U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation
Office of Behavioral Health, Disability, and Aging Policy

COVID-19 AND PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES FINAL REPORT

July 2021

Office of the Assistant Secretary for Planning and Evaluation

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NOTE: BHDAP was previously known as the Office of Disability, Aging, and Long-Term Care Policy (DALTCP). Only our office name has changed, not our mission, portfolio, or policy focus.

This report was prepared under contract between HHS's ASPE/BHDAP and RTI International. For additional information about this subject, you can visit the BHDAP home page at https://aspe.hhs.gov/bhdap or contact the ASPE Project Officers, at HHS/ASPE/BHDAP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201; Emma.Plourde@hhs.gov, William.Haltermann@hhs.gov, Pamela.Doty@hhs.gov.

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ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

CDC	HHS Centers for Disease Control and Prevention
CDPHE	Colorado Department of Public Health and Environment
COVID-19	Coronavirus Disease 2019
DC	Developmental Center
DD	Developmental Disabilities
DODD	Ohio Department of Developmental Disabilities
DOH	Ohio Department of Health
DSP	Direct Support Professional
HCBS	Home and Community-Based Services
HCPF	Colorado Department of Health Care Policy and Financing
HHS	U.S. Department of Health and Human Services
HVAC	Heating, Ventilation, and Air Conditioning
ICF/IID	Intermediate Care Facilities for Individuals with Intellectual Disabilities
ICU	Intensive Care Unit
ID/DD	Intellectual and Developmental Disabilities
ITS	Incident Tracking System
LHD	Local Health Department
LTC	Long-Term Care
LTSS	Long-Term Services and Supports
MUI	Major Unusual Incidents
NASDDDS	National Association of State Directors of Developmental Disabilities Services
PHE	Public Health Emergency
PPE	Personal Protective Equipment

EXECUTIVE SUMMARY

As of July 23, 2021, the United States had approximately 34 million confirmed cases and over 610,000 deaths related to COVID-19 (Johns Hopkins Coronavirus Resource Center, n.d.). Several reports indicate individuals with intellectual and developmental disabilities (ID/DD) may be at increased risk for both infection and adverse impacts of COVID-19 than individuals without ID/DD (Landes et al., 2020; West Health Institute & Makary, 2020). Most individuals with ID/DD who receive services from state ID/DD agencies receive supports through Medicaid, either through home and community-based services or institutional services. During the COVID-19 public health emergency (PHE), state systems that support individuals with ID/DD adapted services, and with great variation across the country, devised the following strategies:

- Detecting COVID-19 exposure and infection among individuals with ID/DD served by state ID/DD agencies and the direct support workforce that supports them.
- Instituting policies and strategies to prevent COVID-19 infection and spread.
- Using data and information to adapt practice.
- Informing vaccine prioritization frameworks.
- Developing approaches to ascertain vaccine penetration among individuals with ID/DD and the direct service professionals that support them.

> ***A national framework for tracking communicable diseases and comorbidities increases understanding of the impacts of illness on individuals with disabilities and informs targeted and coordinated response efforts.***

The findings of this report highlight the wide variation across states in efforts to detect and prevent COVID-19 infection, and to collect COVID-19 vaccination data. During the COVID-19 PHE, states established data collection strategies with haste and urgency. The data collection strategies were influenced by existing state-level relationships and data infrastructure, and resulted in a variety of strategies that may inform future approaches to data collection and information sharing. The findings from this report also highlight the state-level collaboration necessary for a successful pandemic response for individuals with ID/DD.

1. INTRODUCTION

In the United States, there are an estimated 7.38 million individuals with intellectual and developmental disabilities (ID/DD).[1,2] Approximately 1.3 million of those individuals, most of whom are Medicaid beneficiaries, receive Medicaid-funded long-term services and supports (LTSS), through state ID/DD agencies (Larson et al., 2020). State ID/DD agencies are state-level administrations that oversee services and supports for individuals with ID/DD. State-level infrastructure varies. Some ID/DD agencies are cabinet-level departments, while others are administrations within a state's Department of Health or Department of Human Services.

Across the country, more than 300,000 individuals with ID/DD receiving Medicaid LTSS live in congregate settings of three or more individuals, which include group homes, intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), or other group settings. An additional 26,000 individuals with ID/DD live in nursing facilities or psychiatric facilities. The remainder of individuals with ID/DD served by state ID/DD systems, approximately 77 percent, reside in their own home, the home of a family member, or in small foster family homes (Larson et al., 2020).

The population served by state ID/DD agencies varies by state. Some state ID/DD agencies provide services from birth to death, whereas others provide services from the age an individual with ID/DD transitions from formal high school (either 18 or 22 years) until death. In states with formal service administration by the ID/DD agency beginning at age 18 or 22, other state systems, such as children's bureaus and the education system, are often the primary source of supports for children and adolescents with ID/DD.

States sometimes directly provide services to individuals with ID/DD using state-employed direct support professionals (DSPs) in government-owned and operated settings. These are referred to as publicly-operated services. States may also use a network of private providers to deliver services. These are referred to as privately-operated services. Most states have some remaining state-operated institutional services, and a few states manage state-operated home and community-based services (HCBS). These arrangements are in addition to the use of private providers to deliver services. The provision of institutional versus community-based services and

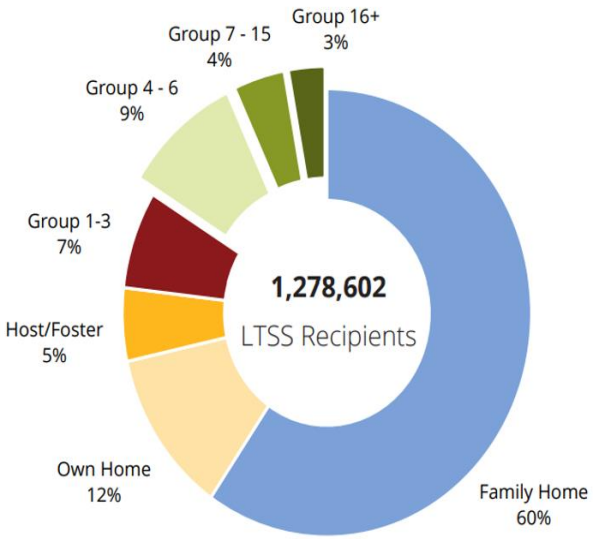
[1] Each state defines eligibility for individuals with ID/DD differently, however, in general, many states are close to the definition contained in the ***Public Law 106-402, 106th Congress***, which defines ID/DD as "severe, chronic disability of an individual that: "(i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated."

[2] The National Institute of Health defines Intellectual Disability as a disability that starts any time before the child turns 18 and is characterized by challenges with both: intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and adaptive behavior, which includes everyday social and life skills (HHS, 2021).

the use of public and private providers result in significant differences in workforce, data availability, and service models.

States also vary in the types of LTSS offered to Medicaid beneficiaries with ID/DD, with some states focusing more on supporting the individual with ID/DD in their own home, while other states focus on offering services and supports to the individual in a residential setting other than their own home. For example, Arizona supports the vast majority of individuals in their own homes or family homes, while Delaware's program, until recently, focused primarily on services in provider-owned and operated residential settings. In addition to these considerations, the presence or absence of managed LTSS, self-directed services, and the manner in which case management operates all vary by state. ***Exhibit 1*** provides the nationwide percentages of individuals served by living setting, but this is highly variable depending on the particular state (Larson et al., 2020).

EXHIBIT 1. LTSS Recipients with ID/DD by Residence Type and Size on June 30, 2017



This report provides an overview of the experiences of state ID/DD agencies and individuals with ID/DD who received state agency services during the COVID-19 public health emergency (PHE). Discussed herein are state practices to minimize COVID-19 infection among DSPs and to maximize COVID-19 vaccine uptake rates among DSPs. From the outset of the pandemic, states recognized the importance of understanding the impact of COVID-19 on the workforce that supports individuals with ID/DD. As a result of the in-person and hands-on assistance frequently provided to individuals with ID/DD, infection rates of essential personnel and strategies for vaccination play a pivotal role in state prevention and mitigation strategies.

