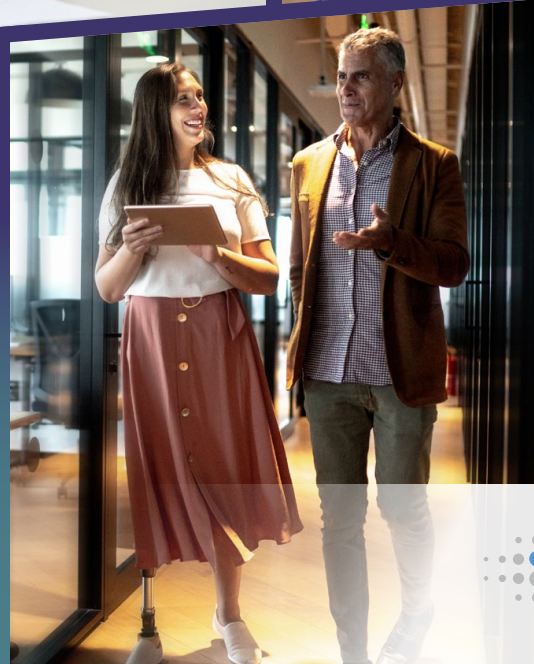# Partnership Guide for Centers for Independent Living and State and Local Health Departments

Considerations and resources to promote collaboration between centers for independent living and state and local health departments to better support the health and wellbeing of people with disabilities.

CDC Foundation
Together our impact is greater

Table of Contents

Acronyms

- ACL – Administration for Community Living

- ADA – Americans with Disabilities Act

- ASTHO – Association of State and Territorial Health Officials

- CDC - Centers for Disease Control and Prevention

- CDC Foundation - National Foundation for the Centers for Disease Control and Prevention, Inc.

- CIL - Center for Independent Living

- ILRU - Independent Living Research Utilization at the Texas Institute for Rehabilitation and Research (TIRR) Memorial Hermann

- LHD – Local Health Department

- NACCHO - National Association of County and City Health Officials

- SHD – State Health Department

- SILC - Statewide Independent Living Council

- SLHDs - State and Local Health Departments

- SPIL - State Plan for Independent Living

Executive Summary

Public health emergencies like COVID-19 have highlighted the importance of collaboration across numerous sectors, organizations and disciplines to address the needs of all people, including people with disabilities. Centers for Independent Living (CILs) and state and local health departments (SLHDs), including tribal and territorial health departments, both support the health of people with disabilities living in their jurisdictions in different ways. Effective collaboration and information sharing between CILs and SLHDs is crucial to ensure that people with disabilities receive adequate, effective, timely, accessible and culturally appropriate services and support.

Partnership Guide Purpose and Methods

The purpose of this guide is to promote collaboration between CILs and SLHDs to support the health and wellbeing of people with disabilities by providing information and tools that will support effective partnerships.

This partnership guide was created through the *Leveraging CILs to Increase Vaccines for People with Disabilities* project. The project was launched in September 2021 with an aim to increase COVID-19 vaccine access for people with disabilities in the United States. This project was led by the CDC Foundation in partnership with Able South Carolina and Independent Living Research Utilization. Through this project, six focus group discussions were conducted with 19 SLHDs by NACCHO and an additional 16 sessions were conducted by the Michigan Public Health Institute with 33 CILs and two SLHDs to provide feedback and guidance on content.

The partnership guide begins with an introduction, which provides information about ensuring equity for people with disabilities and describes the need for effective partnership among CILs and SLHDs to address the needs of people with disabilities. The guide contains two distinct modules for two different audiences. Although there will be some overlapping information, Module One is designed for use by CILs, and Module Two is designed for use by SLHDs. Throughout both modules there are examples of successful collaborations between CILs and SLHDs. Finally, the Resources section provides numerous resources for CILs and SLHDs to foster effective partnerships.

Introduction

Disability, Social Determinants of Health and Inclusivity

Definition of Disability

One in four adults in the United States has some type of disability, making people with disabilities the largest minority population in the country and the largest minority population in the world, estimated at one billion people (CDC, 2023; United Nations, n.d.-a).

There are many ways to define and conceptualize disability. As stated by the World Health Organization, "disability is part of being human. Almost everyone will temporarily or permanently experience disability at some point in their life…Disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings and limited social support" (World Health Organization, n.d.).

The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities in a variety of areas including employment, communications and access to state and local government programs and services and has an expansive definition of disability (U.S. Department of Labor, n.d.-a). The ADA defines disability as "a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment" (U.S. Department of Justice Civil Rights Division, 2022). This broad definition does not specify disabilities covered by the ADA and ensures that protections from discrimination under US law are extended to people who have previously had a disability but no longer do and people who are seen by others as having a disability. Section 504 of the Federal Rehabilitation Act of 1973 additionally ensures that people with disabilities have equal access to programs and activities receiving federal financial assistance such as State and local government entities (U.S. Department of Labor, n.d.-b).

As defined by the Centers for Disease Control and Prevention (CDC), "a disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)" (CDC, 2020b). For the purposes of this guide, this definition of disability will be used, but it's important to note that several definitions of disability exist. Despite the definition used, the materials and resources outlined in this document can be applied to enhance collaborations between CILs and SLHDs. There are many different types of disabilities that can occur across the lifespan that can affect a person's:

- **Vision**
- **Movement**
- **Thinking**
- **Remembering**
- **Learning**
- **Communicating**
- **Hearing**
- **Mental health**
- **Social relationships**

DISABILITY TYPES
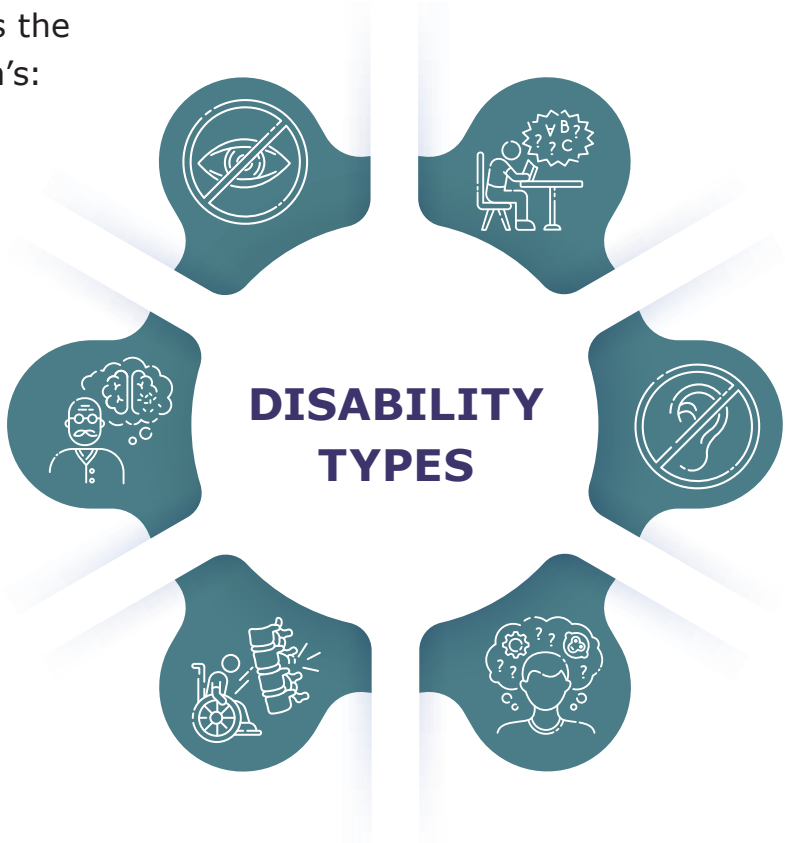
Disabilities can be related to conditions that are present at birth (CDC, 2020b). Disabilities can also be related to injury, longstanding medical conditions (some of which can cause physical disabilities as they progress) or developmental conditions, such as autism spectrum disorder.

Disability Prevalence

An estimated 61 million adults living in the United States have a disability, representing nearly 26% of the adult population; the percentage of people living with a disability is the highest in the South. The percentage of adults with a functional disability or difficulty in performing everyday activities or more complex tasks, is (Okoro, 2018):

- **13.7% - Mobility:** Serious difficulty walking or climbing stairs

- **10.8% - Cognition:** Serious difficulty concentrating, remembering or making decisions

- **6.8% - Independent Living:** Difficulty doing errands alone

- **5.9% - Hearing:** Deafness or serious difficulty hearing

- **4.6% - Vision:** Blindness or serious difficulty seeing

- **3.7% - Self-care:** Difficulty dressing or bathing

Figure 1. Images of people with disabilities. Some of the disabilities are visible and some are not visible.

