



Enhancing Public Health Readiness: Learning from Experience and Future Preparedness for Centers for Independent Living

July 2023



DISABILITY VACCINE ACCESS
OPPORTUNITIES CENTER

This resource was developed by the Disability Vaccine Access Opportunities (DVAO) Center and is a shared initiative by Able South Carolina (Able SC), Independent Living Research Utilization (ILRU), and the Partnership for Inclusive Disaster Strategies (PIDS).

About Able South Carolina (Able SC)

Able SC is a federally recognized Center for Independent Living that represents half of the counties in South Carolina and is a recognized leader in statewide, national, and international programs to increase capacity for disability rights, disability justice, and independent living. Able SC is a disability-led organization seeking transformational changes in systems, communities, and individuals. Since 1994, we've remained a consumer-controlled, community-based, cross-disability nonprofit that seeks to make South Carolina a national model of equity and inclusion for all people with disabilities. To learn more, visit www.able-sc.org.

About Independent Living Research Utilization (ILRU)

ILRU at TIRR Memorial Hermann, founded in 1977, has a long history of providing research, education, and consultation in the areas of independent living, home and community-based services, and the Americans with Disabilities Act. ILRU is operated by community living and disability law experts with disabilities. To learn more about ILRU, visit www.ilru.org.

About The Partnership For Inclusive Disaster Strategies (PIDS)

PIDS is the only U.S. disability-led organization with a focused mission of equity for people with disabilities and people with access and functional needs throughout all planning, programs, services and procedures before, during and after disasters and emergencies. To learn more, visit www.disasterstrategies.org.

The Disability Vaccine Access Opportunities Center was supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,325,000 with 100 percent funded by CDC/HHS. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Table of Contents

5	Chapter 1: Introduction	39	Chapter 7: Addressing Access Barriers
		39	Introduction
6	Chapter 2: Why CILs are Ideally Positioned to Support Persons with Disabilities During Public Health Emergencies	41	Medical Barriers
6	Introduction	42	Barriers When Accessing Digital Spaces
6	CILs: Community-Based Subject Matter Experts	43	Physical/Architectural Access Barriers
7	Advocacy: A CIL Core Service	44	Informational Barriers
		45	Financial Barriers
9	Chapter 3: Relevant Disability Rights Laws	45	Identification/Immigration Status Barriers
9	Disability rights are human rights, and they aren't optional.	45	Disability Implicit Bias
10	Requirements Under the ADA	46	Important Practices to Address Barriers
11	Obligations to People with Disabilities Under the ADA	48	Sources
11	Rehabilitation Act of 1973		
12	Affordability Care Act	49	Chapter 8: Engaging with Multiply Marginalized Communities
12	Conclusion	49	Introduction
		49	Intersectionality
13	Chapter 4: Maintaining Operations During a Public Health Emergency	50	Using an Intersectional Lens
14	Keep Doing What You're Doing	51	Health Equity
15	Good Practices for Maintaining Operations During a Public Health Emergency	51	How to Become More than an "Ally" to Marginalized Communities
17	What is a Continuity of Operations Plan (COOP)?	52	Sources
18	Critical Areas of Creating a COOP		
20	Independent Living Responsibilities	53	Chapter 9: Reaching and Supporting Individuals in Congregate Settings
21	Conclusion	53	Introduction
		54	Strategies to Transition People Out of Institutions
22	Chapter 5: Strengthening Community Response through Relations	55	Partner with Other Organizations and Agencies
22	Key Partners in the Community	55	Partner with Institutions
24	Building Relationships Before, During, and After Public Health Emergencies	56	Programs that Can Support Transitioning into the Community
27	Build a Diverse and Intersectional Coalition	58	Establishing a Relationship with the Consumer: Support Their Planning Process
		59	Following Up: Ensuring Success
28	Chapter 6: Supporting Vaccination Efforts	59	Specific Considerations During Public Health Emergencies
28	Introduction	60	Effective Transition Programs at CILs
29	Vaccine Hesitancy in the Disability Community	60	Additional Resources
31	Addressing Barriers	61	Chapter 10: Expanding and Enhancing Services, and Providing Supporting During Public Health Emergencies
33	Difficulty Navigating Vaccine Information and Systems	61	Prior to the Public Health Emergency
35	Barriers that Impact Multiply Marginalized People with Disabilities	62	During the Public Health Emergency
36	Direct Outreach and Service Provision to Consumers	63	Areas Where a CIL May Need to Expand or Enhance Services During a Public Health Emergency
38	Sources	66	Programs and Initiatives that CILs Have Established and Strengthened to Help Consumers During the COVID-19 Pandemic
38	References	67	Protecting Employees and Volunteers
		69	Sources

Table of Contents

70	Appendix
70	Appendix 1: Sample Letter Requesting At-Home Vaccination
71	Appendix 2: Providing Information to Address Vaccine
73	Appendix 3: Public Health Emergency Reopening and Operating Procedures
85	Appendix 4: Incorporating Intersectionality and Health Equity
88	Appendix 5: Sample Internal Communications Plan
92	Appendix 6: Sample Mask Policy
93	Appendix 7: In-Person Community Activities
94	Appendix 8: In-Office Consumer Appointments and Meetings
96	Appendix 9: COVID-19 Vaccine Frequently Asked Questions
112	References



Introduction

As grassroots, cross-disability-focused, and disability-led organizations, Centers for Independent Living (CILs) are often in the forefront of adapting and responding to emergencies in their respective communities. This included the COVID-19 pandemic. Although CILs have always worked closely with community partners, the COVID-19 pandemic, the resulting shutdown of non-essential services, and the stay-at-home restrictions changed routine collaboration among community and health service providers. CILs, with deep roots in the community, quickly identified new partners who could join them in supporting people with disabilities during the crisis. CILs added or significantly expanded programs and services to address the community's needs, some of which were not previously provided. Those newly developed services included distribution of food and pandemic supplies, virtual peer services, increased information, and referral. They also included services to assist students with disabilities in schools, distribution of and training on how to use tablets and laptops to reduce isolation, and expanded efforts to transition individuals out of skilled nursing facilities, among others.

While the COVID-19 pandemic affected everyone, it significantly impacted people with disabilities, their family members, and caregivers. States often did not include people with disabilities in the planning and implementation of COVID-19 response or often reached out to disability organizations that may not have been disability-led, which created more ableist barriers and challenges. Further, the pandemic highlighted health disparities facing individuals with disabilities and further exposed the disparities of those with disabilities who were multi-marginalized due to race, gender, age, and economic status. Finally, those living in institutional settings such as skilled nursing facilities and group homes were especially at risk. In many cases, CILs were the only organizations to rise to the challenge, serving individuals with disabilities in need and partnering with other community organizations.

The onset of the pandemic was sudden and unpredictable, and CILs had to invent services to ensure people with disabilities were being heard. Recent history has taught us that it is essential that we prepare for future health emergencies even as we continue to respond to the public health emergency at hand. This toolkit was developed to help CILs to better prepare for and respond to public health emergencies now and in the future. The toolkit highlights lessons learned during the COVID-19 pandemic, strategies to help CILs become partners in future emergencies, and to provide practical tips and suggestions for every organization.



Why CILs are Ideally Positioned to Support Persons with Disabilities During Public Health Emergencies

Introduction

Public health emergencies pose new challenges for providing services in the community. Such emergencies require that organizations forge partnerships with local and state health departments, other service providers, local businesses, and other non-traditional collaborators. CILs are primed to work alongside the disability community to advocate for full inclusion as community services adapt to new challenges. CILs are deeply connected to the disability culture as they are mandated to be disability-led and consumer-driven. CILs are positioned to be the best organizations to respond to the needs of people with disabilities during public health emergencies. While the majority of CILs have already been heavily involved in efforts around community planning for emergency response and individual disaster preparedness, they also have an understanding of the specific barriers that individuals with disabilities experience during emergencies. This expertise significantly helped CILs in their response to the COVID-19 pandemic.

CILs: Community-Based Subject Matter Experts

CILs are hyper-local subject matter experts supporting people with disabilities and are advocates for reducing systemic barriers. CILs are required to be led by people with disabilities who live in the communities they serve, and their staff and board members are familiar with the needs and challenges of their respective service areas. This expertise grows from the personal experience that many CIL staff have as people who live with disabilities every day, and is strengthened by the organizations' consumer-led mandate as established in the Rehabilitation Act. CILs are also often the only cross-disability entity in their community, which adds another level of expertise to ensure people with all disabilities are being included and heard. Further, CILs frequently seek input from community members through strategic planning, needs assessments, and other methods. This ongoing feedback helps CILs understand the barriers facing people with disabilities and develop effective services to appropriately serve their constituents. CILs know what will and won't work in their communities. Therefore, when CIL staff are present at the table with other providers, they aren't only providing disability representation but also bringing the voices of their consumers, allowing them to anticipate and plan for a more inclusive and equitable response during disasters and public health emergencies. CILs should endeavor to be added to committees, advisory boards and other organizations, to help plan for emergency response. By acting as a voice for the disability community, CILs can better prepare public health departments and other partners to support disabled individuals during the next public health crisis.



During COVID-19, CILs saved lives, whether it was through individual or systems advocacy, responding with new and innovative programs and approaches of serving their community, or their peer philosophy. Advocacy efforts resulted in improved access to vaccines. Using CARES Act funds to provide personal assistance services, assistive technology, or personal protective equipment.

CILs help emergency response partners to provide services that are accessible and equitable. Not only are CILs, by the nature of their mission and structure, leaders in their communities, but they also provide an immediate resource for consumers when other community-based, state, or federal systems are strained or fail to understand the needs of people with disabilities. People with disabilities, their families, and support providers understand the benefits of their local CIL as they are often the first called in emergencies and support.

Advocacy: A CIL Core Service

One of the core services of a CIL is individual and systems advocacy. CILs have been working in the community to advocate for greater inclusion and access since their inception. However, individual and systems advocacy is much more important during public health emergencies.

Centers demonstrated the importance of advocacy during the COVID-19 pandemic. For example, during the rush to get vaccines to those most in need, people with disabilities were not prioritized as an at-risk population. CILs from around the country led efforts to ensure their state understood the risk of infection, hospitalization, and death due to COVID-19 for people with disabilities. In many states, the advocacy of CILs was the reason why people with disabilities were later added as a priority group. Another example was a general lack of accessibility. Whether it was a press conference, COVID-19 education materials, resources, testing, or vaccine sites, CILs led the way as accessibility and compliance with disability rights laws were often not prioritized. (Musumeci and Chidambaram, Marcy 1, 2021).

In addition to the barriers already faced, the pandemic highlighted other issues for people with disabilities. Below are some examples of the barriers during COVID-19:

1. Press conferences did not include captioning, American Sign Language interpretation, or visual descriptions.
2. Websites and smartphone applications used to register for testing or vaccine appointments were not always compliant or accessible.
3. Materials used for education and resources was not in plain language to assist those with intellectual, developmental, and other disabilities.
4. Program modifications to ensure equitable access were not provided—for example, in-home vaccinations, drive-up vaccinations, or other accommodations that may be required.
5. Vaccine and testing sites were frequently not accessible, and staff and volunteers working the sites were unfamiliar with accommodating people with disabilities.

6. Education and information did not represent people with disabilities, leaving them concerned about whether COVID-19 or the vaccine would impact their current disabilities.
7. Bans on masks or other anti-masking education did not include or protect the needs of people with disabilities at higher risk of infection, hospitalization, or death.
8. During the pandemic there was a lack of personal protective equipment, including masks, hand sanitizer, and other items available to consumers, caregivers, and family members.
9. Many people with disabilities faced a lack of access to technology and options for accessing virtual services, including telehealth, programs, and education.
10. Many people living in institutional settings did not have access to home and community-based services and other supports that would have allowed for transition to the community.

CILs also provided individual advocacy in challenging situations. For example, some consumers found it difficult to maintain safety and independence due to a lack of personal assistance services and individuals willing and able to come to their homes to provide support, leaving them at risk for institutionalization. CILs worked on behalf of these consumers to educate local and state officials about the challenges being experienced and the risk of institutionalization. In some cases Centers were able to pay for personal assistance services for those most at risk with one-time funding extended to Centers due to the pandemic.

While CILs provided outstanding leadership during COVID-19, many opportunities remain for Centers to strengthen programs, services, and advocacy. CILs should continue building and establishing partnerships with local and state health departments. Additionally, Centers should focus on building solid connections with emergency preparedness organizations. This includes state' emergency response entities such as Government agencies, including their emergency management, health departments, social service organizations, and American Red Cross, Federal Emergency Management Agency (FEMA), and Partnership for Inclusive Disaster Strategies, and advocacy organizations to name a few.

Another important role of CILs is to ensure that people with disabilities are prepared for disasters and public health emergencies. Such efforts could include ensuring consumers have an emergency plan, providing preparedness training, and ensuring they have the equipment and supplies needed to survive, with the understanding that some equipment and supplies will need to be modified to be accessible for the person.

Sources:
[COVID-19 Vaccine Access for People with Disabilities](#)
Mary Beth Musumeci and Priya Chidambaram
March 1, 2021

Relevant Disability Rights Laws

Disability rights are human rights, and they aren't optional.

Disability rights laws are not new and have been in place for decades. However, many people with disabilities encounter challenges in attempting to receive vaccines and other healthcare or emergency services due to disability rights laws not being respected or followed. As advocates, Centers should understand the legal obligations of providers and the rights of consumers. Clarity about these obligations will help CILs support consumers in gaining access to vaccines and health care in general. Understanding the laws will also help CILs support emergency and healthcare providers in meeting their obligations to people with disabilities.

CILs and consumers must understand that civil rights are never suspended during disasters or public health emergencies. This means that agencies and organizations cannot tell people with disabilities they don't get access to programs and services during these times. Federal disability rights laws always apply and supersede state laws. CILs can provide leadership to agencies and organizations, helping them establish plans to meet their legal requirements within disability rights laws.

Disability rights law may seem complex. However, staff can educate themselves and share the information with consumers, co-workers, and state and local agencies. CIL staff might not always know the answer to the questions people ask about the law. However, Center representatives can know where to look for answers and provide further resources. If CIL staff are asked a question and don't know the answer, they should always point the individual to the regional [ADA Center](#) or the local [Protection and Advocacy \(P&A\)](#) agency in the state to ask their question.

This chapter highlights important disability-rights laws and provides basic information about the statutes that protect people with disabilities during emergency disasters and public health emergencies.

The difference between legal advice and legal information and education:

Legal information and education

describe the law and how it may apply to consumers, partners, and agencies. Legal information and education can be provided by anyone who is knowledgeable about the topic. All CILs are encouraged to be knowledgeable regarding disability rights laws.

Legal advice, on the other hand, applies the law to your specific situation. Lawyers representing clients provide opinions on specific legal problems, considering the specific situation of their client. Only lawyers should be providing legal advice.

Requirements Under the ADA

Under the ADA, state and local governments and public accommodations cannot discriminate against people with disabilities. Discriminating against people with disabilities means excluding them from participation in programs and services. Places that are covered under the ADA are required to take certain actions to provide access to people with disabilities. These are known as obligations.

Examples of what the ADA requires are as follows:

- Having accessible buildings and programs. Note, the ADA does not apply to housing; that would be the Fair Housing Act.
- Providing equally effective communication to people with hearing, visual, and speech disabilities: such as sign language interpreters, Video Relay Interpreting (VRI), electronic material that is screen reader accessible, large print, or other accessible formats, or taking the time to understand a person with a speech disability may be legally required.
- Making reasonable modifications to policies and practices, such as assisting someone who can't write due to a disability in filling out a form.
- Accommodations are free to the individual. It is illegal to charge people with disabilities for access accommodations.
- Providing websites that are accessible to people with disabilities. For example, a clinic should ensure that people who use screen readers can use its website when they need to go online to get information or schedule an appointment.

If a consumer feels their rights under Titles II or III of the ADA have been violated, they can file a complaint with the United States Department of Justice. This must be filed before 180 days have passed since the discrimination. The consumer can sue an entity they think violated the ADA without filing a complaint.

To file an ADA complaint, contact:

U.S. Department of Justice Civil Rights Division
950 Pennsylvania Avenue, N.W. Disability Rights Section
Washington, D.C. 20530
Phones: 800-514-0301 (voice)
1-833-610-1264 (TTY)
Online form (2022): <https://civilrights.justice.gov/report/>

Title IV of the ADA addresses telephone and television access for people with hearing and speech disabilities. It requires telephone companies to set up telecommunications relay services (TRS) 24 hours a day, 7 days a week. TRS enables callers with hearing and speech disabilities who use TTYs and callers who use voice telephones to communicate with each other through a communications assistant. Title IV also requires closed captioning of public service announcements.

For more information about TRS, contact the Federal Communications Commission (FCC) at:

Federal Communications Commission
445 12th Street, S.W. Washington, D.C. 20554
Phones: (888) 225-5322 (Voice)
(888) 835-5322 (TTY)

www.fcc.gov/general/disability-rights-office

Obligations to People with Disabilities Under the ADA

Under Title II of the Americans with Disabilities Act (ADA), state and local governments are prohibited from discriminating against people with disabilities. This applies to state and territory agencies, counties, cities, and towns, including health departments within these covered entities. Public hospitals and clinics run by the state or local government also have obligations under Title II.

Under Title III of the ADA, public entities have obligations to people with disabilities. Public entities are places people go to, such as pharmacies, doctor's offices, private clinics, and non-religious private hospitals.

In both Titles II and III of the ADA, local and state governments and public entities must have accessible facilities, programs, and information. More information about the Americans with Disabilities Act can be found at www.ada.gov.

Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act (Rehab Act) says that government agencies, businesses, nonprofits, or any other organizations or programs that receive money from the federal government must not discriminate against people with disabilities. That means if an agency or business accepts funding from the federal government, including federal grants and contracts, they must not discriminate against people with disabilities. This also applies when federal money is passed on to other parties. Many local and state agencies receive federal funding in some capacity and have responsibilities under Title II of the ADA and Section 504 of the Rehabilitation Act of 1973.

While somewhat similar to the ADA, the Rehabilitation Act reaches further by stating that persons with disabilities may not be excluded from receiving federally funded services on the basis of disability. Like the ADA, the Rehab Act includes: providing programs and services that are accessible to, and usable by, people with disabilities; providing accommodations such as sign language interpreters and materials in an accessible alternate format; and making modifications to policies and practices where necessary to avoid discrimination including allowing service animals to accompany people with disabilities. Obligations under Section 504 of the Rehabilitation Act are essentially the same as obligations under Title II of the ADA. Websites must also be made accessible to people with disabilities.

Affordable Care Act

While the Affordable Care Act (ACA) includes obligations to people with disabilities, virtually all of these obligations exist already under the ADA and the Rehabilitation Act. The ACA says that healthcare centers and services, like hospitals and clinics, cannot discriminate against people with disabilities. Also, healthcare programs receiving money from the federal government cannot discriminate against people with disabilities. For example, a vaccine program funded by the federal government cannot discriminate against people because of their disability.

Conclusion

Federal disability-rights law prohibits discrimination by government entities, including states, territories, counties, cities, and towns; places of public accommodations, including pharmacies, doctor's offices, and private non-religious hospitals based on disability. Requirements prohibiting discrimination under these laws apply to more than exclusionary practices. They require the government and businesses to accommodate people with disabilities, even in a public health emergency or disaster. In short, all people with disabilities should have access to the same services, programs, information, and facilities as people without disabilities.

Disability rights are never suspended during public health or other emergencies. CIL staff and consumers must understand the basics of disability rights laws and advocate for them to be respected, implemented, and enforced. Being effective advocates to ensure entities comply with federal disability rights laws can mean the difference between life and death in public health emergencies and disasters as history has proven.

Maintaining Operations During a Public Health Emergency

People with disabilities and emergency officials need CILs more than ever during emergencies. While some entities may be able to temporarily shut down or reduce operations, CILs will often need to increase efforts while safeguarding the health and well-being of their employees and consumers. CILs may be called upon to do more in emergencies, possibly even with staff and supply shortages. They may also experience a higher demand for Information and Referral (I&R), Peer Support, Advocacy, Transition Support, and other services. CILs may be called upon to create practical solutions to ensure the emergency response includes people with disabilities.



Examples of services could include the following:

- Making sure the needs of the disability community are being met.
- Ensuring information and education materials are accessible.
- Providing individual and systems advocacy to ensure people with disabilities are included in the response.
- Educating state partners about program modifications and considerations for people with disabilities.
- Sending accessible communication to consumers.
- Ensuring people with disabilities have the supplies needed for survival.
- Increasing efforts of socialization if isolation is expected.

This chapter provides information that will prepare CILs to support and protect the health and safety of its employees and ensure operations continue by providing regular programs and support while adjusting or creating programs to meet the needs of the disability community.

Keep Doing What You're Doing

CILs are expected to keep operations open during public health emergencies. The good news is that CILs have learned how to operate and provide services during a public health emergency in support of the COVID-19 pandemic as they had to make critical decisions during that time. Additionally, CILs adjusted or created additional services to meet the needs of the disability community within their area. Therefore, some promising examples exist of how CILs did this work during COVID-19.

Examples of decisions CILs made during COVID-19 included:

- Identifying sources of information to trust, inclusive of disability-specific information
- Whether or not to keep the physical office open
- When to re-open the physical office
- Whether or not to close the office to visitors
- When to re-open the office to visitors
- Whether personal protective equipment, (PPE), such as masks or gloves would be required in the office.
- If PPE is required, what type should be used
- If masking is required, how to communicate with deaf or hard-of-hearing employees and other consumers.
- How to locate and acquire transparent masks that prevent the spread of airborne viruses like COVID-19.
- How to provide services and conduct accessible virtual meetings.
- Whether or not to hold or support vaccine clinics.
- Informing other entities when their services don't include people with disabilities.
- What information should CILs share with consumers about the public health emergency and how to:
 - Share information about a public health emergency,
 - Make information accessible to consumers who are Deaf or hard of hearing, deafblind, blind or have low vision, or do not read print; and
- How to help keep consumers safe while assisting with testing and vaccine appointments.

Each public health emergency is unique and requires different responses. However, CILs can learn from past experiences, while also recalling that people with disabilities can experience multiple public emergencies simultaneously. During the COVID-19 pandemic, CILs simultaneously led efforts to support consumers during fires, flooding, storms, and earthquakes. For example, when emergency shelters opened due to evacuations from a storm, CILs worked with emergency officials to help with making shelters accessible, safe, and healthy while maintaining social distancing and the use of PPE.

A CIL's response to public health emergencies will depend on the following:

- The type of public health emergency
- How long the emergency lasts
- Training and understanding from CIL employees
- How widespread is the emergency
- The amount and type of disruption it causes
- Availability of funding that would allow for expanding or enhancing existing programs

Not all public health emergencies have vaccines immediately available.

Not all public health emergencies are a result of an infectious disease. Vaccines may or may not be available for an infectious disease outbreak. CILs would not need to assist with or set up vaccine clinics if vaccines are not available or not needed. In cases where vaccines are being created, CILs are critical to ensuring and working with state officials by providing that the launch is accessible and inclusive to people with disabilities.

If vaccines are not needed or required for the emergency, CILs would focus on other ways of supporting the disability community by protecting their health and well-being, and providing advocacy to ensure access, equity, and the needs of the disability community are respected.

Good Practices for Maintaining Operations During a Public Health Emergency



The best way for CILs to continue providing programs and services to consumers and the community is to plan how they will do this before a public health emergency happens. Plans should be flexible and easy to adapt to the specific crisis. There will always be impacts caused by a public health emergency that planners did not think about ahead of time. One of the essential things CILs can do in an emergency is quickly solve problems by making additional changes as needed while not

losing focus on accessibility, the needs of the employees and consumers, and the Independent Living Philosophy.

Examples of good practices for planning are as follows:

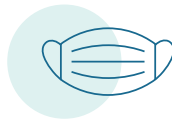
- Regularly review what the CIL has learned in other public health emergencies, disasters, and disease outbreaks. This will require ongoing modifications to your policies and emergency plans.
- Decide what practices worked and what didn't. Determine how the CIL could apply these lessons to public health emergencies happening now or that might occur in the future.
- Test or practice your plans annually to ensure you are prepared and current technology or equipment is available.
- Train CIL employees on the emergency plan to ensure they know what to do in the event of a situation.
- Develop a written plan to help your CIL continue providing services during the public health emergency. This plan is called a continuity of operations plan or COOP, which is further described below.
- Stay up-to-date on how best to meet consumer needs during a public health emergency.
 - Receive regular up-to-date information from reliable sources, such as a county or state public health department and the Centers for Disease Control and Prevention (CDC).
 - Participate in specific disability training on emergency planning from Independent Living Research and Utilization (ILRU), Partnership for Inclusive Disasters, and another national disability-rights-focused providers.

Below are practices that will often be critical to implement to prevent the spread of diseases.



Social distancing

Not being too close to other people is critical in preventing the spread of COVID-19 because COVID-19 primarily spreads through the air. Social distancing might not be as crucial with other diseases. Adapt the plan as new information becomes available or the community needs change during a public health emergency.



Types of masks

At the beginning of the COVID-19 pandemic, bandanas were considered adequate protection against the spread of COVID-19. Later it was learned that masks are needed to have the best protection. N95 or KN95 masks offer the best protection.



Handwashing/Surface Sanitation

Constant handwashing prevents the spread of disease along with sanitizing surfaces. During COVID-19, some CILs had to get creative with making disinfectants with alcohol or hydrogen peroxide and making bulk orders for hand soap to ensure consumers and CIL employees had appropriate supplies.

What is a Continuity of Operations Plan (COOP)?

A COOP is a written plan that a CIL creates to help keep the organization operating and serving consumers during public health emergencies.

Pre-event planning is the key for a CIL to continue operating and providing services and activities in a public health emergency. Think about the rapid onset of the COVID-19 pandemic and how helpful it would have been to have a written plan to follow as offices were closed, employees transitioned to remote work, and service delivery methods were drastically changed. A COOP can help a CIL to maintain operations and keep providing services and activities during this time, even if the way CILs provide them must change.



Examples of essential considerations for the CILs COOP:

- Hour-of-operation adjustments. At the beginning of the COVID-19 pandemic, some CILs operated a 24-hour hotline to ensure people with disabilities had appropriate support
- Requirements for PPE and other office modifications such as air purifiers, temperature thermometers, plexiglass dividers, appointment-only in-person services, hybrid employee scheduling, etc
- The location or method of community programs and services. For example, programs delivered by telephone, virtual platforms such as Zoom, or meeting outdoors
- Ensuring accessibility and program modifications for services
- Ensuring continuous payroll, accounting, and financial processes
- Mail services
- Virtual employee meetings to provide support and supervision
- Information Technology (IT) and support needs
- Reporting requirements
- Other business-related tasks

Critical Areas of Creating a COOP

Human Resources

- How will employees track their time virtually?
- How will they be supervised?
- What policies are needed to ensure the CILs' human resource policies and procedures are captioned virtually?
- How will you keep the CIL employees safe?
- Create a succession plan that identifies who will take on responsibilities if critical employees cannot make it into the physical work location.
- Make sure that more than one person has access to passwords. Consider implementing password management software. Make sure key staff are informed about the chosen people.
- How are employee accommodations being met

Remote Work

Create a work-from-home policy with agreements that include the following:

- Accommodations staff might need to work remotely.
- How work equipment, including computers and other devices, will be transported to staff and inventoried.
- Standards for a good work environment, including adequate seating and lighting.
- Training in keeping consumer information private and protecting Personal Identifiable Information (PII).
- Training in keeping consumer information private and following the Health Insurance Portability and Accountability Act (HIPAA) when it applies.
- Any necessary training in submitting timesheets, reporting, maintaining consumer records, I&R, and other records, and required administrative tasks.
- How employees will communicate with consumers, community members, and work locations.
- How employees will access internet and telephone services.



