



Immediate Release – April 7, 2020

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#WeAreEssential

Dear Hoosier peers with disabilities, older adults, family members, and our partners/allies,

During these uncertain and unnerving times, the Indiana Statewide Independent Living Council (INSILC) and its staff extend our solidarity and support to you amidst this COVID-19 pandemic.

As Hoosiers with disabilities, we know and understand how COVID-19 is impacting Hoosiers in our disability community differently than other Hoosier citizens. We see and feel the strain it is placing on our public systems compromising our healthcare, home care supports, education, employment, and transportation services, which can be especially terrifying for those of us who struggle to navigate everyday barriers and utilize and rely on these public services to maintain our independence and life in the community. Many of us are sensing with increasing urgency the need to take measures to be safe even though safety and security often already feel scarce for us. We are frightened that what little choice and control we currently have over our lives may be in jeopardy. The risk of institutionalization has never been more real. And for some of us, it feels like death may be lurking just around the corner.

Exacerbating these feelings and concerns, is the distressing and disturbing news about policies and practices being implemented across the country of discriminatory healthcare rationing and denials for much needed accommodations putting all our lives as disabled individuals at great risk. INSILC finds these types of policies and practices to be unacceptable! **#WeAreEssential – and as individuals with disabilities, we have the right to be free from discrimination, even during this time of emergency we are ALL facing.**

Neil Romano, the Chair of the National Council on Disability, made this point in an open letter to federal authorities on March 18, 2020:

“The lives of persons with disabilities continue to be devalued in the medical profession due to pervasive negative biases and inaccurate assumptions. The belief that people with disabilities have a lesser quality of life and are less valuable to society has led to deadly consequences - physicians choosing to provide medically scarce resources to non-disabled or healthier people – [which is] a violation of human rights, civil rights and a reinforcement of the belief that people with disabilities are lesser-than and less deserving of life itself.”

And this past Saturday on March 27, 2020, the Health and Human Services Office of Civil Rights issued a [bulletin](#) to protect our peers with disabilities from unlawful discrimination in decisions about their treatment during the COVID-19 crisis which states that:

"...persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient and his or her circumstances, based on the best available objective medical evidence."

Recognizing the multiple and intersecting social identities embodied by our peers with disabilities, INSILC strives to ensure that its peers in the disability community are provided the knowledge and tools necessary to be resilient self-advocates and advocates for others in all efforts to defend and uphold their human and civil rights. This includes information based on anti-discrimination laws which is essential during times of emergency or crisis to safeguard access to effective communications, needed reasonable modifications or accommodations and vital healthcare services and medical equipment in order to prevent any unnecessary deaths of our peers with disabilities.

Therefore, on our website at <https://www.insilc.org/covid-19/> you will find a document titled "**Notice of My Healthcare Rights**". This is a form that our peers with disabilities, including older adults with conditions of aging and our peers with disabilities with limited English proficiency, can use when seeking or receiving healthcare. The second page of the document contains contact information for federal, state and local agencies and organizations that are available to assist you with additional resources, referrals and legal and advocacy efforts if you feel as though your rights have been or are being violated. To meet various accessibility needs of our disability community, this document/form is provided on our website at <https://www.insilc.org/covid-19/> in English and Spanish, in PDF and plain text, in standard and large print, and in easy-to read, plain language. We hope that this document will help inform, support and empower you if you need to seek and receive healthcare during this trying time.

In addition to the "Notice of My Healthcare Rights" document, you will also find on our website at <https://www.insilc.org/covid-19/> the "**KNOWLEDGE IS POWER**" document which lists regularly updated, disability-specific COVID-19 resources and information we highly recommend from a majority of organizations directed and managed by our peers with disabilities. Again, to meet various accessibility needs of our disability community, this document is provided on our website in a PDF and plain text and standard and large print.

If you believe your rights as one of our peers with disabilities have been violated as a result of unlawful policies/practices of healthcare rationing or denial of reasonable accommodations or you believe you have a family member with disabilities who's rights have been violated, please reach out to us to share your story or experience and seek additional direction/guidance at info@insilc.org.

To file an official complaint or report a disability-related rights violation, please contact Indiana Disability Rights at 1-800-622-4865 or info@indianadisabilityrights.org.

These are days of both fear and fortitude, and we hope you can find strength in us and in our disability community because **#WeAreEssential**.

Much Love and Solidarity,

The INSILC Team

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Indiana Statewide Independent Living Council (INSILC) is a 501c3 nonprofit organization and governor-appointed council, independent and autonomous from the state. INSILC is led and directed by a majority of diverse Hoosier leaders with disabilities. The Council addresses needs and concerns of the disability community ensuring no decisions that impact us are made without our input and direction. INSILC acts as the administrative body for the Indiana Independent Living Network providing oversight of the Indiana State Plan for Independent Living (SPIL) and the coordination of services with public and private entities to improve services provided to its peers with disabilities. INSILC use its platform to advocate for meaningful change within the disability community and provide opportunities to empower its peers with disabilities to ***#BeTheVoice*** to lead and control their own lives.