Across the United States, as of April 20, 2021, more than 31 million cases of COVID-19 had been confirmed resulting in more than 568,000 deaths (Johns Hopkins Coronavirus Resource Center, n.d.). Several reports indicate individuals with ID/DD may be at increased risk for both infection and adverse impacts of COVID-19 than individuals without ID/DD (Landes et al., 2020; West Health Institute & Makary, 2020). A recent study reviewing approximately 65

million patient records, including those of more than 128,000 individuals with ID/DD, found the presence of an intellectual disability is a significant risk factor for acquiring COVID-19 and is the strongest risk factor, besides age, for dying from COVID-19 (Gleason et al., 2021). The high prevalence of comorbidities among individuals with ID/DD likely contributes to, or compounds, the risk factors associated with adverse outcomes for individuals with ID/DD. Individuals living in congregate settings--such as nursing homes, group homes, psychiatric facilities, and other institutions--may be at greater risk for exposure from other residents and essential personnel who provide hands-on assistance with activities of daily living and instrumental activities of daily living.

Race, ethnicity, socioeconomic status, and health care access also interact with and affect outcomes for individuals with disabilities (Goyat et al., 2016). Racial and ethnic groups--particularly American Indian/Alaska Natives and Blacks--may experience disability at a higher rate than Whites or other racial and ethnic subgroups (Courtney-Long et al., 2017). In addition, individuals with disabilities who are part of underserved racial and ethnic groups, are between the ages of 5 and 17, or are female are overrepresented in counties with high COVID-19 incidence (Chakraborty, 2021). Consequently, many state ID/DD agencies aim to understand the impact of COVID-19 on individuals with ID/DD from underserved racial and ethnic groups.

Despite indications of high infection and mortality risk, there is no standardized national framework in place to facilitate the collection and sharing of COVID-related information on individuals with ID/DD receiving supports and services from state ID/DD agencies. This report explores the following questions to ascertain COVID-19 data collection, disease mitigation, infection control, and vaccination practices in use across the country:

- What COVID-19 data do states collect and report for people with ID/DD? How do COVID-19 surveillance and reporting systems for the ID/DD population vary across states?

- How is the ID/DD population prioritized for vaccination compared to other populations in state or local vaccination plans? How closely does state or local agencies' implementation of their vaccination plans align with their intended vaccination plan (e.g., is the priority order followed)?

- What department (i.e., state ID/DD agency, state Department of Health, or local Department of Health) is in charge of vaccination for ID/DD populations in most of the states?

- What coordination processes are in place between the state ID/DD agency and state and local departments of public health to vaccinate individuals with ID/DD?

- What are the patterns of vaccination uptake and decline among the ID/DD population and their DSPs?

2. METHODS

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) actively engaged with member state ID/DD agencies from the onset of the PHE to ascertain effective practices for infection detection, prevention, and treatment of COVID-19 among individuals with ID/DD through each phase of the pandemic. Beginning in March 2020, NASDDDS convened monthly calls with state ID/DD directors and medical directors. Initially, these calls collected qualitative information on personal protective equipment (PPE) acquisition, testing availability and policies, infection rates, and spread mitigation strategies and mortality. In November 2020, the focus shifted to vaccine prioritization strategies and distribution approaches.

From January 2021 to February 2021, NASDDDS fielded an online query of states regarding the nature of data collection related to infection, mortality, and vaccine distribution across a number of factors, including living arrangement, race, ethnicity, and age for people with ID/DD and DSPs for people with ID/DD. Twenty-eight states in total responded to the query.

NASDDDS gathered the information in this report from these discussions, as well as data and information submitted directly from state ID/DD agencies. Findings also were informed by subsequent conversations with approximately 12 states to better understand their promising practices and strategies to overcome obstacles in the areas of COVID-19 infection control, data collection, and vaccination prioritization and administration.

3. FINDINGS

3.1. State Approaches to Data Collection

3.1.1. COVID-19 Surveillance Information: Exposure, Infection and Mortality Data

Most state ID/DD agencies require routine reporting of information on hospitalizations and mortality across settings for individuals with ID/DD receiving services. ***Exhibit 2*** depicts the results of an informal query of 28 states regarding data collection about people with ID/DD enrolled in services.[3] Twenty-seven of the 28 responding states indicated they were able to identify deaths due to COVID-19 of individuals with ID/DD receiving services. Twenty of the 28 responding states reported they collected data on hospitalizations resulting from a COVID-19 infection. Importantly, these data were not always linked, as certain deaths may have occurred outside of a hospital setting. Twenty-five of the 28 responding states reported they collected data on individuals receiving services who were COVID-19 positive, either presumed or confirmed through testing. States indicated collecting data on COVID-19 infections may differ for people who live on their own or with family, as requirements for reporting infections generally only apply to formal residential services outside of the family or private home. Sixteen of the 28 states indicated that they have some data available for people who live with their families or in a home/apartment of their own, though the sources and contents of that information varies by state and is significantly less comprehensive than data available from formal provider-owned and operated residential settings.

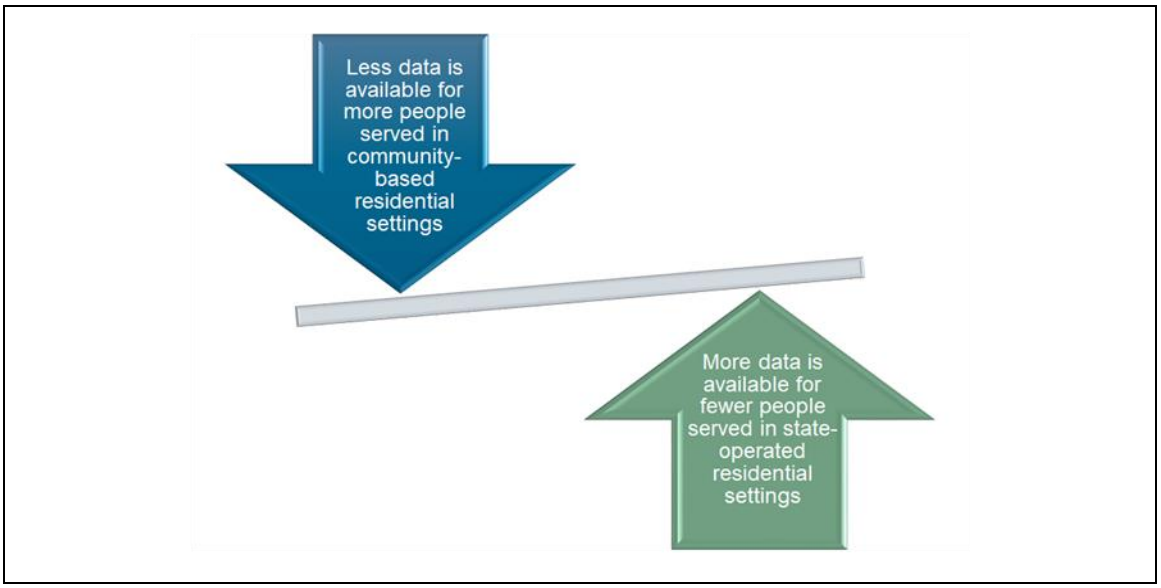
EXHIBIT 2. States Reporting Data Collection on People with ID/DD Enrolled in Services in Specific Areas of Concern

N=28	Majority/Most	Many/Some	Few/None
Individuals enrolled in services who tested or were presumed positive	25 (89%)		
Number of people hospitalized due to COVID-19		20 (71%)	
Aggregate number of people tested or presumed positive, from start of pandemic	25 (89%)		
Number of people tested for COVID-19 and the results of such tests			9 (32%)
Deaths directly attributed to COVID-19 infection	27 (93%)		
Deaths directly attributed to COVID-19 infection, by race/ethnicity and age		12 (43%)	
Number of people admitted to an ICU or who became ventilator-dependent due to COVID-19			4 (14%)
Number of people who have recovered from COVID-19		11 (39%)	
Number of people fully vaccinated against COVID-19		12 (43%)	
Number of DSPs working in HCBS regulated group settings or publicly-operated ICF/IID who tested positive		14 (50%)	
Number of DSPs fully vaccinated against COVID-19			4 (14%)
Case rate for COVID-19		19 (68%)	
Mortality rate for COVID-19		19 (68%)	
NOTE: With the exception of the information about DSPs, all other data reference people receiving services through state ID/DD systems.			