Return to office plan

A return to the office policy will help the CIL plan and prepare staff for reopening. Examples of information to include in the return to office plan:

- Securing PPE for employees and visitors as the physical office re-opens.
- Social distancing practices and how the information will be communicated with employees and staff while ensuring accessibility.
- Will the CIL enforce temperature testing if applicable? If so, is the thermometer accessible?
- Hours of operations and employee scheduling. Will there continue to be remote options?
- Who will maintain the inventory of PPE and sanitation supplies?
- What is the CIL's policy if an employee has COVID-19? Will the policy include contact tracing, requiring employees to work remotely or use paid time off, etc.?
- How will the CIL ensure accessibility and accommodations to its return to office plan?
- How will CIL employees get to work if they require public transportation?
- How will consumers and partners know the policies to keep them and employees safe?
- Will employees be required to wear PPE at the office and community meetings? If so, is the CIL required to supply it?

NOTE: Given that CILs are disability-led and serve people with significant disabilities, it is strongly recommended that mask mandates are required in the office and community during active public health emergencies if applicable.

Board Engagement

- How are you providing information to the CIL's board?
- CILs will be required to continue having board meetings. How are meetings accessible and virtual?
- Does the CIL's board of directors have access to technology to participate in board meetings?
- How will the CIL's Executive Director engage the board during an emergency?
- Does the CIL's bylaws allow virtual meetings and voting?

Finances

- Do the CIL's fiscal policies provide appropriate alternatives for maintaining internal controls and separation of duties when working remotely to process invoices, checks, and payments?
- How will you do payroll and distribute checks to employees?
- How will you function if your financial processes are not electronic/digital?
- How will you collect documentation for approvals for financials?
- Authorize another decision-maker to sign checks and other documents. Ensure that selected employees are fully aware of the financial policies.

Information & Technology

- Do employees have laptops that they can take home?
- Do employees have secure access to internal documents from home?
- How will employees answer and return phone calls from home?
- How will employees communicate with one another remotely?
- How will employees engage in community activities such as meetings?

Independent Living Responsibilities

All core services need to continue during emergencies. If the CILs have other sources of revenue, such as grants and contracts, it will be essential to communicate with those funders. Funders will expect programs to continue though they will likely understand that service delivery methods will change. For example, during COVID-19, the Administration on Community Living (ACL) communicated regularly with grantees to support ongoing programs. ACL also helped connect CILs with partners, education, and tools to address barriers the pandemic caused for people with disabilities. This response was similar to that of other funders. Therefore, it is essential to include methods of providing core services in the CILs COOP.

The core services required of CILs include individual and systems advocacy, peer mentoring, independent living skills training, information and referral, transition and diversion from institutional settings, and youth transition from school into the community. All other requirements for independent living under Title VII, chapter 1 of the [Rehabilitation Act of 1973, as amended](#), must also continue.

A COOPs should include details explaining how a CIL will continue to provide these and other services:

Program Delivery

- Develop a policy to ensure the CIL uses appropriate PPE when interacting with consumers. There is a significant chance that the CIL staff and consumers will be at higher risk during a public health emergency.
- If a CIL staff member cannot work with people one-on-one due to their disability and being at increased risk, the CIL may want to provide temporary accommodation and reassign the employee to projects or all virtual duties.
- If the CIL has a small staff, prioritize situations caused or worsened by the public health emergency. Anything that severely and negatively impacts consumer health and safety should be a top priority. This should include transitioning consumers out of nursing facilities and other institutions.
- Choose who will decide if services should be provided differently and how this should be done.

- Not all consumers may benefit from virtual services. Determine how CIL support will be individualized and remain consumer controlled.
- Consider other methods of program delivery, including but not limited to:
 - Virtually on Zoom or another platform
 - By telephone
 - Individually rather than in groups
 - In smaller groups
 - At a consumer's home
 - At a place other than the CIL if the CIL can't be used because of a public health emergency.

Note: If CIL employees provide a service or activity in a place other than the office, ensure the facility is accessible and near public transportation.

Other emergencies to consider when developing a COOP:

- Create a plan for how the CIL will continue serving if:
 - Transportation is not available.
 - Stay-at-home mandates are ordered.
 - The office is damaged or destroyed.
 - It is not safe for people to travel due to road conditions.

Conclusion

CILs are often models for other entities on disability rights and accessible program delivery. Since people with disabilities are at increased risk and face significantly more barriers to services, CILs must not only plan for continued operations, but all aspects of the plan must include strategies to protect the health and safety of those most at risk, including employees and consumers while ensuring equity and accessibility.

Strengthening Community Response through Relations

CILs must build relationships with local and state public health officials, emergency management, and other stakeholders to create a disability-inclusive response to public health emergencies. The best time to connect with community partners is before an emergency happens or as soon as possible after the emergency occurs.

Building these types of strong relationships, specifically with public health departments and healthcare providers, before a public health emergency allows for an immediate, effective, and equitable response during and after an emergency. These relationships ensure that people with disabilities are not an afterthought in a response and will most likely save lives.

When partnerships are formed, collaboration is more likely to happen before, during, and after public health emergencies. Engaging and collaborating with public health, healthcare providers, community organizations, and coalitions can help ensure that disabled people are included in and have equal access to public health emergency-related programs and services. Overall, these efforts help strengthen the whole community's response to public health issues and improve the community's health.

In this chapter, CILs will learn about the importance of partnerships, examples of key agencies and organizations to build partnerships, and strategies to leverage the CIL to play an essential role for public health and emergency partners.

Key Partners in the Community

When considering engaging in efforts to create inclusive emergency response strategies in your communities, it is essential to understand the various organizations that will be significant partners. Such partners will include local, state, territorial, and federal governmental entities, nonprofit organizations, and community leaders with a mission to support the community during public health emergencies and disasters.

1 Public Health Departments

Building relationships and actively working with state and local health departments is a significant first step. State health departments serve multiple public health functions. Some often include other areas of focus such as licensure of health professionals, developing state policies, regulation, and air quality. Despite a wide range of structures, each state's health department is often the primary public health authority and plays a crucial role in supporting the delivery of public health services. It is important to note that State Health Departments sometimes have medical-model practices. This means they strongly promote the use of medicine, surgical intervention or other treatments with the goal of fixing the disabled individual instead of modifying the environment and

or recognizing disability as a natural part of the human condition. This is even more of a reason for CILs to become involved since we know the medical model to be damaging.

Local health departments at the city and county levels provide leadership within their community. Local health departments secure life-saving medicines and resources, including shelter supplies, vaccinations, and first-aid equipment. They know how to quickly respond and deploy these resources during public health emergencies due to preparedness planning, training, and exercises. (Local Health Departments Impact our Lives Every Day). As a CIL collaborates with local public health departments, the organization will likely find opportunities to educate health departments about health disparities, disability rights, laws, disability bias awareness, accessibility accommodations, and disability community needs. CILs also ensure that local health departments have disability representation from actual people with disabilities.

2 Emergency Management

Another vital stakeholder to connect with is the CIL's county, territorial, and state emergency management agencies. While the name of these entities may vary, they are typically responsible for preparing for emergencies and coordinating the activation and use of resources controlled by local, territorial, or state governments. While emergency management is often focused on disaster prevention and response, they remain an essential partner during public health emergencies. Similar to health departments, a CIL can provide education and advocacy on behalf of individuals with disabilities in the community, helping to ensure inclusive planning and response.

3 Healthcare Providers, Community-Based Organizations, and Individual Leaders

In addition to public health and emergency management, CILs need to develop and strengthen relationships with healthcare providers and community-based organizations. These organizations provide vital programs and services, such as vaccine clinics and community resource centers, to people with and without disabilities in public health emergencies. CILs should reach out to their typical networks and beyond.

As with public health and emergency management, there will likely be an opportunity to educate organizations and groups about health disparities, barriers, disability rights, accommodations, disability bias awareness, and disability community needs. Make an effort to connect with local community leaders who will be able to support the CIL in its efforts and steer it in the proper direction.

4 Additional stakeholders may include:

- Disability-led organizations such as the Federation for the Blind, deaf associations, and self-advocacy organizations.
- State agencies that serve people with disabilities as CILs can be vital to them during emergencies.
- Leaders with disabilities who have expertise in public health emergencies.
- Community-based organizations that serve people with disabilities or older adults.
- Faith-based organizations
- Nonprofits that may serve disabled people during public health emergencies
- Advocacy organizations that serve marginalized communities, since disability intersects with all populations and multi-marginalized communities experience increased health disparities and barriers
- Healthcare and pharmacy providers, including public clinics and vaccine providers
- The state's Independent living Network

5 National Resources

In addition to community partners, there are resources and partners nationally as well, including:

- American Association on Health and Disability
- American Red Cross
- Association for Programs for Rural Independent Living
- Centers for Disease Control and Prevention's Division of Human Development and Disability
- FEMA's Office of Disability Integration and Coordination
- National Council for Independent Living
- The Partnership for Inclusive Disaster Strategies

Building Relationships Before, During, and After Public Health Emergencies

By establishing relationships with key stakeholders in advance, CILs can create a network that can be mobilized quickly during public health emergencies. CILs should work to develop and maintain working relationships with individuals within local and territorial or state health departments to facilitate equitable responses for people with disabilities in public health emergencies. CILs should also consider joining or establishing coalitions of stakeholders.



Strategies for Building Relationships Before Public Health Emergencies

Some strategies for building relationships before public health emergencies include:

➤ IDENTIFYING KEY STAKEHOLDERS.

Identify community members, organizations, and agencies with a vested interest in the health and well-being of the whole community. These could include local, territorial, state, and federal governmental entities, such as local health departments and emergency management agencies; nonprofit organizations focused on preparedness and responding to emergencies; organizations serving people with disabilities and the broader community; and healthcare providers. Prioritize building relationships with them.

➤ BUILDING TRUST AND ESTABLISHING CREDIBILITY.

Demonstrate the CIL's expertise in disability and commitment to the community by following through and being transparent about work and plans. CILs can be extremely important in ensuring partners are serving people with disabilities, complying with disability rights legislation, and providing disability representation.

➤ FOSTERING COLLABORATION AND PARTNERSHIPS.

Work with other organizations and agencies to share resources and expertise and coordinate efforts during public health emergencies that include disability. Invite stakeholders to CIL events and meetings and ask to be invited to theirs. CILs will most likely be the only cross-disability and disability-led organization within the partnership.

➤ PREPARING AND PRACTICING AHEAD OF AN EMERGENCY.

Inform stakeholders that the CIL is willing to observe, give feedback, or participate in drills, exercises, and tabletop exercises to test and refine emergency response plans. This could help the partner ensure their practices include people with disabilities.

➤ ESTABLISHING ACCESSIBLE METHODS OF COMMUNICATION.

Ensure all communications and meeting materials sent to stakeholders meet everyone's access needs. This means CIL employees may need to make materials accessible in multiple formats, such as screen reader accessible, in plain language or large font, and languages other than English. Additionally, be inclusive of the Deaf community by including plans captioning, American Sign Language, and other forms of sign language (i.e., deaf-blind tactile sign language, non-English sign language, etc.).

Strategies for Continuing Relationships During Public Health Emergencies

Stakeholders must work together during public health emergencies. CILs should take time to communicate and collaborate with stakeholders while continuously promoting transparency. Ensuring information about public health issues is widely available and easily accessible to community members can help build trust and encourage participation in public health efforts.

Below are actions CILs can take to continue building relationships and meet the needs of the community:

➤ COMMUNICATE REGULARLY.

Whether virtual meetings, email conversations, or group texts, CILs should collaborate with stakeholders to set up regular discussions.

➤ **SOLVE PROBLEMS TOGETHER.**

Share problems that people with disabilities may experience and solve problems together. By doing this, partners will better understand the barriers people with disabilities experience while receiving solutions from CILs' experts representing people with disabilities.

➤ **COLLECT AND SHARE INFORMATION.**

Share ongoing disability-related data and resources regarding establishing disability equity within emergencies.

➤ **CREATE ACCESSIBLE MATERIALS.**

Partner with stakeholders to create and disseminate accessible educational materials for the public. Materials should be made in multiple accessible formats and languages.

➤ **CROSS TRAIN.**

Training each other is essential to sustainability. CILs can provide specific-disability related training such as disability rights legislation, effective communication, social determinants of health for people with disabilities, common barriers, disability culture, etc.

➤ **ESTABLISHING A MEMORANDUM OF UNDERSTANDING.**

CILs may have much smaller budgets than other organizations. However, CILs are required to conduct resource development. Engage in conversations about funding opportunities to ensure the CIL has the funding to serve.

➤ **ACCOUNTABILITY.**

Assist with holding the partners accountable, as they most likely have responsibilities under the disability rights laws. While doing this, you are not only assisting them with creating equitable and inclusive programs and services but also with compliance and protection from disability rights litigation and complaints.

Regular communication creates an opportunity to discuss any:

- Unmet needs of people with disabilities.
- Barriers people with disabilities are experiencing.
- Solutions for meeting the unmet needs of people with disabilities.
- Community resources that benefit the disability community.
- Disability rights concerns.
- Effective communication, accessibility, and equity of services.
- How CILs can support the community in emergency response (e.g., hosting vaccine clinics free from barriers for people with disabilities in partnership with local public health departments and healthcare providers, diversion and transition services to keep people out of institutional settings, home deliveries, engaging in disability outreach, etc.).

Strategies for Continuing Relationships After Public Health Emergencies

Even after a public health emergency ends, stakeholders must maintain regular contact. CILs should make sure to:

➤ CONTINUE TO COMMUNICATE REGULARLY.

Regularly communicate with stakeholders to stay informed about their needs and concerns and to keep them informed about the CIL's work and plans after the public health emergency response ends. Consider establishing monthly meetings or creating a disability-specific coalition where the CIL can bring all the partners together.

➤ CONTINUE THE COLLABORATION.

Continue to invite stakeholders to CIL meetings and events and request to attend stakeholder meetings and events.

➤ PROVIDE RESOURCES AND SOLUTIONS TO STAKEHOLDERS.

Continue approaching stakeholders with help and solutions and encouraging others to share them.

Build a Diverse and Intersectional Coalition

Along with establishing relationships with individual stakeholders, establishing new or joining existing coalitions of stakeholders can be vital to ensuring equity for people with disabilities during and after disasters.

Some strategies for establishing diverse and equitable stakeholder coalitions:

- **Identify critical goals.** Clearly define the purpose and objectives of the coalition, and ensure they align with the community's needs and concerns.
- **Intersection of disability.** People with disabilities intersect within all communities. Make sure your strategies include diverse community organizations.
- **Foster collaboration and partnerships.** Work with other organizations and agencies to share resources and expertise and coordinate efforts to address unmet needs and civil rights violations during public health emergencies. This may include signing memorandums of understanding (MOUs) or other formal agreements to establish partnerships.
- **Practice inclusivity and respect.** Ensure all coalition members are welcome and valued, and their perspectives and experiences are considered when making decisions.
- **Ensure the group meets all access needs.** This may include translating spoken and written material into languages other than English, such as sign languages or Spanish, and making accommodations for people with disabilities.
- **Disability rights and inclusion are not optional.** Help the partnership know that they must include people with disabilities in planning and that their practices must be inclusive.
- **Use data and evidence to inform the coalition's decisions.** Collect and analyze data to better understand the needs of groups within the community. Use this information to develop strategies that address the community's needs. CILs and coalitions they participate in can collect their data by conducting surveys and focus groups. They can also analyze existing data.

Sources

Local Health Departments Impact our Lives Every Day.

National Association of County and City Health Officials, 2017.

<https://www.naccho.org/uploads/downloadable-resources/transition-appendix-A-Infographic.pdf>

Supporting Vaccination Efforts

Introduction

During the COVID-19 pandemic, people with disabilities were at higher risk of contracting COVID-19, having a severe illness, and even dying (CDC). Despite this, the disability community faced significant barriers to maintaining their health including the lack of access to vaccines, treatment, and information. Public health agencies and their partners can use lessons learned during the COVID-19 pandemic to shape future health and disaster response plans.



Both vaccine access and vaccine hesitancy were barriers to people with disabilities staying healthy during the COVID-19 pandemic. Without education focusing on vaccine access for public health agencies and vaccine hesitancy among consumers, these barriers will likely continue in a future public health emergency.

Since CILs are run by, and for, people with disabilities, they have the trust of the disability community as well as expertise in addressing access barriers. CILs are a natural fit for supporting vaccination efforts and responding to vaccine hesitancy.

During COVID-19, the inequitable response included:

- Lack of information that included people with disabilities,
- Lack of sign language interpretation during televised notifications and announcements about the public health emergency,
- Lack of sign language interpreters or Video Remote Interpreting (VRI) at vaccine sites,
- Lack of access to electronic information and vaccine registration websites for blind and low-vision individuals,
- Inaccessible websites and language,
- Physically inaccessible vaccine sites, and
- Vaccine sites located in overstimulating environments.

Although some barriers experienced during the pandemic are specific to COVID-19, many could occur in future public health emergencies. This chapter uses the COVID-19 pandemic and disability vaccination efforts as a template for addressing barriers to the disability community and disability-related hesitancy toward public health initiatives.

The needs of people with disabilities tend not to be addressed in most public health emergency plans, and people with disabilities are often not consulted when communities are developing them. CILs are uniquely positioned to inform partner agencies about disability perspectives and help shape public health and disaster policy.

This chapter will address the following:



Sources of vaccine hesitancy and how to counter them.



Lack of access to vaccines and lack of accessible, accurate information about vaccines.



The role that CILs can play in supporting vaccination efforts.



How CILs and the disability community can incorporate lessons learned during the COVID-19 pandemic into the response to future public health emergency planning.

Vaccine Hesitancy in the Disability Community

Just like people without disabilities, people with disabilities experience considerable vaccine hesitancy for many of the same reasons. However, the disability community has additional reasons for COVID-19 vaccine hesitancy. It is critical for CILs to develop and distribute accessible disability-specific information and to provide education and solutions. Some of these reasons for vaccine hesitancy existed before the COVID-19 pandemic. This is not an exhaustive list, and regional concerns may be unique to a CIL service area. Recommendations on responding to common hesitancies can be found in the resource section of this manual.

Reasons for Vaccine Hesitancy

There are many reasons someone with or without a disability may experience vaccine hesitancy, such as:

- not trusting the safety and/or effectiveness of the vaccine,
- disability not being mentioned or represented within the information,
- concerns about possible long-term side effects of the vaccine, and
- misinformation.

Disabled people may also experience additional vaccine hesitancy because of:





- fear of worsening their disability or underlying medical conditions,
- lack of accessible information,
- fear of short and long-term side effects from the COVID-19 vaccine,
- previous medical trauma,
- mistrust of medical professionals,
- previous reactions to vaccines, and
- mistrust of the vaccine information because it does not include disability-specific and/or available information and is not accessible.

Responding to Disability Vaccine Hesitancy

CILs are critical to help address vaccine hesitancy and provide information about how COVID-19 vaccines and boosters are safe and effective and how they may be related to their disability. CILs can also emphasize the need to continue to engage in additional protective practices, such as social distancing, masking, and hand washing. It is important to remind consumers and the community that efforts to protect their health are not political but are lifesaving for people with disabilities. Remind consumers that these practices also help protect against diseases other than COVID-19, including influenza and the common cold.

It is critical to communicate to consumers that research shows people who are up-to-date on their vaccines are less likely to get very sick, be hospitalized, and die from COVID-19. Studies also show that staying up-to-date on COVID-19 vaccinations reduces the likelihood of developing long COVID-19.

CILs can respond to vaccine hesitancy:

-  Through outreach and education,
-  through one-on-one services,
-  during the information and referral process, and
-  whenever staff becomes aware of vaccine hesitancy.

Addressing Vaccine Hesitancy

CILs should be aware of their role in providing accurate information about vaccines and other public health initiatives. Some individuals will choose not to get a vaccine, and that is their choice. CILs should never be coercive about the vaccine or any other public health initiative but instead, provide information and education so that consumers can make an informed decision. However, it's also important to make sure consumers talk with their medical provider if they have specific medical questions.

CILs can use the following approaches to respond to vaccine hesitancy:

- Debunk misinformation by providing facts and addressing disability-related concerns.
- Provide accessible information that addresses disability-related issues. Ensure the CIL creates information that is available in alternative accessible formats, including large print; braille, as requested; and Section 508-compliant electronic information. CILs should also have information available in multiple languages. The lack of accessible information is one of the disability community's most significant barriers to vaccination, so CILs must ensure that the information it is sharing is accessible.
- Elevate stories of leaders in the disability community who got vaccinated. If they experienced hesitancy before being vaccinated, it is a good idea for them to share how they resolved it. Because disability stories are not generally promoted, CILs need to share these stories. This provides consumers with peer role models and credible sources.

- Provide information about how some people with disabilities are at an increased risk of getting very sick or dying from COVID-19. Remember, disability or a diagnosis may not be the only reason someone may be considered high risk. Some people may have difficulty engaging in safety practices, like wearing masks or maintaining social distancing, due to their disability or disability-related needs. They could also be at increased risk because they are multiply marginalized, including being Black, Indigenous, or a person of color, having low income or experiencing poverty, and speaking languages other than English.
- Respond to hesitancy individually and within safe groups. Provide peer-to-peer support to build trust between trusted people.
- Listen carefully without judgement and address their concerns.
- Share personal stories of people with disabilities getting vaccinated.

Addressing Barriers

People with disabilities, including Black, Indigenous, and People of Color (BIPOC) disabled people, encounter barriers that can put them at greater risk of getting very sick and/or dying during public health emergencies. The barriers to healthcare during the COVID-19 pandemic were not new to disabled people. Vaccination and public health emergency response outreach efforts to the disability community are not successful unless these barriers are acknowledged and addressed.

Common barriers to access include:

- lack of access to vaccines in remote or rural areas,
- limited or no access to accessible transportation,
- limited options for in-home vaccinations or mobile clinics,
- limited or no internet access,
- limited or no access to medical specialists or medical professionals knowledgeable about specific disability risk factors,
- poverty and limited income,
- lack of accessible clinics and websites,
- lack of easy-to-understand and accessible information about the public health emergency,
- lack of telehealth options,
- hidden costs,
- disability bias and ableism, and
- concerns about not having legal identification documents or proof of citizenship.

Some examples of barriers to vaccination, testing, and treatment consumers could encounter due to their location include:

- living far away from vaccination centers, testing sites, doctor's offices, and emergency response operations;
- living in an institution where they do not have independent access to information, vaccination, testing, and treatment;
- needing an expert medical provider that does not have an office near their residence;
- not having transportation or living in an area without access to public transportation, especially in rural and remote areas; and
- difficulty finding information about public health emergency updates, such as COVID-19 vaccination, due to lack of internet access or internet-connecting devices.

People that disproportionately lack internet access include people:

- living in rural and remote areas,
- experiencing poverty, and
- who are unhoused.

POTENTIAL SOLUTIONS:

Transportation

CILs can:

- offer transportation services or services to connect people with local, accessible providers;
- partner with local public transportation systems to give free rides for vaccines and/or other public health response services;
- help consumers access paratransit;
- pay for and arrange rides through rideshare companies;
- find out if rideshare companies such as Uber, Lyft, and others will provide free or discounted rides to people seeking publicly supported healthcare response activities. CILs need to be informed of the resources available in their area; and
- offer gas cards or reimburse mileage to those seeking vaccinations.



POTENTIAL SOLUTIONS:

In-Home Vaccination and Treatment Outreach

CILs can:

- develop partnerships with local health departments and hospitals to schedule mobile clinics;
- assist with advertising and outreach about these options for consumers; and
- assist with advocacy, organizing, and education.

These partnerships may also allow CILs to assist consumers with identifying a provider in their service area who can give in-home vaccinations. This information can be provided at various staff-consumer contact points, such as in the Information and Referral process or during the goal development process between consumers and independent living staff.



POTENTIAL SOLUTIONS:

Navigating Lack of Internet Access

CILs can assist consumers without internet access by:

- Provide access to a computer, such as through community computers at the Center,
- collaborating with community partners to problem solve and share resources,
- providing print materials with the same information that is shared electronically,
- helping them schedule appointments over the phone, and
- partnering with and promoting organizations in the community that provide internet access, such as the local public library.



POTENTIAL SOLUTIONS:

Hidden Costs

Some ways that consumers may experience costs related to getting vaccinated include:

- childcare,
- transportation,
- parking, and
- missing work.

These factors can make accessing free public health resources like COVID-19 testing and vaccinations more difficult.



Difficulty Navigating Vaccine Information and Systems

Some reasons consumers may have trouble accessing vaccine information, and services include:

- a history of negative experiences with their medical care, particularly for those within the BIPOC community;
- lack of access to medical professionals with disability-specific expertise;
- inability to undergo medical exams because the doctor's office is not accessible or accommodations are not provided;
- inaccessible medical equipment;
- disability bias on the part of medical professionals;
- lack of clear, easy-to-understand instruction from medical professionals; and
- lack of medical professionals that communicate in or prioritize languages other than English, along with a lack of interpreters and credibility for people with disabilities who speak non-standard English.

Accessible Information

Under the Americans with Disabilities Act (ADA) or Section 504 of the Rehabilitation Act, when federal funds are expended, people with disabilities have the right to access information and specific accommodations when accessing healthcare. During the COVID-19 pandemic, CILs and advocates had to educate public health entities about their obligations under these laws to provide accessible information.

These accommodations include:



Physically accessible vaccine and treatment sites;



Access to American Sign Language (ASL) interpreters;



Materials in multiple accessible formats; and



Accessible information in multiple languages.

CILs should share disability-related information about public health emergencies with consumers. Consumers are most likely not getting this information anywhere else or it may be incomplete.

There are several ways CILs can help consumers exercise their right to accommodations.

CILs should:

- assist consumers with advocating for accommodations related to any appointments or events sponsored to provide aid in a public health emergency;
- provide advocacy and education when local websites and online registration are not accessible;
- support consumers who wish to file complaints or report inaccessible public health services by connecting them to the local protection and advocacy system and the US Department of Health & Human Services Office for Civil Rights (HHS OCR); and
- partner and provide guidance on how to make the vaccine and other service provision sites more accessible.

Navigating Healthcare and Telehealth Options

The COVID-19 pandemic accelerated the adoption of telehealth practices to keep people safe and healthy. Although telehealth reduced some disability-related barriers, such as transportation and architectural access, it is essential for CILs to be aware of the access barriers that continue to exist online.

These barriers include:

- the unavailability of telehealth for people who do not have internet access or devices that can access the internet;
- lack of adequate technology skills or training; or
- websites and telehealth services that are not accessible.

Addressing these barriers now will make it easier for consumers to receive services in a future pandemic or public health emergency.

