

# CIL Early Response to Coronavirus Challenges and Needs

## Introduction

During the beginning of the COVID-19 pandemic, the IL-NET conducted webinars to facilitate peer-to-peer communication regarding the challenges centers for independent living (CILs) and statewide independent living councils (SILCs) were facing and their responses to meet the needs of the individuals they serve. Additionally, ILRU surveyed CILs across the country to determine the impact of COVID-19 and how they were meeting needs. CILs were finding creative and effective ways to ensure that their consumers have their basic needs met and continue to have access to core services and social support.

This document reflects some of the major themes from comments during the webinars and responses to the survey. The responses clearly reflect the fact that the needs are generally the same as before the pandemic—just amplified because now entire communities have greater needs, not just people with disabilities. The responses are organized around four major areas: consumer needs, organizational needs, community needs, and systematic needs. The bullet points summarize major needs in each of these categories. Examples and individual stories follow.

## Consumer Needs:

CILs have extensive experience in identifying, with the consumer, their goals and the activities needed to achieve them. Supporting individuals with significant disabilities to remain in their community with access to the services and supports they require is the overall mission of CILs. It is unlikely that CILs have ever faced the challenges that COVID has presented to them, their staff, and most of all, to their consumers.

Consumers were faced with a significant disruption to their lives and most of their supports became unavailable or severely limited. Some examples of these disruptions include –

- Increased challenges pertaining to food, shelter, employment, and financial insecurities and the inability to safely obtain them.
- Concerns about getting appropriate health care, having to ration their medications and medical supplies, maintaining an appropriate supply of PPEs-masks and gloves, and continuing to have personal care attendants providing needed services.
- Fear of ending up in nursing homes and losing their independence.
- Lack of access to the internet, communication technology, and the training to use it effectively.
- Significantly increased social isolation, despair, and depression. Consumers with mental illness are in very challenging situations and they are even more isolated, anxious and upset.
- Consumers want to be part of the conversation.

## **CIL and SILC Responses:**

- 'Social isolation' is necessary [during the pandemic], but we want to minimize the impact that isolation can have on people's physical and emotional health. Isolation, loneliness, and fear are big threats right now in uncertain times. The health and safety of both consumers and staff are our first priority. To be proactive, staff are contacting consumers by phone, teleconference, and we are sharing this information with other CILs and SILCs in the spirit of teamwork and community." –Sue Premo, Executive Director, Options for Independent Living, Green Bay, WI
- We are finding a lot of situations around personal care attendants. Are their attendants coming in to work? If not, why not? It will also help us to find out about resources that our customers may know about in their communities that can be shared with others. We will be able to determine if individuals need some IL Skills training that we can help with remotely, such as learning how to order groceries online for delivery or pick up. It will help us to find individuals who are isolated and scared so that we know that they need to be followed up with to contact more often. We will find out if someone's attendant is not coming into their home so we can help them find someone to hire. Whatever the case is, those questionnaires are giving us information about what many of the needs are, which helps me as a systems advocacy manager." –Lou Ann Kibbee, Systems Advocacy Manager, Hays office (SKIL of Western Kansas) of the Southeast Kansas Independent Living Resource Center, Inc., Hays, KS
- "We found that 23 out of 210 people who were about to participate in our survey didn't have access to a phone or a tablet or a computer. So, 23 was a significantly small number, smaller than we anticipated. However, what we found was over 50% of the people that we surveyed did not have access to Wi-Fi. So we have really found that that has been probably the greatest barrier, because Wi-Fi is pretty necessary in order to use many of these different platforms, or it becomes very expensive if we're asking people to use data on their cell phones, for example." The Ability Center of Greater Toledo, Toledo, OH
- "Able South Carolina has used CARES act funding to make sure our consumers are safe and informed during the pandemic. We have been offering free COVID-19 sanitation kits to our consumers and have delivered 390 kits so far. Those kits have impacted the lives of at least 853 consumers and their families. We have also worked to make sure our community knows how to stay safe. We have created a safety handout, and created a video explaining the need for masks and how to use them in plain language." – Able South Carolina, Columbia, South Carolina
- "Continuing to provide peer mentoring and support group sessions using Zoom and telephone meetings. Used CARES Act funding for purchase of technology, so consumers can participate in group sessions. Continuation of group sessions for PWD has really helped those in isolation feel connected and supported. We have groups of six individuals who attend regular phone meetings and connect with others, they really appreciate the support as some of them live in isolated, remote areas of native lands." Food/Essential Distribution in collaboration with other groups/programs. –Assist To Independence, Tuba City, Arizona