[3] NASDDDS Member Query; February 2021.

Aside from the 16 states that reported collecting information about people living in their own homes or with family, states generally reported, both through the query and in related discussions, having more limited data on individuals receiving Medicaid-funded HCBS living in their own homes or the homes of family members, which includes over 70 percent of the ID/DD population that receives LTSS (Larson et. al., 2020). Many states advised such individuals to follow the general community guidance for testing and treatment and did not immediately stipulate data reporting requirements for individuals and families, assuming that other lagging data sets, such as claims, would provide the needed information.

Pursuant to the U.S. Department of Health and Human Services (HHS) Centers for Medicare & Medicaid Services' expectations related to health and welfare, states generally have structures in place to detect instances of abuse, neglect, and exploitation. Despite these structures, ready access to timely health claims and demographic information varies greatly by state ID/DD and Medicaid systems. Many individuals receiving state ID/DD services may have primary health coverage outside of Medicaid, for example through private insurance, making claims information difficult to obtain for individuals living in community residences. Sixteen states reported having data to further analyze rates of positive cases by race, ethnicity, age, and other health factors, though this appears quite variable within and across states.[4] Through individual conversations, additional states that did not respond to the query also indicated potential ability to conduct COVID-19 analyses by race, ethnicity, age, and other health factors, with greater likelihood for analyses as additional data sets or data comparison capabilities emerge.



The availability of tests and disparate testing strategies across all settings, as well as each state's related reporting structures, affect statewide understanding of rates of infection among individuals with ID/DD. In general, however, states have the most real-time, comprehensive information available for state-operated institutional and state-operated community-based

[4] NASDDDS Member Query; February 2021.

residential settings. These settings often had early access to testing and established testing protocols for the individuals supported and the staff. Because states employ DSPs in state-operated services, these data tend to include information on both individuals supported and DSPs.

States often have comprehensive data on individuals living in provider-owned and operated group residential service settings. Many states facilitated testing in these sites and require service providers to share information on exposures and positive cases. However, states have somewhat less reliable information regarding the DSPs in these settings due to privacy considerations.

States generally have the least reliable information on exposure and positivity among individuals living in their own home and/or their family home despite the fact that they receive some level of service from the state systems. Given that these individuals live in private residences, many states advised these individuals to follow the generally recommended approach for all community members to testing and isolation, without an established information pipeline for COVID-19 information.

EXHIBIT 3. Selected State Data Sources and Strategies: Exposures and Infections

State	Public ICF/IID	Private ICF/IID	HCBS Congregate	HCBS Own Home/Family Home
Louisiana	***Database:*** Office of Public Health COVID-19 Database ***Data submitted through:*** public health reporting mechanisms ***Database:*** Employee and Resident Survey Database ***Data submitted by:*** providers	***Database:*** Office of Public Health COVID-19 Database ***Data submitted through:*** public health reporting mechanisms	Louisiana does not have any facilities classified as HCBS Congregate	***Database:*** Office of Citizens with Developmental Disabilities Recipient Survey Database ***Data submitted through:*** Survey fielded periodically with individuals and families
Ohio	State Developmental Centers reporting directly to state DODD and to Ohio Department of Health ***Database:*** State ITS--Subset--Reported Hospitalizations ***Data submitted by:*** providers and/or case managers in accordance with required incident reporting	County Boards--Reporting to Ohio Association of County Boards Facilities reporting to Ohio DOH ***Database:*** ITS--Subset--Reported Hospitalizations ***Data submitted by:*** providers and/or case managers in accordance with required incident reporting	County Boards--Reporting to Ohio Association of County Boards ***Database:*** State ITS--Subset--Reported Hospitalizations ***Data submitted by:*** providers and/or case managers in accordance with required incident reporting	County Boards--Reporting to Ohio Association of County Boards ***Database:*** State ITS--Subset--Reported Hospitalizations ***Data submitted by:*** providers and/or case managers in accordance with required incident reporting
Pennsylvania	***Database:*** ITS ***Data submitted by:*** DSPs directly reporting from facilities to Department of Human Services	***Database:*** ITS ***Data submitted by:*** providers and/or case managers in accordance with required incident reporting DSPs provided separate reporting	***Database:*** ITS ***Data submitted by:*** providers and/or case managers in accordance with required incident reporting DSPs provided separate reporting	***Database:*** ITS ***Data submitted by:*** providers and/or case managers in accordance with required incident reporting DSPs provided separate reporting

States with robust data infrastructure within ID/DD agencies prior to the COVID-19 PHE were best able to institute methods for data collection on infection and mitigation status. Some states relied entirely on their public health reporting mechanisms; some cross-referenced other data sets (such as Medicaid eligibility data sets) or separate alert strategies to enable provider-specific information on positivity or exposure rates. For example, some states may use provider-reported information on infections and exposures and attempt to cross-reference with Medicaid claims. Many other states focused on data from critical incident management systems for exposure, positivity, hospitalization, and mortality information. Some states used a combination of these, with the goal to inform responses that mitigate further infections while addressing the infrastructure needs of the provider community. The methods for data submission also vary, with states relying on email, spreadsheets, or verbal contacts with identified key personnel. ***Exhibit 3*** depicts some selected systems for data collection across various settings within states, highlighting that there is no uniform approach. Each database identified in ***Exhibit 3*** is state-specific. The manner in which data populates these sources varies by state and may have evolved over time.

3.1.2. Data Reporting and Communication Informed States' COVID-19 Responses

States with the most comprehensive data, infection response, and prevention strategies, cultivated and relied on key partnerships between state ID/DD agencies, Medicaid agencies, emergency management and public health agencies, hospitals, and pharmacies (including their associations), as well as with local entities supporting the delivery of LTSS (e.g., county boards, administrative entities, service providers).

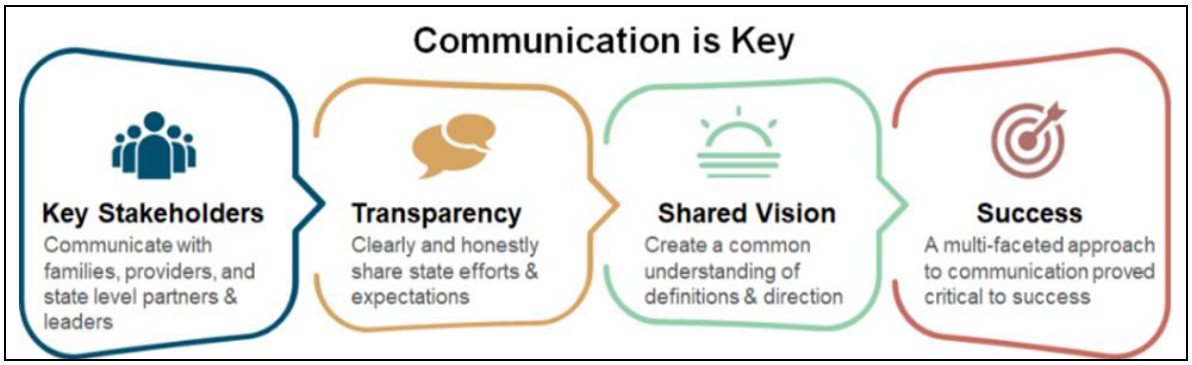
For example, a Colorado task force, led by the Department of Health, Emergency Management and the Department of Health Care Policy and Finance, which oversees ID/DD services within the state, made test kits and test processing available to all residential care settings, and if needed, hands-on assistance with sample collection was provided on-site. The state even activated the National Guard to support the work of test distribution and sample collection. Colorado's task force developed and expanded data systems, created a testing support request form, designated regional lab coordinators to assist providers, and designed data dashboards for displaying and analyzing test results. The state also adapted an existing emergency management database to collect key information on current PPE supply, available beds, COVID-19 cases, and staffing, and used the data to identify facilities needing support or resources.

