

Indiana Statewide independent Living Council
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Remote CART

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>> Check one two, check one two three four. Hey check one two, three four.
Indiana Statewide Independent Living Council.

Please stand by. The program will begin shortly.

>> Check one, two, three, four, five, six, seven eight. This is one of the handheld mics, check one two.

Are you able to hear me in Zoom? Check one, two, three, four, five, six.

>> Okay. Let me test the podium mic.

Indiana Statewide Independent Living Council

Please stand by. The program will begin shortly.

>> Hey, good afternoon everyone. We're going to get started with our presentation today. First I would like to welcome you guys to INSILC's town hall for South Bend. I'll like to introduce myself first. My name is Mike Foddrill. I'm the executive director of the Indiana Statewide Independent Living Council. Been there for about a year. A little over that now. Thrilled to be here in South Bend with you guys today. Let me tell you guys a little bit about who we are. We're the Indiana Statewide Independent Living Council. We're part of the independent living network and with us in the independent living network be the centers for independent living and/or partners at the state of Indiana and together we all work to benefit people with disabilities. And our role is to help bring the rest of the network and our friends at the state together to work on statewide issues that require a statewide effort to make a change and make an impact.

And one of the ways that we do that is by putting together a strategic plan that addresses those concerns. We do that every three years. We call that the SPIL and don't worry there will be a quiz on all the acronyms at the eastbound end. But we have a three year plan that goes through 2027 and one of the main goals is for us to hear from unserved and under served parts of the state where we currently could not have a member of the independent living network and South Bend happens to be one of those areas.

So we are here today to hear from you guys on a variety of important issues that we think affect people with disabilities. We had a virtual in March -- [muffled] -- and we will have another virtual forum in the December of this year and more dates to announce 2026 later and the purpose of our town hall today is really to accomplish two things

One is for people with disabilities and their families and people who care about them, about issues that are going on in their community have a chance to have a real dialogue with people and ask questions and build that sense of community in South Bend. So that's the first part of our event today.

The second piece is more related to our strategy plan so for that we're going to have round tables over there on five target subject areas that we think are going to impact the community and those areas are transportation, employment, guardianship and alternatives, healthcare and emergency preparedness and so we invite you guys to stay after the speakers today, and we'll share more information on how to do that later on. We're making every effort to make this event as accessible as possible so we have our ASL interpreters, if you need them, we have CART services available. We have a QR code if you need to access that, so let one of us know and we'll make sure you get that.

I would like to thank a few folks for making today possible. Senator David Niezgodski. Representative Maureen Bauer and mayor James Mueller will be with us later today in our program and so a very big thank you so them.

I would like to thank our facilitators, who will be facilitating our round tables later. Our exhibitors who are here to share information about community resources for you

and our SPIL and marketing committees for helping us put this together and lastly our operations manager, Katie Myers for being the point person, 'cause without her efforts we wouldn't be here today. So thank you Katie. Yeah, that's right, give her big hand. She deserves. Lastly, I'd like to turn it over to Cathy Heys. She's been a fantastic partner for us. She -- I think of her as a jack of all trades, like a Swiss army knife because she has about every skill in the book. She's one of the first people that I call, because she probably can do it or knows somebody who can and one of the things is helping us to moderate these discussions, she's great at helping facilitate these conversations, letting you guys have input from the public and keeping the conversation going so I'm thrilled that she is able to be here with us today so with that I'm going to turn it over to her and let her get started with the policy maker Q&A.

>> Good afternoon, everyone. How's it going? Good. Well today, as Mike said is all about you all. It's really a town hall and -- let me put this down here -- so we have some guests today and I have an opportunity to introduce them and then we're going to hear from them for a few minutes and then it's really all about you. So we want to get to your questions. I have a roving mic that I will bring around, so if you have a question, let me know. Wave me down. We'll be looking for you.

So first up, somebody senator David Niezgodski -- did I do it? Good. I wrote it down. So state senator David Niezgodski was elected today to serve Indiana's tenth Senate district in November 2016 after serving a decade in the Indiana House of Representatives. Before serving in the general assembly, Niezgodski held several positions at the local level such as a member of Portage township advisory board, the St. Joe county council and as county commissioner. He was a board member for the transportation district for eight years and served as chair for seven of those years from 2000 to 2006. He is -- [muffled] -- plumbing heating and cooling contractors and former president of the St. Joe MHPCC. He has been active in the plumbing industry and former president of the South Bend achievement forum. Okay. So we welcome you today and I'm going to give representative Bauer's bio and they be we'll dive it and.

State Representative Maureen Bauer born and raised in the same South Bend community she lives in today. A graduate of John Adams high school and Purdue University in Indianapolis. She is committed today supporting public school teachers and students. She is currently serving on the South Bend advisory board. Her legislative work at the Indiana House of Representatives, includes serving as a member of the environmental affairs committee, judicial contrary committee and public health committee. In her second term, she successfully offered three pieces of bipartisan legislation that were signed into law. One, creates a pilot program under the Indiana Department of Homeland Security to monitor polyfluorinated substances, you guys are getting me today, in the blood of a thousand former and current firefighters.

She has worked in small vineyards and sell letters in the Lake Michigan area including the only vineyard in South Bend. She has been working with small vineyards and grape growers. She is a member of the world caucus and cochair of the I object Indiana assemblies future caucus. Serves as member of the corn marketing council and was a -- Maureen was the 2022 and 24 Indiana state lead of the national conference of environmental legislators and received the environmental activism award so let's welcome our speakers.

So I will first turn it over to Senator Niezgodski to talk a little bit to us for maybe ten minutes and we'll give the same courtesy to the representative and then we'll get rolling on questions.

>> DAVID NIEZGODSKI: Thank you everyone for the opportunity to be here today. I'm

probably not going to take ten minutes for the introduction. Did you want me to go up there or -- okay, okay.

Well, I'm very honored to be here today. Alongside representative Bauer and every one of you that are here today. I want to thank INSILC for hosting the support and discussion and the critical work you do every day to advance disability rights for independent living here in Indiana.

