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Connecting Communities During Crisis: A Case Study of Nonprofit Agencies, People with Disabilities and Access to COVID-19 Vaccines

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NORTHERN ILLINOIS UNIVERSITY

Connecting Communities During Crisis: A Case Study of Nonprofit Agencies,
People with Disabilities and Access to COVID-19 Vaccines

**A Capstone Submitted to the
University Honors Program
In Partial Fulfillment of the
Requirements of the Baccalaureate Degree
With Honors
Department Of**

Nonprofit and NGO Studies

By

Brittany R. Blomquist

DeKalb, Illinois

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Capstone Faculty Approval Page

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**Connecting Communities During Crisis: A Case Study of
Nonprofit Agencies, People with Disabilities and Access to
COVID-19 Vaccines** _____

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**Connecting Communities During Crisis: A Case Study of Nonprofit Agencies,
People with Disabilities and Access to COVID-19 Vaccines**

Brittany Blomquist

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Connecting Communities During Crisis: A Case Study of Nonprofit Agencies, People with Disabilities and Access to COVID-19 Vaccines

Abstract

Individuals with disabilities often face unique challenges not experienced by the general population. These circumstances are further exacerbated in rural communities where health care equity is disrupted by a lack of access to transportation resources to health care providers and economic hardships. The COVID-19 pandemic further amplified these inequities, creating new barriers in rural regions, to health access and health information, by demanding virtual access in place of physical access, requiring individuals to own, afford, and knowledgeably operate technology. This case study explores methodologies employed by three nonprofit Centers for Independent Living (CIL) agencies assisting people with disabilities, in rural central Illinois, in accessing the COVID-19 vaccine. Current research demographics on health care access gaps divide populations by geographic region, ethnicity, income, and sex leaving out communities encompassing the shared experience of living with a disability. Using methods of literature review, structured interviews with three CILs, structured interviews with CIL support agencies, and statistical data from government resources, health care access gaps in rural central Illinois were identified and strategies to mitigate these gaps were discovered. CILs used old methods in new ways to close gaps created by the pandemic for their consumers. These methods continued to align with the five core competencies of CILs, ensuring support through knowledge and access, independent health care choices for consumers. CILs implemented individual phone calls, social media campaigns, virtual health programs, and on-site clinics to connect consumers to the COVID-19 vaccine. These methods enabled full service in the face of changing pandemic environments.

Introduction

Understanding the ways in which nonprofit agencies have successfully supported the community of individuals with disabilities during a pandemic is vital for creating a foundation for future support during times of unique and uncertain circumstances times. While research exists on the subjects inequity in healthcare, nonprofits serving individuals with disabilities, and guidance for public safety during a pandemic, there is no comprehensive body of research on the intersection of all three subjects. Current research demographics on health care access gaps divide populations by geographic region, ethnicity, income, and sex leaving out communities encompassing the shared experience of living with a disability. This lack of data leaves agencies whose populations include this community without statistical knowledge of past access gaps and unable to anticipate future challenges. The primary research question in this case study aims to identify methodologies implemented by nonprofit agencies assisting people with disabilities, in rural central Illinois, in accessing the COVID-19 vaccine.

For the community of individuals with disabilities, central nonprofit agencies include state recognized Centers for Independent Living (CILs). CILs support this community through five core competencies, including advocacy, information and referral, independent living skills, peer support and mentoring, and transition support. These five core competencies are met through services typically provided on-site at CIL locations. Being centrally located and serving multiple counties, CIL support requires that individuals with disabilities have the means for physical access, including transportation or the ability to pay for and access public transportation.

The fluid circumstances of the COVID-19 pandemic have demanded a level of flexibility and adaptability, not seen during previous crises, from nonprofits providing physical services.

Often, a shift from physical to virtual has created new demographics of underserved individuals, left behind in the “digital divide” of having no access to usable technology, means to purchase technology, or knowledge to operate it. Specific to individuals with disabilities has been the separation from in-person support services at CIL locations, diminished access to home health aides, and a fear of using public assistive tools and transportation to access CILs, such as braille signage, that requires touch during a time of messaging focused on hand sanitation. Additionally, because CILs strive to maintain strategies that support independent living, it was incumbent on CILs to develop methods that supported independent health care choices and did not create perceptions of vaccine advocacy. Learning effective methods that nonprofits have employed to bridge access gaps during the pandemic will support agencies and community networks in future responses to health care equity.

Limitations

Literature

COVID-19 has presented a unique set of circumstances, not only for nonprofits agencies, but for the understanding of related fields and spheres of knowledge. It has emphasized current and new access gaps and changed understandings of who participates in health care initiatives. As such, with the knowledge of COVID-19 encompassing only two years, there are limitations to the full understanding of its impacts on society within published literature. The literature cited in this paper encompasses several topics that focused on aspects of the proposed research question, including rural health care access, health equity for individuals with disabilities, vaccine rate data, and health equity.

Because there is little information published on COVID-19 vaccine trends, data from influenza vaccine rates among multiple demographics have been used to establish trends in vaccine participation. Specifically, influenza was selected for data because it is an airborne virus that is mitigated by an annual vaccination. Additionally, trends in the dissemination of health care information in rural areas will include comparisons to health campaigns targeting cardiovascular disease and cancer interventions; these studies focused specifically on messaging campaigns in rural communities.

Typically, peer reviewed literature studying marginalized demographics categorizes groups based upon ethnicity, income, age, geographic location and sex. No journal article in this literature review defined individuals with disabilities as a distinct demographic to be compared in a health equity analysis.

Methodology

Participation in this case study was voluntary. Participants were solicited for participation via email, with two follow-up phone calls. Of the three CILs asked to participate in this case study, all three responded via phone interviews. Of the thirteen county health departments asked to participate in this case study, three responded via phone interviews. The results of this case study were limited by the minimal response to my request for interviews from support agencies. A greater response would have provided depth to the role in which these agencies support local nonprofit CILs.

