



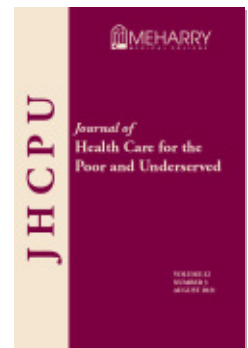
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Responding to the Needs of People with Disabilities in the COVID-19 Pandemic: Community Perspectives from Centers for Independent Living

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Abstract: Centers for Independent Living (CILs) are federally funded, community-based organizations designed and operated by people with disabilities that provide individual and systems advocacy, peer support, information and referral, independent living skills training, and transition services throughout the U.S. and its territories. Centers for Independent Living therefore offer a rich and detailed perspective on the needs of people with disabilities during the COVID-19 pandemic. In this brief report, we summarize COVID-19-related issues raised by 144 CIL administrators and staff in a national survey conducted in April and May 2020 and discuss their research and policy implications. Respondents voiced concerns about health and safety, long-term supportive services, social isolation, and economic insecurity. In the words of one center director, “The pandemic has pulled back the curtain on the depth of need in our local disability community.”

Key words: Access to health care, health disparities, economic issues related to disability, health policy, disability services.

Disability is not inherently linked to risk of COVID-19 infection,¹ but people with disabilities are much more likely to have underlying medical conditions that are associated with severe illness and death.² Adults with disabilities in the U.S. generally report poorer health, greater use of health services, and more problems with health care access and costs of care than those without disabilities.³ As a disadvantaged minority population, they also face significant deficits relative to the general population in terms of income, education, employment, housing, transportation, and community participation.⁴ This combination of limited resources and high needs creates a relatively thin “margin of health” and much greater vulnerability to communicable disease.⁵

The severe impact of the pandemic is most evident in the alarmingly high rates of COVID-19 mortality observed among residents of nursing homes.⁶ Most adults with disabilities live in the community, but they share many of the same risk factors as those

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who live in institutional settings (e.g. multiple comorbid health conditions, older age, frequent interactions with medical professionals and service providers).^{7,8} Unfortunately, CDC surveillance efforts do not currently track rates of COVID-19 infection, hospitalization and death by disability status, though they have started reporting prevalence rates for some specific co-morbid conditions.⁹

As COVID-19 spread in the early spring of 2020, the Independent Living and Research Utilization Center (ILRU) at TIRR Memorial Herman began to receive communications from CIL administrators across the country, describing a surge in consumer needs and significant disruptions in the provision of independent living services. In response, the Collaborative on Health Reform and Independent Living (CHRIL) developed a CIL needs assessment using the ILRU/IL-NET contact database and survey platform.

Our needs assessment provides a unique report on the needs of local disability communities in the early months of the pandemic. We identified two broad classes of issues—CIL operational concerns and the personal concerns of CIL staff and consumers with disabilities. In this brief report, we will focus on the second class of issues, but a full summary of our survey findings and methodology are now available on the CHRIL website at www.chril.org/covid19. Our discussion of problem domains begins with a brief summary of key concerns, followed by several verbatim or lightly edited quotations from survey respondents, and an overview of federal legislative proposals and laws that address these concerns. We end with a discussion of key research questions that could inform public policies and protect the interests of people with disabilities during and after this public health crisis.

Methods

Data collection and analysis. Study population. According to the National Council on Independent Living (NCIL), CILs are “community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities . . . they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization.”¹⁰ Centers for Independent Living provide individual and systems advocacy, peer support, information and referral, independent living skills training, and transition services. Consequently, CIL personnel can provide important and detailed insights on the current needs of people with disabilities during this public health crisis.

To reach CIL administrators, we used CIL-NET, a contact database and survey platform maintained by ILRU. On April 20, 2020, all current CIL-NET contacts were invited to complete a CHRIL/IL-NET COVID-19 Needs Assessment and were reminded about this invitation on May 14 and June 4. After data-cleaning, our final sample included 144 non-duplicative surveys from CIL administrators and staff.

Data analysis. Our survey included four open-ended questions: 1) Right now, what are the biggest pandemic challenges your CIL is facing in providing services to adults with disabilities? 2) What are the biggest pandemic concerns of your consumers? 3) What are the biggest pandemic concerns of your staff? and 4) What do you think the Administration for Community Living needs to know about the current needs of your local disability community?

