



## THE COLLABORATIVE ON HEALTH REFORM AND INDEPENDENT LIVING (CHRIL)

Start Date: **10/1/2015**

Length: **60 months**

Funded by: [National Institute on Disability, Independent Living and Rehabilitation Research](#),  
U.S. Department of Health and Human Services, [Administration for Community Living](#)  
[Disability and Rehabilitation Research Project: 90DP0075-01-00](#)

### *Institutional members:*

[Washington State University](#) (WSU)

[University of Kansas](#) (KU)

[George Mason University](#) (GMU)

[Independent Living Research Utilization](#) (ILRU), [TIRR Memorial Hermann](#)

### *Strategic partners:*

[National Council on Independent Living](#) (NCIL),

[American Association on Health and Disability](#) (AAHD)

[Association of Programs for Rural Independent Living](#) (APRIL)

[Disability Research Interest Group](#) (DRIG) of [AcademyHealth](#)

### *CHRIL personnel:*

Jae Kennedy, Principal Investigator – Professor and Chair, [Department of Health Policy and Administration](#), WSU

Lex Frieden, Co-Investigator – Professor of Biomedical Informatics and Physical Medicine and Rehabilitation,

[University of Texas Health Science Center](#) and Director, ILRU

Gilbert Gimm, Co-Investigator – Associate Professor, Department of Health Administration and Policy, GMU

Jean Hall, Co-Investigator – Research Professor and Director of the [Institute for Health and Disability Policy Studies](#), KU

Elizabeth Blodgett, Research Associate – [Department of Health Policy and Administration](#), WSU

Karl Cooper, Dissemination and Utilization Consultant – Project Associate and Director of the [National Disability Navigator Resource Collaborative](#), AAHD

Noelle Kurth, Research Associate – Project Coordinator, [Institute for Health and Disability Policy Studies](#), KU

Richard Petty, Training Director – Program Director, [Independent Living Research Utilization](#)

### *Contact:*

#### **Jae Kennedy, CHRIL Principal Investigator**

Department of Health Policy and Administration, [jjkennedy@wsu.edu](mailto:jjkennedy@wsu.edu)

Washington State University Spokane

Innovate Washington Building, Suite 430

PO Box 1495, Spokane, WA 99210-1495

(509) 368-6971 voice | (509) 358-7984 fax

## THE COLLABORATIVE ON HEALTH REFORM AND INDEPENDENT LIVING

The US has historically relied on employers to provide health insurance for working-age adults and their families.<sup>1</sup> However, there are approximately 18.4 million adults aged 18-64 whose workforce participation is limited due to a disability or chronic health condition, and most of these adults do not have access to employer-based coverage.<sup>2</sup> Until very recently, the purchase of nongroup private insurance was not a viable option, due to high costs and structural barriers such as lifetime spending caps, waiting periods, and pre-existing condition exclusions.<sup>3,4</sup> Consequently, many working-age (18-64) adults with disabilities relied on public health insurance (i.e., Medicare and Medicaid), usually linked to enrollment in the Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI) programs.<sup>5</sup> Application to these programs is often a time-consuming and uncertain process, and their benefit structures tend to discourage full-time workforce participation.<sup>6</sup>

This tenuous insurance situation for adults with disabilities should change after 2014 with full implementation of the 2010 Affordable Care Act (ACA).<sup>7</sup> However, it is up to the disability community to make sure that their insurance situation does change, and improves the community living opportunities and integration of working-age adults with disabilities. Effective disability advocacy in this arena will require precise and rapid assessment of the impact of public policies and regulation on the disabled population.<sup>8,9</sup> The Collaborative on Health Reform and Independent Living (CHRIL) brings together researchers and disability organizations to meet this urgent need for accurate, accessible and timely information.

### BACKGROUND

***“Independent living means controlling what is done in your life, and making your own decisions.”***  
***Frieden, Roberts, Starkloff, Fay, Heumann, et. al, (1977)***

Working-age individuals with disabilities are uniquely vulnerable to gaps in health insurance coverage. Compared to people without disabilities, this population is much more likely to be in fair or poor health, to experience serious psychological distress, and to report multiple co-morbid health conditions.<sup>10,11</sup> They are also more than twice as likely to have incomes below the poverty level.<sup>11</sup> Consequently, they are at higher risk of delaying or skipping needed medical care due to cost.<sup>12,13</sup> Even though they have more access problems,<sup>14,15</sup> average healthcare expenditures for adults with disabilities are 4 to 5 times higher than those without disabilities.<sup>16,17</sup>

People with disabilities also have a smaller margin of health,<sup>18</sup> meaning that even small gaps in access can result in adverse health outcomes.<sup>19</sup> Given these vulnerabilities, it is not hyperbolic to describe the ACA as “the most significant law for people with disabilities since the enactment of the Americans with Disabilities Act.”<sup>20</sup> The CHRIL will investigate how the Affordable Care Act’s implementation affects working-age adults with disabilities and systematically disseminate these findings to disability stakeholder groups.

