of the time, we're focused on getting set up, but we are designed to help members of the Legislature, members of State Agencies, and the Governor's Office understand rare diseases and the challenges that our group faces. And the reason I'm talking to you today about what our advocates in our State are supporting, but it's not just supporting Bill 5367. This Bill is very personal to me. My daughter, Kelly, today would fall into this group of children. She was born very floppy at birth, had seizures 36 hours after birth, spent the first week of her life in the ICU.
She was extremely ill, and the first two years of her life were just a nightmare of constant hospitalizations, visiting specialists in New York, Boston, Baltimore, hospitalizations at the two hospitals here. So I understand what these families go through. And the key to managing these children effectively, we're not even talking about just improving the quality of their life is what I'm talking about, is an early diagnosis. And this is also a group of children, they are not picked up in newborn screening. Newborn screening to us is a wonderful program. This is designed to augment that.

And newborn screening in our State identifies about 130 children. CMS estimates that we have between another 100 and 130 children born with rare genetic diseases that are not detected by newborn screening. The problem is there's 10,000 of these diseases, most of them are genetic, so they're present at birth. And some of these diseases manifest like Tay-Sachs disease or metachromatic leukodystrophy is very, very violent. These children are extremely ill, and their life expectancy is a maximum of 3 to 5 years. So they need help as soon as possible just to make them comfortable. And what CMS noticed that these children are major drivers of pediatric healthcare cost right now.

So they sponsored studies in a number of states, and public studies in California, Michigan, and Florida indicated that 40% of these children end up with a diagnosis that results in improved quality of care and reduced costs to the Medicaid programs. So we're seeing that. So this is huge. CMS is now paying for this or sponsoring it. I'm sorry. And 10 states have adopted it. Another town are now considering it, and in those states that have already passed it, we're also seeing private insurers, most of the Blue Cross Blue Shield family joining in and paying for it. Actually we have private insurers covering this in 17 states.
The estimates since the price of this testing is coming down. We're estimating if we focus only on children under the age of one, it'll have minimal impact on almost the cost neutral for the Department of Social Services. The other Bill, Senate Bill 206, you've already heard the number of children on this. We're asking that you find a way to get rid of the waitlist, expand Katie Beckett Waiver by 300 slots, or as the advocates in other states have pointed out, we are the only State in New England, and you mentioned that it has to do with the way we manage this program.

Our Katie Beckett Program is a Home and Community-Based Waiver Program. And whereas in other states, their Katie Beckett programs are what they call TEFRA sponsored program, or the TEFRA option. And under the TEFRA option, there can be no waitlist. And so it's something for us to consider maybe looking at the way that the Department of Social Services currently manages this program. If you have any question, yeah.

SENATOR LESSER (9TH): Well, have you concluded your testimony?

MS. LESLEY BENNETT: Yes, I have.

SENATOR LESSER (9TH): Okay. We wouldn't interrupt in the middle of--

MS. LESLEY BENNETT: No, no, no.

SENATOR LESSER (9TH): --your testimony to ask you questions.

MS. LESLEY BENNETT: I know.

SENATOR LESSER (9TH): But thank you so much.

MS. LESLEY BENNETT: Okay.
SENATOR LESSER (9TH): And thank you for sharing your own story. This is super helpful. And I think we'll ask that question of DSS about the TEFRA. Yeah.

MS. LESLEY BENNETT: I think you have to at this point. It's essential. These families need the help immediately. And in the other states where they fast track, advocates have told me that what happens in like New York or Massachusetts, for instance, which I'm very familiar with, Kelly spent half her life up there, what they do is the hospital works with these families of these children that are critically ill. And before they go home, they're already working on the waiver, and they notify the State if this child has a disease like Tay-Sachs, for instance, so that they can get the waiver immediately. It's one of the things, I don't know if we do that here. So it's something that we should be considering. Thank you.

SENATOR LESSER (9TH): Thank you. Don't go anywhere.

MS. LESLEY BENNETT: Okay. Okay.

SENATOR LESSER (9TH): We got some questions for you. One other question that I had, there was testimony in opposition to the Genetic Screening Bill that we got from DSS that says it just wasn't compatible with the way that they fund healthcare programs, that have--

MS. LESLEY BENNETT: The rapid whole-genome sequencing?

SENATOR LESSER (9TH): Yeah. So, they say because they do a bundled payment, and it doesn't work with that. And so I didn't know if you'd had a chance--if you knew anything about that.

MS. LESLEY BENNETT: No, I haven't viewed that from them.
SENATOR LESSER (9TH): Okay.

MS. LESLEY BENNETT: They had hit me with another objection to it and the fact that, oh, CMS is, and I said, yeah, they are. I have friends down there, I've already talked to them about that. But they're bundling so that they wouldn't cover this, is what they're saying?

SENATOR LESSER (9TH): They're saying that it wouldn't work with their bundling payment system they have, at least the way it's constituted right now.

MS. LESLEY BENNETT: Maybe it's a time for us to reexamine that and step into this century.

SENATOR LESSER (9TH): Not arguing. I just figured-

MS. LESLEY BENNETT: A lot of their practices are behind the times, and that's what we've noticed. It's time for them to do this, and this is something that's essential. It will end up saving them money. In states like California, I think the savings was like $6 million. In other states that are smaller, more comparable to our State size, it's like $2 million that this would save. So we're talking about something that would be actually saving them money. It wouldn't even be cost neutral, it would be cost positive to them. So it's something you really have to consider and really look at deeply rather than object to automatically.

SENATOR LESSER (9TH): Thank you.

MS. LESLEY BENNETT: Okay.

SENATOR LESSER (9TH): You're still not able to go anywhere--

MS. LESLEY BENNETT: Okay.
SENATOR LESSER (9TH): --because Representative Gilchrest has a question for you.

MS. LESLEY BENNETT: I was figuring, I'd leave.

REP. GILCHREST (18TH): Thank you, Mr. Chair. Thank you for your testimony.

MS. LESLEY BENNETT: Thank you.

REP. GILCHREST (18TH): What is TEFRA?

MS. LESLEY BENNETT: According to my friends, TEFRA is the Tax Equity and Fiscal Responsibility Act of 1989. And what it does is with our Home and Community-Based Waiver Program, we have to show that, I guess, it's cost neutral in the way the programs set up. Whereas the TERFA Program, that's not necessarily the case. CMS allows states to be a little more flexible on that. So it's an option 19 states apparently have adopted. So it might be something that might be worth looking at as a way to solve this problem.

REP. GILCHREST (18TH): Yes, it is. Thank you so much. That's very helpful.

MS. LESLEY BENNETT: I talked to a couple of friends about it because you were asking questions about why the other states in New England were.

REP. GILCHREST (18TH): Yeah.

MS. LESLEY BENNETT: It's a table to cover that.

REP. GILCHREST (18TH): Thank you very much.

MS. LESLEY BENNETT: Well, thank you.

SENATOR LESSER (9TH): Thank you.

MS. LESLEY BENNETT: Okay.
SENATOR LESSER (9TH): Okay, now you're off. All right. Next, we have Megan Scharrer, followed by Anne Manusky.

MS. MEGAN SCHARRER: Hello, Senator Lesser, Representative Gilchrest, and senior Members of the Human Services Committee. First off, thank you so much for giving me the opportunity to testify today and staying on a long day to listen to so many testimonies. My name is Megan Scharrer. I'm a resident of West Hartford. I'm also the Policy Advocacy Manager at the Hispanic Health Council. And today, I'm testifying in support of SB 314, AN ACT CONCERNING EMERGENCY MEDICAID COVERAGE FOR TREATMENT OF EMERGENCY MEDICAL CONDITIONS.

SB 314 would upgrade policies to provide Emergency Medicaid coverages for more outpatient treatments of emergency medical conditions. The Hispanic Health Council is the largest service provider for the Latino community in the State of Connecticut. Our mission is to promote equity and address health disparities for Hispanics, Latinos, and other vulnerable communities through research, advocacy, and culturally resident services. Too often, I encounter community members that are uninsured and have reoccurring medical symptoms but refuse to go to the hospital because of the expensive Bills that a visit will result in.

Lack of access to health care means that chronic health issues such as diabetes and heart disease that could be easily managed or treated, develop into more serious conditions that require more medical interventions and become more expensive in the long run. I know Connecticut is working to ensure that all residents are covered. I see the hard work that so many of the legislators are doing, and it's greatly appreciated. But in the meantime, we need a solution to ensure that if manageable conditions turn into emergency medical emergencies,
it will not result in crippling debt for the uninsured residents.

And I believe SB 314 is a step forward in improving health outcomes for all Connecticut residents, and is a much needed upgrade to Connecticut's Emergency Medicaid policies. This Bill would change policies of Emergency Medicaid by expanding the conditions which are eligible for EMC to include treatments for chronic conditions in an outpatient setting and allow people to apply in advance for Emergency Medicaid. These much needed upgrades will ensure that Connecticut's uninsured residents have better health outcomes when facing life threatening conditions.

And given that about 6% of Connecticut residents are uninsured, while 58% of Connecticut's undocumented immigrant community are uninsured, I am particularly hopeful that SB 314 can be a step to tackling the health care access crisis in Connecticut's immigrant community. And particularly why I'm very interested in this Bill is because a large portion of our clients at the Hispanic Health Council are undocumented. Our amazing community health workers and staff go above and beyond daily to ensure that our clients can receive the care they need, but there really is a limit on what they can do when they do not have health insurance.

Our work is focusing on fighting for health equity and ensuring everyone can reach their highest level of health, but there really is a limit when they are not insured. I see many times that clients are refusing medical intervention because of the cost, and this can lead to death. If our clients decide to receive life-saving care, then they face economic insecurity in debt simply because they did not want to die. I do not believe any human being should have to decide between death or debt. I don't think they should ever be an option.

SENATOR LESSER (9TH): Can you please summarize?
MS. MEGAN SCHARRER: Yes. I asked the Committee for 314 so that we can ensure more residents can be insured in the medical emergencies as well. I also support the reasonable amendments that are provided Revised Bill, languages, and testimonies from [Kathy Riviera] and Sheldon [Tuman] that I encourage you all to read that expand some conditions covered. So, thank you.

SENATOR LESSER (9TH): Thank you very much for your testimony. Are there questions from members of the Committee? Seeing none. Thank you for testifying and your time.

MS. MEGAN SCHARRER: Have a great day. Thank you.

SENATOR LESSER (9TH): You too. Next, we have Anne Manusky, followed by Thomas Burr. No Anne. Okay. We will go to Thomas Burr. Thomas.

MR. THOMAS BURR: Yes. Good afternoon, Senator Lesser, Representative Gilchrest, and Members of the Human Services Committee. My name is Thomas Burr, and I'm the Public Policy Manager of the Connecticut Chapter of the National Alliance on Mental Illness, otherwise known as NAMI Connecticut. I am testifying today regarding SB 205 and SB 306. As the country's largest grassroots mental health organization, we know that getting access to treatment in a timely fashion is key to recovery from a mental health condition. We feel that these two Bills can help in making sure that people can access these critical services.

Regarding SB 205, AN ACT ELIMINATING INCOME AND ASSET LIMITS IN THE MED-CONNECT PROGRAM FOR EMPLOYEES WITH DISABILITIES, the purpose of this Bill is to eliminate these income and asset limits in a program providing Medicaid benefits for employees with disabilities. And now, I mean, we know that people with mental health conditions are always in a better place when they can work and
contribute to society. However, oftentimes, disabled people may be afraid to work as they fear they may lose benefits, especially health insurance. Eliminating the income and asset limits on the Med-Connect Program will go a long way to removing this barrier.

These limits can also prevent many from saving up for emergencies, such as car and home repairs, security deposits, home appliance replacement, etc., and add an additional barrier for many who need the program. And of course, people who work also pay taxes. So this is truly good public policy and a win-win for both the disabled individuals and the Connecticut taxpayer. And I would also ask that a marketing campaign be funded for this very important, but largely unknown to the public program. It's amazing how many people don't know about this.

Regarding SB 306, AN ACT PROVIDING FOR THE PHASED-OUT ELIMINATION OF ASSET LIMITS IN THE HUSKY C PROGRAM, the purpose of the Bill is to eliminate the asset limits for HUSKY C health benefits over a five-year period. HUSKY C is the Medicaid program for people who are blind, disabled, or 65 or older and have low income. Medicare does not cover other kinds of health care covered by HUSKY C. HUSKY C home health care services, vision and dental care, hearing aids, medical transport, long-term care, and more. The income limit for HUSKY C is currently $1,234 a month, but it's scheduled to increase significantly in October of 2024.

The asset limits for HUSKY C are just $1,600 for a single person. This is very low as these asset limits set decades ago, sometimes make it impossible for elderly or disabled people to get on HUSKY C or to stay on it and save money for emergencies like the aforementioned car repair, security deposits, etc. This has not changed since the '70s when the price of bread was less than $2 a loaf. SB 306 is a good start, but it still perpetuates discrimination
against people with disabilities and older adults, and it slowly removes asset limits until 2028. They will still be singled out for the asset limits. Less discrimination is still discrimination. Therefore, in summary, we ask you to please pass SB 205 and implement the asset limit changes delineated in SB 306 immediately instead of during the next five years. Thank you for your time and attention.

SENATOR LESSER (9TH): Thank you so much for your testimony, Thomas. It's good to see you. I think we haven't seen you since our last hearing, and probably won't see you again until the next one.

MR. THOMAS BURR: Something like that.

SENATOR LESSER (9TH): Are there questions from members of the Committee? Seeing none. Thank you so much for being here today, or being here virtually.

MR. THOMAS BURR: Thank you, and have a great evening, guys.

SENATOR LESSER (9TH): Thank you. Take care. All right. Next, we have Benjamin King, followed by Dan Lewi.

MR. BENJAMIN KING: Good afternoon, distinguished Members of the Human Service Committee. Can you hear me?

SENATOR LESSER (9TH): We can.

MR. BENJAMIN KING: Great. My name is Ben King. I was asked and feel humbled to participate in this hearing as Olivia LaForte King's dad. Thank you for the opportunity to honor her in support of House Bill 5367. I've been so inspired by some of the stories that I heard from other participants today. And some of them touched me on a very personal level. So I want to thank everyone for sharing. Olivia was born with an ultra rare genetic condition in 2022. Olivia is my daughter.
At the time, she was one of only 100 known cases worldwide, and just one in nine with her specific variant. Her disease was EEF1A2 related neurodevelopmental disorder. She presented with hypotonia, unexplained apnea, microcephaly, failure to thrive. She had her first life-threatening apneic episode just three hours after birth, and lived only four months. Since her death, my wife and I have become passionate about increasing awareness and access to what we feel should absolutely be the standard of care for newborns in the NICU who are, as my daughter Olivia was described, a mystery.

