

Transcript

INDEPENDENT LIVING RESEARCH UTILIZATION (ILRU) ILRU-CHRIL PRESENTS...HEALTH INSURANCE COVERAGE AND HEALTH CARE ACCESS DISPARITIES-(ZOOM) JUNE 13, 2018

>> Good afternoon. And welcome to our webinar, health care coverage and healthcare access disparities. I'm Carol Eubanks, instructional designer 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. Where you will find all of 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. If you move your cursor on the screen, you should be able to see a bar on the bottom of your screen. And there in the middle, one of the options is Q&A and you can use that to type questions. You can type your questions at any time, and we will address them during our Q&A breaks.

Captioning will also be available by opening the CC tab on the main screen of the webinar or if you prefer, you can view the full screen captioning. You are welcome to log into the CHAT there and enter your questions, and we will respond to them during our Q&A breaks as well. You can find the URL on the chat in the main webinar screen that I will be posting shortly.

And one final bit of housekeeping. At the end of the webinar, an evaluation form will open in your web browser. Please do fill that out. It's short and it's easy why I to complete. We use them to improve the work that we do in the future. We really would like to have your thoughts.

And now I'd like to introduce our moderator, Lex Frieden. He is director of Independent Living Research Utilization and the ILRU. Lex has served as chairperson on the National Council on Disability, president of Rehabilitation International, and chairperson of the American Association of People with Disabilities.

He is 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, right here in Houston.

Welcome, Lex.

>> Thank you very much, Carol, and welcome everybody, to this webinar. It's a pleasure for me to be here today with Jae Kennedy. I'm introduce Jae in a moment.

First let me just say that the collaborative on health reform and Independent Living is one of the most important projects that ILRU has undertaken since its founding nearly 30, or 40 years ago right now.

So the CHRIL really is designed to help us understand and discover the essential health reform issues and the impact of health reform on people with disabilities.

We're focused on working aged adults with disabilities at this point. But I think CHRIL has many opportunities in the future to extend beyond that. The collaborative is funding with a grant from the national institute of disability on Independent Living and rehabilitation research. And we certainly do appreciate the support of NIDILRR and our grant officer in the process of chairing out this project.

We also appreciate all the activities that you all have been engaged in helping us. We have a number of partners in the CHRIL. ILRU is only one. Along with Washington State University, that's the lead center in this activity. And we also have partnered at the University of Kansas, George Mason University, and the Association of Health and Disability.

The AHD is a valuable partner in our program. And the University of Kansas provides us with a great deal of background information. Our partners there are very adept at canvassing databases and pulling up information that we otherwise would not have the ability to reach.

Other partners in the CHRIL are NCIL, the National Council of Independent Living, APRIL, the Association of Rural Independent Living programs and the Urban Institute. We really do value our partnerships with all of our groups and particularly NCIL and APRIL because we have so many independent living centers and center directors and consumers who are engaged with us in this process. Both learning from us, contributing to the CHRIL, and hopefully benefiting from the efforts that we've made.

The presenter today is our leader, Jae Kennedy. And Jae has a long history of Independent Living. Some of you may remember Ed Roberts. There are just a few of us around who knew Ed very well. But Ed was the pioneer in Independent Living. And he really put together the Independent Living center in Berkeley. At some point, Ed said to me, you know, we're right next door to one of the most incredible brain factories in the world at the University of California at Berkeley. And he said, at some point, I'm going to create an institute and borrow from the brains of Berkeley to do research on Independent Living and to spread the word about Independent Living around the world. And he actually did do that. And he reached out to people across the street at Berkeley.

And one of those young people that he encouraged to come over and see what was happening with was a young fellow named Jae Kennedy. And Jae joined Ed at Berkeley with a number of other colleagues. And did some really important, founding work in the relationship between healthcare and the Independent Living.

I remember attending one of the meetings that Jae helped put together in Washington in the 1980s. And that meeting had a profound impact on the way I recognized healthcare in the context of Independent Living. So Jae has been a lead in our field for a long, long time.

He graduated, of course, from the University of California Berkeley. And he now leads the department of health policy and administration at Washington State University. Jae's department continues to recruit and train young people in the area of health policy and Independent Living. And I really do appreciate Jae's continued focus and commitment to the principles Independent Living. Jae's got a number of publications. If you scan Google, you'll find more than 50 peer review articles that he's written.