As a law maker I've long believed that policy making must start with listening specifically to the most impacted by its decisions that we make. That's especially true when it comes to ensuring accessible, dignity for all abouts living with disabilities. Whether we're talking about transportation or housing or employment, these are building blocks of independence and quality of life.

I've supported legislation that strengthens -- for those managing chronic conditions. With you I also recognize the challenges ahead. Especially as federal and state policies have reduced funding and very possibly services to so many families that rely on them.

That's why I'm looking very forward to today's discussion. I hope we can dig in on how to create systems on how to work with people living with disabilities, not around them and see how we can do more to remove barriers and expand opportunity for all Hoosiers. I look forward to today's discussion.

>> REPRESENTATIVE BAUER: Thank you all. Thank you again for the invitation to be here. As state legislator, I believe that one of the most important and powerful ways that we can advance disability rights is by ensuring that the people with disabilities are not only consulted but are leading the way on the policies that affect your own lives. We need people with disabilities shaping healthcare policy from the start. That means more than checking a box. It means real inclusion. The phrase nothing about us without us means centering lived experiences in every step of decision making so that includes funding, disabilities advisory councils, enforcing ADA compliance and digital health services and ensuring that disabled individuals are part of policy design, not just consulted after the fact.

So this past legislative session, we made some important progress at the state house. I was proud to coauthor house bill 1474, the FSSA matters bill which does impose oversight of Medicaid services. It ensures that payments for attendant care through HCBS waivers and training for our direct support workforce.

We also passed legislation which expanded the role of Indiana's disability ombudsman and requires annual reporting on access so families and advocates have the information that need.

Launched through Medicaid diversion pilot focused on home motor vehicles and telehealth to help more people stay out of institutional care. So these policies reflect a simple principle. Care should be -- should meet the people where they are. In their homes, in their communities, and with dignity. And while this progress matters, you know that there is a lot more work to be done so I look forward to having this conversation with you all here today and answering your questions.

>> Is this on? Okay. Great. I'll get us started. First question I know that is of interest to everybody here. How should constituents respond to proposed Medicaid cuts.

>> DAVID NIEZGODSKI: I think that those within INSILC and those with disabilities, right now for everyone in this room, this has got to be extremely scary for everyone. How should we react? Um, you know, the thing is, so there is Senate bill two that came out of the Indiana -- or Senate enrolled act two now and house resolution one combined. And even though we know a lot of aspects that are in them, we haven't seen or really felt them yet. To my knowledge, I haven't heard phone calls

coming in saying what the great damage is doing. What I can tell you is the number one that I think we have to do -- I've got a lot of different things I put together here, but it's just reality. That's where we're at right thousand and we're all trying to face that together. One of the first things that we can do is reach out to Representative Bauer and I, by FSA is going to play a critical role in this and I hope they're up to it. Because you're going to have to check with them. You're going to have to make sure that you've got everything done correctly and you're going to have to check with them several times during the year.

And if there are any problems at all connecting or speaking with someone from FSSA to try to help you, you have to reach out to us, other legislators, but do not take no for an answer. There are gonna be some things that probably will become navigable, but what we don't know is, there's just a lot of fear right now and you know, I refuse to allow my succumb to fear and you should not either. What we have to do is all work together. We have to form -- continue to be within our coalitions and we're gonna have to find our way through this and we're gonna have to emerge on the right side of it.

>> Thank you. Representative Bauer?

>> REPRESENTATIVE BAUER: Just as -- hello. I don't know if she has a question or not, but just as Senate bill two went into effect July 1 so we will be seeing some of the impacts of the changes to Medicaid before the rest of the country does with the passage of HR1. Those are the work requirements. Those are the proof of the exemptions that were created, about eight exemptions to the work of volunteer requirement. So what we always encourage is your advocacy, you know, there are barrier to providing that, we don't allow virtual testimony. You do have to go in person in Indianapolis, but you can write a letter to your senator or representative. We take those into consideration whenever we're making a vote, but with FSSA, they're examining to be making changes to that home community paced vendor waiver soon. I think it's open now to give comment so we encourage your lived experiences, whether you're a caretaker or you have a story to share, that is incredibly powerful. Don't underestimate your voice and these budget decisions can be reversed. We've seen it where there is loud community out cry and maybe they don't know what -- I like to think maybe they don't know what they're doing when they make a policy change that will impact the people that they're serving

So you though, when we saw expansion of Medicaid, we saw expansion of benefits and so when we see this taking away, it takes away some of your autonomy and that's something we need to make sure we get that message across to the policy makers.

>> DAVID NIEZGODSKI: I think I would like to add part two and it's kind of what I said. What we don't know, there are parts of Senate bill two that, even though they're enacted prior to house resolution 1, they called for requirements that had to wait for that bill to be passed. And yes, they went into effect on July 1, but just can't use that name, so we'll keep on saying house resolution one. House resolution one doesn't go into effect until 2027, so there are parts of Senate bill 2 that they're gonna have to get approval from to go ahead with because so far, Washington still pays a bulk of that. So that's the part that is gonna be very, very interesting, first of all for FSSA to already be on board on July 1 with all of the changes, that seems very difficult to me and just knowing like some of these work requirements, it's -- we're gonna find -- [muffled] -- day to day. I have put together one sheet of the basic things that it does, but that sheet only says what those things are supposed to happen. I'm not saying that they're not gonna happen. You know, that's -- again, that's our greatest fear, but the point is, until they do, we don't know how exactly to react to them. So 2027 with the Washington bill and some of these

have to have approval from Washington to -- and get paid for or, you know, that's unknown yet right now.

