Voluntary National Guidelines for Respite Care Agencies, Providers, Family Caregivers, and Respite Care Recipients

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PROVIDING AND RECEIVING RESPITE CARE SAFELY DURING THE COVID-19 PANDEMIC
UPDATED WITH GUIDANCE ON COVID-19 VACCINATIONS
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ACKNOWLEDGEMENTS

Frontline Workers and Family Caregivers

We want to acknowledge all the frontline workers, including public health professionals, doctors, nurses, certified nurse assistants (CNAs), and other essential workers, who are working tirelessly to help keep our communities safe and healthy during the COVID-19 pandemic. We also want to thank all those who are continuing to support family caregivers and individuals with special needs during these challenging and uncertain times, including direct support professionals, personal care workers, home care and home health aides, and respite providers. To family caregivers – your dedication to caring for your loved ones is what inspired and motivated the creation of these guidelines. Our wish for you is that you can safely receive the breaks you deserve and need so you can continue to provide care for your loved ones who need you now more than ever!

About the Principal Author

Kim Whitmore, PhD, RN, CPN has more than 20 years of progressive leadership experience working with communities as a personal care worker, home-care nurse manager, private duty nurse, Local Health Officer, Policy Section Chief and State Health Plan Officer for the Wisconsin Division of Public Health, educator and research scientist. Currently, Dr. Whitmore is an Assistant Professor in the College of Nursing at Marquette University where her research focuses on understanding and supporting the respite care needs of families of children with special healthcare needs. Dr. Whitmore is also the Founder and Chief Change Officer of Ujima United, LLC – a public health consulting agency that works to plant seeds of change, nurture sustainable partnerships, and grow happy, healthy, harmonious communities. Dr. Whitmore’s experience as a nurse, public health professional, and respite care expert make her uniquely qualified to lead the development of these guidelines.

Workgroup Members

A workgroup convened by the ARCH National Respite Network and Resource Center (ARCH)3 helped inform the development of this document. ARCH is grateful for their expertise and valuable input. Members of the workgroup included:

- Meghan Baskett Kluth, Vice President, Colorado Respite Coalition, a program of Easterseals Colorado, Lakewood, CO
- Geene Delaplane, Lifespan Respite Program Manager, Washington State Department of Social and Health Services
- Jill Kagan, Director, ARCH National Respite Network and Resource Center
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- Jennifer Sanchez, Sr. Social Services Program Director, YMCA of San Diego County, San Diego, CA
- Lisa Schneider, Executive Director, Respite Care Association of Wisconsin; and Family Caregiver, Appleton, WI

ARCH National Respite Network and Resource Center

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs, to help families locate respite and crisis care services in their communities, and to serve as a strong voice for respite in all forums. ARCH consists of the training and technical assistance division, which provides support to government agencies, national and state organizations, service providers and families through consultation, training, evaluation, and research; the National Respite Locator that helps family caregivers and professionals locate respite services and funding sources in their community; the National Respite Coalition, the policy division; and the Lifespan Respite Technical Assistance Center which is funded by the Administration for Community Living in the U.S. Department of Health and Human Services. The Lifespan Respite TA Center provides training and technical assistance to state Lifespan Respite grantees, their State Respite Coalition partners, and others interested in building statewide coordinated systems of respite services for all family caregivers.
INTRODUCTION

What is Respite Care?
Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult. Caregivers not only get a much-needed break from the demands of caregiving, but respite care also has been shown to have a positive impact on many individual and family outcomes, including: reduced stress, decreased fatigue, increased family quality of life, reduced social isolation, and improved relationships. Respite care can be provided across the lifespan to individuals with a variety of special needs. Respite care is funded by multiple sources and can take place in a variety of settings, including facilities, community settings, and in the homes of individuals with special needs.

The Impact of the COVID-19 Pandemic on Respite Care
The global COVID-19 pandemic began at the end of 2019 and has continued to impact our lives in many ways. To help reduce the spread of this highly contagious and potentially life-threatening virus, most communities closed non-essential businesses and encouraged people to stay home. As a result, many families have been quarantined for months without access to respite care and other supportive services. Additionally, the closure of day programs, childcare centers, and schools has increased the amount of time family caregivers are providing care for their loved ones. The pandemic has greatly increased demands on family caregivers while at the same time reduced the amount of respite care available at a time when it is needed more than ever.

While COVID-19 vaccines have now become widely available in the US, the pandemic is not over. It will take time for enough people to receive the vaccine in order to protect others from the virus. In the meantime, it is important to continue to follow appropriate safety protocols.

Purpose of the Guidelines
As more communities across the country continue to be impacted by the ongoing pandemic, many respite care agencies and other respite providers are also working to adapt services, as needed. The guidelines provided in this document are designed to assist you with careful and thoughtful planning and implementation strategies to provide and receive respite care as safely as possible during the ongoing COVID-19 pandemic. We want to emphasize that information from the World Health Organization, Centers for Disease Control and Prevention (CDC), and Local Public Health Departments should be your primary source for guidance on COVID-19 and other health-related issues. It is important to closely monitor local guidance and consult with your healthcare professional to ensure your health and safety.

“COVID-19 has shut down most of the [state]. Some respite services are continuing but all on a limited scale. Many agencies have stopped respite services entirely, either due to the shelter in place order, lack of available providers, limited access to Personal Protective Equipment and/or families not feeling comfortable using services.”

Quote from the Supporting Caregivers During the COVID-19 Pandemic Survey
Information about COVID-19 continues to evolve rapidly as we learn more about this emerging disease, so not all information in this guide may be relevant by the time you read this. As new information and resources become available, we will continue to update this guide on the ARCH National Respite Network and Resource Center website. If you have any questions, additional ideas, resources, or examples of success stories, please email Jill Kagan at JKagan@archrespite.org.

Note: All references are hyperlinked to the website of the source of information. The full URLs are also listed in References on page 21 in numbered order as they appear in the document.

**Target Audiences**

These guidelines were developed specifically for Lifespan Respite grantees, State Respite Coalitions and other partners, respite care agencies, respite providers, family caregivers, and respite care recipients. However, we recognize and hope that this information may be useful for other individuals or organizations.

For the purpose of this document, the term “respite care agencies” refers to both community-based agencies and consumer-directed respite voucher or reimbursement programs. The term “respite providers” refers to paid staff hired by respite care agencies or family caregivers, unpaid volunteers, or friends and family who provide respite care.

**DECIDING WHEN IT IS SAFE TO PROVIDE OR RECEIVE RESPITE CARE**

**The Decision-Making Process**

The decision to resume or continue respite services is a continuous process that involves thorough assessment, detailed planning, ongoing monitoring, and regular reassessment. Individuals and agencies must carefully consider all potential risks, benefits, and barriers before making an informed decision. It is important to remember that information and guidance related to COVID-19 is evolving rapidly. Additionally, depending on where you are located, the risk for exposure may vary and change over time. As a result, it is important to continually monitor and regularly reassess the safety of providing and receiving respite care. You may need to resume services in a step-wise or phased approach and you should be prepared to stop providing or receiving respite care services as the situation changes. It is important that all individuals involved in providing and receiving respite care feel comfortable with the decision and are kept in close communication regarding any changes.

**Decision Guides**

To help respite agencies and families decide when to resume respite services, we developed a Respite Agency Decision Guide (“Appendix A”) and a Family Decision Guide (“Appendix B”) that can be used along with the information in this document to help inform the decision-making process. You can download fillable PDF forms of the Respite Agency Decision Guide and Family Decision Guide on the ARCH National Respite Network and Resource Center website.
IMPORTANT INFORMATION ABOUT COVID-19

What is COVID-19?

