The background of the slide features a microscopic view of biological structures. On the left, there is a large, detailed cluster of cells with visible nuclei and cytoplasm. Scattered throughout the blue background are several spherical virus particles, each covered in small, protruding spikes. The overall aesthetic is scientific and clinical.

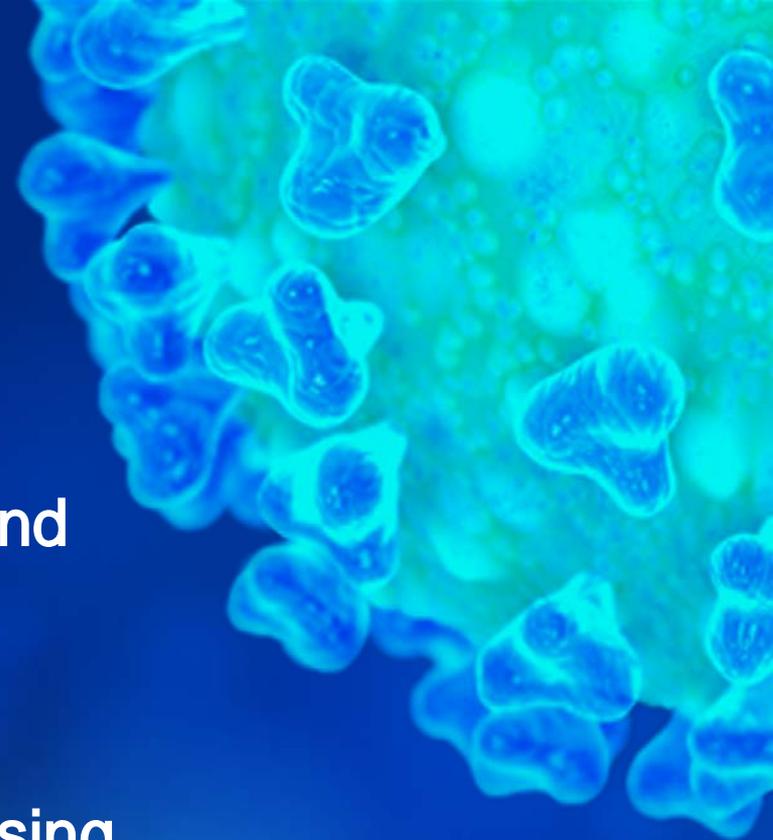
**Preliminary Results of the
Supporting Caregivers
During the COVID-19
Pandemic Survey**

Webinar 63-20

Presented By

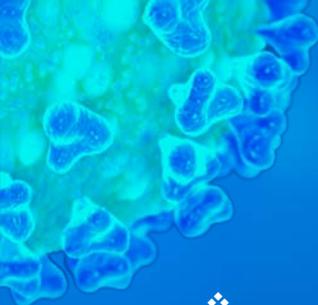
Susan Janko Summers, PhD
Senior Consultant
ARCH National Respite Network and
Resource Center

Kim Whitmore, PhD, RN, CPN
Assistant Professor, School of Nursing
University of Wisconsin-Madison



Co-Hosted By





Webinar Overview

- ❖ About the BREAK Exchange
- ❖ Preliminary Results of the *Supporting Caregivers During the COVID-19 Pandemic Survey*
 - ❖ Background
 - ❖ Purpose and Method
 - ❖ Preliminary Results
 - ❖ Implications
 - ❖ Limitations
 - ❖ Discussion
- ❖ Updates and How to Get Involved