>> Gonna be very important for all of us to realize that there are groups in this state that right now are actively working on the Medicaid issue. We have -- there is a group called the nonviolent Medicaid army that's doing a lot of work with that. I'm involved and another person here with us is involved in Hoosier action, which is basically, we meet with the chief deputy for -- [muffled] -- and the interesting thing about Indiana is robe wants to go farther than the cuts that are happening at the -- he's all about finance. So I -- I made very clear to them when we had our last meeting with him, which was just a couple of weeks ago, is the problem is not necessarily waste and abuse of people. It's waste and abuse of FSSA. They're inefficient. They -- their vendors don't know what they're doing. They don't know what they're doing. We're having people call us about -- that they get information from FSSA. They have all these -- all these -- they've out sourced all of this, you know, Medicaid information where nobody knows what anybody else is doing. It's a disaster. Just like pathways was a disaster when it just got thrown on the table to people and, you know, these -- you might think everything's gonna be fine because of what you did, but if Indiana toss not wake up, if you people could not wake up, home -- home healthcare people being able to stay in their own holes, home and community based services are going to take a very direct hit. And people are going to have -- people that are in nursing homes or whatever are gonna be homeless because they have nowhere to go because they're shutting down. There's hospitals all over this state, 12 of them, that are on the chopping block. Where are they at? Rural areas, where you're going to have people with emergency needs that are going to have to go 50 miles and they're gonna be dead before they get there, so, you know, wake up people. Actually, there is gonna be an action, there is a national day of action is on July 26 and there is a group in South Bend. I'm trying to get the information from Hoosier action to call me back or who the group is here, actually having an action here in South Bend. So that he's kind of exciting, so if anybody knows who that group is, be sure and shout it out to people. Because we have to wake up. We can't wait for the legislature to do something. We're gonna be -- we got to take action now.

>> DAVID NIEZGODSKI: I appreciate your comments very much and I thank you. And I agree with you. You know, that's part of it. Bringing these events or precincting that -- the bill in Washington on 2027, here's what our greatest hope has to be, is that people, um, they've already, uh, had their fill and they're realizing why they are not putting it into action until January 2027. So but we have to, uh -- it's not a -- it's past wake up time, but we just have to engage and it does have to be in a way that it's -- it just involves people's lives and that's what matters right now.

>> REPRESENTATIVE BAUER: I'm just curious also how the information today, where today's meeting was disseminated, as well and how other information is disseminated. I'm not only a parent of a now adult, but I'm also a provider. We just received information this morning approximate this particular meeting, so you can -- you know, we got it out to parents as quickly, obviously, as we could. But I also know like for a lot of the FSSA meetings we're a for gotten entity up here in South Bend so they think just come to Indianapolis, I'm like are you kidding me? We have parents and individuals with disabilities, that's not always available and secondly, when they do put our information and we is it call them on it in the meeting last week, they somehow miss inform the dates and times and they change them three or four times so we asked them, are you doing this purposely pause we can't get this out quick enough to families to make sure that they attend because I know we had several families that would like to attend today, but for last minute reasons or whatever the case may be, but I know FSSA

is doing that quite often as well, so.

>> I'm going to ask Katie to respond to that from the organization.

>> The first question that you asked is how do we promote this event. So we relied on some other local partners like the South Bend vet center and the ARC and in source which are some organizations that are located up here. Part of the challenge of posting this event today is that we don't have a representative of the center for independent living in this region, so we don't have a lot of resources to -- we don't have a lot of resources at the moment, so we are currently in the process of building our presence in this area so that we can host more events in this area that are not located in the center of the state. So I can't speak to any of the FSSA issues, but we are making a concerted effort to be more present in the South Bend area specifically because it doesn't already have a lot of resources for it.

>> Katie, can we add them to the mailing lists or --

>> Let's connect afterwards.

>> Okay. Yeah. Great. I think we had a question here.

>> The only other comment I would make to that would just be that when they're making these decisions, there is comment period, but you can also submit a written comment and they put the address on that website, as well so you can submit something which mail or even e-mail, so like for the home based community service waiver that's going on now and we can share that information with you, too, I -- I don't know if your organization is a member of the ARC, but they have a great presence at the state house during legislative session and they might provide additional resources like that for their members. It's just something I can't I can't quite detail, but that might be a route to connect with the ARC as well, because they have a good presence and good relationship with law makers.

>> Yes. I have a question for the two, um, um, speakers, thank you. Yes, as a community we need to start to do our own thing and make our voices heard, but what are you guys going to -- what are you guys doing to combat some of what's going on? Because the perception is, is that it's marquis of Queensbury rules over here and the other side is knife fighting because they're blatantly ignores, especially on the -- particularly on the national level, the constitution and I just -- the perception is that nothing is happening, that there hasn't been a concerted effort to stop that and it feels almost funereal, frankly, it's pretty infrequent to me, that's my perception and if I'm wrong fair enough, but I want to be what actions are taking place in the legislature -- legislation to try to stall or out right -- [muffled] -- or sabotage this nonsense that's going on, thank you.

>> DAVID NIEZGODSKI: I guess the beginning of my response is that the things you're feeling are, um, I think -- I can't believe that everyone is not feeling these things. It does seem that there are a lot of deaf ears right now. I got to be honest. I've never been personally an advocate of pounding your chest and going out in the streets and yelling about it. Because that just seems to be turned against you and they're just a bunch of people that, you know, have way too many things you're yelling about.

You know, I'll tell you what. There's -- I've been in the state house 19 years thousand and I was in -- the majority for the first four years and seriously, all through the way I've never tried to approach things from that stand and I've taken some very, very hard stands throughout my time, but I mean, what we have to do is continue to advocate. We've got to be -- we have to be intelligent. We got to tell the truth. It's going to be some of the hardest things of our lives pause we -- we can't go back and just keep pointing fingers because that just turns around and they do the same thing, so what I'm saying is that you know, it's time to stop looking at doing those things and it's

time for people to feel about people. And the lot of these representatives, legislators, that's what I was going to start to say earlier, they live in their own home towns and time and time again, they will still be certain things that will happen that seem like how -- how could that happen. This one here, I -- I think is gonna have -- these things are gonna have real consequence and I just don't know how some of them are gonna go forward, because for me, I'll tell you what, this is a time when you talk about these profiles of courage.