CILs can assist consumers by:

- aiding in finding a healthcare provider and telehealth options;
- initiating education and advocacy efforts to state or territory health departments regarding the need to continue telehealth;
- advocating for accommodations needed to participate in telehealth visits; and
- supporting them by contacting a medical provider when needed.

Navigating Vaccine Sites

With the release of the COVID-19 vaccines, the United States launched a large-scale vaccination outreach campaign. As vaccination sites opened, CILs needed to advocate to make the vaccination process accessible to people with disabilities. The vaccination process includes getting to, through, and from the vaccination appointment. The efforts made to ensure vaccine site accessibility can be used as a model for ensuring the accessibility of future public health events.

CILs can:

- ensure vaccine sites are accessible before assisting consumers with scheduling appointments;
- provide education to vaccine sites and local health departments about accessibility and working with people with disabilities; and
- assist consumers with arranging accommodations at the vaccine site. Accommodations at vaccine sites include:
 - drive-thru vaccinations;
 - modified hours for people who may need additional assistance;
 - extra time before and after receipt of treatment such as a vaccine;
 - wait time reduction;
 - communication needs, such as ASL interpretation, plain language, accessible forms, etc.; and
 - accessible information.

Reducing Disability Bias and Ableism

Educating public health workers about conscious and unconscious disability bias is necessary to create an environment that is meaningfully inclusive of people with disabilities. When policies that support awareness and inclusion of people with disabilities are put into practice, access increases for all. CILs can work to dispel disability bias and ableism by providing disability bias and anti-ableism training to local health departments and clinic staff.

CILs should:

- educate providers about disability and required accommodations to ensure everyone can access public health response efforts; and
- demonstrate the need to be inclusive by providing education about the needs of and barriers encountered by the disability community.

Barriers that Impact Multiply Marginalized People with Disabilities

Multiply marginalized disabled people have additional barriers and concerns to consider in public health emergencies.

Multiply marginalized consumers may be:

- asked for an ID or Social Security number when getting a vaccination, or
- told that they must be U.S. citizens or have immigration documentation to receive the vaccine.

Education about identification Requirements

An ID card was not required to get a COVID-19 vaccine. ([National Immigration Law Center](#)) ([American Red Cross](#)).

- Workers at vaccine sites may have asked for ID, but it was not required to show one to them.
- If a provider insists on receiving documentation, the consumer can go to another provider, such as a community health center or clinic.

Note that proof of insurance, government issued identification, and other requirements may be required to receive other vaccines.

Education about Immigration Status

During the declared public health emergency caused by COVID-19, people who were not U.S. citizens were able to receive the COVID-19 vaccine for free. The vaccine was free and available to everyone over six months old in the United States regardless of immigration status. ([National Immigration Law Center](#))

Education on Deportation and Vaccination

The Department of Homeland Security (DHS) has stated that the “U.S. Immigration and Customs Enforcement (ICE) and U.S. Customs and Border Protection [CPB] will not conduct enforcement operations at or near vaccine distribution sites or clinics. Consistent with ICE’s long-standing sensitive locations policy, ICE does not and will not carry out enforcement operations at or near health care facilities, such as hospitals, doctors’ offices, accredited health clinics, and emergent or urgent care facilities, except in the most extraordinary of circumstances.” ([DHS Statement on Equal Access to COVID-19 Vaccines and Vaccine Distribution Sites](#))

When they go to get vaccinated, someone may ask for an ID or Social Security Number. People are not required to give anyone an ID or Social Security Number to get the COVID-19 vaccine. ([National Immigration Law Center](#))

These sites shouldn’t keep you from getting a vaccine because of your immigration status. DHS said ICE will not enforce immigration laws at or near vaccination sites.

Direct Outreach and Service Provision to Consumers

The previous sections of this chapter have focused primarily on public education and advocacy campaigns aimed at both consumers and public health response workers. In the spirit of “nothing about us without us,” this toolkit aims to ensure that the lives and needs of people with disabilities are reflected in public policy and practice. This spirit is also reflected in CILs’ direct work with consumers in the assistance of developing goals to increase and enhance the independence and dignity of people with disabilities. The following sections illustrate how disability access to life-saving public health initiatives can be supported through direct service provision to consumers.

These direct services can be provided at a number of staff contact points. CILs can:

- provide services to assist people in accessing public health emergency response outreach events;

- educate consumers on their rights to access public health initiatives and support them in advocating to protect those rights; and
- encourage the community to participate in public health initiatives, such as receiving the COVID-19 vaccine. When friends, family, personal care attendants and direct support providers, and the public take steps to protect their own health, they reduce the spread and impact of disease. This makes the community safer for everyone including people with disabilities who may be at high risk.

In order to best support and educate consumers, CIL staff must be aware of disability civil rights laws. For a brief overview of laws protecting and supporting people with disabilities related to accessing healthcare and medical facilities, see Chapter 3.

Scheduling Appointments

CILs can assist consumers in:

- identifying accessible and qualified pharmacies, medical providers, hospitals, or clinics for antiviral COVID-19 treatment;
- scheduling appointments;
- creating a plan to help the consumer remember the appointment;
- developing a plan for securing transportation; and
- arranging any appointment accommodations, such as late or early time slots, if needed.

Information and Referral: Responding to Callers

One of CILs' primary goals is to provide accurate information and peer support to the disability community. They are not medical professionals, and information given to callers should come from a position of understanding that CIL staff cannot give medical advice. CILs are trusted representatives of the disability community and staff are disability experts. CILs have the power in this role to provide information, support, and to address hesitancy about public health emergency practices.

If a consumer/caller has specific questions about how they might respond to vaccines and treatment, CIL staff should tell them to contact their doctor or another medical professional. I&R staff can assist with locating a doctor or medical professional if they do not have one.

If a family member or a personal assistance service provider is calling to seek assistance persuading a disabled person to access public health resources, ask to speak with the consumer directly. Be mindful that the person with the disability has the right to choose whether or not to receive any type of healthcare, including vaccinations. If the person with a disability has a guardian or conservator, the disabled person should still be included in the decision-making process.

Many people with disabilities are anxious about vaccines and healthcare. If a consumer contacts the CIL and indicates that they have a high level of anxiety about receiving vaccinations or treatments related to the public health emergency, offer peer support and engage in problem-solving.

When helping to schedule appointments for vaccines or healthcare needs related to a public health emergency, CIL staff must communicate with the consumer throughout the process. If a consumer is anxious or otherwise uncomfortable about calling to schedule an appointment or having trouble

getting assistance on the phone, offer to three-way call with them to schedule an appointment. Be ready to offer other types of support as needed.

Even when a consumer calls for services unrelated to a public health emergency, CILs may wish to include questions in the initial intake process to identify whether a consumer needs assistance. This way CILs can provide information and make resources available as soon as possible.

Sponsoring a Public Health Emergency Response Clinic

Due to their credibility in the disability community and subject matter expertise in the rights and needs of people with disabilities, CILs are uniquely qualified to partner with local health departments to host vaccine clinics and public health resource events. CILs can provide information about selecting accessible venues and onsite and remote registration accommodations. CILs can also host the event at their offices.

When promoting or hosting an event such as a vaccine clinic, CILs, and other hosts should prioritize accessibility. For a blueprint for hosting an accessible vaccine clinic, see the accompanying toolkit “How to Host a Barrier-Free Vaccine Clinic.”

Sources

- [People with Disabilities \(CDC\)](#)
- [Complaint Portal \(U.S. Department of Health and Human Services Office for Civil Rights\)](#)
- [Answers to Common Questions about Immigrants' Access to the COVID-19 Vaccines \(National Immigration Law Center\)](#)
- [COVID-19 Vaccines for Undocumented People \(American Red Cross\)](#)
- [DHS Statement on Equal Access to COVID-19 Vaccines and Vaccine Distribution Sites \(DHS\)](#)
- [COVID- 19 Vaccines and Testing Must be Free for Patients \(New York Times\)](#)

References

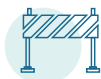
- [Getting Your COVID-19 Vaccine](#)
- [Link: Assisted Living Facility Database as of 2023 \(SeniorLiving.org\)](#)
- [Environmental Injustice and Disability: Where is the Research? \(Environmental Health News\)](#)
- [Patient Tips: Healthcare Provider Appointments for Post-COVID Conditions \(CDC\)](#)

Addressing Access Barriers

Introduction

Centers are essential for providing education regarding barriers to healthcare for the disability community and educating the broader community about solutions. This was especially true during the COVID public health emergency. Centers should be prepared to fill this need before the next public health crisis impacts our community.

While not exhaustive, this chapter will look at:



Types of barriers that can prevent equitable access,



Solutions for resolving these barriers, and



Additional resources to use when providing education and advocacy.

After reading this chapter, a CIL will be better prepared with strategies and solutions to advocate for barrier removal. Remember that barriers are often a form of discrimination, and many disability rights laws prohibit barriers to services.

Geographic and Transportation Barriers

For many people with disabilities, the availability of accessible transportation can heavily depend on the geographic location where they live. When asking people with disabilities to attend a health related event, transportation may be a barrier. Part of barrier removal may include providing accessible transportation, transportation reimbursement, or providing in-home services.

Accessible transportation needs can differ depending on the disability. For people with mobility disabilities who use power wheelchairs or scooters, accessible transportation requires a wheelchair-accessible vehicle. People with mobility disabilities who drive or have transportation to the event will need to have appropriate accessible parking.

When arranging accessible transportation, CILs must consider time, cost, and availability. It takes time and planning to arrange accessible transportation. Many accessible transit options, both public and private, require a minimum of 24 hours of advance notice to provide a ride. If a CIL is looking at alternative options, such as renting a vehicle, including this line item in the agency budget or grant application is essential.

Lastly, when seeking accessible transportation, CILs may not find many options, especially in rural or remote areas. Under the Americans with Disabilities Act, (ADA), paratransit is only required to cover an area within three-fourths of a mile of a fixed bus route. Rideshare services such as Uber and Lyft rarely offer accessible transportation. Taxis, when accessible and available, tend to be expensive. Although taxi companies may advertise that they have accessible vehicles, they may be limited in availability, require reservations, and have long wait times.

Like transportation, parking can be a barrier for people with disabilities. CILs can address this barrier by ensuring healthcare sites have designated accessible parking spaces. The ADA requires at least one accessible parking space for every 25 total parking spaces provided. One out of every six parking spaces must be van-accessible, which means they're either a minimum of eight feet wide with an eight-foot-wide access aisle or 11 feet wide with a five-foot access aisle. Van-accessible parking spaces allow room to deploy a lift or ramp for people with mobility disabilities to exit the vehicle. Note that where state or territory standards are stricter, those standards must be complied with to meet ADA obligations.

Under the ADA, temporary accessible parking spaces may be permitted at temporary vaccine clinics or for other temporary events. Temporary accessible parking spaces at vaccine clinics should comply with the ADA requirements mentioned earlier, including being as close as possible to the accessible entrance of the clinic, having a stable and slip-resistant surface, and complying with the parking dimensions above. It is also essential to ensure that there is an accessible path of travel from the parking space to the entrance of the clinic.

Lack of Easy-to-Access Vaccination Sites

Some people with disabilities live far away from vaccine clinics, and/or accessible transportation is not feasible. Others may benefit from getting their vaccine in a familiar setting. In these situations, scheduling an in-home vaccination should be requested as a program modification.

To ensure CILs are reaching people with disabilities so they can access in-home vaccinations, Centers can partner with the following:

- other CILs,
- local public health departments,
- nutrition agencies like Meals on Wheels,
- transportation agencies for people with disabilities,
- community health workers,
- community-based group homes,
- healthcare providers,
- home healthcare facilities, and
- other local organizations that work with people with disabilities.

If CILs are supporting in-home vaccination initiatives, CILs should ask the consumer if any personal care attendants, friends, or family members would like to get vaccinated at the same time. This helps make sure everyone is protected as much as possible from COVID-19. If consumers can go to vaccine sites, encourage them to ask their support network to get vaccinated.

Medical Barriers

Access to Health Insurance

When considering barriers to healthcare for people with disabilities, not all disabled people have medical insurance. CILs should support consumers in identifying if they qualify for Medicaid, Medicare, or health insurance under the Affordable Care Act (ACA). CILs should be providing assistance with increasing access to healthcare, which could include assisting with the application process and advocating for removing any barriers they might encounter with that process. Barriers might include an inaccessible application process, language being difficult to understand, the application located on the website is not accessible for blind users, etc.



During COVID-19 and the Public Health Emergency, vaccines were available for free to everyone. However, free vaccine access is not always guaranteed once the Public Health Emergency ends. Therefore, CILs need to be in regular communication with state Medicaid and Medicare providers to stay up-to-date on the status of coverage. CILs should also support consumers in staying updated with Medicaid/Medicare recertifications and coverage from other providers. Another vital effort CILs should engage in is advocating for free vaccine programs within their states to ensure costs are not associated with lifesaving vaccines when people with disabilities may be uninsured.

Sensory and Trauma-Related Barriers

Many people with autism or intellectual, developmental, psychiatric, and other disabilities may have difficulty with stimulation from multiple senses simultaneously (multi-sensory inputs). Some factors that may create barriers during vaccine events include loud noise, lighting, multiple processes, uncomfortable temperatures, or crowded spaces. Therefore, it is essential to remember this when creating an event. Strategies around creating sensory-friendly inclusive events can be found in the appendix.

It is also expected that disabled people might have experienced medical trauma in the past. Medical trauma means a set of psychological and physiological experiences from invasive or frightening treatment experiences. Medical trauma is highly prevalent within the disability community due to several factors but is often associated with ableism and how standards of care are not always inclusive of people with disabilities. These traumas increase anxiety for many people in the disability community as ongoing concerns that medical judgments and lack of understanding of healthcare providers regarding different approaches to medical care may be required would be compromised by underlying ableism and a lack of belief in the value of disabled lives. As a result, medical trauma causes barriers and often creates distrust of medical providers. Since CILs are part of the disability community as they are run and operated by the majority of people with disabilities, they are trusted among the disability community. Therefore, CILs must be involved in helping remove these barriers to ensure that people with disabilities are accessing lifesaving vaccines.

The presence of ambulances, police cars, and other first responders, in addition to the medical procedure itself, can trigger their memories of medical trauma. A CIL should provide warnings about music, sirens, images, and other triggers whenever possible. They should also seek consumer

input on how the CIL can best prepare them for the vaccines. Sometimes this is providing inclusive and accessible information, peer-to-peer support, learning the vaccine process and benefits from people with disabilities, and preparing a consumer for getting the vaccine by providing step-by-step instructions. But most importantly, the CIL should ensure the consumer controls the process and is heard, as they are the best experts for their own needs.

Barriers When Accessing Digital Spaces

At the start of the COVID-19 pandemic, much of everyday life moved to digital spaces. Medical appointments, meetings, and even day-to-day socializing moved to telehealth platforms, video conferencing meetings, and video or phone calls. Virtual spaces, especially telehealth, are often a safe and convenient option for people with disabilities, allowing access to spaces without stresses like lack of transportation, stimulation, or other anxiety-inducing barriers. However, it also poses a set of unique barriers for many in the disability community.

Lack of Internet-Connected Device or Internet Access

Participation in digital spaces like telehealth or online registration forms requires access to a smartphone, tablet, or computer and a reliable internet connection.

Many people with disabilities are unemployed, have very limited income, or live in an area with limited internet access. This means it is possible they may not have access to:

- electronic devices needed to access the internet,
- devices that support assistive technology,
- appropriate training and education opportunities to familiarize themselves with current technology,
- internet service due to limited or no income.

Centers should be ready to share information and resources regarding options for technology devices and accessibility with the disability community. It is also essential that CILs provide consumers with opportunities for training and guide them to low-cost technology options such as Computers for the Blind or low-interest assistive technology loan options. Most states also have programs that include a lending library where disabled people can try out a device before exploring options for purchasing the equipment. Therefore, as CILs think about the equipment needed for loan closets, consider technology options that could be loaned out or given to consumers if technology is essential for accessing programs and other community supports.

People with disabilities intersect within all communities, including rural or remote areas. This means internet access may be limited or completely unavailable. Given the already limited access to transportation in many rural areas, the combination can result in significant barriers when attempting to access medical care or receive services.

Information about programs to offset the cost of devices and internet service can be found in the resource section of this chapter. As a Center, it is essential to ensure consumers are aware of these programs and any other initiatives allowing for affordable internet access or access to devices in

rural areas. CILs may also be interested in providing a community computer housed at the CIL for consumers to access telehealth appointments or vaccine appointment registrations if transportation is available.

Digital Accessibility Barriers

Digital spaces like telehealth can also pose some unique digital barriers. People with a wide variety of disabilities benefit from implementing digital accessibility. These disabilities include, but are not limited to:

- deafness or hard of hearing,
- blindness, low vision, or other visual disabilities,
- disabilities impacting speech,
- intellectual or learning disabilities,
- difficulty reading print due to a disability, and
- anxiety.

One example of barriers in virtual spaces is telehealth applications or web portals that do not use captions during appointments, which excludes many people with disabilities. Other digital accessibility barriers might concern the design of the smartphone/tablet app or the web portal. If these platforms aren't designed with accessibility in mind, they will not be usable by many people with disabilities. Platforms should follow digital accessibility standards defined in the Web Content Accessibility Guidelines (WCAG) and Section 508 of the Rehabilitation Act. More detailed information about digital accessibility can be found further in this chapter, and the full texts of the relevant standards can be found in the appendix.

Another example of barriers in virtual spaces could include people who communicate in ways other than verbally. Therefore, it is essential to ensure communication devices can be used for texting options.

Strategies for efficiently working around inaccessible websites and applications are few. However, later sections include some considerations of which to be aware, including ways to advocate for digital accessibility and equitable access. With these tools, CILs will be better equipped to explain inaccessibility issues in digital spaces as needed and assist consumers and promote equity.

Physical/Architectural Access Barriers

When physical spaces are not accessible, this creates a barrier to getting into the space to seek services. Many people with disabilities encounter significant barriers in healthcare settings where they may seek vaccination, testing, or treatment. However, all healthcare settings must be accessible via federal law so it's important to provide education to all healthcare providers, public health entities, and vaccine providers. When considering vaccine or testing sites for a referral or developing an event, CILs need to review the accessibility of the building to determine if the site is accessible. CILs should never provide general resources without knowing if the individual would be appropriately served, as this would just create another barrier.

Note: Only asking another entity if a building is accessible often does not lead to accurate information. People often do not understand accessibility requirements and may believe a facility is accessible when it is not. CILs should send someone trained in ADA access requirements to assess the area physically or ask very specific questions of a provider. CILs can learn about ADA architectural standards by going to www.ada.gov. Also, remember that accessibility goes beyond just architectural accessibility, as mentioned in other sections in this chapter.

Informational Barriers

The saying “knowledge is power” is valid during a public health emergency. The more high-quality, factual, and understandable information CILs and the disability community can access, the easier it is to be well-prepared. However, people with disabilities may have difficulties accessing information, so Centers should be ready to provide easy-to-understand, accurate, and up-to-date details to the disability community.

The Misinformation Problem

The internet and media are packed with information that isn’t accurate, also known as misinformation. This was true about COVID-19, vaccines, and treatments. CILs need to have access to accurate and up-to-date information. The best places to find factual information are credible sources like the Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), and credible national news sources. Additionally, accurate and reliable information for local communities can be provided by local and state governments as well as their health departments. While these aren’t the only sources of accurate information, they are an excellent place to start. Likewise, it is also essential to make sure that it is known that people with disabilities may have a higher chance of contracting, getting sick, and even dying from diseases. Misinformation often does not provide information about the people with a higher rate of dying, so ensuring the CIL includes disability-specific facts is essential.

It’s also important to know the most common misinformation consumers are learning. This ensures you can research ways to help them understand clearly and accurately what is happening with a public health emergency, vaccines, or other related topics.

Information in Plain Language

Plain language is a way of writing designed to ensure everyone can easily understand what is being communicated. This writing style uses short sentences, small syllable words, with one idea in each sentence. When writing in plain language, try to use familiar words, avoid jargon and technical words, and always explain acronyms when first using them. More tips about how to write in plain language can be found in the resource section of this chapter.

EXAMPLE OF PLAIN LANGUAGE WRITING

Example of a statement that is not in plain language:

COVID-19 vaccinations are the most effective measure to prevent sickness; still, vaccinations are not 100% effective at preventing the spread of COVID-19. Therefore, precautions are still needed to be effective with limited the spread of COVID-19.

Example of the statement above made into plain language:

The vaccine works well to keep you from getting sick. But you might still be able to give COVID-19 to other people. We still need to be careful so everyone can stay safe.

Information In Languages Other than English

People with disabilities are the largest minority group in the United States and often hold other marginalized social identities. CILs should seek out or create information available in various languages to meet the needs of non-English readers or speakers. Language doesn't always refer to written or spoken communication. As CILs are cross-disability, CILs should never send information that is not accessible to the community. For example, if the CIL shares videos, they should include closed captioning and American Sign Language. If the CIL is developing print information and /or sharing information online, they should include materials in languages other than English.

It is also crucial for CILs to hire people who communicate in the languages consumers use. If CILs do not have staff to connect with people with disabilities that communicate in languages other than English, reach out and establish relationships with local interpreting agencies to ensure accurate information is shared.

Financial Barriers

While financial barriers impact most people in some way, they can be particularly problematic for people with disabilities. There is a high percentage of unemployment in the disability community, meaning many people with disabilities experience poverty or have limited income. When addressing consumers' concerns related to public health emergencies, CILs should work with them to find out if their insurance provider covers vaccinations, tests, and treatments.

If you are hosting a vaccine clinic, you might also want to consider the financial barriers people with disabilities face. One way you could do this is by offering gift cards to help cover transportation costs if permitted by the funding stream you are using, reimbursing for gas, covering public transportation fees, arranging and paying for rideshare, or arranging in-home vaccinations.

Identification/Immigration Status Barriers

Many people with disabilities may be under the false belief that they are required to provide documentation of immigration status or other identification when receiving vaccines or tests during a public health emergency. This is not true. Individuals can seek out medical treatment without either of these. CIL staff should inform consumers that documentation or identification is optional. Additionally, should immigrants with disabilities wish to seek identification, legal immigration status, or citizenship, CIL staff should be prepared to provide them with the necessary skills and resources.

Disability Implicit Bias

The most apparent barrier for Americans with disabilities is attitude and misconceptions about disabilities. Implicit bias impacts people with disabilities significantly. An implicit bias is an unconscious association, belief, or attitude toward any social group. It is a belief in favor of or against a particular group based on predetermined characteristics. Implicit bias is deeply engrained within healthcare.

Bias impacts healthcare for people with disabilities as it can lead to becoming:

- distrusting of medical professionals;
- reluctant to engage in preventative measures like receiving vaccines;
- reluctant to receive medical treatment; and
- perhaps receive treatment later than is recommended.

CILs can support public health departments and other healthcare professionals in mitigating disability bias by:

- providing disability implicit bias mitigation training,
- creating accessible materials that demonstrate disability-affirming language and behavior, and
- supporting clinics in being inclusive (offering low stimulation rooms, providing fidget devices, etc.),
- and being legally compliant.

Important Practices to Address Barriers

Accessible Vaccine Sites

When considering potential vaccine clinics or health fair sites, prioritize accessibility requirements. It is required for clinics or other programs to be accessible. Therefore, all facilities used for public health-related activities should be thoroughly surveyed by people with a deep understanding of accessibility requirements. Trained professionals with disabilities are proven to be the best when surveying for accessibility.

When publicizing vaccination clinics the CIL is hosting, CILs should always include contact information for a designated staff member who can assist with requests for accommodations. This way, CILs can ensure the clinic meets all needs.

Sample Accessibility Statement for People to Request Accommodations

If you need any accommodation to participate in this event, please contact [name] by [deadline date] via email at [email address], phone at [number], or by dialing 711 (Free Relay services) on your phone to discuss your accessibility needs. Accommodations may include but are not limited to sign language interpretation, curbside vaccinations, visual aid, assistance with completing paperwork, and materials in alternative formats.

The best practice is to include a form field on the website so people can register for the event. You can provide options for standard accommodation but also leave the field blank so people can type in their accommodation needs. Remember: even if you do not receive any accommodation requests, it is the law that your event follows the ADA, Rehabilitation Act, and other disability rights laws. As disability-led organizations and leaders in the community, it is also essential that all CILs are modeling this.

Creating Accessible Content and Materials

The two federal primary laws that pertain to digital accessibility are the Americans with Disabilities Act (ADA) and the Rehabilitation Act, particularly Sections 504 and 508. While Section 508 has its own enforceable standards and pertains only to federal agencies and other entities receiving federal funding (such as many public entities, including local and state government agencies, nonprofits, CILs, and SILC), the ADA is a bit more complex.

As with issues of physical accessibility, the ADA pertains to both public and private sector entities with digital accessibility. However, unlike Section 508 of the Rehabilitation Act, the ADA doesn't provide guidelines for what is required for something in the digital space to be considered fully accessible/compliant. To achieve ADA compliance, the Web Content Accessibility Guidelines (WCAG) created a set of standards.

WCAG covers every aspect of digital accessibility and is measured with three levels of success criteria:

- **Level A:** Items that achieve level A of the WCAG are seen as only having baseline accessibility. They are seen as neither accessible nor compliant and do not meet the expectations of digital accessibility in the ADA.
- **Level AA:** Level AA is seen as the level required to achieve full accessibility/compliance. There still may be small accessibility errors, but at level AA, a website can be used by most, if not all, people with disabilities.
- **Level AAA:** In terms of digital accessibility, level AAA is seen as going above and beyond. It is not at all necessary to achieve, or even aim for, level AAA with all digital content. However, doing so often enhances the accessibility and usability of a site in many ways. It can be helpful if people with disabilities are a website's only/primary audience.

Creating websites, applications, and documents that meet all the accessibility standards is technical and time intensive. If CIL staff are creating content or helping others to create accessible content as part of a fee-for-service program, make sure they refer to the full text of the required standards in the resource section of this chapter. Below are some tips that may be helpful:

Considerations for Digital Accessibility

Note that these considerations are not a complete list of standards but refer to the most common errors in accessibility testing.

➤ ALTERNATIVE TEXT (ALT TEXT)

Short text description, no more than two sentences, describing the critical details within an image. All essential images in digital content must have alternative text descriptions. Alt text is programmed into digital content for screen reader users to have information that would be represented visually. Alternative text can also be added to documents, presentations, and social media posts.

➤ IMAGE DESCRIPTION

A written explanation that describes essential information about an image in more depth than alt text. Image descriptions are usually provided in the written content of a web page and are accessible to everyone. Image descriptions can also be as long as a paragraph, whereas alt text should only be one or two sentences.

➤ **AUDIO DESCRIPTION**

An audio track that narrates and describes the visual parts of a film, TV show, video, or performance as the content is playing. An important note: narration/description usually occurs when no spoken dialogue occurs.

➤ **CAPTIONS**

Text displayed in the video and audio content that describes the audio, including sounds, conversations, and music. Captions can be either open or closed. Closed captions can be turned on and off, while open captions are always available on the screen. Open captions are most commonly preferred for many disabled people.