The 144 respondents often listed multiple challenges, concerns, or needs for each question. These responses were separated and independently sorted. The authors used thematic analysis¹¹ to identify and validate four main categories of COVID-19 related needs (i.e., health and safety, long-term supportive services and personal assistance, social isolation, and economic security), and selected illustrative quotations describing those needs.

Results

Issues facing CIL staff and consumers with disabilities. *Health and safety.* Survey respondents noted that stay-at-home orders, medical office closures, and supply shortages made it much more difficult for people with disabilities to manage their chronic health conditions. Another common concern was procurement and distribution of personal protective equipment (PPE) for people with disabilities, given widespread shortages and prioritization strategies.¹² The abrupt transition to telehealth was also disruptive, particularly for consumers who require regular visits for primary or specialty health services.¹³ Quotations illustrating these ideas follow.

[Consumers are having difficulty with] physical acquisition of medical care/prescriptions, [as well as] scarce PPE.—respondent from New York

We are helping with food, water, wood, and other (cleaning supplies) deliveries to native people with disabilities and elderly citizens who are homebound and in very rural areas. Staff need gloves and masks.—respondent from Arizona

Even with food assistance, many grocery stores are low on supplies. Medically necessary diets are limited due to limited food.—respondent from Colorado

Many [consumers] have health issues that cannot be addressed through video calls or phone calls by doctors.—respondent from Indiana

Consumers are immuno-compromised and some are reliant on special equipment. They fear getting sick and hospitalized, especially now that discriminatory practices, such as rationing of resources/equipment for those less “chronically ill” is occurring.—respondent from Texas

Food security was already a problem for many people with disabilities,¹⁴ and disruption of supplies and delivery systems was a challenge for many CIL consumers in the early months of the pandemic. States were given the option of expanding Supplemental Nutrition Assistance Program (SNAP) eligibility and benefits under the Families First Coronavirus Response Act (FFCRA, P.L. 1116-127), and most have done so.¹⁵ However, several respondents said consumers were having difficulty ordering food with their SNAP cards, and were worried about maintaining benefit eligibility.

Worries about infection, illness, and death from COVID-19 are not limited to people with disabilities, but concerns in this population are heightened by the real possibility of discrimination if they require medical treatment in crowded hospitals.^{16,17} The Consortium for Citizens with Disabilities (CCD) and other disability groups raised

concerns about emergency rationing plans with the Secretary of HHS,¹⁸ and the Office for Civil Rights responded with a bulletin noting that multiple laws and regulations prohibit discrimination on the basis of disability, even during a medical emergency.¹⁹ However, the Disability Rights Education and Defense Fund (DREDF) observes that nearly a dozen discrimination complaints have been brought by disability groups against state agencies, and many have not been resolved.²⁰

Long-term supportive services and personal assistance. Consumers living in nursing homes and other institutional settings were a particular source of concern for CIL administrators, given the high rates of infection and death in these facilities. However, transition services that help institutionalized residents return to the community have been suspended or scaled back at many CILs during the pandemic. Survey respondents attributed these changes to new state restrictions on visiting, concerns for the safety of CIL staff, administrative delays, and limited community resources. Illustrative quotations follow.

Nursing facility transitions are difficult when staff cannot enter facilities and there is a provider shortage.—respondent from Colorado

The percentage of COVID-19 related nursing home deaths should be center-stage in changing how America deals with people struggling to live at home. So, massive increase in funding, directed at making homecare the “go to” option, needs to happen now!—respondent from New York

Many consumers who live in the community do so with the help of paid attendants and non-paid caregivers. It is already a challenge to maintain dependable, long-term providers without the pandemic adding another layer of complications. Without aid, people with disabilities may not complete daily tasks like dressing, toileting, cooking, cleaning, eating, taking medications, etc. Some might not even get out of bed.—respondent from Texas

With many families practicing social distancing, a lot of our consumers’ attendants are not able to work with them.—respondent from Virginia

We have had many personal assistants unable or unwilling to come to work, and we are unable to provide PPE to those that are.—respondent from Illinois

Centers for Independent Living help consumers obtain and manage home and community-based services (HCBS) in their homes and communities, and survey respondents said that the pandemic has significantly disrupted these support arrangements. Some CIL staff struggled to help consumers and attendants get the PPE they need in order to receive and provide personal assistance safely. More broadly, there were concerns about increased demand and limited funding for personal assistance services.

