Webinar Transcript

Centers for Independent Living (CILs) Survey and Executive Director Follow-up Interview Findings
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 >> ALEXANDER ZARUTSKIE: Good afternoon, and welcome to our webinar, Centers for Independent Living executive director follow‑up interview findings, presented by Independent Living. Partnership of leading national disability research and information organizations. I'm Alexander Zarutskie, senior research assistant with the ILRU.
 This webinar is being recorded and will be available on demand within a few days. You can go to the collaborative website at CHRIL.org where you will find all the materials for the presentation, including the PowerPoint, the audio, and any other supplemental materials that may be posted subsequent to this presentation.
 Today, you'll have an opportunity to ask questions during the webinar, and we do have a number of ways to do this. First of all, in the Zoom platform, notice one of the menu options says Q&A. You can click there to ask questions any time during the call. We're going to wait ‑‑ we're going to wait until we do our Q&A breaks to address them, but please share your questions there. If you accidentally type a question into the chat, that's okay. We'll find it there and be sure to address it. But try to put them in the Q&A if you can.
 There is captioning available. You can view the captioning by selecting the CC tab in the Zoom platform. You can make the box larger by clicking the arrow in the top right‑hand corner. If you still prefer to have a larger font or be able to change the font or contrast, I recommend you check out the full screen CART captioning. You can find the URL in the chat in the main webinar screen.
 Also, if you are on the full screen CART captioning today, there's also a chat option available there. We'll be logging into that chat, and you can ask your questions there as well. I will be voicing those during the Q&A break.
 Finally, when we finish today, you'll have the opportunity to do an evaluation opened up by your screen. So when you close the webinar, that evaluation form will pop up, and it's very short and easy to complete. I hope that you give us some of your thoughts on a presentation there. We do take your evaluation feedback very seriously. We use it all the time to make decisions about how to operate and improve CHRIL projects, so thank you in advance for that.
 And now, I'd like to introduce Lex Frieden. He's the director of the Independent Living Research Utilization, ILRU. Lex has served as chairperson of the National Council on Disability, President of Rehabilitation International, and chairperson of American Associations of People With Disabilities. He's recognized as one of the founders of the Independent Living movement by people with disabilities. He was instrumental in conceiving and drafting the Americans with Disabilities Act, ADA of 1990. He currently serves on the board of The Metropolitan Transit Authority of Harris County, Texas, or metro. Welcome, Lex.
 >> LEX FRIEDEN: Thanks a lot, Alexander, and welcome to our webinar. It is a privilege for me to work with the members of the Collaborative Health Reform in Independent Living, and one of the projects that we have taken on early on is this survey and follow‑up with the Independent Living Centers pertaining to healthcare, and we're mostly interested in how people with disabilities maintain a healthy good life in Independent Living.
 So the objective of today's program is to discover and share essential information about health reform in working age adults with disabilities. The survey that we've done I think will enlighten you as to some of the efforts that we've made, but also it's helpful to enlighten the collaborative where Independent Living Centers are with respect to this issue.
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 The collaborative is made up of researchers from several different universities, including Washington state university, which is the hub of our program, and Jay Kennedy is the PI of the program there, an outstanding policy researcher whom I've known for many years. Jay has taken on this role of leadership with the CHRIL and doing a magnificent job.
 ILRU has joined as partners with the University of Kansas and George Mason University, and we're glad to be working with them.
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 In addition, we have several strategic partners with the CHRIL, including NCIL and APRIL, and the Association of Health and Disability, AAHD, the Association For Rural Programs, of course, you know, and the disability research interest group, DRIG, and we continue to collaborate with the Urban Institute.
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 So, at this point, we're focused on CHRIL Project 2, which is health insurance information and training and technical assistance needs of Centers for Independent Living. There are several aspects to this particular project that we're engaged with. The central hypothesis is that CILs throughout the United States are really the front line of communication with many people with disabilities who want to live independently, and therefore, it's necessary for CILs to understand, be able to advise people on their rights and on their benefits as it relates to healthcare and the Affordable Care Act, which you know has been altered in the past several months and years.
 So, it's important for CILs to know about these things, and we wanted to know how well prepared CILs are to address issues that consumers have about health insurance and how to maintain sponsorship, really, of their healthcare needs.
 In addition to finding out the status of knowledge that the CILs have, what kinds of information is important for the CILs to have going forward, and what are the major health policy concerns of CILs. We believe the research that we are doing will provide some information to policymakers, and we intend to shed light on what some of the issues that are sort of behind the curtain, as far as people with disabilities are concerned have.
