



## Developmental Disabilities Administration (DDA) Updates

#### **Bernard Simons, DDA Deputy Secretary**

August 7, 2020



# **Deputy Secretary's Agenda**



- **Opening Remarks**
- Deputy Secretary Update
- COVID-19 Regional Update
- David Ervin, Chief Executive Officer, Jewish Foundation for Group Homes, Inc.
- Questions



# **Deputy Secretary's Opening Remarks**

- The DDA's highest priority is the health, safety, and wellbeing of people with intellectual and developmental disabilities, their families, staff, and providers
- The DDA is committed to transparency with all of our stakeholders to ensure we are all working with the same information to support our shared missions
- Thank you for your continued support in joining me during these webcast so that we can stay in-touch and be able to provide you with the most current information



#### **Provider Relief Fund: Medicaid and CHIP Provider Distribution**

 The federal Office of Health and Human Services announced a new deadline extension for Medicaid provider applying for the Provider Relief Funds Medicaid Targeted Distribution. The new deadline is August 28, 2020

<u>https://www.hhs.gov/about/news/2020/07/31/hhs-extends-application-deadline-for-medicaid-providers-and-plans-to-reopen-portal-to-certain-medicare-providers.html</u>



#### Maryland Nonprofit Recovery Initiative (NORI) - Reminder

- The DDA and Behavioral Health Administration (BHA) <u>Notice of Funding Availability</u> for PPE and Cleaning Supplies Costs is a time-limited funding opportunity
- A total of \$10 million is earmarked for nonprofits—that are providing services to people with disabilities and are licensed by BHA and DDA—to help defray an increase in costs directly related to the ongoing need to purchase Personal Protective Equipment (PPE) and related cleaning supplies in response to the COVID-19 pandemic
- Application portal opened on Wednesday, August 5th. The application portal closes August 19th or when grant requests exceed available funding, whichever is sooner



#### Maryland Nonprofit Recovery Initiative (NORI)

- Not every application is accepted if they are not complete properly or if the provider are ineligible
- For those providers whose application were rejected because of technical issues, such as address on their W9 does not match the address they listed in their application form will have the opportunity to resubmit
- Please read the full notice and check for updates at <u>https://dhcd.Maryland.gov/Communities/Pages/BHA-DDA-NOFA.aspx</u>
- For questions, email us at <u>dda.ppeapp@maryland.gov</u>



#### **Meaningful Day Services Reopening Framework**

- The DDA has continued to engage stakeholders and providers on considerations for a Meaningful Day Services Reopening Framework. The discussions have been robust and we all have learned so much from each other. Thank you all for your time and efforts as we continue to deal with this health emergency and focus on keeping the people we support, staff, and families as healthy and safe as possible
- The framework has been reviewed the Director of Community and Facility Initiatives and is leading all non-regulatory COVID-19 matters involving nursing homes, assisted living facilities, group homes, and other congregate living settings



#### Transformation

- Until the DDA system is fully transitioned into LTSSMaryland, the DDA will be operating in two systems: LTSSMaryland and the legacy Provider Consumer Information System (PCIS2)
  - Person-centered plans will be completed and approved in LTSS*Maryland*,
  - and Services will be authorized and billed through PCIS2
- To help stakeholders navigate between the two systems:
  - The DDA shared "At a Glance" documents related to service mapping for the different service names, units, scope, and billing instructions for the two systems. They are posted on the <u>DDA LTSSMaryland webpage</u>
  - The DDA will also be sharing additional guidance related to person-centered planning and service authorization to operate between the two systems



#### **Transformation continued**

- The DDA will provide guidance that includes:
  - Process in LTSS*Maryland* and PCIS2
  - Service Mapping
  - Policy
  - Process flow charts
  - Operating procedures
- Our goal is to share this information with all stakeholders by the end of next week