About the BREAK Exchange

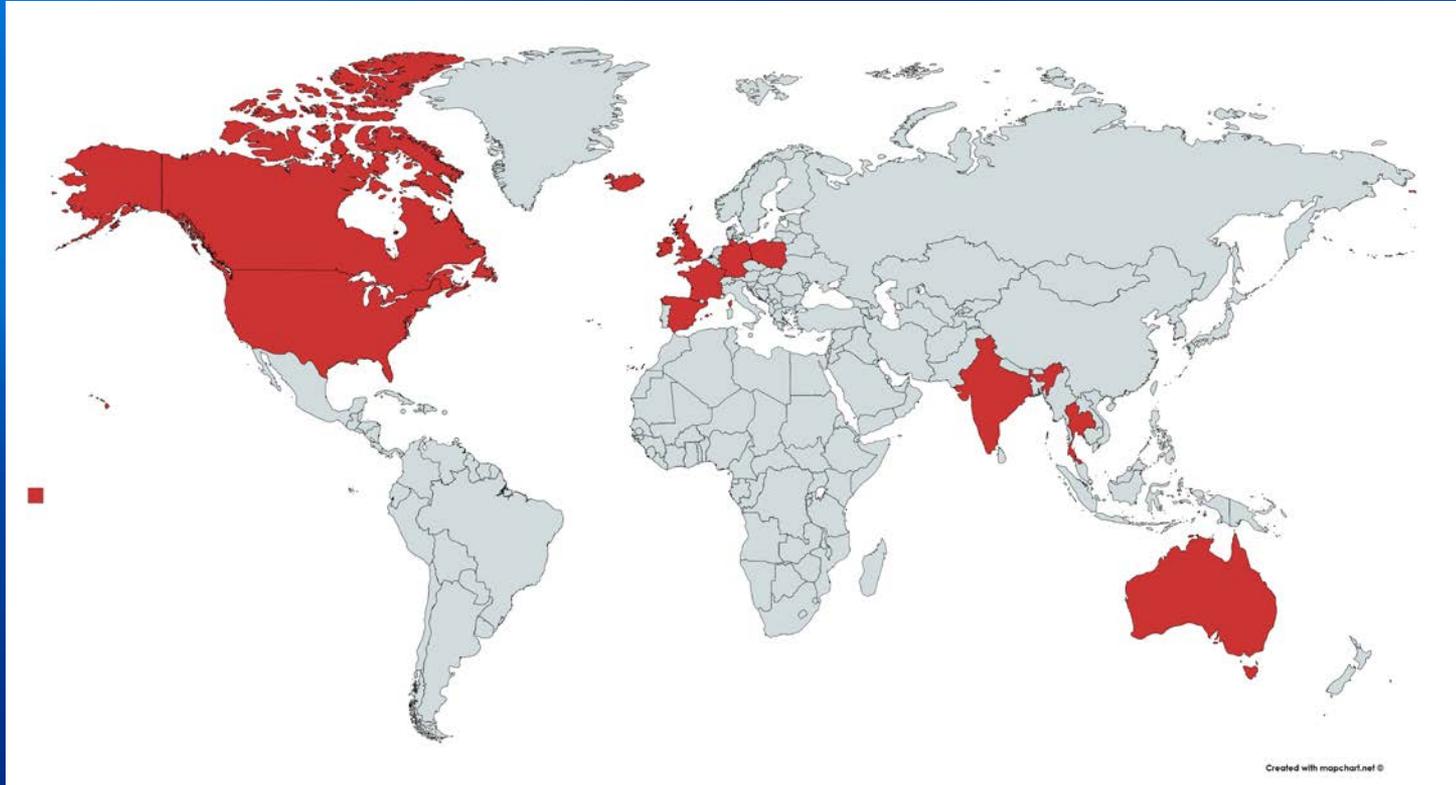
The Building Respite Evidence and Knowledge (BREAK) Exchange is an international group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidencebased respite care



BREAK Exchange Partners



130 members from 13 countries



Benefits of Joining



CONNECT



LEARN



SHARE



COLLABORATE

CONNECT

- ❖ Connect with a global network of researchers, respite providers, agencies, and individuals



LEARN

- ❖ Learn about evidence based respite care practices and research happening around the world



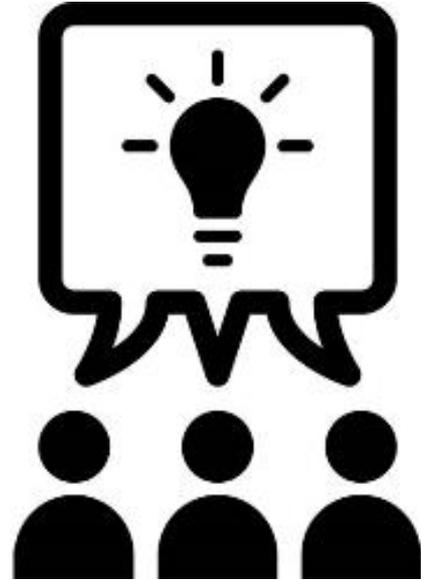
SHARE

- ❖ Share your evidence based practices or research with international partners
- ❖ Feature your work in the monthly e-newsletter, on the BREAK Exchange website, or present a quarterly webinar