Groups such as the CCD and Center for Public Representation are supporting provisions in federal legislation such as the Health and Economic Recovery Omnibus Emergency Solutions Act (HEROES, H.R. 6800), which would provide supplemental Medicaid funds for HCBS and recognize attendants and home health aides as essential workers.²¹ Americans Disabled for Attendant Programs Today (ADAPT) argues that

the pandemic highlights the importance of passing the Disability Integration Act (DIA, H.R. 555/S. 117), which would require all public and private insurance plans that cover long-term services and supports (LTSS) to allow consumers to choose where those services are received.²²

Social isolation. Independent living services facilitate inclusion and participation for people with disabilities.²³ The provision of these services has been disrupted by the pandemic, leaving CIL staff concerned about the unmet mental health needs of their consumers. As one administrator noted, the mental and emotional impacts of the pandemic can be severe and potentially long-lasting, particularly for consumers and others with pre-existing conditions, such as depression and anxiety. Monitoring and ameliorating mental health effects of COVID-19 among vulnerable populations, including people with disabilities, is a long-term research and policy priority.²⁴ Quotations relevant to these points follow.

A population that is already isolated now feels even more isolated and that is having a negative impact on their mental health. People are calling wanting reassurance that someone is there for them and cares for them. – respondent from Minnesota

For some, the mental and emotional trauma is going to be short term, but for others—and I daresay for most—this is going to have a long-term impact on everyone’s mental health.—respondent from New York

Many people, especially young adults, need face-to-face interaction. Many do not understand the “why’s” of isolation, even though many have been isolated much of their lives.—respondent from North Dakota

The Deaf community has been left out of most of the official updates in New York State. People who are blind are now afraid to touch anything, which is impacting independence and mental health.—respondent from New York

An essential aspect of any emergency is communication. So many consumers are unable to access information that is web based or being pushed out via social media because they lack the financial resources to obtain and retain a data plan and/or Wi-Fi.—respondent from Nevada

Centers for Independent Living administrators report that many of their services have moved online, leaving many of their consumers behind. Phone calls or Zoom meetings are often a poor substitute for face-to-face peer interactions, but even these are complicated by significant economic and technological barriers. People with disabilities are less than half as likely as people without disabilities to have access to a computer at home, and are less likely to use the Internet.^{25,26} Furthermore, public information related to COVID-19 is not reliably communicated or disseminated in accessible formats for people with cognitive or sensory disabilities.²⁷ The CCD has called for an increase in funds for the FCC’s Lifeline program, which provides discounted or free phones or broadband to low-income households,²⁸ and the proposed HEROES Act includes \$5.5 billion in grants and subsidies for increased broadband access during and after the pandemic.²⁹

Economic insecurity. Centers for Independent Living are staffed by people with

disabilities, and many of the staff's concerns regarding employment, health insurance, and childcare during the pandemic mirror those of their consumers. Centers for Independent Living were allocated \$85 million in financial assistance from the Coronavirus Aid, Relief, and Economic Security Act (CARES, P.L. 116-136), but some staff and administrators worry about "being able to keep our doors open after our SBA loans run out." The National Council on Independent Living (NCIL) suggests that an additional \$200 million will be needed to sustain CIL services and staff in the coming year.³⁰ Some responses illustrating these points follow.

Employment options are now virtually nonexistent.—respondent from Illinois

[CIL staff are concerned about] future income and continued paid health insurance, if the pandemic continues.—respondent from California

Staff are trying to work remotely during regular business hours but it is hard to do when you have young children at home, and they end up working later into the night as a result.—respondent from Illinois

Financial concerns if employment was lost and how to access unemployment benefits.—respondent from Michigan

Main concerns [from consumers] are getting mail from services such as section 8 or SNAP and not being able to complete paperwork without assistance. They are concerned the assistance will be denied due to not completing recertification.—respondent from New York

As is illustrated above, survey respondents noted that, after passage of the CARES Act, some consumers struggled with applying for unemployment benefits and stimulus checks. Centers for Independent Living help consumers apply for and maintain public benefits such as Social Security Disability Insurance (SSDI), Medicare, Supplemental Security Income (SSI), Medicaid, SNAP, Section 8 housing, and rental assistance. Administrators reported increased demand for these services during the initial months of the pandemic, and some had significant challenges in providing such support remotely. The proposed HEROES Act explicitly states that people receiving disability benefits should automatically receive stimulus payments, and expands funding for SNAP, Medicaid, and emergency housing assistance.