We spent over half of Olivia's life in the NICU every single day fighting for someone to tell us what was wrong with her. Losing a child is devastating, and it's left us with a lot to process. But the hardest thing for me to reconcile is how close we were to being sent home without a diagnosis. I cannot imagine what that would have meant for our family. Following Olivia's life, I left my athletic career and became Central Virginia's Rep for the genetics lab that diagnosed Olivia. What I have learned in this role only further supports what we learned from our personal experience.

The diagnosis had personal financial and clinical value. I made some bullet points that speak to those, and how our life changed both pre and post-diagnosis. After Olivia was born, we were transferred to a Level 4 NICU that was over an hour from home. We were then transferred back to another Level 4 NICU that was closer to home after four weeks. We spent six weeks in the agonizing unknown. Olivia continued to experience life-threatening symptoms, and no one could tell us why or what was wrong with her.

We felt a constant need as her parents to advocate for answers. Doctors were daily encouraging us to
feel comfortable with taking her home. We had consults with many specialists. There were so many tests run on her. She had two EKGs, two EEGs, labs, Airway Scope, GI Scope, Swallow Study, and even uninformative limited genetic testing that ultimately delayed our diagnosis. We were forced to make extremely difficult choices without any information.

And if rapid whole-genome sequencing had been ordered in her first week of life when she first started experiencing mysterious life threatening episodes, we could have avoided all of these financial emotional and time costs. After receiving the diagnosis, we became a team where we felt more aligned with the hospital staff. We were streamlined to the appropriate specialists, we could take confidence in the care plan moving forward. The prognosis enabled preparation for the future.

She qualified for Medicaid waivers and outpatient support programs enabled by the label provided by a molecular diagnosis. I do live in Virginia and our experience with the Medicaid waivers also speaks to the value of the bill for the Katie Beckett Waiver Program. I think the families who have shared their own private journeys, I'm sure some of these families can also describe the terror and other indescribable feelings between the onset of symptoms and the diagnosis of their child.

We joined and remained active in family support groups of other families managing the same or similar diagnoses. We had the confidence to bring Olivia home for seven weeks with the necessary equipment. We brought her apple picking, we brought her to Smith Mountain Lake. Her brother, cousins, grandparents, smothered her with affection.

We were referred to palliative care and eventually hospice leading to comfort during her end of life care. Caring for a child with special needs and medical complexities, many of which have an
underlying genetic condition, is unimaginably challenging. In my wife's words, the diagnosis should be the easy part. And it's hard for rare disease patients and their families to advocate for themselves because the parents are at home. It's hard to leave the house with a child on a ventilator in a wheelchair and they're forgotten.

I feel in many ways by society that is not built for them. So thank you for the opportunity to present you with this testimony and to strongly support this important new policy to help critically ill Children. I would be happy to answer any questions you may have.

SENATOR LESSER (9TH): Thank you, Ben. And I think I speak for the committee, the birth of a child should be a moment of absolute joy. And to have that denied you is manifestly unfair. And so just deeply sorry for your loss and for just the pain that you've gone through.

So thank you for being an advocate and for being here today, for sharing Olivia's story. And wishing you and your family the very best right now. Are there questions for members of the committee? No, thank you very much. I actually do have one question you. You're a Virginia resident, did you say that?

MR. BENJAMIN KING: Yes, sir. My wife lived in Stamford, Connecticut, when we were dating. So that's my Connecticut connection, but--

SENATOR LESSER (9TH): Got it. That--

MR. BENJAMIN KING: Olivia opened our eyes to the world of rare disease and it's not isolated to Virginia. We've connected with patients and families all over the world and it also exposed us to the truth that rare is not rare, it affects so many children. Olivia was one in nine, but combined with all of the other rare diseases, there are a lot
of families and children out there who are suffering and in need of answers.

SENATOR LESSER (9TH): So, one of the-- I'm going to ask you about a bill that you're not testifying on. One of the other bills we have today is about Connecticut's Katie Beckett Waiver Program, which provides Medicaid services for sick kids. And we have in Connecticut, a long wait list for kids to get into the program. It doesn't sound like you have one in Virginia. Is that-- I'm not asking you to be an expert on Virginia's Medicaid program.

MR. BENJAMIN KING: No, it's still a challenge. We're part of a Facebook group for Virginia Medicaid Waivers Program, and it's not easy to get on. And I read stories from the families every day about how challenging it is and how difficult it is to advocate for themselves with a rare disease child at home, or a child with severe medical complexities.

We were fortunate to have a member or a staff member at UVA help us qualify before we left. But it's like many have said, it's a long waitlist now. Some may have to wait some time to qualify, but the diagnosis is the first step in that process to start getting the ball rolling, and I think it would be great for more patients to have access to programs like that.

SENATOR LESSER (9TH): Okay. Thank you very much. Any questions?

MR. BENJAMIN KING: I could also try to speak to a question that was asked previously about the Medicaid bundle.

SENATOR LESSER (9TH): Sure.

MR. BENJAMIN KING: If it would be helpful. That was one of the objections.

SENATOR LESSER (9TH): Yes. No, please, go ahead.
MR. BENJAMIN KING: So the hospital has a budget for per patient per day that's based, I believe on the clinical presentation. The hospital then bills the patient's payer, in this case Medicaid, for this day. My understanding is that this bill would provide for an allotment outside of that bundle in order to accommodate for a test that would hopefully lead to a reduced hospital stay.

I know in our case we would have saved, the payer fronting the bill for our stay, would have saved a lot of money because we would have left the NICU weeks sooner if we had known what was wrong with Olivia and could make a plan to get her home. That was all we wanted. The whole time we were there, we couldn't wait to leave the NICU and we were being encouraged to do so, but we didn't feel comfortable without knowing what was wrong.

SENATOR LESSER (9TH): Okay. I'll ask another question then, you've piqued my interest. How much does rapid whole genome sequencing cost?

MR. BENJAMIN KING: I believe that would depend on the lab. And there's another point to be made to that, I think a rare disease child is a Medicaid patient for life, and they're going to have expenses after their hospital stay. That early diagnosis, again, it has immense clinical value as has already been demonstrated by some of those testifying today.

Some of these conditions that would be diagnosed are treatable, in our case, it didn't change the outcome, although it still had clinical financial and personal value to us. There's downstream reduced cost for those patients because they avoid seeing unnecessary specialists. They're streamlined to the appropriate specialists and their care is just more efficient, if that makes sense.

SENATOR LESSER (9TH): Thank you very much. Representative Hughes. I saw her hand up.
REP. HUGHES (135TH): Yeah, thank you so much. This is super helpful because I don't think these kinds of costs analysis was taken on by DSS as we look at, as you say downstream, both that, the Katie Beckett Waiver. And I'm just curious, you had a deeply medically complex baby that you were trying to bring home. If you were a Medicaid eligible family, would Medicaid covering the diapers been one more thing, one last thing I should say, to worry about if that was the status that your family found yourself in?

MR. BENJAMIN KING: So we didn't qualify for Medicaid as a family, but Olivia, through the Waivers Program, did qualify, and Continuum Health was the organization that actually did provide diapers for Olivia, and it was very helpful. It was one last thing that we had to worry about. It was hard to get to the store for things, but we brought her home on a G-tube and so we had all of the supplies and things necessary. We also brought her home with an oxygen monitor so that we could check her SpO2 sets because apnea was one of her life threatening, and ultimately what took her from us. I hope that--

REP. HUGHES (135TH): Was the apnea, is what you're saying. The breathing?

MR. BENJAMIN KING: Yes, ma'am. Well, that was all part of it. Her body was incapable of producing healthy proteins necessary for her brain to develop and her brain wasn't telling her to breathe, but that same protein also impacted her digestive system and she was just going downhill. Then she took a severe turn for the worst one day and we could just tell something was different with her, and we wanted to keep her as healthy as possible.

REP. HUGHES (135TH): Thank you.

MR. BENJAMIN KING: Oh, sorry. We wanted to keep her as comfortable as possible towards the end of
life, and the diagnosis and hospice support enabled that.

REP. HUGHES (135TH): And forgive me, I'm just wondering in terms of other families that are dealing with a similar situation, did you have other children at home?

MR. BENJAMIN KING: Oh, I'm sorry, that was one of the biggest post diagnosis points that I had hoped to make. So with rapid whole genome, this type of broad genetic testing, we'll often do trio, what's called trio testing or test, the patients are tested, the parents are tested as well or other family members. And that allows us to filter out different variants because we all have thousands and thousands of variations in our DNA.

It allows us to deliver a more accurate analysis and results to determine which variants are attributing to the patient's symptoms. Through that, we were able to learn that Olivia's variant was what's called de novo, meaning it was not inherited from us. So Olivia has a healthy three year old brother, and with that information that we were not carriers of Olivia's condition, we felt comfortable trying again soon after and Holly was born in September, Holly Olivia King.

REP. HUGHES (135TH): Thank you. Thank you. This is really helpful.

MR. BENJAMIN KING: That's really important I think for parents to have that information for family planning, and it's only possible with the acute diagnosis.

REP. HUGHES (135TH): So your experience really helps us inform good policy on a number of bills, so I appreciate it very much.

MR. BENJAMIN KING: No. Thank you. I think Olivia's life and her short life and our experience
really touches on a lot of different value points of why this bill is so important. So it's a privilege.

SENATOR LESSER (9TH): Are you all set there, Representative Hughes?

REP. HUGHES (135TH): Yes, I am.

SENATOR LESSER (9TH): Thank you. And seeing no other questions, I want to thank you for your testimony here this evening.

MR. BENJAMIN KING: Thank you.

SENATOR LESSER (9TH): Next, we're going to hear from Dan Lewi followed by Paul Pescatello. Is Dan here? Okay. Is Paul here?

MR. PAUL PESCATELLO: So good afternoon, or early good evening.

SENATOR LESSER (9TH): Good afternoon.

MR. PAUL PESCATELLO: Paul Pescatello. I'm a senior counsel at the CBIA, and I'm Executive Director of, it's Bioscience Growth Council, and I'm also a chair of, We Work for Health, Connecticut. All those groups bring together emerging biotech companies, established biopharma companies, research institutions and patient groups, also build the biotech cluster in Connecticut.

I'm here today to support HB 5367, an act concerning Medicaid coverage for rapid whole genome sequencing for critically ill patients. The bill makes sense, first and foremost, for rare disease patients and nearly as important for our health care system. HB 5367 is targeted and solves a critical diagnostic problem facing newborns, their parents caregivers and they're treating medical professionals.

The medical predicament that HB 5367 addresses is this, soon after birth a newborn can present with a
troubling set of medical symptoms for which no standard test or the treating medical team's clinical experience can provide a definitive diagnosis. Often, time is very much of the essence. If the infant's condition cannot be identified, it cannot be treated effectively.

If it cannot be treated quickly, normality left unaddressed, the disease or condition will take its course, which can lead to irreparable damage to organs or death. Rapid whole genome sequencing is a means to provide desperately needed answers in such dire circumstances. Rapid whole genome sequencing is a way for the medical team to "see a patient's complete genetic profile and identify abnormalities that are associated with a rare disease." Rapid whole genome sequencing reduces to days and hours, a diagnostic odyssey that might otherwise take, if the patient doesn't succumb to the underlying rare disease, years.

Indeed, without the use of rapid whole genome sequencing, the typical time to definitive diagnosis for rare disease patients is five years, and more than 40% of rare disease patients are initially misdiagnosed. The rare disease diagnostic odyssey is not only debilitating, exhausting and frustrating for patients and their families, it is extremely costly and inefficient for our health care system.

Rapid whole genome sequencing replaces a multitude of blood and tissue tests, physical examinations by an array of specialists, and multiple hospitalizations with a single definitive genetic test. HB 5367 is not a license to use rapid whole genome sequencing without regard to medical necessity, it is targeted for use only in infants only where three conditions are met, and infant symptoms must suggest that diagnosis would otherwise require multiple non-rapid whole genome sequencing tests.
The treating health care team must provide written documentation that rapid whole genome sequencing is necessary to guide treatment, and the infant must have a complex or acute illness of unknown etiology. 5367 is smart health care, cost effective and cost saving for our health care system, and a hugely impactful advanced for rare disease patients. I'll be happy to answer any questions or expand upon any points.

SENATOR LESSER (9TH): Thank you for being here this afternoon. I'm going to ask you the question I just asked Mr. King a minute ago. Do you happen to know how much these costs?

MR. PAUL PESCATELLO: I do. I have a sense of it. So it varies, as the prior person noted, from lab to lab. But I would say at this point, it's something in the order of four to $5000. The price is coming down dramatically. Non-rapid whole genome sequencing has come down to about $1000 and it's on its way down, it will, within a few years, be something on the order of 100 or $200. But again, rapid whole genome, as expensive as it might seem, it is a cost saver to the system.

SENATOR LESSER (9TH): That's, well, it's a lot of money, but we've thrown around much larger figures in this room as well today. So, thank you. That is why I was trying to figure that out. Are there questions from members of the committee? If not, thanks for being here this afternoon evening, whatever it is.

MR. PAUL PESCATELLO: Yeah.

SENATOR LESSER (9TH): Thank you.

MR. PAUL PESCATELLO: Thank you so much.

SENATOR LESSER (9TH): Next, we'll have Natasha Kuranko, is she here?
SENATOR LESSER (9TH): On Zoom. And after her, we'll have Izarelli Mendieta Martinez. Natasha, are you there?

MS. NATASHA KURANKO: Yes, I'm here.

SENATOR LESSER (9TH): Okay, great. Go Right ahead.

MS. NATASHA KURANKO: Awesome. Well, good afternoon or good evening now, members of the Human Services Committee. I want to thank everyone testifying today, I have learned so much about many important issues and I pray we can find solutions to all of them. My name is Natasha Kuranko, I'm a lifelong resident of Connecticut and a staff member of Connecticut Citizen Action Group. I am here to voice support for several bills.

Firstly, SB 205, proposal to remove HUSKY C asset limits entirely is a significant step toward equitable health care access for older adults and people with disabilities. HUSKY C's asset limits are inherently discriminatory, even modest assets such as an unregistered use vehicle, worth less than $10,000, can be a crucial financial safety net for people with disabilities and older adults.

Their income and capacity for work are limited compared to HUSKY D recipients who have no asset limits. Noting that an adult living with a disability is estimated to require 28% more income to achieve the same standard of living as one without. These unjust barriers to health care access should be removed immediately.