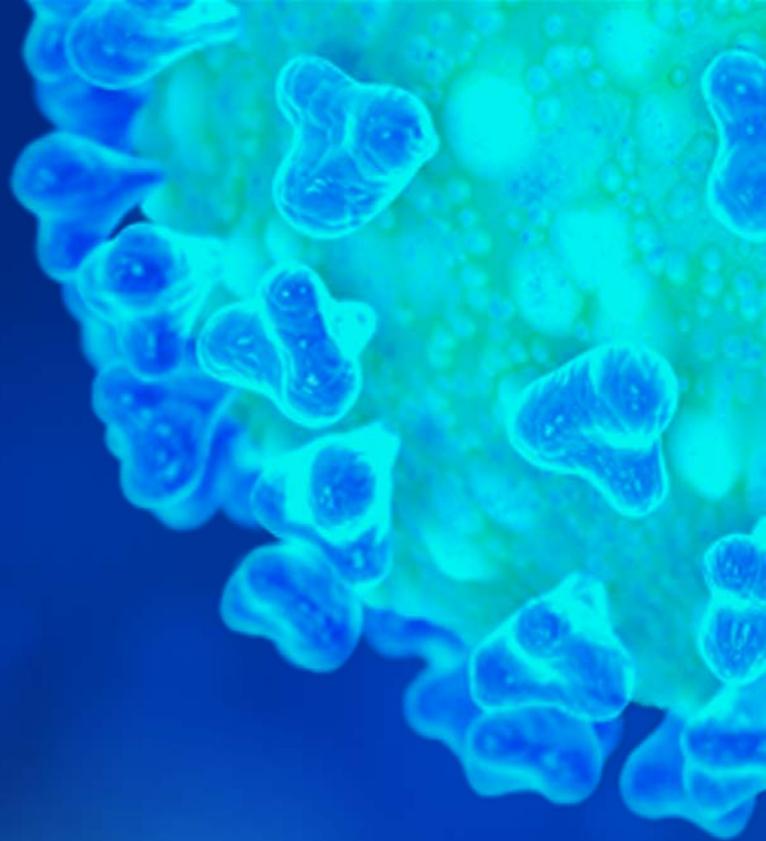


COLLABORATE

- ❖ Collaborate on an evaluation or research project
- ❖ Leverage the Exchange to identify a potential partner for your next project via the online Searchable Member Database

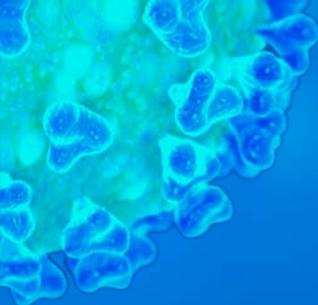


BACKGROUND



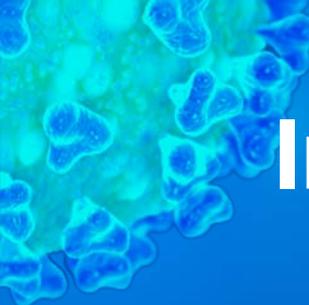
An Inclusive Definition of Respite (aka “Short Breaks”)

“Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, *and which result in some measurable improvement* the well-being of the caregiver, care recipient, and/or family system” (Kirk & Kagan, 2015)



BACKGROUND

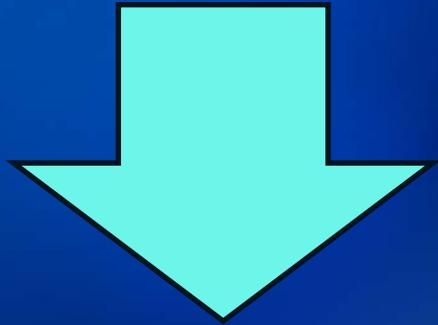
- ❖ Respite services can be provided:
 - ❖ in a variety of settings
 - ❖ to individuals with a range of disabilities and special needs
 - ❖ across the lifespan
- ❖ Unique aspects of respite services
 - ❖ Relational-based
 - ❖ Typically face-to-face