Of the states with the most comprehensive data, infection response and prevention strategies, one commonality is that cultivation of and reliance on **KEY PARTNERSHIPS**:

- ID/DD Agency
- Medicaid Agency
- Emergency Management
- Public Health
- Hospitals
- Pharmacies and Pharmacy Associations
- Local and county boards and administrative entities
- Service providers

Although some states quickly forged new relationships, others leveraged long-standing partnerships, sometimes facilitated by state leadership expectations. Ohio's Department of Developmental Disabilities (DODD) partnered with the Department of Health (DOH), Department of Medicaid, and Department of Aging throughout the pandemic. While these agencies had existing relationships, the governor set forth the expectation at the outset of the pandemic that there would be a coordinated, cross-agency effort to address COVID-19. Together, the agencies created an LTSS pre-surge planning toolkit that includes concept diagrams and tools related to COVID-19 mitigation, including symptomology tracking tools for institutional and community-based settings. This toolkit distilled complicated concepts into simple terms and focused on the importance of person-centered practices throughout the pandemic (Ohio DOH, 2020).

Many states reported communication has been the most effective tool in their COVID-19 response effort, including in PPE allocation, testing strategies, specialty skill team dispatch, and vaccine prioritization and distribution approaches. Regular interaction with stakeholders--including providers, advocates, individuals, and family members--has been key in establishing a common understanding and commitment, fostering transparency, instilling confidence, and ensuring timely information sharing related to COVID-19 and response efforts. These engagements provided states with crucial pathways for sharing and gathering information with all stakeholders, thus strengthening states' knowledge and influencing their response options, enabling them to effectively support individuals with disabilities and the providers caring for them.



Almost universally, states reported that they have used information from stakeholder communication, such as weekly family and provider meetings and periodic--sometimes daily--email updates, to inform policy and practice and to apprise stakeholders of the current status of the virus.

For example, Indiana's state ID/DD district office staff utilized weekly phone calls with community provider organizations to collect data on issues such as access to and on-hand supply of PPE. This provided vital information to the Bureau of Developmental Disability Services and Bureau of Quality Improvement Services on resources for available PPE, providers with large stock, and providers in imminent danger of running out of supplies. Such information enabled key connections and resource sharing to ensure adequate PPE was available for all group residential settings.

In New York, the State Office for People with Developmental Disabilities holds a biweekly stakeholder forum that includes families, individuals receiving services, provider associations, and other stakeholders. This communication contributed to the development of the *COVID-19 In Plain Language* website[5] and enabled advocates to better engage in conversations about vaccine prioritization for people with ID/DD.

States have interpreted the HHS Centers for Disease Control and Prevention (CDC) guidance related to long-term care (LTC) settings differently, with some interpreting the guidance as applying only to assisted living and nursing facilities, whereas others have interpreted the guidance to include any settings where individuals receive LTSS.

During the first two months of the PHE, some individuals across state agencies were unsure how to fill out the CDC's individual reporting form. The form included a question about the presence of a neurologic disability. Instructions on how to complete the CDC form stated all disability types should be considered, but in the early days of the pandemic, many data reporters at local county public health levels did not understand the instructions to include all disabilities. CDC updated the form and modified the questions to "Disability: Yes/No/Unknown," with options to indicate neurologic, neurodevelopmental, intellectual, physical, vision, or hearing impairments.[6,7] While this change was minor, it provided the necessary clarity for reporting entities on including disability status. With the updated version, CDC also clarified and expanded response options for type of residence "where this person was staying at the time of illness onset" to include the list noted in the sidebar. This level of detail provides insight into the types of settings where the incidence of infection may be more likely, informing both short-term mitigation strategies, as well as longer-term service setting design decisions.

CDC Report Options for Housing Type, as of May 2020:

1. House/single family home
2. Apartment
3. Hotel/motel
4. Long-term care facility
5. Nursing home/assisted living facility
6. Acute care inpatient facility
7. Rehabilitation facility
8. Correctional facility
9. Mobile home
10. Group home
11. Homeless shelter
12. Outside, in a care, or other location not meant for human habitation
13. Other, specify
14. Unknown

In addition to the CDC requirements for public health reporting of COVID-19, some states also required infection reporting by ID/DD service providers to other entities within the state.

[5] See https://opwdd.ny.gov/coronavirus-guidance/covid-19-plain-language.

[6] See https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf.

[7] See https://www.cdc.gov/coronavirus/2019-ncov/downloads/php/COVID19-case-reporting-datadictionary.pdf.

These requirements added administrative complexity and challenge for many providers who were in the midst of emergency spread prevention, securing PPE and ensuring adequate staffing capacity. In many states, nearly one-half of all contracted service provider agencies employ 20 or fewer direct support employees, making both outreach to and data collection from these entities extraordinarily complex undertakings (National Core Indicators, 2021). In such organizations, it is not unusual for computers with data reporting system access to be located in one office, requiring additional logistics to coordinate and centrally convey the necessary information. States heard from service providers that multiple reporting requirements existed, from the state and federal levels, often with inconsistent definitions or requiring significant time to complete. Sometimes, requirements across state and local entities differed, contributing to additional complexity.

3.1.3. States' Use of Data to Drive Policy Actions

From the beginning of the PHE, state ID/DD agencies, often in partnership with state public health agencies, state Medicaid agencies, and state emergency management entities, implemented state-specific responses, informed by data, resource, and infrastructure availability.

To the extent possible, states are relying on data to make policy decisions. For example, Missouri's access to real-time infection rates across all local counties provided source information for the state ID/DD agency to make data-informed service modality changes. This included the adjustment of case management in-person monitoring to remote monitoring so that risk of spread was mitigated in areas with high levels of infection. As rates declined, the state, informed by data, permitted case managers to resume in-person visits, using social distancing and other protective measures.

> ***One state noted that a "key objective of reporting was to provide situational awareness to inform our immediate intervention to outbreaks at the provider/individual level and to identify trends, etc. to inform other response activities".***

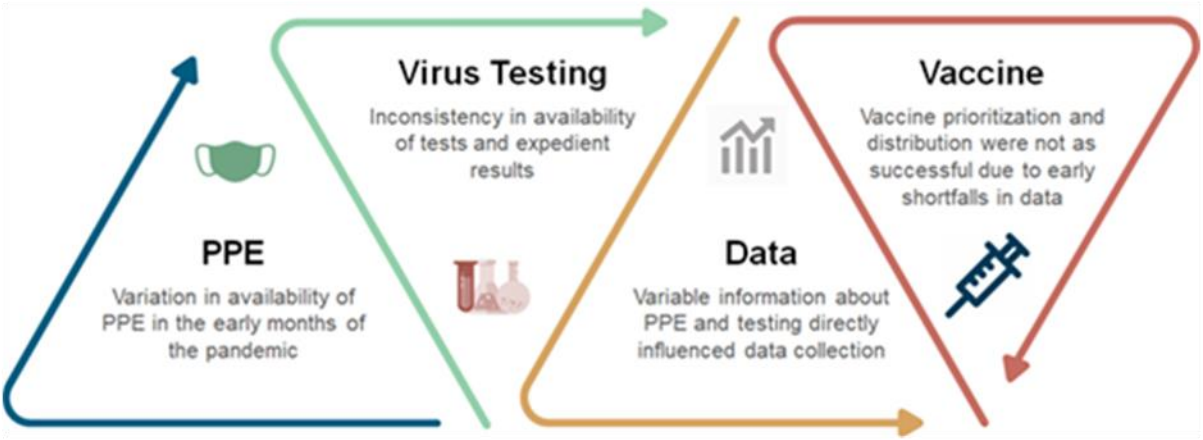
States also used exposure and infection rate information to inform targeted payment strategies for both provider agencies and DSPs to ensure continuity of service provision for individuals with ID/DD. For example, Arkansas instituted an enhanced tiered payment based on the acuity of individuals served who had tested positive for COVID-19.

From the beginning of the pandemic, circumstances on the ground in states had cascading and interconnected implications for the long-range strategies employed by states to support individuals with ID/DD. Availability of PPE and strategies for its distribution impacted infection rates in congregate settings; testing availability, reliability, and deployment directly impacted data availability; state infrastructure and roles and responsibilities impacted the capacity of states to collect and use surveillance data; and the availability and quality of data drove policy decisions, including vaccine prioritization strategies.

3.2. State Vaccine Prioritization Among Individuals with ID/DD

The availability of PPE, virus testing, and reliable infection data impacted states' decisions about vaccine prioritization categories and, consequently, approaches to vaccine distribution (***Exhibit 4***).