People with disabilities often have lower incomes than people without disabilities and are more likely to be unemployed (American Psychological Association, 2010). People with disabilities face numerous barriers to accessing healthcare. One in four people with disabilities does not have a usual healthcare provider and has an unmet healthcare need because of cost in the past year (CDC, 2023).

Every social, racial, age, gender and ethnic group includes people with disabilities. However, the prevalence of disability varies across racial and ethnic groups. According to a 2017 article based on data from the 2007–2010 Behavioral Risk Factor Surveillance System, one in 10 people who identify as Asian has a disability while one in four people who identify as Black, one in five people who identify as White and one in six people who identify as Latino or Native Hawaiian/Pacific Islander have a disability (CDC, 2019b). American Indian/Alaska Native people are the most likely

to have a disability (three in 10) (CDC, 2019b). The prevalence of disability also varies by gender. Women across the world are more likely to have a disability than men (World Health Organization, 2011). Gay, Lesbian, Bisexual, Transgender and Queer (LGBTQ+) people are more likely to have a disability than people who are not LGBTQ+ (Pharr & Batra, 2021; Fredriksen-Goldsen et al., 2012).

The lived experiences of people with disabilities are diverse. Some disabilities are not always obvious and may not be visible. People with the same type of disability can be affected in very different ways and have different needs (CDC, 2020b). Health conditions can also affect people differently over time, meaning that their disability could affect their daily life more on some days than others. For example, a chronic condition could cause pain that makes it difficult for someone to walk one day but cause less severe pain the next day. A disability could cause pain or discomfort to one person but be inconsequential to another. For these reasons, it's important that public health programs and services aimed to serve people with disabilities be tailored to the specific community of focus and include people with disabilities as collaborators, as they know best how their disability affects them and what they need.

Medical and Social Models of Disability

Traditionally, disability has been framed by the "medical model of disability" (Olkin, 2022). This model frames disability as a structural or functional impairment within the individual person. The person with a disability is the focus of intervention by health care professionals to correct something that is not "normal" rather than focus on changing external factors that may keep the person with disabilities from fully participating in activities of daily life (Gill, 1987).

The social model of disability, instead, defines disability not only by "the physical qualities of an individual but also by the corresponding response of the social environment." For example, a person in a wheelchair is not able to go to a restaurant because there is no curb cut on the sidewalk or there is not a ramp to access the elevated front door. In this case, the social model would focus on interventions to remove these barriers, rather than seeing the person's wheelchair as the limitation. Within this model, interventions to support people with disabilities are not solely provided by health professionals to individuals but can also be provided by peer support, political activism, self-help, environmental modification and barrier removal.

The social model also helps to focus on the commonality of lived experiences of people with disabilities across different types of disabilities. This includes viewing people with disabilities as a social group that, while very diverse, can have shared experiences of discrimination, identity, culture and resilience.

Approaching public health interventions and advocacy for people with disabilities through a social model of disability often requires cross-sector and specialty collaboration between health departments, organizations serving people with disabilities and advocates to address the complex social, environmental and medical barriers that people with disabilities face.

The Importance of Disability Inclusion

Discrimination, Stigma and Structural Barriers

People with disabilities are often stereotyped and incorrectly assumed to have a low quality of life, be unhealthy or to be a burden to others and society (CDC, 2019a). As a result of negative stereotypes and prejudice, people with disabilities are often discriminated against. This can take the form of active exclusion from employment, housing and education. Discrimination can also be interpersonal, where people are excluded from social groups or are the targets of violence. People with disabilities report a higher level of violence than people without disabilities and those with visible disabilities or who were perceived to have more significant disabilities are reported to experience higher levels of discrimination and violence than those without a disability (Dammeyer & Chapman, 2018). Women with disabilities are more likely to face discrimination and experience intimate partner violence more often than women without disabilities (Dammeyer & Chapman, 2018).

While people with disabilities often experience active discrimination from overt bias, some experience implicit or unconscious bias from others. Studies have shown that preference for people without disabilities is strong even among people who have disabilities themselves (Nosek et al., 2007). In a study of over 3,500 lawyers with disabilities, 38.5% reported perceptions or experiences of subtle but unintentional biases in the workplace (Blanck et al., 2020). People who identify as a member of multiple minority and marginalized groups may face additional challenges and social marginalization. Whether the result of overt exclusion or systemic inequities, people

with disabilities can experience many barriers to full societal participation. These can include (CDC, 2019a):

Attitudinal barriers (e.g. stereotyping and discrimination due to one's disability)

Communication barriers (e.g., people who are Deaf and use American Sign Language to communicate will not be able to access health information if it is not available in American Sign Language)

Physical barriers (e.g., steps that prevent a person with a wheelchair or mobility impairment from entering a building)

Policy barriers (e.g., denying people with disabilities from participating in a public service through legislation or company policies)

Programmatic barriers (e.g., lack of accessible equipment)

Social barriers (e.g., difficulty seeking employment because of job requirements)

Transportation barriers (e.g., lack of access to accessible or convenient public transportation for people who are not able to drive because of mobility, vision or cognitive disabilities)

People with disabilities have a right to the same opportunities to access all aspects of life as people without disabilities. Barriers to inclusion must be addressed in collaboration with people with disabilities themselves.

How Disability Relates to Health Outcomes

People with disabilities often experience poor health outcomes due to a variety of factors including underlying medical conditions or systemic health and social inequalities (CDC, 2022a). Unequal access to or inaccessible education about

screening and preventative treatments can lead to negative health outcomes. For example, people with disabilities are less likely than people without disabilities to receive mammograms within the recommended time frame to screen for breast cancer (Courtney-Long et al., 2011). Other factors, such as the increased rate of smoking among people with disabilities than people without disabilities, affect individuals' health (Courtney-Long et al., 2014). Adults with disabilities are more likely than adults without disabilities to have certain health conditions such as stroke, heart disease, cancer and diabetes (CDC, 2020c). Moreover, poor health outcomes among people with disabilities are even more pronounced among racial and ethnic minorities who often face additional barriers and discrimination.

Disability Culture and Identity

Disability is not simply a health outcome but is a description of a person's way of living in and interacting with the world. A person's disability is often considered as a core part of their identity and while people with disabilities are diverse, many people consider themselves to be part of a larger cross-disability community. Disability identity refers to a sense of self in relation to one's disability and a sense of connection with a larger community of people with disabilities (Forber-Pratt et al., 2020).

Within the broader disability community, there are a number of additional specific communities. For example, many people who are Deaf consider deafness as a cultural identity. American Deaf culture is characterized by shared history, values, traditions, ways of interacting with others in the world and the use of a shared language, American Sign Language (National Association of the Deaf - NAD, n.d.).

People with disabilities can have many additional identities. As mentioned previously, people with disabilities are included in every sociodemographic group, and this intersectionality means that they have "overlapping health and social inequalities, as well as overlapping strengths and assets" (CDC, 2022b). This is important to consider when working towards health equity. The disability community often uses the motto "Nothing About Us Without Us" to emphasize the goal of "full participation and equalization of opportunities for, by and with persons with disabilities" (United Nations, n.d.-b). It should not be assumed that people with disabilities all share the same views, needs, identities or experiences. For this reason, public health interventions should include people with disabilities at every stage of service development and implementation to ensure equity and success.

How Centers for Independent Living Support People With Disabilities

CILs are community-based, cross-disability, consumer-controlled, non-profit organizations that are designed and operated by people with disabilities to provide various services to empower individuals to achieve independent living (National Council on Independent Living, n.d.). CILs are non-residential organizations, meaning they are not assisted or congregate living facilities, but advocacy organizations that serve people with disabilities within their communities. At a minimum, all CILs provide five core services:

- Independent living skills training

- Peer support

- Information and referral services

- Individual and systems-level advocacy

- Transition services which support people with disabilities seeking to live free and independent lives outside of institutionalized care (National Council on Independent Living, n.d.)

Figure 2. The Five Core Services of Centers for Independent Living

In addition to these core services, as disability-led organizations, CILs can offer various services to assist SLHDs reaching people with disabilities. Such services could include providing training and technical assistance regarding disability culture and relevant disability rights laws, conducting ADA architectural and website accessibility assessments and participating in advisory groups to represent people with disabilities. According to surveys of CIL consumers, the constellation of services provided by CILs helped them to achieve their independent living goals in ways that one service alone could not (CESSI & WESTAT, 2003).