- “WASILC staff want to make sure that SILC staff, consumers, and networks receive accurate and accessible information about safety measures, phishing emails and scams related to COVID-19, and web access to local Health Departments and Districts. We have provided the link to our website at [www.wasilc.org/post/novel-coronavirus-covid-19](http://www.wasilc.org/post/novel-coronavirus-covid-19). We regularly update the page with additional pertinent information and disability-specific information as it becomes available.” –Kim Conner, Executive Director, Washington State Independent Living Council (WASILC)
- “We are implementing an emergency transition program to both move individuals out of congregate facilities and also provide employment and housing to individuals who are currently unhoused. We are using CARES act funding for technology access, food access, and staff time for this pilot. We are partnering with several other local organizations for this pilot, one specifically that provides employment support for people experiencing homelessness. We are working together to get folks who are currently unhoused hired to provide attendant supports through one of our state's consumer directed models. This allows us to transition individuals out of facilities while simultaneously transitioning individuals out of homelessness, many of whom also have disabilities.” –Atlantis Community, Inc. Denver, CO
- Able SC is also creating more opportunities than ever before for students to learn and receive peer support online. We will be hosting online peer mentoring classes, so students with disabilities can safely interact with one another AND learn useful tips like how to manage anxiety and how to "adult." These fully accessible classes are free and available online to all youth with disabilities! A few things we will discuss together: Time Management at Home, Managing Stress during Uncertain Times, Self-Advocacy: How to Speak Up at the Doctor's Office, Job Interview Skills and Practice, and Managing an Online Presence and Fact-Checking Fake News.” – Kimberly Tissot, Executive Director, Able SC, Columbia, SC
- “We are continuing services through our established Zoom technology for our virtual groups. We have developed, as a response for the youth out of school, hosting a virtual class for all students with disabilities. Individuals can join these free, virtual classes that cover topics such as peer support, advocacy, time management from home, fact-checking news, and more. Monday through Thursday EST 10:00 am – 11:00 am ages 10-13 and 1:00 pm – 2:00 pm ages 14 and up. Initially teachers showed up to see what it was about and then really spread the word for us.” –Kim Gibson, Executive Director, disABILITY LINK, Tucker, GA

### **Organizational Needs:**

In March 2020, the extent of the pandemic became a stark reality for CILs across the U.S. and its territories. After closing offices/buildings, having staff relocate to their homes, and determining how to best support them, CILs had to address the formidable task of keeping the administrators, board members, and staff connected technologically. The focus then quickly pivoted to provide the supports and services needed by the consumers. Policies and practices that had been implemented successfully for decades now had to be reconceptualized significantly at all levels of the CIL. This process required CILs to determine which services were critical and how to provide them to their

often isolated and vulnerable consumers. Some of the organizational needs experienced by CILs include –

- Requests to use additional funds to creatively address the gaps in services in our community. Rules need to be relaxed for use of federal grant funds. Part C funds were not available for the financial assistance people needed and Part B funded centers were not included in additional funding.
- Increased ability to use technology effectively for staff and consumers including English learners.
- Consumers in nursing homes who were being assisted by the CIL in transitioning to the community are now caught in the COVID rules and can't move out. Advocacy is required to get folks out of rehab/nursing homes.
- Hazard pay and overtime pay for personal care attendants. Some personal attendants (PAs) can't/won't accompany consumers to doctors. Replacing caregivers when current ones can't/won't assist the consumers.
- Adequate supplies for PPEs for consumers, staff, caregivers, and PCAs. Timely accessibility testing for the above groups is also needed.
- Strategies for conducting IL Skills training remotely including strengthening youth in transition services with schools and universities closed.
- People with disabilities are not asking for help, just "toughing it out".