#### FY'21 Payments – Service Providers

- Q1 payment was issued without the 4% provider rate increase
- DDA will post updated rate tables, invoices, and Cost Detail Sheet by COB Monday, 8/10
- DDA will issue an interim payment to service providers that will include the difference between the Q1 payment and what would have been paid with the 4% increase
- DDA confirmed that the Q1 payment was calculated with the additional hours for residential and personal support services
   Marvland

DEPARTMENT OF HEALTH

#### **Targeted Case Management Rates – 4% & Geographical Differential**

- FY'21 rates have been updated to include the 4% increase
- DDA created a Geographic Differential for Targeted Case Management
  - Target date for implementation was July 1, 2020
- However, the DDA was recently notified that this Geographic Differential was substantive enough of a change in the DDA's current rates to require Maryland Medicaid to submit a State Plan Amendment (SPA) to the Centers for Medicare and Medicaid Services (CMS). This means that effective immediately, and back-dated to July 1, 2020, the DDA will have to revert all counties to the standard rate until the SPA is approved by CMS



#### **Retainer Payments**

- DDA's Appendix K includes retainer payments for providers who normally provide services that include habilitation and personal care, but are currently unable to due to the state of emergency
- The time limit for the retainer payment may not exceed the lesser of 30 consecutive days or the number of days for which the State authorizes a payment for a "bed-hold" in nursing facilities (Reference: <u>State Medicaid</u> <u>Director Letter Olmstead Update No: 3</u>)



#### **Retainer Payments Continued**

- Currently, Maryland Medicaid State Plan nursing facility "bed-hold" days are limited to 18 days
- On June 30, 2020, the Center for Medicare and Medicaid Services (CMS) issued new <u>Frequently Asked Questions</u> that included Retainer Payments
- While retainer payments up to 30 days may be implemented, states may authorize up to three 30-day episodes of retainer payments for an individual during the period of the disaster using the Appendix K



#### **Retainer Payments Continued**

- DDA will be requesting an increase from 18 Retainer Days to 30 Retainer Days
- The DDA will not be pursuing multiple periods at this time
- The DDA will revise the Appendix K as CMS requires to include the language that the Retainer Payments are based on the lesser of the nursing facilities bed hold days or up to 30 days



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# Training & Technical Assistance project in partnership with ICI at UMass Boston Opportunity

- 8 provider agencies participate over 13-months
- Open to current DDA employment service provider with a commitment to shifting focus of services from center-based work to competitive, integrated employment





#### NCI- Staff Stability Survey

- The National Core Indicators<sup>™</sup> (NCI) Staff Stability Survey gathers data on the workforce of Direct Support Professionals (DSPs) serving adults with I/DD
- Survey asks about the status of your agency's DSP workforce employed between January 1, 2019 and December 31, 2019
- 2019 data is critical as it will provide a benchmark of Maryland DSP data prior to COVID-19
- National Core Indicators Staff Stability Survey data due from providers by August 31
- For Questions or information, please Contact <u>Staci.Jones@Maryland.gov</u>



# **COVID-19 Regional Updates**

- **SMRO** Onesta Duke <u>onesta.duke@maryland.gov</u>
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# **DDA Tracking**



There are 17,764 people supported in services by the DDA of which 3% (502) have tested positive for COVID-19.



# **DDA Tracking**



There have been 466 participants reported as having tested positive for COVID-19 of which there have been 36 deaths.



The 36 deaths represents approximately 7% of all (502) participants that tested positive.





## David Ervin, Chief Executive Officer

# Jewish Foundation for Group Homes, Inc.



# **Jewish Foundation for Group Homes**



# Responding to COVID-19 7 August 2020

David A Ervin, CEO

# Timeline



JEWISH FOUNDATION FOR GROUP HOMES<sup>®</sup> Independence starts here.

# Early Experience

- PPE virtually inaccessible and/or unaffordable

   Four requests to governmental jurisdictions
   2.00 a.m. calls to China
- No testing
- No contact tracing
- People with IDD and our DSPs...crickets!