EXHIBIT 4. Factors Influencing COVID-19 Data for the ID/DD Population



State approaches to vaccine prioritization efforts are as variable as data collection efforts. The practices are similarly dynamic, with states continuing to make adaptations to their prioritization categories. Although most states are currently vaccinating all adults over the age of 16, the categories of prioritization in place prior to that milestone were critical for individuals with ID/DD. Some states immediately included individuals with ID/DD and their DSPs in their top or near-top priority categories, such as Ohio and Colorado. Some states, such as New York, added groups of individuals with ID/DD as information emerged and confirmed the risk factors associated with ID/DD. Other states, such as Connecticut, moved away from condition-specific considerations and instead prioritized solely on age, while several states have gone back and forth.

Over time, more states explicitly or implicitly included individuals with ID/DD and the DSP workforce among the highest priority categories. Some states may not mention ID/DD directly, but may include them by nature of the LTSS settings in which individuals receive services, or because they require DSP assistance with activities of daily living. ***Exhibit 5*** represents the vaccine prioritization approach for individuals with ID/DD and DSPs in selected states.

Prior to opening vaccines to all adults, some states continued to include only a portion of individuals living in their own homes and family homes depending on their other comorbidities. Emerging data contributed to a few of those states, including New York and California, adding ID/DD as a qualifying factor for vaccine prioritization (with variation on which prioritization level).[8]

[8] Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). The devastating impact of COVID-19 on individuals with intellectual disabilities in the United States. *NEJM Catalyst*.

EXHIBIT 5. Selected State Vaccine Prioritization Approaches for Individuals with ID/DD and DSP Workforce	
Colorado	Colorado defined its LTC settings to include ID/DD community-based settings in Phase 1a and included "individuals with disabilities who require direct care in their home, and people with disabilities that prevent them from wearing masks" in Phase 1.b.2 (Colorado Department of Public Health and Environment and Colorado State Emergency Operations Center, n.d.; Dooling et al., 2021).
Pennsylvania	Pennsylvania prioritized people with disabilities and, if applicable, their paid and unpaid caregivers in Phase 1a or Phase 1b of the state vaccination plan.
Oregon	Oregon included individuals with disabilities and their caregivers in Phase 1a (with variation on group sequencing depending on living situation).
Ohio	Ohio defined congregate care settings as housing two or more people with disabilities. This expanded definition qualified people with disabilities living in about 4,000 non-licensed waiver settings (some family homes) for Phase 1a of the state vaccination plan. Individuals with ID/DD and congenital conditions were identified through a Medicaid data match to receive the vaccine as part of Ohio's Phase 1b.

3.3. Vaccine Distribution Among Individuals with ID/DD

The vaccination rate among individuals with ID/DD differs across and within states. As of late April 2021, many states report high rates of vaccination among individuals in congregate settings, but efforts to maximize vaccine uptake continue.[9] For example, Kentucky reported that all individuals living in congregate settings who wanted to get a vaccine received one.

From December 2020 through March 2021, state ID/DD agencies experienced challenges including inadequate vaccine supply and, in some instances, a lack of viable partners, such as pharmacies with capacity to assist in a targeted distribution effort to individuals with disabilities. State ID/DD agency access to vaccines varied widely across the country. Some states leveraged the Federal Pharmacy Partnership Program for supply and distribution. Other state ID/DD agencies had vaccine set-asides from public health allotments. Still others negotiated with additional retail pharmacies, including independent pharmacy associations, for dedicated vaccine supplies and distribution strategies.

State ID/DD agencies, in partnership with their public health colleagues, forged creative approaches to vaccine acquisition and distribution, through specific agreements with pharmacies or pharmacy associations, hospitals and, in some instances, federally qualified health centers. Early efforts largely focused on individuals living in HCBS provider-owned and operated congregate settings, supporting two or more individuals. Many states advised individuals living in their own homes or with families to access vaccines through typical community venues. This presented challenges due to limited vaccine supply, the complexity of finding and securing

[9] NASDDDS State Director and Medical Directors call. April 20, 2021.

appointments using technology, and the difficulty of identifying vaccine points of distribution that are accessible for individuals with mobility or other support needs.

States' Efforts Using Available Data

- Assist with rapid response and need for testing
- Mitigate the spread of the virus in congregate settings
- Prioritize response options
- Target and address capacity issues
- Connect providers to vaccinator/vaccine supply

States are now devising approaches to more effectively link these individuals to a vaccine. For example, some states revised their policies related to non-emergency medical transportation to enable individuals to get to vaccine sites, while others boosted reimbursement to enable home visits for individuals unable to travel to a vaccination site. At least one state utilized a "reverse paratransit" approach where public transportation brings vaccinators to individuals. Another state negotiated a special arrangement with independent pharmacies for in-home inoculations. Yet another state engaged in a partnership with emergency response personnel to provide home-based vaccines.

State ID/DD agencies faced significant challenges obtaining timely data on vaccinations among individuals with ID/DD. In an effort to maximize the number of individuals receiving vaccines, many state public health agencies kept vaccination record-keeping as simple as possible, often requiring vaccinators to submit minimal data elements to general public health data systems. Furthermore, states may have multiple data sets for collecting information on vaccinated individuals. Claims data may be less reliable than usual due to methods employed across states to reimburse vaccine providers for their distribution activities--for example, early efforts, particularly at mass vaccination sites, did not collect insurance information or seek reimbursement for vaccinations.

However, some states directed their case managers to provide updated vaccination status information on clients to the state ID/DD agencies. For example, California issued such a directive for its case management partners in early March 2021.[10]

Despite promising, emerging efforts, gaps may remain. States are seeking strategies to compare data elements from various sources to get a clearer picture of the vaccine's penetration among Medicaid-eligible individuals served. Missouri and the District of Columbia report new capabilities to compare state-level vaccine data against enrollment data, enabling greater clarity on penetration rates and patterns across individuals served. The District is hopeful that analyses of these data will enable targeted outreach for any individuals or groups declining vaccinations.

A number of states also are building or adapting systems for their ID/DD provider networks to capture this information. Maryland, for example, uses a weekly Google form survey of providers and has a real-time data capture related to individuals vaccinated and, when

[10] See https://www.dds.ca.gov/wp-content/uploads/2021/03/DDSDirective_ContactingConsumers_VaccineEligibility_03092021.pdf.

possible, DSPs and family members. As of the publication of this report, states continue to refine these efforts, both to understand penetration rates and to devise strategies to combat vaccine hesitancy.

Exhibit 6 summarizes Colorado's, Missouri's, and Ohio's approaches to pandemic response and data collection. Their efforts reflect three key features: knowledgeable leadership familiar with the needs of the ID/DD community at the top levels of state government; strong partnerships across state and local entities; and prioritizing people with disabilities in their COVID-19 vaccine distribution plans. Appendices A-C provide additional information about these three states.

EXHIBIT 6. Promising Approaches to Data-Informed Decision-Making from Colorado, Missouri, and Ohio

Colorado	Missouri	Ohio
Leadership: At the direction of the governor, Colorado created a cross-agency team that was co-chaired by a Medicaid expert and a senior leader at the state health department to develop and implement the residential care strategy.	**Leadership:** The governor convened an all-cabinet response effort that included all agencies and divisions, including the Division of Developmental Disabilities. The Division developed a webpage in March 2020 that provides COVID-19 information for stakeholders, including individuals, families, and contracted providers, featuring real-life stories from providers and families "from the field" and describing successes among the challenges during the pandemic. The Division also held weekly calls with stakeholders.	**Leadership:** Ohio's governor ensured cross-agency coordination and ensured the Department of Developmental Disabilities, which is a cabinet-level department in Ohio, was engaged in response efforts from the outset. Ohio identified several key lessons as a result of its COVID-19 management efforts. These focused on the importance of internal agency coordination across policy, residential, regulatory, and support divisions and relationships at the local level between local health departments, County Boards, and across state agencies.
Data Collection and Use: Colorado adapted an existing database (EM Resource) to collect key information on current PPE supply, available beds, COVID-19 cases, staffing, and the state used the data to identify facilities needing support or resources.	**Data Collection and Use:** Missouri required reporting through the state's incident reporting portal and an additional Electronic COVID-19 Case Reporting system. The state also established a role for the state's regional reporting Quality Enhancement Registered Nurse process for follow-up with service providers supporting individuals testing positive for COVID-19. The Division of Developmental Disabilities also worked with the Missouri Pharmacy Association to "match" providers with approved vaccinators if they were struggling to obtain access to the vaccine.	**Data Collection and Use:** Major Unusual Incidents (MUI) Daily Monitoring was in place prior to the pandemic but was modified to enable COVID-19-specific information. This system, which includes data and trends on case, hospitalization, and mortality, was a key source of data. Ohio County Boards of Developmental Disabilities tracked positivity rates and partnered for on-the-ground response. The ability of the state and local County Boards and providers to exchange data was critical. The developmental disabilities agency's Weekly COVID-19 Report informed prioritization decisions.