I think in this context, you should also know that NIDILRR in the year 2000, made Jae a distinguished research fellow in the Switzer fellowship is something he can be very proud of. Jae, I won't take any more time. Before I pass it over to you. I want to, on behalf of those of us who have been working in Independent Living for so long and who need the kind of support that you have given us, I just want to thank you very much.

>> Okay, I think I unmuted there. And, uh, thanks for that introduction, Lex. Feel free to unmute at any time and weigh in on this presentation. You're one of my co-authors.

So we're going to talk today about looking at coverage access, and utilization of health services for adults with or without disabilities.

So most of the stuff I'm presenting today is, uh, included in this article that Lex and I wrote last year. I'd also like to acknowledge our third co-author, Elizabeth Wood is is not able to join us today because she's heading back to Chapel Hill to defend her dissertation on Monday. If you have extra good thoughts to send her way, please do so. But she's been a long time protégé of mine and helps me move forward in? Of these disability policy work.

I would note that this journal article, Disparities and Insurance Coverage, Health Services, Use and Access following implementation of the Affordable Care Act is publicly available it was published in the journal inquiry which is an open access journal. And, you should be able to access it and counsel load a PDF of the file for free if you're interested in learning more about these issues or just seeing what I was talking about in this presentation.

Next slide, please.

So the purpose of this paper is really twofold. We're looking at comparing, adults working age adults with and without disabilities and we're also looking at changes in insurance coverage and use of health services and access problems in obtaining needed health services over time. And particularly looking at the change that may have been, may have been introduced by the implementation of the Affordable Care Act in 2014.

You may remember that the Affordable Care Act was actually passed in 2010. And some features of the legislation went into effect almost immediately. But we chose 2014 as the critical date because that's when nationally we instituted the health insurance exchanges there each of the states. This is when many states chose to expand their eligibility for their Medicaid programs. So this was an inflection point in the way we handled insurance regulation and expanded access. So that's why 2014 is so important.

So again, in essence, we're looking at time by disability status. And we're going to be looking both in friends over time and then also post ACA what the continuing disparities are between people with and without disabilities.

Next slide, please. So when we were writing up the CHRIL application, we hypothesized that the Affordable Care Act would have a particularly significant impact on working age adults with disabilities because they tend to use a lot of health services, and they also have been historically locked out of the private insurance market. So insurance coverage options were very limited prior to the reform of the private insurance market and consequently people with disabilities relied much more heavily on public insurance options like Medicaid and Medicare.

In this-- to the best of our knowledge, the first study like this, it seems like an obvious thing that you would see a report or a journal article about-- we did a good faith literature review at the time. This was really the first systemic comparison of a variety of health services and health access issues before and after the Affordable Care Act for adults with disabilities.

I guess I should also note here that the reason we focused on working aged adults with disabilities is because most seniors in the U.S. are eligible for Medicare. There were significant changes to the Medicare program as well as the Affordable Care Act. But we thought that the working age population is the most vulnerable subset of adults with disabilities in the current health system and consequently the ones most likely affects by the Affordable Care Act.

Next slide, please. So in this paper, we're using data from the NHIS, or National Health Interview Survey. This is ongoing national survey conducted by one of the Centers for Disease Control, the national center for health statistics. It's really kind of

an essential way of looking at changes in the health system over time and the impact on populations so a lot of disability researchers including myself, used the NHIS frequently over the years.

When we give our trend analysis, we started in the year 1998 which was, there's a major revision of the survey designed and estimates before and after 1998 were kind of different. So we've used essentially the same survey over an 18 year period for this analysis. It was comprised of 1.1 million respondents. And then to get more detailed looks at what's happening currently, post ACA implementation, we used the most recent panel of the health interview survey at the time which was the 2016 panel. It included a sample of 57.6 thousand working age adults. And at the end of the presentation of the results, I'll introduce this fairly complicated logistical regression model where we're looking at the impact of disability status and changes in the health system and how that affects access with both people with or without disabilities.