Research for this case study was conducted with prior knowledge of the COVID-19 vaccine, its disbursement to local agencies, and challenges surrounding disbursement. As an employee of the LaSalle County Health Department, working directly with individuals affected

by COVID-19, the capacity of my current job requires that I be knowledgeable of current Centers for Disease Control (CDC) and Illinois Department of Public Health (IDPH) guidance and vaccine protocols, as well as knowledgeable on access to vaccine locations within LaSalle County, Illinois, communities.

Literature Review

Health Equity

Health equity varies across the United States, with communities drawn along geographic, economic, and racial lines. Specifically, in central Illinois, communities are primarily rural and geographically isolated, with small town populations and travel distances that require modes of transportation, as well as travel time (Ratcliffe et. al., 2016; Crosby et. al., 2012). In these communities, facilities for basic healthcare are located, on average, twelve minutes away by car (Lam et. al., 2018). Additionally, these communities are economically depressed, with the majority of counties in central Illinois below the state median income level (Heartland, 2021). These circumstances present these communities with multiple challenges when attempting to access healthcare facilities for basic services (Purnell et. al., 2016; Crosby et. al., 2012). The challenges include physical access to care, accessible transportation services for individuals with disabilities, vaccine knowledge, and access to trusted healthcare information sources.

Rural Health Care

As Ratcliffe et. al. (2016) outlines, rural areas are defined by what they are not: urban. Several factors determine spaces that are considered rural, including population density, geographic distance and land use (Ratcliffe et. al., 2016). While there exists a gradient as to how rural a rural area is, it is consistent that health care access within these spaces is directly affected

through spatial proximity (Crosby et. al., 2012). Facilities that provide vaccine administration in these areas are primary care facilities, hospitals and urgent care clinics (Bennett et. al., 2011). Often, these providers are within the same physical space, creating the necessity of transportation to a single location by vehicle (Crosby et. al., 2012). With transportation comes the cost of owning a vehicle or paying transportation fare. In an economically depressed area, the cost of access can become a barrier to accessing health care.

Individuals with Disabilities

For individuals with disabilities, these challenges are amplified, as these individuals may need specialized vehicles, a public form of transportation, financial assistance to travel and/or support aides (MacLachlan et. al., 2011; Leeder & Dominello, 2005). COVID-19 and related restrictions for public health have created new challenges, as typical means of physical access to healthcare facilities and healthcare protocols have changed. For example, individuals who are blind may be concerned about going to public facilities where the need to touch public surfaces, such as braille signs or handrails, to navigate contradicts COVID-19 protocols of avoiding commonly touched surfaces to minimize transmission (Kennedy et. al., 2021). Group home facilities cannot guarantee socially distant living spaces or reliable quantities of personal protective equipment (PPE) and pose a greater risk to disease spread (Kennedy et. al., 2021). Nursing shortages within health care facilities have drained home health resources, leaving many individuals who rely upon aides to access healthcare without resources (Kennedy et. al., 2021). Those who are deaf or struggle with literacy may not be able to stay apprised of current health risks, protocols or mitigations (Kennedy et. al., 2021; Prins et. al, 2017). As individuals with disabilities attempt to navigate the pandemic and resulting healthcare concerns, nonprofit agencies with a mission to help these communities are called upon to help meet the challenges of

rural locations, with the intent of bridging gaps to create a more equitable access to basic healthcare services, such as vaccines (INCIL, 2020; Kennedy et. al., 2021).

Vaccine Trends

In comparing rural and urban vaccine rates for the influenza vaccine, Bennett et. al. (2011), noted that women were more likely to receive a vaccine than men, white individuals were more likely to receive a vaccine than Latino, Black or Asian individuals, and urban areas had higher rates of community vaccination. Bennett et. al. (2011), noted that vaccine administration in rural areas most often occurs at a primary care facility. This may be attributed to primary care facilities being the only health care facility within the area and/or to patients perceiving primary care physicians being a valid source of health care information (Bennett et. al., 2011). Bennett et. al. (2011), stated that vaccine administration sites such as pharmacies, were perceived as lacking the medical knowledge that patients sought to educate themselves about vaccines; this often determined the rate of patients choosing to receive a vaccine. Findings by Brewer et. al. (2021), and Prins et. al. (2017), echo the influenza vaccine trends noted by Bennett et. al. (2011), with white patients more likely to receive a vaccine and access to primary care facilities being a “structural inequity.” Current trends in COVID-19 vaccine administration in Illinois mimic trends outlined in literature on influenza vaccine trends, demonstrating that the demographics of individuals seeking vaccination remain the same across vaccine types (see Appendix A). For COVID-19, there are three potential vaccines an individual can receive: the Pfizer Comirnaty™ vaccine, the Moderna vaccine, and the Johnson & Johnson vaccine. In addition to primary care facilities, other locations such as pharmacies, mobile vaccine vans and public clinics have provided more points of access for the COVID-19 vaccine in rural communities (Nguyen et. al., 2021; Prusaczyk, 2021). Unlike other vaccines, which are currently

accessible to all demographics, the COVID-19 vaccines were released in stages to certain groups divided by disease risk and age (Nguyen et. al., 2021). Nguyen et. al. (2021), stated that between September 2020 and December 2020, individuals who were able to receive the vaccine included healthcare staff, essential workers, individuals 65 years of age and older, and individuals ages 16 through 64, with underlying health conditions. During this time period, these individuals were surveyed twice, demonstrating a 10% increase in willingness to receive a COVID-19 vaccine over time. COVID-19 vaccine trends followed the influenza vaccine data along racial groups; however, in data collected by Nguyen et. al. (2021), it was more likely that men would elect to receive the COVID-19 vaccine.