Coronavirus – commonly referred to as COVID-19 – is an illness caused by a virus that is thought to spread very easily through close contact from person-to-person. According to the CDC,\textsuperscript{10} the Delta variant is currently the most widespread variant and is more contagious and causes more severe illness than previous variants in unvaccinated people. New variants of the virus are expected to continue to emerge.

We are still learning about how the virus spreads and the severity of the illness it causes. The World Health Organization (WHO) offers answers to common questions about COVID-19 on their Myth Busters\textsuperscript{11} webpage. Important considerations about the spread of COVID-19 from the CDC include:

- The virus spreads between people who are in close contact with one another (within about 6 feet)
- The virus travels in respiratory droplets produced when an infected person coughs, sneezes, or talks. These droplets can land in the mouths or noses of people who are nearby or possibly be inhaled by the lungs.
- Respiratory aerosols (produced from activities such as exercise, singing, and shouting) can potentially spread the virus even further than 6 feet.
- It may be possible that a person can get COVID-19 by touching a surface or object that has the virus on it and then touching their own mouth, nose, or possibly their eyes.
- Some people without symptoms may be able to spread the virus.

COVID-19 Variants

Viruses constantly change through mutation. When a virus has one or more new mutations it’s called a variant of the original virus. Currently, several variants of the virus (SARS-CoV-2) that causes coronavirus disease 2019 (COVID-19) are creating concern in the U.S. According to the Mayo Clinic, the Delta variant is now the most common COVID-19 variant in the U.S. It’s nearly twice as contagious as earlier variants and might cause more severe illness, and the greatest risk of transmission is among unvaccinated people. The recent emergence of the Omicron variant (B.1.1.529) further emphasizes the importance of vaccination, boosters, and prevention efforts needed to protect against COVID-19. For more information on the COVID-19 variants, visit the CDC web page: What you Need to Know about Variants.\textsuperscript{12}

Symptoms of COVID-19

The CDC has created an infographic that describes the common symptoms of COVID-19. However, it is important to remember that some people with COVID-19 have no symptoms.

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Symptoms of Coronavirus (COVID-19)

Know the symptoms of COVID-19, which can include the following:

- Cough
- Fever
- Chills
- Muscle pain
- Shortness of breath or difficulty breathing*
- Sore throat
- New loss of taste or smell
- Cough
- Chills
- Muscle pain
- Shortness of breath or difficulty breathing*
- Sore throat
- New loss of taste or smell

Symptoms can range from mild to severe illness, and appear 2-14 days after you are exposed to the virus that causes COVID-19.

*Seek medical care immediately if someone has emergency warning signs of COVID-19.

- Trouble breathing
- Persistent pain or pressure in the chest
- New confusion
- Inability to wake or stay awake
- Bluish lips or face

This list is not all possible symptoms. Please call your medical provider for any other symptoms that are severe or concerning to you.

\textsuperscript{12}cdc.gov/coronavirus
The CDC has developed a Coronavirus Self-Checker\(^{13}\) to help make decisions about seeking appropriate medical care. If you or someone you care for develop symptoms, it is important to contact a healthcare professional and get tested, if available. For information on community-based testing locations near you, visit the U.S. Department of Health & Human Services\(^{14}\) website.

**Who’s at Risk?**

While COVID-19 can impact anyone, unvaccinated people are at the greatest risk of contracting the coronavirus. In the general population, older adults and people of any age who have serious underlying medical conditions might be at higher risk for severe illness. Many individuals who are respite care recipients may be at higher risk. Recent research\(^{15}\) suggests that individuals with intellectual and developmental disabilities may be at greater risk for poorer COVID-19 outcomes. It is important for people to consult their healthcare professional to discuss their individual risk.

According to the CDC, those at high risk for severe illness from COVID-19 are:

- People 65 years and older
- People who live in a nursing home or long-term care facility
- People of all ages with underlying medical conditions, particularly if not well controlled, including:
  - People with chronic lung disease or moderate to severe asthma
  - People who have serious heart conditions
  - People who are immunocompromised (many conditions can cause a person to be immunocompromised, including cancer treatment, smoking, bone marrow or organ transplantation, immune deficiencies, poorly controlled HIV or AIDS, and prolonged use of corticosteroids and other immune weakening medicines)
  - People with severe obesity (body mass index [BMI] of 40 or higher)
  - People with diabetes
  - People with chronic kidney disease undergoing dialysis
  - People with liver disease

For additional information on extra precautions based on specific conditions and risk factors, visit the CDC website\(^{16}\).

**Preventing Illness**

The best way to prevent illness is to get vaccinated and avoid being exposed to the virus by taking the following steps recommended by the CDC to slow the spread:

- Maintain at least 6 feet of social distance from other people
- Avoid close contact with people who are sick, even inside your home
• Wash your hands often with soap and water for at least 20 seconds
• If soap and water are not available, use hand sanitizer that contains at least 60% alcohol
• Routinely clean and disinfect frequently touched surfaces
• Cover your mouth and nose with a cloth face covering or mask when around others
• Cover coughs and sneezes with a tissue and then immediately wash your hands

• Avoid touching your eyes, nose, and mouth with unwashed hands
• Monitor your health for symptoms of COVID-19, stay home if you are sick, and contact your healthcare professional

The CDC has developed a Stop the Spread of Germs poster (available in several languages) that can be downloaded, printed, and posted as an important reminder about how to prevent the spread of COVID-19.

IMPORTANT CONSIDERATIONS

Emergency Preparedness Plans
Respite care agencies should develop and regularly update their emergency preparedness plans. The Emergency Preparedness Packet for Home Health Agencies provides templates and tools that could easily be adapted for respite care agencies.

Disability Voices United developed a Webinar and Resources on Coronavirus Emergency Preparedness Planning for People with Disabilities and Their Families. Family caregivers can use the What is Your Plan? Worksheet developed by the Respite Care Association of Wisconsin to help develop an emergency plan for their family during the COVID-19 pandemic. The CDC website also has information about Disability & Health Emergency Preparedness Tools & Resources.

Additionally, the American Red Cross has information and resources on How to Prepare for Emergencies that can help everyone during a public health emergency, like a pandemic.

Monitoring and Screening for COVID-19 Symptoms
Even though some people without symptoms may be able to spread the virus, it is important for everyone to regularly self-monitor for symptoms of COVID-19. The CDC also recommends businesses establish screening methods. Respite agencies should carefully consider feasibility and potential liability issues related to establishing screening of staff and/or clients. The following are important considerations related to monitoring and screening for COVID-19 symptoms:

• Screening methods should occur regularly (prior to providing/receiving respite services) and should inquire about any symptoms or possible exposure to COVID-19 in the past 14 days
• Document results of screenings and store information in a way that protects confidentiality
• Encourage family caregivers, care recipients, and respite providers to self-monitor for symptoms and call-in/stay home versus wait to be screened on-site
• Respite agencies should contact clients to screen for symptoms prior to having respite providers travel to the homes of care recipients
• Respite care providers or staff who have a fever of 100.4° F (38.0° C) or above (without medication) or other signs of illness should not enter respite care facilities or the homes of care recipients
• If respite care recipients or other members of their household have a fever of 100.4° F (38.0° C) or above (without medication) or other signs of illness, respite care should not be provided in-home
• Screening methods should incorporate social distancing or social barriers to eliminate or minimize exposures due to close contact with someone who has symptoms during screening
- Use disposable or non-contact (temporal) thermometers, if possible
- If performing a temperature check on multiple individuals, use a clean pair of gloves for each person and ensure that the thermometer has been cleaned thoroughly with an alcohol wipe between each check

Respite agencies, respite providers, family caregivers and care recipients should consider implementing the following to monitor and screen for COVID-19.