Next slide, please. So for this comparison, we came up with a very broad definition of disability. We defined someone as having a disability if they're age 18 to 64, and they either receive SSDI Social Security Disability Income or SSI, Supplemental Security Income. Or people that said that they are unable or limited in the amount or type of work they can do or people that reported that they need assistance with personal care activities or activities of daily living or people that reported needing assistance with household chores and instrumental activities of daily living or people that reported difficulty walking without special equipment or difficulty remembering or periods of confusion that affected their ability to function.

Next slide, please.

So using this definition, we estimate that the approximately 23.6 million non-institutionalized adults age 18 to 64 have a disability. That's about 12% of the population. And within this group, of 23.6 million, about 42% receive some sort of disability benefit either SSDI, SSI or both. The most common form of disability in this sample was folks reported they were unable to work due to a physical or mental limitation. I'm not going to read off all of these. But, I wrote note, too, that these counts could sum to more than 23.6 million because some of them, for example, might be receiving SSDI and say that they're unable to work and that they have difficulty walking without equipment. So they'd be counted multiple times than this. So this is not going to sum up to 23 million.

Okay, next slide, please. So this table is just looking at some very basic population attributes of young adults with and without disabilities. So working adults with disabilities are significantly older than those without disabilities. If you look at this breakdown.

Over 55% of the disabled population here is age 50 or older. So we have lots of folks that are, you know, in the end of their working careers in some ways or getting to the end of their working careers. And it's important to distinguish that from a much more, you know, wide range of age groups in the nondisabled category. You can also see that there are racial disparities here. African-American in particular, are more likely to report disability than white, Caucasian respondents. And, uh, in the incidents of disability among Asians is actually lower than the general population. Likewise, there are fewer Latino, young adults with disabilities than non-Latinos. Next, slide, please.

And this probably won't come as a surprise to any of you, but you know, the workforce participation rates of young adults with disabilities are significantly lower than the population without disabilities. So about 83% of working age adults without a disability report paid work in the previous 12 months compared to less than 35% of working age adults with disabilities.

And among the folks that are working, working age adults with disabilities are more likely to be working part-time rather than full-time. And presumably this is one of the things that's driving a far higher poverty rate in the working age population with disabilities. You can see that over 26% of the population of working age adults with disabilities has an income, annual family income less than the federal poverty level compared to the 10% of the population without disabilities. And that has consequences for receipt of disability benefits, and subsidized health insurance programs like Medicaid as well.

Next slide, please. So this is a comparison of types of insurance, health insurance coverage folks had after implementation of the Affordable Care Act.

Again, in 2016, you can see that people with disabilities are much more likely to rely on public benefits. 27% of the population received Medicare. Nearly 38% of the population, received Medicaid. Those rates are much higher than the population of working age adults without disabilities. Notably, people with disabilities are more likely to have health insurance of some kind than people without disability. So if you just do a simple comparison about insurance rates, it appears that, working age adults with disabilities are fairing better. But that's due in part to their low income which makes them eligible for a variety of subsidized health insurance programs like Medicaid.

Next slide, please. So I'm going to start on a series of longitudinal graphs now, looking at rates of different variables like in this one, insurance coverage from 1998 to 2016. So you can look at trends by looking along the axis, the bottom of this graph over time. And you compare the side-by-side graphs, you see the relative grades for working age adults with or without disabilities.

So as you can see here, in the first figure, insurance coverage has changed quite a bit for working age adults with disabilities over the last observation period here from 1998 to 2016. And one of the big stories is rates of private insurance for working adult with disabilities, has declined in 2014.-- actually, private insurance for working age adults with disabilities peaked in 1998 in a period of close to full employment. And up to that point, they've been dropping by, let's see here, by -- by 2008. Private coverage was much less in adults with disabilities. You don't see a big change in insurance rates with adults with disabilities until after the implementation of the Affordable Care Act.

But if you can trust the working age of population of adults without disabilities, you can see private insurance was and remains a dominant source of insurance coverage of working adults without disabilities.

The other important thing, I guess you can see here is that, with the uninsured line is in 2014, well actually in 2013 and 2014 you see the rates of insurance decline. This was after a pretty bad recession that we were getting out of.

So employment was also going up and that was one of the reasons the uninsured rate is going down. But the Affordable Care Act obviously plays into this as well.