#### **CILs Responses with Organizational, Policy, and Procedural Changes:**

- "From the perspective of a small center I have four-and-a-half staff, including myself, and we found that continuing weekly staff one-on-ones for an hour, and then two-hour weekly staff meetings, allowed us to continue the flow of conversation of what we need to do to stay organized and continue running sufficiently. So, we utilized Google Suite, including Calendar, Drive, Chat, and Hangouts. So staff can utilize the Chat function to ask questions and maintain communication throughout the day and we can share documents we're either all working on or a couple of staff are, and that has kind of kept us as a cohesive unit. Additionally, our state IL Network has started a weekly call to discuss what each center is doing. We have shared state funding opportunities that are available, grants and such, and then also state and federal legislative efforts. So that has allowed us to come together to be cohesive in what the concerns are in the State of Iowa and also keeping an ear out on federal issues that we can all use our voices to raise awareness." –Sarah Martinez, Executive Director, Access 2 Independence, Iowa City, IA
- "We decided that we were going to pay our employees through this epidemic [now pandemic]. So, we had to clarify that. We had to clarify time off, time away, the application of the Fair Labor Standards Act, paid and unpaid leave, which is growing. Now we have federal leave, and we also have state leave, which we did not have before. So, we've had to add those into our policies so that people know in addition to the Family Medical Leave Act all of the ways that they now can access leave if they become ill or dealing with a family member who has. We had to change our bereavement policies and procedures. People are being hit with taking care of several family members at one time. Or their own illness, which is extending beyond

normal sick leave policies. We had to deal with insurances and which of our insurances covered communicable diseases and covered COVID-19. And we had to relook at our technology policies. What did our employees have to know about being home with a phone, with a laptop, with a printer, with hot spots, and how they should deal with that technology? And we had to develop telecommuting guidelines. What were our expectations for responding to inquiries? What were our expectations for staying in touch with your colleagues and your supervisor and for CIDNY as an organization, knowing what's happening in the field?" –Susan Dooha, Executive Director, Center for Independence of the Disabled (CIDNY), New York, NY

- “We have really opened the door of opportunity to a lot of different types of technology. We are using platforms all the way from Zoom to Google Hangouts, Facebook Messenger. We have connected consumers through Netflix parties. Crip Camp came out recently and we were able to connect through a Netflix Party to watch it together. Skype and FaceTime - we have continued intakes and informational sessions that we have provided over these platforms. Also, just as a way for people to connect. Because social isolation has been such a big issue and such a hot topic right now that it is something that we really want to address while people must physically isolate from each other. And then in addition to that, one of the things that we have been able to use so that we can still make phone calls to our consumers, but also protect staff's information is the CoreNexa app. CoreNexa gives the option of your business phone number being what comes across the screen so that it looks like the Ability Center is calling. But it also protects the staff from sharing their personal cell phone or information with the consumer. And then they can call back through that app as well. So that has been a really great way for us to continue making phone calls and connecting with people. We found that a lot of people just weren't as comfortable with virtual options and how to make those connections.” – Dawn Bentley, Director of Core Services: Youth & Transition Services, The Ability Center, Toledo, OH

### **Community Needs**

Although CILs have always had community partners, COVID-19, the ensuing shutdown of non-essential services, and the stay-at-home restrictions changed routine collaboration. New partners were identified and the CILs expanded their relationship with existing partners. These new/expanded partnerships significantly increased the CILs capacity and reach to more effectively meet the needs of their consumers. Some of the community needs experienced by CILs were –

- Increased widespread food insecurity in the disability and senior communities now and concerns for the future.
- Insufficient PPEs for individuals with disabilities, group homes, senior centers, rehab facilities, etc.
- Subject matter experts need to be allowed in the local environment to drive the goal setting.
- Disability services work in silos, need to change this to enable quicker collaboration.