**Respite Agencies**
- ✓ Develop/revise health screening policies and procedures (See “Appendix C” for a Health Screening Policy and Procedure)
- ✓ Communicate screening policies and procedures with respite providers, family caregivers, and care recipients
- ✓ Review your sick leave policies to more easily enable staff to stay home from work, if needed
- ✓ Post signage at entrances to remind people to avoid entering if they have symptoms
- ✓ See additional guidance for Adult Day Services Centers from CDC

**Respite Providers**
- ✓ Review and follow health screening policies and procedures
- ✓ Self-monitor for symptoms of COVID-19
- ✓ Do NOT provide respite care if you are sick or develop symptoms of COVID-19
- ✓ If you develop symptoms of COVID-19, contact your healthcare professional and follow recommended guidance related to self-isolation and symptom management

**Family Caregivers and Care Recipients**
- ✓ Review and follow health screening policies and procedures
- ✓ Self-monitor for symptoms of COVID-19
- ✓ Do NOT receive respite care if you or anyone in your household are sick or have symptoms of COVID-19
- ✓ If you develop symptoms of COVID-19, contact your healthcare professional and follow recommended guidance related to self-isolation and symptom management

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**Social Distancing Activities**

Although it may be difficult to do some activities, there are many fun and creative ways for respite providers to interact with care recipients while still maintaining social distancing, including:
- Go for a walk
- Bike ride
- Enjoy time in nature
- Read a book or listen to an audiobook
- Garden
- Get and care for a virtual pet
- Host a talent show
- Cooking and baking
- Play sports that do not involve contact or sharing equipment, such as football toss, soccer, golf, and obstacle courses
- Exercise or practice yoga
- Play video games, online games, virtual card games, or virtual board games
- Watch TV or movies
- Play trivia
- Go on virtual fieldtrips
- Take a virtual vacation
- Write letters, poetry or journal
- Photography
- Make a music video or short film
- Knit, crochet, or sew
- Learn a new language
- Color or draw together
- Listen to or play music, dance, or participate in karaoke or a singalong
- Make crafts, origami, scrapbook, or create sidewalk chalk art
- Make a time capsule
- Build with Legos
- Work on a puzzle (online or in-person)
- Have a scavenger hunt
- Call, video chat, or have a virtual get-together with friends and family
- Sit around a bonfire
- Play charades

Remember to wear face coverings and don’t forget to properly clean and disinfect all items used for activities!
COVID-19 Vaccines

COVID-19 vaccines are safe, effective, and free. Getting vaccinated is the most effective way to prevent severe illness and death from the COVID-19 virus, including the Delta and Omicron variants. The CDC recommends COVID-19 vaccination for all people 5 years and older, including people who already had COVID-19, people with underlying medical conditions, and people who are pregnant, breastfeeding, trying to get pregnant, or might become pregnant in the future.

People with weakened immune systems may not be fully protected by the vaccine and should continue to follow all precautions recommended for unvaccinated people until advised otherwise by their healthcare provider. If you have questions or concerns about getting vaccinated, you should talk with your healthcare provider.

There are currently three vaccines authorized for use, and other vaccines are in development. The Pfizer and Moderna vaccines initially required two doses, and a third vaccine, developed by Johnson & Johnson requires only one dose for effective protection from COVID-19. CDC recommends boosters for EVERYONE ages 12 and older.

While serious side effects from COVID-19 vaccines are extremely rare, there are some common vaccine side effects, which are normal signs that your body is building protection. Common side effects include pain, redness, and swelling at the site of the shot and flu-like symptoms (i.e. tiredness, headache, muscle pain, chills, fever, nausea). The side effects are more common after the second dose and generally go away in a few days. Some people have no side effects.

According to guidance from the CDC, once you are fully vaccinated, you can resume many activities that you did prior to the pandemic. However, if you are in an area with a high number of COVID-19 cases, the CDC recommends wearing a mask indoors and in crowded outdoor settings. Individuals who have weakened immune systems or have an underlying condition that puts them at greater risk of severe illness or death from COVID-19 may still choose to continue to wear masks.

More information about COVID-19 vaccines can be found on the CDC website.25

COVID-19 vaccines are now widely available for anyone 5 years and older. CDC recommends boosters for EVERYONE ages 12+. Search vaccines.gov, text your zip code to 438829, or call 1-800-232-0233 to find COVID-19 vaccine locations near you.
**Social Distancing**

Social distancing, also called “physical distancing,” means keeping space between yourself and other people. To help prevent the spread of COVID-19, the CDC recommends staying at least 6 feet (about 2 arms’ length) from other people. However, it may be challenging for respite care recipients who have limited mobility or trouble understanding information to practice social distancing.

According to the CDC, social distancing is the most effective way to prevent the spread of COVID-19.

Additionally, respite providers often cannot avoid coming into close contact with care recipients. In these cases, it is important to practice social distancing, as much as possible. Social distancing may also be difficult in shared living spaces and facility-based respite agencies. We recommend the following:

- Limit nonessential visitors and staff
- Consider limiting the number of people involved in transitions, such as drop-off and pick-up
- Consider expanding shifts to limit the number of people in the facility at a time
- Use signs, floor markings, and physical barriers to help promote social distancing
- Close common areas or limit the number of people allowed at one time
- Adjust and stagger activities to limit the number of people in the same area at a time
- For in-home respite, try to keep the respite provider and care recipient separate from other family members as much as possible, consider limiting the number of areas in the house that respite care services are provided, and use outdoor spaces, if available
- Exercise, singing, chanting, or shouting activities can increase the distance the virus spreads in respiratory aerosols. Consider temporarily suspending these types of activities or increase distance between people to greater than 6 feet and encourage the use of masks.
- Keep track of all visitors and staff who enter the facility using a sign in/out log that records the day, time, name, and contact information. This log can be very helpful for contact tracing purposes should someone in the facility be diagnosed with COVID-19.
- Provide easy to understand information about the importance of social distancing to clients, such as this [Social Distancing Social Story](#) developed by the Autism Society

**Where to Get PPE**

PPE is available without a prescription but may be difficult to obtain due to the high demand during the pandemic. Most retail pharmacies (i.e. Walgreens, CVS, etc.) and general merchandise retailers (i.e. Costco, Walmart, Target, etc.) sell PPE but supplies may be redirected to hospitals and healthcare professionals. You can purchase PPE online (i.e. Amazon, eBay) but supplies are often limited and prices may be inflated. Medical supply companies are another potential source for PPE. Community based-organizations, including respite care agencies, can request cartons of 500 cloth face coverings for free, while supplies last, through the U.S. Department of Health & Human Services.

If you are having difficulty obtaining PPE, contact your Local Health Department to inquire about possible solutions. Many State and Local Health Departments have developed programs that allow respite agencies and families to request PPE. You can also contact your [state respite coalition](#) to see if they can help you obtain PPE.

**Personal Protective Equipment (PPE)**

Personal protective equipment (PPE) creates a physical barrier to help prevent the spread of germs. The type of PPE that may be most helpful to providing respite care safely during the COVID-19 pandemic includes disposable gloves, masks and face coverings. If care recipients receive respiratory treatments, additional PPE, such as gowns and face shields, may be needed.
Conserving PPE

Due to shortages of PPE, respite care agencies should consider taking steps to conserve the supply of PPE. The Wisconsin Department of Health Services has developed additional guidance on the use and conservation of PPE for Home and Community Based Service Providers and for Recipients of Home and Community Based Services.

In order to conserve the supply of PPE, there have been numerous creative solutions proposed, such as using raincoats, plastic garbage bags, or graduation gowns. However, these alternatives have not been approved by the CDC and should be avoided or used only in an emergency situation when PPE is not available.

