CONTENTS

3 INTRODUCTION
  3 What is Respite Care?
  3 The Impact of the COVID-19 Pandemic on Respite Care
  3 Purpose of the Family Decision Guide

4 IMPORTANT INFORMATION ABOUT COVID-19
  4 What is COVID-19?
  4 COVID-19 Variants
  4 Who’s at Risk?
  5 COVID-19 Vaccines
  5 Preventing Illness
  5 Special Considerations

6 SUPPORTING POSITIVE MENTAL HEALTH AND WELL-BEING

7 DECIDING WHEN IT IS SAFE TO RECEIVE RESPITE CARE
  7 The Decision-Making Process

8 EXAMPLE FAMILY DECISION GUIDE

10 SUMMARY

10 REFERENCES

10 ACKNOWLEDGEMENTS
  10 Frontline Workers and Family Caregivers
  10 About the Principal Authors
  11 Layout
  11 Community Advisory Board Members
  11 ARCH National Respite Network and Resource Center

12 APPENDIX A: FAMILY DECISION GUIDE

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INTRODUCTION

What is Respite Care?
Respite is a temporary break from caregiving. It is having another person step in to provide care for your loved one so you can get a much-needed break. Respite care can also be positive for the person receiving care and the entire family by reducing stress and fatigue, increasing quality of family life, reducing social isolation, and improving relationships.

The Impact of the COVID-19 Pandemic on Respite Care
The global COVID-19 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 Family Decision Guide
The information and guidelines provided in this document are designed to assist you and your family with careful and thoughtful decision making to ensure respite care is received as safely as possible during the ongoing COVID-19 pandemic.

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.

Because information about COVID-19 continues to evolve as more is learned about the disease, not all the information in this guide may be relevant by the time you read it. Your primary source of information on COVID-19 should be from the World Health Organization and Centers for Disease Control and Prevention (CDC). It is also important to understand local guidance provided by your Local Public Health Departments and consult with your healthcare professional to ensure your health and safety.

For more detailed information about COVID-19, please visit the CDC website. For more detailed guidance about receiving respite care safely during the COVID-19 Pandemic, refer to the Voluntary National Guidelines for Respite Care Agencies, Providers, Family Caregivers, and Respite Care Recipients.
Receiving Respite Care Safely During the COVID-19 Pandemic

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. 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.

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 nearly twice as contagious as earlier variants and might cause more severe illness, and the greatest risk of transmission is among unvaccinated people. The Omicron (B.1.1.529) variant might spread more easily than other variants, including Delta. For more information on the COVID-19 variants, visit the Mayo Clinic web page: COVID-19 variants: What’s the concern?

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. Recent research suggests that individuals with intellectual and developmental disabilities may be at greater risk for poorer COVID-19 outcomes. It is important to consult your loved one’s healthcare provider to discuss if they are at higher risk. For additional information on extra precautions based on specific conditions and risk factors, visit the CDC website.

Symptoms of COVID-19

- Cough
- Fever
- 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
- Inability to wake or stay awake
- Persistent pain or pressure in the chest
- Blush lips or face
- New confusion

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

Get a COVID-19 shot

Stay safe from COVID-19

[cdc.gov/coronavirus]
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. Getting vaccinated helps protect you and your loved one. The CDC recommends COVID-19 vaccination for all people 5 years and older, including people who already had COVID-19 and people with underlying medical conditions. Certain groups of people are now also eligible for booster shots. 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 COVID-19 vaccines, you should talk with your healthcare provider. More information about COVID-19 vaccines can be found on the CDC website.

Preventing Illness

The best way to prevent illness is to get vaccinated and avoid being exposed to the virus by taking the steps listed in the CDC’s “Stop the Spread of Germs” poster.

Special Considerations

Special considerations may be needed if your loved one has dementia or a developmental or behavioral disorder, especially if they have difficulty understanding information, changing their routine, or have sensory issues. The CDC suggests the following considerations:

- Social distancing and isolating may be difficult, and reminders or supervision may be needed.
- Wearing face coverings may be difficult for people with sensory, cognitive, or behavioral issues. Face coverings 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 your loved one cannot tolerate wearing a face covering, consider 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.

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

The Respite Care Association of Wisconsin developed a free course Finding Your NEW NORMAL during COVID-19, which covers a variety of topics, including links to activities for children and adults and self-care resources.

Call the NAMI HelpLine at 800-950-6264 or in a crisis, text “NAMI” to 741741 for 24/7 confidential free crisis counseling.

If you or someone you know is in immediate danger, CALL 911!
DECIDING WHEN IT IS SAFE TO RECEIVE RESPITE CARE

The Decision-Making Process

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 receive respite care services.

It is important to remember that information and guidance related to COVID-19 and its variants continue to evolve 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.

To help families decide when to resume respite services, we developed a Family Decision Guide (“Appendix A”) to help inform the decision-making process. You can download fillable PDF forms of the Family Decision Guide on the ARCH National Respite Network and Resource Center website.

The following shows an example of how a family may use the Family Decision Guide worksheet to help them decide if it is safe to receive respites services.
### EXAMPLE 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.