Methodology

Case Study Region

The case studies at the focus of this research encompass specific demographics present in rural central Illinois. Specifically, the geographic region encompasses thirteen counties: Bureau, Dewitt, Ford, Fulton, LaSalle, Livingston, Marshall, McLean, Peoria, Putnam, Stark, Tazwell, and Woodford. These counties are primarily rural, and economically depressed, with the average annual household income at \$59,271, a figure below the state median income of \$65,886, or 11.2% less (American Fact Finder, 2019). Three nonprofit agencies were analyzed, each serving multiple counties within each agency's jurisdiction. These agencies – Advocates for Access, Illinois Valley Center for Independent Living, and LIFE Center for Independent Living – are recognized by the State of Illinois as three of twenty-two CILs within the state (INCIL, 2020). As such, their role is to provide non-residential support for individuals with disabilities, allowing them to find equitable access to basic services within the community.

Information Sources

For this case study, data collection and analysis were specific to agency response to COVID-19. This analysis included data collection from two distinct populations – CIL staff and agency support organizations. Through data collection and analysis, methodologies for bridging gaps to health care access were identified within each agency and results of the methodologies were considered in the assessing effectiveness of connecting individuals to COVID-19 vaccine access.

This case study includes both qualitative and quantitative data collection, using primary source data analyzed in the context of secondary source data and statistics. Primary data sources included CIL staff and agency support organization staff, e.g., local health department advisors, and encompassed both qualitative and quantitative data. Secondary data sources included published literature, research and statistical data encompassing themes and trends relevant to data points identified by primary sources.

First, structured interviews with key staff members of the three CILs were conducted to identify agency perspectives on, 1) perceived gaps in access for agency consumers, 2) perceived reasons for identified gaps existing in the community, 3) perceptions on forms of aid or services for consumers, 4) identified hardships resulting from COVID-19 impact, and 5) employed methodologies to connect consumers with the COVID-19 vaccine (see Appendix B).

Second, structured interviews with agency support organizations were conducted to identify community perspectives regarding, 1) community challenges to healthcare access, 2) perceptions on support methods for community nonprofits, and 3) utilized support methods for

the three agencies in this case study in connecting the community to vaccine access (see Appendix B).

Third, qualitative data was obtained from nonprofit agencies on vaccine success rates. This data was obtained via structured interviews.

Fourth, statistical data was obtained from the IDPH website, demonstrating percentages of vaccinated individuals within each county. This data encompassed all individuals within the county, not just those with disabilities.

Fifth, informal conversations occurred throughout the case study via phone, email and/or in-person. Data collected via informal conversation was considered within the context of the structured data analysis. In certain cases, additional information was researched on specific topics mentioned in conversations to understand context.

Results

Role of the Nonprofit

Centers for Independent Living are non-residential, nonprofit organizations that support individuals with disabilities. In Illinois, each CIL serves multiple counties, with the average being four counties per agency. As nonprofit agencies, CILs rely upon state and federal grants, as well as private grant funding and donations, to support programs and services. During interviews, staff emphasized their commitment to the five core competencies of CILs: advocacy, information and referral, independent living skills, peer support and mentoring, and transition support. The goal of these competencies is to help individuals “live life on their own terms.” As such, the goal of these nonprofits is to “not be a medical model,” but instead, empower individuals with disabilities to make educated decisions for themselves. This support takes the

form of advocacy for issues affecting individuals with disabilities at local, state and federal levels, as well as advocating for the success of the individual. As CILs, agencies are required to have at least 50% of their staff be individuals with disabilities. This allows CIL staff to offer peer support to their consumers, providing knowledge that comes from personal experience to individuals at CIL locations. Additionally, CIL locations aim to educate their consumers. This education includes information on available health care choices and ways in which to access health care. CIL locations do not provide any direct health care on-site. As such, CIL agencies must coordinate with health care providers, hospitals, transportation services, other health-focused nonprofits, local health departments and health support agencies to provide their consumers with current and relevant information and access.

Advocates for Access

Advocates for Access is located in Peoria Heights, Illinois, serving consumers in the counties of Fulton, Peoria, Tazwell and Woodford. Of the three CILs interviewed, Advocates for Access is located in the most populated city; however, outside of Peoria and its immediate surrounding towns, the counties served are primarily rural farming communities. Peoria, Illinois, hosts two major medical facilities – OSF Saint Francis and Methodist hospitals. Advocates for Access aligns its programs and services with the five core principles of CILs, with a focus towards empowering its consumers to make independent choices. Through these programs Advocates for Access has developed a network of service providers to enable access to individuals with disabilities across served counties. This includes the services of other agencies in areas of transportation, health care, and independent living support. Advocates for Access does not provide healthcare services at its physical location.

Illinois Valley Center for Independent Living

The Illinois Valley Center for Independent Living (IVCIL) is located in LaSalle, Illinois, serving consumers in Bureau, LaSalle, Marshall, Putnam and Stark counties. The majority of communities in these counties are rural, with medical facilities located only in Bureau, LaSalle and Stark counties. IVCIL follows the five core principles of CILs, with programs and services connecting consumers to programs that offer transitional services, personal assistants and mobile meals. Like other CILs, these programs and services are meant to support individuals in making informed, personal choices. Typically, IVCIL does not offer healthcare services at its physical location; however, during the pandemic, following the Food and Drug Administration's (FDA) Emergency Use Authorization of the COVID-19 vaccines, IVCIL applied to be a location for vaccine clinics through the State of Illinois. These clinics are open to the public, encompassing clients who are not currently consumers of IVCIL services. IVCIL promotes the idea of making informed health care decisions and supporting preventative care, such as vaccinations.

