

# **Support Guidelines for Individuals with Intellectual and Developmental Disabilities during the COVID-19 pandemic**

## **Background**

Complications from and death rates due to coronavirus disease 2019 (COVID-19) for people with intellectual and developmental disabilities (IDD) are disproportionately higher when compared to people without IDD. People with IDD are at high risk from sustaining complications and dying from COVID-19 (Turk, et al., 2020; Landes, et al., 2020). COVID-19-related fatality rates among people with IDD who have tested positive for COVID-19 are, in some states, more than three times the mortality rates among the general population who have tested positive for COVID-19. Extensive research has established the high rate of chronic morbidities and poorer health status common among people with IDD (Ervin, et al., 2014; Sullivan, et al., 2018; Anderson, et al., 2013). Many of the risk factors that are associated with severe outcomes from COVID-19 infection, such as cardiovascular disease, diabetes and chronic lung disease (Stokes, et al., 2020; Centers for Disease Control and Prevention, 2020a), are common in adults with IDD.

In the United States, over 591,000 people with IDD live in community residential settings of six or fewer people (Tanis, et al., 2020). These environments include group homes and other congregate support settings in which people with IDD are in frequent and close proximity with one another. According to the Centers for Disease Control and Prevention (2020b), shared living environments may “facilitate the introduction and spread of COVID-19.” Therefore, this group faces substantial risk for contracting COVID-19 and experiencing severe outcomes similar to that of people who reside in nursing homes.

Despite these risks, the public health recommendations targeting this population are relatively sparse and vary greatly across states. The American Academy of Developmental Medicine and Dentistry (AADMD) strongly believes that there needs to be clear guidelines applied nationally to reduce the impact of COVID-19 on individuals with IDD.

## **Personal Protective Equipment**

Access to and availability of personal protective equipment (PPE), at and immediately following the US outbreak of the pandemic, was extraordinarily limited across all of healthcare. This was well documented, and impacted hospitals and other traditional healthcare systems. As the US government urged Americans to take precautions in order to ‘flatten the curve’, urgent efforts to address shortages of PPE and critical medical equipment such as ventilators were undertaken. Beyond traditional healthcare, community support systems, which have not historically been considered healthcare systems, across the US struggled to find private sources of affordable and United States Food and Drug Administration (FDA)-approved PPE. On April 22, 2020, the United States Federal Emergency Management Agency (FEMA) issued guidance to non-healthcare organizations on acquiring PPE during shortages. In its guidance, FEMA acknowledged that non-healthcare organizations “may face challenges in obtaining PPE while available supply is prioritized for healthcare workers and first responders.” Among steps recommended was requesting assistance through local emergency management agencies (US Federal Emergency Management Agency, 2020). This and other, similar recommendations to non-healthcare organizations, including those that provide support to people with IDD in congregate settings, did not account for local emergency management agency shortages of PPE, leaving these organizations little recourse.

In the State of Maryland, Governor Larry Hogan, on March 31, 2020, issued an Executive Order designating employees of organizations supporting people with IDD as essential healthcare workers (Hogan, 2020). Other states have issued similar proclamations. However, it did not appear to substantially improve access to PPE and related equipment.

Organizations that are providing essential supports to vulnerable children and adults with IDD, particularly in any congregate environment, need local government jurisdiction-based and located distribution of and financial support for Personal Protective Equipment (PPE).

1. The type and quantity of PPE for staff working in congregate settings such as group homes should be identical to recommended PPE for healthcare providers.
2. Organizations should assess current and projected PPE needs for surges in and/or the predicted second wave of COVID-19 outbreaks.
3. Coalitions of organizations should consolidate orders for PPE, whenever possible, to create scale, purchasing power and to drive affordability. Use or 'burn' rates should be monitored to drive re-order needs.
4. Training must be provided to Direct Support Professionals (DSP) who are otherwise unaccustomed to PPE use, particularly to include donning and doffing. Monitoring of ongoing proper PPE use must be maintained.
5. For N95 masking, fit testing must be provided for each user.
6. Used PPE may be considered hazardous medical waste, requiring special disposal protocols. Costs associated with disposal should be financially supported.