 Among the things that we know of for years and years about disincentives to healthcare are current issues that relate, particularly, to health insurance environment as it is now.
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 A little bit about the background. We've already conducted one phase of the research, and that is to reach out to the CILs and do a survey, and then we've done a follow‑up in order to give additional information and fill in some of the blanks that we had from the survey itself. You know, it's not our intent to do a full representation of all the centers. It would be virtually impossible for us to do that, given the resources we have. But we do believe that we have reached enough of them to be a representative sample, and based on our knowledge of ILRU and the centers and the range of services they provide, we believe that we have sampled both a good array of the smaller centers and a good array of the larger centers that have multiple services and multiple locations.
 So, with that, next slide, please.
 I'm going to introduce Alexander. Alexander will talk some more about what we have actually found during the research. Alexander came to us actually from the school of biomedical informatics where he was my student, and a good one, I might add. Alexander got his master's degree in biomedical informatics. And before that, he graduated from Baylor University. He also worked as a research assistant and in the partner of obstetrics and gynecology, focusing on the advancement of fetal imaging methods to improve the diagnosis and treatment of people with congenital abnormalities.
 So, with that, let me invite Alexander to come back and share with you what you've been waiting for, the results of our survey.
 >> ALEXANDER ZARUTSKIE: Thank you, Lex. I appreciate it.
 So ‑‑ yes. So, initially what I'm going to be presenting on is the phase one part of the study, which is the needs assessment of Centers for Independent Living. So, the main goal, as Lex mentioned, the whole project, essentially of this survey, was to conduct a survey to determine the information, training, and technical assistance needs of CILs as the health consumers access healthcare and maintain or obtain health insurance coverage.
 So basically, the big question of this project is, do CILs provide these types of services in, like, counseling and enrollment assistance, and if yes, to what degree do they provide these services. And if no, how can we help them do this and what are the kind of steps that we can help improve them to be able to provide services to consumers.
 So a little bit about the methodology for the survey. It was a qualitative study design using a convenient sampling technique. So we wanted to target all the CIL executive directors across the country, and so we sent out a ‑‑ we designed a survey, electronic survey and Survey Gizmo, and that had 15 total questions, and it included general questions about their location, the amount of staff and volunteer time committed to counseling and enrollment assistance for health insurance. Then there's also things about how the CIL informed their communities about how they provide these services, and then there were a lot of open‑ended responses that were designed to identify some of the main consumer concerns as well as the main and technical assistance needs of the individual surveys. The individual CILs. Excuse me.
 So, we ‑‑ the survey itself provided confidentiality and was anonymous because we didn't request any personal information. The only thing that came out of the survey was the state where the CIL was located, and the 15 questions were derived from Centers for Independent Living, different staff, staff in the individual CILs, as well as ILRU experts in other methods.
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 So the procedure was, we sent the short survey to the email addresses of all the federally funded CIL executive directors and made follow‑up calls in the following weeks after. And this was all conducted in the summer of 2017. And the descriptive for the data analysis, we mostly relied on descriptive statistics, bar and pie charts, stuff like that, as well as just trying to draw correlations.
 So, I'm going to present some of the main findings from the study. So we ended up having 149 CILs respond to the survey, which is 42% of the total of 354 total CILs. And 75.7% of the CILs responded that they do ‑‑ they do provide health insurance counseling and enrollment assistance for the consumers. Individual or face‑to‑face or telephone was the most reported way that they provided this assistance. And then the individual CIL websites were the main means that they educated everyone that they do provide these services.
 And the interesting point was only 8.7% of CILs responded that they were doing well in providing health insurance counseling and enrollment assistance, and then in that same light, 91% of CILs indicated that they needed ‑‑ they indicated a need for more information and training, specifically with more up‑to‑date, easily accessible ways to find information on health insurance rules and advocacy training.
 And then lastly, the CILs reported that almost 92% of the CILs responded that consumers have directly expressed concerns regarding the uncertain climate of healthcare reform.
 Okay. So, this pie chart shows the primary ways that CILs provided health insurance counseling and enrollment assistance. So, as I mentioned on the previous slide, one‑to‑one counseling or the face‑to‑face was the primary way that the centers provided these services, and that's about 45% followed by things like workshops, and peer‑to‑peer groups, and there were other means, but almost half were individual counseling per request. And so the level of effort varies in between the CILs. About 22% reported that they served under one consumer per month, while the vast majority or 62% reported serving between 1 to 25 consumers each month, and 16% reported serving more than 25 consumers a month. The average there is about 22‑23 consumers per month. However, the most common response was three consumers per month.