EXHIBIT 6 (*continued*)		
Colorado	**Missouri**	**Ohio**
Vaccine Prioritization*: • Phase 1a of COVID-19 vaccine prioritization in Colorado included all LTC facility (nursing facilities, intermediate care facilities, assisted living residences, and group homes) staff and residents. • Phase 1b.1 included Coloradans age 70+ and health care workers with less direct contact to COVID-19 patients (e.g., home health, hospice, pharmacy, etc.). Home health workers in Phase 1b.1 were defined broadly to include all HCBS workers. • Phase 1b.2 included Coloradans ages 65-69. • Phase 1b.3, which included people with disabilities who require direct care in their homes and people with disabilities unable to wear a mask.	**Vaccine Prioritization:** Missouri included individuals with ID/DD in category 1.B High Risk Individuals.	**Vaccine Prioritization:** Ohio defined congregate care settings as housing two or more people with disabilities. This expanded definition qualified people with disabilities living in about 4,000 non-licensed waiver settings (some family homes) for Phase 1a of the state vaccination plan. Individuals with ID/DD and congenital conditions were identified through a Medicaid data match to receive the vaccine as part of Ohio's Phase 1b.
Resource Deployment: Colorado's Strike Team helped facilitate the Federal Pharmacy Partnership for Long-Term Care Program. The teams also worked to ensure that providers who failed to sign up through the federal program had vaccine clinics facilitated and overseen by the state.	**Resource Deployment:** Missouri conducted surveys with contracted providers regarding COVID-19 testing and vaccination needs for individuals served. Missouri used repeated messaging statewide about free testing and vaccines	**Resource Deployment: A**ssisting residential providers to coordinate and communicate during the DSP staffing crisis that occurred throughout the pandemic was essential.
*Colorado's vaccine prioritization framework can be accessed at https://covid19.colorado.gov/for-coloradans/vaccine/find-out-when-youre-eligible-for-a-covid-19-vaccine.		

3.4. Promising State Practices

Certain challenges emerged as states managed efforts around vaccinations. ***Exhibit 7*** and ***Exhibit 8*** describe the strategies that several states devised to address two prominent challenges, vaccine prioritization for individuals with ID/DD and vaccine acceptance among individuals with ID/DD and their DSPs. ***Exhibit 7*** shows strategies to ensure that individuals with ID/DD are included in top vaccine prioritization categories. ***Exhibit 8*** highlights states' efforts to improve vaccination acceptance among DSPs and individuals with ID/DD.

EXHIBIT 7. State Reported Efforts to Prioritize Vaccines for Individuals with ID/DD	
State	**Action**
Missouri	A disability advocate was involved in vaccination planning from the start of the pandemic and was able to prioritize anyone who received disability waiver services, including HCBS, in Phase 1b of the state vaccination plan.
New York	The Office for People with Developmental Disabilities holds a biweekly stakeholder forum that includes families, individuals receiving services, provider associations, and other stakeholders. Members of the forum advocated to prioritize people with ID/DD in Phase 1b of the state vaccination plan.
Ohio	Congregate care settings are defined as housing two or more people with disabilities. This expanded definition qualified people with disabilities living in about 4,000 non-licensed waiver settings (some family homes) for Phase 1a of the state vaccination plan. Individuals with ID/DD and congenital conditions were identified through a Medicaid data match to receive the vaccine as part of Ohio's Phase 1b.
Pennsylvania	The rates of COVID-19 infection, hospitalization, and death among people with disabilities in the state were tracked starting in March 2020; these data were influential in prioritizing people with disabilities and, if applicable, their paid and unpaid caregivers in Phase 1a or Phase 1b of the state vaccination plan.

EXHIBIT 8. State Reported Efforts to Address Decline Rates Among Individuals with ID/DD and DSPs	
State	**Action**
Delaware	In partnership with the Developmental Disabilities Council, the state is launching a mobile application that will use text messages to debunk myths and misperceptions about vaccines. This effort is aimed at DSPs who opt-in to receive the communications.
Louisiana	The state partnered with Electronic Visit Verification vendors to identify agency providers and/or geographic areas where DSP vaccine rates are low. This effort enables targeted outreach.
Missouri	Facilities in Missouri offered service providers multiple opportunities to be vaccinated. Some providers refused the first opportunity, but took advantage of a second or third opportunity after attending a townhall, talking with colleagues, or watching a "myth busters" video.
North Carolina	The state conducted research on vaccine attitudes and then developed fact sheets, personal videos, and department led "Vaccine 101" presentations. North Carolina also partnered with historically marginalized populations and faith leaders to educate others about the safety and efficacy of COVID-19 vaccines.

4. SUMMARY

This assessment of available data and state pandemic response is a point-in-time snapshot. As additional data sets can be compared and combined for analysis, the true picture of infection rates, population health impacts, and rates of vaccination among specific groups will become clearer. This snapshot, however, can be used to inform future state and federal practices and policies.

States may consider the following approaches to improve access to actionable information on individuals with ID/DD and the workforce that supports them:

- Educate state-level leadership on ID/DD population needs.
- Establish and maintain active relationships with public health and emergency management partners within the state, and engage in discussions regarding data sharing capabilities.
- Invest in data systems that enable interoperability across state systems.
- Devise uniform policies for the use of incident management systems to report suspected and confirmed infectious disease exposure.
- Develop regular communication strategies with all stakeholders, including individuals and families, providers, case managers, and advocates. Standing these up prior to a crisis enables problem identification and resolution.

Federally, the following approaches may ensure a future cohesive national strategy for data collection, use, and response:

- Ensure cross-collaboration and education on LTSS systems among all health and human services agencies, particularly among agencies responsible for administration of LTSS, distribution of vaccines, and development of infection control strategies.
- Issue joint guidance to state public health entities, LTSS agencies (including ID/DD agencies), emergency management organizations, and Medicaid authorities on effective partnerships to enable quick mobilization of system resources in times of crisis.
- Establish a national framework for data collection on infectious diseases across all LTSS service models, and provide financial support to states to build or adapt data systems to enable necessary interoperability.
- Convene discussions between state and federal agencies to discuss data collection efforts for the future to address post-COVID conditions and residual disabilities caused by COVID-19, as well as evolving COVID-19 infection status or need for vaccine boosters.

- Engage regularly and jointly with state-level associations and state representatives to capture lessons learned from the COVID-19 pandemic and to devise a roadmap for an effective emergency response.

As the United States moves forward from the COVID-19 PHE, ensuring a solid and consistent foundation in data collection, data reporting, and partnerships between state, local, and federal entities may foster more comprehensive and data-informed practices and policies in the future.

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APPENDIX A. COLORADO DEVELOPMENTAL DISABILITIES SYSTEM PANDEMIC RESPONSE

Colorado included all residential group settings serving older adults and people with disabilities, including nursing facilities, intermediate care facilities, assisted living residences, and group homes, in its COVID-19 response. In total, this response encompassed nearly 1,100 facilities. Additionally, at the direction of Governor Polis, the ID/DD agency created a cross-state agency team that was co-chaired by the ID/DD Director and a senior leader at the state health department to develop and implement the residential care strategy. This close partnership with public health proved essential to a successful response throughout the pandemic.