## Diagnostic Testing

Research in March and April 2020 on transmission of COVID-19 indicated that carriers of the virus were infectious, on average, 2.3 days before any onset of symptoms. In fact, people infected with COVID-19 were most likely to spread the virus hours *before* symptoms appeared; and, researchers estimated that 44 percent of SARS-CoV-2 transmissions occur before people get sick (He, et al., 2020; Li, et al., 2020). Furukawa, Brooks and Sobel (2020) note that asymptomatic transmission enhances the need to scale up the capacity for widespread testing and thorough contact tracing to detect asymptomatic infections.

Nonetheless, diagnostic nasopharyngeal testing has not been consistently available for people receiving supports in congregate settings or for their DSPs. When testing has been available, it has required the presence of symptoms and a physician's order. These criteria have resulted in people receiving supports and DSPs being denied testing.

The AADMD recommends that organizations that support people with IDD, particularly but not only in congregate environments be given immediate access to free US Food and Drug Administration (FDA)-approved nasopharyngeal rapid testing for every person with an IDD being supported and their DSPs with the following provisions:

1. Presence of symptoms NOT required. We recommend following testing guidelines outlined by the CDC for nursing homes in group residential settings for individuals with IDD. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/nursing-homes-testing.html>
2. Dedicated testing sites and/or protocols, to include testing in a person's home, for example) at which testing personnel are trained in supporting people with IDD.
3. Service organizations with licensed nursing staff should be provided with testing kits in adequate numbers and appropriately trained in specimen collection in order to relieve congestion at general testing sites.

4. Multiple drive-thru testing sites should be made available and accessible for low- to no-contact testing processes.
5. There should be no arbitrary limit on the number of tests per person, and all appropriate clinical guidelines should be followed.
6. Service organizations' human resource departments must be notified of results, in addition to all DSPs tested, in order to implement appropriate/associated agency protocols around employee leave needs, quarantining/isolation, back-up staff deployments, and prioritization of PPE.

## **Contact Tracing**

In many communities, congregate residential supports are provided in small group homes. Typical staffing models in group homes include rotating, shift-staff schedules, which offer continuous support to people with IDD living in group homes through the week. It is common for DSPs to work multiple jobs and/or at multiple agencies and with multiple people with IDD. Shifts tend to start at or around 3.00 p.m. and go through 11.00 p.m., at which point the next DSP reports to work the overnight shift. This continues each weekday, interrupted only by the added 7.00 a.m. to 3.00 p.m. shift on the weekends in order to cover the whole of the day. In this model, five different DSPs or more work in a group home each week. This scenario increases exposure risks to COVID-19 as community living support agencies are unable to monitor staff for exposures once they leave a shift and not on provider agency time.

The World Health Organization (WHO) defines contact tracing as identifying and informing anyone who has come into contact with a person who is infected with a virus, directing their follow-up action, and monitoring them for symptoms or signs of infection (2020). Contact tracing, according to the CDC, requires “well-honed skills” and financial and human resources that provider agencies do not have. Nonetheless, “case investigation and contact tracing are fundamental activities” and “prevents further transmission of disease by separating people who have (or may have) an infectious disease from people who do not. It is a core disease control measure that has been employed by public health agency personnel for decades” (Centers for Disease Control and Prevention, 2020c).

