

Overview of the 2018 National Survey on Health Reform and Disability (NSHRD)

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(CHRIL)

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Acknowledgments/ Disclaimer

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Today's Panel

- **(Liz Wood) Noelle Kurth:** NSHRD background, development, recruitment, sample
- NSHRD Findings
 - **Liz Wood**, Washington State University: "Insurance Instability and Access to Care in the NSHRD"
 - **Meredith Repke**, University of Montana: "The Association between Rural Residency and Self-reported Health"
 - **(Jae Kennedy) Jean Hall**, University of Kansas: "Health and health care experiences of Americans with disabilities identifying as LGBTQ+"

Background: What is CHRIL?

- NIDILRR-funded DRRP, October 2015 - September 2020
- **Objective:** To discover and share essential information and research findings regarding how health reforms affect working-age adults with disabilities.
- **CHRIL:** Washington State University (WSU), University of Kansas (KU), George Mason University (GMU), Independent Living Research Utilization (ILRU) at TIRR Memorial Hermann. Additional collaborators: The Urban Institute, UM RTC:Rural, University of NC at Chapel Hill, NCIL, APRIL, American Association on Health & Disability (AAHD), Disability Research Interest Group (DRIG) of AcademyHealth
- Secondary analyses
 - WSU and GMU analyses using national data sets (e.g. MEPS, NHIS)
 - KU, UNC, Urban Institute analyses of Health Reform Monitoring Survey-addition of disability question in 2013
(Hall, Shartzter, Kurth & Thomas, AJPH 2017 & 2018)

What is the National Survey on Health Reform and Disability (NSHRD)?



- First fielded in February – June 2018; U.S. adults (18-62) with disabilities, n=1,246 complete
- Online survey with telephone/alternate format and proxy options
- A majority of respondents took 20 minutes to complete (5 min – 60 min)
 - Dependent on complex skip patterns (e.g. coverage and unmet need by each insurance type)
 - ability to program certain fields to populate based on individual respondents (e.g. FPL grouping)
- Development informed by previous secondary analyses, national interviews, CHRIIL expert advisory board, input from people with disabilities of all types and field-testing
- Utilized items from existing surveys (e.g. HRMS, NHIS, MEPS, BHIS, BRFSS)

NSHRD Content Areas

- Health status
- Access/Barriers to health insurance and health care services
- Use of and access to paid and unpaid PAS
- Health Insurance Motivated Disability Enrollment (HIMDE)
- Employment, SSI and SSDI participation
- Community participation
- Insurance type(s) and coverage, including uninsured
- Unmet health care needs (type, level, service & visit limitations)
- Demographics

NSHRD Recruitment

- 50+ national disability, advocacy, chronic disease organizations provided survey info, toll-free number, website, link to survey (1-6 times each)
 - Websites, newsletters, flyers, social media, calls with CILs, conferences, listservs, emails to consumers
 - Occurred in waves based upon ongoing monitoring of demographics (November 2017 – March 2018)
- Limitations
 - Ultimately a convenience sample
 - disability-related organizations assisted with recruitment therefore, their staff participated (higher levels of education and employment)
 - Under-representation: males, people of color and individuals from southern states
 - Over-representation: individuals with college degrees, employed, LGBTQ+ gender-nonconforming; advocates who are more aware of and connected to disability issues
- Led to the need to develop a weighting methodology for national representativeness

NSHRD Weighting

- Despite best efforts in recruitment the sample was still not nationally representative of people with disabilities therefore a weighting methodology based upon ACS Census data was developed
- Variables used in weighting: geographic location, gender, race/ethnicity, education level
- Some analyses presented today use the whole sample and therefore will be using weighted data (Liz, Meredith), while the analyses Jean will present were with a sub-sample that was over-represented (LGBTQ+) and does not use weighted values

Disability measures in the NSHRD

HRMS disability item

HRMS updated item

KU open-ended disability item

Disability onset item

6 American Community
Survey items

Initial screening question

Do you have a physical or mental condition, impairment, or disability that affects your daily activities OR that requires you to use special equipment or devices, such as a wheelchair, walker, TDD or communication device?

Follow-up questions as part of Demographics

1. Do you currently have a health condition that has lasted for a year or more or is expected to last for a year or more? This could be a physical health condition (such as arthritis, asthma, cancer, dementia, diabetes, heart disease, hypertension, or stroke), a behavioral health or mental health condition, or a developmental disability.
[Assesses permanent, versus temporary, status of disability.]
2. What is your disability and/or health condition(s)? If you have more than one, please list your main one first. (Responses from this open-ended item were used as written and also coded into categories: Mental illness/psychiatric disability; Physical disability; Chronic illness/disease; ID/autism; cognitive; Sensory; Neurological (includes paralysis, spinal cord injury, cerebral palsy, epilepsy, multiple sclerosis, traumatic brain injury, etc.)
[Provides verbatim self-reported disabilities, rather than disability categories such as with the ACS questions.]
3. What age were you when your main disability or health condition began for you?
[Assesses permanent versus temporary disability, but also allows for examining different needs and outcomes among those with life-long versus more newly acquired disabilities.]
4. ACS-6 disability questions
 - a. Are you deaf or do you have serious difficulty hearing?
 - b. Are you blind or do you have serious difficulty seeing even when wearing glasses?
 - c. Because of a physical, mental or emotional condition, do you have serious difficulty concentrating, remembering or making decisions?
 - d. Do you have serious difficulty walking or climbing stairs?
 - e. Do you have difficulty bathing or dressing?
 - f. Because of a physical, mental or emotional condition, do you have difficulty doing errands alone, such as visiting a doctor's office or shopping?