Masks and Cloth Face Coverings

The CDC recommends that the general public wears masks and provides guidance on How to Select and Properly Wear a Mask. While now more readily available to the general public and more protective against COVID variants, surgical masks, N-95 or K-95 respirators or other PPE intended for healthcare workers are not required unless instructed otherwise by healthcare professionals. It is important to note that cloth face coverings may not fully protect the wearer; however, they may keep the wearer from spreading the virus to others.

The following are important considerations when wearing a mask or face covering:

- Make sure you can breathe through it.
- Wear it whenever going out in public or when unable to practice social distancing.
- Make sure it covers your nose and mouth.
- Wash after using.
- Keep clean, unused cloth face coverings separate from dirty, used cloth face coverings to avoid cross-contamination (consider having two plastic baggies labelled “Clean” and “Dirty”).
- Do not use with children under two years old.
- Do not use with individuals who experience anxiety or confusion when wearing.
- Consider wearing a mask with a clear window if working with individuals who are deaf or hard of hearing and rely on lip-reading.
- Many public health departments have issued orders that require people wear face coverings in public and certain employment spaces regardless of vaccination status.

The CDC has developed posters (available in several languages) that can be downloaded, printed, and posted as important reminders.

Disposable Gloves

The CDC recommends wearing disposable gloves:

- When you are routinely cleaning and disinfecting
- When caring for someone who is sick
Providing and Receiving Respite Care Safely During the COVID-19 Pandemic

When touching or having contact with blood, stool, or body fluids such as saliva, mucus, vomit, and urine

In most other situations, wearing gloves is not necessary. After using disposable gloves, throw them out and wash your hands. Never reuse disposable gloves.

Handwashing

Handwashing is one of the best ways to protect yourself and your family from getting sick. For handwashing to be effective, it is important to follow the steps recommended by the CDC.

- **WET** your hands with clean, running water (warm or cold), turn off the tap, and apply soap.

- **LATHER** your hands by rubbing them together with the soap. Be sure to lather the backs of your hands, between your fingers, and under your nails.

- **SCRUB** your hands for at least 20 seconds (Tip: Sing “Happy Birthday” twice).

- **RINSE** hands well under clean, running water.

- **DRY** hands using a clean towel or air dry them.

Washing hands with soap and water is the best way to get rid of germs in most situations. However, if soap and water are not readily available, you can use an alcohol-based hand sanitizer that contains at least 60% alcohol. It is important to rub hand sanitizer over all the surfaces of your hands and fingers until your hands are dry (which takes around 20 seconds). Keep in mind that young children, as well children and adults with disabilities, may need additional supervisor or assistance with handwashing.

For more information on handwashing and to download printable posters (available in English and Spanish) that can be displayed near sinks, visit the [CDC website](https://www.cdc.gov/handwashing).

There are also many great [online videos](https://www.youtube.com/watch?v=dQw4w9WgXcQ) that demonstrate proper handwashing technique.

Cleaning and Disinfecting

Cleaning and disinfecting are important ways to help reduce the spread of COVID-19. The CDC has developed the following guidance for cleaning and disinfecting.

Consider the following:

- Develop/revise policies and procedures, as needed, to increase the frequency of cleaning and disinfecting.

- Ensure respite providers, family caregivers, and care recipients receive proper training and education about how, what, and when to clean and disinfect.

- Wear gloves for routine cleaning and disinfecting.

- Cleaning with soap and water reduces the number of germs, dirt and impurities on surfaces; and disinfecting kills germs on surfaces.
• Clean frequently touched surfaces more often, including: tables, countertops, doorknobs, light switches, handles, desks, phones, remote controls, keyboards, toilets, faucets, and sinks.
• Wheelchairs and other assistive devices should be cleaned and disinfected regularly.
• When arriving home, respite providers should immediately remove their clothes and place them in a plastic bag for laundering and take a shower or bath.
• Download, print, and follow the EPA’s 6 Steps for Safe & Effective Disinfectant Use.36
• Always read and follow the direction on the label of cleaning and disinfectant products to ensure safe use.
• Diluted household bleach solutions can be used and should be prepared by mixing 4 teaspoons bleach per quart of room temperature water. Bleach solutions will only be effective for disinfection up to 24 hours.
• For additional guidance on topics such as cleaning of restrooms; ventilation issues; and checking the water system in buildings that have been closed for a long time to prevent the spread of Legionnaire’s disease, see the CDC guidance on Maintaining Healthy Environments.37

For more information on how to clean and disinfect, visit the CDC website.38

Food Safety
Although COVID-19 is not a food-borne illness, there are still important considerations related to storing, preparing, and serving food that should be followed to help reduce the spread of COVID-19.

Whether you are in a facility, at home, or in the community, we recommend the following food safety tips:
• Thoroughly clean and sanitize all food prep, storage and serving areas regularly.
• Avoid communal/shared food, potlucks, and self-service.
• Ensure social distancing of at least 6-feet while eating, when possible.
• Remove food from carry-out containers before eating.
• While heat can kill the virus, there is limited evidence about the effectiveness of microwaving carry-out food and it is not generally required.
• Carefully label leftovers or avoid saving leftovers to prevent cross-contamination.

For more information on Food Safety and COVID-19, visit the Food and Drug Administration (FDA) website.39
Providing and Receiving Respite Care Safely During the COVID-19 Pandemic

Caring for People with Dementia or Developmental and Behavioral Disorders

Special considerations may be needed for people with dementia or developmental and behavioral disorders who have difficulty accessing information, have trouble understanding information, have difficulties with changes in routine, or sensory issues. The CDC suggests the following considerations:

- Social distancing and isolating may be difficult and reminders or supervision may be needed.
- Wearing masks or face coverings may be difficult for people with sensory, cognitive, or behavioral issues. Masks are not recommended for children under 2 or anyone who has trouble breathing, is incapacitated, or otherwise unable to remove the covering without assistance.
- Cleaning and disinfecting odors may affect those with sensory or respiratory issues.
- Handwashing or using hand sanitizer may require assistance or supervision.
- Cleaning and disinfecting may require assistance or supervision.
- Consider using social stories, video modeling, picture schedules, and visual cues to help develop new routines and follow recommendations.

If a respite care recipient cannot tolerate wearing a mask or face covering, consider using a face shield instead. If neither can be tolerated, we recommend limiting respite services to a single consistent in-home provider, preferably a friend or family member. Social distancing should be maintained as much as possible to help reduce the risk of spreading the virus. However, respite care agencies and respite providers need to carefully weigh the risks and liability concerns before agreeing to provide respite services to someone who cannot wear a cloth face covering or face shield.

For additional information, visit the CDC’s webpage on Caring for People with Developmental & Behavioral Disorders40 and COVID-19 Materials for People with Intellectual and Developmental Disabilities and Care Providers.41

The following organizations provide additional condition-specific resources related to COVID-19:

- Alzheimer’s Association42
- Autism Speaks43
- Autism Society44
- Children and Adults with Attention-Deficit/ Hyperactivity Disorder (CHADD)45
- Lucile Packard Foundation for Children’s Health (Children with Special Healthcare Needs)46
- Positive Approach to Care (Dementia Care Videos)47
- Boggs Center on Developmental Disabilities (Wearing a Face Mask Social Story49 and Helping Adults with Intellectual and Developmental Disabilities Become Comfortable with Face Masks50)

Legal and Ethical Considerations

The following are important legal and ethical considerations for respite care agencies, respite providers, family caregivers, and care recipients.

- Family caregivers and care recipients have a right to choose if they want to receive or refuse respite care services.
- Local, state, and national guidance related to COVID-19 are changing frequently as the situation evolves. Closely monitor messaging and consult with your Local Public Health Department51 for updated guidance.
Respite care agencies should notify local health officials, staff, and families immediately of any possible case of COVID-19 while maintaining confidentiality consistent with the Americans with Disabilities Act (ADA), the Health Insurance Portability and Accountability Act (HIPAA), and other applicable federal and state privacy laws.