<table>
<thead>
<tr>
<th>WHO should be involved in the decision-making process?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Who is impacted by the decision? Me (primary caregiver) My son with a disability My husband and daughter Grandma who lives with us</td>
</tr>
<tr>
<td>2. Who should be informed about the decision? All who are impacted</td>
</tr>
<tr>
<td>3. Consider other family members, friends, and other providers. Physical therapist who comes to the house Homecare nurse</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>What is the LOCAL context?</th>
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<tbody>
<tr>
<td>□ YES □ NO □ UNKNOWN 1. Are there any local or national guidelines that need to be considered? Indoor mask mandate</td>
</tr>
<tr>
<td>□ YES □ NO □ UNKNOWN 2. Is the number of new cases of COVID-19 high or going up in your area?</td>
</tr>
<tr>
<td>□ YES □ NO □ UNKNOWN 3. Have there been any recent outbreaks or surges in the number of cases of COVID-19?</td>
</tr>
<tr>
<td>□ YES □ NO □ UNKNOWN 4. 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>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>What are the possible RISKS?</th>
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<tbody>
<tr>
<td>1. What are the possible risks for everyone involved? Consider social, emotional, mental, social, financial, or spiritual needs. I am burned out from providing care 24/7 now that my son is doing school virtually. I haven’t slept well in months. I am exhausted. My son’s condition makes him high risk for COVID so I am worried about him being exposed to others.</td>
</tr>
<tr>
<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.)? I don’t know how much longer I can provide this level of care without losing my mind!</td>
</tr>
<tr>
<td>□ YES □ NO □ UNKNOWN 3. Has there been any impact on the family caregivers’ ability to provide quality care? I am exhausted and irritable – I have no patience and am concerned that my short fuse may cause problems.</td>
</tr>
<tr>
<td>□ YES □ NO □ UNKNOWN 4. Does anyone involved have an underlying condition or other risk factors that make them more likely to become seriously ill or hospitalized? I am worried about Grandma who has a heart condition.</td>
</tr>
<tr>
<td>□ YES □ NO □ UNKNOWN 5. Does anyone involved have other high-risk exposures (i.e. exposure from being or living with an essential worker, recent travel, etc.)?</td>
</tr>
<tr>
<td>□ YES □ NO □ UNKNOWN 6. Do you have a plan for what to do if someone gets sick?</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.
   
   If we resume respite, I can get a break, take a nap, and have more energy to care for my son. My entire family will benefit because I'll be less irritable.

2. **How would respite care benefit family caregivers?**
   
   I would be mentally and physically recharged.

3. **How would respite care benefit care recipients?**
   
   My son would benefit from me being less irritable and more able to focus on providing him quality care. Plus, my son loves his respite provider and would have lots of fun after being isolated for so long.

4. **What is the current stress level of family caregivers?** (Highlight number to indicate level.)

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Little stress</td>
</tr>
<tr>
<td>2</td>
<td>High stress</td>
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</table>

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.)?**

   While the weather is nice, we can have our son’s respite provider take him to the zoo or local park.

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?

   I can try to hang on for another month -- two at the max.

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?**

   We will review our decision each week as a family as well as if there are any significant changes to our situation.
SUMMARY

We hope that you found the information provided in this guide helpful as you consider ways to 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.

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 Authors

Kim Whitmore

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.

REFERENCES

All references are hyperlinked to the website of the source of information. The resources referenced throughout this document 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 authors are responsible for URLs that may have expired or changed since the document was prepared.
Lisa Schneider
Lisa Schneider is an accountant with a social conscience. She is an accomplished executive with demonstrated ability to deliver mission-critical results. Lisa is skilled at creating strategic alliances with organizations and community leaders to effectively align with and support key community and organizational needs and initiatives. She is a results-oriented leader with an innovative spirit.

Mom to Kelsey, who has Angelman Syndrome, Lisa has over 30-plus years’ experience advocating for persons with disabilities and navigating the myriad of bureaucratic programs. Being a family caregiver herself, and her long history of non-profit leadership, and volunteerism on numerous boards and committees, Lisa brings a unique perspective to her role as Executive Director of the Respite Care Association of Wisconsin.

Layout
ARCH wishes to thank Norma McReynolds for her beautiful and compelling design and layout of the guidelines.

Community Advisory Board Members
A Community Advisory Board (CAB), comprised of family caregivers and respite care recipients, reviewed the contents of these guidelines to help ensure the relevance of the information to family caregivers. Their feedback was invaluable! Members of the CAB included:
- Erica Andres
- Stephanie Birmingham
- Linda Featherly
- Julie Frese
- Lynn Gall
- Jane Mahoney
- Carol Ortman
- Hector Portillo
- Harriet Redman
- Diane Small
- Leslie Thede
- Cynthia Thompson
- Amy Urbanski

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.

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.
FAMILY DECISION GUIDE
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4. What is the current stress level of family caregivers? (Highlight number to indicate level.)

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## How can risks be **MINIMIZED?**

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<td>2.</td>
<td>Can you adapt the time, frequency, environment, or types of activities to minimize risk?</td>
<td>3.</td>
<td>Has everyone involved been fully vaccinated?</td>
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<td>Do you have access to PPE (i.e. gloves and face coverings)?</td>
<td>5.</td>
<td>Do you have access to cleaning and disinfecting supplies?</td>
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<td>Can everyone involved tolerate wearing masks or other PPE?</td>
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## What are the possible **ALTERNATIVES** to respite care?

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<td>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?</td>
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## Making the **DECISION.**

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</tr>
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<tbody>
<tr>
<td>1.</td>
<td>Does anyone involved have additional or ongoing concerns you should talk about more?</td>
<td>2.</td>
<td>Do the potential benefits outweigh the potential risks?</td>
<td>3.</td>
<td>What is the BEST decision at this time?</td>
<td>4.</td>
<td>How will you continue to monitor the situation in order to re-evaluate your decision regularly?</td>
<td>5.</td>
<td>Resume respite care</td>
<td>6.</td>
<td>Not resume – continue to assess the situation</td>
<td></td>
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</tbody>
</table>