Transcript for Webinar―

Health Reform and People with Disabilities:

Lessons to Date from the CHRIL

January 31, 2019

3:00 p.m. EST

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>> Good afternoon. Welcome to our webinar, Health Reform and People with Disabilities, Lessons to Date from the CHRIL, presented by the Collaborative Health Reform and Independent Living, a partnership of leading national disability research information organizations. I'm Alexander Zarutskie, senior research assistant with 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 or you can find all the materials for this presentation, including the PowerPoint, the audio and any other supplemental materials that may be posted subsequent to this presentation. Today you have an opportunity to ask questions during the webinar, and we do have a number of ways for you to do this. First of all, in the zoom platform, notice one of the menu options that says Q&A. You can click there to ask questions any time during the webinar. We are going to wait until our Q&A breaks to address them but please share any questions you have here. If you accidentally type a question in the chat, that's okay. We'll be able to find it there and we will voice it during our Q&A session. Please put it in the Q&A if you can. There is captioning available. You can view this captioning by selecting the CC tab on the bottom of the Zoom platform. You can make the box larger by clicking the arrow in the top right‑hand corner. If you prefer to have a larger font available, change font or contrast, I recommend checking out the full screen CART captioning. You can find the URL in the chat of the main webinar screen. Also, if you are on the full‑screen CART captioning today, there is also a chat option within that function. We'll be logged in the chat and you can ask your questions in there as well. I will be sure to voice those during the Q&A break.

Finally, when we finish today, you'll see an evaluation open up on your screen. It's very easy to complete. I hope you'll give us your thoughts on the webinar there today.

We do take this evaluation feedback very seriously. We use it all the time as we make decisions about how to operate and improve the CHRIL project. So thanks in advance for that. Now I would like to introduce our three presenters. First, Dr. Jae Kennedy is the principal investigator of CHRIL and shares the chairs of department of health policy and administration at Washington State University. His research focuses on understanding the health and employment disparities experienced by people with disabilities, people with chronic illnesses and disabilities and on developing effective programs and policies to lesson those disparities.

Second, Dr. Jean Hall is the director of the institute for health and disability policy studies at the University of Kansas and professor of the University of Kansas Medical Center department of health policy and management. Her current research focuses on the effects of coverage expansions under the Affordable Care Act on individuals with disabilities using national surveys and interviews. A priority of her research is to give a voice to people with disabilities and their experience within the healthcare system.

Our last presenter Lex Frieden, a professor of health informatics and rehabilitation at the University of Texas health Science Center at Houston. He also directed the Independent Living Research Utilization, ILRU, at TIRR Memorial Hermann. He is recognized as being one of the founders of the Independent Living movement by people with disabilities and most notably he was instrumental in conceiving and drafting the Americans with Disabilities Act or ADA of 1990.

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So for today I'm going to go ‑‑ quickly go over the agenda and I'll talk about the objectives, give a little overview before I pass it to the other presenters. As I mentioned we'll start today with a brief overview of the CHRIL project, next talk about health insurance coverage, health services usage and access problems before and after the implementation of the Affordable Care Act in 2014, we'll look at information and training needs of Centers for Independent Living, next we'll look at using the health reform monitoring survey or HRMS, to assess effects of the ACA on people with disabilities. And lastly we'll do a summary discussion about the lessons learned from the CHRIL, the challenges and rewards of this disability policy research. Inform next slide, please.

So our main objective of CHRIL is to discover and share essential information about how health reform affects working‑age adults with disabilities. Our institutional members are made up of Washington State University, the Independent Living Research Utilization, or ill rule, at TIRR Memorial Hermann, University of Kansas and George Mason university. We also have many other strategic partners like the American Association On Health and Disability, or AAH, NCIL, National Council On Independent Living, association of programs for rural Independent Living, or APRIL, Disability Research Interest Group, or DRIG, of AcademyHealth and Urban Institute.

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Now I'm going to pass it to Dr. Jae Kennedy from Washington State University who will talk about our first topic. Thank you. Jae, welcome.

>> Thanks, Alexander. Thank you all for joining us today. I appreciate your time. In the first part of this presentation I'm just going to briefly go over some of the key trends in healthcare coverage ‑‑ or health insurance coverage, healthcare access and utilization and the impact and differential impacts on working adults with and without disabilities. This is a highlight of earlier research we presented on it as a publicly accessible journal article and a plain language summary available on our website.

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So, first of all, I just want to point out the CHRIL is focused on working‑age adults with disabilities. We made a decision to focus on this group because they're particularly relevant from a health policy perspective. Seniors are already in a single payer system for the most part with Medicare, but working‑age adults have been historically excluded are because of preexisting medical conditions from a private insurance market and subject to a variety of state health insurance systems through Medicaid or they're on Medicare because they're enrolled in SSDI, but the working age population are particularly vulnerable to changes in the health system, the variety of health policy reforms in the Affordable Care Act changed both the regulation of the private insurance market and access to the public insurance market meant this population is particularly of interest and importance. So that's why we decided to focus the CHRIL on working age adults with disabilities.