Next slide, please. So this is breaking up public insurance coverage during the same period. I'm comparing disabled and nondisabled population for working age adults with disabilities. We look at Medicaid, Medicare, and folks that are eligible for both make and Medicare. Dual eligibles which is an interesting population.

But you can see in each of those public insurance categories, enrollment for people with disabilities grew over the observation period. And you can see with implementation of the Affordable Care Act in 2014 a big jump in the number of people enrolled in Medicaid only programs.

You see a particular kind of jump among the population of adults without disabilities, but the magnitude of the jump is smaller because there are fewer working age adults receiving Medicaid. Presumably this is what's happening when many states decided to

expand Medicaid eligibility and open up income eligibility requirements for adults that were categorically eligible. Medicaid jumped after the Affordable Care Act. Which we would have expected after the expansion.

I'm letting my closed captioner figure out what I just said here. Okay, next slide, please.

Again, this is not surprising. We know that people with disabilities have gotten multiple chronic conditions in a lot of cases and require more services. We're comparing two measures of intensive health service use. #1 the proportion of the group that stayed in the hospital overnight in the previous year, at least once, and also the proportion of the population that had visited a physician on an outpatient basis at least ten times over the preceding year. So both of these are expensive indicators of use of health services. And, uh, people with disabilities use more hospital care and more outpatient services.

So if you're comparing the two figures, you can see that the absolute rate of heavy use is much higher in this population. But you also see that there's not a whole lot of change in the observation period the portion of the population that's using the hospital or using outpatient services frequently.

And that's particularly important if you look from 2014 to 2016 after implementation of the Affordable Care Act. There was a concern as we expanded insurance coverage, we would have a big jump in the volume that services Congress assume particularly by people with high healthcare needs like adults with disabilities. That hasn't happened. Hospital rates have continued to decline. There's a slight jump in office visits immediately following implementation of the Affordable Care Act. But it's not a large absolute number.

But really the important point here is that, even both before and after the Affordable Care Act, heavy use of healthcare services is concentrated among people with disabilities, multiple chronic conditions.

Next slide, please. Okay, this is data that we got from another survey called the medical expenditure panel survey. And this is done by another federal agency and gets a lot more into cost data.

So if we compare average cost for people with working age adults with or without disabilities in the year of implementation of the Affordable Care Act, you can see the people with disabilities, have much higher average cost and consequently higher out-of-pocket costs. In fact, average total healthcare cost with working adults with disabilities are five times higher than those without disabilities. We break those out terms of hospital cost, outpatient, emergency department cost. Physician office visits and prescription medications. And I think in some as, prescription medication disparity is one of the more interesting ones. So adults with disabilities have five times as many prescriptions as those without disabilities.

But more troubling their costs were not were not five times higher. They're more like seven times higher. Not only working adults with disabilities are pay working with disabilities-- they're paying more for them. Despite the reforms, there is more cost for people with chronic conditions.

And it also suggests that we still have a way to go in containing prescription costs.

Next slide, please. Um, so this slide shows that, working age adults with disabilities are much more likely to report delaying receipt and receive medical care and skipping receipt of needed medical care because of cost. So access problems have always been a bigger issue. So you can see here the impact of not so much the Affordable Care Act of the great recession. The proportion of population of adults with or without disabilities who reported affordability problems peaked at the same time as the great

recession in 2009 and declined thereafter as the economy recovered and during that time, the Affordable Care Act was implemented. In this analysis we can't really tell what the discreet impact of the Affordable Care Act does.

The upshot though is after some really difficult times in the late 2000s, access began to improve. Next slide, please. And here's a little more detail on that with 2016 data. So for example, 31% of the population of working age adults with disability say they have problems for paying with medical services compared to 13.4% without disabilities. There's comparable differences on other access issues as well.

Next slide, please. Okay, so this is the logistic regression model I was warning you about. Uh, so what we're trying to get at here, we're trying to compare people with disabilities to people without disabilities. And also compare rates of access problems before and after implementation of the ACA. What we did was we took two years of population data before the implementation of ACA in 2014 and two years after implementation. 2015 and 2016. And we compared those groups and tried to look at the independent effects of reality reform and disability status.

And basically, what you see here, I don't want to get into explaining odds ratios. I'll be happy to do that and chat if you'd like, but I'm not going to bore the rest of you with it.