As of 2022, there are approximately 460 CILs and 56 Statewide Independent Living Councils (SILCs) in the United States (National Council on Independent Living, n.d.). Each state is required to maintain a SILC and these SILCs develop State Plans for Independent Living (SPILs), which are three year plans for providing independent living services and addresses the development and support of a statewide network of CILs and the working relationships among programs providing independent living services (Independent Living Research Utilization, 2023). The plan must address how federal, state and other funds will be used within the state to develop and maintain an Independent Living program. SPILs are jointly developed by the SILC and CILs after public input from individuals with disabilities (Massachusetts Statewide Independent Living Council, 2023). ILRU and the Administration for Community Living (ACL) host directories where consumers, advocates and practitioners can find their local CIL or SILC (Independent Living Research Utilization, 2023; Administration for Community Living, 2023). Additional information about specific CIL services, organization and funding are outlined in Module Two of this partnership guide.

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"Our CIL covers four counties in Northeast Ohio. In addition to the five core services, we provide braille instruction, collaborate with organizations on emergency preparedness, teach independent living skills to many specific groups including people experiencing homelessness and those in addiction recovery and provide pre-employment training for youth in schools."

Pam Davies, Western Reserve Independent Living Center

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Independent Living Model

CILs operate under a philosophy of independent living, which is defined by the Federal Rehabilitation Act of 1973 as amended "including a philosophy of consumer control, peer support, self-help, self-determination, equal access and individual and system advocacy, in order to maximize the leadership, empowerment, independence and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society" (*Rehabilitation Act of 1973 [As Amended Through P.L. 114–95, Enacted December 10, 2015],* n.d.). People with disabilities can live successfully outside of institutions when provided with the support they need.

Consumer control is important because people with disabilities know best what their needs are and how to address those needs. Peer support is important for the same reason – people with disabilities are often best able to offer support and guidance to people who share their lived experience. According to the National Council on Independent Living, "the Independent Living Movement is founded in the belief that people with disabilities, regardless of the form, have a common history and a shared struggle, that we are a community and a culture that will advance further banded together politically" (Independent Living Research Utilization, 2023).

Independent living philosophy focuses on addressing barriers in the environment, such as lack of transportation or appropriate medical services, to ensure that people with disabilities can live independently with dignity.

Legal Obligations

People with disabilities are a protected class and under requirements of the law are guaranteed the same rights as everyone else. Equal opportunity and rights to employment, access to programs and services and full participation in society should be standard for people with disabilities.

The Rehabilitation Act of 1973, Section 504, prohibits discrimination on the basis of disability and specifies safeguards to prevent people with disabilities from being excluded from any program or activity receiving federal financial assistance (U.S. Equal Employment Opportunity Commission, n.d.; U.S. Department of Labor, n.d.-c).

The ADA was signed into law in 1990 and is considered federal civil rights legislation. It was designed to protect people with disabilities against discrimination in all public spaces. In 2010, there was a revision to the ADA that detailed accessible design standards in architecture which apply to all commercial buildings. Knowing what the ADA, Rehabilitation Act and other laws or regulations say about accessibility is important to ensure people with disabilities are provided equitable access to services. It is also important that service providers understand their legal obligations under the law.

Title II of the ADA covers State and Local Government Programs and Services. This section of the ADA prohibits discrimination against qualified individuals with disabilities in all programs, activities and services of public entities—including state and local health departments. This also includes state executive agencies,

courts, legislatures, towns, cities, counties, school districts, universities, community colleges, regional transit authorities other state and local government instrumentalities (New England ADA Center, 2017).

According to Title III of the ADA, people with disabilities must be able to obtain or enjoy the same goods, activities, services and benefits that are available to other members of the public (U.S. Department of Justice Civil Rights Division, 2012). This includes public spaces that may be used for temporary or pop-up vaccine sites such as schools, recreation facilities and medical offices or facilities. ADA compliance is important to ensure all people have equitable access to participate fully in society.

Interdependence and Advocacy

CILs are more than service providers. CILs empower consumers to make decisions and advocate for themselves while providing support. CILs also engage in systems-level advocacy to ensure that people without disabilities, organizations and governments understand their legal obligations. They're knowledgeable of the needs of people with disabilities in their local communities both through their work but also because staff often have disabilities themselves. CILs also have a vast array of partnerships with local and national organizations that can be leveraged to support people with disabilities to live as they choose. By ensuring people with disabilities are informing all aspects of their work, CILs' approaches are effective and culturally relevant for the people that they serve.

Following an independent living model does not negate the importance of community support and collaboration. For people with disabilities to be fully integrated into their communities, cooperation is required between individuals and organizations across all sectors through education, employment, interpersonal relationships and cultural acceptance.

How State and Local Health Departments Support People With Disabilities

SLHDs, Public Health and Core Services

SLHDs are on the front lines for delivering public health services to communities in the United States. While some SLHDs operate clinics and offer direct services to consumers, their primary focus is to promote public health. Public health is the science of protecting and improving the health of people and their communities with a focus on entire populations (CDC Foundation, 2023). CDC defines the 10 Essential Public Health Services that all communities should undertake as:

- Assess and monitor population health status, factors that influence health and community needs and assets
- Investigate, diagnose and address health problems and hazards affecting the population
- Communicate effectively to inform and educate people about health, factors that influence it and how to improve it
- Strengthen, support and mobilize communities and partnerships to improve health
- Create, champion and implement policies, plans and laws that impact health
- Utilize legal and regulatory actions designed to improve and protect the public's health
- Assure an effective system that enables equitable access to the individual services and care needed to be healthy
- Build and support a diverse and skilled public health workforce
- Improve and innovate public health functions through ongoing evaluation, research and continuous quality improvement
- Build and maintain a strong organizational infrastructure for public health (CDC, 2022f)

The 10 Essential Public Health Services
To protect and promote the health of all people in all communities

These 10 essential public health services illustrated in Figure 3 can operate differently in states and jurisdictions depending on SLHD size, scope and capacity as well as the specific needs of the populations that the SLHD serves. These services and functions can include developing emergency plans, supplying medical and emergency resources to the community, responding to public health emergencies such as infectious disease outbreaks and providing community health education.

Assessment

Assess and monitor population health

Investigate, diagnose and address health hazards and root causes

Build and maintain a strong organizational infrastructure for public health

Improve and innovate through evaluation, research, and quality improvement

Assurance

Build a diverse and skilled workforce

Equity

Communicate effectively to inform and educate

Strengthen, support and mobilize communities and partnerships

Policy Development

Create, champion and implement policies, plans, and laws

Enable equitable access

Utilize legal and regulatory actions

Figure 3. The 10 Essential Public Health Services, CDC

State Health Departments (SHDs) work in numerous subject areas to promote public health (*What We Do State Health Agency Activities, ASTHO 2016,* n.d.).

- SHDs prevent disease in communities by:

  ◦ Performing screenings for diseases

  ◦ Providing population-primary prevention services (e.g., tobacco use prevention, sexually transmitted infection counseling and partner notification, etc.)

  ◦ Vaccine order management and inventory distribution for childhood and adult immunizations

- SHDs promote health by providing vital public health services such as:

  ◦ Treatment for diseases

  ◦ Maternal and child health services (supplemental nutrition for women, infants and children [WIC]; home visits; services for children and/or youth with special healthcare needs)

  ◦ Other clinical services (oral health, substance abuse education and prevention, pharmacy services, etc.)

- SHDs protect health by collecting and maintaining real time data through:

  ◦ Laboratory activities (e.g., testing for foodborne illnesses or typing influenza)

  ◦ Tracking information in public health registries on a number of topics (e.g., cancer and childhood immunization)

  ◦ Disease investigation and surveillance activities

Figure 4 demonstrates how Local Health Departments (LHDs) operate and work in several different topic areas including but not limited to:

- Immunization
- Food safety
- Infectious disease
- Tobacco control
- Chronic disease
- Environmental health
- Injury and violence prevention
- Maternal and child health
- Emergency preparedness

Figure 4. How local health departments operate. Graphic created by NACCHO (Local Health Departments Impact Our Lives Every Day, NACCHO 2017, n.d.)

Services SLHDs Provide for People With Disabilities

The general services that a SLHD provides can offer benefits to people with disabilities, even if the services are not specifically designed for them. Under the ADA, services, information and physical space provided by SLHDs are required to be accessible to people with disabilities.

Several LHDs have dedicated staff and programs to further support the needs of people with disabilities in their jurisdiction. Some state health departments have State Disability and Health Programs, funded by CDC, which aim to reduce disparities experienced by adults with intellectual and developmental disabilities and adults with mobility limitations. These programs help by strengthening partnerships, training healthcare personnel and implementing interventions and systems changes to improve the lives of people with disabilities (CDC, 2021b). Other SLHDs may have work groups on disability, partnerships with organizations that serve people with disabilities, data monitoring systems to identify the needs of people with disabilities, emergency response plans specifically focused on meeting the needs of people with disabilities or trained "disability specialists" (NACCHO, 2020).

