# SURVEY REPORT: COVID-19-RELATED NEEDS OF CENTERS FOR INDEPENDENT LIVING, CIL STAFF AND CONSUMERS

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## ABSTRACT

**OBJECTIVE**: To understand how the COVID-19 pandemic has affected the operations of Centers for Independent Living (CILs), CIL staff and CIL consumers.

**BACKGROUND:** People with disabilities are at much higher risk of COVID-19 exposure, infection, hospitalization, and death than those without disabilities. Policymakers and program administrators should consider the perspectives of local disability service providers and advocates when developing appropriate pandemic services and policies.

**STUDY POPULATION:** Over 400 CILs provide individual advocacy, systems advocacy, peer support, independent living skills training, transition services, and, information and referral to people with disabilities across the US and its territories. CILs are staffed and led primarily by people with disabilities, and they have a unique perspective on the needs of people with disabilities in their local communities. This report summarizes responses from 144 completed surveys from CIL administrators and staff.

**FINDINGS:** Survey respondents reported significant pandemic-related service disruptions at their Centers and widespread hardship among CIL consumers and providers. Centers restricted or eliminated face-to-face provision of independent living services, so staff and consumers abruptly switched to phone calls, e-mails, and videoconferencing technologies. Unfortunately, many consumers, particularly those living in low income or rural communities, currently lack access to affordable and reliable telecommunications. CIL staff and consumers are also experiencing significant disruptions in their medical, rehabilitative and social support networks, and report difficulties in obtaining personal protective equipment (PPE) for themselves and their caregivers.

**CONCLUSIONS:** COVID-19 constitutes an existential threat to the disability community. While CILs are a key resource in countering this threat, they are struggling to meet the growing demand for independent living services. Resources are constrained, revenues are down, and CIL staff are worried about their health and job security. CIL consumers face a variety of challenges including a.) disrupted health and disability support services, and b.) new barriers to work, transportation, communication, and social participation.

# SURVEY REPORT:
# COVID-19-RELATED NEEDS OF CENTERS FOR INDEPENDENT LIVING, CIL STAFF AND CONSUMERS

The Collaborative on Health Reform and Independent Living (CHRIL), in partnership with the IL-NET National Training and Technical Assistance Center for Independent Living at ILRU and the National Council on Independent Living (NCIL), used the CIL-NET platform to conduct a national survey of CILs to assess the impact of the pandemic and the impact of local, state, and federal policy actions on people with disabilities. This report summarizes findings from 144 survey responses completed between April and June 2020.

## BACKGROUND: DISABILITY AND COVID-19 RISK

People with disabilities are at higher risk of COVID-19 exposure, infection, hospitalization, and death than those without disabilities. This situation is most evident in the shockingly high rates of COVID-19 mortality among residents of nursing homes, nearly all of whom are disabled.[1] Most adults with disabilities live in the community, but they share many of the same risk factors as those who live in institutional settings (e.g. multiple comorbid health conditions, older age, frequent interactions with medical professionals and service providers). It is likely the recent surge in excess mortality[2] is also concentrated among people with disabilities.[3]

People with disabilities are an at-risk group that faces significant inequities in income, education, employment, housing, transportation, and community participation. Disability also intersects with other sources of disadvantage and discrimination, with higher rates of prevalence among racial, ethnic, gender minorities, and sexual minorities. Many people with disabilities also have chronic health conditions or injuries, and therefore require much higher levels of healthcare and support services than those without disabilities. This

[1] Barnett ML, Grabowski DC. Nursing homes are ground zero for COVID-19 pandemic. *JAMA Health Forum*; 2020. p. e200369.

[2] The World Health Organization defines excess mortality as a surge in population death rates above pre-crisis levels. In this case, excess mortality can be attributed to people who died at home with COVID-19 but weren't diagnosed, and people who didn't obtain critical medical care because of hospital crowding and/or restricted access to clinics and healthcare providers.

[3] Although current public health data is limited, it seems likely that people with disabilities will also be at greater risk of "deaths of despair" from drug or alcohol abuse and suicide, due to increased unemployment, social isolation, depression and anxiety.

combination of limited resources and high needs creates a relatively thin "margin of health" and a much greater vulnerability to communicable disease.[4]

## Study Population: Centers for Independent Living

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." CILs provide individual and systems advocacy, peer support, information and referral, independent living skills training, and transition services.[5] Their staff, administrators, and boards understand the ways in which health and disability services facilitate or impede independent living for people with disabilities in their local communities. Consequently, CIL personnel can provide important and detailed insights on the current needs of people with disabilities during this public health crisis.

## Study Sample: Survey Respondents

NCIL estimates that 403 CILs are currently operating in the US.[6] CIL-NET is a regularly updated contact database and survey platform for CIL administrators 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 completed and non-duplicative surveys from CIL administrators and staff.

We should note that the study sample represents *individuals who work at a CIL, not the CILs themselves*. About half of survey respondents opted to identify themselves and/or their centers, and in this subset, we found that 5 centers had submitted more than one survey. We opted to include only the most complete and recent survey from each of the 5 centers in our final sample. However, in the absence of identifying

[4] DeJong G, Batavia A, & Griss R. America's neglected health minority: working-age persons with disabilities. *Milbank Quarterly* 1989:311-51.

[5] See https://acl.gov/programs/aging-and-disability-networks/centers-independent-living

[6] See https://ncil.org/about/aboutil/

information from a large segment of our sample, However, in the absence of identifying information from a large segment of our sample, it is possible that multiple survey responses from the same CIL were included among our 144 surveys.

## SURVEY INSTRUMENT: THE CHRIL/IL-NET COVID-19 NEEDS ASSESSMENT

Frequent communications with the CILs in the first months of the pandemic gave IL-NET personnel a broad understanding of the challenges the centers were facing, and these informed the development of four multiple choice questions about center operations, service delivery, new services and staffing. These were complemented by 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?*
4. *What do you think the Administration for Community Living needs to know about the current needs of your local disability community?*

## SURVEY RESULTS

### QUESTION 1: RIGHT NOW, WHAT ARE THE BIGGEST PANDEMIC CHALLENGES YOUR CIL IS FACING IN PROVIDING SERVICES TO ADULTS WITH DISABILITIES?

The most common frustration about the pandemic was the disruption of personal, face-to-face relationships with consumers. One of the most powerful aspects 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, healthcare, housing, transportation, and community living. Laptop screens and cell phones cannot fully replace this relationship. There were also a host of technical and economic challenges faced by CILs who abruptly changed to primarily or exclusively remote operations. Particularly in low income and rural communities, many CIL consumers did not have access to reliable and affordable communication technologies, broadband internet services, or cell phone service. Regardless of the community setting, large portions of CIL consumers may not be able to use these technologies even if they are available. These include people with sensory limitations, communication disorders, intellectual disabilities, traumatic brain injury, paralysis, or other conditions.

For the safety of both staff and consumers, many CILs have paused some of their major services during the pandemic such as nursing home transition services and in-home modifications. Enrolling new clients remotely was particularly challenging. Staff reported concerns about unmet needs of people with disabilities in their communities: although the CIL staff reach out and send applications to would-be clients, those applications were rarely returned mail without in-person follow up. Lack of Personal Protective Equipment (PPE) was also a major concern for CIL staff. PPE is needed for the CIL staff to be able to interact safely with their clients, as well as for direct service providers working with clients.

- *"A majority of the disability community are older adults who are not used to going online to use a computer to access information; that is, if they even own a computer. Since many don't have internet, we can't do FaceTime or Zoom meetings or trainings with our consumers either. Currently all but one of our staff members are all working from home and we have to rely on the one employee in the office to relay messages to us that someone called us. We then end up playing telephone tag to reach the consumer and [it's] frustrating for them and us."*

- *"Not being able to meet in person. I think that it makes them feel more reassured when they see a real person in front of them and know that that person is truly empathetic to how they are feeling."*
- *"Not being open to the public. It is difficult to get applications back from the consumers for new services. We send the applications electronically and also paper with a return envelope with postage, but I am finding that by not being able to visit and do in-home intakes I am not getting applications back."*
- *"Cannot do installation of AT devices in homes. Waiting list is at 50 right now. Our volunteers that do the work are all older adults, so we will not put them at risk."*

### **QUESTION 2:** WHAT ARE THE BIGGEST PANDEMIC CONCERNS OF YOUR CONSUMERS?

Overwhelmingly, the three biggest concerns of the consumers were food, healthcare, and social isolation. Respondents noted that the many of the local grocery stores were low on stock, and they feared that consumers would run out of medically-needed supplies. Difficulty finding safe and reliable transportation exacerbated these concerns. CIL staff were also concerned that their consumers would lose the ability to pay their rent and utilities due to lack of income caused by the pandemic. In addition, CILs expressed concern over the ability of consumers to maintain support from their aides and whether the aides would have proper PPE.

Respondents expressed concern that both CIL staff and consumers were particularly vulnerable to the virus due to underlying health concerns. If they did contract the virus, they were concerned that disabled patients will be "sidelined for more viable patients." Therefore, many consumers were foregoing regular medical appointments to avoid exposure. Finally, there was a lot of concern that consumers are facing isolation due to social distancing guidelines. One respondent wrote, "Many do not understand the 'why's' of isolation, even though many have been isolated much of their lives." There was also concern that the isolation will lead to depression or exacerbate existing mental health issues in the consumers.

- *"Access to food, and then also PPE for home services. People are also scared about riding public transit or paratransit, about making rent, and about accessing healthcare."*
- *"Most of our consumers do not have a computer. They would have come in the Center to use the computers. Another concern is that they will be able to pay their bills, and that their medical insurance won't change. Too much uncertainty!"*
- *"Having a disability and being valued less when it comes to decisions such as who gets the ventilator when there is a shortage."*

- *"The greatest concern is contracting COVID-19 as they are a vulnerable population. This is limiting consumers from leaving their house and even attending necessary doctor's appointments."*
- *"The need for peer support and coping with depression. Isolation is driving a lot of that."*

### **QUESTION 3:** WHAT ARE THE BIGGEST PANDEMIC CONCERNS OF YOUR STAFF?

The main concerns of the staff were work security, health and safety. Their commitment to meeting the needs of their consumers remained strong, but some staff said they find themselves caught trying to balance the fears of COVID-19 with providing appropriate services. Many feared exposure to the virus if offices re-opened and resumed face-to-face services prematurely. Staff were also concerned about the possibility that they themselves may unknowingly pass the virus to their vulnerable consumers or their own families. A reported lack of PPE supplies heightens these fears. While staff were grateful to be able to maintain their jobs through remote work, they missed the comradery and supportive work environment provided by the CILs and they fear how the pandemic will impact their job security in the long term.

- *"The health and welfare of our consumers."*
- *"Fear for themselves and worried about losing their jobs."*
- *"Social isolation. We are a tight knit group. We meet twice a week for 1.5 hours but [it's] not the same. Everyone is healthy (so far) and working."*
- *"We are concerned that we will be made to return to face to face visits too soon and we will expose ourselves, our consumer's or our families to COVID."*
- *"Continuing to serve the consumers with the resources (financial, technology, time) we have as well as addressing the pandemic related isolation, fear, lack of normality/routine."*

### **QUESTION 4:** WHAT DO YOU THINK THE ADMINISTRATION FOR COMMUNITY LIVING NEEDS TO KNOW ABOUT THE CURRENT NEEDS OF YOUR LOCAL DISABILITY COMMUNITY?