➤ **COLOR CONTRAST**

The difference of color between contents (text and graphic components) and their background. The version of WCAG, when this toolkit was published requires a minimum of a 4.5:1 ratio for accessibility. Color contrast can be tested using an automated checker such as the Adobe Contrast Analyzer from Adobe Color.

➤ **HEADINGS**

Text coded into webpages and added to documents and presentations using styles to help navigate screen reader. While headings assist in navigation, the primary purpose is to provide document structure by breaking documents into sections. Headings must be nested correctly to be effective. Heading level one, for example, should only ever be used for the title of a document. Headings at level two represent the titles of large sections of your documents, and headings at level three onward represent subsections within those larger sections.

➤ **MEANINGFUL LINK TEXT**

When the text linked on a document or webpage is very descriptive and tells you exactly where that link will lead and what you will find there. Links that say click here or read more are called generic link text and are not considered accessible.

➤ **KEYBOARD NAVIGABLE**

Not all people with disabilities can navigate websites and documents with a mouse. Instead, they use the keyboard. Keyboard navigable means your website/document/presentation can be navigated using only the keyboard.

Sources:

- [Disability Stigma and Your Patients](#)
- [Life Line support for affordable communications](#)
- [WCAG V 2.1](#)
- [Information on section 508](#)
- [State/Territory Assistive Technology Programs Directory](#)
- [ABA Resources Identify Implicit Biases Against People with Disabilities \(americanbar.org\)](#)

Engaging with Multiply Marginalized Communities

Introduction

Disability intersects with all communities, including other marginalized communities. It is essential to actively engage with disabled people with multiple marginalized identities and organizations led by multiply marginalized people to ensure that the CIL's response during a public health emergency is as effective as possible and considers other barriers that may be experienced by disabled people who may belong to more than one marginalized group.

People are marginalized due to their:

- disability,
- race,
- economic class,
- age,
- sex,
- gender,
- sexual orientation,
- immigration status,
- ethnicity,
- religion,
- and more.

People with disabilities are one of the largest minority groups in America and are deeply marginalized. However, when a disabled person is marginalized in more than one area, they face additional discrimination and have additional barriers. Marginalization is a byproduct of oppression, or the combination of prejudice and institutional power, that creates a system that regularly and severely discriminates against some groups and benefits others. Prejudice and power rely on the system where certain groups are seen as “better than” other groups and are subsequently privileged, while these “other groups” are pushed to the margins to be forgotten.

Systemic oppression exists throughout the United States, and powerful groups often carry out structures or processes (i.e., non-disabled people, white leaders, wealthy people, etc.).

Some forms of systemic oppression include:

- ableism,
- racism,
- classism,
- sexism,
- ageism, and
- many more.



Intersectionality

Intersectionality is a framework coined by Kimberlé Crenshaw to help describe how people often experience multiple marginalized identities that compound experiences of oppression where they intersect. This framework is used to demonstrate how multiple forms of oppression interact with each

other and impact a person and allows for treatment of the root of the issue rather than focusing on the symptoms of the problem. Many people face systemic oppression and often in multiple ways at the same time.

For example, a person with a disability is often discriminated against. This form of oppression can compound with other forms if the disabled person is also a woman, person of color, member of the LGBTQ+ community, persons whose first language is not English, if they are working-class/poor, or are many other identities. These identities do not exist separately. It is impossible to only look at one form of oppression when discussing barriers marginalized and multiply marginalized people face when accessing vaccinations. In short, it is dangerous for CILs to focus only on the marginalization of people with disabilities. For example:

- People with disabilities experience discrimination and increased barriers more than non-disabled people.
- Disabled women face more discrimination than disabled men.
- Black disabled people are discriminated against more than white disabled people.
- A nonbinary person with a disability may experience additional barriers than a disabled woman.

It is vital to use an intersectional lens when addressing barriers to vaccinations for people with disabilities because people with disabilities are often also members of other marginalized communities. CIL staff must consider all parts of someone's identity to understand how to support them best.

Use an Intersectional Lens

An intersectional lens is always needed since everyone has intersectional identities. Understanding that people are made up of multiple identities that influence how society interacts with them, instead of focusing on specific experiences, will enable a Center to support the consumer in overcoming the barriers they face in public health emergencies.

The first step is to apply the intersectional lens to your consumer base. Reflect carefully on the following questions:

1.

Which communities do we serve?
Which communities do we not serve?
Why?

2.

Whose participation is prioritized and valued?
Whose participation is not?
Why?

3.

Who has the most access to support and resources?
Who doesn't?
Why?

4.

Whose voices do we uplift the most?
Whose voices are often ignored?
Why?

These questions can help highlight when the CIL excludes specific communities, even without meaning to.

Health Equity

Many populations are marginalized and discriminated against in healthcare settings. CILs can be more effective in getting people with disabilities vaccinated by using a health equity lens.

The CIL can center health equity during a public health emergency by:

- Understanding that ableism and other forms of oppression impact health and healthcare access;
- Recognizing that information must be accessible in terms of both disability and culture;
- Include information that incorporates the barriers of other marginalized communities, not just the barriers within the disabled community;
- Avoiding implying that a person or community is at fault for their increased health risks or adverse health outcomes; and
- Emphasizing that equal health access and opportunity benefits everyone.

How to Become More than an “Ally” to Marginalized Communities

What does it mean to be an ally to marginalized communities? For many, an ally to marginalized people is someone who believes in equality and supports marginalized communities.

It is essential, however, to remember that allyship is more than a declaration. It requires deep reflection on one’s actions and beliefs and centering the impacted communities.

Authors Tsedale Melaku, Angie Beeman, David Smith, and Brad Johnson describe allyship as “a strategic mechanism used by individuals to become collaborators, accomplices, and coconspirators who fight injustice and promote equity ... Allies endeavor to drive systemic improvements to ... policies, practices, and culture.” ([Harvard Business Review](#))

Some best practices to use to move from ally to accomplice include:

Use Inclusive Communication

To reach as many people with disabilities as possible and encourage them to seek vaccination, CILs can make sure their communication is inclusive of all people and does not stigmatize or harm anyone.

CIL staff can practice inclusive communication by:

- Avoiding dehumanizing language and using identity-first or person-first language while always using the language the individual prefers
 - Example: Instead of “inmates,” say “people who are incarcerated.”
- Avoiding blame
 - Example: Instead of “people who refuse to get vaccinated,” say “people who have not yet received their vaccine.”
- Using terms preferred by members of certain communities
 - Example: Instead of “transgenders,” say “transgender people” or “trans people.”
- Avoiding assumptions about gender and using gendered language
 - Example: Instead of “this man/woman/lady/gentleman,” say “this person.”
 - Example: Instead of “excuse me, sir/ma’am,” say “excuse me.”

Prioritize Gender Inclusion

While centering the goal of helping people with disabilities to get vaccinated, it is necessary also to be inclusive of people of all genders.

CIL staff should:

- Ask everyone what their name and pronouns are when meeting new people;
- Share their own name and pronouns;
- Use the name and pronouns that people ask staff to use;
- Collect what information is necessary to serve the person;
- Explain why they are collecting information; and
- Acknowledge the mistake, apologize, and use the correct name and pronoun if they use the wrong name or pronoun.

CIL staff should avoid:

- Only asking people who they think might be transgender what their name and pronouns are;
- Using the wrong name or pronouns;
- Asking invasive or irrelevant questions about birth names, genitalia, or gender-affirming surgeries;
- Assuming gender, pronouns, or what gendered language someone uses;
- Making a scene when they use the wrong pronouns; and
- Assuming that there are only two genders.

Note: sex and gender are two different things. Sex refers to one's biological and physiological characteristics, and is often discussed using words like male, female, and intersex. Gender "refers to the characteristics of women, men, girls, and boys that are socially constructed," such as "norms, behaviors, and roles associated with being a woman, man, girl or boy, as well as relationships with each other." ([World Health Organization](#))

CILs may be required to collect data on gender identity. However, if not, it is encouraged to do so. Below are some examples of how to be respectful when asking about gender identity:

- "My name is _____. What is your name? Do you have a name that you prefer to be called?"
- "My pronouns are _____. What pronouns do you use? Do you use she/her, he/him, they/them, or other pronouns?"
- "What is your gender identity? Are you a man, a woman, non-binary, or another gender?"

Sources:

- [What Does Marginalized Mean and Why Does it Matter? \(CultureAlly\)](#)
- [Social Identities and Systems of Oppression \(Smithsonian\)](#)
- [What Is White Privilege, Really? \(Learning for Justice\)](#)
- [The urgency of intersectionality | Kimberlé Crenshaw \(TEDTalks\)](#)
- [The intersectionality wars \(Vox\)](#)
- [What Does It Mean to Be a True Ally to Women of Color? \(Harvard Business Review\)](#)
- [Be a Better Ally \(Harvard Business Review\)](#)
- [Gender and health \(World Health Organization\)](#)
- [Health Equity Guiding Principles for Inclusive Communication.](#)

Reaching and supporting individuals in congregate settings

Introduction

Centers for Independent Living have raised red flags for decades, stressing that nursing homes and other congregate settings are unsafe places for people with disabilities. During the COVID-19 pandemic disabled people living in congregate settings were significantly impacted. While it is difficult to identify exact numbers, we know from many sources that severe illness and deaths caused by COVID-19 were significant in institutional settings.

While reaching individuals in institutions and coordinating transition services is complex under normal circumstances, the work becomes even more difficult when combined with public health emergencies. CIL employees were challenged by restrictions that limit who can access a nursing home, along with difficulty arranging face-to-face meetings with consumers and other stakeholders when planning for and following the transition. This chapter will review the basics of the transition process and highlight strategies that can be used during public health emergencies. Many of these strategies were successfully utilized during the COVID-19 crisis.

In 1999, the United States Supreme Court Olmstead decision interpreted the Americans with Disabilities Act. The Supreme Court held that people with disabilities have a qualified right to receive state-funded support and services in the community rather than institutions when the following three-part test is met:

- the person's treatment professionals determine that community supports are appropriate;
- the person does not object to living in the community; and
- the provision of services in the community would be a reasonable accommodation when balanced with other similarly situated individuals with disabilities.

All states have a community integration mandate. Therefore, Centers must advocate in order to enforce this. It is important to note that a state's obligations under the ADA are independent of the requirements of the Medicaid program. Providing services beyond what a state currently provides under Medicaid may not cause a fundamental alteration, and the ADA may require states to provide those services under certain circumstances. For example, the fact that a state is permitted to "cap" the number of individuals it serves in a particular waiver program under the Medicaid Act does not exempt the state from serving additional people in the community to comply with the ADA or other laws. Therefore, don't take no for an answer.

CILs are powerful community-based organizations that provide education, advocacy and help enforce Olmstead in their states. But most importantly, they are one of the only federally funded organizations who are mandated to facilitate transitions of people with significant disabilities. In 2016, in section 7(17) of the Rehabilitation Act as part of its implementation of the Workforce Innovation and Opportunity Act (WIOA), Congress amended the definition of Independent Living

core services provided by CILs to include a core service around transition. In Independent Living, transition means many things, but this chapter will only focus on transition from congregate settings. Community transition means:

- Facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences, with requisite support and services.
- Provide assistance to individuals at risk of entering institutions so that the individuals remain in the community.

Institutions are:

- Nursing homes
- Intermediate care facilities for individuals with intellectual disabilities
- Hospitals, including medical and psychiatric
- Sheltered workshops
- Adult day programs
- Psychiatric institutions
- Prisons
- And other institutions

Strategies to Transition People Out of Institutions

Transitioning people from institutions to the community can seem like a daunting task. While it may take time, and CIL staff may need to try various strategies, it is doable. The consequences of not transitioning disabled people to the community are so significant that it might be the most important work that a CIL can do.

Whether a CIL is transitioning a disabled person from a hospital emergency room, psychiatric institution, group home, nursing facility, prison or another facility, the services and supports that must be in place are similar. The individual needs at least temporary housing in a non-congregate setting, a plan to move to permanent housing, personal assistance, and other supports as required, plus necessities including food, medication, clothing, durable medical equipment, and consumable medical supplies, wound care supplies, incontinence supplies, etc..

Strategies that CILs learned for transitioning people relatively quickly from institutions to the community during the COVID-19 pandemic can be used in the future, even if there is not an existing public health emergency. The strategies discussed in this chapter are effective in transitioning people with disabilities into the community from a variety of institutions or congregate settings.

While what is needed for a disabled person in terms of transition planning may stay static, regardless of the congregate setting or institution where an individual lives, access to the individual and the facility may vary. For example, some nursing facilities may be more amenable to collaborating with CILs to discharge people with disabilities into the communities than others.

Certain institutions, such as psychiatric facilities or prisons, and other carceral facilities, must engage in legal procedures before a person can be released. The fact that a disabled person's release must be adjudicated does not mean that CILs cannot support people who have been committed to psychiatric facilities or received prison sentences in transitioning to the community. Probate courts or other adjudicators of civil commitment to psychiatric institutions might take the fact that a person who has been committed has housing, a support network, and a well-thought-out plan into consideration when determining if an individual is ready for release from a psychiatric facility.

While advocacy efforts from a CIL may not substantially reduce a prison inmate's sentence, it may support an inmate with a disability in receiving parole. Again, a well thought out plan combined with a strong support network can help in release.

Partner with Other Organizations and Agencies

It is critical to engage with partners when working with consumers to transition them out of an institution. Every state has a protection and advocacy agency that can be an invaluable resource.

Protection and advocacy organizations have statutory authority to access institutions that CILs do not. For example, staff from these organizations must be allowed into nursing facilities, group homes, and other facilities to serve as an advocate or investigate claims of abuse or neglect in certain circumstances. Staff from protection and advocacy for individuals with mental illness program must be allowed into psychiatric facilities. Staff from this program also may have additional access to institutions, depending on state law. Partnering with these organizations can help CILs with efforts to transition someone out of a facility when access to an individual or to a facility is a barrier.

CILs should also consider partnering with individuals, agencies, and organizations that have resources that CILs do not. This could include food banks, equipment closets, municipal social workers, and other organizations that can provide assistance during a transition.

During the COVID-19 public health emergency Atlantis Community, Inc., a CIL based in Denver, Colorado, partnered with nine agencies and organizations, including personal assistance services providers, the City of Denver, state government including the department of health, department of housing, and disability advocacy organizations. This coalition combined forces with support from CARES Act funding to temporarily move people out of congregate settings, including hospitals and nursing facilities, which became even more dangerous during the PHE, and move people temporarily into hotels and more permanent housing in the community.

Partner with Institutions

Relationships can be key to advocacy. To facilitate community transition, CILs can build and nurture relationships with the staff at the facilities where they are working to transition consumers. Try to get the institution to support and help plan for a consumer's release from the institution. You may need to remind staff from the institution that the fact that the person is ready for release means that they have successfully done their job.

Programs that Can Support Transitioning into the Community

Money Follows the Person

A key program that may be available is Money Follows the Person (MFP). MFP allows states to use their long-term care spending for home and community-based services (HCBS) instead of the typical institutional care. This allows consumers to seek services, such as personal assistance, in the community instead of being forced to remain in a nursing facility to meet their needs. Not all states have the MFP program, so it is essential to [check which states have MFP available](#). If your state does not have an MFP, you can also work with your state’s Medicaid agency to advocate for home and community-based services.

Although this chapter is about transitioning individuals out of institutions, CILs need to be aware of and facilitate systems advocacy initiatives necessary to facilitate the transition. This includes partnering with local housing authorities to increase accessible, affordable integrated housing, increasing employment opportunities for people with disabilities, and advocating for increased home and community-based services.

Making Connections and Effective Outreach

One of the first steps in planning for the initial contact is establishing a relationship with the institution. The Centers for Independent Living in Arkansas found that one of their best strategies involved the nursing home staff from the beginning. The response has not always been positive, but not involving them ensures “at the very least, a lack of cooperation and, at the worst, sabotage against your efforts.” They found the nursing home social workers to be one of their greatest assets. Social workers helped the consumer to fill out required applications, switch social security payments to the individual, go shopping for necessities, find a local doctor, and ensure they received their medications and personal belongings from the nursing home before leaving. The Centers found that establishing a working relationship with the nursing home staff significantly reduced their workload. Other groups have suggested offering training from the local Center for Independent Living to the nursing home as a way to establish a positive relationship.

In some instances, congregate setting staff may need to be more receptive to having CIL staff visit someone in the facility. If the institution is a nursing facility, every state is required under the Older Americans Act to have an Ombudsperson Program to help address complaints in the long-term care system. An ombudsperson advocates for nursing home residents and can assist residents in resolving quality-of-care complaints. Work with the nursing home ombudsman because they are familiar with and connected to the facility’s people.

Having established relationships with staff inside of nursing facilities can be especially helpful during public health emergencies. During the COVID-19 pandemic, it was often impossible for CIL staff, members of the public, and family members to gain entry to nursing homes as these facilities were hard-hit by the virus. Nursing home staff and social workers played a vital role in reaching and supporting consumers. Transition specialists were able to successfully arrange for support and services through alternative



methods, including telephone calls, use of video conferencing platforms, mailing or faxing documents, and other methods. In some instances, CIL staff met with individuals at the outside window to their rooms at nursing homes to provide services.

Working with Family Members and Other Support People

While some people lose contact with their family and friends when becoming institutionalized, many in nursing homes and other institutions have family members and friends who can assist. Get families and friends involved in the transition process as early as possible if possible. A good support system is essential and increases the likelihood of successful transition.

The ILRU guidebook [ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators](#) provides some practical first steps in working with family members and others who can provide support. Some key strategies include:

- keeping the family or friends informed of progress; and
- inviting them to attend planning meetings and the future home of the consumer to help envision the disabled person living independently.

Regardless of the circumstances, it is vital for the disabled person to choose if and how family members or friends are involved in their transition. Ensure CIL staff listen to the consumer throughout the transition process.

Friends and family members can also be helpful when supporting someone transitioning to the community. These individuals may be able to serve as providers of personal assistance in states with consumer-directed services. However, some family members may actually oppose the move to the community. Communicate with the consumer to ensure their choices are being respected and prioritized.

This support can be especially important during emergencies. During the COVID-19 pandemic, it was often difficult to find and maintain personal assistance services due to the impact of COVID, fears concerning COVID, and the impact on caregiving work. Family and friends played a vital role in supporting individuals who transitioned to the community before and during the pandemic.

It is important to recognize that it may be necessary for a CIL to assist in providing PPE, including masks, face shields, gloves, and other items, such as hand sanitizer, to caregivers. Helping safeguard the health and well-being of both consumers and caregivers is crucial, especially during public health emergencies.

Reaching and Supporting Individuals in Congregate Settings

In working with people with disabilities, advocacy is often defined as representing preferences and needs of a consumer as they articulate those preferences and needs. This is to say that the role of the advocate is not to determine what is best for the person but to pursue the interests of the person as they have defined them.

This includes supporting the individual in defining and clarifying their own goals and desires. Advocacy should never replace self-advocacy by the individual. Sometimes advocacy is necessarily embedded in transition work.

Some issues transition facilitators encounter can be:

- resistance of congregate setting staff when an individual wishes to move to the community because of concern over safety or access to medical treatment;
- family (or guardian) concerns about/or opposition to community placement;
- limited experience of the individual in living independently;
- accessing housing with poor or no credit history; and
- obtaining and maintaining utilities, food, and household goods, when the individual has limited financial resources or income.

Establishing a Relationship with the Consumer: Supporting Their Planning Process

The goal for individuals who want to move out of an institution is to regain control and be in charge of their own lives. It is critical for the person moving to be in charge of all the steps and decisions during the transition to living in the community. This may be difficult for people who have been living in institutions for a long time whose preferences were not acknowledged. Many people living in institutions have been told and come to believe they no longer have the ability or the right to be in charge of their own life.

Some individuals may require additional support to take the lead in planning meetings. If this is the case, do not automatically take charge, but rather encourage the individual to be an active participant in the process. As the individual gains confidence, gradually step back. The individual should never feel as though they were in the transition process without support.

Consider the following to ensure consumers feel supported when leading the transition process:

- The person moving must attend all meetings. A planning meeting cannot be held without the person in attendance and able to participate fully.
- The person moving chooses who shall attend the meetings. Anyone not invited by the person moving is not allowed to attend the meetings. This may result in excluding family members or professionals who are accustomed to attending all such meetings in the past.
- Meetings are held in the community as often as possible. This is to remind everyone of the goal of being a part of the community. However, do not let facility rules against this be a barrier to assisting the person in transitioning.
- Non-paid people (community members, family, friends, and others) who care about the individual may attend the planning meetings when requested by the individual. This helps to begin to build the personal support system that the person will need once they are living in the community.
- The individual moving to the community or someone selected by the individual should lead the meetings.

Following Up: Ensuring Success

It is helpful to be with the individual during the actual transition and ensure that all of the household equipment and goods, medical supplies, food, and other necessities, are in the apartment/house. If the individual agrees, have frequent contact after the transition, particularly in the first weeks and months. For the first few weeks, it is important to check in with the consumer regularly in person, by phone, or text, and to let them know that you are available. It is a lot easier to solve problems when they are small than to wait until they become big issues. The frequency of contact should gradually decrease depending on the level of support required by the individual.

Specific Considerations During Public Health Emergencies

Providing transition services during a public health emergency can be challenging. However, continuing transition during a PHE is more necessary than ever. This was illustrated during the COVID-19 pandemic with high levels of infection and deaths in congregate settings. CILs must be prepared to support consumers in transitioning out of congregate settings during public health emergencies.

Centers should ensure they have access to technology that will enable them to reach consumers in a variety of ways. This includes phone and video meetings on platforms such as Zoom, Microsoft Teams, or GoTo Meeting. Make sure the platforms the facility provides are accessible to the consumer. If possible, provide accessible tablets or smartphones to consumers in institutions as permitted. This will not likely be permitted in carceral facilities, may be permitted in psychiatric facilities, and should be permitted in nursing facilities and group homes and ICFs.

Think about how CIL staff will assist individuals with obtaining household items including furniture, dishes and other items they will need to live at home. Traditionally, CIL staff may have gone to the store with or on behalf of a consumer to find these items. During a public health emergency, it will likely be necessary to purchase these items online and have them delivered. Decide where CIL staff will purchase these items, who is authorized to make these purchases, and how consumers will be assisted in receiving deliveries and unpacking items if they need support. Develop written standard operating procedures.

It is likely that despite the public health emergency, consumers may need in-person support and assistance. In addition to having the appropriate PPE available, Centers should establish safety policies and procedures that outline when and how in-person support may be provided. Consider social distancing, use of PPE, safety of all involved, and any other factors related to the public health emergency. Be prepared to support consumers if outside vendors will be delivering furniture or other items to their home. All involved should follow safety requirements.

Diversion

The best way to keep people in the community is to never have them leave it in the first place. Diversion can prevent placement into an ICF and other institutions. CILs should be mindful of ways they can prevent people from being institutionalized.

This can include:

Educating Consumers About Community Living Options

Make sure consumers, and where relevant, family members, know about personal assistance and other resources that support people living in the community, including CILs.

Emergency Relocations Toolkit:

A [toolkit](#) is provided by the National SILVER (Save Institutional Lives Via Emergency Relocations) Coalition and provides information on how Centers for Independent Living and other community-based organizations can access emergency relocation funding through FEMA for federally-declared disasters. While resources in this document may not be applicable in all public health emergencies, this resource is an essential step in reviewing the process, lessons learned, and successful nursing home transition during the COVID-19 pandemic.

Effective Transition Programs at CILs:

- ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators (ILRU): <https://www.ilru.org/abcs-nursing-home-transition-orientation-manual-for-new-transition-facilitators>
- Community Integration: A Holistic Approach to the New Core Services for Transition & Diversion (ILRU): <https://www.ilru.org/training/community-integration-holistic-approach-new-core-services-for-transition-diversion>

Additional Resources:

- Olmstead Decision: www.olmsteadrights.org
- Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. <https://www.ada.gov/resources/olmstead-mandate-statement/>
- SILVER Emergency Relocations Toolkit: <https://www.ilru.org/emergency-relocations-toolkit>
- FEMA Addendum: Delivering Personal Assistance Services in Congregate and Non-Congregate Sheltering: https://www.fema.gov/sites/default/files/documents/fema_personal-assistance-services_addendum_12-07-2020.pdf
- Strategies and Resources to Reduce Homelessness | Independent Living Research Utilization (ILRU): <https://www.ilru.org/strategies-and-resources-reduce-homelessness>
- Expanding CIL Capacity Through Youth-Driven Transition Services | Independent Living Research Utilization (ILRU): <https://www.ilru.org/expanding-cil-capacity-through-youth-driven-transition-services>
- How CILs Can (and Should!) Support Consumers in the Criminal Legal System | Independent Living Research Utilization (ILRU): <https://www.ilru.org/training/how-cils-can-and-should-support-consumers-criminal-legal-system>
- Community Integration: A Holistic Approach to the New Core Services for Transition & Diversion (9 Hours) | Independent Living Research Utilization (ILRU): <https://www.ilru.org/training/community-integration-holistic-approach-new-core-services-for-transition-diversion>
- Transitions Out of Institutions (ACL): <https://acl.gov/HousingAndServices/Transitions>

Expanding and Enhancing Services, and Providing Support During Public Health Emergencies

During public health emergencies, it is more important than ever for a CIL to continue to provide a high level of services and to be able to expand and offer additional programs as needed. CILs are mandated to be consumer-led and responsive to the needs of the disability community.

If a CIL does not continue to provide support and services during a public health emergency, often no one else in the community will. Without the services offered by a CIL, consumers are more likely to experience devastating effects from a public health emergency as we saw during COVID-19. This could include being disproportionately excluded from services and treatments, leading to a detrimental inability to access essential healthcare services. This exclusion frequently results in the worsening of health conditions, worsened by the loss of independence. Many people with disabilities face the risk of being placed in an institution, a situation that can contribute to severe sickness and even death. The persistent disregard for the needs and rights of people with disabilities leads to isolation, as well as an increase in incidents of abuse and neglect. (National Council on Disability).

Enhancing or expanding services can be challenging given that CILs often don't have enough funding or staff support. Chapter 4 of this toolkit describes how CILs are experienced in meeting consumer needs during a public health emergency since they provided services during the COVID-19 pandemic. Additionally, this chapter addresses the need to sustain services to better prepare consumers for future public health emergencies and to address long-standing challenges facing people with disabilities.

Prior to the Public Health Emergency

CILs should always be prepared and ready for a public health emergency before it happens. It is important to develop policies and procedures so that the CIL will have a baseline to work with when a public health emergency occurs. Plans need to cover how the CIL will continue to deliver services to consumers. Additionally, the plan should anticipate what employees will need to do, how they will be kept safe, when they will work, and what technology they will need. The plan should also include steps to identify who will take over critical duties if one or more key employees are affected by the public health crisis. Finally, the plan should address how the CIL will be able to quickly meet the needs and increased demand for services from consumers.

Having detailed but flexible plans in place will help increase the CIL's ability to provide services, ensuring mandates are followed, responding to increased needs, while also protecting its employees from getting sick from public health emergencies.

Educate and Inform:

Educating consumers and sharing essential information can help people with disabilities to be better prepared before, during and after public health emergencies. This can go a long way in protecting consumers' health, safety, and independence.

Educate and inform consumers about their rights during a public health emergency and how to prepare before it happens.