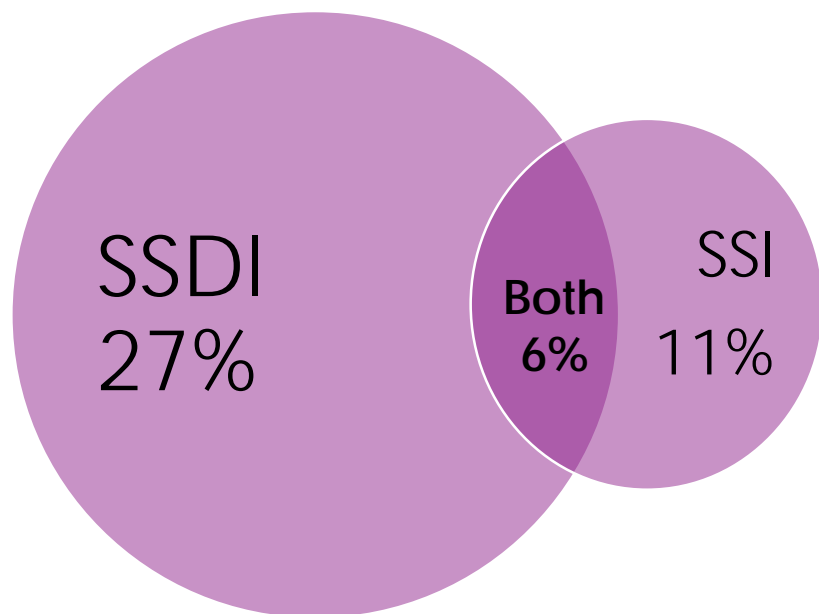
Sample Characteristics (N=1,246)

- **Age:** Mean of 44.1 years (Range:18-62 years)
- **Gender:** 68% female, 30% male, 2% other
- **Race/Ethnicity:** 81% white, 7% black, 5% native American, 5% Hispanic, 3% Asian, 2% other
- **Region:** 28% South, 26% Northeast, 24% West, 22% Midwest (62% from expansion states)
- **Primary disability type:** 28% neurological, 23% physical, 20% chronic illness/disease, 16% mental illness, 7% IDD/Autism/cognitive; 6% sensory; 5% undisclosed

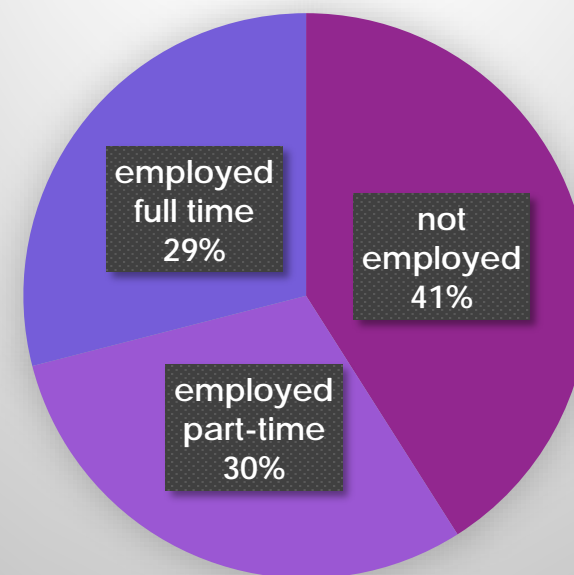
Current Coverage Type

- 7% with no insurance coverage
- 47% have employer-sponsored insurance⁺
- 32% have Medicare coverage
- 32% have Medicaid coverage
- 6% have a plan purchased from the Marketplace
- 3% have TRICARE or other VA health coverage
- 1% utilize Indian Health Services (IHS)
- 40% report having more than 1 coverage type

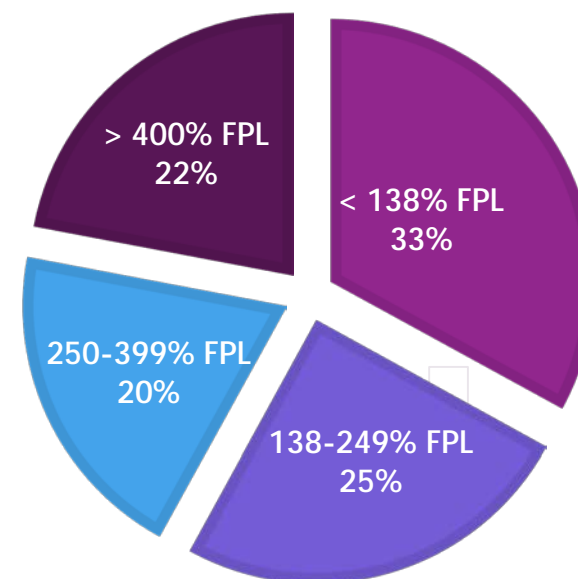
⁺ includes coverage through respondent, spouse or parent employer



Employment Status



INCOME LEVEL, ADJUSTED FOR HOUSEHOLD SIZE



Other Selected Descriptives

- Among PAS users (n=647), 60% report receiving unpaid support only, 22% report receiving paid support only and 18% report receiving both paid and unpaid support
 - 7% (n=85) reported needing PAS but **do not** receive it
- 17% reported getting NEW health insurance through the Marketplace since 2014
- 14% reported getting NEW health insurance through Medicaid expansion in their state
- 26% (n=311) reported that **not having reliable transportation** limits their ability to get the health care services they need

Next Steps

- **NSHRD Data Analysis Group**

- Researchers from 6 institutions working together right now to conduct analyses, present and write manuscripts. Those being presented today, plus others.
- We are open to having others who are interested in using the de-identified data set to get in touch with Noelle Kurth at the University of Kansas. Data will be made available publicly at a later date, but if anyone is interested in working as part of the Analysis Group now, please let us know.

Second administration of the NSHRD will be in Fall 2019. We will begin revising in June, if you have ideas for items to include, please reach out.

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Insurance Instability and Access to Care in the NSHRD

Liz Wood, PhD
Washington State University

Background



Life transitions – like gaining or losing a job, or gaining or losing a spouse – are often accompanied by changes in health insurance, also called **insurance instability**.



In the general population, insurance instability is often associated with access problems.



Because of high health care needs and associated costs, people with disabilities are particularly vulnerable to disruptions in coverage.



Our understanding of the effects of instability on people with disabilities is limited.

Objective

This presentation will explore insurance instability for people with disabilities, using data from the NSHRD.

- Document prevalence of different patterns of coverage.
- Test for an association between insurance instability and healthcare access problems when controlling for other factors.



Methods



NSHRD asked respondents questions about coverage and access over 12 months prior to survey participation



Conducted logistic regression models, marginal effects, and predictive margins using STATA.



Models controlled for age, sex, race, education, employment status, marital status, household composition, family income relative to poverty level, and region.