When asked what the Administration on Community Living needs to know about the current needs of their local disability community, many respondents expressed major concerns related to access. Respondents were concerned that members of their local disability community lacked access to needed medical supplies, food, and PPE. In addition, lack of access to transportation and unstable housing were major concerns for their consumers. Communication technology was also a major concern.

Respondents expressed concerns about providing services to consumers in new ways and the ability of their offices and staff to keep up with the changing needs of the community. The COVID-19 pandemic has disrupted their ability to provide some of their regular services such as youth transition and nursing home transition. They asked for increased funding and flexibility in use of funds so that they are better able to react to the changing needs of their communities. These funds are necessary not only to maintain staff and services but to help meet the consumer need for technology and necessary supplies.

Respondents were very concerned about people with disabilities being left out of important decisions made by policymakers. They stressed that there is great need in the disability community and that the lives of people with disabilities are precious. Respondents support advocacy that puts the needs of the disability community at the center rather than treating people with disabilities as an afterthought. Speaking directly to the ACL, several respondents also expressed their appreciation of the support that they have received so far.

- *"The needs of the disability community should be considered in legislation and their lives should not be considered appropriate trade-offs for reopening society."*
- *"The lack of access to technology in a now technologically driven world is abysmal in the disability community. Even if CILs purchased tablets or computers for consumers, they still would not be able to afford the monthly internet costs. This is leading to intense isolation and will likely increase the need for mental health assistance. Additionally, consumers are fearing (if not already facing) institutionalization as a result of the pandemic."*
- *"We are just in the beginning. Be flexible. Our needs are similar to others across the country. Allow us to be creative with the additional funds. Whether this is to develop programs/services. Allow the funds to fill in the gaps that we're seeing in providing nursing home transition services (e.g. hotel rooms, meals, hazard pay for staff)."*
- *"I think ACL provides very helpful information to our Center, always. The access to webinars and free training materials are very beneficial."*

### **QUESTION 5:** IF YOUR CIL IS CONTINUING OPERATION, HOW ARE YOU OPERATING?

When asked how the CILs are continuing to operate during the pandemic, the highest frequency responses indicated that CILs were working with consumers via individual phone calls, conducting daily or frequent wellness checks with consumers, and working with consumers by individual computer or smartphone video sessions. Many respondents also indicated that they had closed their offices entirely and were working remotely. These respondents were assessing disability community needs using telephone and online surveys,

conducting group video conferences, advocating with local leaders and emergency response officials to ensure the needs of the disability community are met, and working with local emergency response leaders and community service organizations to help prevent institutionalization of people with disabilities in this emergency. Some respondents indicated that their office remained open with limited consumer or community contact, and only one respondent indicated that they were closed and not providing any services.

| How is your CIL continuing operations? | N | % |
|---|---|---|
| We are working with consumers by individual phone calls | 141 | 97.9% |
| We are conducting daily or frequent wellness checks with consumers | 125 | 86.8% |
| We are working with consumers by individual computer or smart phone video sessions | 113 | 78.5% |
| Our office is open, and we have limited consumer or community contact | 103 | 71.5% |
| We are advocating with local leaders and emergency response officials to ensure the needs of the disability community are met | 98 | 68.1% |
| We have closed our office entirely and our staff works remotely | 82 | 56.9% |
| We are assessing disability community needs using telephone or online surveys | 73 | 50.7% |
| We are working with local emergency response leaders and community service organizations to help prevent institutionalization of people with disabilities in this emergency | 72 | 50.0% |
| We are conducting group sessions with consumers using video conferences | 67 | 46.5% |
| Our office remains open | 17 | 11.8% |
| We are closed and NOT providing services currently | 1 | 0.7% |
| Other | 32 | 22.2% |

Respondents also had the opportunity to indicate other ways in which they are continuing operations. Frequently, respondents mentioned using social media to stay connected with their consumers with some even using digital media such as podcasts and YouTube videos. While many respondents stated that their staff was working remotely, there were many who referred to staggering staff shifts in the office as a social distancing measure.

- *"Our office is closed to the public during the state's stay at home order, staff are mostly working remotely but some still work out of the main office in staggered shifts."*
- *"We are using Facebook to provide IL instruction on daily living skills."*
- *"We are producing YouTube videos for our cooking and crafting classes."*

### QUESTION 6: WHAT CORE SERVICES ARE YOU CURRENTLY PROVIDING TO CONSUMERS?

When asked what core services and additional services the CIL is currently providing to consumers, the highest frequency responses were information and referral, individual advocacy, and peer counseling and support. Many respondents also indicated that they were providing systems advocacy, independent living skills training, and institutional transition and diversion.

| Core services you are currently providing to consumers? | N | % |
|---|---|---|
| Information and referral | 142 | 98.6% |
| Individual advocacy | 133 | 92.4% |
| Peer counseling and peer support | 123 | 85.4% |
| Systems advocacy | 110 | 76.4% |
| Independent living skills training | 105 | 72.9% |
| Institutional transition and diversion | 96 | 66.7% |
| Transition of youth | 76 | 52.8% |
| Other | 41 | 28.5% |

When asked to specify other services, respondents mentioned accessibility, food delivery, benefits counseling, and outreach. Many remarked on how the pandemic has impacted their regular services.

- *"We are able to provide youth transition services, but families are opting to wait out the pandemic. Staff are still maintaining contact with them."*
- *"We are currently trying to figure out how to do relocation services without contact.*
- *"We do provide diversion services but are currently not allowed into any institutions during lockdown. We offer transition of youth but are finding it difficult to reach those youth.*

### QUESTION 7: IS YOUR CIL PROVIDING ANY NEW SERVICES OR HAVE YOU INCREASED SERVICES DIRECTLY RELATED TO THE COVID-19 PANDEMIC?

When asked whether the CIL is providing any new services or increased services directly related to the COVID-19 pandemic, respondents were split between yes and no, with a slightly higher frequency of respondents answering, "yes." Of the respondents who indicated that they were providing new or increased services related to the COVID-19 pandemic, the highest frequency of respondents indicated that they were providing individual COVID-19 prevention and awareness information/education. Many also indicated that they were providing emergency preparedness and response directly related to the COVID-19 pandemic and advocacy with emergency and public officials to ensure the rights of people with disabilities are maintained during the

crisis. Respondents wrote that providing food and water supplies to their consumers has become a new or increased service of the CIL. Several also indicated that they were proactively reaching out to consumers to assess their needs, including their emotional support needs during the crisis. Some respondents also mentioned assisting clients with their pandemic-related financial needs.

- *"Food security- we are receiving donations from individuals that we have been passing on. Eggs, milk and produce from local farmers and producers have been a huge help."*
- *"Peer support to groups of individuals with disabilities who didn't receive peer support through a support group yet now are receiving peer connection services. Examples include a weekly volunteer group meeting where there is conversation and games. Additional 1-1 wellness checks to individuals who didn't receive wellness checks prior to COVID-19."*
- *"Assisted SSI consumers with dependents on registering for stimulus payment."*

Respondents partnered with a variety of community-based organizations to increase services. Frequently, respondents indicated that they were partnering with Legal Aid, charitable non-profits, their state's Protection and Advocacy agency, and food pantries as well as local government. Respondents also referred to collaborations with their SILCs, local agencies on aging, and local advocacy organizations.

| New services or increased services directly related to the COVID-19 pandemic? | N | % |
|---|---|---|
| Any | 84 | 58.3% |
| Individual COVID-19 prevention and awareness information/education | 71 | 49.3% |
| Emergency preparedness and response directly related to the COVID-19 pandemic | 52 | 36.1% |
| Advocacy with emergency and public officials to ensure the rights of PWD are maintained | 52 | 36.1% |
| Other | 33 | 22.9% |

### QUESTION 8: HAS IT BEEN NECESSARY TO REDUCE STAFF HOURS OR CONDUCT LAYOFFS OR FURLOUGHS?

When asked whether it has been necessary to reduce staff hours or conduct layoffs or furloughs, most respondents (86%) answered "no." Some respondents reported having to reduce the hours of staff, with a few mentioning staff furloughs. In addition, respondents indicated that they laid off staff in specific categories such as corporate staff or administrative staff. Some said that staff members voluntarily chose unemployment as the more financially viable option.

- *"Some staff have taken the unemployment insurance option. Others are on reduced hours."*

- *"Staff work whatever hours they can legitimately get in; however, those hours are usually less than a typical work week."*
- *"We have not furloughed any front-line staff, but have laid-off/furloughed 20 corporate staff and reduced working hours for another 8 staff."*

### OTHER COMMENTS:

When asked for other comments, respondents indicated that they have appreciated the support, webinars, and training that have been provided so far to help them through these unprecedented circumstances. Respondents reported slowly adjusting to providing new services as well as new means of service delivery through remote work. Some respondents applauded their leadership. Some requested additional training and support specifically related to technology. Finally, respondents expressed concerns regarding contracting the virus and providing services to a high-risk community.

- *"The increase in trainings from NCIL, ILRU, ILNET, etc. have made coping with this new way of working much better, and I feel better prepared to help our consumers."*
- *"I feel like the Executive Director/Board of Directors of our CIL are doing a great job during this pandemic, putting our consumers first and trying to support staff as much as possible given the resources available to them."*
- *"If possible, it would be helpful to hear how other CILs are conducting remote sessions to accommodate a variety of disabilities."*
- *"The current concern we are hearing from consumers, community members and staff is that they are scared of the state re-opening too early and that there will be grave consequences*

## CONCLUSIONS

While many Americans are now dealing with social isolation and financial insecurity, those with disabilities were already struggling before the COVID-19 pandemic struck. In the words of one respondent, "the pandemic has 'pulled back the curtain' on the depth of the need for our local disability community." Across the country, CILs are struggling to meet the demand for independent living services, but resources are constrained, revenues are down, and CIL staff are worried about their health and job security.

Perhaps the most important feature of CILs is the opportunity for people in the local community to share their common experience of living and coping with disability. These relationships have been disrupted by the

pandemic, while at the same time, more people are recognizing their need for independent living services. Intakes are down in most CILs, and service offerings are limited. 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. The disability community has been pushing policymakers and telecommunications companies to bridge the digital divide for decades,[7] but it is now an emergency. The Federal Communication Commission's E-Rate and Lifeline programs should be dramatically expanded and targeted to people of all ages with disabilities, particularly in rural and low-income communities.[8]

Widespread stay-at-home orders have highlighted the urgent need for housing modifications, durable medical equipment, PPE, and safe and reliable personal assistance services. Given the appallingly high rates of infection and death in institutions, transition services for people being discharged from hospitals and intermediate care facilities are now literally a matter of life or death. As the job market shrinks and higher education options become more limited, youth transition services are becoming more important than ever. Under these circumstances, emergency aid, preferably in the form of unrestricted grants or forgivable loans, must be included in the next federal stimulus package. COVID-19 constitutes an existential threat to the disability community, and CILs are a key resource in countering this threat.

## CONTACT INFORMATION

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[7] See Jaeger, Paul T. *Disability and the Internet: Confronting a digital divide*. Boulder, CO: Lynne Rienner Publishers, 2012.