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Here's the article, and you have got the URL if you want to read the whole thing. Like I said, we have a plain language summary as well on the CHRIL website.

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I'm going to present, I think, four slides here and they're all going to be in this format. We're comparing adults with disabilities on the lands adults without disabilities on the right‑hand side. I'm looking at changes over time from 1998 through 2017. The journal article I just cited I believe stops in '16, so we have another year of data here. It didn't change things that much, but this is a little more up to date.

So you can see here in this first set of slides, both for working‑age adults with disabilities and without disabilities, the Affordable Care Act coincides at least with the decline in the proportion of the population that's uninsured. And this was intentional. This was one of the things that the ACA was supposed to do, was improve access to private and public health insurance, and it appears to have done this.

If you compare what we call the payer mix, the proportion of people with different kinds of insurance, you can see that starting in about, what, 2006 or 2007 people with disabilities started using public insurance more than private insurance, whereas working‑age adults with disabilities have always relied primarily on employer‑based private insurance.

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We just break out the public insurance coverage so you can see a little more detail on that. For people with disabilities, we also include Medicare and people that receive both Medicare and Medicaid or dual eligibles, that's because you can get Medicare as a young adult if you're enrolled in SSDI, eligible for and enrolled in SSDI. So those are those purple lines underneath. But you can see here after implementation of the ACA in 2014 there is a big jump in Medicaid participation for adults with and without disabilities. But the overall rate of public insurance use is much higher for the population of adults with disabilities.

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I guess the most interesting thing about this slide, you can see that the rates of intensive healthcare utilization, i.e., hospital use and relatively intensive use of physician services, the light purple line, is 10 or more doctor visits per year, people with disabilities, not surprisingly, are much heavier users of healthcare, and we don't see a big change in use rates after implementation of the ACA. That's kind of a good thing, I guess. It depends. I mean, it doesn't show things like use of primary care and preventative services, which you would hope would go up after the ACA, but as far as expensive services we're not seeing heavier use of costly services after implementation of the ACA, but kind of the big takeaway of mine is people with disability and chronic illness use a lot more health services in general.

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The kind of reddish purple line at the top is people who reported delay getting needed healthcare because they were afraid ‑‑ or didn't know how to pay for it or worried about cost. And the other purple line underneath that is people who said they didn't obtain needed healthcare because of the cost. And you can see here the rates of cost associated access problems peak at around 2008, 2009, and that's not surprising. If you think back, that was the height of the recession when people were losing their jobs and employer‑based health insurance. So affordability for lots of things, including healthcare, was a problem for a lot of Americans at the peak of the great recession. That started to get better over time but you see kind of a change in the slope after implementation of the ACA in 2014. So it's going down but it goes down more sharply after implementation of the Affordable Care Act. And we see at least in the adult population with disabilities a little bit of the bounce back up. So we'll have to keep an eye on that as we're moving forward. The bottom line is it looks like the ACA improved affordability and access.

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So the takeaway points again is just that working‑age adults with disabilities use a lot more health services. Consequently they bear more costs and are more vulnerable to changes in the healthcare system. So ‑‑ particularly because of the high rates of use of Medicaid in this population, state variation of Medicaid policy is an urgent issue. But for both working‑age adults with and without disabilities, the Affordable Care Act improved health insurance coverage and improved access. I can answer any clarifying questions right there. I think I'll just pass it on to Lex after this. Alexander, anything popping up? Okay. We'll move it over to Lex.

>> We didn't have any questions yet. We'll address that in Q&A if anything comes up.

>> DR. LEX FRIEDEN: So I want to echo Jae's thanks to all of you for joining us. We know your time is valuable. We want to use it as well as possible, and we think it's important to share the information that we've gained through our CHRIL project on the Affordable Care Act on health insurance for people with disabilities more generally and on what we as Independent Living advocates and center programs can do to improve opportunities and access to healthcare for people with disabilities.

We wanted to find out what the centers were doing, so we engaged in a study ‑‑ next slides, please ‑‑ you already got it. The hypothesis of our study was very clear, and that is that we need information for the centers, and we need to find out what kind of services centers are already providing, what kind of information they need. Obviously if the centers don't have up to date information about healthcare options or don't understand what the current events are as it relates to the Affordable Care Act and other legislation and programs that are defining the way in which people with disabilities receive health insurance, if they do, we wanted to be able to provide that information to the centers in an efficient manner and to provide them the information they need.

So we have undertaken a series of inquiries with Centers for Independent Living, and I won't repeat what's on the slides, but simply say that we feel like this was a good study, a valid study, and we want to share the results with you.

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So, the question that we asked CILs when we called them quite simply was does your center provide information pertaining to health insurance and healthcare, and, if so, how do you do that? What services do you actually provide? And we got a variety of answers that we'll share with you here now.

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75.7% of the centers that responded said that they did provide health related information, including counseling to people with disabilities who called them and who were their clients or participants in their program. Only 8.7% of those CILs stated that they were doing well in offering this service. So you can see there's a disparity between the centers that want to and, in fact, are trying to provide information and assistance to people and those that feel like they're really accomplished in doing so.