Given the significant increase in exposures that results from the rotating, shift-staff model; and, because contact tracing is an essential to reducing infection rates (Bi, et al., 2020), the AADMD recommends:

1. Contact tracing that focuses on people with IDD and the DSPs that support them, whenever circumstances warrant, should be done by appropriately trained and resourced experts, for example, local Department of Health personnel.
2. Because of the unique needs of the community of people with IDD, their disproportionately higher risk for infection and the higher mortality rates associated with these members of the larger community, service provider agencies need a limited number of consistent contacts, for example with a local jurisdiction public health or infectious disease nurse, if possible, to:
  - a. Plan and implement contact tracing protocols, when necessary;
  - b. Assess, discuss and plan infection control resources;

## **Cohorting**

On April 2, 2020, the Centers for Medicare and Medicaid Services (CMS) issued guidance for long term care facilities that included the need to “separate patients and residents who

have COVID-19 from patients and residents who do not, or have an unknown status” (p. 3). Also known as isolating, this practice of cohorting is designed to minimize, if not eliminate interaction of people who are infected with COVID-19 from those who are not, and it is considered an effective means of infection control (Rosenberger, et al., 2012).

In small group homes, cohorting can be a significant challenge, either due to a lack of space or because of the inability or unwillingness of a person with IDD who, in their own home, refuses to isolate. In addition, service provider organizations may lack adequate staff resources that would allow them to assign one staff to supporting people who have tested positive for or have been exposed to someone who has COVID-19 and another to those who have tested negative for or are not at risk for contracting COVID-19.

AADMD’s cohorting recommendations are based, in part, on work by service agencies that were required to adapt to soaring caseloads in New York State early in the pandemic, and can be applicable to other states as case numbers have been rising. The following conceptual framework is based on delineating risk and can guide cohorting needs for the individuals in residential settings (Korca, 2020). Potential monitoring parameters are provided to assist service provider organizations in considering staffing requirements as cohorting is considered and planned for.

Levels of COVID-19 risk can be assigned to group homes and can guide monitoring and cohorting. See Table 1.

**Table 1.** COVID-19 Group Home Risk Stratification

<b>Risk Level</b>	<b>Description</b>
Severe	Confirmed COVID-19 case in the home.
High	Person in the home has had a direct exposure to a confirmed COVID-19 case.
Moderate	Home has had indirect contact with a confirmed COVID-19 case.
Low	No known exposure to COVID-19 in the home and among people living and working there.

In homes in which there is a confirmed case of COVID-19, appropriate monitoring for symptoms among all people living in the home should be defined by the service agency nursing staff guided by their medical providers, and can include checks every two (2) hours by staff trained to look for cough, fever, O2 saturation, respiratory rate, shortness of breath, changes in mental status or lethargy. High risk homes can be monitored every four (4) hours, moderate risk every six (6) hours, and low risk homes can be monitored every shift or twice daily. Among people confirmed to have COVID-19 being supported in a group home, monitoring parameters and clear guidelines for seeking emergency care should be established for each individual, with clear guidelines provided to DSPs in chart form. Nursing staff should be available 24/7 to guide DSPs when needed, to review vital signs and monitoring parameters and to assist with obtaining a higher level of care or hospital when necessary and act as liaison for both families and medical providers. When symptoms of COVID-19, such as fever, cough, GI symptoms present in a person living in a home, the home should adopt monitoring protocols and precautions assuming COVID-19 infection until ruled out medically and cleared.

Within a home, isolation of individuals with confirmed COVID-19 or COVID-19-like illness can be implemented as much as possible. Individuals should stay in their own individual room as much as possible. Exposure should be limited to one DSP if possible during each shift, which ideally would remain consistent across days. All affected individuals should use a single bathroom that is cleaned regularly according to CDC recommendations.

Homes determined to be High Risk can be downgraded to a lower risk levels once staff and all people living in the home(s) have met both testing and non-testing criteria for COVID-19 clearance. Homes should also be prepared to upgrade to higher risk levels as circumstances warrant. Training on these and related standards, as well as access to PPE and other supplies, should be provided to DSPs, nurses, and service agency administrators and/or home supervisors administrators ahead of time to enable immediate conversion of a COVID-19-negative, Low Risk status to a COVID-19-positive Severe Risk status. People living in the home should be prepared for this possibility ahead of time to normalize the change as much as possible and avoid significant emotional distress.