[8] Holt, Lynne, and Mary Galligan. "Mapping the field: Retrospective of the federal universal service programs." *Telecommunications Policy* 37.9 (2013): 773-793.

## APPENDIX 1: FULL SET OF RESPONSES TO OPEN-ENDED QUESTIONS IN THE CHRIL/IL-NET COVID-19 NEEDS ASSESSMENT

| Question 1. Right now, what are the biggest pandemic challenges your CIL is facing in providing services to adults with disabilities? |
|---|
| How to move to remote supports, changing needs and navigating this new landscape. |
| We are not doing nursing home transition or diversion. |
| We have had a big decline in requests for services which makes me worry they are going without assistance. |
| Keeping staff safe yet still being able to provide services. |
| Technology to provide virtual services. Obtaining PPE for our consumers and their staff. |
| Not prepared for virtual delivery of advocacy and workplace preparedness. |
| As an agency all staff are working remotely without reductions. Our biggest challenge is keeping in touch with consumers who do not have internet or have limited minutes on their cell phones. |
| Contact with people who have limited forms of remote communication in an area that is very rural. Many people use phones without contracts, buying data cards when funds are available. So, numbers change a great deal. If someone had the ability to pay for internet it is sometimes dial up internet, so it's very slow and difficult to use. Some consumers are by mail, no other ways to communicate. |
| Communication for core services in our rural community of Yuma and La Paz County Arizona. Contact accessibility for information in areas with no internet, phone services. |
| Unable to work in person with consumers. We have to rely on phone calls, emails, mailing items, etc. Not all consumers have a phone or computer. Voice mailboxes are often full or not set up. Consumers don't answer their phone. Calls are taking longer than usual in person meetings, as consumers need to talk and express their concerns. Unable to provide all the services we would like to. |
| Everyone operates on essential personnel only. It is extremely difficult to reach service providers/agencies by phone. The system is overwhelmed. |
| Inability to make home visits and have face-to-face appointments. Communications challenges with remote work. |
| Trying to provide remote services to our consumers. Many consumers don't have access to technology or have limited minutes. Trying to reach new consumers. Trying to get resources out to people. No PPE, limited food assistance. Many places are closed so fewer options for referral. Transition services. Shortage of attendants, social isolation, need for quarantine make transitions difficult. |
| Transitioning consumers from nursing facilities when we aren't supposed to be in close contact and can't get supplies. |
| The spread/access to information being provided by local governments, emergency personnel, media, and other resources. Much of the information is being provided via social media that many of our clients, especially the elderly community don't have access to. |
| Being able to meet with consumers in person to be able to provide further services and purchases for consumers. |
| Accessing PPE for our consumers and their PAs. Also, people who are participating in our Community Reintegration Program and presently live in nursing homes are not permitted to be discharged. So, that ultimately stagnates their transition process. |
| Helping them find disability related items, such as gloves, sterile dressings, etc. |
| Inability to safely access and get direct services to those sheltering in place because our staff and they are at risk. |
| Connecting to consumers. Because we are relying on cell phone use or home phone use, people don't recognize who is calling and won't answer. |

| |
|---|
| It seems to be transportation to get food and supplies. |
| Lack of technology and what we have doesn't always work. A majority of our consumers do not have access to internet or smart phones. |
| 1. Lack of PPE.<br>2. Staffing of attendant care employees.<br>3. Visual communication to rural areas (cell service, internet service, Skype). |
| Getting PPE to Direct Care Workers, access for PWD to get needed items from stores, pharmacy. |
| As a CIL in a rural area our biggest challenges include food and other daily needs, PPE, mental health, isolation and accurate information. |
| Assisting with access to barriers for medication, groceries, etc., while maintaining social distancing. |
| Having the right technology in place to have all staff efficiently work remotely. |
| Not being open to the public. It is difficult to get application back from the consumers for new services. We send the applications electronically and also paper with a return envelope with postage, but I am finding that by not being able to visit and do in home intakes I am not getting applications back. |
| Non face-to-face contact consumers without internet capabilities, consumers without transportation. |
| Having the doors opened. |
| Fear of the unknown. Struggling with losing their Direct Service Worker or the DSW not following protocols. |
| PPE and wipes. |
| Not being able to interact in person. Not being able to safely protect ourselves or them d/t lack of PPE and testing. |
| Getting all staff set up remotely and the cost of technology. However, our DHS grants are continuing so that we can pay our staff. Another issue is trying to serve consumers remotely, especially those that do not have phones. |
| Talking to consumer's and PCW's and reviewing safety precautions and their health status, explaining signs and symptoms of COVID-19. |
| The biggest concern is having appropriate PPE for the personal care workers. Inability to find or procure N95 masks. Difficulty in finding/receiving medical grade gloves in the correct sizes. |
| Making sure that all consumers are contacted and getting their needs met. |
| That we cannot see our consumers in person. Most of the contact is by phone. |
| Because we are also considered High-risk, we can't go help our peers directly and it is heartbreaking to deal with such extreme need so remotely. |
| Lack of technology that consumers have and the knowledge of how to use that technology. Without such, CILO is experiencing difficulty in providing services remote to consumers. |
| Lack of internet services for most of our rural consumers. |
| PCW's are upset about lack of supplies. |
| Maintaining the one-on-one relationship with our consumers. We have been working remotely and still have contact but don't have the personal contact some consumers need. |
| Shifting from one-on-one to a remote approach and consumers ability to access proper technology. Being able to access rural undeserved communities in our catchment area. |
| That we can't see anyone face-to-face. Some clients don't have the technology that allows for virtual visits and some don't have the technology background to understand how to do it either. |
| We do not have PPE, no masks, no gloves were provided until April 13th. |
| 1. It was easy to contact our consumers to assess their concerns and needs, however, identifying other people with disabilities in the community who may have needs has proved challenging.<br>2. The learning curve in how to provide services remotely and electronically.<br>3. Bridging the digital gap as many people with disabilities do not have resources that allow them to connect. |

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| Not being able to provide that one-on-one assistance. Consumers with no technology skills. Consumers with no support at home. Assisting with applications remotely. |
| Working remotely, trying to provide resource information to consumers with disabilities. |
| We are a rural community and many of our consumers are seniors. Many of our consumers don't have internet, and many of them only have the SafeLink free phone with limited time. |
| Consumers are not aware of the issues threatening them till it is too late. Medical rationing, long term care COVID issues, unemployment discrimination even higher, ride sharing, attendant care shortages. When they do become aware it's too late for fighting! |
| PPE equipment. 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. Lack of internet connectivity, sometimes the system stops working. Trying to get more donations of cleaning supplies, masks for consumers, and even food as most food distributions run out very quickly. So CIL has to go further out to border towns to pick up food for consumers (works for now due to having 5310 program which allows us to use for deliveries to consumers). Needing to buy more laptops and software and cell phones for staff to use from home. |
| Supporting them through telework only. Staying in touch. |
| Outreaching to disabled youth |
| A majority of the disability community are older adults who are not used to going online to use a computer to access information; that is, if they even own a computer. Since many don't have internet, we can't do face time or Zoom meetings or trainings with our consumers either. Currently all but one of our staff members are all working from home and we have to rely on the one employee in the office to relay messages to us that someone called us. We then end up playing telephone tag to reach the consumer and it's frustrating for them and us. Our agency is working on getting us work cell phones the agency will pay for to have quicker access to our consumers. Our town has multiple sources to get food from, but not as many sources to get other things with some many businesses being closed. |
| Providing services to consumers (adults with disabilities) who have no phone or internet. |
| We are not able to meet face to face with our consumers. Many of our consumers who have language barriers, elderly, or don't have video capabilities that prefer to communicate with their Service Facilitator in person are missing that face-to-face connection. With the sudden routine change in our consumers, especially school aged children it is more difficult to schedule telephonic assessment with parents who have to work full time as well as home school. Some assessments have to be conducted after normal work hours to accommodate the families. |
| Lack of internet service and lack of devices for individuals, attendants not being welcome in the homes and concern that these individuals will not return post-emergency. |
| Need PCAs, need someone to grocery shop, consumer limit in communications, undocumented individuals can't get services, Medicaid staff can't do F2F home visits. |
| Inability to communicate with those who do not have internet access or enough minutes on their cell phones |
| Comprehension of the pandemic itself. Disability community is just not prepared to deal with this pandemic. |
| Although Disability Network Southwest is fortunate to have multiple means of connecting with people with disabilities through Zoom 1-1 and group meetings/workshops/peer support groups, phone calls, texts, Facetime, USPS mail; there are pieces of customer service delivery that aren't able to occur as efficiently and as effectively without the face-to-face contact. |
| The biggest challenge is the lack of technology/computer access of many of the consumers. |
| The logistics of providing services in rural areas that we now cannot travel to. The lack of technology in those rural areas making meeting virtually next to impossible. Initially, it was a lack of communication and guidance from the DSE. |

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| Technology, high anxiety among employees and consumers. |
| Our biggest challenge is getting the consumers to use our services and programs since they are through virtual methods. Not having transportation is for essential use and most of them do not have email to get information of resources. |
| 1. Digital divide.<br>2. Some supports are best providing sitting next to the person to fill out paperwork, make phone calls, etc.<br>3. Competing priorities. COVID response should be the top priority, but other responsibilities and functions of CILs cannot be put on hold. |
| Not being able to reach some consumers because they don't have phones or internet access. Assisting them with finding food and free meals. Helping them how to use technology to communicate with us, and that video calls can help them "see" staff. |
| Face-to-face services that do not always show the response of the client. Family dynamics influencing the outcome. Less support from one another for more immediate connection. |
| Having the time to coordinate the response. |
| 1. How to use the CARES funds.<br>2. Staff are nervous about the approaching relaxation of sheltering orders and allowing people to come into the office. They worry if they will be safe and I cannot find sources to purchase good quality masks. |
| No face to face contact. Having to serve people remotely such as phone contact only and most families don't have good phones or cannot afford phones. Letting tribal leadership know about collaborations between agencies and individual groups to make sure everyone is checked on. Limited internet and phone services for staff and consumers. |
| Not enough access to resources with staff working from home. Files are not easily accessed. We need more face masks for staff interfacing with the public. |
| It is more of an adjustment instead of challenge. We just are figuring different ways to reach out and help our consumers from phones, text, e-mail to delivering food and medical supplies via a PA, staff member or delivery service. |
| Communication, consumers who lack access to adequate technology (smartphones, data plans, Wi-Fi). |
| Making contact through telecommunications, video, or other social media due to the fact that many of our consumers may not have accessibility to basic technology. |
| Reaching out for training when not all have access to phones and internet. |
| 1. Survival by institutionalized participants and access to services and resources by participants living in the community and relying on community base resources.<br>2. Access to food, medicine, sanitation and cleaning supplies and/or PPE due to transportation or delivery access.<br>3. Information & communication access and technology barriers due to cost and availability to broadband and/or telecom. |
| Our participants don't have access or know how to utilize technology to be able to receive services virtually. |
| The biggest challenge I've faced is not being able to provide independent living skills training and advocacy services in person. |
| Lockdowns in nursing homes mean we can't transition or prep people for transition. Shifting to online work for our group meetings is rough, especially for people without phones. Our donor network is taking a hit. |
| No face-to-face so no fee for service, which is about $48,000 a month. The fragility of our staff both physical and mental health. Funders refusing to maintain contracts. Recruitment of new staff. Being able to keep our doors open after our SBA loan runs out. |
| PC/SHC Service provision when PPE is difficult to acquire. Supporting Staff working remotely who live in rural areas. Funding due to loss of fee for service. |