Collaborate with Local Public Health Departments

A CIL should work to build a strong, mutually beneficial relationship with public health departments before a public health emergency occurs.

It is important that CILs work with local and territorial or state public health departments to make sure consumers have access to:

- accessible information about the public health emergency,
- services, and
- any available vaccines or other prophylactics.

Ways to build productive relationships with public health departments include:

- hosting meet-and-greet events with public health officials,
- asking to be invited to public health meetings and events,
- inviting public health officials to CIL meetings and events,
- asking to be included in their public health emergency planning process, and
- creating Memoranda of Understanding (MOUs) with public health departments.

Working to provide training with the goal of educating public health employees about disability concerns before public health emergencies will benefit both the CIL and, more importantly, consumers. Training topics could include:

- providing accessible communications,
- providing accessible public health services,
- conducting accessible and inclusive meetings,
- the Independent Living philosophy, and
- the disproportionate effect of public health emergencies on people with disabilities, especially multiply marginalized disabled people.

During the Public Health Emergency

It is critical that CILs continue to engage in the following activities during a public health emergency. These activities will help CILs handle higher demand and meet increased requests for services by consumers.

Plans

Since every public health emergency is unique, emergency plans must evolve and be updated to meet the needs of consumers as they relate to each public health emergency. Things to think about when reviewing and revising plans include evaluating the situation that caused the public health

emergency, the expected duration and severity of the public health emergency, and the time of year. If the emergency is long-term, it will likely be necessary to continue to update plans as the emergency changes and new information becomes available.

Educate Consumers and others who have Disabilities

Provide information about a specific public health emergency or emergencies in an accessible format to consumers. Share educational information on social media, by email, in newsletters, through virtual presentations, and any other means available.

Work with Public Health Departments

Work with local and territorial or state public health departments throughout the emergency to ensure that public health services are:

- **Accessible.** This means spaces meet Americans with Disabilities Act and Section 504 of the Rehabilitation Act requirements.
- **Inclusive.** This means people with disabilities, especially multiply marginalized disabled people, feel included and are welcomed when using the service. Spaces may need to go beyond ADA and Section 504 requirements.
 - **Example:** An inclusive vaccine site might have American Sign Language Interpreters, quiet space, fidget devices or lowered lighting even though it is not required under the ADA and 504.

Inclusive spaces help to make sure that everyone can participate in the activity, regardless of race, ethnicity, country of origin, class, sexual orientation and gender identity, disability, and other marginalized identities.

Services offered by a local public health department include sharing information, tracking cases and potential sources of outbreak, hosting and supporting vaccine clinics, testing, and distributing personal protective equipment. CILs can support this work and people with disabilities by partnering with their local health department.

If a CIL has not yet formed a strong relationship with their local public health department, now is the time to do so. Make sure that public health departments are involved in the CIL's efforts to support consumers in maintaining health and independence during public health emergencies.

Areas Where a CIL May Need to Expand or Enhance Services During a Public Health Emergency

Information and Referral

During a public health emergency consumers will have the same needs as they would at any other time. However, they will almost certainly need additional services to address needs they did not have before the public health emergency. CILs should anticipate a significant increase in information and referral requests during an emergency and expect this when planning. Most CILs saw a significant increase in information and referral requests during the COVID-19 pandemic.

Example: A consumer who needed accessible housing before a pandemic will still require accessible housing during the pandemic. During a public health emergency, they may also need information about vaccines or accessible transportation to a vaccine site.

Requests for information and referral may be more complicated than usual because referrals will likely be made to different community resources than usual. I&R staff will also need to do research to find new information and resources. This will result in staff spending time conducting research online and attending meetings where resources are shared. All staff should be encouraged to share helpful resources and information during the emergency as this can greatly assist I&R. Because information and referral are such a critical function of a CIL during this time, additional employees should be trained so they can serve as backup during busy times or if primary staff cannot work due to illness.

Assistive Technology Distribution and Training

Delivery and repair of assistive technology (AT) will very likely be delayed or disrupted during public health emergencies. This leaves consumers having to deal with both the impact of the public health emergency and the loss of their technology. For many individuals, having access to assistive technology devices is key to their independence and ability to work. The absence of appropriate AT can also lead to new or more significant disability related impacts, illness, loss of independence, and an increased risk of being placed in a nursing facility.



As observed during the COVID-19 pandemic, CILs should be prepared to assist consumers during public health emergencies in acquiring and delivering new and gently used assistive technology or having a trusted partner to take referrals. Providing technology to consumers will allow them to access virtual meetings, have increased social opportunities and reduced isolation, and access to healthcare appointments. CIL staff should also be prepared for consumers to request training in using new technology. Equipment can be delivered or picked up at the CIL office. Consider providing easy to read getting started instructions, recording easy to

understand training videos or audio tracks and making them available online, and other methods that will help consumers get started with using the equipment. Staff can also provide individualized and group trainings virtually. Be mindful that consumers may not have advanced knowledge of technology and broadband Internet access may be unavailable for some individuals. Provide basic getting started information and training in multiple formats as a way of getting around these potential barriers.

Delivering Independent Living Core Services Virtually

During public health emergencies when it is necessary for people to maintain distance from each other, CILs should be prepared to provide services virtually and remotely. The good news is that CILs have been doing this since early 2020 during the COVID-19 pandemic. CILs have offered a range of services virtually including cooking classes, peer support groups, independent living skills training, and others. CILs have taught consumers how to use Zoom and other platforms, allowing them to take

advantage of video conferencing. These skills can be used by staff and consumers in future public health emergencies and in times where it is more convenient for consumers to participate virtually.

It is important to remember that not every consumer will have access to high-speed internet or devices that can access the internet. CILs need to continue to be creative in finding ways to include these consumers in programming. This can include seeking donations of used technology and applying for grants from public and private sources.

Distribution/Delivery of Food, Household Goods, and Supplies

Although not a core service, CILs have been called upon to distribute and deliver food and water, household goods, PPE, hand sanitizer, and other supplies during the COVID-19 public health emergency. This makes sense because CIL staff are peers and have the trust of consumers. Also, CILs know where many individuals with disabilities live in the community and how to best get in touch with them. Assume that CILs will be called upon to distribute food and supplies in future public health emergencies. CILs should develop a plan for how to accomplish this. Options could include establishing a formal partnership with an existing program in the community such as Meals on Wheels or a food bank.

Consumer Check-Ins

COVID-19 caused people with disabilities to be isolated which increased depression and other health concerns. (National Council on Disability). CILs have played a critical role in ensuring consumer well-being by conducting check-ins. A check-in is when CIL staff or trained volunteers reach out to consumers to see how they are doing and if they have unmet needs during a public health emergency. Many CILs began check-ins early in the COVID-19 pandemic and continued to do so for an extended period. These contacts can also help a CIL to better identify community needs and where best to direct time and resources. During check-ins, CILs can establish if a consumer is in imminent danger, or in need of food or water, personal assistance services or life-sustaining equipment such as durable medical equipment.

Check-ins can be done by:



phone,



text (with prior approval),



email,



mail,



or another method.

Check-ins can assist consumers in solving problems that may otherwise increase chances of getting sick, losing independence, or being placed in a nursing facility. CILs may want to consider training peers, including volunteers, to assist with consumer check-ins.

Programs and Initiatives that CILs Have Established and Strengthened to Help Consumers During the COVID-19 Pandemic

CILs will need to continue to provide essential services that they did before and during the public health emergency. These include the five core services required by the Rehabilitation Act and those mandated in any other federal, state, or local contracts. However, CILs also established a number of new and innovative programs during the COVID-19 pandemic.

Many of the programs and initiatives that CILs established or strengthened during the COVID-19 public health emergency can benefit consumers in future public health emergencies or even during non-emergencies. CILs should consider looking to local foundations and other funding sources to sustain or expand these programs.

One possibility would be for CILs to partner with local public health departments in pursuing grants. It is possible public health departments may have funding for initiatives, especially programs to decrease disability bias or increase access to public health programs and services for people with disabilities. Please click on the Building Capacity with Federal Funding Opportunities toolkit for other ideas about funding sources.

Some of the programs and initiatives CILs may have developed or strengthened during the COVID-19 public health emergency might include:

Being a resource of accessible information about COVID-19, prevention and mitigation steps, and the vaccine/vaccine eligibility.

CILs can and should be a source of accessible information in all public health emergencies, as well as outbreaks of influenza and other diseases. Providing this information in an accessible format can be a great opportunity for CILs and public health departments to collaborate.

Producing accessible materials.

CILs can and should produce accessible electronic and print materials about how consumers can maintain their health during future public health emergencies and disease outbreaks, as well as preparedness plans for personal assistance during public health emergencies. This could be another opportunity to collaborate with public health departments.

Engaging in outreach to reduce isolation among people with disabilities.

One of the things that CILs noticed during the COVID-19 public health emergency was the degree to which people with disabilities were isolated. Many CILs developed ways to reach out to consumers to check in with them and to provide information when needed. Not only will this type of outreach be necessary in future public health emergencies, but it is a safe assumption that some consumers, particularly ones transitioning out of institutions, could benefit from this during times when there is no public health emergency.

Advocacy for disability rights. In addition to typical advocacy work, CILs found the need to advocate in new areas.

This included advocacy for:

- equitable Crisis Standards of Care,
- access to vaccines, and
- telehealth access. Although telehealth use has highly risen in the pandemic and it reduces barriers to healthcare access for some disabled people, its continued use after the end of the public health emergency is in question. Given CILs will have to support advocacy efforts for telehealth for consumers who want it and accessible telehealth for people who are Deaf, hard of hearing or do not read print due to a disability, they should consider looking for funding sources for this initiative.

Protecting Employees and Volunteers

CILs have a unique responsibility to safeguard their direct service staff. These individuals are the frontline workers and primary support for many, providing essential services that people with disabilities heavily rely on. Their health and safety are critical not only to the organizations they represent but also to the communities they serve. Below are some key strategies CILs can implement to keep their direct service staff safe during public health emergencies.

Promote Health and Hygiene Practices:

CILs should provide training to staff on best practices for maintaining personal hygiene, as recommended by trusted health authorities like the World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC). This includes regular hand washing, use of hand sanitizer, cough and sneeze etiquette, and wearing masks properly when required. Provide necessary supplies such as soap, sanitizers, masks, gloves, and other PPE.

Implement Flexible Work Arrangements:

Where possible, CILs should consider flexible work arrangements, such as remote work or staggered work hours, in order to reduce the risk of exposure. In situations where direct service staff cannot work from home, due to the nature of their roles, consider adjusting workflow to minimize contact with others, such as using individual offices or partitions, and limiting the number of staff in shared spaces.

Maintain Safe Work Environments:

Regular cleaning and disinfecting of workspaces should be a priority. CILs should also ensure there is adequate ventilation in indoor workspaces, and where possible, encourage activities to be moved outdoors or conducted virtually to minimize risk of transmission.

Enforce Social Distancing Measures:

When direct interactions are necessary, CILs should ensure that staff, volunteers, and consumers maintain a safe distance as recommended by health authorities. This can be facilitated by markings or signs that denote safe distances, rearranging furniture, or arranging services to limit close contact.

Develop and Implement Safety Protocols:

CILs need clear protocols for dealing with suspected or confirmed cases among staff, volunteers, and consumers. This includes procedures for reporting illness, contact tracing, isolation, and potential facility closures. Be sure to communicate these protocols effectively to all stakeholders.

Prioritize Mental Health:

Recognize that public health emergencies can significantly impact mental health due to stress and anxiety. Providing support services such as teletherapy, employee assistance programs, and other mental health resources can go a long way toward maintaining staff wellbeing.

Encourage Vaccination and Regular Testing:

When vaccines or testing are available, encourage and facilitate access for staff. Clear communication about the benefits, safety, and effectiveness of vaccines and regular testing is crucial to mitigate fears and misconceptions. CILs may choose to require vaccinations recommended by the CDC for employees and volunteers.

Keep Communication Lines Open:

Regularly update team members on any changes or updates to procedures, new information about the health crisis, and any other relevant information. Clear and transparent communication can help to reduce concerns and ensure everyone understands their roles and responsibilities in keeping each other safe.

Ensure Adequate Staffing Levels:

Plan for possible staff absences due to illness or caretaking responsibilities. Cross-train staff members to perform essential functions so the organization can operate even if key staff members are absent.

Provide Training and Resources:

Equip staff with the knowledge and resources they need to stay safe and carry out their roles effectively during a public health crisis. This includes training on new protocols, access to reliable health information, and resources for personal support. It is also important to ensure team members have access to technology that will enable them to perform their roles.

Public health emergencies, such as the COVID-19 pandemic, create new challenges for CILs. However, with thoughtful planning and consistent implementation of safety measures, organizations can help protect their direct service staff and, by extension, those served by the Center.

Human Resource Considerations

Many nonprofit organizations, including CILs, do not have the financial ability to have a formal human resource position on staff. However, it is vital that CILs prioritize awareness of legal requirements and other aspects of human resource functions during a public health emergency. It is important to stay up to date with local, state, and federal laws related to employment and public health. This includes understanding rights and obligations under laws such as the Family and Medical Leave Act (FMLA), the Americans with Disabilities Act (ADA), and the Occupational Safety and Health Act (OSHA). These laws can have significant implications for sick leave, remote work, and workplace safety during a public health emergency. Additionally, it will be essential to establish

written procedures around how staff should report illness resulting from the public health emergency, how that information will be safeguarded and kept confidential, and how employees, volunteers, and consumers will be notified in the event of exposure.

These are just a few examples of how a Center may be impacted from a human resources point of view. CILs should take time now to consider their current capacity in relation to human resources and how they might take steps to make improvements if needed.

Sources

- [2021 Progress Report: the Impact of COVID-19 on People with Disabilities](#)
- National Council on Independent Living

Appendix

Editors Note:

The following pages include a number of informational items and documentation that may be of assistance in future public health emergencies. The documents were developed in response to the COVID-19 pandemic and therefore contain specific information relevant to the emergency. While it is anticipated that much of this information will be useful during future public health emergencies, the reader is encouraged to make any edits, or additions to these documents as needed.

Appendix 1

Sample Letter Requesting At-Home Vaccination

Sample Reasonable Modifications Letter

From CILs to Health Departments for At-Home Vaccination Advocacy

Health Department Name

Address

To Whom It May Concern,

My name is _____ and I am reaching out to request at-home COVID-19 vaccination. Due to my disability, I am unable to leave my home to access a COVID-19 vaccine. [Add any relevant details about your disability here]

Clearly noted by the U.S. Department of Health and Human Services Office for Civil Rights, civil rights laws remain in effect during emergencies, including the COVID-19 pandemic. Additionally, Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act prohibit discrimination on the basis of disability.

Under these laws, as well as Titles II and III of the Americans with Disabilities Act, my disability does not exclude me from being allowed to participate in services, programs, or activities of covered entities such as the COVID-19 vaccine provider.

It is the legal obligation and responsibility of the health department to make reasonable modifications to improve the accessibility of vaccines. Making arrangements for my in-home vaccination is a reasonable modification.

My in-home vaccination can be scheduled by calling _____ or emailing _____@email.com.

Thank you for your time. I look forward to hearing from you.

Sincerely,

Providing Information to Address Vaccine Hesitancy

While experiencing disability-specific barriers related to healthcare and public health, people with disabilities also experience fear-based hesitancies. In order to counter vaccine hesitancy, CILs should be prepared to provide the latest, most credible information available from sources like the Centers for Disease Control and Prevention (CDC). Below is information that can help ensure CILs are best equipped to address vaccine hesitancy.

Information to Address Hesitancy About Side-Effects

Many people know they might experience side effects from vaccines and boosters. While not all people experience vaccine side effects, they impact people with and without disabilities. Not everyone will experience side effects but providing education about what consumers may experience is important.

Common temporary side effects of vaccines and boosters are:

- pain, redness, or swelling where you received the vaccine,
- fever and chills,
- headache,
- nausea, and
- brain fog and difficulty focusing.

Inform consumers that:

- not everyone experiences side effects,
- side effects are temporary and usually disappear within a few days,
- severe side effects such as anaphylaxis are extremely rare,
- side effects may mean the vaccine is working, and their body is learning to protect itself and
- the vaccine will not bring more pain, illness or discomfort than getting sick.

If consumers experience significant side effects or are concerned about side effects, they should contact a healthcare professional.

Another tool that could potentially ease concerns about side effects is V-safe, which tracks side effects associated with the COVID-19 and other vaccines. V-safe lets consumers tell the CDC about any side effects they may have after the COVID-19 vaccine. Depending on the side effects they disclose, someone from the CDC may follow up with them.

Information to Address Hesitancy Regarding the Vaccine's Impact on Disability or Health Conditions

COVID-19 will impact the health of the infected person, regardless of disability status or medical condition. Some people with disabilities may be affected more than other people with different disabilities or people without any disabilities.

Inform consumers that:

- People with certain disabilities and medical conditions have a higher risk of getting sick and dying from COVID-19 ([CDC](#)).
- Clinical trials show that COVID-19 vaccines are safe and work in people with disabilities and medical conditions ([Johns Hopkins Medicine](#)).
- Early data indicates that staying up-to-date with the COVID-19 vaccine and boosters not only reduces the severity of COVID-19 if a person does contract the virus after vaccination, but also reduces the likelihood of developing long COVID.

Information to Address Mistrust of the COVID-19 Vaccine

Because of past medical trauma or historical experience, people with disabilities may not trust the medical industry. This is one of the many reasons that they might be hesitant to receive a vaccine.

When the COVID-19 vaccines were initially developed, some people were concerned that they were produced too quickly. Remind consumers scientists have been developing vaccines for a long time. When new conditions arise, researchers look at what they have done in the past and start testing to see how they can use what they already know to treat a new health problem.

Talking points to address COVID-19 vaccine hesitancy due to suspicion about the vaccine development process include:

- research that led to these types of vaccines has been going on for over 50 years ([National Institutes of Health](#))
- the COVID-19 vaccine was subject to the same safety protocols as other vaccines ([Wellcome](#))
- the COVID-19 vaccines were made quickly to save lives but not at the cost of safety of the public ([Wellcome](#))
- COVID-19 vaccines were developed by scientists around the world working together, ([Council for Foreign Relations](#))
- the COVID-19 vaccines and boosters are safe and effective ([Johns Hopkins Medicine](#))

Talking points to address COVID-19 vaccine hesitancy due to concerns regarding the safety of the vaccine include:

- The evidence shows COVID-19 vaccines are safe for people without and with disabilities ([CDC](#))
- Vaccines help slow the spread of COVID-19 and lower the chances of getting very sick or dying from COVID-19 ([CDC](#))
- Black scientists were involved in the development of the vaccine ([American Society for Microbiology](#)) ([IntraHealth International](#))
- Black doctors have promoted the vaccine ([Kaiser Family Foundation](#))
- Many government officials, including all living U.S. presidents and governors at the time this toolkit was published, got COVID-19 vaccines. ([COVID Collaborative](#)) ([Stanford News](#))

Sources:

- [Myths and Facts about COVID-19 Vaccines \(CDC\)](#)
- [People with Disabilities | COVID-19 \(CDC\)](#)
- [Finding Credible Vaccine Information \(CDC\)](#)
- [NMA COVID-19 Task Force on Vaccines and Therapeutics \(National Medical Association\)](#)

Public Health Emergency Reopening and Operating Procedures

Introduction

A public health emergency can impact communities across the globe with painful and sometimes deadly consequences. Centers should be prepared to protect the lives of employees, consumers, and the public while continuing to provide vital services and supports. This document serves as an example of a written plan for how CILs can continue operations and reopen offices during and after a public health emergency while ensuring the health and safety of staff, volunteers, consumers, and the public.

Background

A CIL should consider a public health emergency to be a high-risk event, especially because the organization represents and serves the disability community. These risks are universal because even as someone without symptoms contracts the virus, they can pass the virus to family members, colleagues, and other community contacts. A CIL should also consider a public health emergency to be a personal health risk. There is a fair chance that a public health emergency will be more likely to have negative and deadly outcomes in individuals that have underlying health problems or disabilities. However, Centers should verify with information from the Centers for Disease Control and Prevention (CDC) and as many peer-reviewed studies as possible. Understanding the two types of risk and mitigating all potential spread of a public health emergency is the goal of this plan.

Governmental Orders and Other Administrative Guidance

CILs should comply with all reasonable orders issued by relevant Federal, State, and Local governments. In the extreme case where an order conflicts with prevailing guidance and safety, CIL management may choose to provide additional guidance. CILs should recognize the quickly evolving nature of what is known about the current public health emergency and the impacts that it may have on the community. CIL management should adjust parts of this plan as appropriate with notice to staff as needed. Any adjustments made should be data driven and with the health and safety of employees, consumers, and the community as the top priority.

Timeline of the Plan

Until society is completely safe from a public health emergency, CILs should implement permanent measures to protect the health and safety of staff, consumers, and guests. Providing appropriate protection from the public health emergency should be permanent until otherwise communicated. Staff should be notified of any changes in the plan at least one week in advance.

Reasonable Accommodations

Providing accommodations should be part of a Center's culture. It is expected that staff will need to and will be confident in requesting accommodations. The accommodations process for any of the provisions of this plan should follow the CIL's Employee Handbook.

Communication and Public Health Emergency Responsibilities

Communication

Staff should be encouraged to speak to their immediate supervisor if they have any questions or need clarification regarding any aspect of the plan. Staff members should wait to share information with consumers, community partners, and the general public until authorized to do so.

Protection and Safety of Colleagues

All CIL staff have a responsibility to each other, each other's families, consumers, and the community to engage in practicing health safety in and out of work and self-monitoring health concerns. Any observed symptom of oneself should be reported to a direct supervisor and automatically trigger a requirement to work remotely. Staff may return to work after adhering to current CDC guidelines.

Janitorial Services

CIL offices should be cleaned regularly by a professional janitorial company. If a staff member is directly affected by a public health emergency, such as being infected with an emergency-level disease, the office in which that staff occupies should be fully sanitized prior to any staff returning to the physical office.

Disease Testing/Vaccination

If a staff member is exhibiting any symptoms and testing is needed, the employee should be permitted to take time off from work as covered time for disease testing. CIL staff waiting for test results should not be allowed to work from the office or have physical contact with consumers and colleagues until test results are determined. Staff with positive results should be asked to either telework or be placed on paid administrative leave until they quarantine for the recommended days per CDC guidelines.

Staff should be allowed to take paid leave in order to receive vaccinations. Employees receiving a multi-step vaccination series should be allowed to take paid leave for each dose.

Contact Tracing

A senior officer with the Center should be required to track positive cases among employees. Information collected in the process of tracking vaccinations, testing, and positive cases must be kept strictly confidential. If an employee tests positive for the disease, the designated senior officer should interview the employee to determine if coworkers/consumers/agency visitors have been in "close contact" with the employee within the last week ("close contact" will likely be defined by the CDC; an example would be within six feet of the infected employee for a prolonged period of time). Center management should alert those that have been in close contact with the employee as soon as possible while protecting the confidentiality of the individual who was infected.

If it is determined that an employee may have been in close contact with another who has tested positive for the disease, that individual should be asked to quickly prepare to leave the office (if working in the office), and monitor symptoms at home per CDC's guidance. They can return to work once they have no symptoms and test negative.

Office Safety

Centers should ensure that adequate resources are available in each office to protect against the spread of a virus or disease during a public health emergency. In addition to using plexiglass or a similar barrier at the front desk and other locations in the office, the following should be provided in all office locations.

Hand Sanitation Stations

A hand sanitation station should be available in the lobby of all CIL office locations. Individual hand sanitizers should be available at each workstation and in common areas. Hand sanitizer should be available for all CIL consumers and guests. Soap should be provided in all restrooms, break areas, and kitchen facilities.

Personal Protective Equipment (PPE)

PPE should be available to CIL staff, consumers, and guests. Items should include:

- Reusable Masks (clear masks, modified masks, and face shields)
- Disposable Masks
- Hand Sanitizer
- Surface Disinfectant Spray and/or wipes

UV LED Sanitizing Boxes

For small items that can't be sanitized using disinfectant, a UV LED box should be available in each office. The boxes use ultraviolet-C light to significantly reduce microscopic germs and other health hazards.

Non-contact Thermometers

Non-contact digital forehead thermometers measure the temperature of an individual from a distance.

Air Purifiers

Air purifiers can help reduce airborne contaminants, including viruses in confined spaces. Air purifiers should be placed in common areas in all CIL office locations.

Signage

Signage should be displayed throughout all CIL offices in order to remind staff and guests of COVID 19 procedures. Public health safety procedures for guests should also be made available on websites, social media, and employees to share with individuals who are planning to visit the office for appointments. All staff members have the responsibility to enforce COVID-19 procedures with consumers and/or guests.

Office Reopening

Centers should consider using a strategy that includes three phases for reopening offices. public health emergency cases and deaths should be closely monitored and be used when determining the appropriate reopening phase. Any phase may be repeated and/or be changed in accordance with public health activity in the community served by the CIL. Any change should be communicated fully with staff at least one week before the scheduled phase change.

During a public health emergency and with all phases, CIL staff members should all be required and expected to follow general hygiene safety which includes:

- Cough/sneeze into sleeve, preferably into elbow. Use a tissue and discard it properly. Clean/sanitize hands immediately.
- Avoid touching face, particularly eyes, nose, and mouth with hands to prevent infection.
- If coughing/sneezing on a regular basis, avoid close physical contact with coworkers and take extra precautionary measures, such as requesting sick leave or teleworkig.
- Wash hands after touching face, after using the restroom, and after touching any object that may not have been sanitized. Handwashing is recommended to be thorough (at least 20 seconds minimum with warm water and soap). Handwashing tips should be displayed in all restrooms.

Public Health Emergency Safety Practices for All Phases

Depending on Equal Employment Opportunity Commission (EEOC) guidance, a CIL may uniformly enforce temperature checks, social distancing, and depending on OSHA guidance respiratory protection. All personal protective measures may be adjusted when necessary, from a request for reasonable accommodation.

REOPENING: Phase One



During phase one, staff can begin returning to the office in shifts. However, teleworking is still strongly encouraged. If staff wish to return to work, they should be required to submit a request using a return to work form or other procedure so shifts can be established by management. This form or process should be clearly communicated to staff. Once established, a schedule for staff member returning to the office should be provided weekly or as updates are needed.

Staff who wish to work from the office must follow the below:

1. Temperature Testing

Staff should be required to self-administer temperature testing at each office when arriving for their shift. The temperature testing site should be marked with signage. Employees will check their temperatures on arrival. If temperature is at or above the maximum temperature accepted by the CDC's guidelines, employees must inform a supervisor as soon as possible. These employees must return home and await instructions.

Detailed procedure:

1. On arrival to the worksite, proceed to the temperature station.
2. Place gloves on hands before touching the thermometer. It is important that the thermometer not come in contact with the skin. Employees should request assistance from others if needed.
3. Note the temperature if needed. Only report the temperature if the thermometer reads at or above the maximum temperature accepted by the CDC's guidelines.
4. Wipe and clean the thermometer with an alcohol wipe that will be located at the station.
5. Remove gloves and dispose.
6. Use hand sanitizer.