We used a number of approaches and asked people how they were actually providing services, and we discovered that there were an array of methods that the centers were using to reach out to people with disabilities. 91% of the CILs indicated that they offered more information and training, but not so much in terms of what they did as related to individual counseling.

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So most of them would like to have more information. The question is, now, what kind of information do they need? They want more detailed information on aspects that relate to making judgments about which insurance plan to select and what insurance options one might have. They wanted to see training on how to identify major areas of concern for consumers, because many consumers come in, they give them call, they meet with them, and the consumers themselves are not even clear about what questions they have pertaining to their needs. The centers want more up to date, more easily accessible information. And they want training on how to be better able to acquire the information they need and advocate for specific consumers. We found that a lot of centers felt like they needed to intervene on behalf of or at least along with the consumers whom they were trying to serve, and they themselves found it difficult to have an appropriate role or to know what steps to take in order to have an advocate or ombudsman role in the process. And finally the centers want more training on how to provide assistance in the legislative process, how to be part of health reform and how to change and effect the programs that are actually funding the services that are currently provided, how to change the rules the rules of those programs that are currently funded and, in effect, so that people are more adequately served.

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We discovered that there are different ways that CILs receive information about the insurance programs that exist now. Many of them said there was an inability to efficiently obtain information and they weren't really sure how to reach people in the federal organizations responsible for federally funded, federally sponsored healthcare. By the way, they had the same difficulties reaching private insurers who had taken persons with disabilities. There were a lack of knowledge about specific staff training and technical assistance needs. So some of the people that we interviewed in the process were not that well informed themselves about what their centers were doing, and we've actually discovered that in other surveys that we've done in the past. Many centers have a few staff who are responsible for a lot of different things, and yet not everybody in the center staff knows what everybody else is doing. And sometimes the responses that we give consumers are not consistent from one provider to the next, even within the same center. That, by the way, is a finding that we may need to address with additional programs and additional research. Additionally let me say that there were uncertainties in the addressing of consumer concerns. So people really weren't sure, effective as advocates, and again it speaks to the need for additional training for the centers.

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I think we all have issues with obtaining information, and the centers, like everybody else, are concerned about the way in which information is presented by the providers, by the insurance companies, by the federal government, by Medicaid, Medicare, whoever we're talking about. It's difficult to stay up to date with information. We get a lot of emails, we get a lot of bulletins, but we're sometimes never sure which one is the latest one and how, in fact, one program or programmatic change affects another. Again, this has an impact on those who would provide technical assistance because we're a little uncertain ourselves, speaking as a technical assistance provider, about what the most up to date answers are and whether those will change tomorrow or not. So we always have to be conditional in the way that we offer information.

We know that the centers are advocacy oriented. The two ways in which the centers desire to be more ‑‑ to ‑‑ desire to make improvements in the way they behave, one of them is better advocates for individual consumers, and the other one is better advocates for program. In order to be a better program advocate, one must know what the current legislative threats are, the thrusts that are moving forward, and where one can have an impact in the process.

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So I think we can conclude, and it's probably apparent, that the centers wish to have more information and training about healthcare, the healthcare environment, and the status of federal programs as well as the private industry offerings that are changing in relation to the federal laws. The centers want to know better how to serve their clients and how to be better advocates. So we'll use these findings and some are quite detailed, because Alexander and others on our staff spent considerable time interviewing center directors, center information providers, center peer counselors on exactly what the ‑‑ what their needs were, and it's difficult in a summary to describe all those details. We'll put that together and find ways to reach out to the centers and assist them in the process of doing that which they desire to do in meeting their mission. More about the training, I think, later in the discussion.

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We'll be planning a number of webinars in the future that will be intended to educate the centers. We're working on some collaborative initiatives that would provide additional outreach and information to the centers. We'll be sharing some of the details of our findings in the form of fact notes and bulletins. We'll post up to date listings of conclusions as well as some of the data to support those conclusions on the CHRIL website and I encourage you all to become familiar with the new website. It's a very user‑friendly format and we want you all to engage in discussion there, but also to see that as a primary source of information and technical assistance. And we'll be developing ‑‑ I think all of you are familiar with our RapidCourses. We have several of those in the process of development right now. There are a couple already on the ground that you can go to the ILRU archives and reach. All together the efforts that we'll be putting into this technical assistance and training support for Centers for Independent Living over the next year or two are substantial. So stay tuned for that.

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>> So this brings us to our first Q&A. Thank you, Lex. If you have any questions, you could please submit them to the Q&A box in the main webinar screen. We have one question already. So I'll go ahead and ask that while we wait for any other ones to come in. This question is for Dr. Jae Kennedy and this person asks did your study look at whether emergency room or E.R. visits or prescription drug use for adults with disabilities changed after Medicaid expansions took effect in 2014?