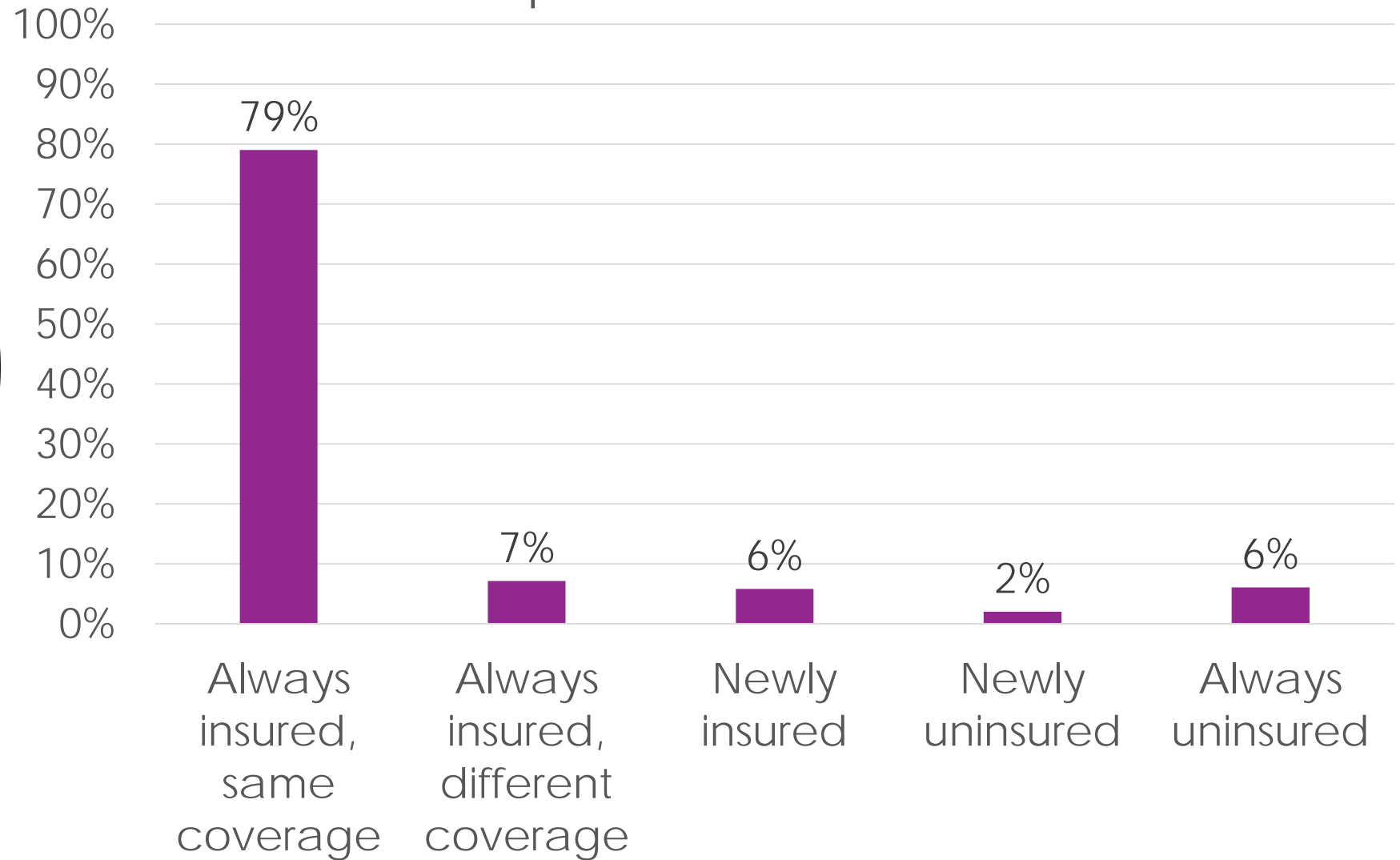
Weighted estimates/models.

Selected Access Outcomes

- Thinking about all your healthcare experiences over the past 12 months, was there any time when you needed any of the following, but didn't get it because you couldn't afford it?
 - General doctor
 - Prescriptions
 - Mental health treatment
- Is there a place where you usually go when you are sick or need advice about your health?
 - Respondents who said yes, or more than one place, and did not indicate the emergency department, were considered to have a usual source of care.

Prevalence of different insurance instability patterns

Prevalence
of different
insurance
instability
patterns
(n=1016)