Even after controlling for things like age, gender, race, ethnicity, region, marital status and health insurance at that time us, the Affordable Care Act had a bigger impact on adults with disabilities than those without disabilities. So-- in technical terms the marginal effect, are larger in adults with disabilities. That's not surprising given the higher rates of access to begin with.

The take away point is that the Affordable Care Act improved access, improved coverage, but glaring and persistent disparities between working age adults with and without disabilities persist.

Next slide, please. So basic conclusion of this article is that, first of all, working age Americans with disabilities use a lot more services than those without disabilities and they have difficulty obtaining and paying for those services.

Consequently this population is particularly vulnerable to policy changes in the health system both for good and for ill. At least trend analysis show significant improvements in healthcare access following the implementation of the Affordable Care Act. They also suggest that effort to whittle away some of those access expansions and financial protections and regulatory protections could diminish the improvements we've seen after the implement the Affordable Care Act. Next slide, please.

So I think we'll take a break here and I'll answer questions and Lex can chime in as well about that paper and we're going to just discuss a couple of other emerging political issues that we're keeping an eye on in CHRIL.

>> Okay, if you want to submit a question for Jae or lex, type it in the bottom of the webinar screen. We don't have any questions yet. But we'll give it a minute or so and see if we get any questions before we move to the next section.

>> Jae, one obvious question is, what are the implications of the current action by the Supreme Court and by certain states and the Federal Government in regard to the Affordable Care Act? You want to address that after another few, a little discussion? Or you want to go into that a little bit now?

>> I don't have a slide for it yet because this basically just came up. We can certainly talk about it. Um, so I believe what Lex is talking about, is there's a court case that's going forward arguing that the repeal of the individual mandate undermines the rationality of Affordable Care Act was Constitutional. It's-- it's a little complicated. But the Supreme Court decided that, you know, the Obama administration was within its rights as a federal agency to enact tax policy throughout the country. It wasn't an

encroachment on state rights except for the Medicaid expansion. That's why it became an option rather than a mandatory policy change.

But the argument now is that, since we're no longer requiring people to purchase health insurance starting next year, it really isn't a tax anymore. And consequently the state should have more flexibility in regulating the private insurance market. I will say that it's a pretty controversial. A lot of Republicans and democrats are worried, that kind of repeal before a midterm election can be disruptive and confusing to the healthcare industry as a whole including adults with disabilities.

And I'd be happy to respond in more specific questions in a minute if somebody has them. Although I'm trying to figure it out myself. I'm not an expert in this latest develop.

>> Jae, some commentators have suggested that it will in fact, remove the requirement that insurance companies ignore preexisting conditions.

>> Yeah, that's one of the implications is that, we wouldn't be able to institute national regulation on the health insurance system. It will fall become to the states. And the states might say, you know, that some insurance products can opt out of providing universal enrollment.

Okay, why don't we go to the next slides? I hope this means somebody is still listening to the presentation. Or maybe I'm doing a wonderful job.

There were a couple of things that I mentioned in the abstract of the presentation that I'm going to talk about next. Next slide.

So these are mostly congressional ideas for health reform that were proposed last year. One of these is kind each time trusted conservative strategy for containing excessive growth in public insurance cost.

So for many years, at least a fraction of the GOP has pushed for block grant funding for state Medicaid programs. The rational is obvious because Medicaid is growing at a much higher rate. Costs are growing at a much higher rate than tax revenues are increasing in the states. So consequently states are having to cut back things like education programs to cover the growing cost for Medicaid.

And the Federal Government is frustrated because they can't really plan long-term for that since the inflation rate is higher. And more erratic and dependent on heying costs-- both for health insurance and health services.

So the idea is instead of giving states a federal match for all their Medicaid expenditures. They will give states a set match at the beginning of the year and the state has to work within that budget. If they spend through their Medicaid dollars and have to pay on state dollars and balance their budget, they will have to do things like add waiting list or reduce reimbursement rates and, if the states have to do that, then the going to reduce access to good comprehensive Medicaid services.