Size and Structure of SLHDs

There are LHDs in all 50 states, five territories, three freely associated states and the District of Columbia (CDC, 2021b). State health agencies and LHDs vary greatly based on the populations they serve (e.g., geographic size, size and nature of population, urban or rural populations, socioeconomic and demographic variables, etc.) and their structure (e.g., governmental structure within which they work, funding sources and governing organization to which they are accountable) (Institute of Medicine (US) Committee on Educating Public Health Professionals for the 21st Century, 2003).

Figures 5 and 6 demonstrate public health governance, the relationships between state health agencies and local public health departments and how they differ across states. There are a variety of government health structures:

• Centralized structures, where local units are led by employees of the state

• Decentralized structures, where local health units are led by employees of local governments

• Mixed structures, where some structures are led by local health department employees and some are state employees and

- Shared structures, where the state or local governments have authority at different local health units. (CDC, 2022e)

Health departments of all structures provide a wide variety of services to diverse communities, often with limited staff and resources.

2019: Governance Annual Survey Responses

Legend:
- New England (HHS Regions 1 & 2)
- Mid-Atlantic & Great Lakes (HHS Regions 3 & 5)
- South (HHS Regions 4 & 6)
- Mountain/Midwest (HHS Regions 7 & 8)
- West (HHS Regions 9 & 10)

Territory labels: CNMI, FSM, Guam, Puerto Rico, Republic of Palau, RMI, US Virgin Islands

Data below are only available for states.

Independent local health agencies	2,197
Independent regional or district offices	99
State-run local health agencies	612
State-run regional or district offices	326

Association of State and Territorial Health Officials. ASTHO Profile of State and Territorial Public Health, Volume Five. Arlington, VA: Association of State and Territorial Health Officials. 2020.
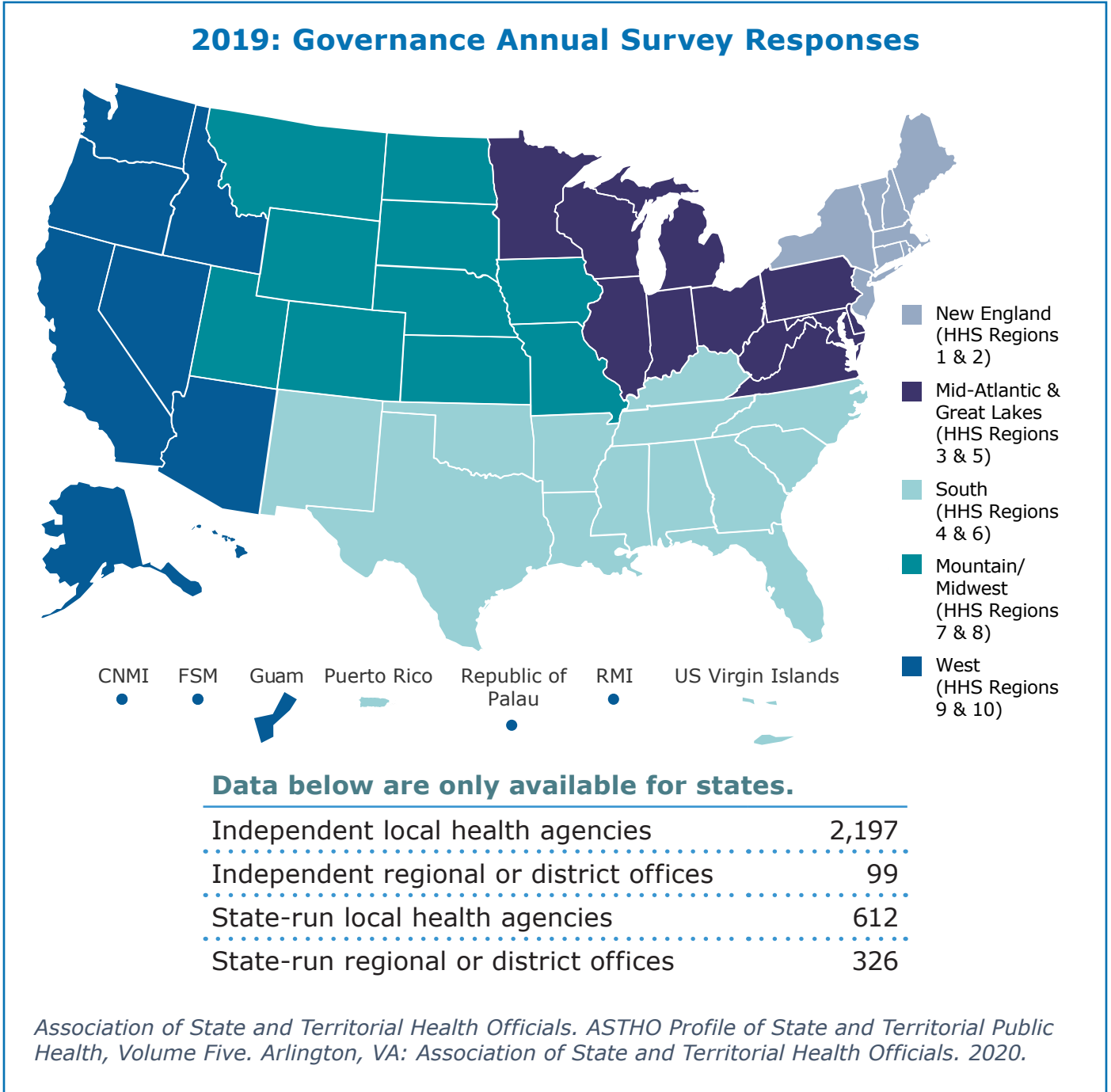
Figure 5. Governments of state and local health departments. Graphic adapted from ASTHO (Association of State and Territorial Health Officials, 2023)

Type of LHD governance, by state

Local (all LHDs in state are units of local government)
State (all LHDs in state are units of state government)
Shared (all LHDs in state governed by both state and local authorities)
Mixed (LHDs in state have more than one governance type)

RI was excluded from the study
N=2,459
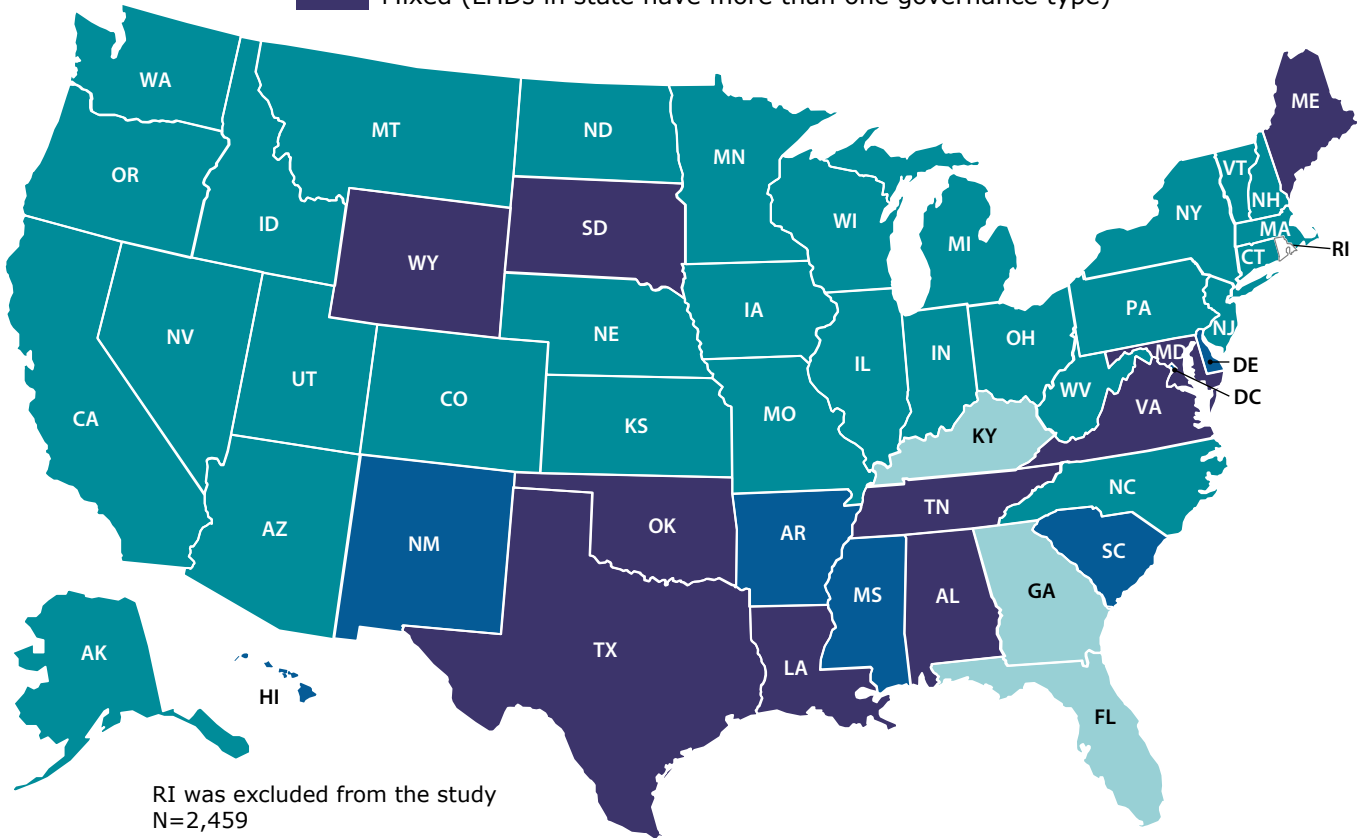
- Of the 2,459 LHDs included in the 2019 Profile study population, 1,886 are locally governed, 405 are units of the state health agency, and 168 have shared governance.