I don't care about if I am to be reelected again and you know what, but there are some that probably do. And they better start thinking about it if they truly want to be of service to the people, they're going to have to think about these things, because this is the -- this is some of the worst, uh, type of legislation that we have seen in all of our lives. And we all know it and it's just beginning to materialize, so, you know, we have to continue to advocate. We have to continue to form groups and we have to say no. This -- you -- this is not right. I -- I don't -- I don't have a better idea than that because it's talking to the people. It's being people, being real.

>> REPRESENTATIVE BAUER: Yeah and as you probably are familiar, our general assembly meets part time so we adjourned in April and we don't go back until January to make new laws, that's why we're attempting to emphasize why it's fortunate submit public comment when FSSA is determining new rules for these waivers, which we have a new governor administration. We are reevaluating and making their cuts and this is where you speak up and say this is necessary.

And now we are here in the community and we're trying to help educate others and we encourage you all to talk to each other and educate others. If this room was packed full, I would say we are to go a good job, but continue to talk to your neighbors, your church groups, local governments, because they're going to be hurting and they can respond quickly.

In regards to Congress and what they're doing, they're now looking at amendments to HR1 because they are hearing some feedback from their districts. They have rallies here in St. Joseph county where they are trying to be heard so you can contact your Congress members or US representatives and senators and share your story and why this is going to be personally impacting you.

But also, you know, we encourage you not to stay silent because there is going to have a ripple effect on the entire community. We are talking about the hospitals that will close, even here in St. Joseph county, we could lose specialists, OB's care is the first thing always on the chopping block, so this impacts everyone's access to healthcare. So that's most concerning to me is I don't believe it is a really thought out plan, this policy and so if we continue to raise our voices and speak up and comment when able, that is the best way to reverse this policy change.

>> Hi. Um, I'm here today speaking on behalf of Indiana National Organization for Women. Two of our pillars have to do with ending -- [muffled] -- in this particular climate we're facing here in Indiana, we have right now exactly one stand alone Rape Crisis Center for the entire state and it's faith based. Our domestic violence shelters are at 110 percent capacity. The hot lines are running -- they cannot keep enough volunteers and paid staff to keep the hotlines going on domestic violence. Indiana is -- I think we're 13th in the state -- I can't remember exactly -- for domestic and intimate partner violence. I talked to my local chapter leaders and they tell me that across the board in every single community, women are very, very scared, especially women with disabilities, and what do I, as the president of Indiana now, tell them that we can do today tomorrow, in order to help protect women with disabilities from harassment network force, from domestic violence, intimate partner violence, sexual assault,

because we all know the more intersections you put on when you -- when you add women, women with disabilities, women of color with disabilities, that we become more and more vulnerable and there are fewer and fewer resources for you.

>> Well, this session we did pass legislation to address our backlog of rape kits. Unfortunately there was no funding for that. It was not a priority when this came town to the short fall that we're facing due to the federal tariffs that impact a state like Indiana, which is largely a manufacturing state.

Now, they did set up the mechanism to fund it, so if we get a rosier picture of Indiana's budge goat, neighbor will come through, but I'm sure they're worried about budge cuts and there are -- they're on pins and needles whether they're going to get their grant. These are real fierce. It is what is happening and I work closely with organization that helps victims of sexual assault and violence and we have worked on policy and we will continue to work on policy neck year and we're come you go up with strategies and ideas. It also comes from using the laws we have in place now, making sure they're being followed. When you talk about workplace accommodations, making sure every individual is educated about their rights. I think back to my first time in office, we were trying to press pregnancy -- [muffled] -- the backlash from people saying I cannot afford my employee to sit in a chair while she's at work while she's pregnant which seems laughable, because she should stay network force even if she is pregnant. She should be going to all her doctor's appointment, making sure ADA compliance is followed, so having those checks at workplaces are important. Making sure law enforcement knows where to turn in those emergency crisis situations. In St. Joseph county we have a crisis intervention team that shows up with social workers, um, I hope that stays funded, as well, but what we can do is create these tools and these pathways with local government and law enforcement and you know the people who are responding to these emergency swayings, like the people who see it every day. I motivated off of law that passed in Florida, but gabby Petito, who was murdered by her boyfriend in Nevada, I introduced legislation to expand our Dale, when a officer responds to a domestic violence situation, whether she needs to be removed or that person needs to be removed or taken to a shelter, but in fact it was Indiana -- [muffled] -- said I shouldn't go forward with that law, because not every community has a shelter. If you can't remove her from that swaying, what's the liability. I'm going to empower or law enforcement officers to know where they can send individuals and we have to empower and educate one another. We passed a piece of legislation which is called rain drops rising, raising awareness about human trafficking. We have a problem with that. Empowering these individuals in these positions of vulnerability, that when they are able to seek care, they have all the tools and they're prepared to find that help.

>> DAVID NIEZGODSKI: I think, representative, you handled that pretty well. We simply need to continue to speak to the power. I don't really think they truly know, they may think they know and they may say we had no other choice, we had to make shes cuts, but this is impacting the lives of women and those disabled and having the feeling of nowhere to go or no one they can go to.

That -- that's, I guess the one thing is we can't allow you or people that are -- feel that to become withdrawn. They have to continue to reach out. We have to reach out. We're gonna have to do a lot more within our local community because they cut health funding, uh, mental health funding was cut and there are gonna be so many ramifications. I -- I -- they're not just gonna be able to say, ordinary care, that -- all these things were necessary and see they're working. They're not going to be able to scoff off people. But people come together and people have within feeling hurt and afraid for

a long time now, but some of these things that if they really start to take hold, the impact is gonna be so great, you though, I -- I hope that there's gonna be regret with the things that have taken place.

>> I'm sorry. Could you repeat that we have --

>> Ordinary care. Yeah. No, I was just saying that so many of our counties that actually have domestic violence shelters, when a large portion of them don't. The ones that to are not necessarily ADA compliant. They cannot take women with disabilities. They can not take women with children with disabilities, so they say families are trapped. They literally have absolutely though where to go until they go to a cemetery and that cannot stand, absolutely not.