LIFE Center for Independent Living

LIFE Center for Independent Living (LIFE CIL) has two physical locations, with the main agency in Bloomington, Illinois, and another location in Pontiac, Illinois, serving the counties of DeWitt, Ford, Livingston, and McLean. Like the other two CIL agencies interviewed, LIFE CIL serves primarily rural, farming communities and aligns its programs with the five core principles of CILs. Not only do LIFE CIL's programs serve individuals with disabilities, empowering them with knowledge to lead independent lives, but LIFE CIL also promotes legal advocacy. Like Advocates for Access, LIFE CIL networks with other agencies to support their consumers, such as transportation services, health care providers, and independent living support services. In accordance with the state CIL requirement to have at least 50% of staff be individuals with disabilities, LIFE CIL exceeds that requirement with a percentage of 100%.

LIFE CIL does not provide health care services at its locations, but networks to connect individuals to outside health resources.

Perceived Health Care Inequities

Information shared by Advocates for Access, IVCIL, and LIFE CIL and local support agencies highlighted similar perceived inequities in access to health care. In a rural geographic region, a lack of available transportation was identified as the primary reason for a lack in access to healthcare facilities. Transportation encompasses more than ownership and the ability to afford the operation of a vehicle; it includes the ability to pay for a mode of public transportation and the availability of public transportation services.

Local health departments described public transit services available to county residents. Unlike public transportation options in urban areas, such as large bus services or trains, rural public transit is limited to vehicle travel only. Identified by the Ford County Health Department, the public transit service in the area is Show Bus, a small bus line that operates in a nine-county region. Each county has specific routes on a timed schedule and appointments to ride must be made at least one day in advance (Show Bus, 2021). Fares for Show Bus are \$5.00 within the county and \$7.00 for travel outside of the county, per ride (Show Bus, 2021).

In Woodford County, the public transit service is We Care Transportation, a bus line that serves a three-county region. Like Show Bus, We Care Transportation asks for appointments to ride at least one day in advance of the scheduled trip, with fares of \$3.00 per ride (We Care, Inc., 2021). For both transportation services, adults over 60 years of age can ride for free and buses are accessible for individuals with disabilities (Show Bus, 2021; We Care, Inc., 2021).

Additionally, the Central Illinois Agency on Aging serves Woodford County seniors with bus

service. This transportation option requires a determination that the bus service is the only available means of transportation to the individual, and trips are prioritized, with doctor visits ranked as third priority (Central Illinois Agency on Aging, 2021).

Identified by the LaSalle County Health Department is the public transit service NCAT, a small bus line that serves LaSalle County. NCAT asks for appointments to ride at least a day in advance, with fares ranging from \$2.50 to \$10 per ride (NCAT, 2021). Public transportation services in rural areas are available, but unlike urban public transit options, difficult to access. These services require the ability to pay for rides and the planning to reserve transportation in advance of needing access. IVCIL noted that there are options for transportation access through insurance providers; however, these options also require advance planning and vary by insurer. For individuals able to own and operate a vehicle, there are fewer barriers in planning to access health care; however, costs are still incurred, in licensing and maintaining the vehicle, and purchasing gasoline for travel. While transportation is identified as the leading barrier to health care access in rural areas, economic factors, such as fixed incomes, remain barriers to overcoming other barriers, especially during a pandemic.

A secondary reason, identified by both CILs and local health departments, that contributed to a lack of access to health care was the lack of available technology and internet access to individuals in rural areas. In the thirteen counties included in this case study, the median percentage of households without a technology device, including a desktop or laptop computer, smartphone, or other technology is 14.6%, with 24.7% having no internet or smartphone data service (see Appendix C). Without digital access, individuals are unable to find answers to health care questions, discern legitimate health care information, and find locations that meet their health care needs. More recently, the internet, email messaging, and social media

have become commonplace forms of health care knowledge and information dissemination. IVCIL noted that they dispersed information about COVID-19 vaccine clinics through email reminders and Facebook. In a broader context, pharmacies and health departments registered individuals for vaccine appointments through form submissions online. LIFE CIL noted that younger consumers frequently found health care information on social media sites; sometimes, this information was incorrect, yet it was the primary information source sought by this age demographic. The lack of technology in rural areas results from a lack of device, a lack of internet service, a lack of user knowledge, and a lack of income to support technology and connectivity.

Hardships from COVID-19

The COVID-19 pandemic has changed the ways in which individuals live their daily lives and the ways in which nonprofit agencies operate. While, historically, there have been circumstances that require shifts in daily routines and operations, such as weather-related closures or routine maintenance to facilities, COVID-19 has affected change on a global scale for nearly two years. During this time, the CDC and IDPH have adjusted guidance in keeping with current knowledge of the virus, causing fluid circumstances and revisions of protocols. Early guidance included lockdowns and minimal access to locations outside of one's home. Current guidance still requires social distancing, mask use, frequent hand sanitation, and the avoidance of public spaces and commonly touched surfaces.

For individuals with disabilities, the primary effects of the pandemic have been realized in social isolation. All three CIL agencies identified social isolation as the leading hardship resulting from the pandemic for their consumers. This social isolation has occurred not only as a result of state and federal mandates to stay at home, but also from individual fears of being in

group environments. Advocates for Access stated that social isolation was “huge” for their consumers. LIFE CIL stated that there is “a lot” of reluctance among consumers towards coming to CIL locations in person, due to personal health fears. Individuals with disabilities can have health conditions or take medications that make them more susceptible to COVID-19 infection. They may rely upon public modes of transportation, where social distancing may not be optimal or common surfaces may need to be used. Additionally, individuals with disabilities may not understand why masking is essential for public spaces. For individuals with disabilities working in public job roles, the combination of public spaces and greater personal health risks have led to unemployment.