- In 30 states, all LHDs are locally governed. These states are referred to as decentrailized.

- All LHDs in Florida, Georgia, and Kentucky have shared governance.

- All LHDs in Arkansas, Delaware, Hawaii, Mississippi, New Mexico, and South Carolina are units of the state health agency. These states are referred to as centralized.

Figure 6. How state and local health departments operate. Graphic adapted from NACCHO
(National Profile of Local Health Departments, NACCHO 2019, *n.d.*)

The Case for Collaboration Between SLHDs and CILs: A Closer Look at the COVID-19 Pandemic

The COVID-19 pandemic highlighted the need for cross-sector and cross-organizational collaboration to support the health and safety of people with disabilities. Some people with disabilities were more likely to be infected with COVID-19 or have severe illnesses due to health conditions or social factors, such as systemic health and social inequalities. To ensure that people with disabilities could protect themselves from COVID-19, information about prevention and mitigation measures needed to be inclusive of and culturally relevant to people with disabilities. For example, guidance for clear masks so that people who read lips or use American Sign Language were necessary. Public health messaging also had to be in formats that were accessible to people with disabilities, such as braille, American Sign Language and texts and graphics that were easy to read. Information posted online, such as text, videos and infographics, needed to be easily navigable for people using assistive technology. Accessibility also applies to COVID-19 vaccine distribution and uptake. This included ensuring that people who could not leave their home could receive a vaccine as well as ensuring that vaccination sites were accessible (e.g., in-home vaccination options, available interpreters, accessible clinics, appropriate accommodations, etc.).

This intersection of public health, accessibility and disability in response to the COVID-19 pandemic served as an opportunity for collaboration between SLHDs and organizations who serve people with disabilities, such as CILs. CILs provided subject matter expertise and served as trusted sources for people with disabilities by promoting public health messaging and supporting SLHDs in ensuring their efforts were accessible. SLHDs supported CILs by offering accessible messaging and services to benefit their consumers.

The remainder of this guide will highlight examples of CIL and SLHD partnerships from the COVID-19 pandemic that are mutually beneficial to both organizations. Each module will offer concrete steps for these organizations to create and maintain a partnership while providing the resources to support that effort.

Module One: Information for CILs to Promote Collaboration With Their State and Local Health Departments

Collaboration With SLHDs Can Benefit CILs and Their Consumers

SLHDs provide services and resources that can benefit CILs and the people that they serve. These partnerships can benefit CILs and their consumers in numerous ways.

- Regular communication with a SLHD or attending community meetings and coalitions that SLHD staff also attend can help a CIL better understand the services that their SLHD offers. SLHDs provide services and programs aimed for the public (e.g., organizing vaccine clinics, educational materials related to maternal and child healthcare, etc.). Some also provide disability-specific programs and services (e.g., inclusive emergency response plans, translation services, accessible shelters for people with disabilities, etc.) that CIL consumers will benefit from.

- CILs can offer information about their services to SLHDs. SLHDs can then share that information to the people with disabilities that they serve.

- CILs can provide subject matter expertise and/or trainings to SLHDs about the health and accessibility needs of people in their jurisdiction which can lead to more inclusive and accessible SLHD services.

- SLHDs often provide grant or contract funding to organizations in their jurisdiction or may work in conjunction with a local organization on federal or private-sector grants. Partnering with SLHDs could open additional funding opportunities for CILs.

- With regular communication or by working with their SLHD on projects, CILs can gain a "seat at the table" to provide input on SLHD programs and services that will best benefit people with disabilities.
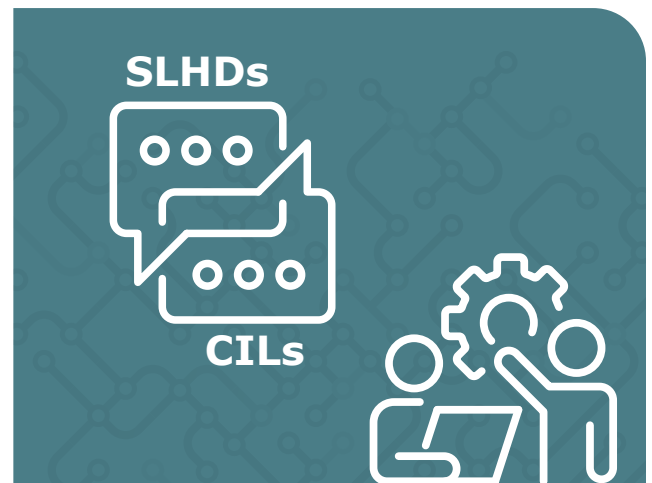
"We partner with our local health department on a variety of projects. There have been health department staff who have served on the board of our CIL and we participate in their emergency preparedness core advisory group where we give feedback on emergency preparedness plans and we have provided input about the accessibility of emergency response materials, such as large print or videos with captions. We also do a lot of events together, promote each other's materials, and give referrals back and forth for customers to receive services. Our CIL often provides equipment, such as wheelchairs, to our health department for their events. There have also been opportunities for funded work, such as a grant funded by our health department which created a transportation advisory group, so that is another way that we provide input and support."

Alex Mikowski, Access to Independence of Cortland County, Inc., New York

How CILs Can Support and Engage With Their SLHD

There are numerous ways that CILs can partner with their SLHD that will be mutually beneficial to both organizations. CILs can:

Provide architectural and website accessibility consulting/advising (e.g., help SLHDs make their communications materials, physical office spaces or events more accessible)

Gather input from people with disabilities for needs assessments, message testing, programming or other SLHD services and efforts

Co-host events with their SLHD (e.g., an accessible vaccine clinic, emergency preparedness conference, etc.)

Disseminate information to people with disabilities (e.g., email educational materials to consumers, contact consumers to give them information about emergency shelters during a natural disaster, etc.)

Lend adaptive and assistive equipment (e.g., wheelchairs)

Connect SLHDs with additional local organizations and partners who serve people with disabilities who can provide a SLHD with subject matter expertise or connect them with specific consumers that a SLHD wants to reach

Provide input on SLHD programming and policies to ensure inclusion of people with disabilities (e.g., provide feedback on a SLHD's emergency response plan, ensure that emergency shelters are accessible, provide contact lists for CILs, coordinate to ensure equipment is provided to people with disabilities during an emergency)

Recommend community members with disabilities to serve on local boards, advisory committees, or coalitions

Represent people with disabilities on advisory committees

Join existing advisory committees or form advisory committees to support health departments (e.g., an advisory committee focused on people with disabilities or on any of the subject areas that SLHDs focus on which involve people with disabilities)

Suggest regularly scheduled meetings (e.g., monthly, or quarterly) with a SLHD staff member to ensure both organizations are informed about the activities of the other

"The majority of the collaboration that we have had with our SLHD has been in a group with other local organizations and agencies. Our CIL sits on numerous committees in our community, such as an emergency medical services council, that our SLHD also participates in.

Health departments play a huge role in emergencies, including in creating shelters or providing vaccines, and our CIL can support to make those accessible. We have set meetings with our health department and, in the past, we have done a preparedness conference together that was then replicated across the state."

Debra Fults, The disAbility Resource Center of the Rappahannock Area, Inc., Virginia

How To Establish Partnerships With Your SLHD

Every SLHD is different, so learning how your SLHD is structured will be helpful when determining how to first contact a SLHD. CILs can focus on partnering on a specific subject area or collaborating on a specific event. It may be helpful to find a SLHD staff member to create a strong relationship with and who can then connect to other staff and departments or collaborating with SLHDs on larger committees and advisory groups.