Respite care agencies and respite providers should familiarize themselves with the provisions in the Families First Coronavirus Response Act (FFCRA), which requires certain employers to provide their employees with paid sick leave or expanded family and medical leave for specific reasons related to COVID-19.

Respite care agencies should discuss potential liability issues with their insurance agency and/or legal team, including:

- Ensuring vaccine mandates and screening protocols are not illegal or discriminatory
- Legal issues related to requiring use and provision of PPE and cleaning and disinfecting supplies

Respite care agencies should develop/revise policies and procedures to enhance safety and ensure staff receive the proper training and demonstrate competency. Respite providers and families have the right to ask for information about policies and procedures.

Respite care agencies should ensure they are following guidance from the Occupational Safety and Health Administration (OSHA) to protect the health and safety of their staff.

It is important to maintain documentation, including:

- Training and competency of staff and clients on policies and procedures
- Screening logs, including name, date, time, temperature and symptom checklist
- Attendance logs including day, time in/out, name, and contact information

Training Respite Care Providers

Respite care agencies are responsible for ensuring that all respite care providers receive the proper training related to all safety policies and procedures, including the following:

- Sick leave policies
- Screening protocols, including taking temperatures
- Hand hygiene
- Proper use of PPE, including gloves, masks and cloth face coverings
- Social distancing
- Cleaning and disinfecting
- Supporting people with developmental or behavioral disorders, or certain medical conditions, that may impede a person’s ability to wear a mask or engage in social distancing

Agape Respite Care, Inc. has developed several reopening policies and procedures that may serve as helpful examples for respite care agencies. Training materials should include written tests and return demonstration of skills to ensure understanding and competency. A Competency Validation Checklist can be found in “Appendix D”.

The World Health Organization has a variety of online COVID-19 Trainings that are available in multiple languages.
SUPPORTING POSITIVE MENTAL HEALTH AND WELL-BEING

It is important to support positive mental health and well-being during the ongoing COVID-19 pandemic. Fear and anxiety about a new disease and what could happen can be overwhelming and stressful. The social isolation from months of quarantine has the potential to increase feelings of loneliness. Additionally, many families are facing increased financial stress due to unemployment or reduced work hours. As a result, there is an increased risk of substance abuse, self-harm and suicide, domestic violence, and abuse and neglect of children, older adults, and individuals with special needs. If you recognize any of the following signs and symptoms in yourself or others, it is important to know you are not alone and there is help available.

- Fear and worry about your own health and the health of your loved ones, your financial situation or job, or loss of support services you rely on
- Lack of interest in doing things you normally enjoy
- Thoughts of hurting yourself or others
- Changes in sleep or eating patterns
- Difficulty sleeping or concentrating
- Worsening of chronic health problems
- Worsening of mental health conditions
- Sudden changes in behavior or acting out
- Unexplained injuries or bruises
- Untreated medical problems
- Coercive or threatening behavior
- Increased use of tobacco, and/or alcohol and other substances

Ways to Support Positive Mental Health and Well-Being

- Eat healthy, well-balanced meals
- Exercise regularly
- Get plenty of sleep
- Avoid alcohol and drugs
- Take deep breaths or meditate
- Take time to relax and engage in activities you enjoy
- Take breaks from watching, reading, or listening to news stories that may increase anxiety
- Connect with friends and family (maintaining social distancing)

Important Resources

- If you or someone you know is in immediately danger, CALL 911!
- Call the NAMI HelpLine at 800-950-6264 or in a crisis, text “NAMI” to 741741 for 24/7 confidential free crisis counseling
- Disaster Distress Hotline66 1-800-985-5990, or text TalkWithUs to 66746
- National Suicide Prevention Lifeline67 1-800-273-TALK (8255) or Lifeline Crisis Chat68
- National Domestic Violence Hotline69 1-800-799-7233 or text LOVEIS to 22522
- National Child Abuse Hotline70 1-800-4ACheild (1-800-422-4453) or text 1-800-422-4453
- National Sexual Assault Hotline71 1-800-656-HOPE (4673) or Online Chat72
- The Eldercare Locator73 1-800-677-1116 TTY Instructions74
- Veteran’s Crisis Line75 1-800-273-TALK (8255) or Crisis Chat76 or text: 8388255
- SAMHSA’s National Helpline77 1-800-662-HELP (4357) and TTY 1-800-487-4889
- Behavioral Health Treatment Services Locator78
REDEFINING RESPITE CARE

The COVID-19 pandemic has forced many respite care agencies to close or temporarily discontinue providing respite care services. However, some respite care agencies have used this opportunity to redefine respite care. The Building Respite Evidence and Knowledge (BREAK) Exchange79 conducted a global survey to better understand how respite care agencies have been impacted by the COVID-19 pandemic.

Key challenges that respite agencies described were related to:

- **Safety**, including lack of clear guidelines and limited access to PPE
- **Technology**, including limited access to internet and computers, poor computer literacy, and the impersonal nature of virtual interactions
- **Difficult Life Circumstances** experienced by both providers and families, including high levels of stress and anxiety and difficulty meeting basic needs
- **Organizational and Bureaucratic Barriers** such as inflexibility and time-consuming red tape in using funds for alternative services

Despite these challenges, many respite care agencies were able to adapt their services or create new services to continue to support family caregivers, including:

- Increased communication, check-in calls, and case management services
- Providing virtual support groups and video calls
- Changing the location of services to in-home or online
- Offering online activities to help support self-care and stress management
- Changes or flexibility in funding, such as providing grants for families
- Delivery of groceries, medications, supplies, meals, and care packages
- Connecting and sharing information via social media, websites and online videos
- Providing electronic pets to help with isolation

ARCH has found that many of these same activities are being provided by Lifespan Respite grantees, state respite coalitions, and providers in the Lifespan Respite Network. ARCH also has a resource list of informal respite options and opportunities81 with more ideas. In addition, some state Medicaid waiver programs, Lifespan Respite Care grantees and their state respite coalition partners have adapted self-directed respite or voucher services by easing restrictions on provider eligibility to include other family members in the home, increasing the number of respite hours or funds for respite vouchers, extending the number of months over which respite vouchers could be used, and permitting alternative respite settings. Some Lifespan Respite programs also lifted income eligibility restrictions.

“The pandemic is terrible for our clients... We call to check on them weekly. We have received a couple of different COVID-19 grants to help with food and gas costs. We know it takes more food during this time to feed our families because the children are home. We are providing gas cards to help them go pick up free lunches and breakfast at the school for children. Our families are more isolated than they ever have been and they have the stress of homeschooling the children.”

*Quote from the Supporting Caregivers During the COVID-19 Pandemic Survey*80
A SHARED RESPONSIBILITY

Ensuring the safety of respite care services during the COVID-19 pandemic is a shared responsibility. Respite care agencies, providers, family caregivers, and care recipients all play important roles in helping to keep everyone safe and healthy. We recommend that you discuss and agree on your shared responsibilities and consider signing an Oath of Responsibility like the one provided in “Appendix E”. The following provides a summary of key responsibilities by role.