Colorado Developmental Disabilities System Pandemic Response
Detection/Surveillance
Colorado initially focused on building the capacity to conduct large-scale surveillance testing and systems to collect and analyze data to inform quick decisions. The State Lab expanded both its physical space and equipment, as well as their direct support staff, going from processing approximately 1,500 samples to 26,000 samples and running shifts 24 hours/day, 7 days/week. Colorado made testing support available to all residential care settings, through the availability of test kits, processing of tests, and, if needed, hands-on assistance on-site with sample collection. The state also activated the National Guard to support this work through test administration, sample collection, and supply distribution. Colorado developed and expanded data systems, with the creation of a testing support request form, designated regional lab coordinators to assist providers, and data dashboards for displaying and analyzing test results. Though testing was made available for free to all residential care settings, the uptake remained low into the early fall. Colorado moved to requiring regular testing for surveillance of outbreaks within all residential care settings. Colorado increased testing capacity by partnering with a large lab to ensure fast turnaround of samples. This testing expansion coincided with the late fall wave and enabled the quick identification of outbreaks and the implementation of outbreak response protocols.
Prevention and Infection Control
Quickly detecting the virus and mitigating spread was a critical approach to Colorado's COVID-19 response. In both residential and other congregate care settings, Colorado immediately put into place requirements around infection prevention and control, such as limiting capacity within settings, limiting non-essential visitation, social distancing, and use of PPE. Providers of medical and personal care services, including residential settings, could request free PPE through the state to ensure cost and access were not a barrier. Understanding the needs and current status of residential care settings was important for ensuring that they had the necessary resources. EM Resource, an online platform used primarily for hospitals, was adapted and adopted to capture this information. Colorado required residential facilities, including nursing facilities, intermediate care facilities, assisted living residences, and group homes, to report daily about their current PPE supply, available beds, COVID-19 cases, and staffing. The state, in turn, used the data to identify facilities needing support or resources. More recently, Colorado added questions to the EM Resource platform about vaccination rates to give the state insight into potential vaccine hesitancy challenges. The EM Resource data supplemented information available through the National Healthcare Safety Network, data collected by the CDC from nursing facilities across the country. In addition to the provision of technical assistance, Colorado implemented strategies in other areas shown to impact the spread of COVID-19. The state identified staffing shortages as a potential contributor of COVID-19 outbreaks in residential care settings and singled out this area to provide intervention. Colorado developed and disseminated resources and education for frontline staff, including making available a free COVID-19 training and tools to avoid stress and burnout. Another Colorado strategy involved recruiting more individuals into the field and raising awareness about the value of these workers. In response, the state launched the ConnectToCareJobs[1] website in May to match job seekers with open positions in LTC, and Governor Polis

Colorado (*continued*)
announced September 6-12, 2020 as Long-Term Care Worker Appreciation week and September 13-19, 2020 as DSP Recognition week. As the virus surged in the late fall and outbreaks in congregate settings soared, more facilities reported critical shortages, threatening the safety of residents. Colorado took additional steps to provide direct staffing support to those settings most in need and hired a Workforce Coordinator at the Department of Health Care Policy and Financing (HCPF) to support the Staffing Workgroup and the Rapid Response initiatives. Colorado invested $1.3 million to pay for temporary staffing in facilities where outbreaks were overtaking their ability to stay afloat. Though the investment of dollars was helpful, the state's ability to find DSPs, even when casting a wide net nationwide, was incredibly difficult. Time was of the essence and recruitment took weeks to complete, so Colorado mounted a more immediate response through the Governor's creation of the Staff Shortage Fusion Center which was designed to centralize staffing requests from across the state. Through this new center, teams of National Guard soldiers served as the first responders to facilities in desperate need. In total, Colorado trained 52 National Guard soldiers as temporary Certified Nursing Assistants and Qualified Medication Administration Personnel to assist facilities across the state. In addition, Colorado activated the staffing contracts arranged during the summer for the potential opening of the alternative care sites, making clinical staff available for quick dispatch to facilities. Finally, Colorado integrated both medical and non-medical volunteers into the response, opening up one more resource for potential support. As of March 9, 2021, the state successfully filled 5,155 shifts within residential care settings through these resources.
Vaccine Priority Planning
Colorado considered people with disabilities and their caregivers in its vaccine prioritization framework[2]. Key highlights of the framework include: • Phase 1a of COVID-19 vaccine prioritization in Colorado included all LTC facility (nursing facilities, intermediate care facilities, assisted living residences, and group homes) staff and residents. • Phase 1b.1 included Coloradans ages 70+ and health care workers with less direct contact to COVID-19 patients (e.g., home health, hospice, pharmacy, etc.). Home health workers in Phase 1b.1 were defined broadly to include all HCBS workers. • Phase 1b.2 included Coloradans ages 65-69. • Phase 1b.3, which included people with disabilities who require direct care in their homes and people with disabilities unable to wear a mask. Colorado is currently in the next phase that began on March 19, 2021, and includes people aged 50 and older.
Vaccine Distribution and Data Collection
The Residential Care Strike Team helped facilitate the Federal Pharmacy Partnership for Long-Term Care Program to facilities. Colorado worked to ensure that providers who failed to sign up through the federal program had vaccine clinics completed by the state. 923 Colorado facilities partnered with CVS/Walgreens for COVID-19 vaccinations, completing 2,603 clinics to-date. To ensure LTC facilities have continued access to COVID-19 vaccine for residents and staff after the Federal Pharmacy Program ends in March, Colorado is implementing an ongoing vaccination plan with LTC pharmacies. Colorado added vaccine data to its online system, EM Resource, in March 2020. This information allows the state to better target vaccine confidence efforts.
Additional Response Efforts Related to the COVID-19 Public Health Emergency
Transparency was important for ensuring the public had access to timely information and remained informed about Colorado's current COVID-19 cases and response. For this reason, the Department of Public Health and Environment (CDPHE) launched several sites, including the Colorado COVID-19 Data[3] webpage, where data is visible, providing state, county and outbreak data[4] for public review. In addition to the availability of aggregate data, CDPHE gave access to an open data portal, where data was available for others to download and analyze independently.

Colorado (*continued*)
Though Colorado provided extensive guidance to residential care settings and other LTC providers about the changing requirements throughout the pandemic, the state recognized the importance of providing one-on-one or setting-focused technical assistants and oversight. Over 1,000 isolation and prevention plans were submitted by facilities for review by CDPHE, with state and CDC epidemiologists offering feedback and support to facilities in response. HCPF and the Residential Care Strike Team distributed over 300 written communications or memos to provide technical guidance and information. The state held 70+ update webinars, tailored to unique stakeholder groups, with a total attendance of over 12,000 people. Colorado ensured compliance with the rules put in place and provided assistance and training by conducting 1,478 infection control surveys across 1,052 residential facilities. Colorado's combined approach of individual support and education, technical guidance and requirements, and larger setting-based communication enabled confirmation that facilities and direct care staff understood infection control expectations and were in compliance, and helped the state quickly offer provider support and training when needed.
NOTES: 1. See https://www.connecttocarejobs.com/#/. 2. See https://covid19.colorado.gov/for-coloradans/vaccine/find-out-when-youre-eligible-for-a-covid-19-vaccine. 3. See https://covid19.colorado.gov/data. 4. See https://covid19.colorado.gov/covid19-outbreak-data.

APPENDIX B. MISSOURI DEVELOPMENTAL DISABILITIES SYSTEM PANDEMIC RESPONSE

Missouri has multiple points of contact for identifying individuals positive for COVID-19, coupled with a state strategy of engagement with providers to address pressing and emerging needs related to infection spread. Importantly, data efforts are underpinned by steadfast and exhaustive information sharing among state leadership and key partners.