>> DR. JAE KENNEDY: With the HIS we looked at what we called cost related non‑adherence. These are people who say they didn't fill a prescription or didn't take a medicine as prescribed because they couldn't afford to do it. So we've got some stats on that. The E.R. utilization question, we don't have trend data on that. We're doing some work, I believe, looking at E.R. use with the MEPS. So we will be looking at that with another survey. And I believe that Dr. Jean Hall and L.L. Kurtz, Jean is going to talk about her new survey they're working on, has questions about access and cost of prescription medication and maybe she can touch on that as well.

>> All right. Thank you, Jae. We don't have any other questions right now but I saw something mentioned in chat. It was talking about the importance of communication at the Centers for Independent Living. So that's from ‑‑ from the Board of Directors down to the CIL staff. Lex, do you want to maybe talk about how we can look to improve the communication?

>> DR. LEX FRIEDEN: Well, I think part of the responsibility for doing that rests with us as technical assistance providers, and that is, we need to provide up to date, timely, clear information about the current status of an array of issues that centers are interested in, and we need to depend on the centers to use that information and stay up to date themselves. Again, just let me mention, that the CHRIL website I think that's important, as well as the ILRU information that we distribute on a routine basis. So please try to keep up with that, because we ‑‑ it will be our responsibility to stay on top of it, but from the standpoint of the centers, in order for you to be up to date, you have to stay up to date with us. The other thing is that's important about that and the person raised the issue of the boards down to the staff, one thing we did find in our survey, and this is, if you think about it, not surprising, but it really depends on who you talk to at a center, what the center seems to know. And a lot of times I think that we don't do a good job as centers in informing our board of some of the issues that we're having to deal with at the routine level of our peer counseling and individual client services. So whatever the centers can do, and if that requires more training provided by us in terms of communication internally with staff and with boards, we'll be glad to help with that, but I do think that most of the directors of the centers are capable managers, and I think given the opportunity to realize the importance of having everybody on the same page with respect to what the center is advising and having all the staff cross trained and the Board of Directors knowledgeable, we will be doing a service to our clientele.

>> All right. Great. Thanks, Lex. We have a couple other questions that I'll ‑‑ any of the presenters can take.

The first one asks: Did this study take into consideration the lack of accessibility in doctor's offices and hospitals?.

>> DR. JAE KENNEDY: I assume that's for me, and we didn't look at specific disability access questions. The survey didn't that we're using. We looked at affordability, that's what I showed you in this set of slides. There's also some questions about transportation and hours of access to physicians, and particularly doctors offices. Your primary care physician, do they have hours when you can see them. How far of a drive is it for you? And people with disabilities reported much higher rates of transportation difficulty.

>> Okay.

>> DR. JAE KENNEDY: So not as much as we'd like, I guess.

>> DR. JEAN HALL: We can talk a little bit about that with our survey, too. I'll remember that when I get to it.

>> DR. JAE KENNEDY: Okay.

>> There's one more question. This question asks: Does CHRIL intend to study the impacts of progressive reform like national, state, sing you payer systems on LTSS, more specifically, personal attendant services or durable medical equipment?

>> DR. JAE KENNEDY: We're looking a little bit about access to independent services and durable medical equipment in the context of additional progressive reforms like national or state single payer systems we have to see what emerges, but we're certainly monitoring those closely and understand that's a very important area. Thanks for that question. You're right.

>> All right. So we'll have another Q&A session at the end. So, please just keep asking questions in the Q&A box and we will address them later. Next we're going to move on to Dr. Jean Hall, who will talk a little bit about her survey. Welcome, Jean.

>> DR. JEAN HALL: Thank you. I'm going to the next slide.

I'm going to try to remember to answer those questions about prescription barriers more particularly when I get to that part. If I don't do that remind me afterwards and also a little about access barriers we've heard from people with disabilities in our surveys.

Backing up a little bit the role of my team at the University of Kansas was to collect primary data from people with disabilities about the affordable care act and coverage expansions in that in the first year, we worked with the Urban Institute using a national survey that they helped conduct called the Health Reform Monitoring Survey and this is a national web‑based survey that started in 2013. It started before the Affordable Care Act was implemented. Then we can look at people's situations before and after implementation of the Affordable Care Act. We were able to work with their institute to include a question about whether or not a person had a disability so that we could examine specifically experiences of people with disabilities. When we used the survey data we looked at two groups, people with disabilities overall and people with psychiatric disabilities. And for people with psychiatric disabilities we found after the ACA people with mental health conditions were less likely to be uninsured and less likely to have unmet need due to the cost of care. So it's making a positive difference for them. They were also more likely to have a usual source of care which is important for maintaining health, physical and mental health, and we found the needs ‑‑ in he can spank shun ‑‑ Medicare he can span shunned and nod expansion states. Ease those findings were published in much little citation there in psychiatric services.

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When we looked at the broader population of people with disabilities in the health reform monitoring survey we found they were more likely to be insured after the ACA, but we found a difference here and found that significantly fewer people with disabilities were uninsured in states that had chosen to expand Medicaid compared to states that did not expand. So we know Medicaid expansion is important to people with disabilities being able to access coverage.