- Severely limited options for public transportation, para-transit or friend/family members available for consumers in the COVID environment. Need safe transportation for daily necessities, health appointments, etc.

### **CIL Responses:**

- So, one of the things that we have done is we have started to work with partner organizations. Owen's Community College put out a helpful resource. In that are different ways that people can access the internet temporarily during the COVID-19 pandemic. But also, the local broadband is offering 30 minutes for free daily so they can have things like their telehealth appointments.” –Dawn Bentley, Director of Youth & Transition Services, The Ability Center, Toledo, OH
- “The bulk of addressing food insecurity comes from our collaboration with our local community action program to get 25 lb. boxes of shelf-stable food to keep on hand in both of our offices. For anyone who says they are food insecure, our staff can do a drop-off of a box to their door. We got a small \$250 grant from Kelly's Kitchen addressing food insecurity to supplement the contents of the food boxes (examples of food box ingredients include rice, dried beans, pasta, spaghetti sauce, canned beans, canned chicken, cereal, and oatmeal). My concern is that while the food boxes address food insecurity, they are not necessarily healthy or nutritious by themselves. We have been purchasing frozen vegetables and meat and including recipes on how to incorporate these ingredients with that of the food box to create a full meal. For example, to utilize canned chicken and cream of chicken soup in the box we bought frozen peas and carrots, and a pie crust to make a homemade chicken pot pie. We will continue to supplement food box ingredients with CARES Act funding. We are looking into connecting with local master gardener programs to have fresh produce donated to us that we could distribute to those in need. We continue to think of ways through recipes or remote services to help consumers utilize these ingredients. We are in the process of trying to get a deep freezer donated to us to store more food in the office, in addition to more shelving to store nonperishables.” –Sarah Martinez, Executive Director, Access 2 Independence, Iowa City, IA
- “In the wake of the COVID-19 world health pandemic, many service providers have reached out for guidance, noting that several of their consumers have had their hours reduced or were laid off. In response to this, Able SC planned and executed a well-attended, live webinar to inform providers and beneficiaries that covered the basics of Disaster Unemployment Benefits and the pending Stimulus Relief Package legislation. The WIPA Team felt it imperative that they get the word out that the team is here to equip them with the knowledge they need to get through this difficult time.” –Able SC, Columbia, SC
- They have been utilizing the VIIB Transition/Diversion funds, and during the pandemic, have assisted 17 consumers transition out of institutions and/or to remain living independently and safely in their homes. –Access to Independence San Diego, CA

### **Systemic Needs:**

The pandemic has brought to light the inability of multiple systems to quickly address the needs of consumers when the federal and state responses were often fragmented. It has also highlighted the pervasive needs of vulnerable populations. CILs provided extensive advocacy for individuals, but also made significant progress with systemic advocacy. Some of the systemic needs experienced by CILs are shown below –

- Significant, pervasive, persistent, and unique systemic issues with the native populations on tribal lands, rural states/populations, territories, and the homeless.
- Could state agencies facilitate the purchase of PPEs for CILs and consumers? There will be an ongoing need for PPEs.
- Nursing home deaths should trigger change in how society thinks about caring for the elderly.
- Employment for individuals with disabilities has always been problematic, but post-COVID-19, it is exponentially more challenging-there are no employment options.
- Significant expansion of HCBS and more choices for in-home supported services and transportation.
- SSDI application process with extension in place for medical documentation and allowing telehealth documentation for the SSA disability process.
- The nutrition services part of the Older Americans Act needs to be amended to include eligibility for people with disabilities under age 60.
- Strong federal policy and advocacy to ensure states and communities think about the needs of people with disabilities.