There are numerous strategies to establish a connection with an SLHD:

Reach out to an SLHD's public health preparedness program:

Emergency preparedness and response is an area where CILs and SLHDs partner the most. Identify the preparedness coordinator or director to offer SLHDs support in reaching people with disabilities in an emergency (e.g., providing a list of people who may need transportation to shelter, etc.). This can be an effective partnership opportunity that could be extended into different programmatic areas. Some health departments might have an access and functional needs coordinator or committee who can assist in highlighting considerations from the disability community.

Connect with SLHD's population health or health education divisions:

Staff that work in this area often collaborate with community-based organizations to create and disseminate health promotion materials. It may be helpful to identify partnerships with this group to ensure materials that are created and distributed are fully accessible and people with disabilities have access to the same information SLHDs are making available to the public.

Identify the SLHD's communications department:	This is an opportunity to reach out to discuss the accessibility of a SLHD's website, social media accounts and educational materials. The communications department likely works with all SLHD programs and could help to facilitate connections.
Join groups and committees that advise the health department:	Take the opportunity to personally connect with an SLHD staff member by joining the same working groups. These could include advisory groups related to emergency preparedness, transportation or other general topics. Some communities also have groups or coalitions specifically focused on health equity, immunizations and people with disabilities. Make sure you attend meetings and communicate your organization's common goals with the group and/or member organizations. These groups may be listed on websites for your state or local government, SLHD, local chamber of commerce or other non-profit organizations in the area.
Identify if the SLHD has departments or staff specifically dedicated to serving people with disabilities:	This information will likely be on the SLHD website. If there are not specific staff or departments listed that address disability, there may be staff embedded in the health department with disability training. For example, a number of federally funded or national organization-funded projects have focused on providing SLHDs with disability-specific training (e.g., projects led by the CDC, the Association of State and Territorial Health Officials [ASTHO], and NACCHO) and/or disability subject matter experts (CDC, 2021b; NACCHO, 2020; Burrous, 2021). Researching whether your SLHD has participated in any of these programs may give CILs an idea of who would be the most appropriate staff or department to reach out to for assistance. Staff dedicated to working with people with disabilities may have a job title or work in a department related to "health equity."

Identify whether the SLHD has an ADA coordinator:	The ADA mandates every public entity that employs 50 or more people to designate an ADA coordinator (Regulation 28 CFR §35.107). Depending on the size and scope of your state government and SLHD, it may have an ADA coordinator or an accessibility coordinator who may be helpful to contact for concerns or suggested improvements related to accessibility. If your SLHD does not have an ADA coordinator, your state government does and may be another place to reach out to for connections.
Contact the SLHDs helpdesk or general information line:	Most SLHDs have a general inquiries email address or phone number on their website that CILs should contact. These inquiries are often triaged to the appropriate department. If a CIL is hoping to set a preliminary meeting with a SLHD, this could be a place to start. If a CIL is hoping to partner on a specific project or topic area, it may be even easier for the SLHD staff to triage the inquiry to a specific department or staff member. While these general inquiry phone numbers or emails may lead to a connection with a specific staff member, CILs often have the best success reaching out to specific departments and staff members.

Additional notes to consider when establishing and maintaining a partnership with a SLHD

- SLHD staff and departments may not be familiar with disability, accessibility or CILs. CILs should be prepared to provide a lot of information to SLHDs about what disability is, the importance of accessibility, their legal responsibility under the ADA, the number of people with disabilities in their jurisdiction and numerous other topics. Some staff may have more knowledge about disability than others depending on their training, job scope and whether they interact with people with disabilities in their personal or professional lives. Providing key background information about people with disabilities, accessibility and how CILs can help to facilitate connections with the people that SLHDs serve will be important in creating and maintaining a partnership.

- SLHDs may be understaffed and underfunded. Be persistent, as it may take a few attempts to reach a department or a staff member who has the capacity to engage with a CIL on a specific project or regularly meet with CIL staff. You may

also encounter staff turnover, which makes establishing contacts with multiple departments and staff members or joining a committee where numerous SLHD staff participate better than having just one staff contact. Sometimes a lack of communication could indicate a lack of interest in partnership, or it could mean that the incorrect staff person was contacted and triaging to the appropriate department did not occur. The staff member may have missed the email or is currently overwhelmed with work. Additional incentives for collaboration may need to be mentioned to increase interest (e.g., a CIL can offer equipment and materials for an upcoming SLHD event). It is often important to "help them help you" by highlighting how a partnership can be mutually beneficial.

- SLHDs may have departments and staff members that are siloed from each other. Contacting a staff member in maternal and child health area and providing information about your CIL's services or disability-related topics may not mean that staff in the SLHD's emergency preparedness department will receive this information. It is important to establish contacts, collaborate on projects and provide training to SLHD staff in numerous departments.

- As mentioned throughout this guide, the structure of SLHDs vary from state to state. Each individual department will be organized differently and the relationship between a state health department and a local health department will also vary. Depending on the types of partnership your CIL hopes to establish and the capacity of your SLHDs, it may also be helpful to reach out to the state health department. When connecting with a state health department, consider working through the SILC. For local work, it may be best for a CIL to connect with their local health department directly. Establishing connections at both the state health department and local health department could be beneficial. It is also important to note that a CIL may operate in the jurisdiction of more than one local health department, so it is important to locate each of these local health departments and establish relationships with each of them.

- In addition to informal partnerships, there are several avenues to establish formal partnerships between SLHDs and CILs. As previously mentioned, CILs can apply for grants that their SLHD offers or could jointly apply to a grant with their SLHD. Another option is to establish a memorandum of understanding (MOU) with an SLHD that will outline specific areas of partnership. This could outline how contact will be established and information will be shared in an emergency, accessibility audits (a professional evaluation of how well a website and other digital properties meet the needs of people with disabilities) or any number of activities.

Module Two: Information for Health Departments To Foster Collaboration With CILs

The Importance of Accessibility and Inclusion of People With Disabilities

To successfully implement the public health practices or mitigation strategies that SLHDs promote, it's important to provide materials and services that are accessible and inclusive of people with disabilities, who represent one in four Americans. Accessibility is a legal obligation for SLHDs.

Addressing the Needs of People With Disabilities

Seeking and Implementing Input From People With Disabilities

Public health practice prioritizes community health needs assessments, message testing and program evaluation that seek input from the end users of products, services and public health interventions (CDC, 2022d, 2021a). This input can help tailor programs to ensure that they are appropriately addressing the need of communities and can generate community buy-in for interventions.
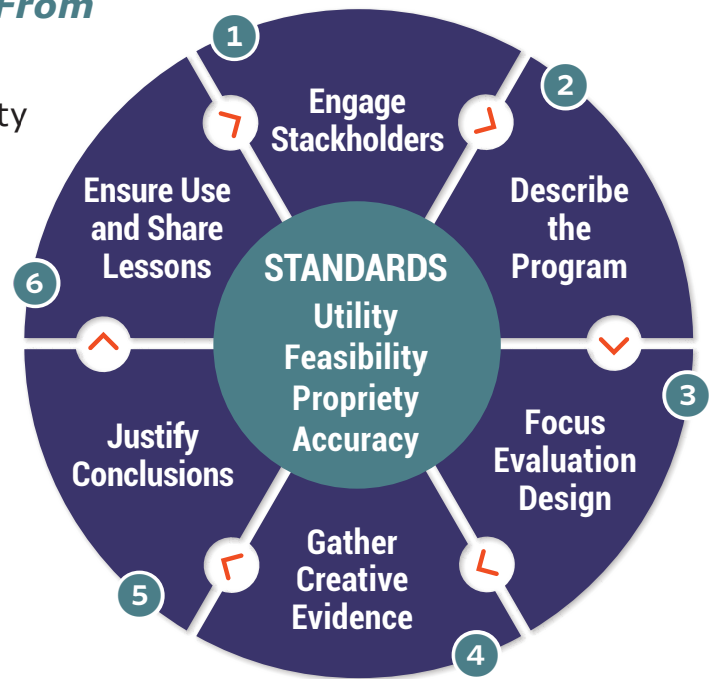

Figure 7. Framework for program evaluation in public health, adapted from CDC (CDC, 2022c)

People with disabilities are often absent from health research and program development despite comprising the largest minority group in the United States (Rios et al., 2016). While there are national data sets that can provide information about the health needs of people with disabilities in states and jurisdictions, this information

alone is not sufficient to create effective and targeted local programs. Figure 7 summarizes the essential elements that can be used to improve effective public health strategies and how evaluation is conducted to benefit existing programs. Input from people with disabilities and collaboration with organizations who serve people with disabilities in your community are the best ways to ensure that programs are effective and successful.