Also when we looked at Medicaid expansion states we found people with disabilities were also significantly more likely to be employed than people with disabilities living in non‑expansion states. In fact, we found that employment in the expansion states increased from 41.3% to 47% from 2013 to 2017. And then when we looked at non‑he can expansion states, their employment decreased over that same time span. If you look at that little graph I hope you can see it the top dark line is the percentage of people with disabilities who report working in Medicaid expansion states and you can see it increased and that bottom line is the number of people with disabilities who report not working due to a disability and you can see that that number decreased over time from 2013 to 2017. So we can speculate that people with disabilities are no longer having to declare a disability and go through the disability determination process to get their health insurance. Instead they are able to work and have their insurance through Medicaid expansion in states that have expanded.

Note that we ‑‑ when doing these analyses we controlled for local employment rates. So it wasn't just more people are employed in expansion states. We did control for those rates.

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We know that Medicaid expansion is really important to providing health insurance for people with disabilities and supporting their employment. We wanted to drill down a little and see if there were features of health insurance coverage available through the Affordable Care Act also helping to support employment and we found that people with disabilities who lived in a state whose marketplace plans, those commercial insurance plans available through the marketplace, those plans were required to have habilitative services without limits. People living in those states with disabilities were more likely to be employed. Habilative services are covered under rehabilitative services. But with rehab you have to ‑‑ it's perhaps not surprising in the states that don't limit those services people with disabilities are more likely to be employed. Similarly when we looked at Medicaid plans state by state we found Medicaid plans in states that Medicaid plans did not limit physical therapy visits people with disabilities were also more likely to be employed. Again, having access to those services that people need to maintain their health and their function is really important to people with disabilities and it allows them apparently to be employed.

We also looked at occupational therapy and speech therapy limits and those were not significant but physical therapy was.

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We also as part of our project at the University of Kansas conducted national interviews with people with disabilities. In our first year of interviews in 2017 we interviewed a total of 22 people with a very broad range of disabilities, living in a variety of states with Medicaid expansion or not Medicaid expansion and having different kinds of coverage. So we really got as broad a sample as we could and asked about their experiences with their health insurance, and when we analyzed all the transcripts from those interviews, five themes really stood out as problem areas for people with disabilities. The first was getting information and understanding of their coverage. That was really problematic to get that information, especially in real time. So people said they were at their doctor, their doctor referred them to a specialist, or said that they needed a particular procedure, and they had no way to find out if that doctor or that procedure was covered, and many of them wound up with medical debt they hadn't anticipated or they weren't able to get a service because it wasn't covered or they didn't know where to get the information to find out if it was covered. So that was a real issue.

Another issue was out of pocket costs. Even though coverage expanded people with disabilities tend to have more healthcare costs overall and this translates into them having more out of pocket costs overall and that remains a barrier to people with disabilities. Cost related non‑adherence as Jae talked about or not seeing a doctor due to cost has decreased for people with disabilities but it is still much higher than it is for people without disabilities.

When we asked about prescription medications or when people talked to us about prescription medications, there are many barriers, and the first of these was cost. Even the kinds of costs sharing insurance forces people to pay to get their insurance ‑‑ to get their medications tended to be high for people with disabilities. But even when cost wasn't a barrier, bureaucracy often was. People with disabilities reported a lot of instances where they had to get prior authorization or pre‑approval or go through a step process to prove other medications didn't work first, and it seemed to happen a lot for people with disabilities. So it seems like that's a bureaucracy that's ‑‑ that creates hurdles for people with disabilities more than it does for other people. Finally we heard that insurance companies don't seem to understand the complexity of disability. One person said that she had heart arrhythmias in addition to her asthma and there was only one asthma medication she could take that would exacerbate her heart arrhythmias and the insurance company wouldn't cover it because it was more expensive. So this having multiple conditions or disabilities, it seems like insurance is not sensitive to that or doesn't care. But that was something we heard a lot. The complexities of a person's condition affected their ability to access the medications they needed. Provider networks that another issue we heard over and over again that people couldn't see the specialist they needed or to see the specialist they needed to they had to go to another county or travel for great distance. People who lived in Alaska often had to fly out of state to see specialists. So that was a huge issue. And that ties also to transportation. Transportation was a very large barrier for people with disabilities in our interviews. Not having their own transportation, not having access to public transportation that was nearby, or safe, oftentimes if someone had to have a person come with them to the doctor's appointment, that wasn't covered, or it wasn't possible for them. One woman's condition required her to have colonoscopies every several months and her family didn't live nearby and she couldn't afford to pay someone to come with her which was required. So transportation was also an issue we heard as a very broad problem for people with disabilities. And I would say overall these issues may be problems for people without disabilities, but when you look at the smaller margin of health that people with disabilities often experience, when they have any of these problems or a combination of these problems, they're much more likely to have an adverse outcome as a result.