Additionally, I urge support for SB 314, which will remove citizenship status as a barrier to Medicaid eligibility for Connecticut residents with chronic health conditions. This inclusive approach recognizes the importance of health care access for all individuals regardless of immigration status.
The erasure of medical debt, as opposed in the governor's budget, will have a profound impact significantly benefiting women and people of color.

Systemic forms of racism and sexism have historically hindered the economic advancement of these populations leading to higher rates of debt accumulation. Housing and hiring discrimination, occupational segregation and wage gaps have perpetuated generational poverty and limited financial independence.

Addressing medical debt will alleviate financial burdens and help mitigate lasting effects of historical injustices on marginalized populations. While I greatly appreciate this positive direction set forward, it will only be a band aid on medical debt without passing SB 205 and SB 314.

Lastly, I strongly support HB 5368, which proposes Medicaid coverage for diapers. This bill is crucial for improving children's health and development by alleviating the diseases and infections associated with infrequent diaper changing. The state's budget may also benefit a reduced need for pediatric care, treating dermatitis and more severe infections, means reduced health care costs covered by Medicaid. Despite the existence of diaper banks, the need for diapers remained significant in Connecticut, highlighting the need for Medicaid coverage. I urge you to support SB 205, SB 314, and HB 5368, to ensure equitable access to health care, prevent further accumulation of medical debt and improve children's health across Connecticut. Thank you.

SENATOR LESSER (9TH): Thank you for your testimony here this afternoon. Any questions from members of the committee? Seeing none, thank you. Next, we'll hear from Izarelli Mendieta Martinez followed by Sheldon Toubman.

MS. IZARELLI MENDIETA MARTINEZ: Good evening, Senator Lesser, Representative Gilchrest, and
esteemed members of the Human Service Committee. My name is Izarelli Mendieta Martinez, and I'm here to advocate for Senate Bill 314, an act concerning emergency Medicaid coverage for treatment of emergency medical conditions. Today I will share a story about my experience with navigating the emergency Medicaid system.

On February 13, 2019, a minor diabetic infection rapidly escalated into a life threatening sepsis for my father leading to an amputation and an extended hospital stay. However, due to his immigration status, he was unable to access essential home care and insurance. We obtained temporary financial aid through local programs such as Project Access and PreCare.

However, it did grant us with limited care. Over the years, this inconsistent care for his diabetes resulted in stage four chronic kidney disease by 2021. The financial constraints on care were really big. We were able to finally secure a nephrologist, during that time, the emergency Medicaid program was not available and the only options they provided with us were to bring him to the emergency room every time he needed dialysis, or have him live in the hospital indefinitely, or being able to pay out of pocket at $500 per session.

He required three sessions a week for four hours. Going to 2021, my father's health deteriorated, making him eligible for the Emergency Medicaid program, he was given a diagnosis of end stage renal failure. Navigating the system's complexity became a hurdle. We faced delays in medication coverage due to coding errors.

Providers were unfamiliar with Emergency Medicaid codes for his essential medication. They quoted his medication with the wrong diagnostic codes. For example, some of his hypertension medication related to his kidney failure was quoted as that for his
diabetic care. Therefore, pharmacies denied some of that medication.

Despite my efforts to explain the intricacies of how the coding system worked, and trying to educate his providers on what the program consisted of, the mistakes continued. We spent back and forth communication causing significant delays in his vital medication. Something like the user friendly website that provides clear information like Senate Bill 3114, would streamline the process and ensure timely access to his critical medications. To fast forward, long story, he was waiting for his renewal of his emergency medication in October, 2022.

We submitted multiple applications, we seek the assistance from the DSS from our local DSS office. However, the staff were unfamiliar with the Medicaid program and were unable to offer us guidance. In the time that we waited for the renewal, my father developed another sepsis infection. He landed in the emergency room and fell into cardiac arrest. Well, his medical team recommended open heart surgery, he was not able to proceed due to his lack of insurance.

If he was able to survive the surgery, he would have needed rehab and wound care and dialysis. Unfortunately, this was something that we weren't able to fund. Upon his last days, we were trying to get hospice for him, but due to his lack of insurance, we weren't able to have him do hospice care. With heavy hearts we made the agonizing decision to withdraw life support.

He passed away on December 19, 2022, and a couple of weeks after we received his renewal for his coverage. I know with proper care we could have had more time with my father. What my family endured is what many families face and struggle with. Senate Bill 314 offers solutions, for example, an early application system for emergency Medicaid, improved
access to treatment and provides clear online information for families and providers and the general public. We hope that my father's story can provide a system that's fair, and therefore people do not have to endure what we endured. Thank you.

SENATOR LESSER (9TH): Thank you for being here tonight and for sharing your story. I am so sorry for what your family has gone through, and please accept our condolences on behalf of your father. But hopefully sharing your story helps us make decisions that will help other families going forward. Any questions?

MS. IZARELLI MENDIETA MARTINEZ: Yes. And I think-- Sorry. And I think that the emergency Medicaid, even though is a great program and we're thankful, it was very hard to navigate, not only for myself but also for providers.

SENATOR LESSER (9TH): Good to know.

MS. IZARELLI MENDIETA MARTINEZ: Thank you.

SENATOR LESSER (9TH): Representative Gilchrest?

REP. GILCHREST (18TH): Thank you, Senator Lesser, and thank you, Izarelli, for being here. And I also want to say I'm sorry for your loss and for what you had to go through with your dad leading up to that loss. I did want to go back when you were explaining how there were different codes. Can you just talk us through that? Because to your point, it seems as though the providers are confused too. I'm just trying to better understand what the issue is there. Thank you.

MS. IZARELLI MENDIETA MARTINEZ: So, some of the issues that existed were, for example, I can give you an example. If he was on amlodipine, which was related to the dialysis, it made him have high hypertension. But because the providing doctor coded him under-- instead of doing end stage renal
code, that specific code, they coded it as related to his diabetes. So when I went to the pharmacy and when I was trying to get under the emergency Medicaid coverage, when I was trying to get his medication, they would deny it because it wasn't specifically coded for end stage renal failure. So,

REP. GILCHREST (18TH): Okay. Thank you.

MS. IZARELLI MENDIETA MARTINEZ: So, even when I called DSS myself and HUSKY, they were providing me with a zip code, and I went back to the pharmacist and provided it for him. But even at that, I didn't get as many responses because the local DSS workers weren't sure what the Medicaid codes were, and the pharmacist who had a hard time navigating. So ultimately, we never got the medication.

REP. GILCHREST (18TH): Thank you very much. That's really helpful clarification. And again, I'm sorry that you had to go through all that.

MS. IZARELLI MENDIETA MARTINEZ: Thank you.

SENATOR LESSER (9TH): Other questions from members of the committee? Seeing none, thank you for being here with us this evening. Next, we're going to have Sheldon Toubman followed by Karen Healy.

MS. SHELDON TOUBMAN: Good afternoon, Senator Lesser, Representative Gilchrest, members of the committee. My name is Sheldon Toubman, and I am the litigation attorney at Disability Rights Connecticut. We are the protection advocacy system for Connecticut, serving individuals with a full range of disabilities.

I'm here to testify about the impact of three bills on people with disabilities. SB 205, 306 and 314, that we just heard about. First SB 306, the bill removing HUSKY C [inaudible 00:30:08], but over a long period of time. The commissioner said today that it would cost $72 million just to raise to
$10,000 or 15,000 for a couple, and without including long term care.

I don't understand that. Kathy Flaherty earlier referred to a report that was done by California when they were assessing how much it was going to cost to get rid of their asset limits, which they ultimately did in January. And they actually costed out almost exactly this thing. They were at 2000 and 3000, and they proposed to go one option, 10,000, 15,000, including for long term care.

The total cost in the state of California was $38 million. And as Kathy said, they were about 11 times as big as us. So that's like $3.5 million, including long term care if you went from California and extrapolated. Sure, there's some differences, sure it's been like four years of inflation, but still look at that number, it doesn't come even close to $72 million.

And then as Kathy also correctly said, their estimate for the entire removal of asset limits was 116 million, although there was also another $2 million saved from getting rid of assets review, which Senator Lesser you asked that question, and Deputy Commissioner Hadler said, yeah, that would actually save money to not to do those anymore.

So given that it's maybe going to cost $10 million, we need to get more information, but that's the dollars. On the policy, just as an example, the Affordable Care Act prohibited asset limits, period, in the Medicaid expansion, that's called HUSKY D in Connecticut. And they did that because it's not just expensive, it's also burdensome and very few people have significant assets at these low income levels.

So it's just basically a bad policy that was rejected by Congress. Now, unfortunately, Congress left the States the option of still having asset limits for elderly disabled, which means of course,
we have that and it's discriminatory. But now that we recognize it's discriminatory, I think there's a real question of why it would take four years to get rid of the asset limits.

And I note that 306, for med connect proposed to get rid of asset limits also singling out people with disabilities, it wouldn't take four years to do so. Lastly, 314. So we just heard compelling testimony about the consequences of not covering a range of services. That the EMC protections for people who are noncitizen have been in federal law for a very long time in recognition of the consequences of not addressing urgent situations, including severe chronic long term conditions.

The states have substantial flexibility in the application of the definition of what is an emergency medical condition under federal law, and still get federal match. For example, Connecticut, relevant to the story, in 21, we finally covered ongoing dialysis that an outpatient faces, not having to be in the emergency room for people who are going to have that condition for years.

The identification of other specific conditions as in this bill is an adjunct to a general definition of what constitutes an emergency medical condition which must be applied by all the states on a case by case basis. Attached to my testimony though, is a set of proposed revisions to this bill, additional suggested conditions which also meet those same standards, which other states have done.

At least one other state is doing each of these. These additional provisions will benefit people with severe chronic conditions which present severe risk if not immediately treated. And finally, I wanted to note that the intention here is to only cover services which are matched by the federal government, and that depends upon which category they would otherwise be eligible for. But for
immigration status, case of HUSKY D, that's 90 cents on the dollar.

Moreover, given that without this EMC coverage, some would avoid any treatment altogether and they'd be rushed to the hospital, and not until the rush to the hospital with a real crisis, as we just heard, when the care will be very expensive. The cost of these changes could well produce a net savings for the taxpayers of Connecticut. Thank you for the opportunity to speak with me today. Happy to answer any questions.

SENATOR LESSER (9TH): Thank you, Sheldon, for your testimony tonight. Are there members of the committee who have questions? on Zoom we have Representative Hughes.

REP. HUGHES (135TH): Thank you, Mr. Chair, and thank you Sheldon for patiently lining out really both the moral policy, violence of not taking this action but also the economic costs. I just want to reiterate that we've heard heartbreaking and preventable violence to people's health and deaths that were preventable by not updating our policy.

And so I'm going to urge us all to take a look at what you've very specifically laid out in your written testimony in terms of ways to improve the proposals we have before us on all three fronts and to take that long overdue action, because it is discriminatory above all else, is we're discriminating against disabled people and that is just not right. So I just want to add that. Thanks.

SENATOR LESSER (9TH): Thank you, Representative. Representative Dathan.

REP. DATHAN (142TH): Thank you very much, Mr. Chairman, and just wanted to say, thank you, Sheldon, for your comments today. They're very well noted. I have a lot of concerns as you know, with
where we are as a state and what disabled people have to do in order to get coverage for basic medical things.

And we are not in a-- a lot of these adults are living independently, and we're not in a society that are putting adults in major congregate living, that happened to be the way 50 years ago when the asset limits were, and the income limits, were established. Times have changed, I think our rates need to reflect this and we need to change. It's something I'm very much advocating for and appreciate your support. And that's all I wanted to say. Thank you, Mr. Chair.

SENATOR LESSER (9TH): Thank you, Representative Dathan. Any other comments or questions? Obviously, we are interested in this issue and have been. Dispute over the fiscal notes at the moment seems all encompassing and surmountable. I hear your arguments about why this might only be a $10 million lift, and if so, we should have done away with it years ago.

But anything that we can do to make that case to DSS, to the governor's office, OPM, could only help. So I understand the arguments, but we need to convince the fiscal analyst that that's the case and then we'll, I'm sure, come up with the money. But thank you for testimony tonight and we'll look forward to working with you on all these proposals going forward.

MS. SHELDON TOUBMAN: Thank you very much, sir. Thanks everybody.

SENATOR LESSER (9TH): Take care. And then next up, we have Karen Healy, and then after Karen we'll go to Selina Osei. Oh, Selina, you need to accept the-- Oh, Karen, you need to accept the promotion to a panelist on. No? All right, we'll go-- Yeah, if you are on the Zoom, you have to accept the promotion to panelist or we cannot hear you. All right, we're
going to go to Selina Osei and then we can go back to Karen if she accepts. Is Selina with us?

MS. SELINA OSEI: Yes.

SENATOR LESHER (9TH): Okay. Hello.

MS. SELINA OSEI: Hello, good evening. My name is Selina Osei. I'm the Director of Health Equity and Community Engagement at the Connecticut Hospital Association. And today I am submitting my testimony in support of House Bill 5368, an act concerning Medicaid coverage of diapers. Diapers are an essential means to ensure diaper hygiene and prevent a range of avoidable medical conditions in infants and young children.

We know that poor diaper hygiene due to lack of access to a consistent and adequate supply has been linked to several maternal and child health conditions, including maternal depression, poor infant sleep, infant and child urinary tract infections and diaper dermatitis. Diaper need has also been shown to be the number one stressor and risk factor for postpartum depression.

Therefore, providing coverage for diapers when medically necessary is essential and appropriate care. In the past year, the National Diaper Bank Network's annual household survey found that diaper need has increased from one in three back in 2010 to one in two households in 2023. And of course, it also showed that three in five parents miss work or school because they can't afford the diapers required to leave their baby in childcare.

In some instances, not having childcare coverage also leads to women and other caregivers not meeting their medical appointments. With this evidence in mind, the Diaper Bank of Connecticut partnered with Connecticut hospitals to implement diaper connections, which is a program to screen for diaper need and support families who are identified with
the need with diapers, with funding supported by the Department of Housing.

That funding is ending, and so medical coverage of diapers through this targeted policy intervention is going to not only readily make diapers available to children and families who have a medical necessity for diapers, but it will enable programs like Diaper Connections, community organizations who are supporting families with a diaper need, be able to serve other families who have a medical necessity for diapers and who, otherwise, don't qualify for public assistance.

Connecticut has already demonstrated its commitment to safeguarding the health of its low income children and families. With the expansion of Medicaid coverage to one year postpartum of all birthing persons, and to children, 12 and younger, regardless of immigration status. Covering diapers for young children likely to experience a series of diaper related conditions and hospital visits is another essential child focused Medicaid preventive health solution that will protect the health of children.