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| Working from home for people with no computers, internet, or smartphones. We call all our consumers weekly. |
| No ability to meet with consumers face-to-face. No in-person group activities. |
| Being able to communicate accurately. Right now, I am speaking with social workers, but it's not the same as getting the individuals feelings or impacts of their emotional state. |
| Contacts in our entire service area (34 counties) that are available to respond to questions about available resources in their communities. |
| Supporting direct care workers financially for the work they do! To physically meet with individuals to assess their real needs. |
| I am a Personal Assistant Advocate; we have had many Personal Assistants unable or unwilling to come to work and those that are we are unable to provide PPE. |
| PPE. |
| Direct Service provision. |
| New aides coming on to the CDPAP program getting medical. Consumers are having problems having aides come in as they are scared of outside contaminations. |
| The social distancing and not being able to help consumers in person. |
| Appointments taking longer than usual since they are not in person. It is challenging to walk someone through something over the phone without being able to see what the person is looking at. |
| Working with consumers who have no access to the Internet and those who are not familiar or comfortable doing things virtually. |
| Not being able to provide hands-on skills training in the same manner we are accustomed to. Providing sufficient services remotely. |
| PPE direct care worker overtime expenses direct care worker 'hazard pay' costs. |
| Limited access to office resources. No in-person consumer contact. Decreased technical assistance. |
| Meeting face to face to improve interactions with consumers. |
| Completing program requirements without being able to be in contact with our Consumers and Leasing offices. Also, staff support to utilize upcoming housing funding through TDHCA. |
| The challenges include moving to a remote platform, how to interact with people who struggle with technology, getting information from Social Security and other agencies that are needed to accurately inform people of the resources available to them. |
| Our consumers who are more technologically challenged are experiencing more social isolation. We are providing supports from our homes, and the use of Google phone numbers helped, but it is still a challenge for our older participants to trust our Google phone numbers and answer our calls, when it is unrecognized number. |
| Not all attendants are getting gloves and masks. |
| Inability to see consumers face-to-face. |
| No access/limited access to PPE for attendants. |
| Concerns over face to face meetings in consumer's homes when the states open back up. Future funding amounts. Continuing consumer and employee safety. |
| Services are being handled by phone and mail so it is slower. But the need did not slow down. Probably increased. |
| Access barriers. |
| None. |
| Needed therapies. Transportation. |
| The biggest challenge is not being able to convene face-to-face assessments. This process enables us to identify and address needs that have not been expressed verbally. In some cases, it allows us the opportunity to access other resources when applicable. |

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| We are unable to meet with them face-to-face and some don't have the means of communicating with us through computers. |
| Lack of equipment, programs/software and supplies to work remotely and provide the full range of CIL services. |
| Safety concerns for both staff and consumers. We are only providing limited phone/email services with the few staff who feel safe to come into the office for limited hours. Other staff work from home. |
| Preparing services for our CIL consumers. Finding PPE for PAS workers. |
| Staff are anxious and require firm but gentle guidance. They are doing great work. The learning curve of transitioning our "regular" day-to-day programing into remote programing is challenging. Some of our very young and very old don't have the needed technology so phone contact remains essential. |
| Internet access to rural areas. |
| Technology and many of our people do not have the technology to communicate with us as we work remotely. |
| Internet and cell service access while working remotely. Antiquated technology for effective remote engagement with consumers. Access to consumers who reside in LTC facilities. |
| The biggest challenge is technology. As a rural community some consumers do not have the technology needed to communicate. These are the consumers that must see a staff in the office as that is the only way they can communicate their needs for services. |
| Contact with consumers. Ensuring that individuals with disabilities know we are available. |
| Providing technology connectivity in order to provide services remotely. |
| We have experienced a great reduction in calls/requests for service. |
| Only way we have to reach out to those we serve is via phone, internet (Zoom) meetings, email or mail. Rural areas some don't have strong internet capabilities -- so it’s difficult. |
| Staff shortage/safety, funding, transportation, lack of technology access for participants. |
| The digital divide that exists for people with disabilities living in rural areas and being able to reach them and push out critical information in a timely fashion. |
| Difficulty engaging with new consumers because we are not meeting in person. |
| Affordable housing, transportation outside of the rail and bus area, and assistive equipment (wheelchairs). |
| The requirement to close our offices has been a large challenge. Transitioning to remote work, and getting employees the tools they need to be successful. Finding new ways to connect with consumers when we are not able to complete face-to-face visits due to existing public health orders. |
| Our community is very rural. A lot of clients don't have transportation. |
| Access to protective equipment, consumer/provider access to technology, housing resources. |
| PPE supply. |
| Unable to meet with consumers face to face during stay at home order. Trying to reach consumers via phone has also proved challenging as some do not have a phone. Virtual meetings have been challenging on the board level as we have a member who is deaf/blind. We have been able to get an interpreter on Zoom for our member who is deaf but the picture is sometimes hard to clearly see. We had to cancel our largest fundraiser of the year and doubt we are going to be able to recoup those lost funds. Going forward, we are trying to determine how to use virtual events that are accessible to all disabilities. Finding and purchasing PPE and sanitation supplies for the office has been difficult, if not impossible. |
| Some consumers do not have internet access or a device to connect with staff remotely. |
| Other than meeting live face to face with our consumers the only other challenge we have figured out how to deliver our services remotely. We are still delivering and picking up DME and AT for our lending library. We have continued doing diversion work and have successfully transitioned 1 consumer from a nursing home back into the community setting of her choice. |

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| Not being able to see them, get masks and gloves for them. |
| Being out of the office on lockdown without any contacts with some consumers. |
| Gaining access to the consumers. |
| The need for transportation. Interpreter services for deaf community. After one week of shut-down, consumers who are alone are in need of food and other necessities started to contact the CIL for assistance. |
| We believe that the mental health of everyone has been the greatest concern. Aside from all of our clients' mental health issues, our staff have experienced loss as well as friends and loved ones have passed because of COVID-19. We cannot grieve the same way and it is very challenging to make sure staff are being taken care of as well as clients. Considering that over 70% of our staff have a pre-existing disability, this has been the unseen hazard of working under these conditions. |
| Not being able to have face-to-face contact with consumers. |
| Providing planned activities such as educational talks and training to consumers because the government does not authorize the opening of facilities and consumers who have access to technology are very few. |
| Assisting consumers in connecting with various local resources. |
| The NYS lockdown has most staff working remotely from home and prohibited from travel. Limiting our connection with financially/technology poor consumers to electronic interface. |

| **Question 2. What are the biggest pandemic concerns of your consumers?** |
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| Food resources, housing, loss of employment, transportation. |
| Food insecurity and transportation. |
| Risk of being subjected to the virus as they all have health issues, worried about being taken advantage of. |
| No face-to-face contact with consumers is difficult. Many are lonely and have limited social interaction. They are asking us to take them for a ride and we feel like we aren't able to do that yet. |
| Obtaining PPE for themselves and their staff. Access to food. |
| Anxiety; lack of internet among consumers. |
| Maintaining housing, lots of confusion about the stimulus check and filing taxes, etc. But in a world that has become even more dependent on electronic communications -- its internet and cell service. |
| We are very fortunate in that the numbers of those affected in our area is currently very low, so we have very few concerns directly related to having the virus. 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. |
| Ongoing services for medical, social, personal and economic needs. |
| Anxiety, isolation, lack of housing, food insecurity, Social Security offices not taking new applications, are they going to get a stimulus check, when will this be over. Can't find in-home care. Fears about in-home care providers bringing in virus. |
| Supply. In Hawaii, 80% of Goods have to be shipped in. Many store shelves are empty and re-stocking is slow. |
| Some consumers are very worried. We have been distributing donated distilled water to those who can't access it for medical equipment because of shortages or not having someone to go to the store for them. |
| Food and shelter. Even with food assistance, many grocery stores are low on supplies. Medically necessary diets are limited due to limited food. People experiencing homelessness are unable to practice social distancing. Public places are closed where people usually access water for drinking, bathing, hand washing, dishes, etc. Mental wellness supports. |
| Ensuring that consumers have adequate personal assistance services or home health. |

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| Financial stability and access to medical care. |
| When they will be able to obtain the services they have been waiting for that may be paused. Will service be cancelled. |
| Getting PPE. |
| Not being able to get out to doctor visits. |
| Home health support not using PPE and insecurity of potential risk or exposure and food insecurity. |
| Having a disability and being valued less when it comes to decisions such as who gets the ventilator when there is a shortage. |
| Loneliness and isolation, especially in instances where there is a residential lockdown. |
| Social isolation and a lack of things to do at home. |
| 1. Lack of PPE.<br>2. Workers not showing up due to their own needs/concerns.<br>3. Concerns around food shortage. 4. Potential shut-in effects as it relates to isolation. |
| Consumers are fearful that they may not have the DCW availability, this would result in placement in a nursing facility for people receiving services at home. |
| Having access to food and daily living needs, financial security, worries about receiving accurate information and concerns about maintaining mental health wellness. |
| Their mental health and recovery. The health and wellness of themselves and those they love. |
| Getting enough food and medical rationing. |
| Health care and food. |
| Fear of running out of food and supplies, no end in sight for restrictions. |
| Many people, especially young adults are in need of face-to-face interaction. Many do not understand the “why's” of isolation, even though many have been isolated much of their lives. |
| Fear of the unknown and of the future. Lack of communication and interaction with others. Not being able to see loved ones and not knowing when they will be able to again. |
| PPE and wipes. |
| The spread of COVID-19 and the severe shortage of testing; unable to get tested because of the shortage, lack of available testing. The politicization of a health pandemic. Should be in the scientists and medical experts hands. |
| Meeting SSA and other appeal deadlines, their home services workers showing up without masks, securing housing. Getting food, supplies, and transportation. |
| They are very concerned about the pandemic situation. Unable to see their families. |
| Consumers are concerned about being potentially exposed to the virus. Consumers would like to have access to masks. |
| Finding resources needed. |
| Most of our consumers do not have a computer. They would have come in the center to use the computers. Another concern is that they will be able to pay their bills, and that their medical insurance won't change. Too much uncertainty! |
| Not being able to use food stamp card to order food or be delivered. Also, if they have no one to trust to go to bank or to use their card. |
| Obtaining food, especially in a timely manner as delivery services are delayed, and applying for stimulus checks for consumers who are unemployed and do not receive SSI/SSDI. |
| Food and medicine security. |
| Consumers are afraid that when we return to face-to-face visits that we will expose them. Some consumers are left without help because they or their PCW has been exposed to COVID. Lack of supplies. |