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In addition to our interviews we field add national survey on health reform and disability first in 2018. This also is a web‑based survey. It's a national cross‑disability sample to learn about people's experiences with health insurance after the Affordable Care Act. We had 1246 respondents in our first year. We are still examining the data. There's lots and lots of it. I wanted to quickly highlight some findings. We are finding differences between the experiences of people who live in rural versus urban areas. For example it seems employment in much more associated with community participation for people who live in rural areas than it is for urban. So having the ability to engage in employment is really important for people living in rural areas to be able to participate in their community. We're finding again things about limited networks or network adequacy affect employment and also result in unmet need for people with disabilities. We're examining that more. We're looking at the experienced of different subgroups of people with disabilities. One is the LGBT community, another is people with intellectual and developmental disabilities, and what we have found for both of these populations so far is that they are much more likely to have multiple disabilities, much more likely ‑‑ and much more likely to report being refused services by healthcare providers. I think that gets to attitudinal barriers that people with disabilities are still encountering in trying to access healthcare and it seems like it's worse for some people with disabilities than others, and it that's something we will explore more as we look at the data. Stability of coverage is an issue that folks that Washington State University are looking at. It's great with people with disabilities are more likely to have coverage as a result of the Affordable Care Act but there might be some shifting back and forth on different types of coverage and when you don't have stability of coverage with the same providers and same networks and everything, then you can still have problems accessing care you need and we are going to look at how much of a problem that is for people with disabilities that that we're also exploring the relationship between health insurance, employment and disability program participation. We know historically that there is had health insurance motivated disability enrollment that people with disabilities had to go on to Social Security disability assistance programs, not so much perhaps because they needed the cash assistance, but that was the only way they could get Medicaid or Medicare and health insurance they needed. So we're looking to see if that has decreased as a result of being able to access health insurance through Medicaid expansion in states that have done that or through the health insurance marketplace. Finally we're looking at sources of Personal Assistance Services and access to paid Personal Assistance Services because we know that's very important for the independence and employment of many people with disabilities and that's something that we hope to be reporting on in the future.

So next slide, please.

Finally, this is our plans moving forward. We currently conducting our second round of national interviews and will also be administering a second round of our national survey in the fall of this year. If you see flyers or information asking you to participate, we hope that you will because the more people that we have respond, the more data we have and the more meaningful conclusion we can draw about the experiences of people with disabilities. We're also working with stakeholders to think about questions we might want to include in that survey. So if that's something you have an interest in please feeling free to contact me. And like I said, we have lots and lots of data we're continuing to explore. We have partners and various universities helping us with that, and if you go to the CHRIL website you can see the various manuscripts or policy briefs and publications that we have so far. So I 234 courage you to do that because I couldn't cover everything in just these few minutes. I hope' didn't talk to fast for the captioner and I'm happy to answer questions. Next slide, please. So I'm going to pay the back to Jae now.

>> DR. JAE KENNEDY: Okay. He we've got questions coming in, and I've got probably too many slides to get through in the remaining time. So I'm going to zoom through some of this. But I just want to talk a little bit about how the CHRIL came about. I think it's safe to say that during the development of the Affordable Care Act and the content of the Affordable Care Act, there was a lot of attention placed on what a lot of analysts were calling a high cost, high needs population, which predominantly is people with disabilities and chronic illness. But the legislation and the Congressional policymakers that were considering these issues didn't really think about Independent Living and community integration and a lot of the important aspects of policy for people with disabilities. So we felt that it was important to get a disability perspective on the Affordable Care Act and to monitor the impact of the Affordable Care Act on this population. For those of you that aren't able to see the slide, we have a little picture of a krill. The name was intentional. The KRILL little things that live in the Arctic and they're at the bottom of the food chain.

Next slide. We knew this was going to be a complicated issue, and we knew we were facing an uphill battle when we started submitting proposals to study the impact of the Affordable Care Act. Jean and I started as competitors, I think it's safe to say, we were both getting low scores on our grant applications, but the content of the reviewer comments was particularly interesting and informative. They were concerned about the volatility of the political environment, you know, the very fraught and adversarial nature of democratic and Republican perspectives on health reform, and more broadly, both the population of working‑age adults with disability and the U.S. health system in general are both complicated things and it was hard to come up with a compelling summary of what we wanted to do without overly simplifying the complexity of the situation.

There were also concerns about our ability to get access to useful data to evaluate the affordable care act because there is kind of a natural lag in national surveys as far as data collection and releasing that data to researchers like us. But probably the comment that bothered me the most, and I want to come back and address it, was the concern that we were just adding more bluntless government reporting to the issue instead of focusing on the real personal impact on people with disabilities and the disability community. So reviewer three in one of my proposals said: Exsiting reports haven't impacted rates of access and the applicant hasn't provided sufficient justification as to how this project will have a beneficial impact on the target population beyond producing yet one more federal report on unequal access. So that smarted and we thought a lot about how to respond to questions like that.