# New Normal

- Live-in Model in group living environments continues

   \$2/hour differential for hours worked
   Approx. \$400k in wage increases/month (reg/OT)
   Testing
- Personal supports, in-home and independent living in-person and virtual (hybrid)
- MOST—transition service is 100% virtual
- New communication platforms opens 'work-from-anywhere' opportunities

EWISH FOUNDATION

• Our Return to Safe Work and Risk Mitigation Plan (SWARM)



- Medical Advisory Panel
- Surveys—PRS, families and staff
- Evidence-based (research, CDC/NIH/MDOH)
- Virtually constant changes/updates
  - Board of Directors
  - o Risk Management Committee
  - $\odot$  Liability/umbrella broker and carrier

https://www.jfgh.org/covid/swarm/





# Stakeholder input Q2 How comfortable do you feel to return to work once JFGH resumes normal operations?

Answered: 155 Skipped: 2





# Surveys I believe appropriate safety protocols will be in place when I return to work.

#### Stakeholder input Assessing themes



Answered: 157

Skipped: 0



# Surveys

#### Stakeholder input Assessing themes

Q2 If yes, how long do you think this model should continue

Answered: 20 Skipped: 3





# Surveys 22 What Personal Protective Equipment would you like to wear when

# Stakeholder input

Assessing themes

Q22 What Personal Protective Equipment would you like to wear when going out into the community?







FOR GROUP HOMES<sup>®</sup>

# Support Guidelines

American Academy of Developmental Medicine and Dentistry

- Research informed
- Evidence-based

https://www.aadmd.org/white-paper

# COVID-19 SUPPORT GUIDELINES for Individuals with IDD during the pandemic



# Lessons

#### Successes

- DSPs, culture
- Health
- The new 'normal'
  - $\circ$  Innovating/evolving supports
  - $\odot$  Partnerships/strategic collaboratives
  - $\,\circ\,$  We're focused on the abilities of humans
- $\circ$  Reaching new stakeholders
- Catalyzed creativity

#### Challenges

- Self-determination vs Paternalism
- Financial
- The Unknown—when will this end?
- Managing fear
- Access to resources (PPE, testing, contact tracing)



# Questions







# COVID-19 SUPPORT GUIDELINES

for Individuals with IDD during the pandemic

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# **PREPARE. PREVENT. PROTECT**

As a vulnerable population, people with IDD, have higher rates of complications and death due to Covid-19, when compared to the general population<sup>1</sup>.

Photo by Rick Guidotti, Positive Exposure

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WHAT IS IDD?

IDD stands for Intellectual & Developmental Disabilities.





#### 66

...there need to be clear guidelines applied nationally to reduce the impact of COVID-19 on individuals with IDD.

#### 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 (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.

The extent of the ongoing impact of COVID-19 in the IDD population is under reported. There exists a lack of data, reports, publications, and inadequate surveillance structure in place to monitor COVID-19, or other public health outcomes, among the IDD population. (Turk, et al., 2020, Landes, et.al., 2020, Krahn, 2019). While COVID-19 monitoring is a global robust initiative, people with IDD are not identified as a category but are impacted due to high risk.

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 and support staff. 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 need to be clear guidelines applied nationally to reduce the impact of COVID-19 on individuals with IDD.

> "COVID-19-related fatality rates among people with IDD... are, in some states, more than three times the mortality rates among the general population."

#### **Infection Control & PPE**

Service agencies supporting people with IDD face a host of challenges posed by COVID-19. Their direct support professionals (DSP) and other caregivers are not necessarily trained in or familiar with infectious disease or infection control that is common to traditional healthcare settings. Accordingly, they need support.



Ongoing emphasis on proper hand washing, face coverings and laundering of potential contaminated clothing is essential. Service agencies should regularly review routes of potential contamination and spread of the virus for DSPs and people being supported, and protocols should be developed to address them.