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| Not having the personal peer to peer relationships described in #1. Not having the class setting to learn skills. |
| Health, nutrition, HCBS being affected. |
| How they will go shopping, get to work, get on with life even after the ban has lifted in our state. |
| The shelter in place started March 13th. Many of the consumers do not have access to the internet to order groceries online or debit cards to use. |
| 1. Getting food.<br>2. Worried about getting sick.<br>3. Worried about isolation and depression.<br>4. Loss of income.<br>5. Applying for assistance when they do not have an internet connection.<br>6. Housing issues<br>7. Cancelled medical appointments and not having the tech to access telehealth appointments. |
| Main concerns are getting mail from services such as section 8 or SNAP and not being able to complete without assistance. They are concerned the assistance will be denied due to not completing recertification. |
| Transportation, healthcare, food, and isolation. |
| Since we are a rural community our resources are very limited. The closest testing site is 1 hour from our area. Also, transportation is an issue. |
| Maintaining needs during seclusion, isolation. |
| Having to stay home without food, water, or other necessities. Lack of communication -- some don't have phones or have phones, but no reception. Who to call if they need help? Keeping in contact with local tribal leaders to see how they are addressing local call in lines for people who need help immediately. Local leaders are overwhelmed right now. |
| Going out for groceries, receiving assistance with understanding their mail, in home workers staying safe. |
| Inability to get a face-to-face with doctors. Many have health issues that cannot be addressed through video calls or phone calls by doctors. |
| The mental health of our consumers, more so the elderly consumers, of dealing with isolation of being alone and scared of getting the virus. I myself am 65 and am considered one of those people that are at risk of getting the virus. Some don't drive and relied on family, etc. to get them items they need and now those same people that helped them can't necessarily get items to the people due to staying home to stay safe. |
| Not being able to get groceries, either having to go to the store to use SNAP card but can't get to the store or don't want to due to disability and susceptibility to the virus, or not having deliveries of food to their door. |
| The biggest concern thus far is that for school-aged children or individuals that require support with managing aggressive behaviors are experiencing an increase in behaviors due to their normal activities being altered, interrupted and postponed. Many of the individuals can't comprehend the severity of COVID-19. With many families practicing social distancing a lot of our consumers attendants are not able work with them due to comfortability, high-risk, and alternative obligations of the attendants. Consumers' families are concerned that their children's school and therapies are not providing any support or enough support which could affect the cognitive and physical development of the consumer. |
| Ongoing supply of food, masks, toilet paper, attendants not coming into the home and fear they will not return post the emergency, isolation. |
| Receiving medical treatment, getting medication & DME, running out of food, children not in school-not enough PCA hours, homeless people can't go to shelters, transportation limited to get food. |
| Ability to access food and goods without endangering themselves on public transit; also, direct care staff not being available if they are vulnerable with underlying conditions. |
| Available provision of services and funds. |

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| Financial concerns if employment was lost and how to access unemployment benefits.<br>Access to needed resources like groceries, personal care items, prescriptions for PWD who are concerned about leaving their home, don't have transportation to get to a store or pharmacy, or are living on a limited income where they are unable to get more than a week supply of items typically when at the store.<br>Staying as healthy as possible and not being exposed to or contracting COVID-19.<br>Social isolation, and the emotional toll this is taking on some consumers.<br>Receiving in-home care and concerns about if a chore provider, aid or care giver is to become ill and not be able to provide care. |
| Becoming infected, or for anyone among family and friends getting infected. |
| Having underlying health issues that make the disease more dangerous for them/us. Not being able to access resources. |
| Fear of the unknown. |
| Our biggest concern is how it has affected our community, those who have caught the virus and those who have died from the virus. |
| 1. Isolation.<br>2. Accessing telehealth, especially without technology.<br>3. Accessing food. Delivery only works with technology. High risk going into stores and using public transportation.<br>4. Loss of income. |
| For the clients to retain information with so many distractions at home with family or alone. Concern for the future and loss of family members being sick. Isolated at home and never being out of their room. For TBI and others change is a learning skill and may not go back easily. |
| Not easily able to access supplies such as masks, wipes, toilet paper, etc. Not able to shop safely. |
| The need for peer support and coping with depression. Isolation is driving a lot of that. Also a few homeless people reported having difficulty connecting with the County's access line to get housing help. We are advocating with the County on that. |
| That there is someone checking on them and they have someone to call if they need help. That family members stay in contact with them. What they need to do if they get sick and they are all alone. |
| Fear. Fear of the virus, now fear of other people, fear of not enough food |
| Not being able to pay their rent and utilities. |
| Food security. Safe transportation. Retaining their housing Isolation. |
| Not being able to have the personal connections and social interactions necessary to both emotional and physical well-being. Simple fear, especially since the facts of COVID-19 can seem very confusing and political. |
| Supplies. |
| 1. Protection from infection and access to healthcare.<br>2. Fear of institutionalization and/or proximity to others who may be infected.<br>3. Nutrition and hygiene supply access. |
| Getting sick and worried there isn't going to be enough room at the ER. Worried that their caregivers are going to get sick and then they won't have in-home care. |
| Our consumers are worried about being isolated and not having services available to them. |
| Access to food, and then also PPE for home services. People are also scared about riding public transit or paratransit, about making rent, and about accessing healthcare. |
| Housing and food insecurity. Loneliness/mental health issues. Lack of essential services, home care, therapies, medication, no access to doctors. No access to internet or computer |
| Unable to purchase food and personal care items due to inability to travel (we are meeting or assisting with meeting this need now but still a concern of consumers). Health concerns related to disability and resulting in |

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| putting PC/SHC services on hold in some cases. Not attending medical appointments. |
| Seniors with disabilities without transportation, rental assistance, discrimination against people with disabilities in healthcare treatment, ability to get food, mental health due to COVID-19. |
| Mostly fear and anxiety. Also fear about not being able to get the necessary medical supplies, equipment and/or any needed repairs or maintenance. |
| Getting the virus mostly. Others have stated lack of home care due to aides being scared also. Having back up aides, having extra food available. |
| Face masks, hand sanitizers, food, knowledge of virus and safety precautions. |
| Scared that they will be infected if they leave their home. If they need medical treatment, fear of nursing home placement. |
| Being exposed to or contracting the virus, in adequate PPE for Personal Assistants, being unable to leave their homes or be with friend/family (social isolation), many do not have technology to do face to face virtually. |
| Testing, and treatment if diagnosed. |
| Access to food, healthcare, and finances. |
| Keeping aides. |
| Being able to get in person help from social security offices or housing offices. |
| Aside from isolation, the lack of accessible technology/internet, affordable housing, financial resources and food. |
| Not being able to pay their rent, losing their homes due to lack of income. Not having access to their regular social network and public facilities, such as the library. |
| Sufficient PPE for self and direct care worker protection. Access to food and cleaning supplies. |
| Staying out of nursing homes. Staying out of hospitals. Not contracting COVID-19 from visitors to their homes. Concern that they will be discriminated against when being triaged at a hospital. |
| Health exposure, uncertainty, financial insecurity, residence instability. |
| Coming in contact with someone that has this virus. |
| Keeping their current housing assistance. For those whose assistance is ending, finding new housing opportunities by being sheltered in place. |
| Staying healthy, not being able to meet their financial needs, evictions, food resources, and fear. |
| Fear of re-entering the stores, offices. |
| When are they going to get their stimulus check |
| Most of the consumers I work with are vulnerable adults, who are susceptible to COVID 19. They are very concerned about getting it. |
| No/limited attendant care and lack of PPE for attendants and consumers. |
| Not getting the virus. |
| The unknown, how to get other services when the offices are closed. Access to PPE to stay safe. |
| Death. Getting the virus. Fear of getting the virus. Job losses. Lack of necessities such as food. |
| No therapies, such as massage. Kids out of school and parents are trying to keep them busy. Kids out of routine. |
| Keeping loved ones safe and continuing services. |
| Many of our consumers are medically fragile and they are afraid of being exposed to the virus once we are allowed to go into their home. |
| Continued access to personal assistance services and caregiver burn-out. Many consumers who live in the community do so w/ the help of paid attendants and non-paid caregivers. It is already a challenge to maintain dependable, long term providers without a pandemic, adding another layer of complication. Without aid, people with disabilities may not complete daily tasks like dressing, toileting, cooking, cleaning, eating, taking medications, |

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| etc. Some might not even get out of bed. Non-paid caregivers usually fill in when paid staff cannot. Some non-paid CG's still have to work outside of the home. Others have to work from home. Some work in-home, and have to spend every waking hour (and during the night) caring for someone else without a moment of respite. Limited access to resources. Most 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. Isolation and mental health. In addition to physical disabilities, many manage mood disorders or other mental health conditions. Some are able to verbalize their feelings but many are not. |
| Loss of income. Food insecurity. Health concerns. Loneliness. Mental health issues worsening. Eviction fears. |
| Transportation, deadlines, emergencies, food access: it depends on where they are in need of services. |
| "When is it going to be over?" |
| Lack of socialization and ability to move freely to appointments, gatherings, etc. for support. |
| Food and rent or utility payments. |
| Food insecurity safe transportation. Unmet healthcare needs. |
| Consumers have been very cautious and using masks. Their biggest concern is their health and fear of contracting the virus. |
| Lack of support system, loneliness, inability or fear of using public transportation. Unable to go shopping without potential exposure to COVID-19. The things that consumers need assistance with we are limited in providing such as utility/rent assistance. |
| Health care/medicine shortages or access. |
| The calls that we have received, most have concerns related to access to community services: DHS/Medicaid/SNAP; SSA; transportation. |
| Food and being safe in the community. Some of PCA concerns. Inability to obtain PPE. |
| Food security, access to services w/o transportation or technology, access to medical care. |
| Increased social isolation -- access to available resources. |
| Stress and isolation, mental health, lack of PPE for caregivers. Difficulty with correspondence and paperwork, loss of supports and services. |
| Affordable housing and maintaining housing. |
| Food insecurity, safety of family members in nursing homes or transitional living environments, safe transportation, availability of caring medical services and how lockdown will impact applications for benefits. |
| The spread of the virus and many have underlying health conditions. |
| Protective equipment bills/rent continuing services. |
| Fear, poor understanding, misinformation. |
| Feelings of overwhelming isolation. Not having internet access, computer, and sometimes even a phone, has made it very difficult to remain in contact with anyone. Being unable to get to the store but cannot use SNAP card for grocery deliveries. Deaf and hard of hearing consumers find it impossible to communicate with masks on and are being banned from places if they don't wear one. Consumers fear having to enter nursing home if they lose their PA services. |
| Access to healthcare. |
| Financial and food insecurities. |
| Being isolated. |
| Consumers at high risks for COVID-19. |
| Will this become a permanent state ?How much will my grandchildren have changed by the time I see them again. |