It is aligned with the Governor's Maternal Health Strategy and the goals of DSS's forthcoming Maternity Bundle Payments Program. CHS strongly supports this proposal to systematically address diaper insecurity through Medicaid coverage as medically necessary. Thank you for consideration of our position.

SENATOR LESSER (9TH): Thank you for your testimony this afternoon. Are there any other questions? Are there any questions from members of the committee? Seeing none, thank you for your testimony. Next, we have—Any progress on number 60. Okay. All right. Next, we have Polly Crozier followed by Tara Lavalle.

CLERK: [inaudible 00:42:54].
SENATOR LESSER (9TH): No. Okay. Is Tara on?

CLERK: Yes.

DR. TARA LAVALLE: I am. Can you hear me?

SENATOR LESSER (9TH): Yes, we can.

DR. TARA LAVALLE: Right. Good evening, Senator Lesser, Representative Gilchrest, Senator Seminara, Representative Case, and the distinguished members of the Human Services Committee. My name is Dr. Tara Lavalle and I'm a health economist and on the Faculty of Tufts Medical Center and Tufts University School of Medicine in Boston.

And thank you for the opportunity to testify in support of House Bill 5367. In my job as a health economist, I evaluate the value of new technologies by comparing their costs and benefits. I have extensive training in doing these evaluations for pediatric health interventions. I was the primary investigator on two research studies that evaluated the cost effectiveness of using rapid whole genome sequencing to diagnose critically ill infants with suspected genetic conditions.

In these studies that I led, we found that using rapid whole genome sequencing in an infant's hospitalization, early in an infant's hospitalization, by doing this, there are substantial downstream savings. In one study, we conservatively estimated that using rapid whole genome sequencing as a first line test resulted in $4400 of testing costs avoided over the next 10 years. This was true for all babies who received rapid whole genome sequencing.

Since rapid whole genome sequencing looks at the whole genome, as people have mentioned earlier, it eliminates the need for most additional tests, even for babies who are not diagnosed. In the most
recent study we did, which was funded by the NIH, we found that nearly 50% of babies received a diagnosis from rapid whole genome sequencing, which compares to around a 9% diagnostic rate from standard testing protocols without rapid whole genome sequencing.

We also found that babies who were tested early in the hospitalization with rapid whole genome sequencing had shorter and much less expensive hospital stays compared to babies who did not receive rapid whole genome sequencing early in their hospitalization. As a result, using whole genome sequencing early in the hospitalization resulted in a net cost savings during the hospitalization and over the course of the year when we followed these babies.

I'm here today because my job is to objectively determine how many in our healthcare system can be used most efficiently to improve the lives of individuals. It is extremely unusual in my role to come across an intervention like rapid whole genome sequencing that can improve the lives of babies and families due to his high diagnostic yield and produce cost savings for the health care system.

This is a technology that all babies should have access to if they need it, including those served by the Medicaid program, who are some of the most vulnerable in our society. Thank you for the opportunity to present with you this testimony, and to strongly support this important new policy. Be happy to take any questions you have.

SENATOR LESSER (9TH): Thank you for your testimony tonight. Are there questions? Yes, Senator Seminara.

SENATOR SEMINARA (8TH): Thank you, Mr. Chair. Tara, I was wondering through your research if you are able to notice or recognize if there's any patterning done by this rapid genome testing? Has there been any research or pattern in terms of
diagnoses or children? Meaning race, color, creed? I'm trying to find out if there's any pattern and if you have been able to notice any patterns developed by doing this testing.

DR. TARA LAVALLE: Yeah, I will say that there are historical disparities in genomic sequencing. So basically the way this test works is that you can collect blood, you evaluate any changes in the DNA that you see, and compare that to what you would expect. But then doctors have to-- scientists have to look at those changes and basically match them up to what they know about those changes and whether those changes are related to a disease.

Unfortunately, those reference groups of people, where they can match them up to a disease, have been mostly drawn from people from European ancestries. And in a lot of cases, nonwhite individuals have been systematically excluded or not included in these types of research studies. So already starting out, people of non-European ancestry are already at a disadvantage going into this.

And that doesn't even include the fact that then you build on top of that further lack of access and further downstream problems accessing services following that. So I really think of this as several incremental problems that people of marginalized populations have faced in the genetics face and getting genomic sequencing, and accessing the test is just one of those problems.

SENATOR SEMINARA (8TH): Okay. Thank you. Thank you very much.

SENATOR LESSER (9TH): Thank you, Senator. Questions or comments from members of the committee? Seeing none, thank you for your testimony tonight.

DR. TARA LAVALLE: All right. Thank you.
SENATOR LESSER (9TH): Next, we have Constanza Segovia followed by Lisa Rosenthal. Constanza here? No Constanza. Is Lisa here? No Lisa? Okay. Is Merrill Gay here? No, Merrill. At this rate we're going to go real quick. Is Kim Harris here?

MR. KIM HARRIS: Yes, I am. Thank you.

SENATOR LESSER (9TH): Hello, Kim.

MR. KIM HARRIS: How are you? And good evening chair, co chair and the Human Services committee. Thank you for your time this evening. I like you, have been touched by the life stories of those who have spoken before me and I want to thank everyone for this learning experience.

My name is Kim Harris. I am in support of HB 5368. I am a center director at Harrison Tucker School, a member of Circle and a community leader that runs children and youth programs for Inspired Communities Inc in the Newhallville neighborhood of New Haven. Today, I'm here to talk about access to opportunity, which can lead to wonderful possibilities. At the Inspired Communities Inc headquarters, we distribute pampers, incontinence products, and period products. In my Newhallville community, which is in the city of New Haven, there is a 47% poverty level for children five and under, and a 30% poverty level overall.

Because of the need for supplies, we cannot serve all who need, we just don't have the need of supplies. I hear stories all the time about parents not being able to go to work or send their kids to school, or teens who are not able to go to school because they just don't have daily living essentials.

Every time I hear a statement like that, I take a moment and I sit with it, I sit with what was said, because to me, I believe that everyone should have daily essentials in order to live. Today, I would
like to urge this committee to move in a direction that will create access to opportunities for people to live with dignity and possibilities. Thank you.

SENATOR LESSER (9TH): Thank you. And you are well under the three minutes or just under the three minutes. Good. Are there questions from members of the committee? If not, thank you for being here tonight and for sharing your experiences and what you have seen in the Newhallville section of New Haven. Next, we will hear from-- Is Liz Gustafson-- I'm having some problems tonight. Is Liz Gustafson on?

MS. LIZ GUSTAFSON: I am.

SENATOR LESSER (9TH): Great. Good to see you, Liz.

MS. LIZ GUSTAFSON: You too. Good evening, Senator Lesser, Representative Gilchrest and esteemed members of the Human Services Committee. My name is Liz Gustafson and I am the Connecticut State Director of Reproductive Equity Now, and I'm here to testify in support of HB 5240. As a state and regional organization, Reproductive Equity Now works in Connecticut and across New England to make equitable access to the full spectrum of reproductive health care a reality for all people.

The decision about if, when, or how to become a parent is one of the most important life decisions that we may make, and everyone should be able to make that decision without barriers, which includes equitable access to and coverage of fertility care. In our fight to protect and expand reproductive equity, we must address systemic reproductive oppression and racial injustice to ensure that no one is left behind.

The current coverage requirement for fertility treatment only applies to private insurers, meaning that people insured through HUSKY are excluded from coverage for fertility care. This is simply a
matter of reproductive and economic justice. While we are grateful that HUSKY covers a range of services for prenatal birthing and postpartum care, the continued denial of coverage for fertility care is fundamentally a denial of people's right to start or build their families.

A lack of coverage for folks enrolled in HUSKY exacerbates barriers faced by people with lower incomes and disproportionately impacts Black and Hispanic residents in our state, particularly black women who are almost twice as likely as white women to suffer from infertility. Without insurance coverage, the cost of paying out of pocket for fertility care such as IVF, can range from 1000 to tens of thousands of dollars, putting this essential health care out of reach for those who want to start or grow their families.

For far too long, people of color, people with lower incomes, people with disabilities, and the LGBTQ+ community have faced insurmountable barriers when seeking to exercise their reproductive autonomy. All people making pregnancy related decisions should be met with compassion and be provided with all of the resources that they need for each and every option.

Now, as a state that continues to lead the national fight for reproductive freedom, we urge this committee and the Connecticut General Assembly to take a critical step towards equity by passing and supporting HB 5240. Combined with its companion bill that is in the Insurance and Real State Committee, this legislation would work to address barriers to assisted reproduction and family building care and ensure all residents in our state, regardless of income or insurer, have equitable access to the medical care they need to start or grow their families with dignity. Thank you for your time.
SENATOR LESSER (9TH): Thank you, Liz, for the testimony. Are there questions or comments from members of the committee? Seeing none, have a good evening. Next, we have Shantana Hazel, followed by Ben Marcus.

MS. SHANTANA HAZEL: Good evening, Senator Lesser, Representative Gilchrest and distinguished members of the Human Services Committee. I'm sorry. My name is Shantana Hazel. I am from Bridgeport. I'm also the founder of the Sister Girl Foundation, where we provide advocacy, support, education and awareness for individuals with endometriosis, infertility, breast and ovarian cancers.

We also just celebrated our 14 years anniversary of being of service within the state of Connecticut. I am testifying in support of Raised House Bill 5240, an act concerning Medicaid coverage for infertility treatment. This bill will improve access to fertility care for people who have HUSKY health insurance or Medicaid. I myself utilize HUSKY at a point in my own health journey after a 14 year delayed diagnosis with endometriosis. I wasn't able to work due to daily excruciating and debilitating chronic pain. I've undergone 17 surgeries to date and one ectopic pregnancy that nearly cost me my life.

I was diagnosed with secondary infertility very late into my endometriosis journey. And due to not having medical coverage, I was unable to continue my family building. I know many people here today, testifying or listening, can relate and understand how devastating that can be. To be completely transparent, it has had a lifetime effect on my life and so many others like myself. One of the reasons I founded the Sister Girl Foundation in spite of all my personal health challenges, was to stand on the front lines, advocating in all capacities as a health change agent so others wouldn't have to suffer in silence and would also have access to coverage.
As a woman with multiple degrees, countless accolades, who has worked since I was 14 years old until moments when I couldn't, I found myself at that time feeling like all my years of paying taxes and giving back was all in vain because I too needed services that I didn't have access to. We often speak of health disparities and social determinants of health and how to begin bridging the gaps in building health equity, but what does that look like for our underserved community? Opening doors to access fertility coverage would stand to be an actionable step in the right direction.

I would also like to take this time to thank Representative Gilchrest for all of your work with the Connecticut Endometriosis Working Group, and this is our awareness month, and so whatever you may need moving forward, please do not hesitate to reach out to us. And I also support Raised House Bill 5240. Access to Medicaid coverage for fertility care is an urgent reproductive and economic justice issue for Connecticut. All people have the right to have children regardless of who they are and how much they earn. I ask this committee to report House Bill 5240 favorably. And I thank you for your time this evening.

SENATOR LESSER (9TH): Thank you for your testimony. I have a hunch that Representative Gilchrest has a couple of things to say to you though. Representative Gilchrest.

REP. GILCHREST (18TH): Yes. Thank you, Mr. Chair. Thank you so much Shantana for being here and for forming the organization, and for sharing your experience, which to your point is the experience of so many folks and why this legislation, I believe, is so important. And I look forward to our continued work together. I will most certainly be following up. So, thank you for being here.

MS. SHANTANA HAZEL: Thank you so much.
SENATOR LESSER (9TH): Thank you. Any other questions or comments from members of the committee? Seeing none, thank you for being here this evening. Next, we have Benjamin Marcus, followed by Katherine Villeda.

MR. BENJAMIN MARCUS: Hi, good evening, Senator Lesser, Representative Gilchrest, and distinguished members of the Human Services Committee. My name is Benjamin Marcus, and I was until very recently a new Haven resident. I'm here on behalf of GLBTQ Legal Advocates and Defenders, where my colleague, Polly Crozier, has been a longtime collaborator in the Fertility Access Connecticut Coalition. GLAD strongly supports House Bill 5240.

Our work involves supporting LGBTQ families and their children. Our community wants to have children and nurture the next generation just like everyone else, but we face tremendous barriers in doing so. We face bias and discrimination in health care settings, we face having to procure gametes, which can be incredibly expensive.

We face a private insurance market that doesn't require employers to have plans that reflect the standard of care and equally cover LGBTQ employees. And for those in our community on HUSKY Health, we lack total access to fertility health care. Indeed no state in the US comprehensively provides coverage for family building health care for people on Medicaid.

This harms LGBTQ people because we often rely on fertility health care to build our families. We believe that Connecticut can be a leader state that provides people with the health care they need to put down roots, thrive, and build their families. As you know, this important bill has a companion in the insurance and real estate committee to ensure that private insurance guidelines align with the standard of care.
We have suggested key amendments to the insurance bill so that it will reflect the American Society for Reproductive Medicine's standard of care and clarifies coverage for fertility preservation. This bill will ensure that patients on HUSKY have similar access. Family-building health care is so vital for so many. We've seen that so clearly in the past few weeks.

The opinion of the Alabama Supreme Court in the page case issued on February, 16th was a shock. In the context of a wrongful death action that was tragic for the hopeful parents, the court found that an embryo stored in the process of IVF was a legal child. The ruling set off chaos in family-building health care in Alabama and stopped it in less than two weeks' time.

And the legislative fix is no fix and doubles down on the fiction that embryos are children and leaves hopeful parents even worse off. Politicians are determined to set back the clock of time and have their sights set on family building health care. So many including in the LGBTQ community are afraid of this new chapter in the attack on reproductive rights and private medical decision making. This bill is a source of hope for LGBTQ people.

GLAD is here to support your work to ensure family-building health care in Connecticut is fair and accessible. My colleague, Polly Crozier, and I have submitted written testimony for the committee as well. So I will end here. Thank you so much for this work. It is so urgent and important.

REP. GILCHREST (18TH): Thank you, Mr. Marcus, for being here tonight. I don't see any questions. Thank you for your testimony. Have a good evening.

BENJAMIN MARCUS: Thank you. You too.
JULIA LEEDY: Good evening. Good evening, Senator Gilchrest, and ranking members of the Human Services Committee. My name is Julia Leedy and I am currently pursuing my master's in public health at Yale University. I am also a student working with the commission on women, children, seniors, equity, and opportunity.