Another problem with the Medicaid block grant is that the Federal Government doesn't need to balance its budget each year. The states usually do. I think all the states do, actually. So states borrow independently, and they have to keep their costs and revenues balanced. And during a recession, tax revenues decline because few people pay into the system, at the same time people demand Medicaid services because they lost their jobs and they're seeking help from the state programs.

Because the Federal Government is kind of able to pay on the fly for this through deficit spending, people, economists will describe the Medicaid program as its set up is counter cyclic. In other words, when there's a downturn in the economic cycle, federal money cannot transferred to the states to help balance their budgets and compensate in part for the growth and demand of Medicaid services.

So if we moved over to a block grant program, that could potentially undermine the counter cyclic program and make recessions longer lasting in states.

Next slide, please. Something that's happened more recently in 2018, they had the centers for Medicaid and Medicare services started approving, new work requirements for the expansion population. So states are opting to expand eligibility for Medicaid but putting additional requirements for these new Medicaid beneficiaries. States are doing this through a mechanism called 1115 waivers. And it's mostly red states that are adding requirements to either have co-pays or require participants to be working or volunteering for a certain number of hours a week as a condition of receiving Medicaid benefits.

So that doesn't have a direct effect on a lot of folks with disabilities who are on Medicaid because they are exempt from this new work requirement. The proposals that CHRIL is approving, saying, that people who are approving SSI don't need to be seeking work or work training or actually working. But the problem with that is that, as many of you know, really we don't want to have this either or system as far as employment of adults with disabilities. We want to encourage as many people with disabilities to work.

So by forcing people to be labeled as medically frail and remain enrolled in SSI programs, it means it's going to be more difficult to support this population if they choose to return to work or enter the work force for the Face Time. In the 1990s, we spend a lot of people for SSI--ticket to work and work incentives improvement act. But so those programs are now going to be going to be undercut by these efforts to force workforce participation instead of incentivizing workforce participation. That's a troubling development even if a significant segment of the population won't be directly affected.

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So Lex and I talked about this a few minutes ago. As you may remember, in 2017, including from the dramatic showdown in the Senate, in the summer of 2017, an effort to fully repeal the Affordable Care Act was placed on the floor and at midnight vote-- Senator John McCain voted down the legislation to repeal the ACA. But later in 2017, the Congress did approve a dramatic set of changes in the taxation rates for corporations and individuals.

And as part of that omnibus budgetary reform they included a repeal of the individual mandates. And the individual mandate requires people to either purchase insurance or pay a fine at tax time. And, it not only encourages people that otherwise wouldn't seek health insurance because it's too expensive and they're often just getting started and other competing financial demands like rent and travel expenses and, you know,-- video games, I suppose. They're young, and healthy, they don't need insurance. Yes, they could be hit by a bus or something and shall seriously injured and require a lot of health insurance coverage, but the odds of that are low.

So it's not an irrational decision for young people to forego health insurance particularly if it's expensive. Part of the Affordable Care Act was forcing these young, healthy population into the insurance pool by finding limits they didn't -- and by repealing the individual mandate we no longer have that kind of short stick to push people that don't want to purchase insurance because they don't think they need it into the private insurance market.

So the problem with that is that, once we take out these younger and healthier adults, then the risk pool, the number of people that are likely to use services gets smaller and more expensive. So if young and healthy people leave the insurance plan, the remaining folks who still need insurance and are willing to pay more for it are going to drive up the total costs for premiums because they use more healthcare and ultimately that can lead to what's called in the industry, a desk file for insurance

companies-- are insuring a smaller and more expensive population each year until the find they can't provide affordable benefits that are used by that population.

So people with disabilities because they use a lot of health services are going to be some of the last to leave insurance pools:

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And finally another change which is going to have a similar possibly a less dramatic effect than repealing the mandate. The insurance services has expanded the regulatory-- provision of short-term duration of insurance plans. These are supposed to be cheap stock gap plan to cover people if they change jobs or move. They were never regulated under the Affordable Care Act because they were a small part of the market. But with the support of the White House and Congress, there's a -- they're going to make it a lot easier to offer these short-term under the duration insurance plans. And those again will potentially peel off a younger healthier section of the insurance market and leave the more expensive, less healthy adults in the risk pool and drive up the cost of that population.

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So I'd be happy to talk about any of those things or get back to the Supreme Court challenge that Lex just mentioned. If you have questions about that, please send them along.