>> Really, I just wanted to make a comment and speak to a point that David had made earlier about a lot of people yelling about a lot of different things. Maybe people are yelling about a lot of different things because a lot of different things are wrong and there is a quote from Fredrick Douglas, I'm not sure if you guys are familiar, but power concedes nothing without demand. It never has, it never will, so how will people know that we are unhappy unless we tell them. Unless we show them what at effect has been on you. Thank you.

>> I just meant don't do things that might endanger you. That's -- thank you.

>> No. My comment is to you, as well, because you made a comment you've never been one to go out in the street and bang your chest, but without people to go that, the 504 would never been passed, ADA would never have been passed. So that's what my comment is.

>> You know what, thank you very much 'cause I guess I shouldn't have said it quite that way because truthfully, there are few things that I did exactly in that way at certain times. Going back right after we came out of the majority and went into minute north and right though work. I did something that probably could have -- that's why I was referring. I is it something that maybe could have had further ramifications. In the constitution I'm not examining to repeat the words exactly, but it states something like the doors of the chamber shall remain open for all manner of depate. Well I chose to, at one point in the third reading of ride to work hearings, since they have speakers and everything today, I go that maybe doesn't apply when you're standing in the hall, but I chose to open the back coarse of that chamber and there was a couple thousand people on the outside and I never moved during probably an hour and a half of can he pate, but I never thought approximate the ramifications of something much worse would have taken place, so I stood there and allowed people to have their voices heard and they were very, very loud. You couldn't hear any debate on that chamber floor and I stood there, I had my foot wedged in that door with about 15 capital at a time police standing around me, but I don't want people to endanger themselves, so I truly did mean that.

>> Hello senator and representative. Thank you for your time. My name is Cody. I'm talking to you as a call to action. I'm certified therapeutic recreational specialist. I'm advocating and deeply concerned about the recent proposed amendment to the Medicaid state waiver. The ability to access for the services we feel are being cut and capped at six hours for the proposed year. This proposal would equate to about forty-five-minute sessions or one and a half hour every other week making it impossible for community outings and social skills development. These changes are more than a policy shift. They are a personal violation of the HCBS setting rule, that would be the home and community paced service setting, reinforcing an individual's right to make choices about the services they receive, including where, how and when they spend their time. This is to ensure members who have disability have full access to -- directly

under might be the spirit of this rule. By restricting choice, limiting service hours and posing systemic barriers that arose, especially with those who depend on it.

Senator, I know you have been an ally to SB 363 and SB 388, and we are once again calling upon you to stand up for those without a voice. Without professional outside providers like recreational therapists, checking in consistently, they increase the risk of exploitation, abuse and neglect.

The last question that I would have would be if those funds would not be used for Rick racial therapy, where would the state propose that money go elsewhere? Thank you very much for your time.

>> I'm not exactly sure I can respond. I'm not exactly sure if you were asking me for a response. You were just stating, I will be there again. I will continue to advocate. I don't -- some of the words that we heard were this was right sizing. This doesn't fit. That doesn't work. That is not good enough. I did not support the -- the legislation that is changing that and I can't -- I know families myself that are gonna be impacted. I also know families that, God forbid, they may lose their loved ones because they're not able to give the proper time and -- and we will continue to advocate. We need your help and your voices and we do need the strength of your voices to be able to change what we're able to do in the state house working with ten out of 40 in the Senate and working with 30 out of -- out of a hundred in the -- in the house is difficult and I am not leaning on that. We're gonna get things done because people are gonna know and they're gonna realize they ask something detrimentally wrong and that is something we have to make sure our voices tell them.

>> And if I could just add, I hope you submit that statement to the state agency to FSA much A, the comment period opened on the ninth and I think we could also add our voices and write a letter to FSA and we both support the services that you provide much we believe that there should be options. We support opportunities for people to age in home or seek care in home versus what the bias has been, pushing people towards some assisted services or where they don't have those services available. So as we said, this is a new governor's administration, so it's a result of elections, right? And that money that they cut will probably be put in the pocket to build up their rainy day fund because they love to sit upon a nice padded chair of cash, but that's the reality of where we are is the difference in governing right now, where they're cutting services where they don't get a lot of push back, which is why it is important to make your voices heard, not just your personal stories, but from those individuals who **rick** in these fields and have the real life storytelling that they can share the experiences with people.

>> I don't know if we're going to get to this part in the program, and it's totally different, it's under trans pouring, but a very, very similar answer applies. If we're trying to figure out how to have better routes and more efficient routes with rider ship here locally on trans 0. To your best to ride public trans pouring. Make public comments. So that's part of it, too. And they are hoping that maybe people aren't going to continue to call in or leave comments. Inundate them with comments. Inundate them with how you feel about this. They can't ignore that. They can say, this is with a we brought -- that can be dug into deeper and so we cannot stop. Our comments have to continue.

>> Thank you. We do have multiple town halls that will be going. Go to my voice, my T.com, they're all on there.

>> Kind of building off what Cody was saying but also that comment earlier about so many different that I think so many people are yelling about. I would ask that you look at each one of those things and ask the question of how does this affect people with disabilities? We are the most cross demographic minority, the largest minority when you look at each -- instead of looking at each individual disability, you look at us as

people and a culture and when you look at each of those things, each one is an attack in one or another on the disability community. All of these things go toward people with disabilities losing independence, losing community based services, being pushed into institutions that no longer exist in Indiana, and ultimately, county hospitals losing the ability to support the people that are coming in. They get more and more folks coming in. This is where you have to look at each individual one of those things and treat them as one big thing because it all has been a systematic attack against this community since the beginning of these current administrations. From the very first DEI executive orders, whether we're talking about federal or state, you have government organizations, organizations that are there to serve people, who instead of doing that are going through their paperwork, removing the word belonging? This is not governance. You are our representatives and our senators, and you need to lead the charge within that house to make certain that the largest minority that is the most under rep becomes the loudest voice.

>> If I can just -- thank you for your comment and I guarantee you we voted against those piece he is of legislation that take away your autonomy and make cuts to healthcare and impact the disability community. What I wanted to say to the comment that Senator Niezgodski made is there are certain legislators who will not meet with constituents pause of how they speak or rally or use their voice, so from his experience in the legislature for a number of years, I have something hanging in my office that says do things in the way that get others to follow you, so that's a Ruth bader begins Berg quote, where some people are saying -- [muffled] -- he's not requesting to sit down and meet with you, so that was a piece of advice from someone who works with educators and can help you advocate.