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| What will I do if I get the virus? Sheltering alone; how do I manage staff unable to make contact with some consumers? Will they be able to get back to the center to continue training? |
| Being in such a rural area, we are coping with people needing services in outlying areas. They are feeling especially isolated and vulnerable. Food Insecurity, concerns over accessibility to medications, and lack of resources (loss of income) have been the three top concerns of our consumers. |
| Isolation. |
| Transportation services, access to food, safety and protection products, hygiene products, economic resources. Fear of getting it due to their conditions and because they are the caregivers of their parents from their old and sick parents; the lack of accommodations in pharmacies and food places. |
| Connecting with various community resources. |
| Physical acquisition of medical care/prescriptions for pre-existing conditions, as well as basic necessities let alone scarce PPEs. |

| **Question 3. What are the biggest pandemic concerns of your staff?** |
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| Fear for themselves and worried about losing their jobs. |
| Unsure about how long we are going to be working from home and when service and resource development activities can begin again. |
| Risk of exposing employees to the virus and not being open to the public. |
| Safety for themselves, also not unknowingly giving COVID-19 to consumers. |
| Maintaining their health and employment. |
| Inability to serve [clients] as we are accustomed. |
| Social isolation: we are a tight knit group. Now we meet twice a week for 1.5 hrs., but it's not the same. Everyone is healthy (so far) and working. |
| Not being able to reach people and since most staff have disabilities themselves fear of the virus and its effect. |
| Staying healthy and safe while providing core services. |
| When will this be over and we can come back to work? Anxiety over not being able to provide the robust services they usually do, missing co-worker connections. |
| Job security. |
| Catching COVID-19 as a person with compromised immunity; passing it on to family or loved ones; passing it on to consumers. |
| Social isolation -- Staff are personally connected and have worked with one another for years. Even with technology, it doesn't replace face to face connection.<br>Health -- many staff are immunocompromised. They are concerned about how we will resume operations after shelter in place orders are lifted without putting themselves or consumers at risk.<br>Communication -- trying to get communication out as frequently as possible without overwhelming everyone.<br>Mental wellness support digital divide. |
| Staying healthy for themselves and their families. |
| When we will be able to go back to the office and operate the same way. Will we continue to work from home effectively provided services to our consumers. |
| Carrying the virus to our consumers. |
| Feeling limited to meeting immediate needs beyond phone or email, being exposed to risk. |
| Catching the virus and bring it home to family. Worry about consumers who live alone and have no back up plan for what happens if they get the virus. |

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| Organizing and finding resources is one of my concerns, many are in need of home health care which seems to be hard to find. |
| They do not like working remotely. Think they are failing our consumers. |
| 1. Having enough PPE.<br>2. Their own safety with contamination (they do not know who else has been in the homes of their consumers).<br>3. Job security.<br>4. Will we as an organization make it through this. |
| Difficulty to see and serve people that are in nursing homes and hospitals. |
| Finding new ways to meet the needs of the consumers. |
| Assisting consumers without endangering ourselves. |
| We live in an epicenter of the pandemic so they worry about catching the virus. |
| We are holding up!! I feel we have an amazing director who keeps us all grounded and supported. But we worry about what will happen long term. |
| Limited contact with consumers; availability of resources. |
| The health and welfare of our consumers. |
| Not knowing when we will get back to what used to be "normal". |
| PPE. |
| The spread of COVID-19, not having the proper PPE for the staff, the difficulty of getting tested. |
| Some are not doing well emotionally with trying to work, take care of their kids, and home school their kids. Transition coordinator cannot get into nursing homes to meet with people, but is serving via telephone. |
| PCW's are concerned because they don't have protection supplies-no masks, no sanitizer. |
| Lack of adequate PPE and inability to procure the PPE. |
| Getting their direct service time in, and not getting to meet face to face with consumers. |
| The biggest concern is when we all get back in the office. Are we safe to go back? We will have precautions such as wearing masks and gloves, wiping everything down with disinfectant. We will also have the consumers wear masks and gloves. If staff or consumers are running a fever or feeling ill, we will have to ask them to leave. |
| Our peers. |
| Ensuring consumers' needs are met without having physical contact with them. |
| When they can go back to working in office instead of remotely. |
| We are concerned that we will be made to return to face to face visits too soon and we will expose ourselves, our consumer's or our families to COVID. |
| Getting the COVID-19 themselves and spreading it to their families. |
| Staying employed, being able to deliver services, getting help to those who need it. |
| Working remotely was a big adjustment for a lot and how to stay busy during the day. |
| If we were exposed to the COVID-19 virus through other office staff who were sick early on or traveled to Mexico or the Southern United States – we need testing for antigens for the COVID-19. |
| 1. Maintaining income. 2. Are we reaching everyone who has a need? 3. Meeting the needs of the consumers, not getting sick. 4. The economy after this virus is over, and concerns for it happening for the second round. |
| Concern for our most vulnerable consumers, that their direct staff will not be able to assist them. |
| Uncertainty of employment, quality of service being provided remotely, and emotional support. |
| The challenges of working from home and taking care of their families while they are working from home, and the health and safety of staff and their families. |
| Vulnerability to COVID-19, overwhelmed with advocacy issues, keeping regular services going. |

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| Staying safe and not getting infected. Being extremely diligent with sanitizing vehicles (enough supplies), and use of appropriate PPE, and practicing giving services while following no contact guidelines. Provides as much services via telephone and no contact with residents upon drop-off. |
| Being there for our consumers, using appropriate distancing and safety for those who do have to be in the office. |
| That we could spread the virus when restrictions are lifted. |
| The time lag in getting necessary signed paperwork back from our consumers that is required due to HIPPA requirements. I can't help my consumers as quick as before, because I have to remind them to mail the signed paperwork back to me before I can go further in helping them access some services. I can give information and referrals of course without that signed paperwork, but it's frustrating to me I can't help them faster. |
| Losing their job. |
| Returning to work safely and ensuring that we have preventative supplies readily available. |
| Isolation, lay-offs, reduction in force, contracting it, having underlying conditions that increase their risk, managing their risk. |
| Being exposed to infected people, can't find individuals to do PCA work, feeling safe in the community and returning to work. |
| Opening up too quickly and putting themselves at risk; 78% of my staff have underlying conditions. |
| Protection and ways assist clients. |
| We have not surveyed staff on this question yet but from multiple meetings staff have expressed concerns about retaining employment. Job security concerns have gone down recently with staff receiving assurance that all staff will remain employed for at least an 8-week period of time. Staff also very much care about the customers they serve and are concerned about individuals having needs met during the pandemic and stay in place orders. |
| Becoming infected, losing contact with some of our consumers, and financial instability. |
| There are different concerns for each depending on their own disability and health status. Possibly losing their job. |
| Potential exposure. |
| Staff is concerned about being safe when returning back to the office. Will they still be protected following the protocols put in place to stay safe. |
| 1. Isolation.<br>2. Financial hardships due to partners losing their income.<br>3. Fear of returning to work. |
| Safety -- how to establish a new protocol when we return to work.<br>Not having the opportunity to assist them with "what if" decisions with their stimulus checks...they are excited to spend it, but forget they have a $400.00 water bill. |
| Adjustment to working from home and family being home. And the isolation. The fact that they are now at home, how do I go back to work. |
| The isolation and resulting depression. Not able to do the job as fully as they were able to do pre-COVID. |
| Staff are nervous about the approaching relaxation of sheltering orders and allowing people to come into the office. They worry if they will be safe. |
| That they stay well and keep from getting infected while helping consumers. Staying well for their families. |
| Fear of getting ill. Fear of dying and leaving family unprepared. Fear of breakdown in the social fabric. What to do if we're going back to work and schools are still closed. |
| How to safely administer top quality services to our consumers once we are physically back in the office and face to face. |
| Personal safety. Continuity of services for consumers while working remotely. |

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| CWDR has not had to furlough or to lay off any staff, but due to safety reasons, staff are trading days at teleworking, so we have 2-3 staff in office and 2-3 teleworking. We are learning how to serve clients very well through distance technology, as we are just providing I/R via phone in the office. Distancing and lack of ongoing staff contact, has caused difficulty in morale; we have tried to manage this via video conferencing several times a week. |
| Safety for all. |
| 1. Access to our participants in institutions and the community.<br>2. Healthcare rationing that will affect people with disabilities.<br>3. Lifeline resources normally available in the era with no pandemic. |
| Getting COVID and not being able to work effectively from home compared to at the office. |
| Contracting the virus and passing it on to someone with a compromised immune system. |
| Not being able to support people face to face, and also being able to access healthcare. |
| Parents trying to balance home school and work. Maintaining their physical and mental health. Isolation. Unsure of the future and what changes may have to take place. |
| Isolation of consumers. Taking care of their families and meeting needs of consumers. Job security. Health and safety of co-workers. |
| Returning to work safely. |
| Since the majority of our staff are people with disabilities and chronic health conditions, many are concerned for their own health and safety if they were to contract COVID-19. |
| Mine is catching the virus, because I have a weak immune system. I can't speak on behalf of all staff members; some have stated that they are not ready to return to work. |
| Safety in the office. Catching virus through someone else. |
| Retaining and paying direct care workers what they deserve. Lack of PPE from the onset! Fear that they may be exposed and pass the virus to their loved ones. |
| Continuing to serve the consumers with the resources (financial, technology, time) we have as well as addressing the pandemic related isolation, fear, lack of "normality/routine." |
| Interaction with the general public. |
| Continued employment. |
| Having aides, consumers or people coming in for loan closet entering without masks. We have some to hand out but not enough if we open to all. |
| Being able to go back to work with the social distancing in place. |
| The expectation of returning to offices vs. local health orders. |
| Future income if pandemic continues. Continued paid health insurance. Not having access to resources available in our offices. Inability to meet with our consumers face-to-face. |
| When will it be safe to reopen and resume in person contact with consumers? Projecting direct care workers. |
| Infection control. Completing tasks remotely. |
| Continued employment. Consumers not able to be adequately served. Lack of transparency regarding management plans. |
| Coming in contact with someone that has the virus that might not know that they have it and spreading it to others. |
| Struggling to keep program supports active while working remotely. |
| Job stability and fear of getting COVID. |
| Mental health impacts while talking with individuals over isolation and loss, all aspects of grief and how to generate excitement about our future, when it seems so endless. |

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| Trying to provide services remotely many services can be done via video and phone but in some cases some cases it is very difficult to provide certain services or goals. |
| Not getting the virus themselves. |
| Lack of PPE, even gloves and masks. The minimum protection is lacking. |
| Getting the virus. |
| How best to serve the consumer and be safe? How to get everything done while working remotely. |
| Fear of getting COVID-19 Loss of employment How to actively engage in a meaningful way Ability to provide resources and help. |
| Paying for and using our own equipment in order to work from home. Are we still going to get paid? |
| Keeping staff safe and the continuum of services. |
| That many more people are already carrying the virus and have not been tested or might not be feeling symptoms and are exposing the public. |
| Maintaining the mission of the agency and ensuring that people with disabilities have access to the things that they want and need. We are concerned for ourselves and consumers safety while delivering qualitative services. Without PPE, equipment, programs/software and supplies to work remotely. |
| Inability to provide the services we want for our consumers. Concerns about individual consumers who need services and supports. Will we ever get back to doing what we do? How will we know when it's really safe to come back? When can we come back? Are we going to lose funding? Will we lose our jobs? What about the consumer who are losing jobs? |
| Making sure we are meeting individual and community needs for disability and accessibility needs for north central Montana. |
| My staff are primarily individuals with disabilities with co-occurring medical issues. They are very concerned about potential exposure. |
| Isolation. Working from home where children are during the daytime hours. |
| When we can return to working in our storefront? |
| Ability to effectively provide services remotely. Health and welfare of themselves and their families. Welfare of residents in long-term care facilities |
| The biggest concern for the staff is consumers that may come into the office while sick. They are also concerned that due to distancing because of the virus, consumers are not receiving the best quality of services, some of the programs cannot run as they are in a group setting. |
| Contracting the virus. Potentially losing consumers. Working from home with little contact. |
| We are in a highly infected area, so a very measured and careful return to the physical workspace is a concern. Although, we are fully operational remotely. |
| Staying healthy and safe. |
| Being safe and not contracting disease. Many miss being social and seeing their co-workers on a daily basis. |
| Personal and participant safety, putting services on hold when it cannot be delivered remotely |
| Working remotely from home has been difficult for staff while balancing mental/ emotional toll of self, consumer, family, etc. |
| Lack of PPE, lack leadership, fear of infection, many staff in high risk categories. Understanding quickly changing resources. |
| Health and safety/continue to telework from home. |
| How we safely provide services in compliance with lockdown requirements, access to technology to help connection with the consumers. How to keep selves and consumers safe when accessing services and performing tasks of daily living. How to advocate for students who are not getting proper supports under IEPs. |