Among group homes in the US, the variety of living arrangements is vast. A small supported apartment with two residents in an urban setting has different staffing requirements and different culture than does a setting that is home to ten or more people with IDD in which bedrooms are shared. Plans for cohorting within a supported residence will be based on staffing, physical layout and the capability of the people living there to be able to adhere to necessary precautions to minimize the spread of COVID-19 within a home. CDC provides some guidelines on managing risk within group homes at <https://www.cdc.gov/coronavirus/2019-ncov/community/group-homes.html>.

In addition to delineating group homes themselves with tiers of risk, service agencies can assign tiers of risk to individuals within homes, for example to prepare for 1:1 staffing or increased monitoring should those individuals require isolation. Those risk tiers should be assigned based on individuals' behavioral support needs and the ability of those individuals to adhere to protocols such as masking and frequent hand-washing.

**Table 2.** COVID-19 Transmission Risk Stratification of Individuals Within a Home

Risk Level	Description
High	Individual frequently puts hands or objects in his/her mouth, or has language impairments preventing them from participating in necessary isolation. Individual's behavior could potentially expose objects or others to saliva or infectious material. Individual has significant difficulty maintaining distance from others. Individual is unable to wear a mask.
Moderate	Individual has behaviors that may make isolation more challenging such as impulsivity or difficulty maintaining physical distancing.

Low	Individual is able to communicate and participate in isolation and appropriate hand hygiene activities, and is able and willing to wear a mask.
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High-risk individuals may require 1:1 staffing as part of maintaining isolation in a higher-risk COVID-19 home, whereas lower risk individuals may not necessarily require changes in staffing ratios.

Rearrangements and planning within a home, such as assigning bathrooms or reassigning bedrooms where one roommate needs to be isolated may require adaptation within a home or significant rearrangement within the home, or may require additional properties to be temporarily utilized.

Service agencies that have access to vacant, unused properties should consider utilizing them for cohorting needs. To that purpose, furnishing and equipping these sites, if possible, and assuring appropriate PPE, food and other supplies are available. Guidance and direction from state and local licensing authorities should be sought in advance.

In addition to or as an alternative to the use of vacant, unused service agency-controlled properties, local provider groups/associations, in partnership with local/municipal governments should explore potential agreements with community hotels/motels or empty/unused dormitories for potential use for cohorting.

Depending on the needs of the individuals served by a particular agency, a property being utilized for cohorting can be assigned as a step-down or transition unit for COVID-19 positive individuals who have been discharged from hospital or emergency-room settings, but who have not yet met testing and non-testing criteria to return to their homes. These dedicated locations could also be utilized to provide a temporary higher level of care if, for example, supplemental oxygen, specialized nutrition support or changes in ambulatory status otherwise would prevent return home.

The above cohorting recommendations should be followed as closely as possible for residential settings with live-in staff or host homes, especially those in which there is more than one person being supported. Service agencies that support these types of settings should consider providing additional monitoring equipment as needed such as pulse oximetry for monitoring of signs and symptoms. These settings will also require cohorting provisions for cases where the live in staff/host home provider contract or develop symptoms of COVID-19. Agencies should prepare to have robust back up systems of care should multiple providers become ill or develop symptoms. Live-in providers/host homes should follow isolation precautions if they develop symptoms or test positive for COVID-19 and should not be supporting people with IDD until they have met testing and non-testing clearance criteria for COVID-19.

### **Emergency Room and Hospital Discharge**

Hospital transition is always a high risk time frame for individuals with IDD, and multiple discrete steps must be taken to ensure a safe transition. Amidst the COVID-19 pandemic, this transition is additionally complex and has the potential to impact the health and safety of other people receiving supports and staff. Communication and coordination between hospital discharging teams and accepting congregate setting teams is crucial. Ensuring

hospitalized patients with COVID-19 have been confirmed negative on retesting before discharge would be beneficial, especially for those people with IDD who may be non-verbal and/or unable to advocate for themselves. We recommend that hospitals and residential settings follow the protocols and recommendations outlined by the New York Disability Advocates for ER and hospital discharge.