In an effort to maintain access to services amid lockdowns, many physical services have transitioned into virtual programs. While, in theory, this transition would seem to remove potential barriers, in reality, it creates them. In rural central Illinois, there is a “digital divide” that stems from a lack of access to affordable internet in rural communities, affordable technology and the knowledge required to use such technology. Individuals on fixed incomes or those currently unemployed are unable to afford technologies or internet services to connect to virtual programs, such as telemedicine. This economic hardship requires that individuals access healthcare in-person, a potential reason to not seek care amid a pandemic.

Role of Support Agencies

Of the three local support agencies interviewed, all were county health departments. Each county health department felt that, in their role as a support agency, their primary focus was to educate individuals on healthcare, either directly or through other agencies. Administratively, county health departments have divisions of environmental health and personal health. Currently, COVID-19 data tracking and vaccine disbursement is administered under environmental health

as a response to a public health emergency. The Woodford County health department stated that “the role of local health departments is misunderstood.” Often, individuals seeking care or information through local health departments are being “reactive, not proactive” in accessing health care. County health departments operate with “limited funding,” leading many to network with other counties and agencies to provide better networks of care to individuals, including hospitals, public transportation agencies, and health care facilities.

As state agencies, county health departments are the points of disbursement for COVID-19 vaccines within communities. This disbursement takes the form of providing vaccine to other agencies for clinics or providing direct vaccination on-site for individuals. County health departments maintain the statistics of individuals vaccinated within the county and report these statistics to the state through an Illinois vaccine database. This database does not include individuals residing in Illinois that received vaccinations outside of Illinois.

Perceptions of the COVID-19 Vaccines

Unlike other vaccines, there are three vaccines for COVID-19. Manufactured under the FDA’s Emergency Use Authorization, with the Comirnaty™ vaccine now FDA approved, the three vaccines vary slightly in effectiveness statistics, dosing schedule and anticipated side effects. In speaking with county health departments, it was noted that the public perceived the COVID-19 vaccine in “highly political” ways, compared to other immunizations. Concerns regarding the COVID-19 vaccine and potential risks were seen as politically divisional. The Woodford County health department stated that, “if you didn’t get the vaccine, you were red [Republican], and if you got the vaccine, you were blue [Democrat], and that meant the health department was blue.” The Woodford County health department felt that this perception caused

individuals to not take their health care seriously – to not participate in a preventative health care initiative – for fear of being politically aligned.

Methods Employed by Nonprofits

Each CIL actively engaged new methods to prevent social isolation from negatively impacting its consumers, countered personal health fears through the home delivery of supplies, and sought and secured funding to bridge gaps created by the pandemic. Additionally, CILs employed methods of engagement focused on the COVID-19 vaccine. All of these strategies helped close new gaps resulting from COVID-19 by maintaining the ability for each CIL to continue to provide services centered on the five core competencies.

Social isolation greatly affected CIL consumers during the COVID-19 pandemic. During lockdowns, each CIL agency tried to mitigate social isolation by hosting specific outreach programs. Advocates for Access made and delivered Christmas goody bags to consumers' homes. All three CILs hosted virtual social programs, conference call programs, and activities. LIFE CIL connected with consumers through one-on-one telephone or virtual check-ins. IVCIL delivered food boxes to consumers through a partnership with a local grocery store, mitigating the need for consumers to be at risk in public places. These methods to facilitate a personal connection helped consumers through the mental health challenges of lockdowns and isolation and extended the organization beyond the physical agency space to serve consumers.

Through federal funding from the CARES Act, each CIL was able to provide financial assistance to individuals with disabilities, either those unemployed due to health risks or job cuts, those in need of food assistance or individuals needing rent assistance. IVCIL used state grant funding from the Illinois Covid-19 Response Fund (ICRF) to purchase locally produced hand

sanitizer products for free distribution to consumers' homes, and later, used local grant funding to purchase technology and technology instruction for loan to consumers at home for social interaction and telemedicine. This secured grant funding by all three CILs was in addition to regular finding sources, requiring dedicated time for grant administration by staff members.

As the COVID-19 vaccine became available, CIL agencies followed their missions to educate and empower within the five core competencies. LIFE CIL engaged their consumers through a personal phone call campaign. Staff called each consumer to ask the individual if he/she had received the COVID-19 vaccine, ask why or why not, and if there was a way in which LIFE CIL could help that individual access the vaccine, such as arrange transportation or connect a consumer with their primary care physician. LIFE CIL found that the majority of their consumers had already received their COVID-19 vaccine. Of those who had not already received the vaccine, the majority did ask for additional information on vaccine options and access points, such as doctor's offices or clinics. A "small" percentage of consumers declined to discuss the vaccine and were "very against it." This CIL agency did not host a clinic on-site, as it was committed to letting individuals make their own choices about vaccination. The CIL noted that it emphasized education on the differences among the three vaccines, with each vaccine having pros and cons for each individual, and recommended that consumers speak to their primary care physician to learn which vaccine was the best option. LIFE CIL supported its consumers through knowledge and education, including education through online resources and social media.

Advocates for Access employed a method of consumer education through connecting individuals to clinic sites and providing supportive services. Using online resources and social media, Advocates for Access shared information about the COVID-19 vaccine with individuals. For consumers interested in receiving the vaccine, Advocates for Access would connect the

person with transportation arrangements, assist in registering the consumer for an appointment online, or network with other agencies to help connect the individual to a vaccine opportunity. In one instance, Advocates for Access staff coordinated paramedics making a home visit to administer a vaccine to a homebound consumer. This coordination was approached on an individual basis.