It is important to get feedback directly from people with disabilities rather than use their caregivers or organizations that serve them as a proxy. While caregivers and community-based organizations can provide initial information and are crucial partners to engage, it is the people with disabilities themselves who can best speak to their needs and the services that will best serve them. Needs assessments, message testing and program evaluation should be accessible and include people with disabilities.

CILs work directly with people with disabilities and can support SLHDs by recruiting people with disabilities to participate in information gathering and research. They can also be invaluable in helping to determine which methods for data collection will be accessible and best received by people with disabilities.

Accessible Communications Materials and Websites

People cannot implement public health recommendations or access public health services if information is not accessible to them. SLHDs have a legal and ethical obligation to ensure that their communications materials, both electronic and printed, are accessible to everyone. In addition to accessibility, it is important that materials, programs and guidance are inclusive of and culturally sensitive to people with disabilities to ensure that people with disabilities can apply public health recommendations and benefit from services. CILs can provide information about how to make documents accessible, with many performing this service regularly as a part of their work.

Web Accessibility

Web accessibility is the inclusive practice of ensuring people with disabilities have no barriers preventing use of websites. When sites are correctly designed, users have equal access to information and functionality. Steps taken to ensure that online materials are accessible to people with disabilities can improve accessibility for everyone. For example, adding captions to a video so that a person who is Deaf or

hard of hearing can access the information can also be helpful for people who are hearing, particularly when there is a lot of background noise. Effective color contrast on web pages and in images not only helps people who have low vision but can be helpful for anyone reading on a screen when there is suboptimal lighting. Adding captions and alternative text to images is not only necessary for people who are blind or who have low vision to access information in images and graphics but can provide clarity and further explanation for graphics to everyone. There are several other examples of how web accessibility can benefit everyone in videos created by the World Wide Web Consortium.

Figure 8. World Wide Web Consortium videos depicting the importance of web accessibility for people with and without disabilities

People with disabilities access web materials in numerous ways, including through the use of assistive technology like screen readers that read text out loud, screen magnifiers that enlarge web content and refreshable braille displays that display lines of braille characters by raising and lowering dots on a touch pad. More examples can be found on the World Wide Web Consortium Tools and Techniques page.

There are a number of resources to ensure that communications materials, social media posts, websites and presentations are accessible to people with disabilities and compatible with the assistive technology they use. There is an ADA Best Practices Tool Kit for State and Local Governments that includes a Checklist for

Web Accessibility. The World Wide Web Consortium has created the Web Content Accessibility Guidelines, which have served as the basis for federal web accessibility requirements. A number of applications including Microsoft Word, Excel and PowerPoint as well as Adobe Acrobat have built in accessibility checkers that can be used as a starting point, though the ADA and World Wide Web guidelines should also be consulted. Working with organizations who specialize in web accessibility audits and consulting can also support a SLHDs ability to meet federal guidelines.

Print Accessibility

Printed materials, such as promotional flyers or forms at a vaccine clinic, also need to be accessible. People with low vision may require versions with large print, meaning that the text is at least size 14-point type, but preferably size 16 or 18-point type (National Library Service for the Blind and Print Disabled Library of Congress, 2022). People who are blind or who have low vision may need forms in braille, forms read aloud or

Figure 9. A braille embosser printing pages of braille

alternative web-based forms that they can access using assistive technology. People who are Deaf or hard of hearing may require an American Sign Language interpreter to translate printed materials. Images and graphics on print materials should include captions and descriptions, just as they should in online versions, and appropriate color contrast should be used. Information about accessible print materials can be found in the ADA Best Practices Tool Kit for State and Local Governments.

Materials for People With Limited Written Literacy Skills

Public health messaging is only effective if it is understood by its target audience. People with lower literacy proficiency are more likely than those with better literacy skills to report poor health (DeWalt et al., 2004). Public health organizations and agencies often follow federal "plain language" guidelines, which can help to create products and materials that are understandable to people who read at approximately a sixth-grade reading level. Plain language focuses on ensuring that writing is clear, concise and well-organized.

While plain language is a great starting place, more is needed to ensure that materials are understandable to people with limited literacy skills. It is estimated that 52 million adults in the United States have low levels of literacy "where only basic vocabulary knowledge is required and the reader is not required to understand the structure of sentences or paragraphs (National Center for Education Statistics, n.d.). Among these 52 million adults are people with disabilities, including people with intellectual and developmental disabilities, who need access to health information that they can understand and apply for themselves. Assuming that caregivers or health professionals will relay information to people with intellectual and developmental disabilities is insufficient.

The Flesch Reading Ease and the Flesch Kincaid Grade Level scores can be calculated to ensure materials are understandable to the intended audience. Microsoft Word and other applications have built in statistics calculators that can also be useful. These statistics include words per sentence as well as readability and grade level scores. CDC health literacy and communication trainings are available online. There are evidence-based guidelines for creating written materials below a third-grade reading level for people with intellectual and developmental disabilities, the Guidelines for Minimizing the Complexity of Text, that were created by the Center for Literacy and Disability Studies at the University of North Carolina, Chapel Hill.

Some people have more difficulty accessing written materials than others and some cannot access written materials at all. For example, some people who are Deaf or hard of hearing rely on American Sign Language as their main or only source of communication. Of high school graduates who are Deaf, only seven percent read English at or above a

Figure 10. Thumbnail image of an American Sign Language Video.

seventh-grade level and reading levels plateau at the fourth-grade level. While some people who are Deaf can access written materials, others cannot. It is important to note that American Sign Language is a distinct language from English with its own vocabulary and grammar and it is crucial that people have access to health information in their primary language. Videos of public health guidance in
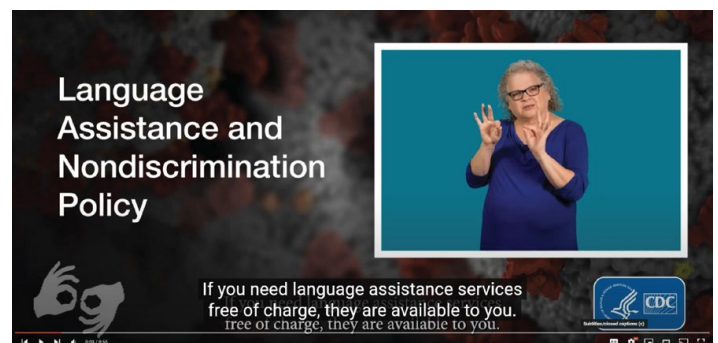
American Sign Language, the use of teletypewriters and the presence of interpreters, as needed, are necessary to ensure that people who are Deaf and hard of hearing have access to information. Additional information about accessibility for people who are Deaf and Hard of Hearing is available in the ADA Checklist for Local Governments.

Figure 11. Thumbnail image of an American Sign Language Video

Inclusive Language

To communicate with respect and have an impact on health equity, it is crucial to use inclusive, non-stigmatizing language. While there are several guides and principles that can be used as a starting point, language and cultural norms change. Engage with the specific people that you are serving in your community and ask them how they would like to be referred to and what language is most inclusive of them. Message testing materials with your target audiences can better ensure that materials will be well-received.

CDC created a set of Health Equity Guiding Principles for Inclusive Communication that can be referenced when Communicating With and About People with Disabilities. CDC and other organizations use people-first language, which emphasizes the person first rather than the disability (e.g., saying "people with disabilities" rather than "disabled people"). However, many people in the disability community prefer identity-first language, such as people who refer to themselves as "autistic" rather than "a person with autism." While organizations can create standards for themselves on this issue, the best way to determine how to refer to an individual or a group of people with disabilities in a specific circumstance is to ask (Bourne, 2021).

Physical Accessibility of Buildings, Programs and Events

In addition to accessible public health information, as outlined in the sections above, physical accessibility of spaces and events is vital. SLHDs are required to follow ADA guidelines, which includes ensuring that office spaces, events, emergency shelters,

and programs are physically accessible to consumers. A few examples of physical accessibility include:

- Accessible parking spaces
- Curb cuts, ramps, and elevators
- Adequate spacing between furniture and removal of tripping hazards
- Availability of necessary equipment, such as wheelchairs

Detailed lists of accessibility considerations, including guidelines specifically for emergency shelters, can be found in the ADA Best Practices Tool Kit for State and Local Governments.

Transportation

Transportation is also an important consideration for accessibility. People with disabilities often lack access to reliable modes of transportation. Public transportation is not always accessible, affordable nor convenient. There are also some people who are unable to leave their homes due to chronic illness or other conditions. Paratransit, which is one accessible transportation option, is a shared-ride service that provides alternative transportation with flexible timetables that do not have fixed routes.