Respite Care Agencies
✓ Encourage all staff to get vaccinated
✓ Monitor local guidelines carefully and adapt services, as needed
✓ Develop/revise policies and procedures to enhance safety
✓ Ensure respite care providers receive the proper training and demonstrate competency
✓ Adopt and implement enhanced hand hygiene practices and procedures to clean and disinfect surfaces
✓ Limit in-person contact and encourage social distancing among staff and clients
✓ Educate both staff and clients about their shared responsibility to help protect each other
✓ Provide PPE and other supplies, as needed
✓ Regularly monitor compliance and provide ongoing support, as needed
✓ See additional guidance for Adult Day Services Centers from CDC

Respite Care Providers
✓ Get vaccinated to protect yourself and others
✓ Do not provide respite care if you develop symptoms or have recently been exposed to someone who has been diagnosed with COVID-19
✓ Carefully follow recommended guidelines, policies, and procedures
✓ Engage in social distancing by staying at least 6-feet away from others, as much as possible
✓ Wear cloth face coverings and use other PPE, as needed
✓ Wash hands regularly and practice good hygiene
✓ Clean and disinfect surfaces regularly

Family Caregivers and Respite Care Recipients
✓ Get vaccinated to protect yourself and others
✓ Let your respite care providers/agency know if you or any household members develop symptoms or have recently been exposed to someone who has been diagnosed with COVID-19
✓ Carefully follow recommended guidelines, policies, and procedures
✓ Engage in social distancing by staying at least 6-feet away from others, as much as possible
✓ Wear masks and use other PPE, as needed
✓ Wash hands regularly and practice good hygiene
✓ Clean and disinfect surfaces regularly

SUMMARY

We hope that you found the information provided in this guide helpful as you consider ways to provide and receive respite care safely during the ongoing COVID-19 pandemic. We appreciate that these are unprecedented and uncertain times for everyone. Working together, with careful planning and consideration, we believe that respite care can be provided safely to families who need respite care now more than ever.
The following is a list of resources that were used to help develop these guidelines that you may find helpful, as well. We also encourage you to explore your state and local resources that support family caregivers and individuals with special needs.

**AARP Caregiver Resource Center**
- Family Caregiving

**Administration for Community Living (ACL)**
- General COVID-19 Information

**Agape Respite Care, Inc.**
- Reopening Policies and Procedures, including:
  - Letter to Families
  - Competency Validation Checklists (Donning and Duffing Gloves, Putting on and Taking Off Face Masks, Taking Temperature with No-Contact Forehead Thermometer
  - Infection Control Log
  - Staff Temperature Log
  - Mask Sign for Front Door
  - Permission for Travel for Essential Workers
  - Infection Prevention Policy and Procedures
  - Temporary COVID-19 Check-In Process Policy and Procedures
  - Temporary COVID-19 Policy and Procedures for Guest Scheduling
  - Staff Training Presentation Slides

**American Association on Health and Disability**
- Resources for People with Disabilities on COVID-19
- Video Series on COVID-19 & Disability
  - COVID-19 & Disability: Who’s at Risk for Complications
  - COVID-19 & Disability: Social Distancing
  - COVID-19 & Disability: Precautions for People in Wheelchairs
  - COVID-19 & Disability: Keeping Wheelchairs Clean
  - COVID 19 & Disability: Being a Self Advocate
  - COVID-19 & Disability: Knowing Your Legal Rights

**ARCH National Respite Network and Resource Center**
- COVID-19 Respite and Caregiving Resources

**Autism Society**
- Download Toolkit: Strategies to Successfully Transition to the “New Normal” Due to Covid-19
- Social Distancing Social Story
- Wearing Masks Social Story

**Boggs Center on Developmental Disabilities**
- Helping Adults with Intellectual and Developmental Disabilities Become Comfortable with Face Masks
- Wearing a Face Mask Social Story

**Building Respite Evidence and Knowledge (BREAK) Exchange**
- Preliminary Results of the Supporting Family Caregivers During the COVID-19 Pandemic Survey

**Care Academy**
- Free online training COVID-19: A Guide for Direct Care Workers

**Caregiver Action Network**
- COVID-19 and Family Caregiving

**Centers for Disease Control and Prevention (CDC)**
- Children and Youth with Special Health Care Needs
- Considerations for Community-based Organizations
- COVID-19 Materials for People with Intellectual and Developmental Disabilities and Care Providers
- Downloadable Materials (available in several languages) to support COVID-19 recommendations, including:
  - Symptoms of Coronavirus
Providing and Receiving Respite Care Safely During the COVID-19 Pandemic

- Stop the Spread of Germs
- Please Wear a Mask
- How to Safely Wear and Take Off a Cloth Face Covering
- What to Do If You Are Sick
- Stop Germs! Wash Your Hands
- Putting on PPE
- General COVID-19 Information People with Disabilities
- People with Developmental & Behavioral Disorders
- What do Direct Service Providers for people with disabilities need to know about COVID-19?
- How to Protect Yourself and Others

Family Caregiver Alliance
- COVID-19 Resources for Family Caregivers

Food and Drug Administration (FDA)
- Food Safety Resources

National Alliance for Caregiving
- COVID-19 Resources for Families Caregiving-Specific Information

National Association of City and County Health Officials
- Directory of Local Health Departments

National Association of Direct Service Providers (NADSP)
- COVID-19 Toolkit for DSPs

National Child Traumatic Stress Network
- Parent/Caregiver Guide to Helping Families Cope with the Coronavirus Disease 2019

Respite Care Association of Wisconsin
- COVID-19 Resources
- Finding Your “NEW NORMAL” During COVID-19
- What is Your Plan? Worksheet

Rosalynn Carter Institute for Caregiving
- Caregivers in Crisis: Caregiving in the Time of COVID-19

Teepa Snow’s Positive Approach to Care Videos
- How to Reduce Risks When You Must Be Closer Than 6 Feet
- How to Talk to Your Family Member Who is Locked In and Living with Dementia
- Managing Dementia Care in the Time of COVID-19
- Using Positive Physical Approach When a Face Mask is Necessary
- Wash Your Hands! Tips for Dementia Care Partners

U.S. Department of Health & Human Services
- General COVID-19 Information

U.S. Department of Labor Occupational Safety and Health Administration (OSHA)
- Guidance on Preparing Workplaces for COVID-19

Vermont Developmental Disabilities Council
- COVID-19 Information By and For People with Disabilities

Washington State Department of Health
- Novel Coronavirus Outbreak Frequently Asked Questions

Wisconsin Board for People with Developmental Disabilities
- COVID-19 Resource Toolkit

Wisconsin Department of Health Services
- COVID-19 Information
- Protecting yourself during a home visit

World Health Organization
- General COVID-19 Information
- Getting Your Workplace Ready for COVID-19
- COVID-19 Myth Busters
- Additional Downloadable Materials
REFERENCES

The resources referenced throughout this document and listed below are not specifically endorsed by ARCH and are provided only as a source of information. References to Internet websites (URLs) were accurate at the time the guidelines were written. Neither ARCH nor the author is responsible for URLs that may have expired or changed since the document was prepared.

2. https://www.ujimaunited.com/
3. https://archrespite.org/
18. https://asprtracie.hhs.gov/technical-resources/resource/3206/emncy-preparedness-packet-for-home-health-agencies
27. https://static1.squarespace.com/static/5ec811b5e52c012ce2e2467fccc/t/5ed5772af1298863283cddf1/1591047999511/Social+Distancing+Social+Story+-+Autism+Society.pdfand
29. https://archrespite.org/state-respite-coalitions
33. https://www.youtube.com/watch?v=RzlG5lMsdtA&feature=emb_logo
34. https://www.cdc.gov/handwashing/index.html
Providing and Receiving Respite Care Safely During the COVID-19 Pandemic

43. https://www.autismspeaks.org/covid-19-information-and-resources
44. https://www.autism-society.org/covid-19/
45. https://chadd.org/guidance-for-uncertain-times/
47. https://teepasnow.com/blog/the-drive-to-survive-putting-on-your-own-mask-first/
51. https://www.naccho.org/membership/lhd-directory
52. https://www.hhs.gov/hipaa/index.html
57. https://www.aacdf.org/
59. https://www.nctsn.org/
60. https://nads.org/
61. https://nads.org/covid-19resources/
64. https://www.nctsn.org/
65. https://www.childhelp.org/hotline/
RESPITE AGENCY DECISION GUIDE

Deciding when it’s safe to resume respite care services during the COVID-19 pandemic

Developed by the ARCH Workgroup

The Decision-Making Process

The decision to resume respite services is a continuous process that involves thorough assessment, detailed planning, ongoing monitoring, and regular reassessment. Respite care agencies must carefully consider all potential risks, benefits, and barriers before making an informed decision. It is important to remember that information and guidance related to COVID-19 is evolving rapidly. Additionally, depending on where you are located, the risk for exposure may vary and change over time. As a result, it is important to continually monitor and regularly reassess the safety of providing and receiving respite care. You may need to resume services in a step-wise or phased approach and you should be prepared to stop providing respite care services as the situation changes. It is important that all individuals involved in providing and receiving respite care feel comfortable with the decision and are kept in close communication regarding any changes.