>> We don't have any questions right now. But if you'd like to submit one, type it in the Q&A tap located on the bottom of your webinar screen. Okay, we still don't have any questions. We've got plenty of time.

>> Okay, well, let's do the next slide then, Carol.

>> That's it. Okay.

>> here's the evaluation. Here's my contact information. If anybody would like to share their thoughts and experiences about health policy or challenges with health insurance in particular. I'd be happy to talk to you individually. I believe we have another slide with the CHRIL website address. There are a lot of resources at www.chill.org. We spent a lot of time getting that website up to snuff and keeping it current. There are a lot of resources there. Freely free to contact me if you want to contact me or be involved with the activities of the CHRIL.

>> Let me add, Jae, that we really do appreciate it when people put forward question. And we appreciate the fact you understand that we won't be able to provide detail and responses for everybody who might have individualized questions. To capture themes from those questions, and we will try to be responsive. The themes are important because the themes give us the information we need to focus the research that we're doing. It also gives us cues with the kinds of questions, the people working and Independent Living Research Utilization and consumers have and that will enable us to produce written materials, background information, and more kinds of generalized information in had laypersons terms that you can transmit to others, share with others and point others to.

A lot of times, working in this area with health policy as you've seen from are the presentation, some of the interpretation has to be technical because we're working with data that has certain conditions. But we can translate a lot of what we learn to layperson's terms.

You see that on the website and some of the materials we produce but to the extent that you provide us with ideas of other themes that are pertinent to the data that we can go ahead and develop in information materials. That's very useful and help. And we appreciate it when you do that.

>> Yeah, I just like to echo that. This is -- we're committed to surveying the disability community. And you need to share your concerns with those so that we can address those.

>> It looks like we have a question.

>> Oh, yay.

>> Yeah, and you open the Q&A box. It says, do you ever see healthcare becoming available to all-Americans and what would need to happen for that to occur?

>> Oh, boy. Uh-- I do see it as something that we can do. If only because most other developed countries are doing this. We're really the only country in the world that has, the only country in the world, the only developed country in the world that doesn't have a mechanism for providing some sort of insurance sort of insurance coverage for most or all of the citizen. The Affordable Care Act tried to build own what we had. I think that there's a move of foot now to start to look at it more bold strategies or start to replace this unstable and increasingly unprofitable supports.

I think the insurance based public insurance system is discriminatory. If we can come up with some other entitlement for people, that are for whatever reason that are not engaged in the private workforce, then-- then we could get to near universal coverage.

Okay. I figured that the healthcare problem access only impacts 30% of the population. That's probably about right, depending on how define access problems.

I mean, one of the reasons that people with disabilities report much higher rates of access problems is because they're more regularly seeking Disability Services. So every time you go to the doctor, you're potentially having a frustrating encounter. You're getting hit with a co-pay you didn't expect or given a prescription that you can't afford to fill or something like that.

So a lot of people are pretty light users of the health system and they don't have complaints in a given year. But, you know, the more that they use the healthcare system, the more likely they were to encounter problems with it. It's the heavy users the healthcare system we need to pay attention to because they rely on the services they need.

>> Jae, for years we have been concerned with the unemployment rate with people with disabilities. In the beginning after ADA we thought a lot of that would resolve itself. We at one point theorized that part of the issue was the education gap. After we integrated the schools and prevented the schools from discriminating on disabilities. The high unemployment rate remained. Unemployment. The biggest problem was the issue of not having health insurance if one were in the workplace particularly with the small employer.

And that there were, you know, many concerns. And that was given as the primary theory why the unemployment rate was so high. Now we've been able to address that partially with provisions in the social security act and later with some provisions in the Affordable Care Act.

And yet, the rate of employment among people with disabilities has not seemed to move significantly. Do you have any thoughts about that?

>> Well, I do. I think, I think, you know, disability discrimination is illegal. It's prohibited by the ADA. But you can imagine a lot of employers just like a lot of landlords or something, they don't need to give you a reason why they didn't offer the job to you or didn't offer the apartment to you. And they can just say they gave it to somebody else.