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| Social distancing and the economy opening too soon, our office is also located next to the main hospital. |
| Connecting to consumers. Reaching consumers. |
| Fear, poor understanding, misinformation. |
| No childcare access so it is difficult to work at home or even come into an office that is open to staff only. 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. We do offer curb-side pick-up and delivery of our durable medical equipment loan program and staff are ok with this limited contact with the consumers but worry about the other consumers that they are not able to meet with right now. |
| Offering effective services remotely and finding ways to secure consumer follow-up. |
| Making sure that our center is prepared with the proper PPE for both staff and the consumers that eventually will return to our center. |
| Not being able to our jobs all the way. |
| To know if everyone is safe and healthy. |
| How likely are the chances of getting ill or transferring the virus to my kids? How are my consumer really doing? Are they putting on a brave face? |
| CIL location is small. Staff retrofitting office to meet distance and other needs is strenuous. Little staff to do much, much. Some staff literally assisting consumers with needs because there is no other alternative. Outreach to as many consumers as possible to ascertain their need for having form 1040 to be filled out and submitted (this is unique to the territory and must be done for them to receive stimulus checks). |
| We have a few different concerns as staff are very diverse. Two staff have opted to stay home, using their PTO, since they are taking care of an elderly parent who lives with them. We have one staff member who has Personal Care Aides for their brother who suffered a TBI years ago and needs round the clock care. Their PCA's have been unavailable as they have to pull mandated shifts at the health care facility where their primary employment is. As a result, he is working reduced hours to help his wife cover the vacant shifts. We have two staff members with multiple school aged children, who now have been having homeschooling responsibilities as well as working full-time. For one who has three young children, this is amplified as her husband is a Correctional Officer. He has been working double shifts since the virus has hit the facility where he works and they are short staffed. |
| Safety of consumers and staff going forward. |
| Achieve the established goals and manage to provide services remotely because the majority of consumers do not have access to technology, lack of equipment and materials to work from home. |
| Their safety when they return to working in our 4 CILs' offices |
| Beyond concern for the unmet need of people we serve, our staff are PWDs with many falling into the COVID-19 high risk of mortality pool. |

| **Question 4. What do you think the Administration for Community Living needs to know about the current needs of your local disability community?** |
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| Continued training and guidance. |
| Funds from the new CARES funds need to be available for direct services. Right now, there is no Part C money available for the financial assistance people need. |
| Financially they seem to be in better shape just like everyone else they are having difficulty obtaining staples as people are buying in a frenzy. |
| None. |
| That our CIL is open and continuing operations through this and doing everything possible to assist/support our consumers. |

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| I'm not sure what ACL needs to know. Our state's emergency management agency has a full-time disability integration specialist who has disability inclusion calls 3 times a week to identify and resolve so many issues. We have a seat at that table. We need to get clearer guidance quicker but I'm not sure ACL can make that happen. |
| We serve a very old population compared to other areas. People that have always been self-reliant and who look at the need to ask akin with failure. We need fast policy work, both in what we can do and how we can utilize funding to best serve folks. We need to continue finding out about best practices so we can duplicate them. And we need their continued support which I believe has been great through to this point. Thank you. |
| This is a process of change in all areas. Need to plan in the best way to continue not only today but tomorrow. |
| More affordable housing. Appropriate access to healthcare, without disparities towards people with disabilities. |
| That our state of Hawaii is unique. That each island within the state has its unique challenges and differences in needs. We are often held up to mainland U.S. standards which are not applicable/workable here. |
| The needs of the disability community should be considered in legislation and their lives should not be considered an appropriate trade-off for reopening society. |
| We are just in the beginning. Be flexible. Our needs are similar to others across the country. Allow us to be creative with the additional funds. Whether this is to develop programs/services. Allow the funds to fill in the gaps that we're seeing in providing nursing facility transition services (e.g., hotel rooms, meals, hazard pay for staff). |
| Consumer needs are so unique and there isn't one solution that addresses everyone and everything. |
| Culture competence. |
| Consumers are lacking new technology to be able to communicate virtually. Aftermath concerns that might arise from the situations. |
| In Cook County, Illinois, I am helping lead efforts to obtain and distribute PPE to our personal assistants and consumers. We have developed a coalition, consisting of people affiliated with Rush University, Univ. of IL at Chicago, Progress Center for Independent Living, Access Living, SEIU, Alliance for Community Services, and Chicago ADAPT. I have already had a solid contact with an individual who is in the import/export industry and has a direct working relationship with government medical supply factories that are making FDA/CE approved PPE. Since he deals with large scale purchases (minimum of 50,000 PPE), we are presently engaged in advocacy efforts to connect with state agencies who could fund this purchase. If ACL or anyone reading this has a contact or knows of funding opportunities please e-mail me at kmeskin@progresscil.org or call me at (443) 934-4226. Thank you. |
| Our transportation system is not working with those who have wheelchairs. |
| Our consumers need direct support dollars to fulfill immediate needs of food and shelter. Some of our consumers are homeless, and while support is available, it's slow to process. |
| People with disabilities may have additional challenges, but we are valuable to and life is as precious to us as to anyone else. |
| Ways to stay in contact when consumers do not have access to technology |
| How rural we really are. |
| We are a single state CIL, we service over 1800 consumers monthly with all of our programs, which include a fee for service programs. We need funding to retain staff to make those much-needed calls to consumers to access for isolation, loneliness, etc. We need to be acutely aware of the unintended consequences of the stay at home order, depression. |
| Greater resources for staff that provide direct service to PWD. |
| The pandemic has “pulled back the curtain" on the depth of the need for our local disability community. Needs always exist for this group of people but the current situation has exacerbated the problem. |
| This is a tricky time with very little guidance from previous experience. I think having a structure in place for individuals with disabilities to be able to connect would be very beneficial. WV is very rural and we need much better internet infrastructure. |

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| Funding needs to come in to help continue the important work that is being done. |
| I do not have an answer for this. I feel the local state and federal government are doing a fantastic job meeting the needs of everyone. |
| Local public transportation has been instructed to transport for doctor's appointments only. This limits consumers in being able to purchase necessary supplies. Also, several rely on public transport to and from essential employment, causing anxiety for job security. |
| The disability world is not left out of important decisions made by the local and federal government. |
| We have lots of consumers in the hard-hit areas. |
| Make testing more available, so people who need help can have that help interact directly with the disabled community. |
| It is difficult to meet the needs of consumers, especially IL Skills training, but we are doing the best we can through video chat and phone to help the best we can. |
| Community needs more protection supplies. |
| Lack of adequate PPE is potentially exposing consumers and workers to the virus. |
| Funds are needed to continue to maintain resources, meet needs, etc. |
| That Disability Resource Center is getting the word out as best we can. We share videos and information about COVID-19, social distancing, hand washing, etc. |
| That we need to set up more available services and programs to address all issues. |
| Lack of means of technology and understanding how to use it. |
| I wish they would provide funding for direct service to individuals. |
| Some people are being left without help. |
| These have been passed on to our PO with ACL. ACL has called several times to check on our status. |
| Access to care without fear. Systems being put in place for gathering of essentials for those who are not able to easily get to pharmacies or stores and the hardship that the changes to public transportation is adding on to the worry. Access to PPE for themselves and their aides, if applicable. To stay healthy. |
| Honestly, ACL has been highly involved since the beginning of this and has been very supporting, especially Dave with Region 5. |
| Sheltering in place is causing a disruption in medical care, a fear to leave their home to seek medical help when they need it. Long waits on the phone and voicemails left to health care providers. |
| 1. Our disability service organizations are fragmented and work in silos, this must change. It is making it more difficult to collaborate quickly when a need like this arises.<br>2. The challenge of getting food to the elderly and disabled who should not be out in the community exposing themselves to the risk of catching the virus.<br>3. There are a lot of services set up for the elderly, which is great, but we need more resources for the disabled community such as fewer requirements when food, hygiene products, medications are involved. |
| They need to know how many are not able to do telemedicine and are scared to leave their house to ask for help. |
| Access to transportation, shelter and foodbanks. |
| Yes, ACL should be aware of our area of service. |
| Staff are working overtime to keep from drowning and to be effective. consumers need resources to jump in in leadership! |
| People with disabilities on tribal lands live very remotely and often without plumbing, running water, and no electricity. If they are lucky, they may have solar power. Due to ESL issues, may have problems understanding instructions around keeping themselves safe in their own homes unless given instructions in their own language. Some have no close family members who can help them because everyone is so afraid of becoming infected. |

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| That social isolation heightened during this time perpetuates despair, and that transportation and safety are necessary during these types of shutdowns. |
| Where I live, my city is one of the most inaccessible cities in Texas, I believe. This is mainly because the Mayor and City Council are very resistant to the historic downtown district being modified to become accessible. They are more concerned about how it would change how the buildings will look if the entrance is modified, for instance, even though there are ways to make a building accessible by ways that aren't tremendously expensive. Many of the business owners think it's ok for people in wheelchairs to have access to the entrance only from the back of the buildings. I live in a retirement community apartment complex and fellow residents have told me how they would love to go to certain businesses and restaurants but can't due to inaccessibility, even though these same businesses would have an increase in sales from these same residents and other seniors. |
| Access to "virtual" anything is impossible without the technology and the internet, both of which many people with disabilities in our community do not have. |
| Transport concerns of how supplies (medical) will be frequently delivered to our consumers safely--to include groceries; sufficient access to healthcare services. |
| The impact of isolation and the incredible need for flexibility in funding and service provision. |
| PWD's depend on services they may have been suspended, online order/delivery from grocery stores will let an individual place an order using food stamps, SNAP, etc. |
| Access to technology and communication everywhere is critical. |
| Accessing services and funding. |
| ACL has been very understanding and supportive of the need for CIL's to modify the way they have traditionally delivered services to individuals and communities. The needs in our disability are diverse based on location, and access dynamics. Individuals in our local disability community want to stay connected, want to stay safe, to be as healthy as possible, to have stability, to have access to all critical resources (transportation, medical care, medications, in home care, food, shelter), and to continue to lead self-determined lives with supports in place that allow this. |
| A need for internet access for this population. With everything closed, if they do not possess computers, tablets, smart phones, they do not have that access to communication. |
| That Centers for Independent Living in Kansas are grossly underfunded and have little resources to provide adequate services and for the needs of the people we serve. |
| Education is difficult and our population is very skeptical. |
| Getting consumers back in touch with their doctors on a regular basis. There are financial needs to those with disabilities such as getting their rent paid and paying for food and utilities. Some of them do not have access to food due to losing services from the shutdown. |
| Some services are just harder to provide. Youth transition services are difficult when post-secondary options are limited during stay at home orders. Nursing facility transitions are difficult when staff cannot enter facilities and there is a provider shortage. |
| The rural nature of a large part of service areas prevents internet access, prevents them from getting food and supplies that are mainly located in "town" because they don't have transportation. We can spend all day delivering needed food, etc. |
| Re-introduce living in small pieces with education and outreach. More choices for in-home supported services, transportation, housing, and work on supportive services and coordination services with senior services and persons with disabilities. |
| As always, everyone's needs are different -- same as pre-COVID. However, it really seems that students with IEPs are the biggest losers because their education is lacking without their usual supports. Parents working from home are not able to give their child the same and varied supports they received in school. |