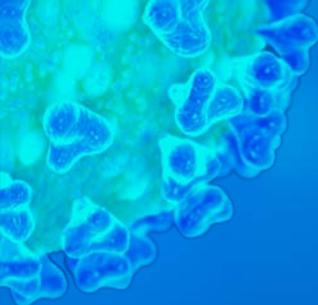
Impact of COVID-19 Pandemic



Increase need for
respite services

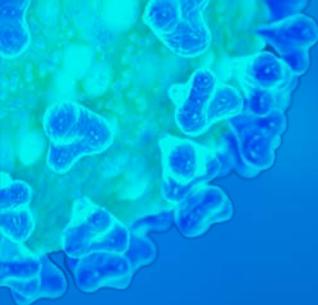


Decreased ability to
provide traditional
respite services



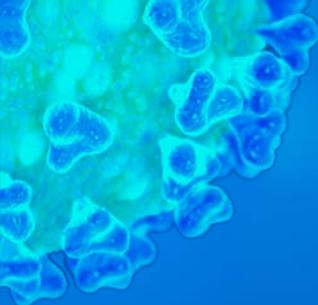
PURPOSE AND METHOD

- ❖ Purpose: to understand the global impact of the COVID 19 pandemic on respite care services and identify best practices for supporting caregivers during this time
- ❖ Online survey open March³¹ through May³¹
- ❖ Option to complete a more comprehensive BREAK Exchange Survey (44 responses)



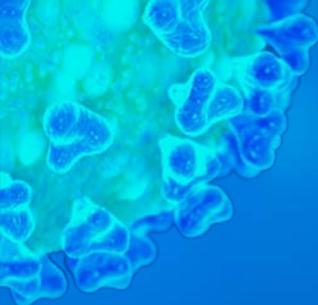
Survey Questions

- ❖ Demographic Information
 - ❖ *Name*
 - ❖ *Organization Information*
 - ❖ *Position*
 - ❖ *Country*
 - ❖ *Email*
- ❖ 3 Openended questions



Survey Question #1

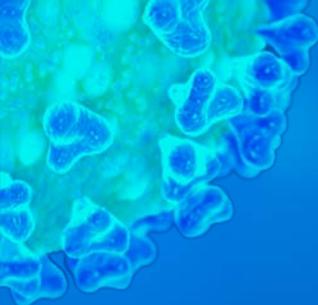
- ❖ Please describe the impact of the COVID pandemic on respite care services in your country, region, and/or organization. Include how your country, region and/or organization is responding and adapting to support caregivers during this time.



Survey Question #2

- ❖ If you have any **EXAMPLES** best practices, innovative ideas, communications, or other resources that you feel may be helpful to share with other respite care partners to help them better support caregivers during this time, *please describe them below** or email the information to break.exchange@son.wisc.edu