1. Is there sufficient client interest in resuming respite services?
   - YES
   - NO
   - UNKNOWN

2. Will resuming respite care services be consistent with applicable state and local orders?
   - YES
   - NO
   - UNKNOWN

3. Is the number of new cases of COVID-19 going up, down, or holding steady in your area?
   - YES
   - NO
   - UNKNOWN

4. Have there been any recent outbreaks or surges in the number of cases of COVID-19?
   - YES
   - NO
   - UNKNOWN

5. Have there been any high-risk events in the past two weeks, such as large gatherings in the community, that could result in an outbreak or surge in cases of COVID-19?
   - YES
   - NO
   - UNKNOWN

6. Have you discussed and resolved any liability concerns with your insurance provider and/or legal team?
   - YES
   - NO
   - UNKNOWN

7. Has everyone involved been fully vaccinated?
   - YES
   - NO
   - UNKNOWN

8. Is it possible to follow the recommended steps to prevent the spread of COVID-19, including: vaccination, screening for symptoms, social distancing, handwashing, PPE, and enhanced cleaning and disinfecting?
   - YES
   - NO
   - UNKNOWN

9. Do you have a sustainable way to obtain the necessary PPE and cleaning and disinfecting supplies?
   - YES
   - NO
   - UNKNOWN

10. Are you able to adjust your budget and/or staffing to meet enhanced safety recommendations?
    - YES
    - NO
    - UNKNOWN

11. Do you have the capacity and the information to provide training and support to staff on safety precautions and in dealing with behavioral issues that may place someone at higher risk because of difficulty wearing a mask or social distancing?
    - YES
    - NO
    - UNKNOWN

12. Do you have a system in place to ensure regular and timely communication with staff and clients?
    - YES
    - NO
    - UNKNOWN

13. Does anyone involved have an underlying health condition or other risk factors that make them more likely to become seriously ill or hospitalized?
    - YES
    - NO
    - UNKNOWN

14. Does anyone involved have other high-risk exposures (i.e., exposure from being or living with an essential worker, recent travel, etc.)
    - YES
    - NO
    - UNKNOWN

15. What are the possible risks and benefits of resuming services for everyone involved? Consider social, emotional, mental, social, financial, and spiritual needs.
Decide

1. Who is impacted by the decision?
2. Who should be involved in the decision?
3. Who should be informed about the decision?
4. Can the decision wait? How long is the current situation sustainable?
5. Do the potential benefits outweigh the potential risks?
6. Are there any other barriers or concerns to consider?
7. Should respite services resume as normal or are there ways to adapt respite services to enhance safety?
8. What is the BEST decision at this time?  □ Resume respite services  □ Not resume, and continue to assess the situation

Plan

□ 1. Ensure there are policies and procedures in place related to the recommended steps to prevent the spread of COVID-19, including: vaccination, screening for symptoms, social distancing, handwashing, PPE, and enhanced cleaning and disinfecting.
□ 2. Ensure there are policies and procedures in place related to staff travel including limiting travel to hot-spots and measures to take once they return back to work.
□ 3. Train and verify competency of all staff on health and safety procedures, including how to support people with developmental and behavioral disorders, dementia, and other high-risk individuals.
□ 4. Plan how to adjust the time, frequency, environment, or type of activities to minimize risk.
□ 5. Create an emergency plan if staff or clients get sick.
□ 6. Identify and share resources and strategies for self-care and stress management with staff and clients.
□ 7. Notify clients of policies and procedures and ensure understanding of expectations.

Act

□ 1. After thoughtful assessment and detailed planning, ACT on the best decision at this time.

Monitor

□ 1. Regularly monitor developments with local authorities.
□ 2. Monitor staff absences and have flexible leave policies and practices.
□ 3. Monitor stock and distribution of cleaning and disinfecting supplies and PPE.
□ 4. Monitor daily and consult with local health authorities if there are cases in program or an increase in cases in the local area and adjust operations, as needed.
□ 5. Keep track of all visitors and staff who enter the facility using a sign in/out log that records the day, time, name, and contact information.
□ 6. Monitor staff travel to help avoid visiting hot-spots.
□ 7. Continue to monitor the situation and reassess decision regularly.
# FAMILY DECISION GUIDE

Adapted from the [Moving Forward Decision Guide](#) developed by the [University of Wisconsin Division of Extension](#)

## The Decision-Making Process

This decision guide was developed for family caregivers and care recipients. Whenever possible, the decision to receive respite care should be made together as a family. Families must carefully consider all potential risks, benefits, and barriers before making an informed decision about whether to resume respite care services. It is important to remember that information and guidance related to COVID-19 is evolving rapidly. Additionally, depending on where you live, the risk for exposure may vary and change over time. As a result, it is important to continually monitor and regularly reassess the safety of receiving respite care. You may need to resume services in a step-wise or phased approach and you should be prepared to stop receiving respite care services as the situation changes. It is important that all individuals involved in providing and receiving respite care feel comfortable with the decision and are kept in close communication of any changes.

### WHO should be involved in the decision-making process?

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<tbody>
<tr>
<td>1.</td>
<td>Who is impacted by the decision?</td>
<td>2. Who should be informed about the decision?</td>
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### What is the LOCAL context?

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<tbody>
<tr>
<td>1.</td>
<td>Are there any local or national guidelines that need to be considered?</td>
<td>YES</td>
</tr>
<tr>
<td>2.</td>
<td>Have there been any recent outbreaks or surges in the number of cases of COVID-19?</td>
<td>YES</td>
</tr>
<tr>
<td>3.</td>
<td>Have there been any recent outbreaks or surges in the number of cases of COVID-19?</td>
<td>YES</td>
</tr>
<tr>
<td>4.</td>
<td>Have there been any high-risk events in the past two weeks, such as large gatherings in the community, that could result in an outbreak or surge in cases of COVID-19?</td>
<td>YES</td>
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### What are the possible RISKS?

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<tr>
<td>1.</td>
<td>What are the possible risks for everyone involved? Consider social, emotional, mental, social, financial, or spiritual needs.</td>
<td>2. What would happen if no respite care was provided (i.e. job loss, impact on mental health of caregiver, out-of-home placement of care-recipient, etc.)?</td>
</tr>
<tr>
<td>3.</td>
<td>Has there been any impact on the family caregivers’ ability to provide quality care?</td>
<td>YES</td>
</tr>
<tr>
<td>4.</td>
<td>Does anyone involved have an underlying condition or other risk factors that make them more likely to become seriously ill or hospitalized?</td>
<td>YES</td>
</tr>
<tr>
<td>5.</td>
<td>Does anyone involved have other high-risk exposures (i.e. exposure from being or living with an essential worker, recent travel, etc.)?</td>
<td>YES</td>
</tr>
<tr>
<td>6.</td>
<td>Do you have a plan for what to do if someone gets sick?</td>
<td>YES</td>
</tr>
</tbody>
</table>
What are the possible **BENEFITS**?