Today, I would like to show my support for House Bill 5371, AN ACT CONCERNING A WORKING GROUP TO STUDY EXPANDING HUSKY HEALTH BENEFITS TO ALL UNINSURED RESIDENTS UNDER THE AGE OF NINETEEN, as its ideals coincide with the commission's beliefs that disparities must be addressed for underrepresented and underserved populations. Before I began my work with the commission, I used to work with a food service company.

Last spring my coworker, we can call him Jeff, and I were working in a shift for a company that had rented the whole garden for an event. As the guests mingled and enjoyed their hors d'oeuvres, Jeff, a DACA recipient, shared with me his troubles in finding healthcare access for his daughter. He and his partner had to conduct extensive research to find someone who would see his family.

And even after they identified a healthcare provider, they still had a long wait until their daughter could be seen. It's not lost on me that I get to tell that story with you today instead of Jeff simply because of our differences in documentation status. Jeff, who takes any second he can to tell you about his three children, would be the first to advocate for them, but he's constantly afraid of sharing his stories and being deported.

No family in Connecticut should have to face the same frustrations as Jeff did. With your support of House Bill 5371, Connecticut can learn more about
undocumented immigrants' current healthcare access through this working group. Additionally, as the group will find, Connecticut hospitals will see savings from the decrease in uncompensated care.

According to a RAND study, those savings could range from $63 million to $72 million due to more families having the ability to access pre-emptive care instead of being forced to wait for emergencies in order to access care. Supporting a working group to study HUSKY Health benefits expansion for all people under 19 will be a step forward for Connecticut in addressing inequities in health care.

The group's findings can potentially save our healthcare facilities millions of dollars, money that can be reinvested in hospitals' community outreach. They also will have the potential benefit every child's health status, eventually leading to healthy adults in our state. The commission asks that the Human Services Committee to please support House Bill 5371 in order to close this health care disparity. Also included within the commission's written testimony was an ask that someone from the commission be put in this work-study. Thank you for your time.

REP. GILCHREST (18TH): Thank you, MS. Leedy. Thank you for being here and for your work with the commission. I don't see any questions. Have a great evening.

JULIA LEEDY: Thank you. You as well.

REP. GILCHREST (18TH): And it looks like Karen Healy has joined us on Zoom. Are you with us? You just have to unmute.

KAREN HEALY: Hi. Good evening. My name is Karen Healy, and I'm a registered voter in Hartford, Connecticut. I'm a person in recovery from mental illness. I spent 24 years of my life in psychiatric hospitals between Hudson River Valley Hospital, New
York, and Cedarcrest in CVH in Connecticut. I am now living successfully in a community with services and support from the Department of Mental Health and Addiction Services Capital Region.

Speaker of House, Matt Lesser, recently presented me with an official citation in recognition of my nine-year anniversary, my release from Connecticut Valley Hospital. I am a member of the Keep The Promise Coalition. I was appointed by Governor Lamont to the Connecticut Council Development Disabilities.

I was chosen to be part of these acts, the committee, because of my story and lived experience which I used to help other people. I am here to testify in support of SB 25 and SB 306. Right now, I get coverage through Medicaid Connect program for working disabled.

In the fall, I'm planning to have a total knee left knee replacement. With my MED-Connect insurance right now, I'm able to get coverage for the surgery and PC services that I need while recovering. As I have-- I'm sorry. As I have coverage for my outpatient nursing agencies, medication, and medpores, and more important services that have made it possible for me to stay in the community.

But I'm worried that if I lose my job before my surgery or I can no longer work at some point, that I will not be able to qualify for HUSKY-C. I will have to get rid of my assets to qualify. This means that I would not have to have any of my own savings in case of emergencies and I cannot grow financially without having to worry about my health insurance.

Everyone deserves an opportunity to live a good life in the community. Please pass SB 306 and get rid of the HUSKY-C asset limits for all, and please pass SB 205 to support people with disabilities while working. Thank you for listening to my testimony today. I'm Karen Healy. Thank you.
REP. GILCHREST (18TH): Thank you, Ms. Healy. So glad you could testify with us tonight.

KAREN HEALY: Thank you. I appreciate it. Thanks.

REP. GILCHREST (18TH): Next, we will hear from John Board. Patiently with us all the time.

CONSTANZA SEGOVIA: Good evening, members of the committee. Sorry to be off camera but my name is Constanza Segovia. I live in Hartford, and I'm the organizing director and co-founder of Hartford Deportation Defense, an organization representing 300 immigrant families in the Greater Hartford area.

We are part of the Connecticut For All Coalition, and we are here to testify in support of SB 314, to expand emergency Medicaid coverage for treatment of emergency medical conditions. We also support the additional language that is attached to the testimony of Katherine Villeda from Health Equity Solutions and Sheldon Toubman from Disability Rights Connecticut.

This bill is a step forward in improving health outcomes for all Connecticut residents and it's much needed-- The upgrade is much needed to Connecticut's Emergency Medicaid policies. It would change policies by expanding the conditions which are eligible for emergency Medicaid and to include many chronic conditions that are not currently covered. These upgrades would of course improve the lives of Connecticut residents and especially when they're facing life-threatening conditions.

We have focused our advocacy the last few years in the expansion of HUSKY to include all income-eligible people regardless of age and immigration status. And we do that because we believe that health care is a human right. And anything this legislature can do to increase access to health care for all people in our state, especially when they're facing life-threatening emergencies is going to be a
step forward and something positive for this committee to support.

So I ask, again, for you to support SB 314, and we understand we have work to do, but this is a great step forward to have Connecticut be more equitable. Thank you.

REP. GILCHREST (18TH): Thank you so much, Ms. Segovia. So good to hear from you tonight. I don't see any hands, so have a great evening. Thank you. Is Kate LeBlanc with us? Oh, she is right on Zoom. Hi, go right ahead.

KATE LEBLANC: Hello there. Good evening. All right. I got this. My name is Kate Weldon LeBlanc and I am the executive director of Resolve New England, which is an independent nonprofit organization that provides support, education, and advocacy that is open to anyone struggling with fertility or family building.

And we strongly support Raised Bill House--Raised House Bill 5240, AN ACT CONCERNING MEDICAID COVERAGE FOR INFERTILITY TREATMENT. And we are a proud member of the FACT campaign, which is Fertility Access, Connecticut. House Bill 5240 will improve access to fertility care for people who have HUSKY health insurance. It is very difficult for anyone to pay out-of-pocket for fertility treatment such as IVF.

But for people with lower incomes, it can be nearly impossible. Fertility care is health care and is a vital part of reproductive health. The best part of my job with RNE is when I have the privilege of getting to know individuals and couples who are trying to grow their families. They are determined, resilient, and hopeful.

However, the hardest part of my job is when I speak to those who have learned that because they are covered by Medicaid, they do not have any coverage for fertility treatment. It is truly heartbreaking
and feels deeply unfair. This includes patients with Medicaid who are dealing with serious health issues such as cancer, endometriosis, or sickle cell disease who desperately want to preserve their fertility for future parenthood but do not have coverage for this either.

Thank you for your attention to my testimony and to all the testimony today. It has been so powerful, and you all are amazing. I respectfully urge the committee to report House Bill 5240 favorably. Connecticut has been a national leader in reproductive rights in fertility care, in fertility preservation, in protecting LGBTQ families, among other key issues. This is an opportunity for Connecticut to be a leader again. You can expand coverage so that more residents of your beautiful state will have access to the essential medical care they need to try to achieve their dream of parenthood no matter how they are insured. Thank you.

REP. GILCHREST (18TH): Thank you so much, Ms. LeBlanc, for being here and for sharing that perspective of a provider who has to have that really difficult conversation that unfortunately, what they need isn't covered. So thank you.

KATE LEBLANC: Thank you.

REP. GILCHREST (18TH): I don't see any questions. Have a great evening.

KATE LEBLANC: Thank you so much.

REP. GILCHREST (18TH): Next, we'll go to Jenny Kohl.

JENNY KOHL: Hi, good evening. Thank you so much. About to say good afternoon. It's literally evening now so thank you. So it's nice to see you, Representative Gilchrest, Senator Seminara, Representative Dathan, and all of the distinguished
members of the Human Service Committee. My name is Jenny Kohl, and I'm the advocacy and outreach coordinator at the Diaper Bank of Connecticut. Thank you so much for the opportunity to testify in favor of how Bill number 5368, AN ACT CONCERNING MEDICAID COVERAGE FOR DIAPERS. So I know you've all heard me say this at least a million times, but a diaper is truly not just a diaper, it's a basic human need.

And the inability to afford an adequate supply of diapers impacts the health and well-being of the entire family, health-wise, economic-wise, and educational-wise, which you've heard from my colleagues this evening speak a little bit more in-depth about that.

So we know that diaper need can lead to an increase in urinary tract infections as well as pediatric visits for diaper dermatitis. And a couple of things that we know on a national level is that pediatric UTIs are the third leading primary cause of rehospitalization after birth for Medicaid enrollees. Children with UTIs account for half a million annual ED visits a year, annually. And children under one represent 40% of all UTI hospitalizations.

So, in my role at the Diaper Bank, I have the privilege to work with a wide net of community members. And a lot of the conversations that I have, I'm often asked, are diapers covered under any programs, support programs? And the truth of the matter is that there are very few support programs for families who struggle to afford diapers.

And although we are one of the largest diaper banks in the country, and we are very grateful for the support that we received from the state, we currently only serve about 7% of diaper need in our state, in Connecticut. This is based on our distribution numbers. And much like food banks, where federal and state support is provided for
supplemental nutrition programs, the need is much greater than is being supported.

And we know that we simply just cannot meet this need alone. The bill extends Medicaid coverage to children from birth to ages three with specific health conditions resulting from extended usage of diapers. And again, as our CEO mentioned, this bill is not intended to cover the entire need. We know that would be an extremely large cost for the state, but this bill is meant to reduce the burden on low-income families with the highest level of need. So we really urge you to consider passing this bill because families across our state really need your support and we really need to prioritize the health safety and well-being of families. Thank you so much for your time, and I'm happy to answer any questions.

REP. GILCHREST (18TH): Thank you so much, Ms. Kohl, and I think that information on UTIs is so important because I think many wouldn't think that infants experience that.

JENNY KOHL: Yeah, absolutely.

REP. GILCHREST (18TH): But the bill specifically calls that out so thank you. Thank you for being here all day.

JENNY KOHL: Appreciate your time. Thank you for being here all day.

REP. GILCHREST (18TH): Next, we'll go to Madison Arenchild who is with us on Zoom.

MADISON ARENCHILD: Hello, Senator Lesser, Representative Gilchrest, Senator Seminara, Representative Case, and the distinguished members of the Human Services Committee. Thanks for hanging on throughout the day and listening to this testimony. I'm excited to be here to talk about my
support for HB 5367, regarding Medicaid coverage of rapid whole genome sequencing.

My name is Madison Arenchild, I work for Rady Children's Institute for Genomic Medicine, which is a nonprofit organization that provides rapid whole genome sequencing to critically ill children in NICUs and PICUs across the country.

And as you've heard in the beautiful testimonies earlier today, rapid whole genome sequencing is a test that's used in a small population. but of a very sick population of infants and children who end up hospitalized with conditions of unknown origin. And what rapid whole genome sequencing does is it reads more than 20,000 genes looking for variants that might be causing the patient to be sick right now. And it results those genomic results to care teams in a matter of days.

And for these ultra-sick kiddos, their doctors and their families need answers fast because early diagnosis enables them to provide early intervention. And that early intervention might be treatment, but in some cases, it also might be withdrawal of care so that families of patients with fatal conditions can maximize the quality of time that they have left together.

And while some babies are born very sick, for some kids, the severity of their disease onset comes just a bit later, they might start life healthy. And I want to talk to you about one kid, Hudson, who's a good example of this. So Hudson, he was a healthy boy. He met all of his major milestones, and then aged 13 months, his daycare called his family and said they'd never heard a child breathing like that before.

So Hudson was rushed to the hospital and after that, his health deteriorated very quickly. He lost his developmental milestones, and he was getting sicker. He was originally misdiagnosed, and then in pursuing
the treatment for that diagnosis that was incorrect, he wasn't responding to those treatments.

And so what happened is his family fought for him to receive this test that they'd heard about, rapid whole genome sequencing. And in 48 hours, those results showed the correct diagnosis which was a riboflavin transporter deficiency. And the treatment for that is actually an over-the-counter vitamin that his body just couldn't produce itself.

That's the same treatment he's on today, nearly four years later. He has some health challenges. He has difficulty breathing, swallowing, speaking, some hearing loss, but he's a happy child who actually just joined his first soccer team. So this test has been studied extensively in more than 30 clinical studies, and also in three statewide real-world demonstration programs and those who are in California, Michigan and Florida.

And what each of these studies results show is that if Medicaid properly incentivizes the right care for the right patient at the right time, what you get is a life-changing intervention that is not only faster and better than alternatives, but it is ultimately more efficient care despite the upfront payment for testing.

And with all of the beautiful testimonies earlier today, I was thinking about what kind of new information I could afford this group. And wanting to emphasize that we know that this is high-quality care, that it can really change the care trajectory for these families, and that it's associated with cost savings. The clinical utility of this test and the cost savings are most impactful when providers are able to do this as a first test.

So they see the kid and they go, I have this in my tool belt and I can order this test, versus having to use it as a last resort because of the expense and not having separate payment for it. And what we
hear time and time again from hospitals is that they are just too financially constrained to be able to provide the testing equitably and sustainably across their unit. And so that's what we're trying to change here.

I don't think anyone argues the powerful nature of this tool in this population, but we know how to address this problem, we know who to address it for, and coverage and payment are really the first steps towards delivering on the promise of early diagnosis and what that allows for this small but very mighty population of kiddos. So thank you very much, and I'm happy to take questions.

REP. GILCHREST (18TH): Thank you, Ms. Arenchild. Senator Seminara.

SENATOR SEMINARA (8TH): Thank you for your testimony, and thank you, Madam Chair. We heard earlier that there was approximately 50% of children that were able to get diagnoses through this testing. Do you have any stats on if-- Obviously there's children that don't get a diagnosis, but are there stats on diagnosis that they can rule out through-- Because it's my understanding when you do this testing, you may not be able to get a diagnosis, but you may be able to rule out other diagnoses. And I'm wondering if there's any statistics on that, if you're aware of anything.

MADISON ARENCHILD: So I can quote a few statistics that regardless of the status of a positive versus a negative finding, 97% of families found the information useful as far as ruling out genetic disease to the best of our knowledge, right? I'll give a clinical example. So you may have a patient that presents with some sort of structural heart defect, for example, and they're a candidate for a surgery.