Photo by Aggie Brooks

#### AADMD Recommendations

The AADMD recommends the following measures for infection control in all residential settings at minimum:



#### HAND HYGIENE

Proper hand hygiene (i.e., hand washing) is among the most significant infection control strategies to prevent the spread of COVID-19 and other infectious diseases (Parida & Bhatia, 2020). DSPs and other caregivers should encourage appropriate hand washing and reinforce those skills. Alcohol based hand sanitizers should be available to all people being supported with appropriate support for safe use. DSPs should teach and encourage frequent hand hygiene. Alcohol based hand sanitizers should not be used when hands are visibly soiled.

#### **RESPIRATORY ETIQUETTE**

Respiratory etiquette should be taught and emphasized. Tissues should be readily available with easily accessible trash cans for disposal.

#### **ENVIRONMENTAL CLEANING**

Additional environmental cleaning parameters should be developed with a specific schedule for cleaning and disinfecting shared spaces and equipment. EPA-registered disinfectants should be used.

- Eating utensils and any adaptive or typical household equipment that is likely to come into contact with a person's mouth must be properly disinfected and stored to lessen chances of cross contamination.
- Surface disinfection of potential airborne droplet spread in areas that saliva droplets may have landed or touched such as a sink, faucet handles, door knobs and even television remote controls. Kampf and colleagues (2020) suggest that coronavirus may remain infectious on surfaces for as many as nine (9) days, and recommend cleaning solutions that contain 0.1% sodium hypochlorite or 62% to 71% ethanol to effectively disinfect surfaces.



#### **ORAL HYGIENE**

Although oral care carries risk of transmission, it should not be neglected. Poor oral health is common among people with IDD (Wilson, et al., 2019; Anders & Davis, 2010), so it is more important to ensure high quality home oral care during the pandemic as routine in office dental care will likely be limited and delayed. Routine oral healthcare is a high risk activity for COVID-19 spread. For example, the use of electric toothbrushes and even manual toothbrushing may produce droplets or aerosols. Therefore, any DSPs or other caregivers who may be assisting a person in or performing toothbrushing should wear proper PPE (minimally, a mask and face shield or other eye protection) to avoid splatter.

#### **PPE Access & Availability**

Access to and availability of personal protective equipment (PPE) at and immediately following the US outbreak of the pandemic was extraordinarily limited across all healthcare systems. 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', efforts to address shortages of PPE and critical medical equipment such as ventilators were undertaken. Beyond traditional healthcare, systems of community support for people with IDD, 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 nonhealthcare 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, they 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 PPE.

#### 01 HEA

#### HEATHCARE GRADE PPE

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<sup>2</sup>.

#### 02

#### PROJECTED PPE NEED

Organizations should assess current and projected PPE needs for surges in and/or the predicted second wave of COVID-19 outbreaks.

03

#### PPE ORDER CONSOLIDATION

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 reorder needs.

#### 04 PPE TRAINING

Training must be provided to DSPs who are otherwise unaccustomed to PPE use, particularly to include donning and doffing. Monitoring of ongoing proper PPE use must be maintained.

#### 05 FIT TESTS

For N95 masking, fit testing must be provided for each user.

#### 06 USED PPE

Used PPE may be considered hazardous medical waste, requiring special disposal protocols. Costs associated with disposal should be financially supported.

<sup>&</sup>lt;sup>2</sup> See CDC recommendations at Infection Control: Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).

#### **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 testing has not been consistently available for people receiving supports in

#### "Diagnostic testing has not been consistently available for people receiving supports."



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.

#### AADMD Recommendations

The AADMD recommends that organizations that support people with IDD, particularly but not only in congregate environments, be given immediate access to free FDAapproved rapid testing for every person with an IDD being supported and their DSPs with the following provisions:

- 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<sup>3</sup>.
- 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.