IVCIL used methods of both consumer education and enabling access to the COVID-19 vaccine in a safe environment. Connecting to consumers via social media, local radio, and paper flyers distributed in multiple locations, IVCIL empowered consumers to make informed decisions about COVID-19 vaccines. Through federal funding, IVCIL was able to host multiple COVID-19 vaccine clinics at their CIL location. To host a clinic, IVCIL had to apply through the State of Illinois website as a clinic location (IDPH, 2021). The clinic materials and resources were provided directly by state agencies; however, local health department staff supported the events by promoting the event. IVCIL promoted the clinics as way to keep individuals and their loved ones safe. By hosting clinics at IVCIL, consumers felt that they were attending a vaccine clinic in a safe environment and CIL staff stated that there were no negative comments from consumers as a result of hosting clinics. Currently, IVCIL's COVID-19 vaccine clinics are ongoing.

Conclusion

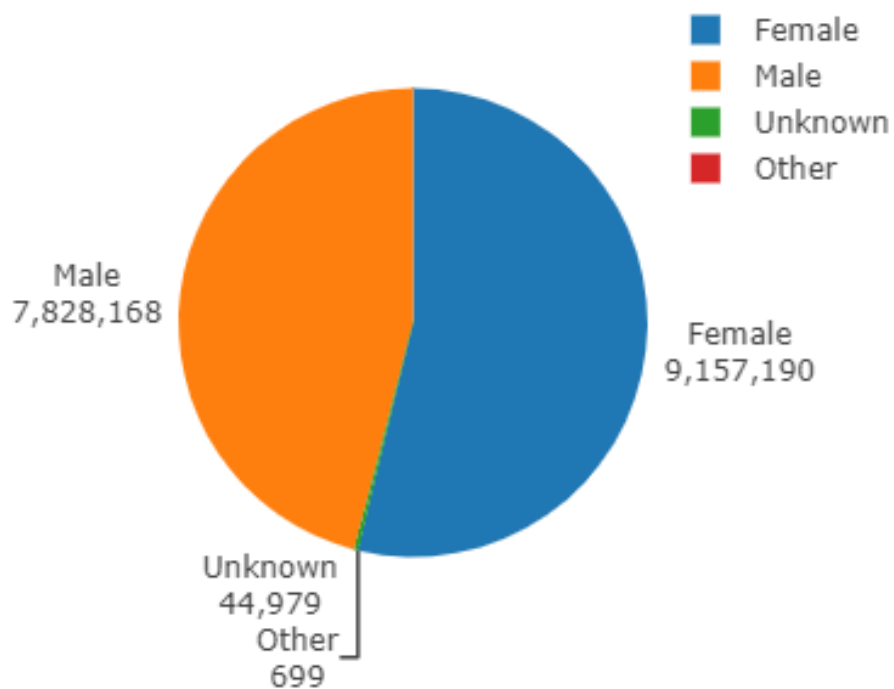
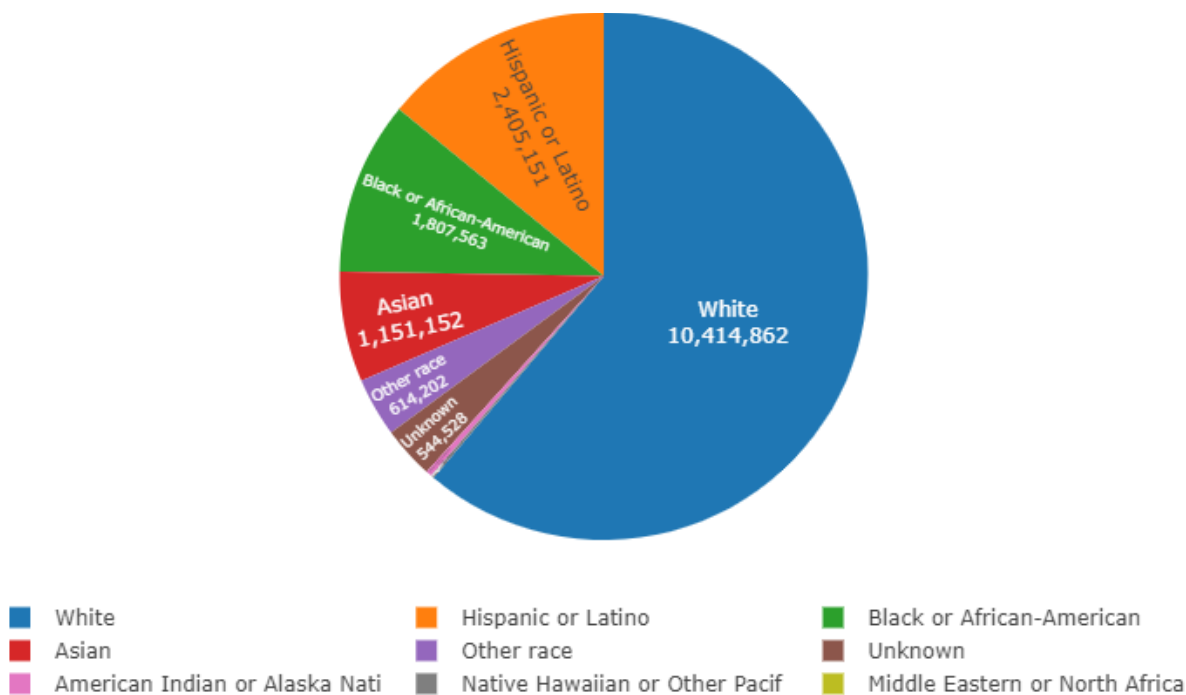
Individuals with disabilities are not an individual demographic typically included on studies of health care access and access gaps. As a result, there is little data that demonstrates access gaps specifically for this group. The regions where these individuals reside greatly impact levels of access, and using regional trends, one can anticipate the struggles faced in accessing basic health care services. The COVID-19 pandemic has created global challenges, regardless of

ability. Yet, for individuals with disabilities, the challenges are amplified through social isolation, transportation services, lack of technology or connectivity and the increased health risks of being in public places. CIL agencies have served consumers for decades, creating a solid foundation of core services to empower individuals to lead independent lives. While COVID-19 challenges CILs in both the way that the organizations operate and the way in which they serve their consumers, by maintaining their core services, CILs have successfully supported their consumers during the pandemic. To maintain these services, CILs have secured pandemic-specific funding from local and government agencies, altered program formats from in-person to virtual or via phone, cultivated knowledge for their consumers to make informed health choices, and created safe spaces within which consumers access the COVID-19 vaccine. Using methods that strengthened a commitment to their mission, CILs have successfully continued their service to their communities.