And part of that is just, you know, social bias and stigma for people with disabilities but for an employer it's a rationale concern that if they're self-insured and paying for the

insurance of their workers and hiring somebody who is likely to incur healthcare cost, that's a problem for them. They'd rather not hire people who wouldn't use high health insurance.

I think what we should do, when somebody is deemed eligible for SSI and SSDI which is a complicated thought process and isn't easy to get. Once you've proven you've got a long-term set of conditions that are going to interfere with your work, they should be guaranteed health insurance, Medicaid or Medicare or something else. But we'll take care of health insurance for people that are deemed disabled by this complicated review evaluation system. And then we'll essentially, we'll say that you don't need to worry about health insurance. Find a job. Your employer wouldn't worry about health insurance.

I think that would be a spectacular improvement on hiring practices on people with disabilities. Instead of being a negative, it will be a positive. Somebody has a disability and has guaranteed health insurance, but first costs is going to be low for that person, they're going to be very low. And then we can figure out ways to integrate people with disabilities fully into the workforce.

>> Interestingly enough, one of the principle sponsors of the ADA, Steve from Dallas Texas actually proposed that and tried to get that provision included in, not in the ADA but in law of that affects the social security programs. They made a compromise that resulted in a provision where people have a right to maintain certain benefits if they go back to work but only for a limited period of time.

>> Yeah, I would like to just make it permanent that everybody is going to be, that's, you know, needs health insurance based on disability status gets it up until the stage that they become eligible for Medicare. And so, I mean, one option is, there were a lot of different terms for Medicaid, what are called Medicaid buy insurance. Some of those are ticket to work incentive programs where you're allowed to continue to purchase Medicaid insurance after you're technically earning more money than you're eligible for.

I would like to see a federal Medicaid buy in program where, you know, nationally, the Federal Government decides to offer Medicaid to people that are determined to have a long-term disability. And that's sort of a Medicaid buy in program could be an "modified slighting fee scale so either the employer or employee can both chip into that and it would be based on a reasonable enough level so it can move people out of these disability programs and back into the workforce.

I don't know a lot of people that are really, you know, living high on the hog on SSI and SSDI benefits. One of the reasons they're in this program is to get access to Medicaid or Medicare. If you couple those income supports for health insurance benefits, I think it would go a long way addressing this employment disparity.

>> Sounds like we have some papers to write.

>> Yes, indeed. We are working on this stuff, folks. Okay, PM mar tell is asking if it's going to change. If we're going to reach I breaking point in the U.S. health system where people rise up and demand a single paying system.

I would say, somebody who got a Ph.D. in health policy, if you ask people about the health system, the American health system, they're not thrilled with it. If you ask them, should we have a universal system that provides universal coverage or single payer or something like that? Political support for that is very high when you start to bet into the details of okay, we're going to have to raise taxes and/or cut reimbursement or people in the strict kind of managed care panel, support for those cost containment measures that would allow us to have the resources to expand coverage to the entire population, that's when things get tricky.

>> and politicians on both sides are exploiting those concerns and leaving us in a stalemate.

I think it's fair to say the Affordable Care Act would not have passed if we hadn't been in the midst of a terrible recession, perhaps if we had another recession, and we're probably due for one in the next couple of years, we're going to be forced to revisit this just because of the tremendous financial burden on both employers and employees.

>> Yeah, I think the probably the public perspective is, if it's not completely broken, then don't fix it because anything that the politicians do next is probably going to make it worse.

>> Yeah, it's-- uh, it's an interesting and frustrating area to be in. But I think I would just echo your earlier point. People with disabilities need to be advocating for themselves and for the system and communicating with us about their concerns so that we can try and provide the evidence to support those concerns and bring them to policy makers.

I mean, I don't think that, uh, the impact of the Affordable Care Act on people with disabilities are foremost in the minds of the folks that developed legislation. It was a concern, but it was. A top concern. And you know, I believe it should have been.

And I hope that the next time we take a stab at this, we'll acknowledge and address those concerns more effectively.

>> All right. Carol.

>> Okay. I don't think we have any more questions. So I think we can start wrapping this up. When you close-- when the webinar ends, you'll see an evaluation. Please do fill that out. We'd appreciate it.

Thank you, Jae and Lex and all of you for joining us today. I think that's it, guys. So bye, everybody.

>> Thanks!

>> Thanks.