All visitors including consumers, stakeholders, board members, volunteers, personal care attendants, etc. should have their temperature checked upon arrival by the designated staff member and asked to leave if their temperature is greater than the maximum temperature accepted by the CDC's guidelines. Staff members administering the temperature checks should wear masks, follow the above instructions, and use a touchless temporal thermometer. All individuals should be expected to be honest and comply with this procedure.

2. Social Distancing

CIL management should enforce social distancing policies. Staff should not be within the minimum distance dictated by close contact of any other individual. No shared workspace should be allowed during this phase. If the conference rooms are used, all chairs should be set up at least the minimum distance apart dictated by close contact. Staff should avoid physical contact with others (no handshakes, high fives, hugs, fist bumps, etc.).

3. Respiratory Protection

In the past, the use of masks has been acknowledged as a best practice by the CDC to prevent individuals from spreading a virus or disease to others. All CIL staff, volunteers, consumers, stakeholders, and guests should be required to wear masks while in the office in common areas. Staff may remove masks in their offices only if they are away from other individuals. Additionally, consider using clear masks while working in the office so that they are more accessible to individuals who are deaf or hard of hearing.

All non-staff who may be unable to wear a mask due to their disability should be allowed an exception from the mask requirement. Staff members unable to wear masks should submit a reasonable accommodation request.

4. Surface Sanitizing

All staff should be required to wipe down all touched surfaces (example: desks, phones, light switches, chair armrests, handles, door handles, etc.) with a sanitizing product at least daily. Wipes and/or cleaning disinfectants should be available throughout your CIL's offices, including the restrooms. If a small item cannot be thoroughly cleaned, your CIL should have UV LED Sanitizing boxes available.

Water cooler dispensers, refrigerator handles, coffee pots, Keurig's, and bathroom faucets all must be sanitized after each use. Water fountains should not be allowed to be used.

Community Work Safety

CIL staff should participate in all community meetings remotely during this phase. Any staff who are meeting the needs of individual consumers or responding to other emergencies will make every effort to serve individuals in a contact-free way.

In-Office Meetings

All in-person group consumer trainings and stakeholder meetings should be provided virtually. Consumers may visit the office by appointment only during Phase One to ensure that few people are in the office during this time. The front suite doors should be locked with a doorbell available for consumers/guests to ring at the time of their arrival.

Limiting Travel and Person-to-Person Contact

Given everything, your CIL will very likely be able to provide services to individuals and the community without interruption. This can be accomplished through an effort to communicate through phone, email, web-conferencing platforms, and more. These activities should continue as much as is possible throughout this phase.

When in-person interactions cannot otherwise be avoided, CIL staff should observe the following safety protocols given the activity types listed below:

Activity Type	Safety Protocol
Delivering supplies	<ul style="list-style-type: none"> • Use respiratory protection. • Use hand sanitizer after leaving the home. • Travel alone in your car. • Drop items, inform consumer, and try to conduct any conversations outside of the home.
Direct Consumer Assistance (in-office, in home, or community)	<ul style="list-style-type: none"> • Continue providing as many services as possible virtually or via telephone. <ul style="list-style-type: none"> <i>Before meeting with consumers, the staff working with them should ask a series of questions about their exposure to the public health emergency. These may include:</i> <ul style="list-style-type: none"> • Have you had a fever in the last week? • Do you have a cough? • Have you been in contact with someone who has been directly affected by the public health emergency or is suspected of being directly affected by the public health emergency in the past two weeks? <i>If the answer is yes to any of the above questions, services should only be provided virtually or via phone. CIL staff should also encourage and assist the consumer with seeking medical care.</i> • All staff must use gloves and respiratory protection. • Gloves must be disposed of immediately after consumer contact. • Practice social distancing. • Travel alone in your car. • Bring two copies of printed materials so the consumer can review one, and the staff can review the other without repeated paper passing. • Documents collected should go directly into a manila folder for holding according to document safety protocols. • Try to meet in a location where there is good air circulation (i.e. Outside or a location with good air quality).
Consumer trainings, community meetings, & CIL-led meetings	<ul style="list-style-type: none"> • Should continue virtually or via telephone.
School-based services	<ul style="list-style-type: none"> • Should follow the policy and procedures of the school, either virtual or in-person services. • Staff should be provided with appropriate PPE to ensure safety.

REOPENING: Phase Two



During phase two, all staff should begin working hybrid shifts, which means staff will work some from the office and some virtually (staff should work from the office at least 2 days per week). An office schedule including each staff member returning to the office should be established and updated as needed. The schedule must be structured to ensure social distancing between staff members.

Mass email alerts and social media posts should be issued when the CIL transitions into this phase. CIL staff should not publicize moving to this phase until approved by the appropriate official.

When working from the office, employees should follow the below

1. Temperature Testing

Staff are required to self-administer temperature testing once at the temperature testing site at each office. The temperature testing site will be marked with signage. CIL employees will check their temperatures on arrival. If an employee's temperature is at or above the maximum temperature accepted by the CDC's guidelines, they must inform a supervisor as soon as possible. They must return home and await further instructions.

Detailed procedure:

1. Upon arriving at the office, proceed to the temperature station.
2. The thermometer should not come in contact with your skin. Please request assistance from the front staff if needed.
3. Note the temperature if needed. Only need to report temperature if the thermometer meets or exceeds the maximum temperature accepted by the CDC's guidelines.
4. If a handheld thermometer is being used, wipe the thermometer with an alcohol wipe that will be located at the station before putting it back.
5. Use hand sanitizer.

All CIL visitors (consumers, stakeholders, board members, volunteers, personal care attendants, etc.) should have their temperature checked by the designated staff member and be asked to leave immediately if their temperature is greater than the maximum temperature accepted by the CDC's guidelines. Staff members administering the temperature checks should wear masks, follow the above instructions, and use a touchless temporal thermometer. All staff are expected to be honest and comply with this procedure.

2. Social Distancing

Staff should not be within 6-feet of any other individual. No shared workspace will be allowed during this phase. If the conference rooms are used, all chairs must be set up at least 6 feet apart. Avoid physical contact with others (no handshakes, high fives, hugs, fist bumps, etc.).

3. Respiratory Protection

In the past, the use of masks has been acknowledged as a best practice by the CDC to prevent individuals from spreading a virus or disease to others. All staff, volunteers, consumers, stakeholders, and guests should be required to wear masks while in the office in common areas. Staff may remove their masks in their offices only if they are away from other individuals. Staff working in cubicles must always wear their mask if their cubicle is in a common space. Additionally, all staff should be required to wear clear masks while working in the office so that they are more accessible.

All non-staff who may be unable to wear a mask due to their disability should be allowed an exception from the mask requirement, but virtual services should be preferred for this population. Staff members unable to wear masks should submit a reasonable accommodation request.

4. Surface Sanitizing

All staff should be prepared to wipe down all touched surfaces (example: desks, phones, light switches, chair arm rests, handles, door handles, etc.) with a sanitizing product at least daily. Wipes and/or cleaning disinfectants will be available throughout the offices. If small items cannot be thoroughly cleaned, the CIL can provide UV LED Sanitizing boxes.

Water cooler dispenser, refrigerator handles, coffee pots, Keurig's, and bathroom faucets all must be sanitized after each use. Water fountains should not be allowed to be used.

Community Work Safety

CIL staff should participate in all community meetings, both virtually and in-person; however, virtual participation is strongly encouraged. Any employees who are meeting the needs of individual consumers or responding to other emergencies should make every effort to serve individuals in a contact-free way.

In-Office Meetings

All attendees at in-office meetings and training should be required to practice social distancing. Consumer visits should be allowed with designated waiting options that follow social distancing.

Limiting Travel and Person-to-Person Contact

Given everything, a CIL will very likely be able to provide services to individuals and the community without interruption. This can be accomplished through an effort to communicate through phone, email, web-conferencing platforms, and more. These activities should continue as much as is possible throughout this phase.

CIL staff should observe the following safety protocols given the activity types listed below:

Activity Type	Safety Protocol
Delivering supplies	<ul style="list-style-type: none"> • Use hand sanitizer after leaving the location. • Drop items, inform consumer, and try to conduct any conversations outside of the home.
Direct Consumer Assistance	<ul style="list-style-type: none"> • In-person services are allowed with following all CIL Phase II procedures. • Continue providing services both virtually and via telephone unless the service needs to be one-on-one. • Practice Social distancing. <p><i>Before meeting with consumers, they should be asked a series of questions about their exposure to the public health emergency. These can include:</i></p> <ul style="list-style-type: none"> • <i>Have you had a fever in the last week?</i> • <i>Do you have a cough?</i> • <i>Have you been in contact with someone who has been directly affected by the public health emergency or is suspected of being directly affected by the public health emergency in the past two weeks?</i> <p><i>If the answer is yes to any of the above questions, services will only be provided virtually or via phone. CIL staff should also encourage and assist the consumer with seeking medical care.</i></p> • Staff should sanitize their hands after each visit.
Consumer trainings, community meetings & CIL-led meetings	<ul style="list-style-type: none"> • Hybrid meetings, trainings, and events can be offered virtually and/or in-person. If in-person meetings, trainings, and events are provided, then staff should follow all requirements listed in this phase. • Sanitize/wash hands after each meeting.
School-based services	<ul style="list-style-type: none"> • Should follow the policy and procedures of the school, either virtual or in-person services. • Staff should be provided with appropriate PPE to ensure safety.

REOPENING: Phase Three



During phase three, all staff are to return to work and carry out day to day duties while taking proper hygiene measures. During this phase, standard operating procedures are followed. Telework options should still be available as an accommodation.

In addition to practicing proper hygiene measures, all staff should follow the below procedures until otherwise communicated.

Surface Sanitizing

Staff should be prepared to wipe down all touched surfaces (example: desks, phones, light switches, chair arm rests, handles, door handles, etc.) with a sanitizing product and will then wash their hands. Wipes and/or cleaning disinfectant should be available throughout the offices. Water fountains will remain out of service.

Community Work

CIL staff should participate in all community meetings in-person and/or virtually as preferred. CIL staff should offer hybrid services so that consumers/stakeholders can decide to participate virtually or in-person.

CIL staff should observe the following safety protocols given the activity types listed below.

Activity Type	Safety Protocol
Delivering supplies	<ul style="list-style-type: none">• Deliver and assist the consumer with setting up the supplies.• Sanitize hands after each meeting.
Direct Consumer Assistance	<ul style="list-style-type: none">• Provide typical service delivery.• Sanitize hands after each visit.
Community Work	<ul style="list-style-type: none">• Conduct community work normally.• Sanitize hands after each meeting.
Consumer trainings, community meetings, & CIL-led meetings	<ul style="list-style-type: none">• Conduct activity as normal while practicing safe hygiene.• Sanitize/wash hands after each meeting.
School-based services	<ul style="list-style-type: none">• Should follow the policy and procedures of the school, either virtual or in-person education.• Staff should be provided with appropriate PPE to ensure safety.

References

The following resources were reviewed and considered when drafting this plan. Able South Carolina's plan is based on facts and science, and what is known so far about this virus.

Local, Federal and State Resources

Columbia Chamber of Commerce Reopening Playbook

Opening Up America Again

SC DHEC Guidance for Businesses

CDC Prevention Guidance

Regulatory Guidance: The ADA, The Rehab. Act, and more

EEOC What You Should Know

EEOC Pandemic Preparedness in the Workplace and the ADA

OSHA Guidance on Preparing Workplaces for COVID-19

Health Risk and Pandemic Spread

Discover Magazine Reporting on Viral Dose and Transmission

Case Study: Seoul South Korea Workplace

Case Study: Asymptomatic Carrier, Chicago IL

Incorporating Intersectionality and Health Equity

Intersectionality

Disability intersects with all populations. Intersectionality is a term coined by Kimberlé Crenshaw that describes how people can experience multiple oppressed identities that compound where they intersect. Many people face systemic oppression along the lines of race, class, sex, gender, sexual orientation, immigration status, ethnicity, religion, disability, and more. Many people face systemic oppression in multiple ways at the same time.

A person with a disability is often discriminated against in many settings. This oppression can compound if the person with the disability is also a person of color, a member of the LGBTQ+ community, a person whose first language is not English, or if they are working-class/poor.

It is important to consider intersectionality when addressing vaccine hesitancy because people with disabilities are often also members of other marginalized communities.



Health Equity

Many populations are marginalized and discriminated against on individual, community, and systemic levels. This discrimination includes healthcare settings. To better encourage self-advocacy for people with disabilities in accessing vaccines, CILs must consider that healthcare settings are not always equitable or accessible.

CILs can be more effective in getting people with disabilities vaccinated by using a health equity lens.

Your CIL can center health equity by:

- Considering that discrimination impacts health and healthcare access.
- Recognizing that information must be accessible in terms of both disability and culture.
- Avoiding implying that a person or community is at fault for their increased health risks or adverse health outcomes.
- Emphasizing that equal health access and opportunity benefits everyone

Inclusive Communication

To reach the most people with disabilities and encourage them to seek vaccination, CILs can make sure their communications are inclusive of all people and do not stigmatize or harm anyone.

CILs can use inclusive communication by:

Avoiding dehumanizing language, and instead using person-first language.

EXAMPLE:

Instead of “inmates,” say “people who are incarcerated.”

Remembering that there are many types of people and communities and being specific.

EXAMPLE:

Instead of “minorities,” say “people from sexual/gender/religious minority groups.”

Avoiding blame.

EXAMPLE:

Instead of “people who refuse to get vaccinated,” say “people who have not yet received their vaccine.”

Using terms preferred by members of certain communities.

EXAMPLE:

Instead of “transgenders,” say “transgender people.”

Avoiding assumptions about gender.

EXAMPLE:

Instead of “man/woman/lady/gentleman,” say “person.”

CILs can find more information about health equity from the CDC's [Health Equity Guiding Principles for Inclusive Communication](#).

Gender Inclusion

While centering the goal of helping people with disabilities get vaccinated, it is necessary to also be inclusive of people of all genders.

CILs should ALWAYS:

- Ask every person what name and pronouns they use
- Share your own name and pronouns
- Collect what information is necessary to serve the person
- Explain why you are collecting information
- Use the name and pronouns that people ask you to use
- Apologize quickly, self-correct, and move on if you use the wrong name or pronouns
- Be an ally to transgender people

You should NEVER:

- Only ask people who you think might be transgender what their name and pronouns are
- Use the wrong name or pronouns for anyone
- Ask invasive or irrelevant questions about birth names, genitalia, or gender-affirming surgeries
- Assume gender, pronouns, or what gendered language someone uses
- Make a big scene when you use the wrong pronouns
- Assume that there are only 2 genders

In addition, your CIL may be required to collect data on gender identity. Below are some examples of how to be respectful when asking about gender identity:

“My name is _____.
What name do you like
to be called?”

“My pronouns are _____.
What pronouns do you
use? Do you use she/her,
he/him, they/them, or
other pronouns?”

“What is your gender
identity? Are you a man,
a woman, non-binary, or
another gender?”

Keep in mind that gender identity is different than sex. Sex is biological, chromosomal, and hormonal, while gender identity is an individual’s self-conception of their relationship to manhood, womanhood, both, or neither.

Sample Internal Communications Plan

This appendix contains sample messages that can be used to establish a strong communications plan for Centers. This includes a sample message that outlines methods of communication at the onset of a public health emergency as well as messaging that can be used as the situation changes and evolves. CIL management should make edits and changes to these sample messages as needed and depending on the situation.

APPENDIX 5.1

Sample Message Establishing Communication Expectations

The goal of the internal communications plan is to ensure clear, efficient, and effective communication between all team members while they are working remotely. It is important to maintain a high standard of communication that is clear and helps to avoid confusion, is timely so that everyone is on the same page, and both respectful and considerate of everyone's time and personal boundaries.

Communication will take place across several platforms as we navigate the changes resulting from the public health emergency. Important messages including policy changes and official announcements will be delivered via email. This will include messages from the leadership team and your immediate supervisor.

For daily conversations, quick updates, and more informal communication, the organization will use Microsoft Teams. This is a free application that is available for computers, tablets and smart phones.

Regular team meetings, one-on-ones, and brainstorming sessions will be conducted via video conference, also using Microsoft Teams.

The CIL will use Google Drive in order to share and access documents. Please be mindful of file and folder organization and structure when accessing documents.

Your immediate supervisor will continue to meet with you on a regular basis. Additionally, team meetings will take place weekly. These meetings will also be held via video conference.

Finally, we will continue to hold monthly staff meetings on video conference. These meetings will be used to share success and challenges, provide timely updates, trainings, and provide an opportunity for everyone to come together.

Communication is not a one-way street. Leadership seeks to ensure we are listening as much as we are talking. With this in mind,

we will regularly seek your feedback on the effectiveness of our communications and areas where we can improve. We also encourage an open-door policy, inviting staff to share concerns, ideas, or suggestions about the communication process at any time. We will make it a point to review and update our communication plan periodically based on the feedback received and the changing needs of our team.

Above all, we aim to create a culture where open dialogue is encouraged, feedback is valued, and everyone's contributions are appreciated.

Sample Initial Internal Communication Regarding Public Health Emergency

The purpose of this message is to provide you with an update on how we plan to address the health and safety of our staff and consumers. The Centers for Disease Control and Prevention (CDC) continues to remind the American public that the immediate health risk from the public health emergency is considered low. However, with active cases and the population that we serve and represent, we must take serious precautions.

For that reason, leadership is asking you all to do the following:

- Identify your symptoms; compare your symptoms to the symptoms identified as being related to the public health emergency
- Stay home when you are sick and seek medical care.
- Stay home if a household member has been exposed to the virus.
- Wash hands regularly (20 seconds minimum with warm water and soap)
- Practice social distancing as much as possible (maintain distance from others).
- Schedule video calls/conference calls instead of in-person group meetings as much as possible. If in-person meetings are necessary, please arrange for conference calls/video to be an option. Internal team meetings can occur via video conferencing.
- Cover cough, tears and sneezes with tissues and then wash your hands.
- Increase regular cleaning of surfaces/items more likely to have frequent hand contact. Everyone should be wiping down their stations at least once a day (this includes desks, phones, keyboards, etc.).
- Conference tables, door handles, armrests of chairs should all be cleaned after being used.
- If you have consumers that are sick, please reschedule their appointments or provide the services over the phone. Assist consumers with identifying symptoms and seeking medical care.
- If you are traveling to a conference during this outbreak, please check local conditions before leaving and get with your supervisor to discuss any potential changes to your travel.

The CIL will provide the following:

- Hand sanitizer for all workstations.
- Cleaning wipes to wipe your office surface down daily and/or every time it's used by guests.
- Increase telework options. Staff members can work from home when they are sick, and as their position allows.
- Increased janitorial services in the office.

As this is an evolving situation, leadership will update you if the plan of action should change. As always, the health and happiness of our employees and those we serve continues to be the top priority.

APPENDIX 5.3

Sample Internal Communications Message – Cessation of In-Person Services

The Leadership Team continues to closely monitor the local impact of the public health emergency. As this situation is quickly changing, there is still so much we do not know. Right now, we are focusing on how we can best prepare and support our staff and the people we serve. Therefore, the purpose of this message is to provide an update and to be as transparent as possible.

At this time, we are closing the office to the public but will remain open for employees. All staff members have the option to telecommute and/or use paid or unpaid leave. Please develop a plan with your supervisor.

If you telecommute, you will need to do the following:

1. Develop a plan with your supervisor on the tasks you will perform at home;
2. Work your set number of hours on service delivery, special projects and/or grant deliverables;
3. Check in with the supervisor to discuss status and open issues;
4. Be available for teleconferences;
5. Check and respond to emails;
6. Check your voicemail remotely every 2 hours.

We are requiring that you do the following:

- Identify any illness; compare your symptoms to those symptoms identified in the public health emergency and be responsive.
- Stay home when you are sick and seek medical care as soon as possible.
- Stay home if a household member may have been exposed to the virus.
- Wash hands regularly (20 seconds minimum with warm water and soap).
- Practice social distancing as much as possible (maintain distance from others).
- Cover cough, tears and sneezes with tissues and then wash your hands.
- Increase regular cleaning of surfaces/items more likely to have frequent hand contact. Everyone should be wiping down their stations at least once a day (this includes desks, phones, keyboards, etc.).
- Sanitize conference tables, door handles, armrests after each use.
- Participate in outside meetings virtually (via phone/online platform). You will need your supervisor's approval prior to attending any outside meetings.
- Schedule consumer appointments remotely unless in-person meetings are necessary, and you have your supervisor's permission. The office will be closed to the public.
- All consumer trainings and peer support activities will be made virtual.
- All outside events requiring the public to attend will be postponed and/or made virtual.
- Reschedule all overnight travel. This means that all overnight conferences/trainings will be suspended.

The CIL will provide the following accommodations:

- Provide hand sanitizer in the office and workstations.
- Provide cleaning wipes to sanitize your office surface daily and/or every time it's used by another employee.
- Increase telework options. Staff members can work from home as their position allows. Staff still have the option of working at the office. Everyone should be prepared to work from home unexpectedly so please bring your laptops home every day. If you do not have a laptop, please get with your supervisor for an alternative plan.
- Increased janitorial services for both offices.

Thanks again for your continued support. We greatly appreciate you all!

APPENDIX 5.4

Sample Messaging Regarding Full Transition to Remote Work

Due to the ongoing public health emergency, all CIL offices are closed to employees, consumers, and the general public. Your safety continues to be the top priority of the leadership team. With this in mind, all employees are encouraged to shelter in place (at home). Employees have the option of working from home or taking paid /unpaid leave.

Please be aware that the Center will not be closing. The CIL will continue to offer programs and services in a virtual environment. People with disabilities need the services offered by the CIL more than ever during this difficult time. While changes may be made in how we are serving the community, the CIL will continue to be available to those in need.

With this in mind, the Center will provide employees with the tools and equipment needed to continue your work during this time. This includes access to computers, phone, voice mail, and other tools. Please work with your supervisor to ensure that you are able to access the tools and equipment needed for you to continue your work. We ask for your understanding and cooperation as we transition to this new way of serving the community.

Remember - as you work remotely, you must follow the below guidelines:

1. Develop a plan with your supervisor on the tasks you will perform at home;
2. Work your set number of hours on service delivery, special projects and/or grant deliverables;
3. Check in with the supervisor to discuss status and open issues;
4. Be available for teleconferences;
5. Check and respond to emails;
6. Check your voicemail remotely every 2 hours.

Please work with your supervisor to address and equipment or technology concerns you may have. They will need to take inventory of any equipment exiting our buildings so please make sure they are aware of your plan.

The leadership team will be issuing additional guidance as needed.

Thanks for your cooperation.

Sample Mask Policy

Many people with disabilities or other health conditions are at a higher risk of becoming very sick with COVID-19. Guidance from the Centers for Disease Control says that wearing masks is one of the best ways to prevent spreading COVID-19 to others. For that reason, the CIL will continue to take precautions to protect staff, volunteers, and the consumers that we serve.

All CIL staff, volunteers, consumers, and guests are required to wear masks while in the office in common areas.

If you need a mask, ask a staff member! We have the following types of masks and personal protective equipment (PPE) available in our office for consumers to use:

- Reusable cloth masks
- Disposable masks
- Clear masks
- Face shields

If you are not able to wear a mask due to your disability, we ask you to notify us prior to make sure we have prepared a meeting space that is safe for everyone.

If you refuse to wear a mask, you will be asked to leave for the safety of everyone. You will need to call or email to schedule an alternative way to meet.

There is always the option to meet virtually or outside while social distancing if needed. We will work with you to find a safe way to provide services.

Please contact our office with any questions or concerns. Thank you for helping to make the CIL a safe place for everyone!

In-Person and Community Activities

CIL staff have an obligation to keep themselves, consumers, and others they encounter safe when delivering services in-person in the community. While CIL staff can be required to report to meetings and activities in the community during a public health emergency in order to fulfill the essential functions and requirements of their job duties, it is vital for them to take precautions in order to protect themselves and others. The following procedures should be followed:

Prior to a Community Meeting or Activity

CIL employees should reach out to their main contact (teacher, administrator, VR Counselor, meeting organizer, etc.) to confirm the event is still happening before leaving to ensure that there were no changes, such as a switch to virtual.

Staff should be required to use a face mask, sanitization supplies, and bring extra masks as needed.

During the Meeting or Event

Social Distancing

CIL employees should follow these social distancing protocols as much as they can any time they are attending a meeting or event in the community.

Staff should try to maintain at least six feet of distance from others. This may be difficult because of the size of the room. Avoid physical contact with others (no handshakes, high fives, hugs, fist bumps, etc.). If contact with another individual occurs, staff should take precautions such as using hand sanitizer or washing hands to mitigate the risk of spreading the virus.

Respiratory Protection

The use of masks has been acknowledged as a best practice by the CDC to prevent individuals from spreading the virus to others. All CIL staff should be required to wear face masks when working in the community.

After a Community Meeting or Event

Testing

An emergency disease test should only be required for staff who show symptoms or have been informed of an exposure. They should not be allowed to return to the office or work in the community until they receive a negative test result back. Your CIL should supply employees with at-home test kits, and/or support efforts for them to make an appointment to get testing at a place of their choosing. CIL staff should be permitted to take 1 hour off work as covered time for disease testing. Testing comes in multiple forms, but all results are helpful to CIL staff who may be monitoring their health because of a possible exposure. Keep in mind that testing too soon after exposure or before symptoms begin can result in a false negative. Staff should consider consulting their doctor for additional support or if they are unsure when to test.

Those employees who may be showing symptoms and or awaiting test results should be required to work from home or to use sick leave until improvement or a negative test result is confirmed. Employees who work from home should make all of their in-person appointments virtual until a negative test result occurs.

Supply Sanitizing

Upon returning to the office from a community meeting or event, all supplies that were used should be wiped down with a sanitizing product. If a small item cannot be thoroughly cleaned, consider using a UV light sanitizing box.

In-Office Consumer Appointments and Meetings

When it is safe to do so, the Center will resume in-person consumer appointments and meetings while taking steps to ensure the safety of staff and visitors during the public health emergency. The following procedures should be followed:

Scheduling Appointments

Providing services remotely helps to ensure the safety and well-being of both staff and consumers. The CIL will continue to offer remote options for consumer appointments and meetings. However, as the impact of the public health emergency improves, the CIL will resume in-person activities. Precautions will be taken to reduce the risk of illness.

When scheduling consumer appointments CIL staff should offer both remote or in-person options for meeting. If the consumer chooses to meet in-person, staff should inform them that the Center requests they cancel the appointment if they are exhibiting symptoms or if they believe they were exposed to someone who may be infected with the virus. Additionally, let them know that someone from the CIL will call within 24 hours of the appointment to confirm and to ask about any symptoms or possible exposure. If there is a concern about illness or possible exposure the appointment should be rescheduled.

The questions to be asked include:

- Have you had a fever in the last week?
- Do you have a cough?
- Have you been in contact with someone directly affected by the public health emergency or is suspected of being directly affected by the public health emergency in the past two weeks?

When scheduling consumer appointments employees should take care to ensure they allow enough time for the meeting. Plan to leave at least 30 minutes between scheduled appointments in order to allow enough time and to reduce the number of individuals who might be waiting.

Office Logistics

Steps should be taken to manage the number of people in the office, traffic flow and consumer appointments and meetings in the office.