Now, if their etiology for their defect is genetic, maybe the surgery doesn't work, but if it's not
genetic, then the surgery will work. And so you might have a case where rapid genomic results allow the providers to then make that decision because they know now whether or not that surgery is going to work and if it's not, then they can proceed down a different route. But there is a lot of value in that negative result so that care teams can move on with a different care pathway.

REP. GILCHREST (18TH): Okay. Thank you very much for your testimony this evening, and being so patient, and waiting all day, so thanks so much.

MADISON ARENCHILD: Thank you very much.

REP. DATHAN (142ND): Thank you very much for your testimony. Have a good evening. Next, we have James Iacobellis. I saw you. There you are. Please come forward.

JAMES ICOBELLIS: Good evening. My name is Jim Iacobellis. I'm the senior Vice President of Government and Regulatory Affairs at the Connecticut Hospital Association. And I'm pleased to be here to testify in strong support of House Bill 5241, AN ACT ESTABLISHING A BUREAU OF COORDINATING SERVICES FOR THE DEAF, DEAFBLIND, AND HARD OF HEARING.

For a number of years, CHA has been working closely with the deaf, deafblind, and hard of hearing community to troubleshoot issues and to work on issues that are across all hospitals. And we enjoy that partnership because every patient that we can ensure has effective communication has significantly better care. So we are pleased to do that. One of the issues that we've heard repeatedly in our conversations is the lack of coordination of services across the state.

We tried something a couple of years ago to have similar websites and web information put on all state agencies, but this is a significantly better solution to have a bureau within the Department of
Aging and Disability Services to coordinate services. And we strongly support it. We would ask for one change or addition in the legislation. Section two creates a working group to look at access for health care for individuals that are deaf, deafblind, and hard of hearing.

CHA is part of that and we thank you for that, but we believe adding a representative of an interpreting agency that doesn't-- health care interpreting would be a great addition to this group. We all know that in-- we have a workforce shortage across the country and in Connecticut on almost all professions, but particularly in health care and with interpreters.

So to have them part of the conversation, we think, will be helpful going forward. Now, I'm going to do something that I really always tell myself not to do and make two comments on a piece of legislation that I was hearing about today, and it's Senate Bill 314, AN ACT CONCERNING EMERGENCY MEDICAID COVERAGE FOR TREATMENT OF EMERGENCY MEDICAL CONDITIONS. CHA, and connect hospitals have long time support of expanding coverage. We know that when individuals have coverage, they seek care and they seek preventative care, and they don't use the hospital in situations where they can get care in a different setting.

The right care at the right time. This bill as another bill related to Medicaid coverage for diapers that you heard my colleagues talk about are a theme, and we are very pleased that the Human Services Committee is looking at the Medicaid program in more creative ways than we have in the past. And my understanding is this legislation will look at what the other states surrounding us have done and to try to model our Medicaid emergency coverage after that, and we support that and strongly support 5241.
REP. DATHAN (142ND): Thank you very much. I had a question but I'm going to ask my ranking senator if she has any questions. No? Okay, great. Thank you so much for your testimony. I know this is something that we have tried very hard as a legislature to address, how we can help those who are deaf of hard of hearing in a medical setting. I know we've put some ARPA dollars towards this in the past to look at this accessibility issues. And we also made some changes to interpreter qualification laws in the medical setting. It seems like to me, we have a workforce issue.

And that's probably one of the areas why so many folks like the folks that came in today and talked about some of their issues that they have received in hospitals was due to a lack of interpreters. As the Connecticut Hospital Association, what do you advise we can do as a legislature to address that workforce issue so that we can ensure that these interpreters are available? Do other states do anything like this to encourage it? I know the Governor's Office of Workforce Strategy is looking very much in the healthcare space, but do we need to maybe, as part of that working group, look at how we can address some of those workforce issues? So if you could talk about that for a minute, I'd appreciate it. Thank you.

JAMES ICOBELLIS: It is a significant problem, and it's increased since COVID, where interpreters have for a long time did interpreting from their homes. And since there's a shortage, you can fill up your entire day interpreting at home as opposed to having a call to drive to a hospital, to drive to a medical setting, and come back, right? So that's changed lifestyles and it has impacted interpreters as well. I believe we have one school in Connecticut that does certification for interpreters. I think we need to keep that in the front of our minds and maybe look to expand that because it's sort of like the conversation we have around nurses is sometimes
we don't have enough of the education slots for people that want it.

And we have to keep interpreters sort of in the forefront of our minds because we talk a lot, and we do as well, and this is sort of a constant reminder, that we talk about a nursing shortage, and respiratory therapist shortage, and a physician shortage. We need to keep interpreters in the front of mind, and I think work with our higher education system to see if we can expand a program, maybe for a two-year time frame to see if we can-- I believe it's this Nantucket.

I don't think it's Northwest is the pro-- And maybe in a different part of the state and try it for two years as a pilot program. And if we have enough people coming in, then work to make it permanent. But we need to build it so people will come. And I think that's one of the things as a legislature that would be extraordinarily helpful.

REP. DATHAN (142ND): Are you familiar with other states that do you focus in on the interpreter pipeline of health care folks?

JAMES ICOBELLIS: I have had some. I can't tell you I've had extensive conversation with my colleagues in other states, but more along the lines of, yes, we have that issue as well. Haven't done the deep dive in whether they have more than one school or more-- or how they have dealt with it, but it's a good challenge to go out and to see if there are other ways in which to do it.

REP. DATHAN (142ND): Thank you. Clearly, we heard today far too many stories of folks that suffered as a lack of interpreters, and we need to address that as a state, and I appreciate that you're willing to be part of the solution there.

JAMES ICOBELLIS: We know that having good health is-- encompasses a lot of different things, and
being able to communicate with your provider is a key part of that, whether it is language or whether it's American sign language, but how you communicate is how you can work with your provider and get the best care you need and get the best treatment and get better, and get preventative care services in physicians offices.

REP. DATHAN (142ND): Absolutely. Absolutely. So thank you so much. Seeing no other-- Let me just check online. Seeing no other questions, thank you for your testimony and your patience today.

JAMES ICOBELLIS: Of course. Thank you.

REP. DATHAN (142ND): Next, we have Alexander Kucherov. Okay, great. Next, we have Sarah Locke. I don't see her either online. Next, we have Michael Ahimsa. Oh, looks like he--

MICHAEL AHIMSA: Yes. Can you hear me?

REP. DATHAN (142ND): Oh, great. Thank you. Sorry, I thought you were in person. Apologies.

MICHAEL AHIMSA: I was in person but we had [crosstalk 00:43:46].

REP. DATHAN (142ND): No, no, no, no, don't worry. I totally understand. Please go ahead, sir.

MICHAEL AHIMSA: Thank you very much. Good evening. I'm here in regards to House Bill 5241, The ACT ESTABLISHING A BUREAU FOR THE COORDINATING-- A BUREAU COORDINATING SERVICES FOR THE DEAF, HARD OF HEARING, DEAFBLIND PERSONS. Good evening, distinguished members of the Human Services Committee.

I'm grateful for your time and the opportunity to testify before this committee this evening. My name is Michael Ahimsa. I am a member of AFSCME Council 4, Local 2663. I'm an interpreter for the deaf and
hard of hearing at the Department of Aging and Disability Services, ADS. I began learning sign language at the age of 12 in my home state of Minnesota, and have worked as a freelance sign language interpreter for 20 years.

As you may know, Connecticut is the birthplace of American sign language and the home to the American School for the Deaf, the first permanent school for the deaf in the United States. Connecticut was also the first state in the nation to have a commission on the deaf.

In 1974, the Connecticut legislature established the Commission on the Deaf and Hearing Impaired, CDHI, to advocate, strengthen, and implement state policies affecting deaf and hard-of-hearing individuals, and their relationship to the public industry, health care, and educational opportunities. CDHI was an independent stand-alone entity with at least 50 employees, 40 of them being interpreters.

For decades, CDHI functioned as a-- essentially as a one-stop-shop for the deaf, deafblind, and hard-of-hearing community, and also served as one of the two interpreting agencies in the state. I've been making notes throughout the day as I've been listening to other people's testimony, so I'll just try to do some bullet points here, I think. The interpreting unit was-- Excuse me, the CDHI was mostly dismantled in 2009 and absorbed into the Department of Rehab Services. And my understanding at that time is the unit or the agency was self-sufficient and was actually bringing in revenue and giving-- bolstering the general fund, is my understanding. And then in 2016, the last remnants of CHI, which was the interpreting unit was dissolved.

As we've heard throughout today, the testimony from many people, there have been significant ramifications from that closure, and really people
didn't know what to do as soon as it happened. And it was very sudden. I do applaud the number of interpreting agencies who have stepped forth--stepped forward to try to help fill the gap in services statewide.

As we've heard tonight that there are--today, there is a limited pool of interpreters. That is true nationally and that is true in our state as well. And with a limited pool of interpreters, those numerous interpreting agencies are really trying to fill assignments with the same pool. And so there is that issue.

The other issue is that with the shift to privatization of interpreting services from the state to private companies, that has really had a negative impact on interpreters, their profession, and the livelihood that they had come to rely on through the state employment. And so that I think is one of the--

CLERK: Mr. Ahimsa, could you please summarize your comments for us, please?

MICHAEL AHIMSA: Yes. So I think that, overall I support the bill. I'm concerned about some of the specifics. I'm mostly concerned about funding and ultimately, I wish that services would be provided and not so much management. I do have ideas about--additional information about remedies to the situation from the interpreter perspective. Thank you very much for your time this evening.

REP. DATHAN (142ND): Thank you so much. Just verifying we don't have any questions for you. Thank you for your testimony, sir.

MICHAEL AHIMSA: Thank you.

REP. DATHAN (142ND): I'm just going to check we have Norma Martinez-HoSang. I don't see her on--She's not? Okay. I do see number 88, Katherine
Kraschel. I'm sorry if I've mispronounced your name.

KATHERINE KRASCHEL: Thank you. No, it's like crashing into something.

REP. DATHAN (142ND): Please go ahead. Thank you so much.

KATHERINE KRASCHEL: Thank you. Senator Lesser, Representative Gilchrest, and distinguished members of the Human Services Committee, my name is Katherine Kraschel. I'm a law professor and my research focuses on reproductive justice, fertility care, and assisted reproduction. I live in The Mystic with my wife and our son, who was conceived via assisted reproduction.

I'm testifying in support of Raised House Bill 5240, AN ACT CONCERNING MEDICAID COVERAGE FOR INFERTILITY TREATMENT. State law in the state of Connecticut has required private insurance companies to cover fertility care for some Connecticut residents for nearly 20 years.

And a companion bill in the Insurance and Real Estate Committee will update the existing mandate to align private fertility care insurance coverage with the medical standards of care, which clearly includes LGBTQ people and single people. The state's employee plan was also updated to clearly cover fertility care including for LGBTQ and single people this fall.

So House Bill 5240 poses a simple question, do people who receive care through HUSKY deserve the same access to reproductive health care as those on private insurance, or the same as the employees of the state government? In order to have strong reproductive rights and reproductive justice answer to that question is yes and yes to HB 5240.
Continuing with the state status quo of private insurance coverage, state employees' coverage, and no HUSKY coverage, will perpetuate racial disparities in care. As others have testified, black women are disproportionately likely to experience infertility but underrepresented in the patient population that accesses care.

Owing to factors including institutionalized racism, Black and Hispanic individuals are also disproportionately represented in our HUSKY program. So while ensuring care for those in the private plans or who work for the state government, improves access for some, it is not adequate to address issues of disparities in care.

In fact, earlier this year, I co-authored a piece published in the American Journal about Secrets in Gynecology with a statistician and a reproductive endocrinologist and showed that states with private insurance mandates that do not provide coverage through their Medicaid program may in fact exacerbate racial disparities. In the wake of the Alabama Supreme Court decision that likened frozen embryos to children, shutting down IVF clinics across that state, legislators across the country have inquired, what can we do to protect IVF? This is it. This is the bill that will protect IVF for everyone. Pass HB 5240. Reproductive rights mean nothing if there is no way to exercise the rights that we protect.

And where you get your health insurance shouldn't dictate your reproductive rights. Reproductive rights movement that led to the decision in Roe has long been rightfully criticized for making concessions that leaves those on the margins behind like the repeated passage of the Hyde Amendment that has banned federal funding to cover abortion. Connecticut does the right thing and covers abortion care 100% since the federal government doesn't kick in. The ability to get pregnant should be no different. And with the family planning 90% match
by the federal government, the state would only need to cover 10% of this cost.

I implore the committee and legislature to vote favorably and improve fertility health care coverage so more Connecticut residents have access to the essential medical care they need to build their families no matter what insurance they hold. Thank you, and I'm happy to take any questions.

REP. DATHAN (142ND): Thank you so much, Katherine, for your testimony. I don't see any questions here. Thank you. I hope you have a good evening, and thank you for being patient with us today. Have a good evening.

KATHERINE KRASCHEL: Thank you.

REP. DATHAN (142ND): David Negron. Oh, thank you. I'm glad I knew that. Bobby Berriault. Okay. Gail Nolan. I don't see her. Oh, wait. Okay, great. Gail, you are up if you'd like to unmute yourself, and please go ahead. You have three minutes, madam.

GAIL NOLAN: Hi, good evening. Thank you so much to you and to all the members of the Human Services Committee. My name is Gail Nolan, and I'm the director of Laurel Family Resource Center in Bloomfield, and I am in support of HB 5368, AN ACT CONCERNING MEDICAID COVERAGE OF DIAPERS to expand Medicaid to cover infant and diapers for babies.

I am one of the ones who passes out diapers, I'm sorry to, for all parents in the community of Bloomfield. We have a diaper bank which is a member of the Connecticut Diaper Bank. So I just wanted to come on and support that.

They do a wonderful job. Diapers are so neat in our community. The cost of diapers is crazy, and especially for people who can't afford it. They can't afford to shop at Costco or Amazon or buy the large amounts, so any support giving them would be
wonderful. In my time as doing it, I've been the director for a few years, we've had the diaper bank, and we have had medically fragile children, and it was really hard to get these diapers for them in the sizes that they needed. One was a boy who was being care taken by his grandfather, and she couldn't afford diapers. She would come and we could get her some help.

But it was really hard as he aged and was waiting for an operation. He had something wrong with his colon, and he was awaiting an operation for that. And so she struggled trying to balance watching him, she would have to get care for him to be able to come and pick up the diapers.

It was just really a struggle that she was made to face because she didn't qualify for subsidized diapers other than the few that we could give her or get her from the program. So just urging for families who are really going through tragedies with their children to be allowed to use Medicaid, if at all possible, to supplement their income.