Missouri Developmental Disabilities System Pandemic Response
Detection/Surveillance
The Missouri Division of Developmental Disabilities posted guidance[1] in March 2020 for reporting COVID-19 positivity for individuals receiving Department of Mental Health developmental disabilities (DD) services. This guidance provides information on required reporting through the state's incident reporting portal and an additional Electronic COVID-19 Case Reporting system. The guidance further provides information on the role of the state's regional reporting Quality Enhancement Registered Nurse process for follow-up with service providers supporting individuals testing positive for COVID-19.
Prevention and Infection Control
The Missouri Division of Developmental Disabilities developed a DD Coronavirus Information webpage[2] in March 2020 that provides COVID-19 information for stakeholders, including individuals, families, and contracted providers. This page features real-life stories from providers and families "from the field" describing successes among the challenges during COVID-19. Throughout 2020 and currently, Missouri provides relevant updated CDC guidance and additional information pertaining to COVID-19 via e-mail blast notifications[3]. Missouri provides this information to stakeholders that are registered to receive the electronic update notifications. Missouri also monitored registrations, email clicks, and website hits.
Vaccine Priority Planning
Missouri's Stronger Together[4] landing page outlines the state's phases for vaccination. Individuals with ID/DD are a prioritized group in the state's vaccination plan. Missouri included individuals with ID/DD in category 1.B High Risk Individuals.
Vaccine Distribution and Data Collection
Missouri created the COVID-19 Dashboard[5] webpage for vaccination supply and distribution data. Missouri, like other states, is working to determine how best to connect the vaccine points of distribution data to their service delivery system information.
Additional Response Efforts Related to the COVID-19 Public Health Emergency
Since March 2020, the Missouri Division of Developmental Disabilities has hosted video conference calls open to all stakeholders. The intent of the calls is to share the latest information and guidance at the state and federal level and to provide a forum for stakeholders to ask questions. Initially, Missouri held the calls weekly and is currently on a biweekly schedule. The Division monitored attendance, recorded calls to be available for review or first view and posted Q&As, as well as monitored website hits and clicks. The Missouri Division of Developmental Disabilities established created dedicated webmail addresses for COVID-19 testing and COVID-19 vaccination questions. Contracted service providers received timely and consistent responses to submitted questions based upon current information available about testing and vaccines.

Missouri (*continued*)
Additionally, Missouri contracted providers responded to surveys regarding COVID-19 testing and vaccination needs. The survey effort was managed by the Division of Developmental Disabilities' central office and supported direct connections between community testing and vaccinator partners. Collaboration also occurred with the Missouri Pharmacy Association to "match" providers with approved vaccinators if they were struggling to obtain access to the vaccine. Missouri's communication strategies involved consolidated emails to the provider distribution list, where providers could opt to receive emails. These messages occurred daily at the outset and then less frequency according to communication needs and the availability of new information. Missouri used this approach to reduce information overload and any risks of miscommunication. Missouri is currently engaged in repeated messaging of statewide, free testing and vaccine opportunities.
NOTES: 1. See https://dmh.mo.gov/media/pdf/reporting-dd-service-participant-covid-19. 2. See https://dmh.mo.gov/dev-disabilities/covid-19-information. 3. See https://dmh.mo.gov/dev-disabilities/e-mail-blasts. 4. See https://covidvaccine.mo.gov/. 5. See https://covidvaccine.mo.gov/data/.

APPENDIX C. OHIO DEVELOPMENTAL DISABILITIES SYSTEM PANDEMIC RESPONSE

The State of Ohio built on an already robust foundation of data collection and communications tools to manage its response to the COVID-19 pandemic. Collaboration across state agencies, county boards of DD, local health departments (LHDs), and COVID-19 specialty offices of the governor was instrumental in early and ongoing success in Ohio. Ohio included individuals with ID/DD as part of the first phase of Ohio's vaccination distribution.

Ohio Developmental Disabilities System Pandemic Response
Detection/Surveillance
Ohio's Department of Developmental Disabilities (DODD) adapted its MUI Daily Monitoring to include data and trends on COVID-19 cases, hospitalizations, and mortality. Ohio DODD relied on the County Boards of Developmental Disabilities to aid in tracking positivity rates among the ID/DD population and these data and information were included in DODD's Weekly COVID-19 Report to Governor DeWine. Ohio DODD established on-the-ground Support Teams to coordinate with designated County Board provider liaisons and providers themselves. These teams provided technical assistance, reinforced and clarified guidance, and managed the direct support staffing crisis. DODD's central office coordination included internal standup meetings 3 mornings per week. Additionally, DOOD state coordination involved frequent stakeholder calls; weekly calls with the DODD Support Teams to address emergent issues; development of a public-facing DODD Dashboard; and daily status briefings to the State Pandemic Response Team, including submission of DODD System Status Report and the DODD Strike Team Dashboard report.
Prevention and Infection Control
Ohio DODD required daily random testing at its State Developmental Centers (DCs) and test kits were made available to 425 ICF/IIDs. DODD's state facilities coordinated with the Ohio Emergency Management Agency to maintain and monitor PPE to ensure a minimum 30-day supply. Ohio DODD coordinated with sister agencies in June 2020 to secure CARES Act funding for the purchase of 300,000 cloth masks that were distributed via the County Board to local providers, people with disabilities, and families. Subsequently, in December 2020, 2 million disposable surgical masks were similarly distributed through County Boards, while ICFs/IID received 250,000 N95 masks and pulse oximeters. DODD's collaboration with the State Bureau of Workers Compensation to access the HVAC Grant Program to improve air flow and ventilation in residential facilities.
Vaccine Priority Planning
Ohio DODD began vaccine planning as early as November 2020 by presenting an environmental data scan of the full ID/DD service system to the Ohio Vaccine Preparedness Office. DODD's action provided critical details that informed Governor DeWine ultimate decision to include people who live in congregate residential settings and their DSPs in the 1a priority category as part of Ohio's vaccination plan for target populations and occupations. DODD coordinated with County Boards in early December 2020 to verify data and develop worklists to share with LHDs for planning and distribution of the vaccine. Inclusion of people with disabilities and DSPs in Phase 1a resulted in vaccination administration in 1,060 state-licensed facilities and 4000+ non-licensed residential waiver settings serving two or more individuals. An additional 26,000+ individuals with ID/DD and congenital conditions were identified through a Medicaid data match to receive the vaccine as part of Ohio's Phase 1b.

Ohio (*continued*)
Vaccine Distribution and Data Collection
Ohio's LHDs designated vaccine allocations in Phase 1a and DODD relied on County Boards to coordinate contacts about vaccine distribution with the majority of licensed and non-licensed settings. Of the 1,060 state-licensed facilities included in Phase 1a, 250 facilities registered through the federal pharmacy program. Ohio DODD's 8 DCs registered to be the vaccine providers for their residents and staff, with a 93% resident vaccine take-up rate. The ID/DD population was the first group to receive the vaccine as part of Ohio's Phase 1b rollout, which began on January 25, 2021. Ohio's LHDs and children's hospitals allocated vaccines in Phase 1b and worked with the County Board to identify lists of people to receive vaccines and set up vaccine administration clinics. Ohio DODD relies on numerous sources for collecting and reporting testing data, including MUI monitoring, as well as case, hospitalization, and mortality data and trends. These data are used in regular and frequent reports to agency and state government leadership, including the "Daily MUI Status Report," the "Weekly COVID-19 Status Report," and the "DODD Weekly COVID-19 Report." DODD relies on County Boards to aid in the tracking of positivity rates. Vaccine data collection was informed by County Boards tracking biweekly scheduling, verifying individuals desiring the vaccine, and monitoring attendance at scheduled clinics during the Phase 1b distribution. This information is included regularly by DODD in the "Ohio Target Population and Occupation Report."
Additional Response Efforts Related to the COVID-19 Public Health Emergency
The Ohio Departments of Developmental Disabilities, Medicaid, Health, and Aging developed the Long-term Service Support Guide. Ohio DODD's "Coordinated COVID-19 Communications" provided direction and strategy for people with disabilities, families, providers, and county boards. These communications enabled more frequent and targeted messaging about COVID-19 and demonstration of partnerships with other state agencies. Communication efforts included family roundtables, resources presented in plain language, and guidance interpretation for families and DSPs. Ohio DODD used creative approaches to communication such as videos on mental wellness featuring Dr. Julie Gentile, and "Dr. Laura's Medical Moments," featuring DODD's Medical Director Laura Sorg. Ohio DODD partnered with the Ohio Department of Health to offer dedicated infection control seminars to ICFs/IID. Additionally, Ohio DODD created resources about the vaccine for people with disabilities, their families and vaccine providers and updated the governor's statewide vaccine panel about vaccine communication initiatives on a weekly basis.