>> So you've mention the public record, both of you. My question would be, how do you draw that public record out into the light before votes are cast.

>> Are you speaking to both Congress and the state legislature?

>> Sure. Whatever public record needs to be seen before votes are cast. How do we make certain that is in front of every voter before they cast their vote.

>> I can speak to my experience as state legislator. Like I mentioned, the ARC is a lobbying organization that **beats** legislators and brings their constituents and our constituents to sit down at a table face to face and have conversations with us.

We -- we stay educated and informed about what is happening in our community and we encourage you -- my phone is always open. I think there is a misconception that people think we have local offices. We only have offices at the state house where I have an individual who works there Monday through Friday. She takes phone calls appear e-mails. I do the same. I have coffee meetings if people request it. We are available. We come back to the community on the weekends when we are not in innap list. We immediate Monday through Thursday, January through March or January through April when it's a budget year. So we stay active attending events like this or other town halls or other neighborhood association meetings, we are the ones that are showing up and listening to the public and representing our community and how they're telling us to vote.

Thousand, I cannot tell you -- the best way to get a hold of your US senator or Congressman, because quite frankly, I don't know where they live, but they have to live in the state of Indiana. Some of them hold town halls -- they're advised not to, but they toad hold community office hours where you can meet with their local staffers, which again we don't have, but these opportunities at the state level to submit comment on these waivers are incredibly important because we are not in session. We don't have the vote right now. It is up to the directors of these state agencies who are going to be

making some serious determinations about your future and your health and we shall write letters, as well and we can talk to media, as well, but that also does fall on you to do, as well and yes, you can rally, but you to the to also be able to the one on one conferrings to get your point across and to be heard.

>> And to respond, a couple different directs. We do -- thank you. Again for this invitation, for this Taub hall we do have town halls, we have third houses throughout the legislative session. We sit on certain committees that, for -- how can we get this information out. I cannot answer Washington either, because sometimes -- I'm not just trying to use this as an opportunity bounce, you know, but reality, it does seem like they just -- just stay didn't exist or no. In committees, we continue to ask for when FSSA in front of us speaking, we continue to ask for the numbers for the publishing comments and that as a legislator, we're supposed to get that, if we don't, then we continue to ask. Going towards some of the things throughout the years. Just one, when most people -- there's nobody that never doesn't feel a little nervous, you know, even -- we're not seasoned professionals just pause we're legislators. There are times that, do you know, Winfield never -- or feel anxious inside when we're go to go go up, but when a member of the public is coming there for the first time, I've seen through the years, different ones that you can clearly see it's difficult on them, so people far and large, most legislators make time, they take the time, give that person time to testimony, but there have been a couple throughout my several years. One happened this last session. This young gentleman, he had been sitting in one of the front rows and I don't even think he really -- I think he wanted to testify toward the end. It was a very, very long testimony. It was probably close to like five hours worth of testimony and he actually almost got physically removed only because this -- he may have had some form of disability, I do not know, but he was so clearly nervous, he was shaking, so when they limited the testimony and shut the testimony down to further a minute, he **spork** up and started calling people and saying, hey, you only got this much time and someone didn't really prefer that. When that young man did get his chance to testify, I'll tell you what, in two minutes time I think he ripped out about 20 minutes worth of word and they were so intelligent and I just felt so good inside because owed his opportunity but to one should ever try to make someone feel like that, so I am one that, uh, those are the kind of things that make me really -- that's when I get free. Maybe it's the same, but I'm going to speak up. I'm not silent, I am not fog stand for that. So people that -- we all have to get involved. It is difficult. It's most difficult when someone has developmental disabilities, but make every effort for those that want to come and testify, it makes it harder, you know, but your testimony matters and your comments matter.

>> Yeah, one -- two thing I want to talk approximate. One of them is is that the FSA has pulled back on the idea of doing the around the at a time listing session on Medicaid because once they pass the great big beautiful bill, they think, ah-ha, I don't have to do it. I don't know how many Democrats you have in the house and Senate, but every one of you people call for -- Mitch **rube** in, you know, the governor saying you need he to make sure these people go around the state and listen to what's going on **bounce** of the thing we're doing with Hoosier action, is if they don't have a listing section, we're going to take it around the state because they need to listen to a people have to say, but they don't want to hear it because they know there's going to be -- they don't want to have the flak that they know they're gonna get.

The other thing is, our biggest problem, people sitting here that this disabilities, living with disabilities, he have day, 24/7, we do not have representation. Unfortunately, even this group does not really give our voice out. INSILC, when they talk about public comments, they put our names. They don't put one damn thing that we

said. Even though they're supposed to talk be about the comments of people across the state. This, if we don't have representatives, if we're not represented, we are going nowhere. And we are gonna be ran over. So you've got to -- you got a choice, you can either be on the track or on the train. I prefer to be on the train.

>> Hoosier action has called possible FSSA to do statewide tours? They have?

>> Yeah. We've had two meetings with the deputy director for Mitch robe and at the first meeting was before the big beautiful bill was passed and they were saying we're gonna do -- listing -- you know, they really going at it. The minute that bill was passed, this next session, we don't know if we're going to could at that or not, because Mitch is planning to take it farther than what the federal government has say. So he's going to save more money an he's -- he's requesting to save it on the back stuff? People like us.

>> But do you know if Hoosier action was publicly called on --

>> Ordinary care, yeah. Yeah.

>> Perfect. Thank you.

>> Yeah. [Laughing].

>> Hi. I came prepared. I'm sorry it might be a little long, but I first want to say thank you guys for meeting with everyone. I've been working with others to try to aid against the changes and getting in touch with anybody in house or Senate has been very difficult so thank you guys very much.