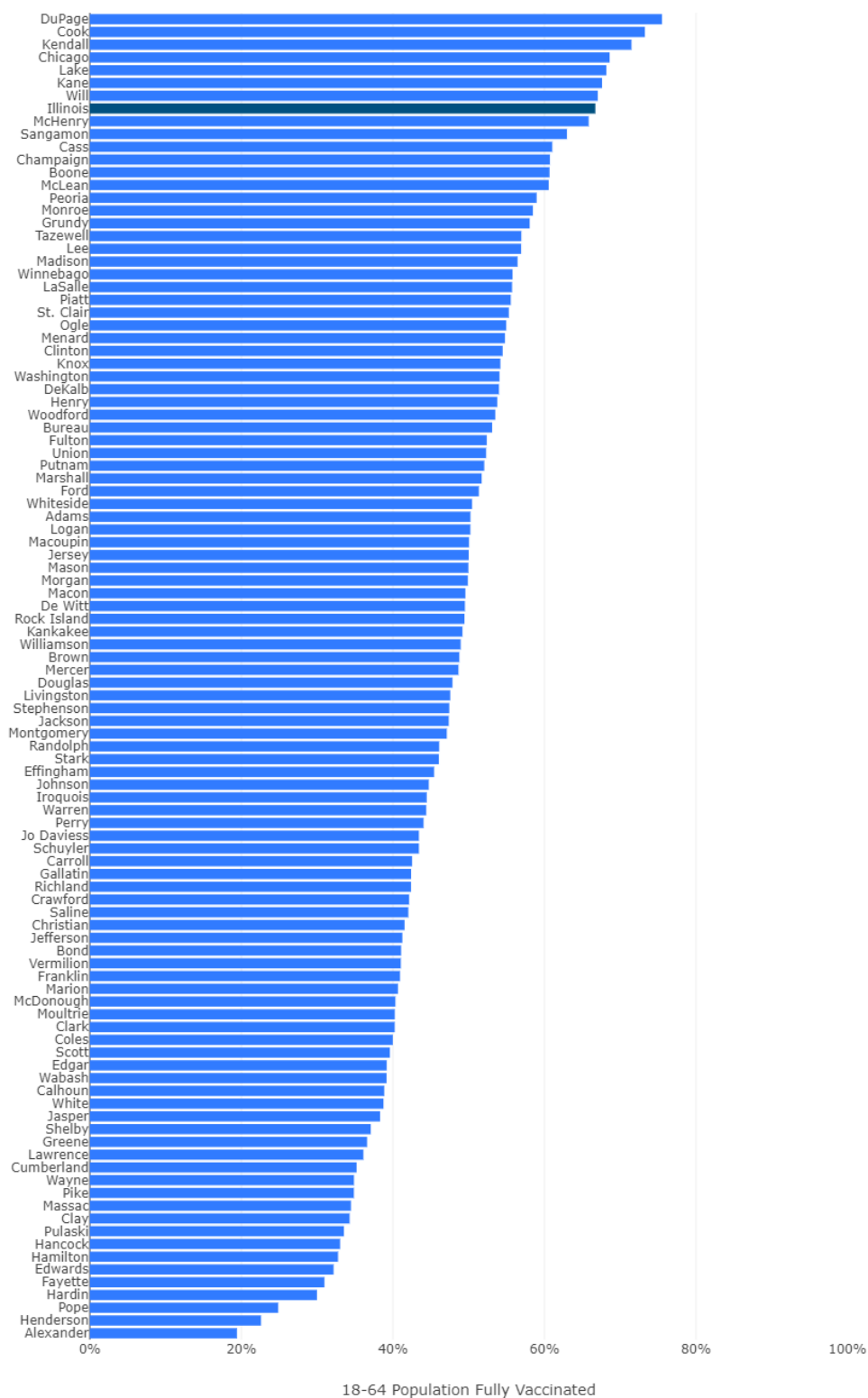
Notes

In the realm of nonprofits, individuals who use nonprofit services are typically referred to as the “beneficiaries” of a nonprofit agency. In speaking with CIL agencies, the correct reference to individuals who use CIL services is “consumers.” As such, the term “consumers” has been used throughout this paper.