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| There is concern for how COVID-related supports could be sustained after the CARES funding is gone. Supports like respite care and food through meals-on-wheels, nutrition cafes, food pantries, and restaurant delivery programs will be gone. People under age 60 with disabilities need to have access to the nutrition services like meals on wheels and cafe programs that now are limited to those over 65 by the Older Americans Act. The nutrition services part of that Act needs to be amended to include eligibility for people with disabilities under age 60. |
| That number of COVID-19 infections are high on tribal lands and despite that community groups and volunteers have come together well to ensure that everyone is checked on and helped during this time. We are collaborating with other programs to provide food, water, and other necessities for people with disabilities and elderly population, and other disadvantaged groups. |
| The deaf community has been left out of most of the official updates in NYS. People who are blind are now afraid to touch anything which is impacting independence and mental health. ACES are skyrocketing -- this will have effects for years to come. |
| I believe ACL is very aware of the needs in the disability community. They have given very good guidance on how we are to administer the CARES ACT grant correctly. |
| 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. Staying in top of health advisories let alone remaining connected to their personal community leads to anxiety, fear and noncompliance. |
| Central Washington Disability Resources has a large independent living community, and we are finding that the aging population are being supported. |
| Zoom training. |
| 1. No one knows better than those living in a community what the need of that community are! Allow the subject matter experts in the local environment drive the goal setting.<br>2. CILs/SILCs want to support ACL/ILA by accurately and effectively reporting data that upholds the goals and achievements.<br>3. CILs/SILCs are an extension of their federal offices that create outcomes that serve our Whole Community. |
| We need patience while we figure out our communities' needs and create a plan to address it. |
| Many people who have disabilities also have a very limited income. This leaves them in a bad place when it comes to things like stocking up on groceries. They also used to be able to go to local food banks, but many of the food banks are very low on food and some have even shut down. CILS need funding for things like essential needs for our participants. |
| People need access to communication technology and to be trained on how to use it (tablets, etc.). We also need a serious shot in the arm with federal funding for HCBS so the overall response network is stronger. |
| People are dying at a higher rate than without a disability. More funding needs to be made available so we can help individuals with the funds. Mental health issues are coming to the surface and Centers are not prepared. How much it costs to set up staff to work from home. |
| The peak of this has not reached our service area and is predicted to not hit until mid-July or early August. We need consideration of our rural communities. We have a high population of Seniors despite a smaller service population and cover a large service area. |
| Congregate situations are hotbeds. Homeless individuals are last to be served. Braille materials are needed to get information to the blind community who do not have technology, especially rural areas. |
| The need for hazard pays and overtime pay for personal care attendants. |
| Take it slow and listen to employees' concerns about returning to our offices. |
| People need to feel supported and cared for. |

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| That CILs are the one provider that people with disabilities can count on when all others won't take the risk!!! Our homes are not nursing homes! There is a need to protect residents in nursing homes. We need to be able to transition people more effectively. |
| Access to technology for many consumers limits their ability to connect, with libraries and other community centers closed. Increase of needs for supports for the non-disabled community makes it even more challenging to access resources for those that are disabled community. |
| Testing is not available to high risk populations. |
| We live in a rural area, so access to food and healthcare are limited but very important, and social isolation is a big problem. |
| That they need to be addressed as well with their different needs. |
| The needs are practically the same as before the pandemic, however, they have been amplified and seemingly harder to meet because these are the needs of the local community as a whole, not just the disability community. |
| There needs to be a big push to make sure that every household has fast internet service -- same importance as electricity -- followed by the equipment and training necessary to keep connected for services and social interaction. |
| There is a huge technology gap in rural areas that we serve. Many consumers would benefit from video check inns as well as phone calls, but they don't have access to reliable Internet service or devices that would allow them to take advantage of video services. We must do more to put technology in the hands of those who will benefit from it. |
| Relax the use of the regular federal CIL grant funding, like the relaxation of the CARES Act CIL funding. |
| Transportation is at a virtual standstill. Telepresence requires training. Technology is no longer optional -- it is a vital public service necessary for consumers to maintain or increase independence. |
| What supplies are needed for PAS staff to keep them safe while they are doing their jobs. |
| That they are concerned about all the supports they have in place to remain independent being affected by all changes in life the virus is causing our community. |
| Working with multiple counties can be a struggle when each county is following separate guidelines. |
| Access to supports for people who are low income, and non-English speaking and easily overwhelmed in using technology. Also, keeping access to Social Security Disability application process and having extensions in place if difficult to obtain medical evidence. Also, to allow tele health documentation in the SSA disability process. |
| There's no standard on medical and dental. Individuals with disabilities need more improved access to medical and dental. Support Skills Training on video calling software. |
| They need to be aware of the needs for all disability communities. |
| We are in DIRE need of masks, gloves, and gowns, as well as sanitizer. |
| Our area is in need of masks and other PPE to ensure safety |
| Not enough resources or resources information. What is here is overwhelmed. |
| They are afraid-fear Caregivers are not being provided necessary equipment or don't want to provide services leading to fear of institutionalization. Isolation is very difficult. Lack of access to transportation. |
| Our consumers might need face masks and gloves and how to provide them with cleaning equipment since they are unable to find or go to the store. |
| They need to know what services are accessible during this time. They need to know how to identify and utilize resources to provide needed services. |
| Many consumers live on limited income and can't afford computers or smartphones to be able to communicate virtually or seek medical treatment by phone. |
| They are concerned about getting sick and dying just like we are, if not more. They want to stay safe in their |

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| homes just like we do. They want the same access to essential equipment and supplies as anyone else who is exposed to COVID-19 has when hospitalized. They want to be part of the conversation when local/state/federal leaders "strategize" and initiate reform to combat this virus, instead of being included as an "afterthought." They do not want to be forgotten. |
| As a B funded Center, we feel very resentful that we provide the same services as C funded Centers, we have to adhere to the 725 Standards & Assurances, etc., etc., but we are NOT included in the additional funding. This is NOT RIGHT. WE SHOULD NOT BE EXCLUDED. IT'S DISCRIMINATORY TO THE CENTERS WHO PROVIDE EXCELLENT SERVICES. |
| How frontier Montana is. |
| We have laid a good foundation with our consumers. They are for the most part doing well and know how to access supports if they need them. We have also had a disaster plan in place for several years and consumers have been using the Get a Buddy, Be a Buddy Program that the agency has been promoting for several years now. |
| I think ACL provides very helpful information to our Center, always. The access to webinars and free training materials are very beneficial. |
| I think our needs echo the countries needs and that is food, rent, toiletries, and transportation. |
| Safe transportation for basic needs (food, medicine, healthcare appts. etc.) has become a serious issue. Surge in physical and behavioral health issues due to physical isolation and fear create additional needs for services and supports for the foreseeable future. |
| As a rural community, people with disabilities are mostly low income and live far apart for those not living within the city limits. The community members need services that will help them with life skills, food, transportation, accessibility, assistance with housing cost and utilities and social gathering. |
| That ensuring compliance is difficult with CARE act money and that vague answers are not helpful when it comes to the types of activities, we can utilize the funding with. |
| Providing remote services is possible and effective, we just need all the tools and trained staff to effectively manage remotely. |
| 1) Many in our rural communities do not have access to effective internet access reducing their ability to interact with family/friends and to access telehealth options.<br>2) Employment options are now virtually nonexistent.<br>3) Protection for those consumer who are residing in nursing facilities.<br>4) access to new COVID-related services-CILs need to be able to use COVID funds for outreach and marketing these services. |
| Accurate and true information as it relates to the disease, how you contract it, symptoms that seem to be constantly changing. Many are afraid of being institutionalized and rationing of equipment because they already had a disability. Uncertainty and trust in the government vs. balancing the need to reopen. |
| Access to PPE in rehabs and group homes (by staff and participants), advocacy to get out of rehabs, tech and internet access. |
| Access to technology is critical along with opportunities to replace caregivers who either contracted the virus or chose to self-quarantine. Transitioning folks OUT of congregate settings has been more difficult while also being more important for our communities. Additionally, people with disabilities were yet again an afterthought when it comes to ER preparedness and how information is transmitted, creating the need for a lot of local advocacy. It would be great to see additional federal mandates and expectations provided to state and local government. |
| Leadership does not respond when PPE is requested. Mental health services needed. |
| Keeping housing is a great need, especially with jobs being lost. |
| Many agencies were unprepared for the requirement to move to telework as the exclusive service provision method. Delays can, and have, occurred as necessary technology and resources are ordered, configured and |

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| provided to staff with appropriate training. Staff want to do more - so we are striving to encourage out of the box solutions without putting them at risk. Strong federal policy guidance and advocacy needs to be in place to ensure states and communities think about the needs of people with disabilities - especially in regard to medical care, quality of life, and accessibility needs. |
| Located on the Navajo Reservation, many people have underlying health conditions, lack of transportation. |
| Issues in the institutions/nursing homes. More trouble transitioning. Lack of equipment. |
| We believe many people with disabilities who are in need are not asking for help. They are used to going without and are simply "toughing it out" through times of hardship. |
| The lack of access to technology in a now technologically driven world is abysmal in the disability community. Even if CILs purchased tablets or computers for consumers, they still would not be able to afford the monthly internet costs. This is leading to intense isolation and will likely increase the needs for mental health assistance. Additionally, consumers are fearing (if not already facing) institutionalization as a direct result of the pandemic. |
| Not sure. |
| All of us have needs every day, this pandemic has just increased all of these needs and added a fear of not only getting the disease, the fear of food and financial insecurity. |
| Depends on which county you are talking about, because SKIL covers a lot of counties. We are trying to provide hand sanitizer, mask, and gloves for each customer and their DSW. |
| To provide better services to those in need who can't get around or fern for themselves. |
| I think ACL is doing a nice job, as this is as I see we are all flying by the seat of our pants. Everyone seems to be paying attention to coronavirus updates and are adapting to the circumstances. |
| 1. There is potential for burnout.<br>2. Not sure how rapidly we can commit to expend the CARES funds, as much of what we need is not available.<br>3. Interpreter service for staff and consumers. |
| Under the circumstances, we need to recognize that everyone now has a disability and open our doors to everyone. 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. |
| Lack of transportation Internet access and affordability of devices to use the internet. |
| Perhaps the totality of planned services and activities will decrease due to security measures taken by the government. |
| Nothing at this time. |
| 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, a massive increase in funding directed at making homecare the "go to" option needs to happen now! |