1 First, care should be taken to reduce the number of people who might be waiting in the lobby at the same time. Removing a few chairs and spreading out the remaining seats can help with this. Additionally, working with staff to limit the number of consumer appointments that can be scheduled at the same time can help. Finally, consider creating multiple waiting areas in the office.

2 Second, consider using separate entrances for entering and exiting the CIL if possible. All consumers should enter through the front doors into the lobby where they should remain until called for their appointment.

All consumers should exit the Center individually. Using a separate door for exiting is one way to reduce possible interaction between individuals. However, this may not be possible. Chairs should be placed near the exit doors spaced 6 feet apart so that consumers awaiting their ride can wait to be picked up. Staff should ensure all consumers use different hallway routes to maintain a 6-foot social distance when exiting.

- 3** **Third**, appointments should take place in a large conference or training room so social distancing can take place. The Center should also provide face coverings in the event a consumer does not have one with them.

After a Community Meeting or Event

If mandated by CDC or local guidance, consumers will be required to have their temperature checked when arriving at the CIL.

Employees should verify the consumer's temperature on arrival. If the temperature is at or above 100.4°, they must not be allowed to enter the office. The individual with the fever should be asked to wait outside while remaining socially distanced. The appointment should also be rescheduled.

Detailed temperature testing procedure:

1. On arrival staff will assist the consumer with taking their temperature using a touchless thermometer. The thermometer should not come in contact with the applicant's skin. Please request assistance from staff if needed.
2. If the thermometer reads 100.4° or higher, the consumer will not be allowed to proceed. The appointment will be rescheduled.

Social Distancing

Social distancing protocols should be followed throughout the duration of the appointment. CIL staff should communicate policies with all consumers. Staff and consumers should not be within 6-feet of each other. A large, unoccupied room should be used during in-person meeting time while chairs are at least 6 feet apart. Avoid physical contact with others (no handshakes, high fives, hugs, fist bumps, etc.).

Respiratory Protection

In the past, the use of masks has been acknowledged as a best practice by the CDC to prevent individuals from spreading a virus or disease to others. All CIL staff should be required to wear facemasks during the appointment. Consumers should be required to wear masks while in the CIL office. Face shields can be used by applicants who can't wear masks.

The room where assessments will be held should have an air purifier to give further protection.

Surface Sanitizing

All staff should be prepared to wipe down all touched surfaces (example: desks, phones, light switches, chair armrests, handles, door handles, etc.) with a sanitizing product at least daily. Wipes and/or cleaning disinfectants should be available throughout the office, including the restrooms. If a small item cannot be thoroughly cleaned, CILs should have UV LED Sanitizing boxes available.

Surface sanitizing should take place after each appointment and should include cleaning all touched surfaces and chairs.

COVID-19 Vaccine Frequently Asked Questions

Below are some frequently asked questions (FAQs) and their responses regarding vaccines that are available in the United States for emergency-level diseases. Although information specific to the emergency will likely change and be updated regularly during a public health emergency, these FAQs are a place to start to learn about vaccines, whether as a provider or a consumer.

A CIL can use these FAQs as a model to provide resources for both internal and public use.

Internally, these can be used to:

- Educate staff at all levels on emergency-level disease disability vaccine facts.
- Train staff on how to answer questions about vaccines from consumers, caregivers, and providers.
- Prepare staff to be better able to combat misinformation about vaccines.

Publicly, these FAQs can be used to:

- Create online resources for the public to access, including consumers, providers, and family members.
 - Example: [SCDisabilityVaccine.org](https://www.scdisabilityvaccine.org)
- Inform public messaging on social media and website content.

Vaccine Frequently Asked Questions from People with Disabilities

Virus & Vaccine Education

[Disease abbreviation] is the nickname for [real disease name]. [Disease abbreviation] is making people sick all over the world, including people in your community. People with disabilities and underlying medical conditions are at a higher risk of getting sick with [Disease abbreviation].

How do you get COVID-19? How does it make you sick?

- COVID-19 is spread through germs from people.
- These germs can be spread when someone who has COVID-19 coughs, sneezes, or when their germs get into the air or on things you touch.
- If you get COVID-19, it can make you feel sick and even make you go to the hospital.
- COVID-19 has made many people sick, especially people with disabilities and health conditions.
- Some of the things that happen when you have COVID-19 are:
 - Have a cough
 - Have a hard time breathing
 - Run a fever
 - Feel achy and tired

I have a disability. Why am I at a higher risk of getting sick and dying from COVID-19?

The Centers for Disease Control and Prevention (CDC) says people with 1 or more medical conditions are 1.5 times more likely to die from COVID-19 (Source 1 - Centers for Disease Control and Prevention, 2021). People with disabilities may have a higher risk of getting very sick or dying if they get COVID-19 because:

- The type of disability you have can make you very sick if you get COVID-19.
- Your disability might mean you have a weaker immune system.
- COVID-19 can make the symptoms you already have get worse.
- If you have a breathing disability, getting COVID-19 can make it a lot harder to breathe.
- You may have limited mobility or cannot avoid coming into close contact with others who may be infected, such as direct support providers and family members.
- You may have a hard time understanding information about COVID-19.
- You may have difficulty washing your hands and staying at least 6 feet away from others to protect yourself from COVID-19.
- You may not be able to communicate or explain how you are feeling.
- Social factors may increase your risk of serious illness from COVID-19.

What social reasons put me at risk because of my disability?

Many other reasons may put you at an increased risk, such as where you live, lack of access to medical care, costs of medical care, or the type of disability you have. Please see below for some examples:

Where you live

- You might live far away from COVID-19 vaccination centers, testing sites, doctor's offices, and other medical help.
- If you live in a care facility, you are more than twice as likely to die from COVID-19 and more than four times as likely to get COVID-19 than people with disabilities who do not live in a care facility.
- You may live in an area that does not have public transportation and/or do not have your own transportation.
- If you live far away from your doctor, you might not get help until much later.

Your type of disability, where you live, access to care, and cost are all things that might keep you away from the doctor or a free testing site.

- If you can't get tested, you don't know if you have COVID-19.
- If you don't know if you have COVID-19, you can accidentally give COVID-19 to other people.
- If you don't know you have COVID-19, you might get very sick before getting help.
- You might not want to go to the doctor. If you don't go to the doctor, you might not learn you are sick until much later, when you could be much sicker and have a hard time getting better.

Access to Medical Care

People with disabilities are at higher risk because going to the doctor and getting care can be more challenging. Below are some of the reasons why going to the doctor can be harder for people with disabilities.

- You may not have been able to get to medical exams because the doctor's office is not accessible.
- You may not have received proper care because the devices or medical table were not accessible.
- You may have felt like the nurses, doctors, or other medical staff had a negative attitude toward your disability.
- You may have had a hard time understanding what your doctor or medical staff were telling you.
- You may have felt your disability was ignored.
- You may have felt that the doctor or medical staff didn't understand your disability.
- You may have gone to the doctor before and felt they didn't know how to care for you.
- You may have felt that you did not get the treatment you needed.

Costs

- You might not have health insurance.
- Without insurance, you might be less likely to go to the doctor or hospital because of the cost.
- You may have other costs like childcare, transportation, parking, or missing work that might make it harder to get to a free COVID-19 testing or vaccination site.

It is important that people with disabilities who are at high risk get the COVID-19 vaccine as soon as they can.

How do I protect myself from getting COVID-19?

- Wash your hands with soap and water or use hand sanitizer.
- Stay away from large groups of people.
- Wear a face mask when you are around other people.
- Get a COVID-19 vaccine.

Vaccines: What is a vaccine?

What is a COVID-19 vaccine?

A vaccine is a type of shot with medicine. The medicine in a COVID-19 vaccine fights the virus and helps protect you from getting sick.

Why are people getting a vaccine?

People get a vaccine to make it easier for their body to fight COVID-19.

What COVID-19 vaccines are available in the United States?

In the United States, the vaccines that have been approved are:

- Pfizer BioNTech
- Moderna
- Johnson & Johnson (J&J)
- Novavax

The **Pfizer BioNTech COVID-19 vaccine** is recommended by the Centers for Disease Control for people 6 months and older (Source 44 - Centers for Disease Control, 2022).

The **Moderna COVID-19 vaccine** is recommended by the Centers for Disease Control for people ages 6 months and older (Source 44 - Centers for Disease Control, 2022).

J&J has been approved under an Emergency Use Authorization (EUA) for individuals 18 and older.*

Novavax has been approved under an Emergency Use Authorization (EUA) for people ages 12 and older (Source 49- FDA, 2022, Source 55- Centers for Disease Control, 2022, Source 57- Centers for Disease Control, 2022).

The COVID-19 vaccines are safe and effective; they have been evaluated in tens of thousands of participants in clinical trials (Source 48 - Centers for Disease Control, 2022).

Vaccines are available to people ages 6 months and older.

Children ages 6 months to 17 years:

- Pfizer BioNTech
- Moderna
- Children ages 12-17
- Novavax COVID-19 vaccine

Adults ages 18 and older

- Pfizer BioNTech COVID-19 vaccine and booster(s)
- Moderna COVID-19 vaccine and booster(s)
- Johnson & Johnson COVID-19 vaccine and booster
- Novavax COVID-19 vaccine

*You will find the most updated information about the J&J vaccine at [Johnson & Johnson's Janssen COVID-19 Vaccine](#).

What is Emergency Use Authorization?

An Emergency Use Authorization (EUA) happens when supplies or medicine like a vaccine are needed quickly in an emergency. The spread of the COVID-19 pandemic is an example of an emergency.

- In an emergency, the Food and Drug Administration (FDA) has the power to approve a vaccine quickly.
- In an emergency, the supplies or medicine will help prevent a specific disease like COVID-19.
- This does not mean that important steps were skipped in making the vaccines safe.

Is it true that the vaccine has the virus in it?

No, none of the COVID-19 vaccines approved in the United States contain the live virus. All three vaccines give your immune system the tools it needs to attack the COVID-19 virus. Each vaccine does this in different ways.

What is a Viral Vector vaccine, and how does it work?

J&J's vaccine is a viral vector vaccine.

- When making viral vector vaccines, scientists use a harmless virus to carry information to the body
- The body makes a harmless piece of protein, and your immune system then makes antibodies in response.
- This teaches your body how to protect you against future infections.
- The harmless virus and the protein it makes cannot make you sick.
- After the J&J vaccine, your immune system can make antibodies to protect against COVID-19 infection.
- You are not injected with the COVID-19 virus.

Is the J&J Vaccine Safe?

Scientists recommend Moderna and Pfizer's mRNA COVID-19 vaccines and boosters over Johnson & Johnson's COVID-19 vaccine and booster. An mRNA type of COVID-19 vaccine and booster is your safest option, unless your doctor says you should not have an mRNA vaccine.

Johnson and Johnson's COVID-19 vaccine and boosters will remain available:

- If you had a severe reaction after an mRNA vaccine dose
- If you have a severe allergy to an ingredient of Pfizer or Moderna (mRNA COVID-19 vaccines)
- If Pfizer or Moderna vaccines are not available to you
- If you want to get the J&J COVID-19 vaccine, even though scientists recommend Pfizer or Moderna

What is a protein subunit vaccine, and how does it work?

Novavax is a protein subunit vaccine.

- When making protein subunit vaccines, scientists only use parts of the virus that do the best job of getting your immune system going.
- This type of vaccine contains S proteins that are harmless.
- When your body recognizes the proteins, in response, your immune system makes antibodies and white blood cells (Source 50 - Mayo Clinic, 2022).
- This type of vaccine has been used for many years. Examples include flu, Hepatitis B, and Whooping Cough vaccines (Source 51 - Centers for Disease Control 2022).
- This type of vaccine is different from the mRNA and Viral Vector vaccines because it contains something called an adjuvant (Source 52 - Yale Medicine).
- An adjuvant is an ingredient used to increase your immune system's response. They have been used for many years in a variety of vaccines and are very safe (Source 53 - Centers for Disease Control, 2022).

What is an mRNA vaccine, and how does it work?

Moderna and Pfizer are messenger RNA (mRNA) vaccines.

- These vaccines deliver a tiny piece of safe genetic material from the virus to cells in the body.
- This material gives instructions for making copies of something called spike proteins.
- Spike proteins stimulate an immune response and produce antibodies.
- If your body is infected with the virus, your cells will remember and plan how to respond (Source 3 - Katella, 2021).
- After the spike protein is made, our body breaks down the mRNA and removes it.
- mRNA vaccines do not and can't change or interact with your DNA.
- mRNA vaccines do not go to where DNA is located in our bodies (Source 4 - Centers for Disease Control and Prevention, 2021).
- Even though this type of vaccine is new, research and development on it have been going on for over 50 years (Source 5 - Dolgin, 2021).
- The vaccines went through the same development and steps as other vaccines. The COVID-19 vaccines were developed quickly to save lives.

Why is the COVID-19 vaccine important for people with disabilities?

People with disabilities may have a higher risk of getting very sick or dying if they get COVID-19. This is because of many possible reasons listed below:

- The type of disability you have can make you very sick if you get COVID-19.
- Your disability might mean you have a weaker immune system.
- COVID-19 can make the symptoms you already have get worse.
- If you have a breathing disability, getting COVID-19 can make it a lot harder to breathe.
- You may have limited mobility or cannot avoid coming into close contact with others who may be infected, such as direct support providers and family members.
- You may have a hard time understanding information about COVID-19.
- You may have a hard time washing your hands and staying at least 6 feet away from others to protect yourself from COVID-19.
- You may not be able to communicate or explain how you are feeling.
- Social reasons may increase your risk of serious illness from COVID-19.

People with disabilities at high risk must get the COVID-19 vaccine as soon as possible (Source 6 - International Disability Alliance, 2020).

COVID-19 is dangerous. The vaccine is not. The effects of COVID-19 are worse than the vaccine's side effects.

You should talk to your doctor if you think you may have a high risk of getting very sick from COVID-19.

What if I'm allergic to other vaccines?

You should still consider getting the COVID-19 vaccine even if you have allergies to other vaccines. If you have had an allergic reaction to other vaccines, talk with your doctor as the COVID-19 vaccine may be very different.

Pfizer & Moderna COVID-19 Vaccines (mRNA) (Source 7 - Warren et al., 2021)

- Studies show that most allergic reactions to the Pfizer and Moderna vaccines are related to an ingredient used in the vaccine called Polyethylene Glycol (PEG).
- Most allergic reactions are to PEG, not the mRNA.

Johnson & Johnson (J&J) COVID-19 Vaccines (Source 8 – Centers for Disease Control and Prevention, 2021)

- For Johnson and Johnson, the ingredient that causes the most allergic reactions is Polysorbate.

Novavax COVID-19 Vaccines

- Polysorbate is also an ingredient in the Novavax COVID-19 vaccine (Source 54 - Melbourne Vaccine Education Centre).

PEG and Polysorbate are common ingredients in vaccines. PEG is a common ingredient in Gatorade or Miralax. Both of these ingredients have been known to cause allergic reactions in some people. Most people are not allergic to PEG or Polysorbate.

If you know you are allergic to one ingredient in the vaccines, ask your doctor if another vaccine would be better for you. You may still be able to get the vaccine because there are different kinds of vaccines (Source 8 – Centers for Disease Control and Prevention, 2021).

You should still get the vaccine if you have other non-medical allergies, such as allergies to some foods, animals, or environments (Source 8 – Centers for Disease Control and Prevention, 2021).

If you are worried about allergies, you should ask your doctor if it is safe to get the COVID-19 vaccine.

What are booster shots? What does it mean to be up-to-date on my COVID-19 vaccine?

- COVID-19 booster shots are doses of a COVID-19 vaccine that will make sure your first round of vaccine is strong for a longer amount of time.
- It is common for vaccines to get weaker over time.
- This could mean you're less protected against virus variants. These variants can be easier to get and spread than the original virus.
- COVID-19 vaccines are working well to prevent severe sickness, keep you out of the hospital, and prevent death. Getting your COVID-19 vaccine can help keep you safe from Long COVID as well (Source 58 - Centers for Disease Control and Prevention, 2022).
- Even though vaccines work, we are starting to see less protection against getting sick (Source 13 – Centers for Disease Control and Prevention, 2022). Booster shots add the protection you need. Getting your vaccine and booster shots at the prescribed time will help you stay up-to-date on your COVID-19 vaccine.
- People with disabilities are at increased risk of getting very sick or dying from COVID-19. Getting booster shots can help protect you better.
- Many vaccines that you had in the past include booster shots. You get booster shots after your first chickenpox, tetanus, mumps and measles, and other vaccines.

What is the difference between bivalent and monovalent shots?

- A monovalent vaccine has ingredients that fight one strain of a virus. The COVID-19 monovalent vaccines and boosters were made to fight the original COVID-19 virus (Source 60 - Food and Drug Administration, 2022).
- A bivalent vaccine has ingredients that fight two strains of a virus (Source 59 - Food and Drug Administration, 2022). The original COVID-19 vaccines were monovalent. The updated COVID-19 vaccine boosters contain mRNA from
 - The original SARS-CoV-2 virus
 - A strain of the Omicron variant to fight against BA.4 and BA.5. (Source 60 - Food and Drug Administration, 2022).

Why is a bivalent booster important?

- The updated boosters will provide more protection against the COVID-19 virus. They provide more protection because they have two mRNA strains that teach your body how to fight the virus. Scientists use mRNA from the original COVID-19 virus. The mRNA from the original COVID-19 virus increases the

protection you get from your first vaccines. They add mRNA that fights the BA.4 and BA.5 variants. The BA.4 and BA.5 variants are making most people sick right now. Scientists expect these variants will continue infecting people into the fall and winter of 2022 (Source 59 - Food and Drug Administration, 2022).

Does the bivalent booster have different side effects?

- Side effects from the bivalent boosters are similar to the side effects from the original monovalent vaccines.
- Most side effects are redness and swelling where you got your vaccine. You may also have fatigue, headache, fever, and joint pain (Source 59 - Food and Drug Administration, 2022).

Will the monovalent vaccines and boosters still be used?

- The monovalent vaccines will still be used for your primary series of COVID-19 vaccines.
- The Pfizer monovalent booster will still be used for children ages 5 to 11.
- The monovalent booster will no longer be used for people 12 years of age and older (Source 58 - Food and Drug Administration, 2022).

Who should get a booster shot?

People 5 years and older should get at least 1 booster shot after completing their COVID-19 vaccine primary series.* Your primary vaccine series is either one shot of J&J or 2 shots of Moderna, Pfizer, or Novavax vaccines.

- *People ages 5 to 11 that got the Moderna vaccine for your primary vaccine series are not eligible for a booster shot (Source 60 - Centers for Disease Control and Prevention, 2022).

You should get the new bivalent booster shot if you (Source 60 -Centers for Disease Control and Prevention, 2022):

- Are 12 years or older.
- It has been 2 months or longer since you had your last dose.

You should get the monovalent booster shot if you (Source 60 -Centers for Disease Control and Prevention, 2022):

- Are between the ages of 5 and 11
- Got the Pfizer vaccine for your primary vaccine series
- It has been at least 5 months since your 2nd dose

Which booster shot(s) should I get?

Children and Youth ages 5 to 17 (Source 60 -Centers for Disease Control and Prevention, 2022):

- Children 5 years old and older should get a single booster shot.
 - If you are 5 to 11 years old and got the Pfizer vaccine for your primary vaccine series, you can get the Pfizer monovalent booster shot.
 - If you are 12 to 17 years old, you can get the Pfizer bivalent booster shot.
 - If you are under 12 and got the Moderna vaccine for your primary vaccine series, you should not get a booster shot.
- What if my child already got 1 monovalent booster shot?
 - If it has been 2 months or longer since their last shot, and they are at least 12 years old, then your child is eligible to get the bivalent booster.
- What if my child has a weakened immune system and already got 2 monovalent booster shots?
 - If it has been 2 months or longer since their last shot, and they are at least 12 years old, then your child is eligible to get the bivalent booster.

People ages 18 and older (Source 60 -Centers for Disease Control and Prevention, 2022):

- If you are 18 or older, you can get the bivalent booster if it has been 2 months or longer since:
 - You finished your primary vaccine series
 - You got a booster shot

- There are 2 bivalent boosters, one is Pfizer, and the other is Moderna.
 - It does not matter which brand you get.
 - For your primary vaccine series, your options are Pfizer, Moderna, J&J, or Novavax.
- I already got the monovalent booster shot. Can I still get a bivalent booster?
 - If it has been at least 2 months since your last booster shot, you can get the Bivalent booster.
- I already got 2 doses of the monovalent booster shot. Can I still get a bivalent booster?
 - If you are 50 years old or older or have a moderately or severely compromised immune system, you may have already gotten 2 monovalent booster shots.
 - As long as it has been at least 2 months since your last booster, you are eligible for the new bivalent booster.

Note: If you had to get a certain vaccine because you are allergic to one of the ingredients in other COVID-19 vaccines, then talk to your doctor about booster options (Source 13 – Centers for Disease Control, 2022).

When should I get my booster shots?

When you should get your booster shot depends on your age and when you finished your primary vaccine series or got your last dose (Source 61 -Centers for Disease Control and Prevention, 2022).

- Children ages 5 to 11 years old, who got the Pfizer vaccine, can get the Pfizer monovalent booster 5 months after finishing their primary vaccine series.
- People 12 years old and older can get the bivalent booster 2 months after finishing your primary vaccine series or getting your last booster.

If you have had an allergic reaction to a COVID-19 vaccine ingredient in the past, then your doctor may tell you to not get that vaccine.

- If you have been instructed not to get one type of COVID-19 vaccine, you may still be able to get another type.
- Talk to your doctor to find out which COVID-19 vaccine booster is best for you.

Booster shots add the protection you need. Getting your vaccine and booster shots at the prescribed time will help you stay up-to-date on your COVID-19 vaccine.

What is the difference between booster shots and additional doses for people with disabilities?

A booster shot is given months after your primary vaccine series of the COVID-19 vaccine because you become less protected against getting sick over time (Source 17 – Centers for Disease Control and Prevention, 2021).

An additional dose is different from a booster shot. If your disability causes a weakened immune system, you may need a third dose in your primary mRNA vaccine series. Additional doses can make your immune system's response to the COVID-19 vaccine better (Source 18 – Centers for Disease Control and Prevention, 2021).

The additional dose is available for people 5 years and older with weakened immune systems. Talk to your doctor or trusted medical professional to learn if an additional dose is right for you.

People over 5 years old with weakened immune systems should get (Source 18 - Centers for Disease Control and Prevention, 2022):

Primary Vaccine Series:

- | | |
|---|---|
| <ul style="list-style-type: none"> • Pfizer for ages 5 years and up <ul style="list-style-type: none"> • Dose 1 • Dose 2 • Dose 3 ("additional dose") • Moderna for ages 5 years and up <ul style="list-style-type: none"> • Dose 1 • Dose 2 • Dose 3 ("additional dose") | <ul style="list-style-type: none"> • J&J for ages 18 and up <ul style="list-style-type: none"> • Dose 1 • Dose 2 • Novavax for ages 12 and up: <ul style="list-style-type: none"> • Dose 1 • Dose 2 |
|---|---|

Booster Shots:

- Pfizer monovalent booster shot
 - 1 shot for children ages 5 to 11 who received the Pfizer primary vaccine series
- Pfizer bivalent booster shot
 - 1 shot for people 12 years old and older who got Pfizer, Moderna, J&J, or Novavax for their primary vaccine series.
- Moderna bivalent booster shot
 - 1 shot for people 12 years old and older who got Pfizer, Moderna, J&J, or Novavax for their primary vaccine series.

Why should I ask my family members, friends, and care providers to get the COVID-19 vaccine?

Sometimes the type of help you need can put you at a higher risk of getting COVID-19. For example, you might be at more risk of getting COVID-19 if you have one of the following:

- You must come in close contact with others who help you, such as direct care providers, personal caregivers, teachers, and family members. People near you could have COVID-19 and spread it to you.
- You have trouble understanding information or practicing safety skills, such as hand washing, wearing a mask, and social distancing
- You are not able to communicate when you are feeling sick.

To help keep you healthy, your family, teachers, personal caregivers, direct care providers, and others who support you should get the COVID-19 vaccine.

COVID-19 Vaccination & Booster Timeline

Primary Vaccine Series

Pfizer Vaccine (mRNA)

For Ages 6 months to 4 years:

- 3 total shots
- First 2 shots given 3 to 8 weeks apart**
- Third shot is given 8 weeks after 2nd shot

For Ages 5 and Up:

- First 2 shots given 3 to 8 weeks apart**

Moderna Vaccine (mRNA)

For Ages 6 Months and Up:

- First 2 shots given 4 to 8 weeks apart**

J&J Vaccine (viral vector)*

For Ages 18 and Up:

- One dose primary vaccine:
- 1 shot

Novavax (protein subunit)

For Ages 12 and Up:

- 2 total shots given 3 to 8 weeks apart**

Booster Shots

For Ages 5 to 11 who got the Pfizer vaccine:

- You should get a booster shot 5 months after your 2nd dose.
 - This booster shot can only be Pfizer.
 - Children under 12 who got the Moderna vaccine do not qualify for boosters

For Ages 12 and up (NEW updated booster):

- You should get the updated booster, 2 months after your last primary vaccine shot OR booster shot. You do not have to have any additional booster shots to get the updated booster.
 - Children 12 to 17: This booster shot can only be Pfizer.
 - People 18 and older: This booster shot can be Pfizer or Moderna

*For Ages 50 and up who got the J&J vaccine:

- You should get the Pfizer or Moderna booster shot 2 months after your 1st shot.
- You should get the NEW Updated Booster 2 months after your 2nd shot. This booster shot can be Pfizer or Moderna.

**A longer time between the 1st and 2nd shot may give you more protection and minimize rare side effects. Talk to your doctor about the timing for the 2nd dose in your primary series.

Talk to your doctor about which booster shot is right for you and the best time to get yours (Source 56 - Centers for Disease Control, 2022).

Addressing Safety & Trust

Safety

I have a disability, and I'm nervous about the vaccine. How do I know it's safe and works for me?

COVID-19 vaccines are the best way to protect yourself from getting very sick or dying from COVID-19. The effects of COVID-19 can be much worse for a person with a disability than any of the side effects from the vaccine.

People with disabilities are often much safer if they get the vaccine. The vaccines do not give you COVID-19.

Getting COVID-19 is much worse than any vaccine side effects.

Let's learn about normal side effects that you may have from getting vaccinated and why the COVID-19 vaccine is safe for everyone, including people with disabilities.

Are there side effects from the shot?

Some people might experience side effects from the shot, and others will not.

- Side effects might include pain, redness, or swelling where you received the shot.
- Other side effects that you might have are:
 - fever
 - pain
 - chills
 - headache
 - nausea

If you have any of these side effects, it can mean the vaccine is working. Your body is learning to protect itself against COVID-19. Side effects should go away after a few days. If you are worried about any side effects that you have, you should contact your doctor.

When you get your COVID-19 vaccine, you can sign up for V-Safe. V-Safe is an after-vaccine health checker app available for smartphones (Source 14 - Centers for Disease Control and Prevention, 2021).

I worry about how the vaccines will impact my disability and health condition. Why should I get vaccinated?

Without the COVID-19 vaccine, you are at the most significant risk of getting very sick, going to the hospital, and dying.