My name's Lowry. I'm soul guard I can't know to my procedure who has moderate intellectual disabilities and receives services including behavior management. I'm also -- one of the owners of recreation, the first and only female owned therapy company in Indiana. I come to advocate as their rights ever approximating threatened and their voices needs ton heard. I want to precinct a disability right dice your attention. Made changes to the waivers from an open budget model where families could **cost** does on to a bucket budget system, which limited the amount of money they can receive for day services of the incompetent ACLU, sued the state of Indiana for violating the right of -- only allowed for 12 hours of community inclusion. In 20 is, the court ruled in favor of the family stating that only 12 hours a week of community inclusion violated the law. Recreation therapy is the only service appear profession offered on the HCPS, where the practitioners have been educated and maintained in community inclusion. The proposed caps would limit the amount a person could use recognize therapy to 6,000 a month, which could equate to for an hour and a half -- once every other week. The at a time's idea is for families to replace with unskill cheaper, which was their words, services. These services include pack attendant cases and are currently available for individuals to use, but are not widely used due to grossly inadequate staff by limiting the services that do have available staffing for community inclusion and are well prepared to invite it, the state is forcing individuals who currently enter the community to one and a half hours twice a month. Individual are not being provided the opportunity for 12 hours a week of community inclusion **nand** new model. Individual we isolated and **retracts**ed to their homes. My question to you guys an maybe you won't be able to take place, but hopefully you can point us in a right direction. The FSSA has made it very clear, they do not want to listen to us. They don't want us to know what's going on, but advise for a council meeting was held without notification for anyone an then with the link taken town, we had to search for it again, with this president already set, arrest the state taken into consideration this president's and is it prepared to revisit the legal issue for community inclusion and the -- [muffled] -- sorry that was really long.

>> So what we're sharing today and the stories are over and over and over again and

that's why we have to continue to meet like this and our presence has to grow. But what we're sharing is our lives. We're sharing the things that are causing pain to us and pain to our families and you know what? I -- I think one way that would be helpful, we've got some members of media here and I think that's a very good thing. What's difficult is for someone to talk about their lives, the things that hurt most. That's one of the most sensitive things in a person's life when they're sharing their lives appear showing what they normally don't do. You're normally just trying to live your life, with resources you've been provided much so I would that as often as possible, that families people call the media. Have them come their door and say hello, say I'm speaking to you right now. I want you to see what my family is enduring and I want you to see that this -- this -- this was what we have to do with every day.

You know, I -- we have to come up with solutions. We can come up with solutions one at a time, but the media does respond and if they send your message directly to us and we do it over and over again, at that's not an easy thing much we don't want to -- we are out every day. We're living our lives, but we don't normally try to broadcast it, but that's the type of things that we're going to have to do and it's not just for those that is disabled, developmentally disabled. This is going to impact so many different people's lives, these are the things we have to do and things we can do sensibly to say you can't do this. Continue it to this and this is what you're gonna see, so that's just one suggestion from me and I think we may have some response from that.

>> And I will add, I have been in Indiana general assembly many years and there has been a piece of legislation that was found to be unconstitutional as a result of a lawsuit. Just every year, so I don't think they're worried about being sued, but I think pause of the press department that set, that is is a food guarantee for our protection and we shall continue to bring that to the attention of the public and the media. I might even encourage you to write a letter to your newspaper. These are the same strategies that we use to try build awareness within the public about legislation. I fasciate you may not know when we're passing a bill or the bills that we authored, but it is a struggle to get your voice heard. So to your question, I think they would be happy to if into other costly lawsuit, which is, you know, expensive for taxpayers, but I think fortunately, we might be protected because of that precedent that you mentioned.

>> Thank you.

>> Thanks. [Muffled] -- just a second. Just want to say thank you for everybody. We have about 15 minutes left. I know there's several people I'm keeping track of that have questions or comments but I wanted to give you a time check and I know we have some information to share too before we kind of take a break around 4:30.

>> The parent of a twenty years old autistic son and I signed him up for services and we were honestly on a waiting list so long that I forgot I even signed him up for anything. What procedures are in place for that? If any or what could be put in place so that people with disabilities aren't waiting so long and the services we got, it just seemed like so unfair, like I been trying to get him services and help, it just seemed so unfair much ordinary care well, I have to get a lawyer, but it seem like there are so many thing that are unfair. What can we do? What can we do?

>> Um, can I ask what services in particular -- or was it state services or something local.

>> State services much I just -- it just seems like we've not really gotten a lot of help into I'm sorry to ask questions and only share what you're willing to, but to help educate me of with a you were applying for an how long that took.

>> Well I'm just specifically, the Medicaid waiver, that took years and years. When we finally to the approve for it, I'm like I'm not even sure what you guys doing here any

more. One thing I wanted to mention is whether it comes to advocacy, we learned a lot, who was left out of vaccinations, who was for to the ten appear I think we can still learn interest that and we're still learning from at that.

During the Biden administration, they expanded the Medicaid enrollment and then instantly people were dropped and we had to help educate people with the you winds process and you might be kicked off your insurance and how that there interrupt your services that you're so acoupled, now we have these work and volunteer requirement, quarterly, check ins, so you can be -- almost four times a year because your paperwork was lost pit state agency or someone didn't return your phone call or all of this red tape and pure rock see. People don't smarter believe in, but here we are with a state agency now that is putting in more red tape, more bureaucracy, making it harder for you to access these services and we get these stories all the time.

And so I don't know if you live in my district, but if you're ever -- I always say if you're ever having difficulty getting services to write your legislator. I've helped people with BMV issues, I've helped people with age and disability waiver, with the pathways, and we often get a quicker response. I'll just tell you as the fact. When our name is CC'd on a e-mail, they get back to us quickly. So that's the best advice I can offer. You just like the justice system it moves at a very slow pace and that is very frustrating and I understand that you and your family are peaked more because of the condition that you are facing with the health of your son and those stories help us advocate for you and if you can write your legislator, they can always contact that state agency on your part of and see what they can do quicker.