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In the proposal ‑‑ this is common in policy research ‑‑ we proposed basically an interrupted time series design. So the hypothesis is when you introduce a new program or policy it's going to affect behavior. So if we look over time before and after the introduction of something like the Affordable Care Act, we should see a change in things here. This is just some mock data I put together looking at the portion of the population would that report affordability problems with health insurance and healthcare. So we talked about in our proposal the ACA has passed now, in 2009. It's going to be fully implemented in 2014. And we wanted to see what the impact of that was on the population.

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Of course, this is what actually happened. Lots and lots of policies, and political environment changed over this observation period. We talked a little bit about the impact of the great recession. But Congress changed hands. The Supreme Court weighed in. We had a change in the party leadership in the White House. And that's all complicated the policy environment, and we have had a number of challenges in responding to that in real time.

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But to get back to reviewer 3's concern, we wanted to get beyond just producing one more federal report.

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So one of the things we did, we published over a dozen journal articles so far, I think, with CHRIL, but we make a point of not just listing those articles, or if we're being fancy about it, putting a PDF file on our website but we're also trying to do common language summaries. So there is these one to two‑page reports that summarize what we did in nontechnical language. So hopefully that's a little bit more accessible, quite possibly more interesting than reading a whole journal article. So those are available at CHRIL.org.

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But we also went beyond that. We're doing ‑‑ our journal articles and our conference presentations at professional conferences, but we're also going to meet with advocates and do webinars and we're producing nontechnical reports on other issues that come up from the community or that come up in our research. So I guess, again, I'm plugging my website but we have a lot of stuff there other than dry journal articles and big government reports.

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We've spent a lot of time training folks. I'll talk more in a minute about the in‑person trainings but we've also produced two self‑‑paced courses ‑‑ two or three self‑‑paced courses on Medicare and Medicaid and general concepts in health policy. We have a summer internship. ILRU is currently taking applicants for that, I believe, and we've had 10 different graduate and undergraduate students participate in the CHRIL at ILRU and that's been a great addition to the program. We've also introduced a new postdoctoral training program specifically for scholars with disabilities. We have our first one at WSU now and we will be recruiting a second one this fall.

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We started out the CHRIL by proposing town hall meetings for NCIL and APRIL, the two big Independent Living conferences, which most of you are familiar with. But as we were waiting for application to be reviewed and approved, town hall meetings became a very politicized arena for policy discourse, I guess. You may recall a lot of disgruntled advocates were showing up at Congressional offices and complaining about efforts to repeal the Affordable Care Act, and so the town hall meeting framework became more loaded than we expected, but also the way that we structured it was just to kind of open it up as a listening session, but one of the first things people told us is that they wanted more concrete information on how health policy worked and specifically how Medicare and Medicaid regulation worked. So we started developing workshops instead and attendance at those workshops between the second and third year has gone way up, and we've had a wonderful engaged audience that's really hungry for this kind of information. We also developed something we're calling the disability policy stories project, which is semi‑structured interviews with disability advocates that we interview in the community and at the NCIL and APRIL meetings. It's kind of a long and complicated process but we're videotaping those and transcribing them and hope to have the transcriptions up as well as video vignettes from those interviews on the website hopefully this summer. But that's been very interesting and we've got some great comments from that. And also we've been able to take the participants in the disability policy stories project and in some cases refer them to journalists or policymakers that need specific testimony on issues.

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So here's a picture of me sitting on the steps of Congress. This was actually the day before the midnight vote to repeal the Affordable Care Act, which you may was pretty dramatic. Senator McCain voted down the repeal at the last minute. It was an interesting time to be in Washington. But what we've kind of learned in this process is that people care deeply about this issue. We knew that, and we certainly care about it, but the disability community is interested and engaged and angry in a lot of cases at the way this debate and this policy has been manipulated by different political interests. So we've had to learn, I'll say, how to accept change and deviate from our kind of, you know, idealized model of policy evaluation when things change and understand that there's a lot of ambiguity at any given time and to accept or really embrace the emotional intensity around this issue. I have gotten a lot more comfortable working with angry people and helping them try to channel that anger in productive ways and that requires kind of defusing some of the negative energy with facts and critical analysis. But it's been actually a lot of fun to work in this arena. It's intense, but it's challenging and people care about what we do.

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I'd say things that we didn't know and in around 2014 when we were writing this proposal, the Supreme Court had just decided that the ACA was basically legal but had said that the mandate that all states expand eligibility was an overreach by the federal government. So states were given the option to participate in the expansion or not. We knew that. We addressed it in the proposal. But we didn't really understand how the issue would split the country and the kind of red and blue divide on participation of Medicaid expansion. Also, I mean, this was already happen in the 2000s, but managed care organizations have almost completely taken over the administration of Medicaid services and that has interesting implications for the disability community and we're trying to grapple with those. And there's some other kinds of issues that are emerging after the 2016 election. CMS is again talking about Medicaid block grants, which we can't get into much right now but this notion that the state would be given a lump sum at the beginning of the year to spend on Medicaid services, or a matched per capita amount for each [indiscernible] and that has interesting, potentially troubling implications for people with disabilities. And I guess the other thing around Medicaid a lot of states are now exploring new eligibility restrictions like work requirements, and that's something we're keeping an eye on.