 So, now nailing down on some of the main consumer concerns that were identified. By far, the most popular was the loss of insurance, either Medicare, mostly Medicaid coverage, and also the uncertainty of the status of the Affordable Care Act. Lesser reported concerns were limited access to healthcare, so that's mostly in rural communities, lack of doctors or the ability to find the right professional. Also, lack of employment options, and then loss of long‑term coverage.
 And then also, these were some of the main information training and technical assistance needs that were reported by CILs. Most notably were ways to ‑‑ a need for more detailed information on how to decipher coverage and compare the coverage in between different insurance plans. Also, more training to identify specific concerns of the consumers. And then also, advocacy plays into this. They want more education on how to better advocate for their specific consumers. And also, in the same light is advocate to legislators on improving these.
 So, some of the main conclusions from this survey was that ‑‑ like, the vast majority of CILs identified a need for more information regarding proposed legislation or the uncertainty in healthcare reform. And then that also ‑‑ exceeding like low number of CILs said they were doing well in providing proper insurance and enrollment assistance.
 And then that basically universally, everyone needed more information on the topics that CHRIL could offer and specific means of education. And specifically, as I discussed before, better ways to compare plans and determine, like, the best plans for an individual consumer basis.
 And then also, CILs reported a better ‑‑ reported a need for determining a better way to get real specific to health insurance reform in their individual state.
 So, what we have done from a CHRIL and ILRU perspective is we really looked at these specific needs and these findings, and this has helped us to develop specific training for CILs. And also, this has helped us identify specific themes that I'll be talking about for the second part of our study.
 Okay. So we've reached the first question and answer session. So please submit any questions you may have into the Q&A box on the main webinar screen, and I will try to address them. We don't have any questions yet.
 >> LEX FRIEDEN: Alexander, I see no questions. How about you?
 >> ALEXANDER ZARUTSKIE: I don't see any questions.
 >> LEX FRIEDEN: I think we've answered all the questions in round one.
 >> ALEXANDER ZARUTSKIE: Oh, I just got a question. I just got a question from Brook Curtis at ILRU. She said, sorry if I missed this, what was the makeup of the CILs interviewed, rural, urban, large versus small? That's a good question. Thank you, Brook I'm going to address that.
 We actually had quite a wide variety. I didn't show the specific breakdown. We had about ‑‑ like 30‑40% urban, about 30% rural, and we had about ‑‑ an equal mix of large and small. So that's what Lex was mentioning earlier, about how we were trying to apply this to like a general sample. So this is not going to be 100% representative of all CILs. But our results from the 150 CILs that we did look at seemed to be fairly ‑‑ show a wide representation.
 I have a second question. This is from Judy, and she says do any of the CILs identify as having CMS contracts to provide healthcare navigator services? Actually ‑‑ so, thanks for asking that, Judy. So, we didn't ask that individually in the first survey, but I'm going to be talking about that in the second part when I do these follow‑up interviews, because that was when we nailed down on the specific navigator. But the short answer to that is no. But I'll be discussing that a little bit more.
 If there's any other questions, please enter them. Okay. So I'm going to go ahead and move on. If you have any more questions, we're going to have another question and answer break in a little bit, so please ask them then.
 Okay. So, now, we're looking at what we've been doing this year, which is phase two of the project, which has been primarily to take the results from this needs assessment survey and do follow‑up interviews with select CIL executive directors to expand on some of the things that we identified in the initial survey. And so the research design for this was to do kind of case study interviews, still a qualitative study, and doing convenience sampling techniques. And so we got IRB Approved for this this past July, and we've been conducting these interviews this entire summer.
 And so the participants for this were all of the 149 CIL executive directors who responded to the 2017 needs assessment survey. And we ‑‑ so we put together a transcript of predefined questions based on some of these main themes that we identified in the ‑‑ from the survey. I'm sorry, I didn't mention, but for the executive director follow‑up interviews, we actually ‑‑ not only did we email all the 150 that responded, but we actually purposely tried to target specific directors that we have a wide variety of centers in terms of geography, consumer population, funding, at the time that the center had been operational.
 So when we're putting this transcript of questions together, we identified nine different unique sections based on survey findings, and this was broken down into how the CIL staff obtains information on rules, concentration on consumer concerns, specific training and technical assistance needs of the CILs, CIL funding, how to improve the overall effectiveness of the CIL, and then looking at other things like marketing and outreach and advocacy for the individual CIL.