### RESEARCH AND KNOWLEDGE TRANSLATION ACTIVITIES

The CHRIL research activities are organized into 5 discrete but complementary research projects. Two projects collect original data on health insurance consumers with disabilities and on Centers for Independent Living administrators, and three projects use large publicly-available population health surveys. These projects will complement an ongoing program of dissemination and utilization, training, and technical assistance.

Research project 1, *Health insurance outcomes for working-age consumers with disabilities*, describes the experiences of working-age adults with disabilities in obtaining and maintaining health insurance coverage, and identifies the impact of health insurance on consumer community living and integration. It begins with a secondary analysis of the Urban Institute's [Health Reform Monitoring Survey](#) in project year 1, followed by interviews with working-age consumers with disabilities in years 2 and 4, and surveys of working-age consumers with disabilities in years 3 and 5.

Research project 2, *Health insurance information, training, and technical assistance needs of Centers of Independent Living (CILs)*, determines the information, training, and technical assistance needs of CILs as they help their clients obtain or maintain insurance coverage. Internet surveys will be sent to all CIL directors in years 2 and 4. Survey findings will be clarified and extended with follow-up interviews in years 3 and 5. The ILRU team will use these survey and interview findings to develop themes for health reform roundtable discussions, to be held at the annual National Council on Independent Living meetings in project years 1, 3 and 5, and the annual Association of Programs for Rural Independent Living meetings in years 2 and 4.

Research project 3, *Trends in health insurance coverage and healthcare access for working-age adults with disabilities*, develops current profiles of how well the new health insurance system meets the needs of working-age adults with disabilities, including measuring changes in uptake rates for various insurance programs and tracking changes in the prevalence of access problems. This project will use the [National Health Interview Survey](#) in years 1 through 5 to track annual changes in important measures of insurance coverage, healthcare access, and health and functional status among working-age adults with disabilities, and compare these measures to those of non-disabled adults.

Research project 4, *Costs of health insurance and healthcare for working-age adults with disabilities*, identifies gaps in coverage and potential areas of undue cost burden for people with disabilities. Multiple ACA policy changes are intended to reduce the price of coverage, limit out-of-pocket and total costs, and reduce the overall number of uninsured individuals. In Project 4, we will assess the impact of these policies by conducting cross-sectional and longitudinal analyses of the [Medical Expenditure Panel Survey](#) in project years 1 through 5. The CHRIL will use these analyses to measure how healthcare spending and utilization, payer mix, and coverage for the uninsured are changing among working-age adults with disabilities.

Research project 5, *State participation in the Medicaid expansion and SSI program enrollments*, uses data from the Social Security Administration and from the [American Community Survey](#) in project years 1-5 to assess whether the provision of new health insurance coverage options, in combination with other state policy factors, reduces disability program application and enrollment rates.

The CHRIL uses conventional channels for dissemination of research findings, such as podium and poster presentations at professional meetings and submissions to peer-reviewed scientific journals. In addition, ILRU will develop and maintain a CHRIL website and prepare and disseminate factsheets and chartbooks to the CILs and other stakeholders. These products will be placed in a variety of accessible formats at the American Association on Health and Disability's [Health Promotion Resource Center](#) and announced in their electronic newsletter, [Disability and Public Health and the Media](#).

CHRIL training products include: (1) semi-annual webinars, which are open and free to the disability community, (2) a series of online tutorials detailing the evolution of U.S. health policy and specific policy concerns of adults with disabilities, and (3) a summer internship program for undergraduate students with disabilities at ILRU. The CHRIL will regularly update our training materials, with ongoing feedback from our advisory board and end users.

## DISABILITY INCLUSION

The PI and most other team members have extensive personal as well as professional experience with disability. CHRIL team members will actively solicit feedback from other adults with disabilities and their family members, and incorporate that feedback into research and knowledge translation activities. This is simply good research practice in the social sciences: the inclusion of people with disabilities enhances external validity (generalizability) and content validity (matching the framing of the research problem to the sociopolitical context). However, this participatory research approach is also intended to give voice to historically marginalized adults with disabilities and chronic conditions. The ultimate goal of the CHRIL is to not simply to identify disparities in health insurance and health care access, but to provide support in addressing these disparities.

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