### **CIL Examples of Systemic Needs:**

- “We are doing a lot of systems advocacy with many different partners and coalitions around our State’s 1135 and Appendix K. We support the complaint filed with [the] Office of Civil Rights (OCR) against our State on medical rationing and have been working on media and action alerts. The Grassroot Advocates for Independent Living (GRAIL) led a group in sending a letter to the Governor three weeks ago with an extensive list of things we thought needed to happen to keep people from going to nursing homes or institutions during this crisis. We have been working to try to get PPE for workers and customers. GRAIL developed a document for individuals that self-direct their long-term services & supports. It includes tips on directing your services through this crisis with your direct support workers. It also contains two pages for individuals to fill out their personal and medical information to have handy in case they do have to seek medical attention. Lastly it contains a one-page essential worker form that individuals can complete for their DSWs to carry with them in case they are questioned.” –Lou Ann Kibbee, Independent Living Program Manager, Hays office (SKIL of Western Kansas) of the Southeast Kansas Independent Living Resource Center, Inc., Hays, KS
- Systemic work continued around Census 2020, offering online, virtual, and telephone assistance to people with disabilities in all our catchment areas, from San Diego, to Imperial County to Hawaii, ensuring people were COUNTED! –Access to Independence, San Diego, CA

- “Able South Carolina has hosted an Advocacy Day for Access & Independence since 2014 to shine a light on the barriers that persons with disabilities face in hopes of improving the lives of all South Carolinians. Although the event is typically held in-person, we announced that it would be held 100% virtually this year due to COVID-19. Taking Advocacy Day for Access and Independence online is a huge opportunity to build the disability rights movement in South Carolina and reach an audience larger than ever before. We did a live stream through Zoom and we used a third-party system called re-stream and social media and YouTube. We had over 13,000 viewers participating in this event. Participants watched, left comments, and started live conversations. CART live-captioning services and American Sign Language (ASL) interpreters were available to all viewers throughout the event. This virtual gathering was a model of online accessibility and accommodations.” – Kimberly Tissot, Executive Director, Able South Carolina, Columbia, SC
- “Resource Center for Independent Living (RCIL) has received calls from concerned Direct Support Workers (DSWs) regarding the need for travel documents while they are working for their consumers during “stay at home” ordered periods. RCIL has received official direction from the Kansas Department of Aging and Disability Services that Home and Community Based Services (HCBS) are considered essential healthcare. RCIL has had direct communication with several local law enforcement agencies and have been repeatedly reassured the individuals traveling in their cars who are performing essential functions will not be asked to provide paperwork regarding their essential functions. If you are asked, “Where are you headed?”, simply be honest and let them know you are providing essential home care duties. During this time of COVID-19 crisis (at least until May 1, 2020), RCIL covered the cost of Direct Support Worker (DSW) background checks for NEWLY HIRED DSWs. RCIL realizes that temporary or additional DSWs may need to be hired and this is one thing RCIL is doing to expedite the process.” –Resource Center for Independent Living (RCIL) website announcement, Utica, NY

### **Personal Stories:**

- “We were part of a local grant that was able to provide help to consumers with food, medical needs, transportation, rent, utilities, etc. as they were impacted financially. It has been awesome to help! We were able to provide 20 individuals so far with food, transportation, medical needs, etc. due financial losses from COVID. One family we were able to make 4 house payments to keep them from foreclosure. This kept them not only from losing their home, but actually paid off their house. With this family we were also able to pay for gas for the wife to go to cancer treatment and the husband to go for PT. Another family we were able to buy food and medical needs as well as a bed for the child. Five people in powerchairs were able to go to dialysis treatment for 2 months when the local transportation systems shut down as we were able to pay for this service. These collaborative efforts were with other social service agencies working together to get this all done with little impact to the consumers but so they could get the biggest relief.” –Northwestern Illinois CIL (NICIL), Sterling, IL
- DRR received a request from a consumer in immediate need for help in several areas to remain independent. He was very close to losing everything he had due to

losing his job because of COVID-19. DRR had the ability through the CARES Act fund to help him with his immediate needs which were housing rent, power bill assistance, and food. By helping the consumer with his back rent, the landlord was then able to fix the consumers electrical issues. We were also able to provide technology so he could work from home and remain independent. We have received a letter from him greatly appreciating DRR's help through such a tough time he was having during the COVID-19 pandemic.” –Disability Rights & Resources, Birmingham, AL