Collaboration With CILs Can Benefit SLHDs and Their Consumers

There are numerous ways that CILs can partner with their SLHD that will be mutually beneficial to both organizations. CILs can:

Provide accessibility consulting/advising (e.g., help SLHDs make their communications materials, events and physical office spaces or events more accessible)

Gather input from people with disabilities for needs assessments, message testing, programming or other SLHD services and efforts

Co-host events with their SLHD (e.g., an accessible vaccine clinic, emergency preparedness conference, etc.)

Lend adaptive and assistive equipment (e.g., wheelchairs)

Disseminate information to people with disabilities (e.g., email educational materials to consumers, contact consumers to give them information about emergency shelters during a natural disaster, etc.)

Connect SLHDs with additional local organizations and partners who serve people with disabilities who can provide a SLHD with subject matter expertise or connect them with specific consumers that a SLHD wants to reach

Provide input on SLHD programming and policies to ensure inclusion of people with disabilities (e.g., provide feedback on a SLHD's emergency response plan to ensure that emergency shelters are accessible or that SLHDs know to reach out to a CIL to facilitate providing equipment to people with disabilities during an emergency)

How SLHDs Can Support and Engage With CILs

SLHDs provide services and resources that can benefit CILs and the people with disabilities they serve. Partnership with a CIL can benefit SLHDs and their consumers in numerous ways.

• Regular communication with CILs or inviting CILs to attend SLHD committees or community forums help a CIL better understand the services that their SLHD offers which CILs can then refer to their consumers

• SLHDs can refer the people that they serve to CILs

• SLHDs can share information about public health practices of which CILs may not be aware. In turn, CILs can educate SLHDs about the health and accessibility needs of people in their jurisdiction which can lead to more inclusive and accessible services

• Partnering with CILs on projects could lead to potential funding streams for both organizations if together they apply for grant opportunities

"The 1:1 facilitated discussion was a great opportunity to meet face to face with CILs and identify areas of shared needs. We appreciated being able to intentionally set aside time to connect with the CILs in Alameda County and check-in with trusted messengers that are serving the disability community. We were able to better identify the needs of CIL consumers and proposed several CIL-based health education activities around COVID-19 vaccination and treatment and additional topics

around nutrition and mental health. We are also working to identify better ways for CIL consumers to be referred to our health department's programs and services."

Benjamin Chen, Alameda County Public Health Department, California

If an SLHD is organizing a vaccine event, partnership with a CIL could support the event's success and help to ensure accessibility in several ways. Some of the ways the CIL can support the event are by:

- Sharing information about the event with the consumers they serve

- Connecting the SLHD with additional organizations that may be able to promote the event to the people that they serve

- Assisting their consumers with vaccine appointments

- Providing or coordinating transportation to the vaccine event

- Providing feedback on promotional materials to ensure that they are accessible to people with disabilities

  ◦ Ensuring that information is written at an appropriate reading level and advising on alternative formats (e.g., American Sign Language, braille, large print, captioned videos, etc.)

  ◦ Reviewing information that is posted online to ensure that it is accessible (e.g., appropriate color contrast, graphics have alternative text to describe them, etc. Such information can be found on the Web Content Accessibility Guidelines (WCAG) Overview page)

- Offering suggestions to ensure that the event space is physically accessible (e.g., wheelchairs and wheelchair ramps, appropriate spacing between furniture so all people can maneuver the space, options for people to get vaccinated in their cars if there are mobility concerns, etc.) and that any information provided at the event is accessible (e.g., interpreters are present, medical forms are in large print or other accessible formats, etc.)

  ◦ CILs could potentially co-host the event or offer to hold the event in their office to promote further ease of access and community buy-in

- Lending adaptive and assistive equipment that may be needed for the event (e.g., wheelchairs)

"Our CIL works very closely with our local health department. We have worked on numerous projects in the past and are currently working towards establishing a more formal partnership with a memorandum of understanding. We attend joint meetings on a weekly basis to discuss COVID-19 related topics, we registered people to get COVID-19 vaccines through health department clinics, and we participate in the local emergency planning committee which meets on a monthly basis where we raise issues and concerns, such as access to in-home COVID-19 vaccinations. It has been really helpful to participate in meetings with our health department where we have the opportunity to present information about our CIL as well as learn about the services that our health department is offering."

Carol Tuning, Disability Rights and Resource Center, Virginia

How to Establish and Maintain a Partnership With a CIL

CILs are staffed and operated by people with disabilities and have a direct connection to people with disabilities that are served by SLHDs. Connecting and collaborating with SLHDs will help both organizations better serve their consumers.

SLHDs can locate the CIL that operates in their jurisdiction using the following databases:

- [ILRU Directory of Centers for Independent Living (CILs) and Associations | Independent Living Research Utilization](#)

- [List of CILs and SPILs | ACL Administration for Community Living](#)

There are numerous strategies SLHDs can implement to engage with a CIL:

Reach out to CILs through the various SLHDs programs:

People with disabilities are present in every group that SLHDs serve, so all departments would benefit from collaborating with CILs. SLHDs are often siloed, meaning that knowledge and connections in one department or branch, may not be shared with another. Ensure that multiple staff across the SLHD are connected with a CIL and establish a CIL contact list to streamline communication between appropriate contacts. An SLHD's emergency response or preparedness coordinator may benefit from working directly with a CIL to reach people with disabilities in an emergency (e.g., providing a list of

people who may need transportation to shelters, etc.). Additional CIL connections with SLHD communications staff, population health and/or health education departments will help to improve engagement across topic areas and can help to ensure disability is considered in public health programs and services from the outset.

Invite CILs to participate in advisory groups or coalitions:	Inviting CILs to participate in advisory groups or coalitions will allow SLHD and CIL staff to connect directly. These groups could include advisory groups related to emergency preparedness, transportation, disability and chronic illness, among others.
Encourage the SLHD ADA coordinator or disability specialist to partner with CILs:	Some SLHDs have staff specifically dedicated to serving people with disabilities, such as an ADA coordinator or disability specialist. For example, a number of federally funded or national organization-funded projects have focused on providing SLHDs with disability-focused staff members and disability-centric training (e.g., projects led by the CDC, ASTHO, and NACCHO) (CDC, 2021b; NACCHO, 2020; Burrous, 2021). These staff would, ideally, partner with CILs in various ways to ensure the services provided by the department are fully accessible.

Additional Notes to Consider When Establishing and Maintaining a Partnership With a CIL

- CILs may not be fully aware of how their SLHDs operate and the many services available for CIL consumers. It would be helpful for the SLHDs to provide CILs with information that can reduce the burden of SLHD staff (e.g., who their main points of contact are, where to find information about services provided, which topic areas and inquiries are best suited for their local health department vs. their state health department, etc.).

- CILs often have small staffs. Reaching out to a CIL through their website or main telephone number will likely be sufficient for establishing contact.

- Some CILs serve more than one county or locality, so it is important to note that they may be working with more than one SLHD which can lead to additional opportunities for collaboration. This could also put additional strain on CIL staff time and resources.

Resources

Communications and Health Literacy

- Health Literacy Hub, CDC
- Health Literacy Trainings, CDC

Disability, or Integrating Disability in SLHD Programs

- 10 Essential Questions for Disability Inclusion in Health Agencies, ASHTO
- ADA Best Practices Tool Kit for State and Local Governments
- Disability and Health, CDC
- Public Health Emergency Preparedness Program and Guidance
- Strategies for Successfully Including People with Disabilities in Health Department Programs, Plans, and Services, NACCHO
- Training for Local Health Departments: Health and Disability 101, NACCHO

Emergency Preparedness and Disability

- ADA Checklist for Emergency Shelters
- Disability and Health Emergency Preparedness
- Disability Equity During Disasters Toolkit (ncil.org)
- Guidance on Integrating People with Access and Functional Needs into Disaster Preparedness Planning for State and Local Governments
- Public Health Emergency, At-Risk Individuals
- Public Health Emergency Planning Toolkit

Locate Your Local CIL

- ILRU Directory of Centers for Independent Living (CILs) and Associations | Independent Living Research Utilization
- List of CILs and SPILs | ACL Administration for Community Living

Locate Your Local Health Department

- Directory of Local Health Departments

Web Accessibility

- ADA Web Accessibility Checklist for State and Local Governments
- Web Content Accessibility Guidelines (WCAG) Overview | Web Accessibility Initiative (WAI) | W3C

Organization Websites

- ACL Administration for Community Living
- APRIL Association of Programs for Rural Independent Living
- ASTHO Association of State and Territorial Health Officials
- CDC Centers for Disease Control and Prevention
- ILRU Independent Living Research Utilization
- NACCHO National Association of County and City Health Officials
- NCBDDD National Center on Birth Defects and Developmental Disabilities
- NCIL National Council on Independent Living

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