>> It has become even more difficult with the administration hired -- administering these weight lists and when you see it portrayed in committee, they do it in a very formalized manner, but for -- that is, again, the thing why you do need to reach out to us much our offices are responsive. There is not -- there is not supposed to be a single e-mail or single call that goes unheard and we are -- we are that conduit, that doesn't mean every time I can -- we can open the door and now the response comes and you get the **Arne** you want, but you know what, they are expect today pick up that phone and they are expected to deal with this. So we're just going to have to -- I don't have the right answer for you, because they've made it for difficult and made it seem like all these changes are necessary, and it's all going to work out just fine, well we all know that it's.

>> Hey, quick question. How will the legislature provide oversight of the division of disability and eastbound day active services.

>> Say that again.

>> How will the legislature provide oversight of the division of disability and rehabilitate active services.

>> When we have someone that actually works outside the agency and they work together and they -- they are working to not fulfill the needs of that department. They're there to fulfill the needs of the people, and those are the things we have to lobby for more, we have that in some cases, but we need much more. We need to continue to file bills and -- and seek additional colleagues that are **campaign** join in. I don't know that we're gonna get -- I don't know what's gonna happen next year in the leg tour, with you I imagine we're going to have more legislators willing to come forward and say these are the things we need, because if they're going to deal out these kind of services, that's got to be a better response.

>> And this may not be specific to your question, but we also have in term summer study they have they have to conclude people October. So that's other opportunity for the legislature to hear from state agencies. We often don't hear from them. They can do things through executive order and **dipping** their own rules to an extent without the legislature. There's some boundaries that are set into place but there will be a Medicaid oversight summer study

committee. I will not personally be serving on that -- okay. Perfect. I would love, but senator Senator Niezgodski will be there, but that's another thing we can do to help you stay informed of not only listening, which will be live **trim** streamed online, but there's a public comment period at the end which would be a perfect opportunity for them to sell their stories. There might be a lot of people from the state agencies there, as well.

>> So uh, any disabled person, all we want in life is to be considered normal. Um, but we can't live a normal life if our resources are very small. Uh and the sad thing is, is, uh, uh, you guys like to tell us to call the office or make a comment online or something, and when we do that, nobody choose to listen to people like us.

>> That's not true. It seems that way, I know. I know, and I'm sorry that we have --

>> It is, though. It's not -- this public office, it -- it's out in public. You -- I -- I -- you -- you guys don't know how many times I'm talked over because people don't think I'm smart enough to hold a conversation. So it's up to you guys to put your best foot forward and to advocate for people with voices that don't necessarily get heard. When we can speak.

>> Thank you. What saddens me today is that the Representative Bauer and I are here and will continue to be here and we'll continue to advocate. It saddens me that we couldn't have a few more representatives here because they need to hear these things also. Look, this is a time of year, people are doing all kinds of things. They're -- people are vacationing and everything. There is -- I will never point my finger and say it's just -- sometimes it's the way of things, but we're listening, I assure you, we're listening to you and thank you.

>> Is it on? Remember I had said there's going to be a national day of action on the big beautiful bill here in South Bend in the person that's taking a lead on it is named Andre Stoner as we make Indiana. We make Indiana. That's the name of the organization. Nope. She just sent me we make Indiana, so that could be the organization is taking the lead on the South Bend national day of action.

The other thing I wanted to piggyback on is this gentleman over here. He is absolutely given a lot so we never see that come to fruition. And it's really -- people can go on vacation and do all had a kind of tough much it used to be -- 'cause at one point in time, I was actually the chairperson of this organization that put this on and I made a statement in a meeting, I said well, you know, at 5:00, a lot of you people can put this up and go home. At 5:00, I take this with me. I'm living this 24/7 and so is my family. So I have skin in the game, you do not. And the fact is is that's the people you have to listen to is the people that have skin in the game. An people wake up, we got to -- we can't accept that we're going to be quiet any longer because what have it takes, yell scream, whatever it takes, we're losing our rights and you know, our -- our governor is not helping anything with some of the, you know, **rear's** gonna get rid of DEI, firing people involved in DEI, ridiculous.

>> Okay. I think we have two more comments. We're really bumping up on time so I want to get those two in, okay? Go ahead.

>> So I had two questions and this is my mom here, so I've been active with her on the waiting list. I'm social worker myself and it is a little disheartening going into the realm of social work and not being able to help my own family because there are so many -- so little resources available. I'm wondering once the ports are in place or will be put in place for family that are navigating appeals to the new service model tells under their revised waiver and I'm also backing to know if the state will publish regular impact reports so families can advocate and raise concerns through some of the resources that you say have a really good relationship with the lawmakers.

>> I would say that we have to not -- there's -- so there's -- they continue to say they have the transparency portal, but I don't know how well that transparency portal works also, so these are the things that we need -- just not to advocate, but we need to do in terms of legislation. Through the last session, representative Bauer and I -- it's it be maybe they weren't a lot of

questions, we have mod tell **thrix** we had for attend landlord issues for affordable housing issues and walking out of there today, I can fascia toe you we're to the approximating to if home and say this is **rail** good meeting today and move on. We're continue to **rick** with you and I can I of few that I think may likely be in the form of a bill or legislation. I have a pretty strong feeling representative Bauer will be happy to carry the same legislation in the house. We'll have two voices on this, more than two, but there's other people listening. But we're in the room and we want to listen to you an talk to you more so we can help to bring forth things that actually do bring answers

>> REPRESENTATIVE BAUER: And to your question specifically, we are often limited into what informing we can access on behalf of the con sit went, but I encourage you to reach out to find out where your waiver or your standing with hearing back from that state agency and we can always check on that for you. We've done that with unemployment claims and emergency rental assistance. I can't tell you how many requests I got in the winter months for that, which is almost, compared to un**plot** claims during coved. So when it comes to health specific, we can always inquire and connect with you an individual in that state agency and I think you understood my question. I'm sorry.

>> Okay. **Get.**

>> Okay. I'm sorry. I don't care you understood my question. My question was, will you publish regular impact reports based on the revisions to this, if they will be available or where we can find them so we can use though though advocate for ourselves and our families.

>> You're speaking specifically to the waiver?

>> Yes.

>> Okay.