It is imperative that both emergency room physicians and hospitalists (responsible for creating discharge summaries, reports and follow-up recommendation) are familiar with, understand and are sensitive to the restrictions and regulations that govern clinical care (carried out by unlicensed individuals) in community based group homes. Discharge instructions should be provided in accord with the skills, resources, credentials and authorization that govern care standards in group homes.

A service agency's designated contact (e.g., nursing supervisor, lead DSP, community living service director or manager) should be responsible for communicating these potential restrictions to the ER/hospital staff at the earliest opportunity, throughout the hospitalization and at the time of the discharge. The patient should not be discharged until the service agency designated contact reviews the discharge instructions and ensures that all aspects of the follow-up treatment plan can be implemented.

Ensuring safe care transitions requires a systematic approach. Three key areas must be addressed prior to discharge:

1. Medication reconciliation: The patient's medications must be cross-checked to ensure that no chronic medications were stopped and to ensure the safety of new prescriptions.
2. Structured discharge communication: Information on medication changes, pending tests and studies, and follow-up needs must be accurately and promptly communicated to outpatient physicians.
3. Patient education: Patients, their families and Direct Support Professionals (DSPs) must understand their diagnosis, their follow-up needs, and whom to contact with questions or problems after discharge. (Agency for Healthcare Research and Quality, 2019)

From a policy perspective, we urge CMS and the federal government to consider methods to provide aid to hospitals and residential settings given financial strain they are experiencing during the pandemic. We recommend providing financial aid to provide PPE for residential care providers and residents as well as aid to help provide emergency placement if needed to allow for appropriate isolation. There is often a financial pressure for hospitals to discharge patients quickly, although as discussed above, discharging a patient with COVID-19 prematurely can put multiple other individuals at risk. As such, CMS should consider providing support such as medicaid enhanced payment to diminish the financial pressures pushing toward a premature discharge.

### **Individual and Local Advocacy**

Major trade associations (e.g., the American Network of Community Options and Resources, or ANCOR) and advocacy organizations (e.g., The Arc, The Autism Society of America) have undertaken significant work in advocating for policy and funding support at a federal level since the onset of COVID-19 in the US. Thompson and Nygren (in press) offer a set of advocacy recommendations on broad issues, from community IDD service

infrastructure to DSP compensation to addressing disparities in healthcare for people with IDD, among others.

Advocacy at the individual and local levels involves engaging with local public health officials, elected officials and others in a coordinated set of activities in order to alert them to the dangers of COVID-19 that are exacerbated among the community of people with IDD. The AADMD makes the following recommendations:

1. Ascertain the availability of local and/or state data on infection rates, testing and results, and mortality rates among people with IDD. Contact state IDD service jurisdictions and local county or municipal health departments to ask for these data. Use the data to bring attention to the need for testing, prevention, PPE and/or contact tracing. For example, the Virginia Department of Behavioral Health and Developmental Services publishes data weekly (found at: <http://www.dbhds.virginia.gov/assets/doc/EI/dashboard-06252020.pdf>). In these data, the mortality rate among people with IDD who have tested positive for COVID-19 in Virginia is shown at 9.36%, against CDC data that shows mortality among all other Virginians who have tested positive for COVID-19 at 2.79%. People with IDD in Virginia who have tested positive for COVID-19 are dying at a rate that is substantially more than three times the rate of people without IDD. This is similar to disproportionate fatalities among people with IDD in other states, including New York and Maryland. Local officials and the communities they represent need to be made aware of these and other information in order to make a priority of supporting communities of people with IDD and the service provider organizations supporting them.
2. Collect and document individual stories from people with IDD and/or the DSPs supporting them. The National Association of Direct Support Professionals (NADSP), in partnership with the Institute on Community Integration (ICI), is collecting personal stories from DSPs across the US to directly capture how COVID-19 has impacted direct support professionals at work, at home, physically and emotionally, and what they've learned, their challenges, the rewards, and more (J. MacBeth, personal communication, June 29, 2020). The Association of University Centers on Disabilities (AUCD) is collecting stories from people with IDD on their experience of COVID-19 (see this project at [https://www.aucd.org/template/news.cfm?news\\_id=14627&parent=16&parent\\_title=Home&url=/template/index.cfm?](https://www.aucd.org/template/news.cfm?news_id=14627&parent=16&parent_title=Home&url=/template/index.cfm?)). These stories, collected locally and used to inform community conversations about the impact of COVID-19 at a local level, can link local experiences to local elected and other officials. State and local elected officials can be introduced to their constituents, both people with IDD and their DSPs, through these stories as a way to illustrate impact and needs for support.
3. People with IDD and their families have been under some form of Stay at Home or Safer at Home order since approximately mid-March. Nearly four (4) months later, people with IDD and their families have necessarily avoided or have been prevented outright from seeking medical care for non-COVID-19 healthcare issues, behavioral and mental health supports, and dental care. There is an urgent need to lobby local and state officials for:
  - a. Increased availability to virtual/tele-health options that are culturally and linguistically accessible to address urgent health needs and prevent the need for emergency care.
  - b. Technology that is affordable and accessible to people with IDD and their families through which tele-health is available--this includes reliable and affordable internet and wifi connection in urban, suburban and rural areas.