Thank you.

REP. DATHAN (142ND): Thank you very much, Mrs. Nolan. We appreciate your comments this evening. I don't see any questions for you. Thank you for your patience. Have a good evening.

GAIL NOLAN: Thank you. You too.

REP. DATHAN (142ND): Next, we have 92, Michael Negron. There you are. Go ahead, sir, when you're ready.

MICHEL NEGRON: Good evening to all the members of the Human Services Committee. My name is Michael Negron. I am a resident of Guilford, and the proud grandfather of Chloe who you met earlier today. Thank you for providing me and all of us an opportunity to speak with you. As you know, Chloe was diagnosed in the fall of 2022 with a rare disease called Juvenile Tay-Sachs. She is one of
only four in the entire country who was diagnosed with that disease.

Another word for rare is exceptional. Chloe is exceptional. She's loving, sweet, funny little girl, and she's a warrior. I support Senate Bill 206 in addressing children with terminal diseases, and how and when decisions and approvals are made on which children will be included in the Katie Beckett Waiver Program.

The existing process has placed our granddaughter, Chloe, on a waitlist that can be as long as five to six years. A child with a terminal disease and their family need various forms of support on a significantly accelerated timely basis. I had some prepared notes but hearing everything today, I've been here for about eight hours, I guess, I'm encouraged. We heard we were the first state with a deaf commission.

We were the first with this. We're in the '70s with that. I'm encouraged because our state is the first to have baby bonds. Our state is the-- Governor Lamont recently talked about eliminating medical debt. I'm encouraged by that. I like the way the pendulum is swinging from where we've been.

Unfortunately, you were not able to hear from Daniel Lewi, who's I think number 62 because he was calling from Europe. He's the CEO and founder and the father of a child he lost to Tay-Sachs, the founder of an organization called Cure and Action for Tay-Sachs. I'm grateful for people like Leslie Bennett.

I'm grateful for this commission, this group. I'm grateful for last week's Rare Disease Day here in Connecticut. I connected with so many individuals, and I can't believe it was only a week ago because various legislators have decided they're going to jump on this, such as Senator Candelora and Senator Looney, who have written to me,.
I'm also grateful for the Tay-Sachs Association which has helped us navigate this, and one of their individuals was here today for most of the day. Chloe's family and all of you as representatives cannot cure this disease. However, you do have the power and the wisdom to support children like Chloe and ensure quality of life for Chloe, her parents, her sister, Christina. You have the opportunity to be warriors like Chloe. Thank you for holding this hearing and considering our testimonial. I look forward to hearing the next steps. Thank you. Oh, I had just one more thing.


MICHEL NEGRON: Thank you. This is heartbreaking. Several doctors have talked to our son and daughter-in-law and asked if they would consider moving to be able to qualify for the Katie Beckett Program, which is horrific to even think about.

In addition, there was some information that maybe was left a little misleading about the numbers. $53,000 per child is the total cost, including what the Federal Government covers. So, it's actually 25,000 for Connecticut, not 53,000. So, if you take the $8 million that the individual who's here from DSS gave, and divide that by the 300 whatever it gets you to that 25,000. It's 16 million with the Federal Government piece, which gets you then to the 53,000. So, we may be the only ones in New England that don't have what other States have, but we have an opportunity to change that. Thank you.

REP. DATHAN (142ND): Thank you so much. Really appreciate you waiting all day. I know this isn't how you'd like to be spending your time when it's so precious.

MICHEL NEGRON: Thank you. I think it's a metaphor for what everyone who's here today will do for their family, be here as long as it takes.
REP. DATHAN (142ND): One of the things we focused in within Human Services last year is ameliorating and eliminating waitlists for folks that are in the IDD community and folks that are on the autism spectrum. And when I heard, we have been trying to chip away at this list slowly over the last several years and when you hear stories like your granddaughters, it breaks your heart because you do want to help them.

And I believe that this is something we can do as a State. But it's important that we hear from folks like you to advocate, and so that no other families have to spend all day up here when they can spend time with their loved one. So, I appreciate your testimony. I'm going to open it up to comments. Senator Seminara.

SENATOR SEMINARA (8TH): I just want to say that, thank you for your patience. It's been a very long day. It's very unfortunate for me to admit this, but I know that this waitlist has been this way for over 20 years. So I'm hoping that we can work in a direction if not to ameliorate the whole entire waitlist to at least take into consideration terminally ill children like your granddaughter.

So, but it is a program that is in some ways, a well-kept secret and I'm also embarrassed to admit that as well, but there's very few people who are aware of the Katie Beckett Waiver. There might be more now that we've addressed this. But I know for a fact that it isn't a waiver that is widespread throughout the disability world.

And I'm not exactly sure why that is. But I know that it isn't. And then when people find out about it's disheartening that you have to wait the five years. But, and I assure you, I've been in the disability community my whole adult life. I don't know anyone who's been pushed up on that list.
So, in this situation, let's hope we can make a difference and make a change because I do think it's a special case and we should take those cases under consideration. So thank you for your patience. Thank you for your testimony. Thank you for your family's testimony. It really does impact all of us and it's important information that we get.

MICHEL NEGRON: Thank you and thank you for what all you do. You've been here all day as well and all week and so on. So, thank you.

SENATOR SEMINARA (8TH): That's our job.

REP. DATHAN (142ND): Next Representative Cook.

REP. COOK (065TH): Thank you Madam Chair.

MICHEL NEGRON: Oh, I'm sorry.

REP. COOK (065TH): Oh no, that's okay. I know how that feels to want to go. I didn't get an opportunity to talk to you while you were up there. And so I would like to address both of you at the same time and your family as all. Having four children, there's something about having a child.

Having grandchildren, there's something totally different. I have two and the hurt that you see with your child, and then having that child hurt because of their child does something to you as a human and I saw Senator Seminara earlier waving tears away and here I go. It's those motherly things, but I don't think that there's any way to put into words what you all are going through. And you've tried and you've done a beautiful job doing it.

I don't think I could, and as much as there might not be people around the table, I know there's people online. I hope that you know, that your story doesn't fall on deaf ears and that what you're going through as much as we can't go through it
with, know that we hear you and that we will do what we can, everything that we can.

I've been sitting in this seat for 16 years, around this table and every year we try to do more, and we try to do more, and we try to do more. And if it wasn't for folks like you that had the courage to come and share the stories that you're sharing and going through, we would have no idea, what's happening to folks that live in our communities without the courage for you to come in front of us. And so as a father, and a grandfather and I love how you signed in Chloe's grandfather. Please don't give up hope and we will continue to fight. She's a special girl. I met her out there. She way cute. The decisions are hard on our side. I couldn't imagine the decisions that you have to make. So please keep the faith.

MICHEL NEGRON: Thank you. And I just want to thank you, all of you. I want to also acknowledge the people that we're standing on the shoulders of, all the different advocacy groups that exist and the people like Ben King and others that have really shared their experiences, resources and so on. So wait, it's for Chloe.

COOK (065TH): It is.

MICHEL NEGRON: Thank you.

COOK (065TH): Thank you. Be safe, please.

REP. DATHAN (142ND): Thank you, sir. Have a good evening, drive home carefully. You're in our thoughts. Next online, we have Gretchen Raffa, unmute yourself. There you go. There you are. Go ahead, madam.

GRETCHEN RAFFA: Good evening Representative Dathan, Senator Lesser, Representative Gilchrest, and honorable members of the Human Services Committee. My name is Gretchen Raffa, Vice President of Public

As the State's largest provider of sexual and reproductive health care to over 45,000 patients last year and 14 health centers across our State. We believe all people should have access to quality, affordable and compassionate health care as a basic human right.

Regardless of who you are, where you live, your income. If you have health insurance or your immigration status. As advocates for reproductive freedom, we believe that every individual has the right to full bodily autonomy and the ability to make decisions about their body life and future, including if and when to start a family. It is our responsibility as reproductive health care providers and advocate that our work must be inclusive to ensure that people have access, not only to abortion and contraception care, but also ensure people have access to pregnancy care and equitable access to infertility, evaluation, treatment and fertility health care.

The reality is far too many people, they require a fertility assistance to have children. Yet it's often out of reach due to the high cost of such health care. That is why we're proud members of the Fertility Access Connecticut Campaign led by Resolve New England, GLAD, Planned Parenthood of Southern New England, and many more reproductive health, fertility health and LGBTQ+ advocates to improve access to fertility health care to all people in Connecticut.

HB 5240 and its companion Bill HB 5378. That was heard this week in the insurance and real estate committee will address a critical need by eliminating barriers to fertility care coverage, including expanding it to public health insurance
and will align fertility health care insurance coverage with the medical standard of care, which clearly includes LGBTQ+ people, single people among others. So that all Connecticut residents have the opportunity to build their family.

The Medicaid's programs lack of coverage of fertility assistant has a disproportionate impact, on women of color. This is particularly concerning because black women are more likely to experience infertility yet like less likely to seek care. The relative lack of Medicaid coverage for fertility service stands in stark contrast to Medicaid coverage for maternity care and family planning services. While there's broad coverage for many of those services during pregnancy and to help prevent pregnancy, there's almost no access to help people with low income, achieve pregnancy.

And this inequity in coverage for fertility care is part of the larger fight for reproductive rights and justice in our State to ensure all people have the freedom to empower, to build their own families. Access to family building care such as IVF is essential health care for so many people.

And you heard from others, The recent Alabama Supreme Court ruling set off chaos in Alabama for patients that rely on IVF to build their families and is the clearest demonstration yet, of the many ways anti-abortion laws including personhood laws threaten contraception care, fertility care and all sexual and reproductive health care.

We strongly support House Bill 5240 and have urged amendments to the companion Bill. House Bill 5378 to align with the current medical standard of care as defined by the American Society for reproductive medicine. These two Bills together will address a critical need by eliminating the barriers to fertility care coverage and is an urgent reproductive and economic justice issue for Connecticut residents, because all people have the
right to have children, regardless of who they are or how much they earn.

Access to family building health care is such as IVF is essential health care for so many people. And that's why we urge the Committee and legislature to vote favorably for House Bill 5240 and improve this fertility health care coverage. So again, that more Connecticut residents have the medical care that they need to build their families no matter how they are insured. Thank you so much for your time and consideration of this important legislation.

REP. DATHAN (142ND): Thank you so much. Gretchen Raffa, it's nice to see you. I know you were in the room earlier today. So thank you for sticking with us all day. I don't see any questions. Have a good evening.

GRETCHEN RAFFA: Thank you. You too.

REP. DATHAN (142ND): Next, we have Luis Luna. I see you on the Zoom. So just go ahead and unmute yourself and please start testifying. Oh dear Lewis oh, good, okay. He's been waiting there so patiently. Sorry. We just lost you for a second if you could start.

LUIS LUNA: No worries. Thank you so much.

REP. DATHAN (142ND): Thank you.

LUIS LUNA: Representative Dathan, thank you so much, Representative Gilchrest and our Lesser and distinguished members of the Human Services Committee. My name is Luis Luna and I'm a resident in New Haven. I serve as the Coalition Manager for HUSKY for Immigrants. I'm here in support of three Bills. SB 314, SB 306, and SB 207.

On SB 314, States are granted considerable leeway in interpreting the definition of an emergency medical conditions under Federal law. This flexibility
enables Connecticut to access Federal funding for a wide array of services not confined to hospital emergency departments or inpatient settings. For instance, Connecticut akin to numerous States extends coverage to routine outpatient kidney dialysis treatment for those with end stage renal disease since 2021.

While certain conditions are inherently EMC's, the termination of an EMC is contingent upon individual circumstances, obligating all States to assess cases on a case by case basis. The proposed updates to SB 314, ensure vital health care access for individuals with severe chronic conditions, preventing potential fatalities, organ damage or enduring physical or mental harm due to delayed treatment.

By granting access to EMC coverage, individuals are spared from receiving treatment altogether, adverting catastrophic outcomes. Moreover, SB 314 includes administrative enhancements aimed at streamlining the claims process for EMC coverage. This encompasses accepting prior applications for ongoing EMC conditions and disclosing a non-exhaustive list of conditions meeting the EMC criteria.

Attached to this testimony are proposed amendments to SB 314 encompassing additional conditions recognized as EMC's by other States and procedural changes such as ensuring medical transportation for EMC related treatments. Mirroring Connecticut's existing provision for kidney dialysis patients, These provisions, are akin to the current draft of SB 314, often offer tangible benefits to individuals confronting severe chronic conditions, with imminent risk in the absence of prompt treatment. It's not worthy that the Federal Government will match at least 50 cents on the dollar for all of these services.

Bearing depending on the medical category of the individual would qualify for, bearing their
immigration status. For elderly adults not categorized as their caretaker, relatives of minor children, pregnant or officially deemed disabled. Such coverage falls under the HUSKY D program entailing a 90% match considering the potential cost savings derived from adverting emergency hospitalizations through EMC coverage.

These changes would yield net benefits for Connecticut taxpayers. Thank you, and I have other things on my testimony for the other Bills. But thank you so much for granting me the opportunity to address these crucial matters today.

REP. DATHAN (142ND): Thank you so much, Mr. Luna. We do have one question here online Representative Hughes.

REP HUGHES (135TH): Thank you Madam Chair and thank you Luis. You mentioned the administrative streamlining and coding cost built into this expansion for emergency medical coverage. Can you say a little bit more about that, in other States, how that has saved both the hospitals and of course the patients in the communities a lot of headache and potential tremendous harm, of course?

LUIS LUNA: Sure. I can speak a little bit about this. I am not an expert on what other States have done. But States like Pennsylvania and Florida have expanded the definition of EMC’s. So when a patient is seen by a doctor and is deemed that the medical condition is under an EMC, then there's procedures that will carry out the care for that patient. So I think that's the extent that I know. I mean, right now, our team has been doing some research on what are the other States have been doing. So I'll be happy to follow up with you on how administrative streamlining has been done by other States.

REP. HUGHES (135TH): I'd be interested in that. I mean, we, you, heard some heartbreaking stories today about quite frankly preventable death.
Especially because these chronic conditions like end stage renal can deteriorate so quickly. And we heard in previous hearings, about people not being transported, timely, getting access to their dialysis, all of these things which could be averted, through this expanded coverage. So, I just wanted to ask you a little bit about the amended language that you have also submitted in your written testimony, can you explain that a little bit more specifically?

LUIS LUNA: Absolutely. So, so our team got together to dive into this Bill. And we wanted to, we had reached out to some doctors and physicians within the network for them to look at the Bill and then see in there, what they have seen on the field and what should be included, and what should be amended in this Bill. So, some physicians got back to us and that's how we compiled some of the amendments that we see in this Bill.