**This statement was added to increase response rate*



Survey Question #3

- ❖ Please provide any additional comments you have related to this survey

Analysis Team

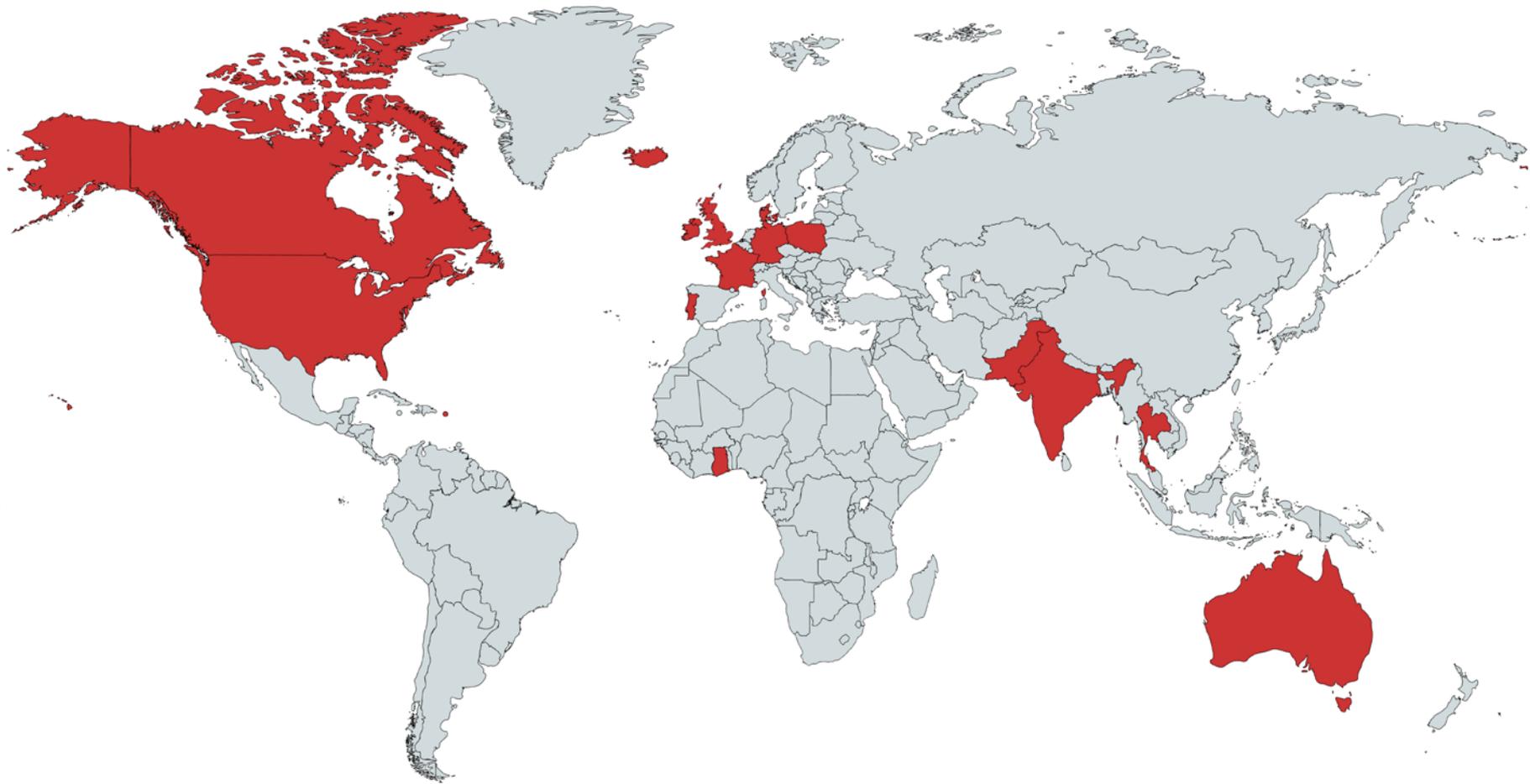
- ❖ Tyler Engel– UWMadison School of Nursing
- ❖ HannaKremsreiter- UWMadison School of Nursing
- ❖ DaniOrtmann- UWMadison School of Nursing
- ❖ SusanJankoSummers- ARCH National Respite Network
- ❖ Kim Whitmore- UWMadison School of Nursing

Inductive Content Analysis

- ❖ An iterative and recursive process
- ❖ Generated propositional statements that could be challenged, supported by data, and explored to further understanding
- ❖ List of *a priori* codes linked to the content of questions
- ❖ Codes developed and refined as coding progressed
- ❖ Weekly data analysis meetings
- ❖ Data coded by two people to check consistency and expand understanding

PRELIMINARY RESULTS

- ❖ A total of 549 responses from 17 countries
- ❖ Only 244 were valid responses
 - ❖ 5 from individual caregivers
 - ❖ Remaining were blank or did not respond to COVID-19 Questions
- ❖ Representing 15 countries
- ❖ Majority of responses from the United States (US)