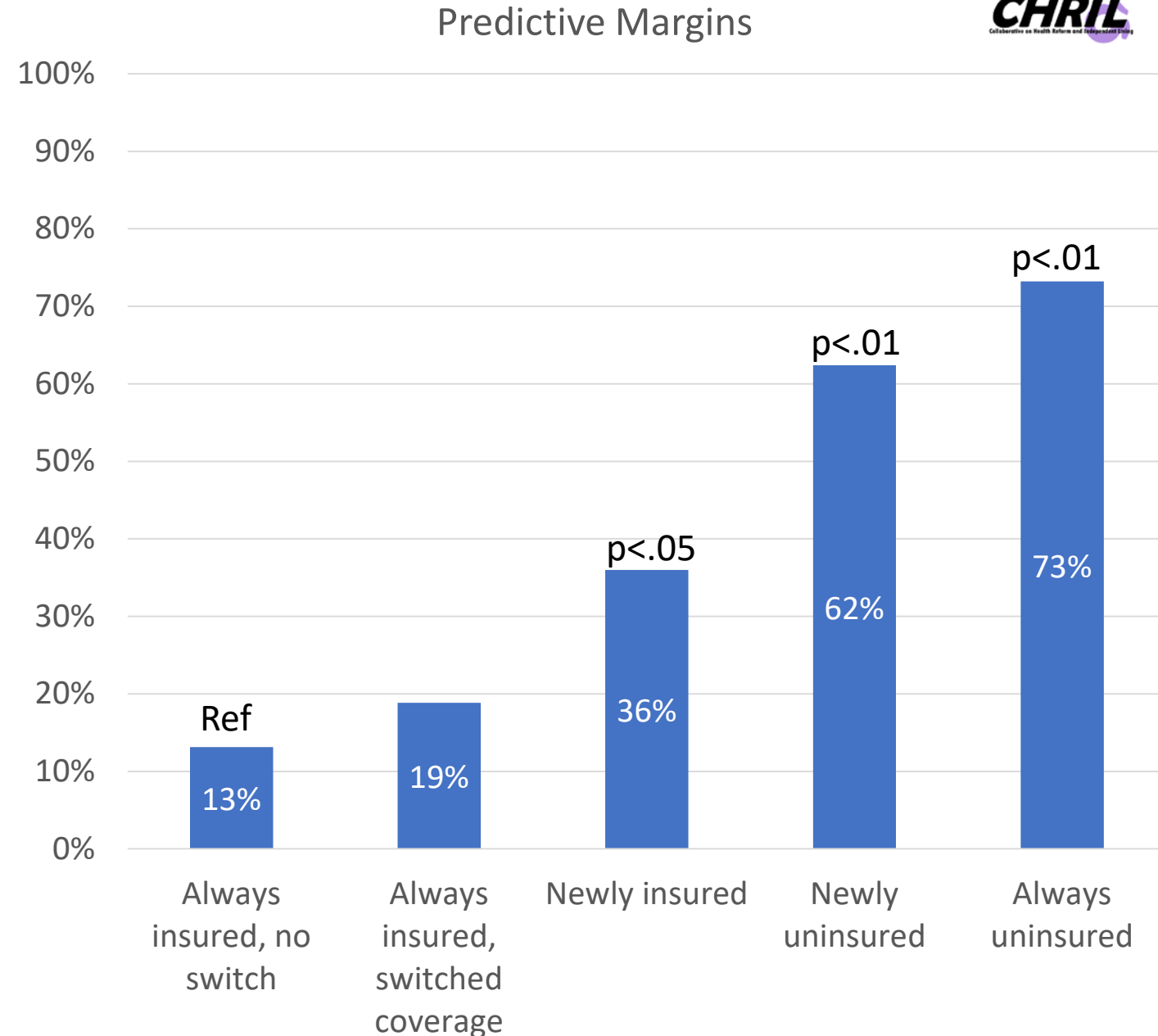


Results

Access to general practitioners

Controlling for other factors, we find that compared to those with stable coverage...

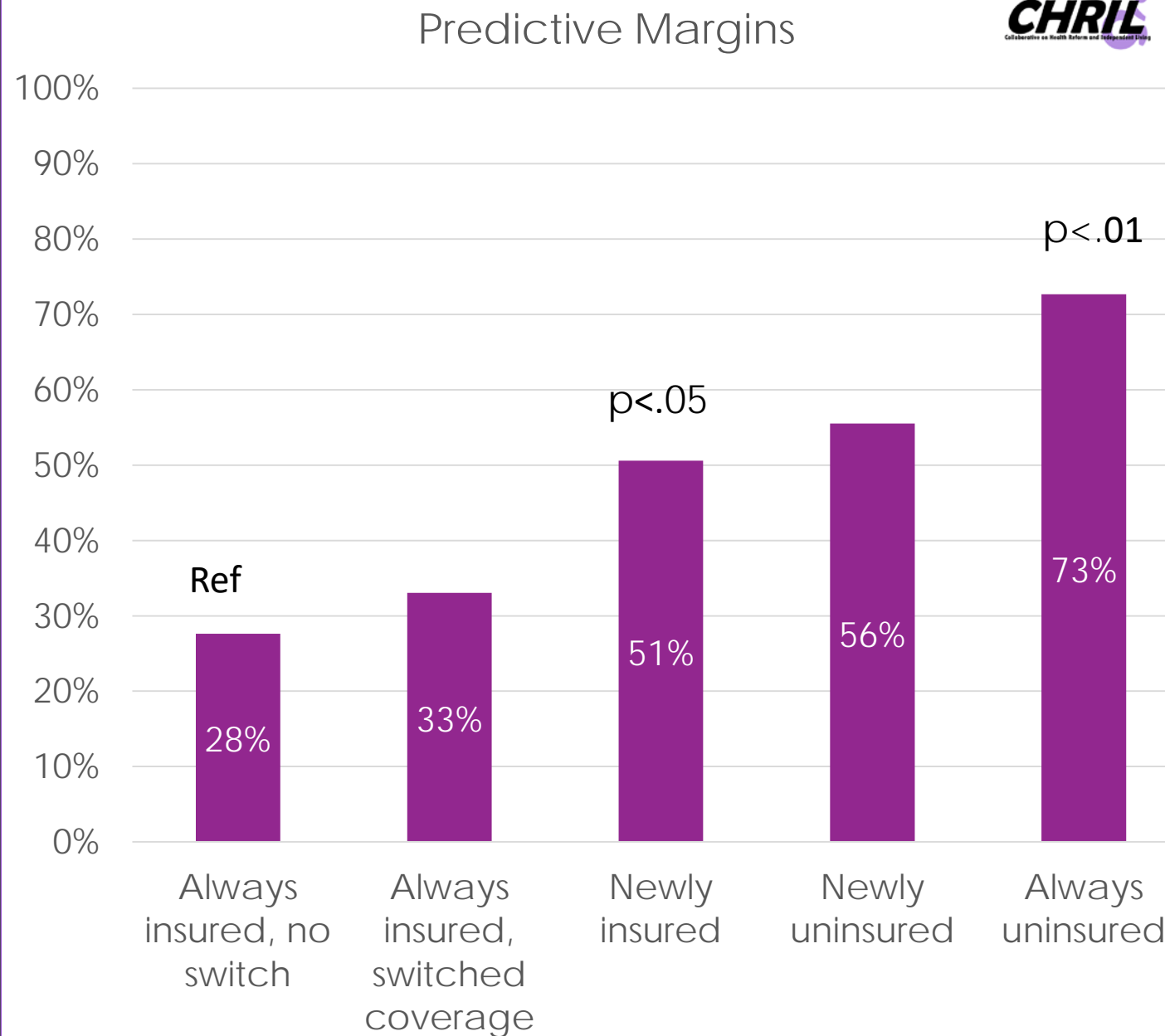
- People who were **newly insured** were 23 percentage points more likely to have problems accessing a general practitioner ($p < .05$).
- People who were newly uninsured were 49 percentage points more likely to have problems accessing a general practitioner ($p < .01$)
- People who were always uninsured were 60 percentage points more likely to have problems accessing a general practitioner ($p < .01$).



Access to prescriptions

Controlling for other factors, we find that compared to those with stable coverage...