We also wanted to make sure that what we have amended, we will also look into the rate of Federal matches. So, that's something that we, because we see that in other States, and these are red States, that have implemented this, so we were very curious as to as to how they're doing. So we're, these are work in progress. I think, we are working to do more research and I'll be really happy to follow up with you and the rest of this Committee with some more information about those things.

REP. HUGHES (135TH): That's really, really helpful. I think that's really important. And the other point that you made that I just want to highlight is you said that, if it's covering the aging and other folks that would otherwise be, under Husky B, it's really helping capture those that maybe were not captured into that program and therefore getting the 90% reimbursement rate. I think that's incredibly important to, to recognize that this expansion would, would help then lift those other folks that were falling through the cracks into the program.
LUIS LUNA: That's correct. And also, I think you mentioned too, having an early treatment for some of these diseases will save also money in the long term too. So we see this Bill as, good policy and having more dollars from the Federal Government coming into Medicaid.

REP HUGHES (135TH): That's really excellent. So I'll look forward to reading your written amended language and any other research that your team has done. And did you want to say anything about the other two Bills that you were going to testify on just real quick?

LUIS LUNA: I mean, I think, we want to make sure that we end discrimination for HUSKY C. I think with the work that we have been doing and the coalition that we have built, We see HUSKY expansion in regards to HUSKY for undocumented folks as a piece of a larger fight to health care equity. And I think that we want to make sure that folks who are on HUSKY C, that they receive the care that they need. And that they have the peace of mind and that their health is taken care of.

REP HUGHES (135TH): Excellent. Thank you. Thank you, madam chair.

SENATOR LESSER (9TH): Thank you Representative Hughes. Next up. Oh, I'm sorry. Are there other questions for members of the Committee? Seeing none? Thank you for your testimony.

LUIS LUNA: Thank you so much.

SENATOR LESSER (9TH): Next, we have Sidney de Lannoy followed by Cheryl Rabe.

SIDNEY DE LANNOY: Oh, sorry about that. So, Senator Lesser, Representative Gilchrest, Senator Seminara, and Representative Case and members of the Human Services Committee.
My name is Sydney De Lannoy and I'm an MSW student at UConn and a policy intern at the Alliance, the Community Nonprofit Alliance. Today, I'm testifying in support of HB 5371 an Act concerning a working group to study expanding health benefits to all uninsured residents under the age of 19. I hope that through this Bill, Connecticut can continue the moment we've built over the past few years by expanding Husky to undocumented youth and mothers and continue to extend needed health coverage to other populations.

Nonprofits play a vital role in delivering health care services to underserved communities regardless of race, income or immigration status. Without access to health care nonprofits serve people when they're in need. Even if they do not have the ability to pay. Increasing access to Medicaid will enable nonprofits to access Medicare, Medicaid reimbursement for services that they already provide. In addition, without care, youth are more likely to have long term health and economic challenges that affect the development and increased burden in State safety net programs and nonprofits. For this reason, the line supports a study widening HUSKY eligibility to include individuals up to age 19.

Further prioritizing children's health and wellbeing today is an essential step for strengthening our State's collective futures. In conclusion, I urge the members of the Human Service Committee to support HB 5371. And to think of expanding the scope of this work group to investigate HUSKY access beyond just those under 19, but to other populations in need like elderly and older undocumented populations. The General Assembly has made major strides in the past few years in expanding HUSKY coverage to undocumented children. But now more than ever, it's crucial to continue this effort and make HUSKY accessible to a greater number of
individuals. Thank you for your time and consideration.

SENATOR LESSER (9TH): Thank you for your testimony. And perfectly times. Are there questions for members of the Committee? Seeing none. Thank you for testimony tonight. Have a good evening. Next Cheryl Rabe followed by Leslie Bennett. No, Cheryl. Okay. Leslie?

CLERK: Leslie testified already earlier.

SENATOR LESSER (9TH): Oh, she was on the list twice. That's right. Okay. Diana Dupuy Faustin. Hello and after Diana, we'll have Jordan Fairchild. Press the red button in front of you. Good evening.


My name is Diana Dupuy Faustin, and I am a student at the University of Connecticut School of Social Work. I want to make three points today. One, having medical insurance is a basic human right. As Obama Stated in 2008, health care should be a right for every American from an ethical viewpoint, we have a duty to protect citizens from suffering from a lack of medical care, due to lack of insurance.

Providing health insurance is a means to improve our health care system. Therefore, providing Medicaid coverage for infertility treatment, will increase care for the infertile women and men through preventive measures and continuity of care. Two, it provides financial relief. Fertility treatment is without a doubt, a very expensive procedure. The price for treatment can range between 15,000 to
30,000. Many people including myself use credit cards. Credit cards and loans to cover fertility treatment. This is a financial burden that many people face. In the study conducted by Prosper Marketplace. They found that 40% of the women surveyed acquired between 10,000 to $30,000 more in debt doing fertility treatments.

Women and men should not have to go into debt for fertility treatment. Hence, providing Medicaid coverage will alleviate the debt burden incurred by many across the nation. Lastly, infertility is in itself traumatic and stressful. I remember in November 2020, when I got the news from my doctor confirming my infertility diagnosis, I was shattered, and heartbroken because I felt, less than a woman. As I could not feel one of the many responsibilities of a woman, that is to procreate naturally. I'm sorry. I cried every day until I seek therapy knowing you're infertile is traumatic and stressful.

So let us alleviate this trauma by peeling away the financial burden associated with infertility treatment. It is for this reason, I support this Bill to provide Medicaid coverage for infertility treatment. As I close, I plead you to see the benefits associated with passing this Bill. Infertility is painful enough. So lessen this pain through Medicare coverage for infertility is fundamental. Thank you for your time and consideration of this crucial matter.

SENATOR LESSER (9TH): Thank you so much for being here tonight and for telling your story.

DIANA DUPUY-FAUSTIN: Thank you.

SENATOR LESSER (9TH): And I'm sorry that you had to go through such a painful--

DIANA DUPUY-FAUSTIN: Thank you.
SENATOR LESSER (9TH): --experience, but I'm hoping that the strength that you've shown tonight helps other women, other families get access to what you would have benefited from. So, it's been really inspirational and thank you for being here.

DIANA DUPUY-FAUSTIN: Thank you.

SENATOR LESSER (9TH): Are there comments from members of the Committee? Representative Dathan.

REP. DATHAN (142ND): Just wanted to say thank you so much for waiting here all afternoon, all evening and sharing your story, it must be really difficult and my heart goes out to you. So, thank you.

DIANA DUPUY-FAUSTIN: Thank you.

REP. DATHAN (142ND): Thank you, Mr. Chairman.

DIANA DUPUY-FAUSTIN: Thank you. Good night.

SENATOR LESSER (9TH): Thank you. All right. So I got to check on Zoom. Anything. No, thank you so much for being here this evening. Okay. Next, we have Jordan Fairchild.

JORDAN FAIRCHILD: Good evening, Senator Lesser and members of the Human Services Committee going to try and keep it quick tonight because I'm feeling a little under the weather. My name is Jordan Fairchild. I am the Executive Director of Keep the Promise Coalition, a grassroots coalition of people with lived experience of mental distress, trauma, and psychiatric system involvement. We build community power as a means of promoting human rights, self-determination, and racial and social justice in Connecticut's mental health system. I am here today to testify in support of three Bills. SB 205, SB 306 and SB 314.

I'll start with 314. We support this Bill with the suggestions made by Health Equity Solutions.
Sheldon Toubman and Luis Luna a few minutes ago. On to 205 and 306, we also support these Bills. And you heard our board member Karen Healy talk a little bit earlier about how necessary it is. And how much of a welcome change it would be to not have to deal with income and asset limits for the MedConnect program. But also some of her anxieties around then, not being able to work for whatever reason. As often happens with these two programs, Husky C and MedConnect. There's sort of two sides of the same coin and those are not mutually exclusive.

People move between one and another depending on their ability to work as people with disabilities often become unable to work. So really, urge passage of 205, but also 306 to make sure that people who have worked hard to save up money, grow financially, can actually maintain those assets when they need to move on, and no longer work and move on to Husky C.

Also just going to echo what a lot of other folks have said about 306, that it's great that this is happening. But five years from now is five years too long. Really should do this right now, not phased out. This Bill is an effort to end discrimination and we can't end discrimination in a phased out way. We have to end it once and for all. So I think everyone else today has already said a lot. I don't have too much else to add. So, thank you for the opportunity to testify today.

SENATOR LESSER (9TH): Thank you so much, Jordan for your testimony. Any questions from members of the Committee? Seeing none. Thank you. Have a good evening and appreciate your testimony and your connection of those two programs in particular.

JORDAN FAIRCHILD: Thank you.

SENATOR LESSER (9TH): Last up on our list of people signed up to testify is Doctor Ellie Proussaloglou. I hope I did that justice.
DR. ELLIE PROUSSALOGLOU: That was pretty good.

SENATOR LESHER (9TH): All right. You're up.

DR. ELLIE PROUSSALOGLOU: Wonderful. Thank you so much. Senator Lesser, Representative Gilchrest, and the rest of the distinguished members of the Human Services Committee. My name is Doctor Ellie Proussaloglou. I'm an Assistant Professor of Breast Surgical Oncology at Yale University, the Director of Smilow Cancer Centers, High Risks Breast Program and a residency trained OBGYN.

I'm speaking today in strong support of raised House Bill 5240, an Act concerning Medicaid coverage for infertility treatment. As many advocates have already discussed today, the current laws in our State are exclusionary and disproportionately affect our neighbors of low income, as well as those of Black and Latinx race and ethnicity.

And ultimately narrowing this gap by allowing HUSKY coverage of infertility care is an issue of reproductive justice. I have been struck all day as I've had the hearing on sort of in the background between patients of how important and pivotal being a parent and grandparent is to both the advocates and the members of the Committee.

And this Bill is a necessary first step towards having equitable access for parenthood for all members and all residents of the State of Connecticut. Diana, thank you, especially for your recent honest and vulnerable testimony. I have committed my medical training and career to the care of patients with breast cancer and those at high risk of developing malignancy.

We treat these patients with a combination of surgery, radiation, chemotherapy, and anti-estrogen therapy. And when we think about infertility care, it's extremely important to understand that
oncofertility care or patients who have cancer, who are at risk of losing their fertility are a very important patient population to consider.

These patients often go into early menopause and their future fertility is often compromised or by the time their cancer treatment is over, age related fertility decline has impacted their ability to have a family. For these patients, infertility coverage is not a luxury. It's not a choice. It's a medical necessity and a human, right.

As we know in Connecticut, our patients with private insurance fortunately have coverage of this. But for our patients with Husky, I as a provider, see firsthand daily, how this inequity causes them to make an impossible choice between choosing their recommended time sensitive cancer treatment or trying to build a family.

And so today being respectful of time, I'll share just two brief patient vignettes that I think really highlight this issue. I have two young patients in their mid twenties, both with breast cancer. I'll call them Sarah and Tanya. Sarah carries a high risk gene variant, increasing her lifetime risk of breast and ovarian cancer to greater than 40 to 60%.

She saw me for a high risk visit unpartnered, recently out of a bad relationship, hoping to move and start a family in the future. Recently was kicked off of her father's health insurance due to aging out and is now on Medicaid. Within a week, she had an aggressive cancer diagnosis due to a palpable mass, and had three weeks to protect her chance of becoming a mother.

She had lost her own mother to metastatic breast cancer when she herself was three and her mother was in her mid thirties. She then had the potential of retrieving eggs and an $11,500 bill, most of which she put on her credit card. She saw me the week later before she started her chemotherapy and told
me she wasn't sure if those eggs that she now had on ice were worth it because she didn't know how she was going to pay that bill.

Tanya is newly married and she and her husband were trying to conceive when her OBGYN felt a large mass in her breast. They both hold regular jobs, are taxpayers have lived in Connecticut their whole life and they just happened to have Medicaid due to the amount of income they make, they tried to fund her egg retrieval on GoFundMe.

And we're told that that could actually threaten their eligibility for the lifesaving insurance that they have through Medicaid by putting them over the income cap. So they ultimately face an impossible trade off. Do they use the support of their community to pay for fertility which is so important to them, or do they risk losing coverage for her necessary chemotherapy to help save her life?

Thankfully, through the dedication of two full time social workers at one of our sites, they were able to obtain grant funding, but it took two people with significant training and a full week of work to make that happen for Tanya.

And for most patients, it does not happen. Patients should never have to choose between treating their cancer and having a family. Their days should not be spent before chemotherapy, searching for grants, or begging loved ones for a loan for a future potential. Our patients with Medicaid deserve the same insurance protections as those in our State with private insurance. Thank you so much for your interest, attention to both me and the entire group here and I'd welcome any questions.

SENATOR LESSER (9TH): Thank you doctor for your testimony and for your advocacy on behalf of your patients. I know a little bit about the oncofertility coverage in Connecticut because a few years ago, I was approached by a young single mom,
named Melissa Thompson battling metastatic breast cancer. And, together we were able to write Melissa's law which provides coverage for fully insured folks, but that coverage at this point does not extend to Medicaid families.

The other question I would have, I don't know if you've, I mean, I guess I shouldn't really ask you about the law more about your patients. But one issue that I could foresee is that a lot of the protections we have for insured folks are covered through an insurance department bulletin.

There's not really, there's a law on it, but there's a lot of guidance that the Connecticut Insurance Department has given to make sure that insurance companies are covering the service that hasn't, it's not clear to me how we would copy that for Medicaid.

So, actually making sure that we're not just copying, this Bill that we're looking at will copy the law but making sure that we get the full gamut of protections for Medicaid clients seeking coverage, I think is really important.

So I guess that's less for you than maybe for some of my colleagues, but I hope we can get, we can get there and make sure that, that protection goes to Sarah and Tanya and to your other patients.

DR. ELLIE PROUSSALOGLOU: Wonderful. Thank you. It's a very important comment and of course, this is a complex decision. But ultimately, at the end of the day, I think whatever we can do to take steps to care for these patients and protect, a really important aspect of their lives. But thank you for your comment.

SENATOR LESSER (9TH): Thank you for being with us and other questions or comments from members of the Committee? Seeing none, I think that brings us to a close this evening and I will thank all of the folks for testifying today. We had heard from 100
different people testifying. And I also want to thank the members of the Committee for sticking with us through a long day.

So with that, we'll bring the -- oh, I guess I should also announce that we're going to be holding our next public hearing on Tuesday at 11, in room 1E, and also online and I wish everyone a wonderful weekend, and we'll see you next week.