People with disabilities may have a higher risk of getting very sick or dying if they get COVID-19 (Source 15 - Centers for Disease Control and Prevention, 2021). This is because of many possible reasons listed below:

- The type of disability you have can make you very sick if you get COVID-19.
- Your disability might mean you have a weaker immune system.
- COVID-19 can make the symptoms you already have get worse.
- If you have a breathing disability, getting COVID-19 can make it a lot harder to breathe.

I heard the vaccines give you the COVID-19 virus. Is that true?

No. None of the COVID-19 vaccines approved in the United States contain the live virus. The vaccines approved in the United States are the Pfizer vaccine, Moderna vaccine, Novavax vaccine, and the Johnson & Johnson (J&J) vaccine. The shots do not use the live virus. They can't make you sick with COVID-19 (Source 16 - Centers for Disease Control and Prevention, 2021).

Why should I bother getting vaccinated if I can still get COVID-19?

In most cases, the COVID-19 shot will prevent you from becoming sick and going to the hospital if you test positive for the virus.

- Most of the people who are in the hospital with COVID-19 have not been fully vaccinated. This means they have not received all of the recommended doses of the shot.
- You can still catch the virus from someone after you get the shot. This is called a breakthrough infection.
- If you got the shot and still get COVID-19, you will most likely have mild symptoms. The vaccine helps you not get as sick as you could if you were not vaccinated.
- Getting vaccinated is your best chance at protecting yourself from getting very sick, going to the hospital, or dying from COVID-19 (Source 17 - Centers for Disease Control and Prevention, 2021).

I've already had COVID-19, so why should I get the vaccine?

It is possible to become sick with COVID-19 more than once. Scientists learned getting the shot may better protect you from COVID-19 (Source 18 - Centers for Disease Control and Prevention, 2021).

- After getting sick with COVID-19, you may have “natural immunity.”
- Natural immunity from COVID-19 happens when your body produces antibodies to fight off COVID-19 after you have been exposed to or gotten sick with the virus.
- This natural immunity does not last very long.
- Natural immunity may not protect you from COVID-19 variants (Source 13 - Centers for Disease Control and Prevention, 2021).
- Consider getting your COVID-19 vaccine to protect yourself and your community

Trust

I don't trust the information I'm getting about vaccines. Why should I trust the vaccine now?

Your doctor may have told you to wait to get vaccinated. We know COVID-19 vaccines are safe for many people with disabilities.

Some people are still worried about trusting the vaccine, especially if they have a disability. Let's talk about common questions about vaccine trust:

I heard the vaccine was made quickly. Why should I trust it?

The three COVID-19 vaccines available in the U.S. (Pfizer, Moderna, and Johnson & Johnson) were developed in response to the global COVID-19 pandemic. A pandemic is a widespread sickness that affects the whole world.

- Research that led to these types of vaccines has been going on for over 50 years.
- The COVID-19 vaccine went through the same steps as other vaccines.
- The COVID-19 vaccines were just made quickly to save lives.
- COVID-19 vaccines were made thanks to funding and scientists around the world working together (Source 16 - Centers for Disease Control and Prevention, 2021).
- The COVID-19 vaccines are safe and are proven to work for people with disabilities (Source 19 - Centers for Disease Control and Prevention, 2021).
- People with disabilities are at greater risk for getting sick and dying from COVID-19 due to their medical conditions, group living settings, or issues in the health and social systems that are not fair or equal (Source 19 - Centers for Disease Control and Prevention, 2021).
- Consider getting vaccinated to protect yourself and your community

Why should I trust the vaccine is safe for me?

Due to past and present discrimination, people with disabilities might not trust medical companies or politicians who encourage vaccination. Even though you may not trust medical companies or politicians, COVID-19 vaccines protect the disability community. (Source 20 - Centers for Disease Control and Prevention, 2021).

- You might be afraid to get the vaccine because of information that isn't true.
- You may have experienced trauma from the medical care you've received. Trauma can include serious physical or emotional harm.
- You may be worried because information about your disability may not be included in what you've learned about the vaccination.
- Maybe you're worried because the scientists keep changing the information.
- Maybe you have read one thing about COVID-19, but a new thing you've read says something different.
- Maybe the information is not shared in a way that you can understand.

It can be hard to know what's right or wrong. Here are the facts about the COVID-19 vaccine:

- Evidence shows these vaccines are safe for people without and with disabilities (Source 20 - Centers for Disease Control and Prevention, 2021).
- The vaccines help slow the spread of COVID-19 and lower the chances of getting very sick or dying from COVID-19.
- Many independent groups, including those led by doctors of color, have done their work to test the vaccines. They say the vaccines work and are safe (Source 21 - National Medical Association, 2020).
- Many government officials, including all living U.S. presidents and current governors, got COVID-19 vaccines (Source 22 - Link, 2021).

How does knowing someone who has already gotten their shot, and is doing well, encourage me to get the vaccine?

The COVID-19 vaccine has been available since 2020. This means you probably know one or more people who have gotten it and are doing well. This is good news for a few reasons

- If you are nervous, it gives you someone to talk to about how it went for them.
- Any common side effects they had will give you an idea of what might happen when you get the shot.
- If they are a person with a disability, they can share how they found an accessible vaccine site.
- Hearing about another person's experience might help to give you confidence.
- You might not know that you know someone who's gotten the shot, but don't be afraid to ask around.
- Having friends and family you know you can trust to talk about it goes a long way to help you feel more confident about getting the shot.

Protecting Yourself & Others

Variant Facts:

What is a COVID-19 variant?

A COVID-19 variant is a version of the COVID-19 virus that's just a little different from the version before it. Some of the most common differences are that COVID-19 variants can spread faster and more easily and can also make you sicker. For example, the Alpha variant spread just a little faster than the original version of the COVID-19 virus (Source 23 - Centers for Disease Control and Prevention, 2021).

Two of the variants that you might hear a lot about are the Delta and Omicron variants. That is because both

of these variants spread easily and can make you very sick.

Variants of viruses are common, and the CDC tells us these variants were expected. People with disabilities are at a higher risk of getting COVID-19 and they are also at higher risk of getting COVID-19 variants.

As a person with a disability, how can I protect myself from COVID-19 variants?

The best way for people with disabilities to protect themselves from COVID-19 variants is by getting a vaccine. A vaccine may not stop you from getting sick, but it will help lower the risk that you will get very sick and go to the hospital with a COVID-19 variant.

If you have already gotten your vaccine, getting a booster shot is another way you can help protect yourself from COVID-19 variants. This makes your immune system stronger to fight the virus.

Wearing a mask also lowers your risk of getting COVID-19 and all of the COVID-19 variants (Source 23 - Centers for Disease Control and Prevention, 2021).

Talk to your doctor, or another medical provider you trust, about which COVID-19 vaccine is the best for you. You should also make sure to wear masks anytime you're inside in a public place and wash your hands often.

I'm concerned about the vaccine for people in my life. How does it impact children, older adults, or pregnant people, including those with disabilities?

Can children get the vaccine?

Yes, children can get the vaccine, including children with disabilities (Source 31 - Centers for Disease Control and Prevention, 2021).

Vaccines are available to people ages 6 months and older:

- Children ages 6 months to 17 years
 - Pfizer BioNTech COVID-19 vaccine
 - Moderna COVID-19 vaccine
- Children ages 12 to 17 years
 - Novavax COVID-19 vaccine

A vaccine booster shot is recommended for people 5 years old and older, unless you are under the age of 12 and received the Moderna vaccine for your primary vaccine series.

- If you are 5 to 11 years old and received the Pfizer vaccine for your primary vaccine series, you can get the Pfizer monovalent booster shot.
- If you are 12 to 17 years old, you can get the Pfizer bivalent booster shot.

The Johnson & Johnson and Novavax COVID-19 vaccines are not authorized for people under 18 years of age.

- Adults ages 18 and older
 - Pfizer BioNTech COVID-19 vaccine and booster(s)
 - Moderna COVID-19 vaccine and booster(s)
 - Johnson & Johnson COVID-19 vaccine and booster
 - Novavax COVID-19 vaccine
- Food and Drug Administration research shows that the Pfizer BioNTech vaccine caused an immune response in ages 6 months to 4 years of age comparable to that of older adults (Source 47 - Food & Drug Administration, 2022).
- Research also shows that the immune response for the Moderna vaccine in children was comparable to the immune response to that of adults (Source 47 - Food & Drug Administration, 2022).

- At this time, the vaccine has not caused any severe side effects in children. Those side effects reported have been mild and are usually more common with the second shot (Source 46 - Centers for Disease Control, 2022)
- Without vaccination, children risk having serious long-term or lifelong health effects from COVID-19, hospitalization, or death. This risk is greater for children with disabilities. The CDC recommends vaccination as soon as possible to protect all young children from COVID 19 (Source 46 - Centers for Disease Control, 2022).
- Children who get the vaccine are less likely to miss school due to COVID-19 because they are less likely to get sick (Source 32 - Centers for Disease Control and Prevention, 2021).
- Vaccination slows the spread of COVID-19. Slowing the spread of COVID-19 will help protect everyone, especially children with disabilities (Source 34 - Centers for Disease Control and Prevention, 2021).
- Parents and caregivers can schedule their children for the vaccination via vaccine.gov
 - If you have a child with a disability who needs a reasonable accommodation to get the vaccine, please make sure to tell the vaccine provider when you schedule the child's appointment.
- A reasonable accommodation could be a quiet room or the ability to have a trusted person present (Source 32 - Centers for Disease Control and Prevention, 2021).

Can someone be too old to get vaccinated?

No. If you are older than 6 months old, you can get a COVID-19 vaccine (Source 24 - Centers for Disease Control and Prevention, 2021).

Should older adults get vaccinated against COVID-19?

Yes. People 65 years of age and older are at higher risk of becoming very sick and dying from COVID-19. The vaccines are 94% effective at protecting older adults from severe sickness and death (Source 27 - Centers for Disease Control and Prevention, 2021 and Source 28 - Administration for Community Living, 2021).

Should people living in nursing or group homes get vaccinated?

Yes, people living in group care facilities—such as nursing or group homes—should especially get vaccinated against COVID-19. A lot of people have died from COVID-19 who were living in a group home or nursing home. It is hard to protect yourself if you live with people and new staff are coming in and out of your home. People ages 65 and older and those with disabilities are at higher risk of having to go to the hospital for help or dying from COVID-19. For individuals who are living in facilities, the risk of catching the virus is higher. Statistics show that over a third of all COVID-related deaths were of people who lived in facilities (Source 29 - United States Department of Justice, 2021, Source 30 - New York Times, 2021, Source 31 - Administration for Community Living, 2021).

I'm thinking about having kids. I heard the COVID-19 vaccine can make me unable to have children. Is this true?

No. There is no evidence that any vaccines, including COVID-19, cause fertility problems or becoming pregnant in people with or without disabilities.

- Many people have become pregnant and had healthy births after getting their vaccine, including people with disabilities.
- Some people that received vaccines during the COVID-19 vaccine clinical trials became pregnant and had healthy babies.
- Antibodies made after vaccination will not cause problems with fertility or becoming pregnant.
- Vaccine ingredients do not cause problems with fertility or getting pregnant (Source 32 - Centers for Disease Control and Prevention, 2021).

If I'm pregnant or breastfeeding, should I get vaccinated?

Yes. The CDC recommends all people ages 6 months and older get the vaccine. This includes people who are pregnant and disabled people who are pregnant.

- Someone pregnant has a higher chance of getting very sick from COVID-19.
- Someone who is pregnant and gets COVID-19 has a higher chance of going to the hospital than someone who is not pregnant (Source 33 – Society for Maternal-Fetal Medicine, 2021)
- COVID-19 is more dangerous for pregnant people with disabilities (Source 34 – Satin & Sheffield, 2021).

If you are pregnant or breastfeeding and a person with a disability, you can likely get a COVID-19 vaccine. Here is the good news:

- COVID-19 vaccines are safe for both the pregnant person and baby before birth, including those with disabilities.
- People who receive the mRNA COVID-19 vaccines when pregnant build antibodies that may protect the baby from COVID-19.
- People who are breastfeeding and vaccinated can pass good protective antibodies to their baby through their breast milk. This may protect the baby from COVID-19 (Source 35 – Centers for Disease Control and Prevention, 2021).

Don't let barriers stop you from getting vaccinated

Transportation

I don't have a car or don't drive. How am I supposed to get a vaccine?

Local CILs can add local transportation information here, additionally, if you are providing transportation assistance, share information here.

Accessibility

I'm worried I won't be able to access the vaccine site due to my disability.

What accessibility accommodations can I ask for as a person with a disability?

Because of the Americans with Disabilities Act, or ADA, people with disabilities are guaranteed certain accommodations when getting their COVID-19 vaccine (Source 39 - Americans with Disabilities Act, 1990). These accommodations include:

- Vaccine sites that are accessible to people with physical disabilities.
- Access to American Sign Language (ASL) interpreters.
- Vaccine materials that include accessible formats, including:
 - Braille
 - Large print
 - Digital
 - Plain language/easy read

If you have a local disability advocacy resource, you can share that information here.

What are my rights to access vaccines?

People with disabilities have many laws that protect their rights. These rights mean that people cannot treat you badly just because of who you are as a person with a disability. You have the same rights to vaccines as people without disabilities.

The Americans with Disabilities Act (ADA) states that you cannot be treated unfairly because you have a disability. The ADA requires public and state agencies to provide accommodations, so people with disabilities have the same access to services as people without disabilities. The ADA also requires that agencies make sure that these accommodations are available for people with disabilities to get information in a way that meets their needs. This includes any type of equipment to provide services and accessible technology like websites (Source 39 - Americans with Disabilities Act, 1990).

Section 508 of the Rehabilitation Act is a national law that states that federal agencies have to provide information in a way accessible to everyone with disabilities. If you need information differently because of your disability, federal agencies have to provide this (Source 41 - Rehabilitation Act, 1973).

Section 504 of the Rehabilitation Act of 1973 is a national law that protects people with disabilities from being treated unfairly because of their disability. This law applies to organizations that get financial assistance from any Federal department or agency. This includes many hospitals, nursing homes, mental health centers, and human service programs (Source 40 - Rehabilitation Act, 1973).

Section 1557 of the Affordable Care Act states that you cannot be treated unfairly because of your race, color, national origin, age, disability, or sex. This includes making sure language assistance is available for people who speak limited English and making sure there are accommodations for people with disabilities to have access to services (Source 42 - Patient Protection and Affordable Care Act, 2010)

References

Source 1:

Centers for Disease Control and Prevention. (2021, October 14). Disability & Health U.S. State Profile Data for South Carolina (Adults 18+ years of age). Centers for Disease Control and Prevention. Retrieved November 18, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 2:

U.S. Food and Drug Administration. (2021, October 20). Covid-19 vaccines. Retrieved October 26, 2021, from <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines>

Source 3:

Katella, K. (2021, October 22). Comparing the COVID-19 Vaccines: How Are They Different? Yale Medicine. Retrieved on October 26, 2021, from <https://www.yalemedicine.org/news/covid-19-vaccine-comparison>

Source 4:

Centers for Disease Control and Prevention. (2021, October 18). Understanding mRNA COVID-19 vaccines. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 5:

Dolgin, E. (2021, September 14). The tangled history of mRNA vaccines. Nature. Retrieved October 26, 2021, from <https://www.nature.com/articles/d41586-021-02483-w>

Source 6:

International Disability Alliance. (2020, December 1). Reach the furthest behind first: Persons with disabilities must be prioritized in accessing COVID-19 vaccinations. IDA. Retrieved November 8, 2021, from https://www.internationaldisabilityalliance.org/sites/default/files/ida_recommendations_on_accessing_covid-19_vaccinations_final_01.12.20.pdf

Source 7:

Warren, C. M., Snow, T. T., & Lee, A. S. (2021, September 17). Assessment of Allergic and Anaphylactic Reactions to mRNA COVID-19 Vaccines With Confirmatory Testing in a US Regional Health System. JAMA Network, 4(9). <https://doi.org/10.1001/jamanetworkopen.2021.25524>

Source 8:

Centers for Disease Control and Prevention. (2021, March 25). COVID-19 Vaccines for People with Allergies. CDC. Retrieved November 8, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 9:

Centers for Disease Control and Prevention. (2021, October 21). Who Is Eligible for a COVID-19 Vaccine Booster Shot? CDC. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 10:

US Food and Drug Administration. (2021, October 20). Coronavirus (COVID-19) Update: FDA Takes Additional Actions on the Use of a Booster Dose for COVID-19 Vaccines. FDA. Retrieved October 26, 2021, from <https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-takes-additional-actions-use-booster-dose-covid-19-vaccines>

Source 11:

Centers for Disease Control and Prevention. (2021, December 16). CDC Endorses ACIP's Updated COVID-19 Vaccine Recommendations. Retrieved December 17, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 12:

Centers for Disease Control and Prevention. (2021, October 1). COVID-19 Vaccination Considerations for Persons with Underlying Medical Conditions. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 13:

Centers for Disease Control and Prevention. (2021, October 18). COVID-19 Vaccines for Moderately to Severely Immunocompromised People. Retrieved October 29, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 14:

Centers for Disease Control and Prevention. (2021, August 9). Register for V-safe. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 15:

Centers for Disease Control and Prevention. (2021, October 14). People with certain medical conditions. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 16:

Centers for Disease Control and Prevention. (2021, Oct 4). Myths and Facts about COVID-19 Vaccines. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 17:

Centers for Disease Control and Prevention. (2021, Aug 16). COVID-19 Vaccine Effectiveness. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 18:

Centers for Disease Control and Prevention. (2021, Sep 24). Immunity Types. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 19:

Centers for Disease Control and Prevention. (2021, June 21). People with disabilities. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from <https://www.cdc.gov/ncbddd/humandevlopment/covid-19/people-with-disabilities.html>

Source 20:

Centers for Disease Control and Prevention. (2021, September 15). Finding Credible Vaccine Information. Centers for Disease Control and Prevention. Retrieved November 18, 2021, from <https://www.cdc.gov/vaccines/vac-gen/evalwebs.htm>

Source 21:

National Medical Association. (2020, December 21). Advisory Statement on Federal Drug Administration's Emergency Use Authorization Approval for Pfizer and Moderna Vaccine. NMA COVID-19 Task Force on Vaccines and Therapeutics. Retrieved October 26, 2021, from <https://www.nmanet.org/news/544970/NMA-COVID-19-Task-Force-on-Vaccines-and-Therapeutics.htm>

Source 22:

Link, D. (2021, September 3). Fact check: 'who's vaccinated?' all living presidents, governors; not most covid-19 victims. USA Today. Retrieved October 26, 2021, from <https://www.usatoday.com/story/news/factcheck/2021/09/02/fact-check-viral-post-vaccinated-politicians-doctors-little-off/5670809001/>

Source 23:

Centers for Disease Control and Prevention. (2021, December 1). What You Need to Know About Variants. Centers for Disease Control and Prevention. Retrieved December 3, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 24:

Centers for Disease Control and Prevention. (2021, Oct 21). COVID-19 Vaccines for Children and Teens. Retrieved October 26, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 25:

Centers for Disease Control and Prevention. (2021, November 2). CDC Recommends Pediatric COVID-19 Vaccine for Children 5 to 11 Years. CDC. Retrieved November 8, 2021, from <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

Source 26:

U.S. Food and Drug Administration. (2021, October 29). FDA Authorizes Pfizer-BioNTech COVID-19 Vaccine for Emergency Use in Children 5 through 11 Years of Age. FDA. Retrieved November 8, 2021, from <https://www.fda.gov/news-events/press-announcements/fda-authorizes-pfizer-biontech-covid-19-vaccine-emergency-use-children-5-through-11-years-age>

Source 27:

Centers for Disease Control and Prevention. (2021, August 2). COVID-19 Risks and Vaccine Information for Older Adults. Centers for Disease Control and Prevention. Retrieved November 19, 2021, from https://www.cdc.gov/coronavirus/2019-ncov/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2Findex.html

Source 28:

Administration for Community Living. (2021, November 11). Strategies for Helping Older Adults and People with Disabilities Access COVID-19 Vaccines. Administration for Community Living. Retrieved November 19, 2021, from https://acl.gov/sites/default/files/2021-04/ACLStrategiesVaccineAccess_Final.pdf

Source 29:

United States Department of Justice. (2021, April 2). Statement by the Principal Deputy Assistant Attorney General for Civil Rights Leading a Coordinated Civil Rights Response to Coronavirus (COVID-19). United States Department of Justice. Retrieved November 19, 2021, from <https://www.justice.gov/opa/pr/statement-principal-deputy-assistant-attorney-general-civil-rights-leading-coordinated-civil>

Source 30:

New York Times. (2021, June 1). Nearly One-Third of U.S. Coronavirus Deaths Are Linked to Nursing Homes. New York Times. Retrieved November 19, 2021, from <https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html>

Source 31:

Administration for Community Living. (2021, November 11). Strategies for Helping Older Adults and People with Disabilities Access COVID-19 Vaccines. Administration for Community Living. Retrieved November 19, 2021, from https://acl.gov/sites/default/files/2021-04/ACLStrategiesVaccineAccess_Final.pdf

Source 32:

Centers for Disease Control and Prevention. (2021, August 11). COVID-19 Vaccines for People Who Would Like to Have a Baby. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/planning-for-pregnancy.html>

Source 33:

Society for Maternal Fetal Medicine. (2021, July 29). COVID-19 Vaccination if You Are Pregnant or Breastfeeding. Retrieved October 26, 2021, from https://s3.amazonaws.com/cdn.smfm.org/media/3040/COVID_vaccine__Patients_JULY_29_2021_final.pdf

Source 34:

Satin, A., & Sheffield, J. (2021, August 23). The COVID-19 vaccine and Pregnancy: What You Need to Know. Johns Hopkins Medicine. Retrieved November 8, 2021, from <https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/the-covid19-vaccine-and-pregnancy-what-you-need-to-know>

Source 35:

Centers for Disease Control and Prevention. (2021, October 19). Vaccination Considerations for People Pregnant or Breastfeeding. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/pregnancy.html>

Source 36:

Centers for Disease Control and Prevention. (2021, September 13). Guidance for Direct Service Providers. Retrieved November 4, 2021. <https://www.cdc.gov/ncbddd/humandevelopment/covid-19/guidance-for-direct-service-providers.html>

Source 37:

Centers for Disease Control and Prevention. (2021, May 24). Covid-19 vaccines are free to the public. Centers for Disease Control and Prevention. Retrieved October 26, 2021, from <https://www.hhs.gov/coronavirus/covid-19-vaccines/index.html>

Source 38:

U.S. Department of Health and Human Services. (2021, September 15). Covid-19 care for uninsured individuals. HHS.gov. Retrieved October 26, 2021, from <https://www.hhs.gov/coronavirus/covid-19-care-uninsured-individuals/index.html>

Source 39:

Americans with Disabilities Act, 42 U.S.C. § 12101 (1990). <https://www.ada.gov/pubs/adastatute08.htm>

Source 40:

Rehabilitation Act, 29 U.S.C. § 701 (1973). [https://uscode.house.gov/view.xhtml?req=\(title:29%20section:701%20edition:prelim\)](https://uscode.house.gov/view.xhtml?req=(title:29%20section:701%20edition:prelim))

Source 41:

Civil Rights Act of 1964, 42 U.S.C. § 1971 (1964). <https://uscode.house.gov/view.xhtml?req=granuleid:USC-1999-title42-section1971&num=0&edition=1999>

Source 42:

Patient Protection and Affordable Care Act, 124 Stat. 119 (2010). <https://www.govinfo.gov/content/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>

Source 43:

CDC Endorses ACIP's Updated COVID-19 Vaccine Recommendations (2021, December 16). <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

Source 44:

Center for Disease Control (2022) "COVID-19 Vaccine Recommendations for Children and Teens" <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

Source 45:

Yahoo News (2022) "What Parents Should Know What Parents Should Know" <https://news.yahoo.com/covid-vaccine-kids-under-5-220303088.html?guccounter=1>

Source 46:

Center for Disease Control (2022) "6 Things to Know about COVID-19 Vaccination for Children" <https://www.cdc.gov/vaccines/covid-19/planning/children/6-things-to-know.html>

Source 47:

Food & Drug Administration (2022) "Coronavirus (COVID-19) Update: FDA Authorizes Moderna and Pfizer-BioNTech COVID-19 Vaccines for Children Down to 6 Months of Age" <https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-moderna-and-pfizer-biontech-covid-19-vaccines-children>

Source 48:

Centers for Disease Control (2022) "Safety of COVID-19 Vaccines" <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/safety/safety-of-vaccines.html>

Source 49:

Food & Drug Administration. (2022, July 20). Coronavirus (COVID-19) Update: FDA Authorizes Emergency Use of Novavax COVID-19 Vaccine, Adjuvanted. <https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-emergency-use-novavax-covid-19-vaccine-adjuvanted>

Source 50:

Mayo Clinic. (2022, July 20). Different types of COVID-19 vaccines: How they work. <https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/different-types-of-covid-19-vaccines/art-20506465>

Source 51:

Centers for Disease Control. (2022, July 20). CDC Recommends Novavax's COVID-19 Vaccine for Adults. <https://www.cdc.gov/media/releases/2022/s0719-covid-novavax-vaccine.html>

Source 52:

Yale Medicine. (2022, July 20). Comparing the COVID-19 Vaccines: How Are They Different? <https://www.yalemedicine.org/news/covid-19-vaccine-comparison>

Source 53:

Centers for Disease Control. (2022, July 20). Adjuvants and Vaccines. <https://www.cdc.gov/vaccinesafety/concerns/adjuvants.html>

Source 54:

Melbourne Vaccine Education Centre. (2022, July 20) COVID-19 vaccine FAQs: allergies, pre-existing conditions, and children. <https://www.fda.gov>

Source 55:

Centers for Disease Control. (2022, July 20) Novavax COVID-19, Adjuvanted Vaccine: Overview and Safety. <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

Source 56:

Centers for Disease Control. (2022, July 20). Staying Up to Date with Your COVID-19 Vaccines. <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/stay-up-to-date.html>

Source 57:

Centers for Disease Control and Prevention. (2022, August 22). CDC Recommends Novavax COVID-19 Vaccine for Adolescents. Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/media/releases/2022/s0822-novax-vaccine.html>

Source 58:

Centers for Disease Control and Prevention. (2022, July 11). Patient Tips: Healthcare Provider Appointments for Post-COVID Conditions. Centers for Disease Control and Prevention. Retrieved June 8, 2022 from <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-covid-appointment/index.htm>

Source 59:

Food and Drug Administration (2022) "COVID-19 Bivalent Vaccine Boosters. Retrieved September 1, 2022, from <https://www.cdc.gov>

Source 60:

Food and Drug Administration (2022), FDA News Release: "Coronavirus (COVID-19) Update: FDA Authorizes Moderna, Pfizer-BioNTech Bivalent COVID-19 Vaccines as a Booster." August 31, 2022. Retrieved September 1, 2022 from <https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-moderna-pfizer-biontech-bivalent-covid-19-vaccines-use>

Source 61:

Centers for Disease Control and Prevention. (2022, September 8). Stay Up to Date with COVID-19 Vaccines Including Boosters. Retrieved September 8, 2022 from <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/stay-up-to-date.html>