1. What are the possible benefits for everyone involved? Consider social, emotional, mental, financial, or spiritual needs.
2. How would respite care benefit family caregivers?
3. How would respite care benefit care recipients?
4. What is the current stress level of family caregivers? (Highlight number to indicate level.)

How can risks be **MINIMIZED**?

1. Are there policies and procedures in place related to the recommended steps to prevent the spread of COVID-19, including: vaccination, screening for symptoms, social distancing, handwashing, PPE, and enhanced cleaning and disinfecting?
2. Can you adapt the time, frequency, environment, or types of activities to minimize risk?
3. Has everyone involved been fully vaccinated?
4. Do you have access to PPE (i.e. gloves and face coverings)?
5. Do you have access to cleaning and disinfecting supplies?
6. Is social distancing (at least 6-feet apart) possible?
7. Can everyone involved tolerate wearing masks or other PPE?

What are the possible **ALTERNATIVES** to respite care?

1. Does the family caregiver have friends or family members who can provide short breaks?
2. Are there other respite options that would help reduce the risks (i.e. virtual respite, outdoor respite, in-home respite, etc.)?
3. Can family caregivers wait a little longer to receive respite care? If so, how long could family caregivers continue to provide quality care without respite care?

Making the **DECISION**.

1. Does anyone involved have additional or ongoing concerns you should talk about more?
2. Do the potential benefits outweigh the potential risks?
3. What is the BEST decision at this time? □ Resume respite care □ Not resume – continue to assess the situation
4. How will you continue to monitor the situation in order to re-evaluate your decision regularly?
HEALTH SCREENING POLICY AND PROCEDURE

Adapted from guidelines developed by the YMCA of San Diego County

Health Screening

Before conducting any respite service, a health screening will be completed based on the county health department recommendations for safe reopening. This screening will occur anytime a provider, client, or any other person enters into the space where respite care is occurring.

- Respite providers must complete their own self-checks 24-hours before a respite appointment so they can cancel in advance if necessary. Providers should re-check on the day of service before entering the space where respite care will occur – typically the client’s home.

- Clients and any other individuals in the space where respite is provided must also submit to a health screening. If any individual refuses to answer or to participate in the health screening, respite care shall not be provided.

- Social distance must be maintained while completing the health screening questionnaire.

- Respite providers should clock in before completing health screenings as this time is compensable.

Health Screening Questionnaire

Ask the following questions:

- Have you traveled out of the country in the last 14 days?

- Do you have any of the following symptoms? (This list does not include all possible symptoms. CDC will continue to update this list as we learn more about COVID-19.)

  - Cough
  - Shortness of breath or difficulty breathing
  - Fever over 100°F
  - Chills
  - Muscle pain
  - Have you been in close contact (within 6 feet for more than 10 minutes) with a confirmed case of COVID-19 within the last 14 days?

If a RESPITE PROVIDER answers YES to any of the screening questions, they should:

- Isolate themselves from others.
- Call their supervisor and provide the information needed for a report.
- Call their respite client(s) to let them know they must cancel until further notice.
- Contact their medical provider. If they don’t have medical insurance call 211 to connect with the COVID-19 nurse line to receive guidance on how to be tested and when it will be safe to return to work.
- Notify their supervisor and client(s) when a medical provider gives them a safe expected return-to-work date.

If a CLIENT or other HOUSEHOLD MEMBER answers YES to any of the screening questions, the RESPITE PROVIDER should:

- Cancel the appointment.
- Notify their supervisor of the cancellation and the reason for the cancellation.
- Ask the client/household member to contact their medical provider and notify them when their medical provider deems it safe to resume services.
- Notify their supervisor with any updates to the situation, especially including the date for resumption of services.

If a respite provider has been in close contact with a confirmed case, they cannot provide respite for 14 days from the point of contact and should follow their medical provider’s or health officer’s recommendations.
Reporting Symptoms, Exposure, or Confirmed Case

RESPITE PROVIDERS should report information about their OWN symptoms, exposure, or confirmed case to:

Name: __________________________________________

Title: __________________________________________

Email: _________________________________________

Phone: _________________________________________

Please include the following:

☐ Name
☐ Age
☐ Symptoms, exposure, and/or confirmed case?
☐ If symptoms: what symptoms and when did you notice them?
☐ If exposure: how, when, where, and by whom were you exposed?
☐ Did you self isolate? If yes, include date.
☐ Were you tested? If yes, include date.
☐ Test results
☐ Management plan per your medical provider (e.g. room isolation, home isolation, hospitalization)

This information will be kept confidential at the respite agency to only the respite program directors and will not be added to staff’s personnel file. It will also be reported to the county health department as per reporting requirements.

RESPITE PROVIDERS should report information about a CLIENT or other HOUSEHOLD MEMBER’S symptoms, exposure, or confirmed case to:

Name: __________________________________________

Title: __________________________________________

Email: _________________________________________

Phone: _________________________________________

Please include the following:

☐ Client’s name
☐ Date by which a medical provider indicates it is safe to resume services

This information will be kept confidential at the respite agency to only the respite program directors. It will also be reported to the county health department as per reporting requirements.
### COMPETENCY VALIDATION CHECKLIST

Adapted from a checklist developed by Agape Respite Care, Inc. [45]

<table>
<thead>
<tr>
<th>TASK: (name of product or skill being observed)</th>
<th>LEGEND (check those that apply)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Review Policy</td>
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<td>Direct Observation</td>
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<td>Skills/Lab Testing</td>
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<td>Written Exam</td>
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<td>Video Review/Testing</td>
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<td>Chart Review</td>
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<td></td>
<td>Other</td>
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<tr>
<td>Date:</td>
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<tr>
<td>DSP Name:</td>
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<tr>
<td>DSP Signature:</td>
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<td></td>
</tr>
</tbody>
</table>

PERFORMANCE LEVEL GUIDE

1 – INSTRUCT (able to train others)
2 – COMPETENT (performs independently)
3 – CANNOT PERFORM INDEPENDENTLY (requires practice and supervision)

<table>
<thead>
<tr>
<th>STANDARD</th>
<th>PERFORMANCE LEVEL</th>
<th>EVALUATOR’S SIGNATURE (on every line)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type in the step-by-step procedures of the standard to be evaluated and signed off by a competent staff person.</td>
<td>Using the guide above, check off the DSP based on demonstrated skill level.</td>
<td>Competent staff evaluating the DSP will sign off on each standard performance.</td>
</tr>
</tbody>
</table>

Evaluator’s Signature: ___________________________ Date: ___________________________

Evaluator’s Credentials: __________________________________________________________________________________________________

This project was supported, in part, by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.
OATH OF PERSONAL RESPONSIBILITY

Adapted from the Oklahoma Center for Nonprofits

We have composed a simple “Oath of Personal Responsibility” that all respite agency staff, respite providers, family caregivers, and care recipients should adhere to. While not legally binding, it does remind all of us of our responsibilities to help reduce the spread of COVID-19 and ensure that respite care services can be provided safely.

I, ________________________________, am aware of the potential spread of COVID-19 that could result in severe illness and potential death. Therefore, I will, to the best of my ability, follow the recommended steps to prevent the spread of COVID-19, including: getting vaccinated, screening for symptoms, social distancing, handwashing, wearing face coverings, and enhanced cleaning and disinfecting. Should I develop symptoms or if I am exposed to someone with COVID-19, I promise to contact the respite agency to let them know. I will work with my healthcare provider and follow current recommendations related to testing and quarantine.

PRINT NAME  SIGN NAME  DATE