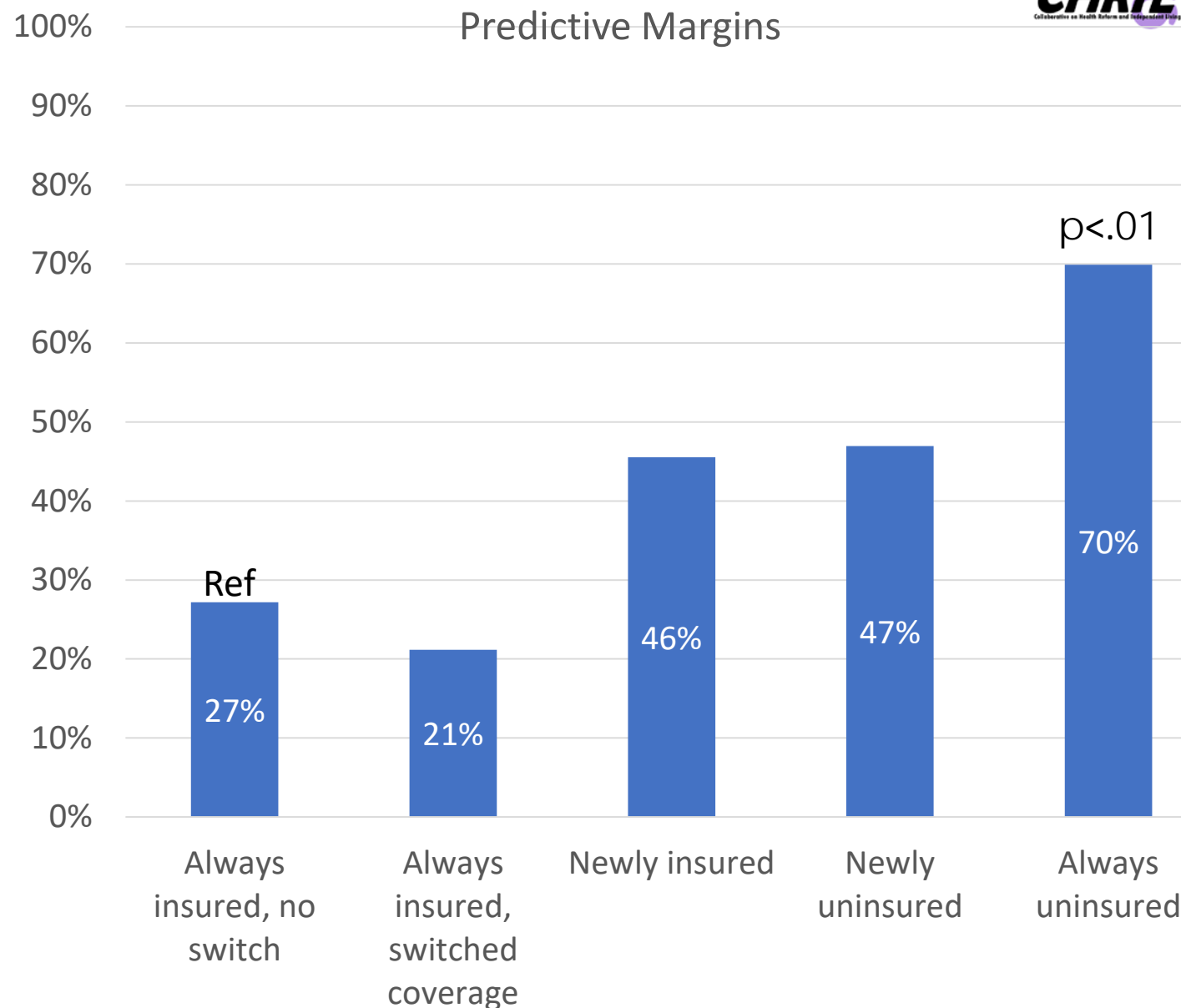
- People who were newly insured were 23 percentage points more likely to report a problem accessing prescriptions ($p < .05$).
- People who were always uninsured were 45 percentage points more likely to report a problem accessing prescriptions.



Access to mental health treatment

Controlling for other factors, we find that compared to those with stable coverage...

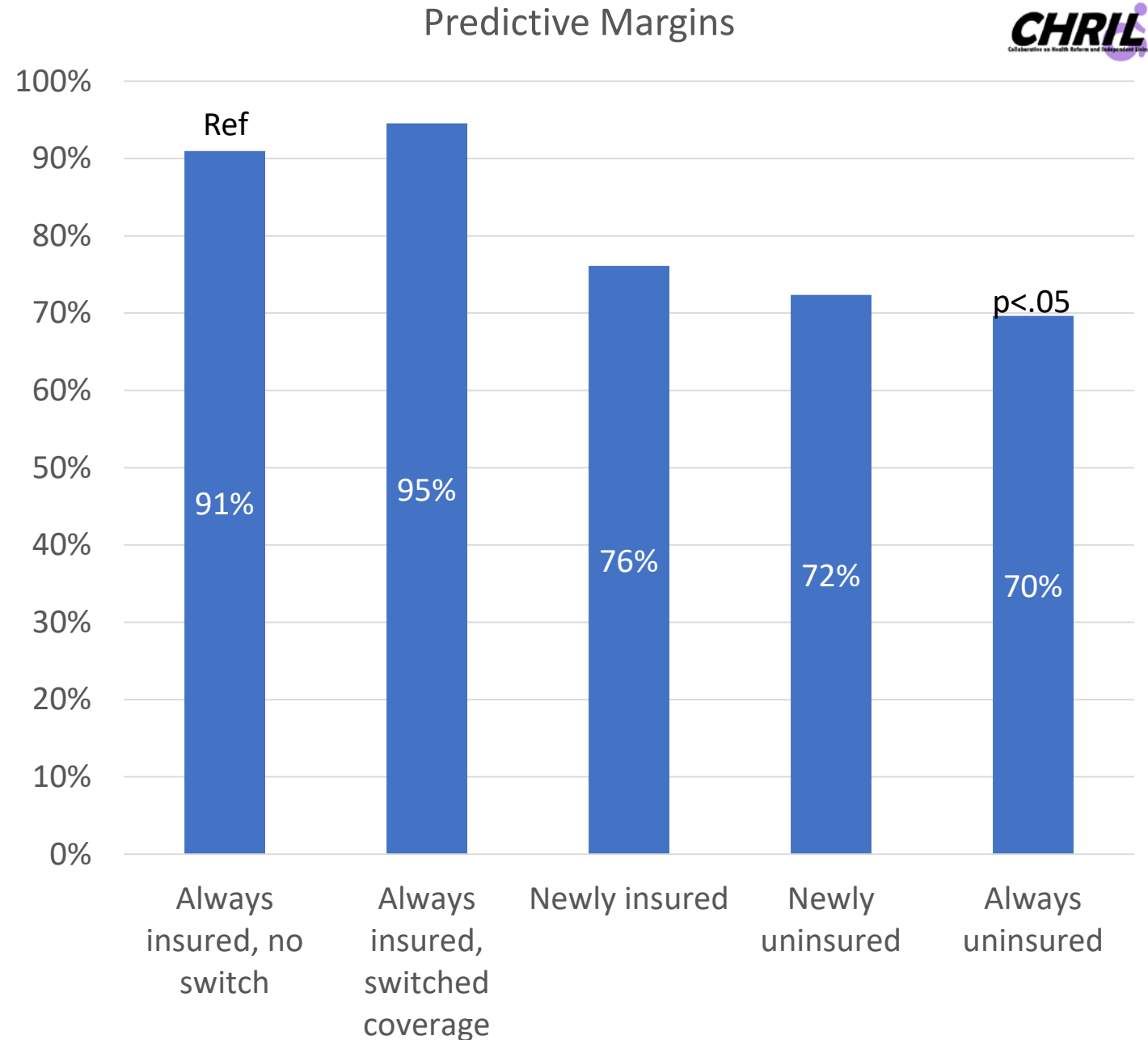
- People who were always uninsured were 43 percentage points more likely to report difficulty accessing mental health treatment ($p < .01$).