 So, the interview is approximately a 30 to 45‑minute phone interview, and it's recorded and transcribed, and we are ‑‑ from these, we're able to do some statistics as well as textual process and analysis. So some of the initial findings that we have ‑‑ so we've done six executive ‑‑ sucks of these interviews so far as of mid‑August, and some of these themes we've been able to look at are the difference in how the CIL staff obtains information on the health insurance rules. There seems to be an inability to effectively find information and a lack of regular updates. So mainly, the staff has been focused on looking up the rules online, whether it be CMS, different federal or state health websites.
 But what's interesting is that all the CILs have a different strategy on how to do this, and they've all expressed a concern about receiving updated information on these types of rules. There's also ‑‑ also what I noticed is that there seems to be a lack of knowledge of specific staff training technical assistance needs, so this doesn't seem to be ‑‑ obviously isn't the largest part of the responsibility of CILs. So they're ‑‑ there's a ‑‑ I guess there's a missing piece in terms of a lot of the executive directors are struggling to identify specifically what they need, because the staff ‑‑ they might have one staff person that's partially responsible for this.
 So there was a disconnect in terms of what specifically is needed, and that's the main concern, that there's really ‑‑ none of the CILs that I spoke to have, like, specific people for health insurance enrollment or coverage inquiries. Sometimes they have specialists come in from different Medicaid ‑‑ either Medicaid managed care organizations or someone that will come in and present to them. There's usually no one on hand to do individual counseling. They'll have another staff person do that and try to look up the rules.
 And then there was a big point about uncertainties and addressing some of the consumer concerns. So, a really big struggle in how people address Medicaid eligibility or loss of coverage for any type of health insurance, as well as really unpredictable or recent healthcare legislations. So it was interesting to hear the executive directors kind of just ‑‑ the struggles that they've been noticing and trying to find these concerns in the individual consumers.
 So, what we ‑‑ we're going to be continuing these interviews the rest of August and September, and we want to have ten to 15 total case studies, and hopefully expand on some of these things.
 Some of the big conclusions, this really comes from both the survey and follow‑up interviews, really a critical need to improve the education and quality of information available for the CIL staff, as to the updated health legislation and health insurance rules. There's really a wide variety of ways that CIL staff address these consumer concerns.
 Further, there's really a large difference in terms of the individual CIL, the processes at each CIL, and the strategies that they use to market and outreach these type of services. So these findings, as well as the individual results from the survey, are going to really help us further develop relevant and up‑to‑date training for CIL staff to hopefully address some of these consumer concerns.
 And so, with that, I'm going to pass this back to Lex, who's going to talk about some of the greater implications as well as the future of our project.
 >> LEX FRIEDEN: Well, I think for most of you, the implications of the survey are going to be obvious. Clearly, we need to improve the availability and accessibility of the information on health insurance for people with disabilities. Most people with disabilities get confused, and that includes me, frankly. When you're looking at the different options, trying to play off Medicare and Medicaid, to private insurance, and now we have the exchanges, and we're not sure what's going on with them, it depends on which state you're living in, what the policies will look like, and it's very important, we believe, for CILs to be able to understand this, at least better than their consumers, so that they can provide some guidance and reference to people who are having questions about what's the best choice for them.
 This will involve some collaborative work between the CILs and ILRU and the CHRIL. We'll be developing some training programs for the centers that we can share with you. And in turn, programs that you can use to help inform staff, and therefore, you know, thereby, I think we'll have a huge impact on the lives of many people with disabilities.
 As you know, there are a lot of people with disabilities who are qualified to work, who would like to work, but who simply can't afford to go to work because they would lose these important healthcare benefits. Part of the initiative for the Affordable Care Act was to protect people so that they didn't lose in the equation to go to work. Now, some of that has been compromised, I think, and this leads us then to the public policy issues. What can we do to effect public policy and change policy.
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 We will have a report of the survey and written findings in the near future. We're in the process of producing that now. And we'll go ahead and begin the process of putting together training programs and following the use of those training programs after we rolled them out, we're going to do some more follow‑up work with their surveys to determine whether or not people actually are coming to get assistance from the CILs and whether or not the CILs feel competent in their role counseling people with disabilities about health insurance.
 It's been an interesting study, one that I'm glad we were engaged in, and I really want to thank all of those of you who participated in the study, took time to give us data, took time with the interviews to share your perspective. That will make it ever so much stronger a report when we publish it. And we will be using them again with your help as a vehicle to share information with policymakers about the status of Independent Living, people with disabilities, and health insurance.