Discussion

Research Implications

Health and safety. Barriers to COVID-19 prevention and treatment identified by survey respondents persist across many parts of the country, and monitoring how people with disabilities and CILs are coping with local shortages, delays, and closures remains a research priority. The health effects of these disruptions are likely to affect people with disabilities disproportionately. We can anticipate a flurry of new studies documenting the health consequences of forgone medical treatment (e.g., not going to the hospital emergency department due to fear of infection, cancelling doctors' appointments or

wellness checks, postponing surgery, discontinuing behavioral health services), and should encourage these researchers to examine disability disparities closely.³¹

In the longer term, a growing number of case reports indicate that a potentially sizable portion of survivors are experiencing long-term clinical complications of COVID-19, including impaired function of the lungs, heart, brain, kidneys, and circulatory system.³² People with pre-existing chronic health conditions and disabilities will likely be at higher risk for these complications, but a portion of previously nondisabled individuals will also develop disabilities as a result of COVID-19 infection, increasing demand for disability benefits and services.³³ Epidemiologists and clinicians should be careful to track the relative risks for people with disabilities as they monitor the long-term health consequences of this new virus.

Long-term supportive services and personal assistance. Broadly speaking, living in a nursing home appears to be an independent risk factor for COVID-19 infection and death, and under these circumstances, residents should be given the option and resources to move to a safer setting if they wish.^{34,35} The Supreme Court's 1999 *Olmstead v. L.C.* decision stated that involuntary segregation of people with disabilities in institutional settings was a violation of the civil rights established in Title II of the Americans with Disabilities Act. Centers for Independent Living have led efforts to help people with disabilities transition from institutions to the community,³⁶ and the pandemic death toll in nursing homes adds new urgency to these efforts. Frankly, we are not sure how much more research is needed here. Federal research and demonstration projects such as *Money Follows the Person* (MFP), described as the largest demonstration project in the history of Medicaid, show that people with disabilities can transition safely from institutions to the community, and improve their quality of life.³⁷ Yet 13 years later, it remains a demonstration project rather than a federal program, and even these demonstration funds are due to run out in 2020 without permanent Congressional reauthorization.³⁸ To rebalance the LTSS system in this country substantively, we will need significant federal support for affordable, accessible housing and personal assistance, with the ultimate goal of preventing institutional placement from the beginning of a person's care.

Social isolation. Well before the COVID-19 pandemic, public health scientists were describing loneliness as epidemic in the U.S., with demonstrable consequences for health and longevity.³⁹ Population studies show that people with disabilities are at higher risk of loneliness than those without disabilities,⁴⁰ and many CIL personnel observed that the pandemic worsened this problem for their consumers. One of the most powerful characteristics of independent living services is the trust and solidarity established by multiple personal interactions between CIL staff with disabilities and consumers with disabilities who face similar challenges in work, health care, housing, transportation, and community living. Trying to maintain these relationships with phones and computers is a real challenge, and applied research on effective and affordable telecommunication technologies is a research priority in the current crisis.

Economic insecurity. According to a recent analysis by the Center for Economic Policy Research, employment rates among working-age adults with disabilities dropped from 31.4% in spring 2019 to 28.1% in spring 2020.⁴¹ During the 2007–2009 recession, workers with disabilities were much more likely than those without disabilities to lose

their jobs, and many left the labor force entirely,⁴² leading to a surge in applications for federal disability benefits such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).^{43,44} In the current and more severe economic crisis triggered by the COVID-19 pandemic, we should expect similar patterns of high unemployment and increased demand for public benefits, and researchers must monitor this trend and evaluate policy and program interventions intended to return adults with disabilities to the workforce.

Study limitations. National Council on Independent Living estimates that 403 CILs are currently operating in the U.S., but there is some overlap in this count. Specifically, branch facilities in a network may be counted as separate CILs, though they are run by a single administrative unit. Consequently, it is likely that some surveys describe more than one CIL, and we cannot provide a precise response rate for this survey.

Conclusion. The U.S., and the rest of the world, faces a long and challenging effort to ameliorate the social and economic consequences of the pandemic, and to develop new and more resilient institutions to weather the next crisis. COVID-19 has reminded all of us about the critical importance of personal relationships with family, friends, and colleagues. We call for kindness and solidarity within the health research community, and a renewed commitment to working in full partnership with people with disabilities and those who support them.

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