Usual source of care

Controlling for other factors, we find that compared to those with stable coverage...

- People who were continuously uninsured were 21 percentage points less likely to have a usual source of care ($p < .05$).



Summary of findings

- One out of five adults in the NSHRD reported some form of insurance instability in the prior year.
- Compared to people with stable coverage, when considering the previous 12 months:
 - People who were **continuously uninsured** were more likely to report problems accessing a general practitioner, prescriptions, and mental health treatment, and were less likely to have a usual source of care.
 - People who were **newly insured** were more likely to report problems accessing a general practitioner and prescriptions.
 - People who were **newly uninsured** were more likely to report problems accessing a general practitioner.

Limitations

- Sample size for certain instability groups is small.
- IHS, Tricare respondents not included.
- Endogeneity – some of the observed effect could be the result of unmeasured other disruptions like moving.
- We do not know whether the access issue occurred before the insurance instability, after the insurance instability, or both.
- Some people experience repeated instability.



Conclusion, Policy Implications

- These findings suggest that insurance instability is prevalent among people with disabilities and is associated with access problems.
- When we assess the impact of coverage on access, considering health insurance experiences over time may be informative for researchers.
- When we make policy decisions that affect coverage options for people with disabilities, the effect of instability on access needs consideration.

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The Association Between Rural Residency and Self-reported Health

A stylized white mountain range graphic with three peaks of varying heights, set against a dark red background.

Catherine Ipsen, Ph.D.

Meredith Repke, Ph.D.

The University of Montana Rural Institute
RTC on Disability in Rural Communities (RTC:Rural)

Social Determinants of Health Framework

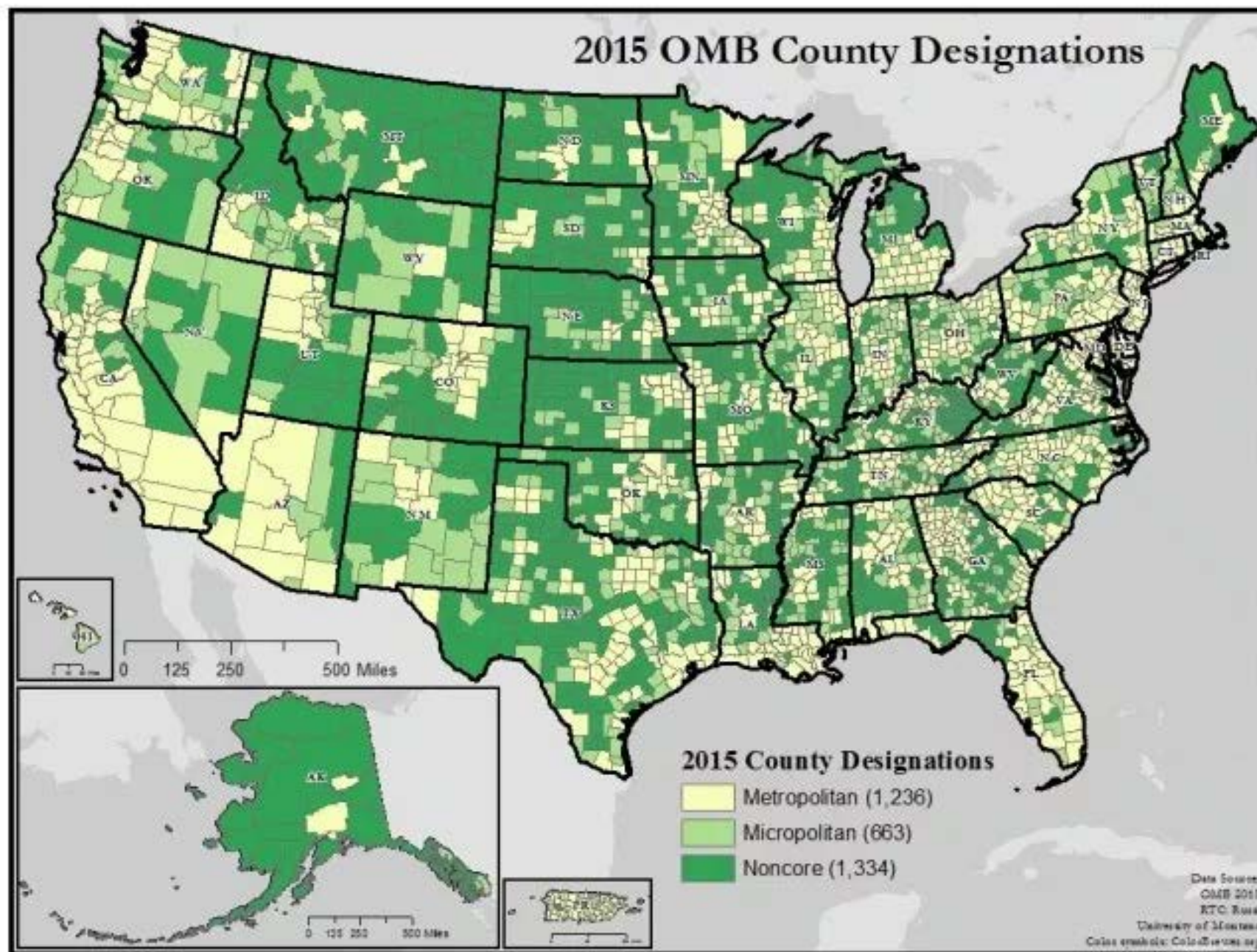
Study Aim

To determine if geography is associated with reported health while controlling for variables representing other social determinants of health.