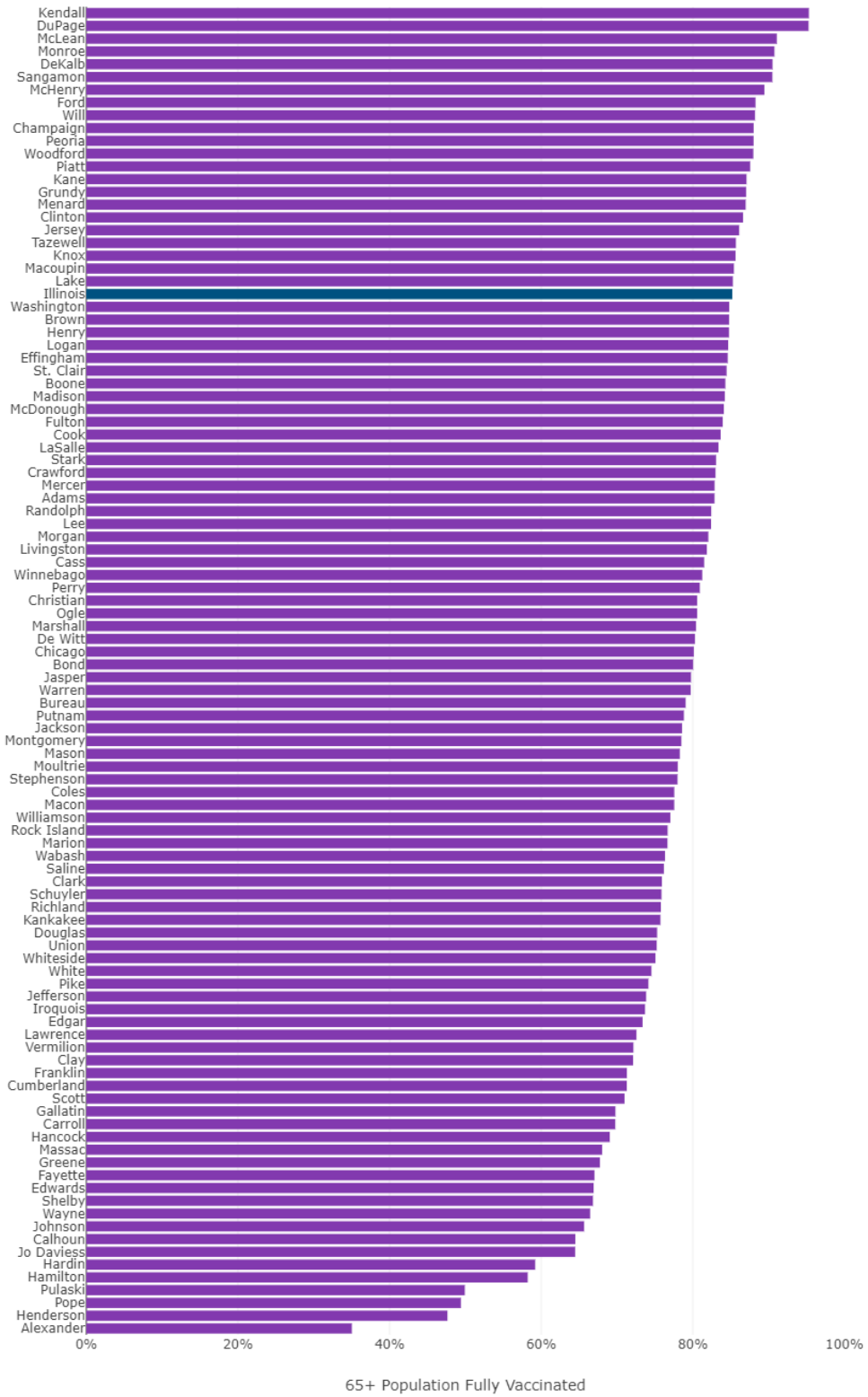
Appendix A – COVID-19 Vaccination Statistics in Illinois as of November 26, 2021



Source: Illinois Department of Public Health, 2021. <https://dph.illinois.gov/covid19/vaccine/vaccine-data.html?county=Illinois>



Source: Illinois Department of Public Health, 2021. <https://dph.illinois.gov/covid19/vaccine/vaccine-data.html?county=Illinois>



Source: Illinois Department of Public Health, 2021. <https://dph.illinois.gov/covid19/vaccine/vaccine-data.html?county=Illinois>

Appendix B – Structured Interview Questions

- Tell me about the goals of your agency. How do you realize your mission?
- Who/what are the communities you serve?
- Do you feel that you are able to accomplish your goals in serving this community?
- What services do you offer your community that relate to healthcare?
- Do you feel that there are any gaps in access to healthcare for your community?
- Why do you feel those gaps exist? / Why do you feel no gaps exist?
- What types of services or aid are available for your community in connecting to health care resources?
- Are there any hardships that your community is experiencing from COVID-19?
- Are you providing any services to help your community handle these hardships?
- Are you helping your community connect with COVID-19 vaccine resources?
- How are you helping your community connect with these resources?

Structured Interview Questions – Support Organizations

- How does your organization support public health?
- What challenges do you see in the community in terms of access to healthcare?
- Do these challenges exist in general or do they only affect a certain group of individuals?
- Do you provide any healthcare services for individuals with disabilities?
- Do you feel that area nonprofits support healthcare access?
- Does your organization ever support these nonprofits with their initiatives?
- Do you support these nonprofits in other ways?
- How have you supported the __(nonprofit name)__ agency?

Appendix C – Technology Statistics in Studied Service Area

Illinois County	Households in County	Households with Technology	Households without Technology	Households with Internet	Households without Internet	Percentage of Households without a Device	Percentage of Households without Internet
Bureau	13,698	11,910	1,788	10,861	2,837	15.0%	26.1%
DeWitt	-	-	-	-	-	-	-
Ford	5,771	4,909	862	4,629	1,142	17.6%	24.7%
Fulton	13,940	11,775	2,165	10,936	3,004	18.4%	27.5%
LaSalle	45,095	39,353	5,742	37,187	7,908	14.6%	21.3%
Livingston	14,307	12,479	1,828	11,396	2,911	14.6%	25.5%
Marshall	4,884	4,090	794	3,748	1,136	19.4%	30.3%
McLean	65,845	61,655	4,190	54,639	11,206	6.8%	20.5%
Peoria	73,253	64,208	9,045	57,565	15,688	14.1%	27.3%
Putnam	2,413	2,096	317	1,941	472	15.1%	24.3%
Stark	2,315	1,971	344	1,787	528	17.5%	29.5%
Tazwell	54,291	47,962	6,329	44,503	9,788	13.2%	22.0%
Woodford	14,499	13,044	1,455	12,124	2,375	11.2%	19.6%

Source: American Fact Finder, 2019.

Note: DeWitt County did not have available data within the census data tables. As a result, no conclusions for technology access in this county can be made.

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