- 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.
- Multiple drive-thru testing sites should be made available and accessible for low- to no-contact testing processes.
- There should be no arbitrary limit on the number of tests per person, and all appropriate clinical guidelines should be followed.
- 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.

<sup>&</sup>lt;sup>3</sup> See CDC guidelines at Testing Guidelines for Nursing Homes.

#### **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 service agencies are unable to monitor staff for exposures once they leave a shift and not on 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).

#### AADMD Recommendations

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

- 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,

#### "In small group homes, cohorting can be a significant challenge."

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 (Table 1) can be assigned to group homes and can guide monitoring and cohorting.

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

Risk Level	Description
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 and 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 should 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 in which two people live 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 adhere to necessary precautions to minimize the spread of COVID-19 within a home. The CDC provides useful guidelines on managing risk within group homes<sup>4</sup>.

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 (Table 2) should be assigned based on individuals' behavioral support needs and the ability of those individuals to adhere to protocols such as masking and frequent handwashing. 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.

#### 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.

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

<sup>&</sup>lt;sup>4</sup> See CDC guidelines at Guidance for Group Homes for Individuals with Disabilities.

needs. To that purpose, furnishing and equipping these sites, if possible, and assuring appropriate PPE, food and other supplies are available, in advance, should be planned. 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.

"Service agencies that have access to vacant, unused properties should consider utilizing them for cohorting needs."





Photos by Rick Guidotti, Positive Exposure

# Emergency Room & 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.

Amid 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 emergency department and hospital discharge (2020a; 2020b).

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 emergency department/ 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<sup>5</sup>.

Ensuring safe care transitions requires a systematic approach. Three key areas must be addressed prior to discharge: 01

#### MEDICATION

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.

#### 02 COMMUNICATION

Structured discharge communication: Information on medication changes, pending tests and studies, and follow-up needs must be accurately and promptly communicated to outpatient physicians.

03

#### PATIENT EDUCATION

Patient education: Patients, their families and 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 the financial strain they are experiencing during the pandemic. We recommend providing financial aid to provide PPE for residential support 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 that incentivize premature discharge.

#### Individual & 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 on COVID-19 infections. In these data as of June 25, 2020, the mortality rate among people with IDD who have tested positive for COVID-19 in Virginia is shown at 9.36%<sup>6</sup>, 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-197. 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. 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<sup>8</sup>. There is an urgent need to lobby local and state officials for:
  - 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 Wi-Fi connection in urban, suburban and rural areas.

<sup>&</sup>lt;sup>6</sup> See Virginia Department of Behavioral Health and Developmental Service data at COVID - 19.

<sup>&</sup>lt;sup>7</sup> See AUCD's call for stories at Stories Needed about impact of COVID-19 on People with Disabilities.

<sup>&</sup>lt;sup>8</sup>The AADMD acknowledges that avoiding emergency rooms and urgent care environments is an appropriate position to take in order to avoid risks of exposure to others who may be infected with COVID-19; however, urgent and emergency healthcare needs cannot and should not be avoided.

#### Vaccine

The end of the pandemic will not occur until there are effective therapeutics and vaccinations.



Individuals with IDD and their DSPs and other caregivers will need to be vaccinated as early as possible, following current CDC guidelines (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

"Individuals with IDD and their DSPs and other caregivers will need to be vaccinated as early as possible..."

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.

Baron and colleagues (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.





#### Mental & Behavioral Health 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 (Vindegaard & 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 recommends that the above guidelines be adopted on a national level in residential settings serving people

"...it is critical to take concrete and specific steps to prevent the spread of COVID-19 among this population."

with IDD. We recognize the disease burden and resource availability varies greatly across states. However, it is critical that testing, PPE, contact tracing resources and eventual vaccine be prioritized for this population as it has been for other high-risk populations. Photo by Rick Guidotti, Positive Exposure

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# **Questions?**

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