NSHRD – Defining Rural

- Office of Management and Budgeting (OMB) classifications
 - Includes commuting patterns
 - Provides a more accurate classification for evaluating access to services than census definitions
- Respondents classified as:
 - Urban (n = 1026)
 - Metro – living in urban core of 50,000+ people
 - Rural (n = 212)
 - Micro – living in urban core of 10,000 – 49,999 people
 - Non-core – not micro or metro



Reported Health

CDC HRQOL Healthy Days Module

- In general, would you say your health is...
 - 1 = poor to 5 = excellent
- How many days in the last 30 days was your physical health not good?
- How many days in the last 30 days was your mental health not good?
- During the past 30 days, how many days did poor physical or mental health keep you from doing usual activities?

Variables from Other Determinants

Social Determinant	Variables	Items
Economic Stability	Employment 0 = not employed 1 = employed	<ul style="list-style-type: none"> Are you currently working for pay or self-employed?
Health Care Access	Transportation limitation 0 = no, 1 = yes	<ul style="list-style-type: none"> Does access to transportation limit your ability to get the health care services that you need?
	Time to doctor	<ul style="list-style-type: none"> How many minutes does it take for you to make the trip to your primary care doctor?
Social & Community Context	Satisfaction with community participation 1 = not at all to 5 = very much	<p>Average of four items:</p> <ul style="list-style-type: none"> I am satisfied with the amount of time I spend doing leisure activities. I am satisfied with my ability to do all the leisure activities that are really important to me. I am satisfied with my current level of social activity. I am satisfied with my ability to do activities in my community that are really important to me.
	Perceived isolation 1 = not at all to 5 = very much	<ul style="list-style-type: none"> I feel that I am isolated from other people in my community.
Education	Education level 0 = no formal education 6 = graduate degree	<ul style="list-style-type: none"> What is the highest level of education you have completed?

Reported Health and Employment

	Not employed	Employed	p-value
Health rating (poor =1 to excellent = 5)	2.54	3.0	< .001
Days in last 30, physical health not good	10.65	7.28	< .001
Days in last 30, mental health not good	12.19	8.37	< .001
Days in last 30, physical and mental health prevented usual activities	13.59	5.25	< .001

THM: Employed people reported better health across all measures relative to those who were not employed.

Reported Health and Health Care Access

Transportation limitation	Not limited	Limited	p-value
Health rating (poor =1 to excellent = 5)	2.9	2.5	< .001
Days in last 30, physical health not good	8.3	11.2	< .001
Days in last 30, mental health not good	9.4	12.7	< .001
Days in last 30, physical and mental health prevented usual activities	8.5	13.3	< .001

THM: Respondents who said transportation limited their access to health care also reported significantly worse health across all measures.

Reported Health and Health Care Access, con't

Time to doctor	B	R ²	p-value
Health rating (poor =1 to excellent = 5)	-.003	.017	<.001
Days in last 30, physical health not good	.022	.009	.001
Days in last 30, mental health not good	.018	.006	.006
Days in last 30, physical and mental health prevented usual activities	.027	.013	<.001

THM:

Increased time to reach primary care doctor was associated with worse health across all measures.

Reported Health and Social & Community Context

Satisfaction with community participation	B	R ²	p-value
Health rating (poor =1 to excellent = 5)	.288	.151	< .001
Days in last 30, physical health not good	-3.073	.141	< .001
Days in last 30, mental health not good	-2.917	.124	< .001
Days in last 30, physical and mental health prevented usual activities	-3.579	.176	< .001

THM: Increased satisfaction with community participation was associated with better health across all measures.

Reported Health and Social & Community Context, con't

Feelings of isolation	B	R ²	p-value
Health rating (poor =1 to excellent = 5)	-.163	.065	< .001
Days in last 30, physical health not good	1.559	.048	< .001
Days in last 30, mental health not good	2.576	.132	< .001
Days in last 30, physical and mental health prevented usual activities	2.530	.121	< .001

THM:

Increased feelings of isolation were associated with worse health across all measures

Reported Health and Education

Education level	B	R ²	p-value
Health rating (poor =1 to excellent = 5)	-.001	.000	.641
Days in last 30, physical health not good	.030	.001	.237
Days in last 30, mental health not good	.086	.009	.001
Days in last 30, physical and mental health prevented usual activities	.022	.001	.403

THM: Education was not associated with the majority of health measures.

Reported Health and Geography

	Metro	Micro/ Noncore	P value
Health rating (poor =1 to excellent = 5)	2.77	2.56	.003
Days in last 30, physical health not good	8.81	11.58	.001
Days in last 30, mental health not good	10.44	10.87	.591
Days in last 30, physical and mental health prevented usual activities	9.76	11.07	.112

THM: Rural respondents reported worse health rating and more days when their physical health was not good, relative to urban respondents.

Regression

- IVs: Employment, transportation access, time to doctor, community participation, perceived isolation, education & geography
- DV: Health rating
- $R^2 = .197$

Variable	β	p-value
Employment (1 = employed)	.133	<.001
Transportation access (1 = access limits)	-.087	.002
Time to doctor	-.079	.004
Community participation	.313	<.001
Perceived isolation	-.056	.071
Education	-.016	.543
Geography (1 = micro/noncore)	-.060	.025

Regression

- IVs: Employment, transportation access, time to doctor, community participation, perceived isolation, education & geography
- DV: Days of poor physical health
- $R^2 = .160$

Variable	β	p-value
Employment (1 = employed)	-.053	.062
Transportation access (1 = access limits)	.045	.111
Time to doctor	.032	.247
Community participation	-.325	<.001
Perceived isolation	.058	.068
Education	.032	.245
Geography (1 = micro/noncore)	.093	.001

Summary

- Geography is significantly associated with health rating and days of poor physical health, accounting for other factors
- Limitations
 - Cross-sectional data
- Future directions

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Health and Health Care Experiences of Americans with Disabilities Identifying as LGBTQ+

Jean P. Hall, PhD, Noelle K. Kurth, MS, and Katie Batza, PhD
University of Kansas

NARRTC Annual Meeting
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Background

- As separate groups, people with disabilities and people who are lesbian/gay/bisexual/transgender/queer (LGBTQ+) both experience significant health disparities when compared to the general American population.
- Little previous research exists on this intersectional group, but one study noted higher rates of disability among older adults who identified as gay, lesbian or bisexual (Fredriksen-Goldsen, Kim, Barkan, Muraco & Hoy-Ellis, 2013).
- Based on interviews and survey responses reported here, health disparities appear to be compounded for working age adults with disabilities who identify as LGBTQ+.