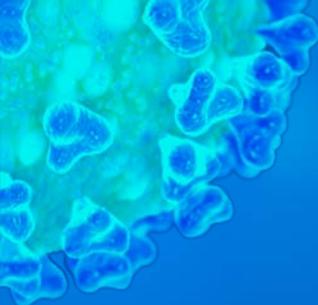
<i>Country</i>	<i>#</i>
Australia	1
Canada	2
Denmark	1
France	2
Germany	2
Ghana	1
Iceland	2
India	1

<i>Country</i>	<i>#</i>
Ireland	1
Pakistan	1
Portugal	1
Poland	1
Thailand	1
United Kingdom of Great Britain and Northern Ireland	1
United States and Puerto Rico	226



PRELIMINARY RESULTS

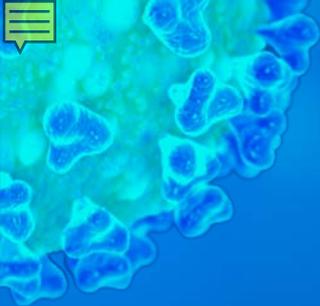
- ❖ Key lessons learned about the impact of the pandemic on respite and caregiver services, including:
 - ❖ *Key challenges*
 - ❖ *How programs have adapted*
 - ❖ *New and innovative services that have been created*
 - ❖ *Helpful resources*



CHALLENGES

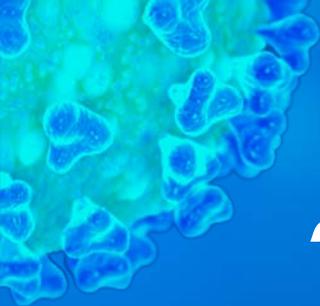
Challenges occurred in the following 4 areas:

- ❖ Safety
- ❖ Technology
- ❖ Difficult Life Circumstances
- ❖ Organizations/Bureaucracies

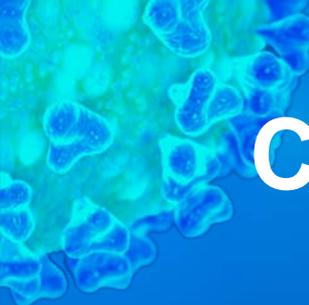


CHALLENGES - SAFETY

- ❖ Providers lacked *access to PPE* for themselves and clients
- ❖ Providers needed *safety protocols and clear guidance* following those protocols
- ❖ Caregivers needed *explicit safety guidelines* for choosing to interact, or interacting with service providers
- ❖ Programs and organizations need *to anticipate and plan for emergency responses* including Covid 19 recurrences

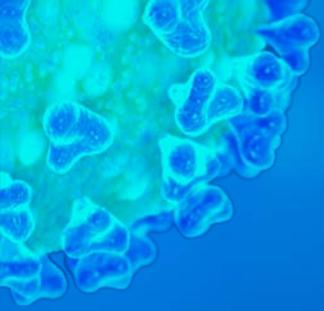


“COVID19 has shut down most of the [state]. Some respite services are continuing but all on a limited scale. Many agencies have stopped respite services entirely, either due to the shelter in place order, lack of available providers, limited access to Personal Protective Equipment and/or families not feeling comfortable using service’s

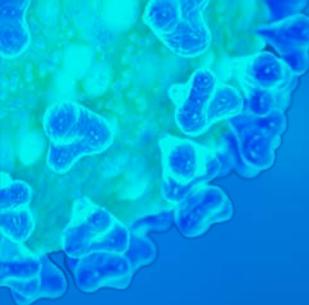


CHALLENGES - TECHNOLOGY

- ❖ Some organizations struggled to *find and use technology in response to new service delivery models*
- ❖ Some caregivers and families needed *access to computers and equipment, including adaptive technology* for persons with disabilities
- ❖ Some caregivers and recipients needed *explicit guidance and support in using technology*
- ❖ Some providers struggled to *find technology platforms that worked* for their intended purpose

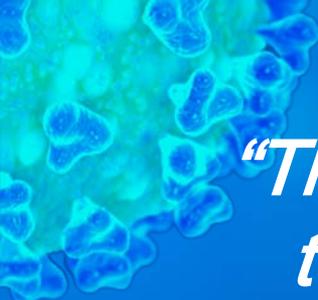


“Per [state] policy, most caregiver and therapy services are not allowed to be provided through a Telehealth format...it would help families if the states would approve the provision of caregiver and therapy services in a Telbealth format”