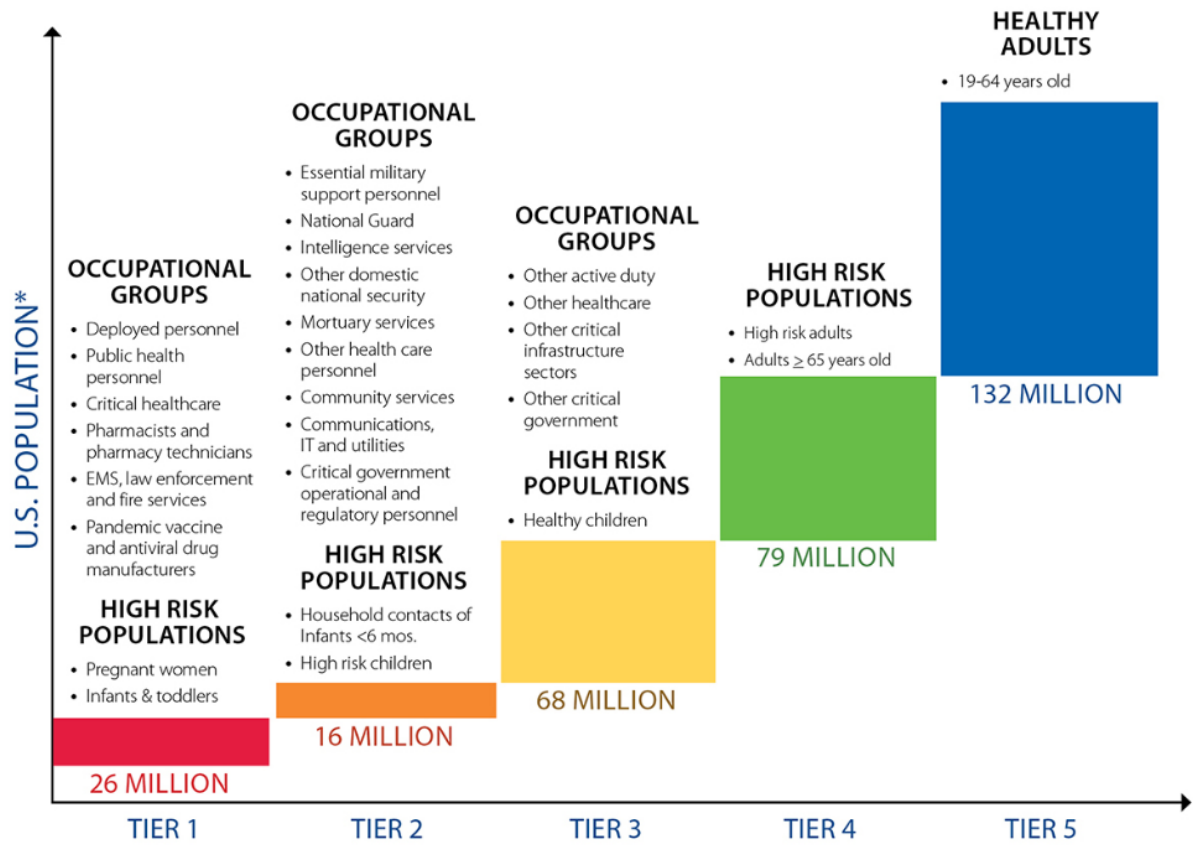
## **Vaccine**



The end of the pandemic will not occur until there are effective therapeutics and vaccinations. Individuals with IDD and their caregivers will need to be vaccinated as early as possible, following current CDC guidelines (See Figure 1) (Centers for Disease Control and Preventions, 2018). Many adults with IDD would most likely be designated as Tier 4, which includes high risk adult populations such as persons aged 19 to 64 years old who have underlying medical conditions and older adults aged 65 years or older. Based on the increased mortality rates observed in patients with IDD, we recommend that all patients with IDD be included in a high risk population tier, regardless of other medical diagnoses. DSPs and other caregivers of people with IDD may be identified as being Tier 1 or 2 based on the severity of the pandemic as well as the particulars on the group of people they are supporting.

Brown, et al. (2009) urge that workers who are part of any healthcare infrastructure receive high priority for vaccination. The US federal government has created Operation Warp Speed (OWS), a partnership among components of the US Department of Health and Human Services (HHS), including the CDC, FDA, National Institutes of Health, and the Biomedical Advanced Research and Development Authority (BARDA), and the Department of Defense (DoD). The stated purpose of OWS is “to deliver 300 million doses of a safe, effective vaccine for COVID-19 by January 2021, as part of a broader strategy to accelerate the development, manufacturing, and distribution of COVID-19 vaccines, therapeutics, and diagnostics” (US Department of Health and Human Services, 2020). The AADMD believes that DSPs supporting people with IDD are essential healthcare workers and recommends that they be made a top priority for vaccination once it is available.

**Figure 1.** Vaccination tiers & population groups for high/very high level of pandemic severity



## Mental & Behavioral Supports

People with IDD, and their families, DSPs, nurses and others who provide supports to them may be experiencing higher levels of stress, anxiety, depression, and behavioral health support needs (Vindegard & Benros, in press). Routines and long standing structures that have allowed people to successfully predict what to expect have been radically changed because of the pandemic. DSPs and other caregivers face risks to their own health and their families' health simply by going to work. Many may face the grief that comes with losing friends, loved ones, staff, and feelings of isolation. The global community, including people with IDD, is facing these and other new emotional and mental health challenges that have arisen during the COVID-19 pandemic.

Service agencies should provide resources and create, with the people they support, formal plans to address the mental health of people and staff during this time. While the details of any such planning are outside the scope of this paper, we recommend, at the very least, that all have access to emergency mental health care including counseling and grief support.

## Conclusion

Individuals with IDD and the DSPs, nurses and other caregivers who support them are often overlooked, high risk populations facing the COVID-19 pandemic. Therefore, it is critical to take concrete and specific steps to prevent the spread of COVID-19 among this population. The

AADMD recommended that the above guidelines be adopted on a national level in residential settings serving people with IDD. We recognize the disease burden and resource availability varies greatly across states. However, it is critical that testing, PPE, and contact tracing resources be prioritized for this population as it has been for other high risk populations.

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