CHRIL interviews, 2017 and 2019

- "If I'm just a queer disabled person and I'm just going to my regular provider, not only are they going to assume that I'm not having sex, but they're also not going to provide any accurate information there."
- "I've actually, literally, never had an OBGYN exam and I need to, and I think one of the reasons I've never had one done is because I was fucking seeing a pediatrician... because didn't you know that autistic people become adults?" (non-binary, age 25.5)
- "The questions that they ask you are still very heteronormative, are still very cis-normative. And you aren't receiving healthcare as a trans or queer person, you're treated as you appear to be. And so even though there are queer people within the system, it's still not set up to address those issues. So obviously the medical professionals and those within the health community are way more aware of disability issues because it is all so health-related."

NSHRD – Self-Reported Disability Types and Health Status by LGBTQ status

Variable	LGBTQ (n=155)	Non (n=1029)	p-value
Mean age	39.3	44.8	<.001
Primary disability type	1: chronic illness; 2: mental illness	1: neurological 2: physical	<.001
Mental illness/psychiatric	50.3%	29.3%	<.001
Physical	29.7%	34.0%	0.522
Chronic illness	51.0%	37.9%	<.01
ID/ASD	15.5%	7.7%	0.002
Sensory	7.7%	8.7%	0.688
Neurological	20.6%	32.1%	<.01
Multiple disabilities	55.0%	45.0%	<.05
Health status	47.7% fair/poor	38.1% fair/poor	<.01
Mean days physical health not good	12.3	9.7	<.001
Mean days mental health not good	12.9	9.3	<.001
Mean d's not able to do usual activities	11.9	9.5	<.01

Employment, Income & Insurance Coverage

Variable	LGBTQ (n=155)	Non (n=1029)	p-value
Employed	60.7%	58.1%	0.701
Full time employment	42.6%	52.1%	0.085
Receive SSI	14.7%	16.9%	0.491
Receive SSDI	30.5%	33.2%	0.506
Receive other public benefits	39.2%	23.1%	<.001
Mean household size	1.8	2.1	0.05
Household income < 138% FPL	40.3%	32.4%	0.228
138-249% FPL	23.4%	25.1%	
250-400% FPL	15.6%	20.4%	
> 400% FPL	20.8%	22.1%	
No insurance coverage	2.6%	2.7%	0.683
ESI coverage	43.3%	49.3%	0.171
Marketplace coverage	16.2%	26.8%	<.01
Medicare	27.5%	33.3%	0.303
Medicaid	40.5%	32.1%	<.05

Access/Cost Issues (all respondents)

Variable	LGBTQ (n=155)	Non (n=1029)	p-value
Difficulty finding type of coverage you need	66.4% very difficult	53.6 % very difficult	.01
Difficulty finding affordable coverage	69.7% very difficult	59.3 % very difficult	0.09
Did not get Rx, due to cost	46.6%	32.5%	.001
Did not see doctor, due to cost	25.7%	18.0%	<.05
Did not see specialist, due to cost	34.1%	29.5%	0.379
Did not get tests/follow-up, due to cost	30.3%	35.0%	0.543
Did not get dental care, due to cost	52.1%	49.3%	0.54
Did not get mental hlth counseling, due to cost	49.3%	36.8%	<.01
Did not get sub. abuse treatment, due to cost	6.2%	6.9%	0.554
Did not get DME, due to cost	51.0%	44.1%	0.119
Access to transportation limits ability to get needed health care	35.8%	24.1%	<.01
Need PAS services but do not get them	11.0%	6.2%	<.05

Unmet Needs/Coverage Issues (among respondents with insurance who needed that service)

Unmet Need	LGBTQ	Non	p-value
Unable to see doctor	26.9%	13.0%	<.001
Unable to get prescriptions	37.8%	23.8%	<.001
Unable to see specialists	34.1%	20.9%	<.001
Unable to get preventive health services	21.8%	15.7%	0.09
Unable to get durable medical equipment	55.9%	36.5%	<.01
Unable to get assistive technology	88.2%	72.2%	<.05
Inadequate provider network	43.0%	28.4%	.001

Reason for Unmet Need	LGBTQ	Non	
Inadequate provider network	43.0%	28.4%	.001
Couldn't afford	40.1%	30.0%	<.05
Insurance would not cover what I needed	38.7%	31.5%	0.074
Problems getting to the doctor/provider office	9.0%	4.9%	<.05
Could not get time off work to go to doctor	3.9%	1.8%	0.097
I was refused services by a provider	7.7%	3.0%	<.01

Summary

- Compared to others with disabilities, respondents who are LGBTQ+ self-report:
 - Higher levels of having multiple disabilities, especially chronic illnesses and mental illnesses
 - Poorer physical and mental health and less access to needed health care services
- LGBTQ respondents were more likely to be receiving public assistance and to be on Medicaid
- Transportation barriers were greater among LGBTQ respondents
- People who were LGBTQ had significantly higher rates of unmet need and were more than twice as likely to have been refused services by a provider

Implications and Future Research

- Historically, medical providers placed a stigma on LGBTQ individuals through pathologizing homosexuality, which even today results in continued distrust of the medical system by many in this population.
- Efforts to provide training on disability issues and training on LGBTQ issues to medical providers should emphasize the potential for intersectionality of these groups.
- Insurers should be made aware of the compounded disparities for this population and consider programs to address them.
- Future research should include screeners for these populations and explore programs and interventions to address the issues identified.
- **We welcome suggestions for potential questions to add to the next round of the NSHRD.**

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www.chril.org

Please see me about participation in the 2019 administration of the NSHRD and about a new position available on our team at KU.

Position Opening: Assistant/Associate Research Professor

The University of Kansas – Research and Training Center on Independent Living (RTCIL), a leading research center in the field of disability and independent living, is searching for a **full-time Assistant or Associate Research Professor**. This position will provide leadership and conduct research that contributes to existing and future grant projects with a focus on designing and implementing large-scale projects in the areas of independent living, employment and health for people with disabilities.

For more information or for questions contact: Jean Hall jhall@ku.edu

A complete announcement and online application is available at

<http://www.employment.ku.edu/academic/14007BR>

Questions?

Contact Information:

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