 Hopefully, when there are additional modifications, when there are amendments to the Affordable Care Act and related laws, they will take our perspective into account, and I think given the data that we've collected, they'll be able to justify and substantiate some of the improvements that we need to have made.
 So that then leads us to another set of questions, correct?
 >> ALEXANDER ZARUTSKIE: That's correct. We're at our second question and answer. This will be our final question and answer session. So if you have any questions, please put them in the Q&A. We don't have anything right now.
 >> LEX FRIEDEN: Comments? Questions? Seeing none... hearing none...
 >> ALEXANDER ZARUTSKIE: There's one here. So, it says, in the interviews, what did centers do if they were not able to find the information needed for the consumer? Okay. So, that's interesting. I did try to probe for this. What I found was that they ‑‑ the centers seemed to refer them to ‑‑ refer the consumers to individual organizations that might be able to address their concerns.
 We have another one. Eileen. Of the CILs responding, how many indicated other collaboration with other providers in their service area providing insurance assistance? So, I didn't see anyone that actually collaborated with any providers in their service area, which was ‑‑ I think that was probably really interesting finding. Go ahead, Lex.
 >> LEX FRIEDEN: Yeah. I mean, we know that there are a few centers who have developed relationships with providers. Why that didn't come out in the survey, it's not clear, but what is clear is that if your center is one that does have a current relationship, it's very rare, and frankly, I don't know more than three in the country right now. It is, I believe, an opportunity, but it requires a lot of preparation and some risk on the part of the center, because these relationships require an investment by the centers themselves.
 That probably is a good subject to incorporate into the training modules that we develop. And in the past, ILRU has actually reached out to the centers to provide some reference to centers, or reference for centers, that are interested in doing this, and surely we need to follow up here, Alexander.
 >> ALEXANDER ZARUTSKIE: Yes, absolutely. That's definitely a key point.
 So I actually wanted to go back and talk about Judy's question, about the CILs providing healthcare navigator services through, like, CMS system. So, actually, I'll be ‑‑ the six that I've interviewed, none of them used the CMS healthcare navigator services, which I found very interesting. But that's definitely something that I have to talk about in these future interviews. Try to probe that more. I don't know if it was a function of them not knowing that the navigator services existed, or are they inefficient? I'm not sure, I can't address that but they did not mention specifically using that when I specifically discussed with them what type of federal organizations that they collaborated with, or what CMS resources that they used. So I found that very interesting.
 I have one more also. This one says, did any of the centers make recommendations for a process that can be implemented, or essential partnerships? I don't ‑‑ I'm trying to think. I don't know if it's a process that can be implemented, but I did hear a lot about essential partnerships. So that's going to be a lot of people wanting to make partnerships with kind of ‑‑ actually, what we were just discussing, about healthcare organizations. These are kind of like desired partnerships that they want to do. But then, this also deals with their ‑‑ with a desire to try to improve the marketing and jut reach efforts for the individual centers. That is what I really heard a lot about, how they're trying to implement ‑‑ market these type of services through the use of social media and other methods like that. Lex, do you want to add anything more about recommendations for processes or essential relationships?
 >> LEX FRIEDEN: No. I mean, I think it speaks for itself.
 >> ALEXANDER ZARUTSKIE: Okay. Are there any more questions?
 >> LEX FRIEDEN: Alexander, let me say you've done a great job putting together, along with the other staff at ILRU, carrying out this survey. The work on the CHRIL I think is most important, and we should all continue to monitor and be engaged to the degree we have the opportunity the CHRIL project. I know that professor Kennedy and I will be reaching out to you and ILRU is eager to continue our partnership with the CHRIL, and identifying more opportunities for people with disabilities for CILs to be involved in the process of effecting improvements in healthcare through insurance. And with us in that regard.
 Alexander, you want to wrap it up?
 >> ALEXANDER ZARUTSKIE: Yeah, that's what I was going to do. It doesn't look like we have any questions. So I'm just going to start wrapping this up. Directly following this webinar, you'll see an evaluation that will pop up on your screen. The link is here on this slide also. But it should come up when the webinar stops. We would appreciate you filling out this. We would like to hear your feedback. An how we can improve our education programs. And if that is it, we just ‑‑ yeah, final acknowledgement to CHRIL and NIDILRR and everyone else that is supporting us on this project. As Lex said, please just keep following us for more results, and for any of the executive directors that are on, just keep an eye out, and I'm going to be sending another email. If you're interested in doing an interview with me, I would love to hear some more of your feedback. So, thank you very much. Bye, everyone.