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So in the coming year we're going ‑‑ this is the ‑‑ we're beginning the fourth year ‑‑ well, I guess we're part way into the fourth year of our five‑year project. So we're looking for money and more ideas, and I would say that the next phase of CHRIL work is going to focus primarily or exclusively on Medicaid and particularly on state variations in eligibility, the impact of new work requirements, the block grants which I mentioned earlier. Jean and Gill Gammon, another person on project at George Mason, have done a lot of work looking at Medicaid buy‑in for people with disabilities, so programs that allow you to keep Medicaid even after you're no longer financially eligible for SSI. So people can still purchase highly subsidized Medicaid services on a sliding fee scale and work. This notion of allowing people to purchase Medicaid even if they don't meet the narrow income requirements is promising for the general population as well. We need to expand it both for people with and without disabilities. And I think this ‑‑ the dominance of managed care provision and Medicaid created business opportunities for the CILs. I guess the other thing that potentially we may be needing to deal with in the next year is as the presidential elections move forward there are a lot of candidates that are pushing variations of Medicaid ‑‑ sorry ‑‑ Medicare expansion, including Medicare for all. So right now it's going to be very difficult to compare and contrast the different plans and evaluate their impact on working‑age adults with disabilities, but as the field of candidates and the options discussed narrows we might be need to be spending more time on evaluating these different Medicare for all or most or for more policies.

Next slide. I think that may be it.

Back to you, Alexander that that.

>> Jae, thank you for that. So we're actually at the time limit. I'm going to try to adjust a couple ‑‑ address a couple questions we are. We won't be able to answer all of them. But I will forward the relevant questions along to the different investigators and they can possibly address your questions.

First, about of we leave, there was a couple of technical questions for Jean Hall. The first one is: How do you ‑‑ let's see. How do you join the survey.

>> DR. JEAN HALL: You can either email me directly at JeanHall@KU.EDU or [healthsurvey@KU.EDU](mailto:healthsurvey@KU.EDU) or you can check the CHRIL website. We'll put up notices when it gets closer.

>>Why did you limit the eligibility of the survey to people under the age of 65?

>>DR. JEAN HALL: We actually initially limited it to people who were up to the age of 63 because we want this to be a longitudinal survey and we were wanting to see if people maintained health insurance and if they turned 65 they were going to become eligible for Medicare. Having done that and said that, we got so many requests from people 65 and older we started accepting all survey respondents and we do have a pretty Good Sam pull of people 65 and older than we are going to look at separately.

>> Great. Thank you. Then a question quickly for Lex. This person is asking: Is training to become a CIL counselor standardized across the nation or does it vary from center to center. How many hours of training are needed to become a peer counselor?

>> DR. LEX FRIEDEN: There is a lot of variability. I would suggest if you are interested in becoming a peer counselor you contact your nearest Center for Independent Living. You can get a list of the centers at ILRU.org and that list is kept up to date. If you have another question about Independent Living center services, don't hesitate to email us at ILRU and we'll get right back to you with that information. Thank you for the question.

>> We'll do one more. There is a question here about how we're trying to bring in social determinants of health and connecting that to health reform. So it says: Are you connecting health reform ‑‑ are you connecting health reform as impactful to social determinants as a means for advocating for health reform? Anyone can take that.

>> DR. JEAN HALL: I can say on the survey we are collecting as many demographics as we can so that we can look at those sociodemographic factors associated with poor outcomes or access to health insurance so we can look at those relationships and to the extent there are strong relationships we can certainly make policy recommendations related to that.

>> Okay.

>> DR. JAE KENNEDY: I guess I would add to that, I think the point is well taken that employment can improve health as well as community living and engagement. So insofar as we can provide health services and allow people to return to work, that will affect their long‑term health and we're aware of that and try to make that point. Doing the research on that I think is a little beyond the scope of our current grants, but it's an excellent point and one that we're well aware of.

>> DR. LEX FRIEDEN: Alexander, before you leave and conclude, I do want to pitch for our internship, our summer internship program. If anybody's on who has colleagues or who yourself are interested in the summer internship program, please send us an email and we'll get back to you with information on that right away. It's a great program. You get to spend a lot of time with Dr. Jae Kennedy and Dr. Jean Hall and all of us at ILRU.

>> I agree. I'm a product of that.

>> DR. JEAN HALL: I would in urge can people that we didn't get to answer their questions if it was something you wanted me to answer, please email me and I'm happy to follow up with you. There was a question out there about Medicaid MCOs and if that person gets in touch with me I can show you some other papers related to that.

>> Yes, that would be great.

Well, I don't think there's any more questions at this time. So I think I'm going to wrap it up. Directly following this webinar you'll see an evaluation survey that will come up on your screen. The link is available also on the CHRIL website CHRIL.org. We take this feedback seriously as we want to hear about what you think about this presentation and how we can improve. If there's nothing more, I think that's it, and thank you so much for joining us today. Thank you. Bye.