- A male consumer with autism contacted Able SC in April 2020 for assistance with his e-learning assignments. The Youth Independent Living Specialist (YILS) met with the consumer two times over video chat to walk the consumer through his assignments and teach consumer how to problem solve (including the steps to contact his teachers when he gets stuck). The consumer has since been able to do his e-learning assignments independently.” –Able SC, Columbia, SC
- “We have partnered with a Community Choices Waiver case manager to provide emergency services for one consumer and her family due to COVID-19. Due to Alzheimer’s and stress, her condition recently destabilized. Her husband/POA (who also has a disability) is struggling to care for her. She has been to the hospital twice, they have dealt with the immediate situation and released her. They are limiting admissions to necessary care because of COVID-19. Nursing homes in the area are not accepting patients. The case manager located an agency to provide care for eight hours a day, in addition to a family member that can come in the evenings. Although we normally do not provide direct care, we are providing respite funding while a long-term plan is developed.” –Rebecca Roberts, IL/Advocacy Manager, Wyoming Independent Living, Casper, WY
- A consumer has been struggling with establishing independence during COVID-19. They decided to learn how to ride the bus independently while practicing social distancing. The ADANC Travel Trainer noticed the consumer’s progress. The consumer understood and followed the safety procedures, and got into the habit of boarding from the back of bus. She also learned that the buses have suspended fare collections due to COVID-19 restrictions. –Alliance of Disability Advocates, Raleigh, NC
- A2I CA assisted a 92-year-old consumer with vision loss in obtaining a specialized phone from the California Telephone Access Program (CTAP). Staff helped her submit the application and the consumer was approved for and received the phone. Through the assistance of family, the consumer was able to set up and use the phone. –Access to Independence, San Diego, CA
- “An Able SC Equip Leader started virtually peer mentoring a consumer that has Asperger's and the consumer's mother. When they first started mentoring them, they observed that the mother was struggling to understand and recognize when the consumer was self-regulating and assumed that the consumer's stimming was a bad thing. The Equip Leader has been working with them for a few weeks now and has been able to help the mother understand more about when the consumer begins to self-regulate and now works to identify what about the environment overstimulated the consumer and how to adjust. The mother has remarked after sessions that Able

SC has offered a new perspective to think about her daughter's behaviors, and she continues to work on improving her understanding as well as learning more about Asperger's with the consumer." –Able SC, Columbia, SC

- A consumer stated the following, "I wanted to say, thank you so much for the grocery program. I honestly don't know how we would have survived these last few months without it. Every time we get our order I am overwhelmed with humility and gratitude. It has allowed me to keep fresh fruit and veggies in our home. We have cleaning supplies and laundry items. I hope this email has some impact on how much a program like this can do for a small family like ours. I have always been an advocate, I have never had one." –Northern Nevada Center for Independent Living, Sparks, NV
- Staff assisted a 72-year-old consumer who is blind to get registered with the Census so that she could complete it over the phone. The Consumer said she wouldn't have been able to figure out how to do this without staff's help." –Access to Independence, San Diego, CA
- Staff worked with a 21-year-old youth transition consumer to learn basic ASL. She attended in-person workshops prior to the COVID-19 pandemic and then received services from the A2I Youth Transition Services Coordinator virtually. The Consumer reported that she had a lot of fun and thought it was very successful. –Access to Independence, San Diego, CA

#### **Some insightful comments:**

- "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 [community] 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."
- "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 is important for our communities and has been more difficult while also being more important. Additionally, people with disabilities were yet again an afterthought when it comes to the emergency room 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."
- "The disability world is not left out of important decisions made by local and federal government. I think the Administration for Community Living (ACL) is doing a great job, they and their staff are under the same constraints as we are and asked to do a great deal with less tools to get it done with. Our people here are less affected than other areas of the country, so we look to ACL as the bell weather on how we should prepare."



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