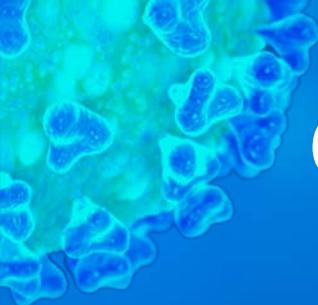


CHALLENGES – DIFFICULT LIFE CIRCUMSTANCES

- ❖ Both families and providers reported feeling *high levels of stress and worry*
- ❖ *Meeting basic needs* especially for food and medicines, challenged families
- ❖ Families needed *information and support to find and use community resources*

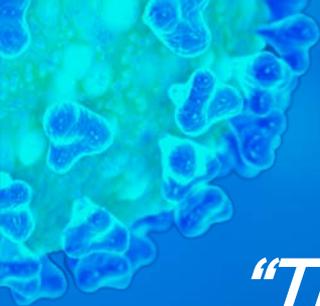


“The pandemic is terrible for our clients... We call to check on them weekly. We have received a couple of different COVID-19 grants to help with food and gas costs. We know it takes more food during this time to feed our families because the children are home. We are providing gas cards to help them 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”

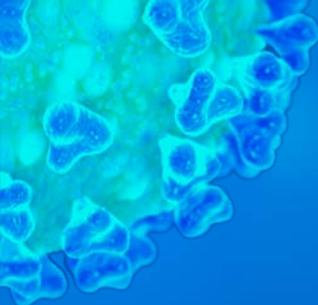


CHALLENGES – ORGANIZATIONS/ BUREAUCRACIES

- ❖ Some programs encountered *inflexibility, or time - consuming red tape, in using funds* for alternative and responsive service delivery models



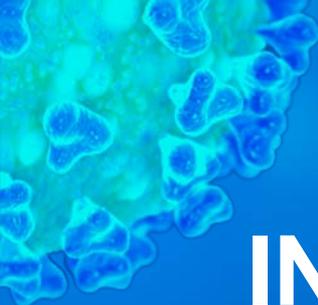
“There has been no workforce to deliver respite services. There has been inconsistent workforce to deliver supported living (i.e., no support for three weeks, support for 3 out of 5 days)... As a family caregiver there was no communication to families or family members...”



ADAPTED SERVICES

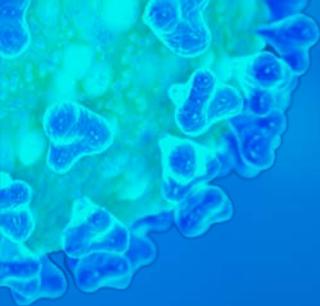
Organizations have adapted their services in 4 main ways:

- Increased communication
- Virtual support groups
- Changes in service location
- Changes in funding



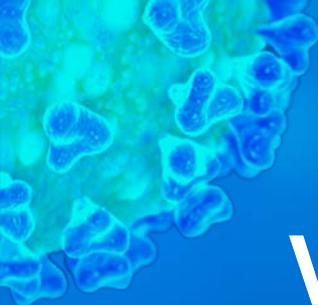
ADAPTED SERVICES – INCREASED COMMUNICATION

- ❖ Making more calls to *check in* with clients
- ❖ Regularly assess needs *holistically*
- ❖ Increased *case management* services
- ❖ Increased *referrals* and connections to resources



“[We are] making calls to ask everyone if they want more frequent check ins.”

“Staff has been on constant phone call support and guidance. Although helpful, it limits how much support the consumer receives. We use social media to promote and educate our community and consumers.”

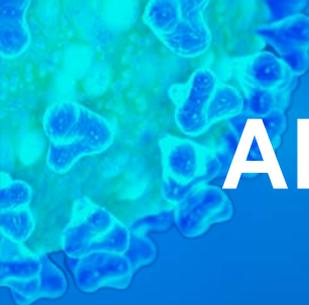


ADAPTED SERVICES – VIRTUAL SUPPORT GROUPS

- ❖ Conference calls and other virtual support groups have become prevalent among many organizations

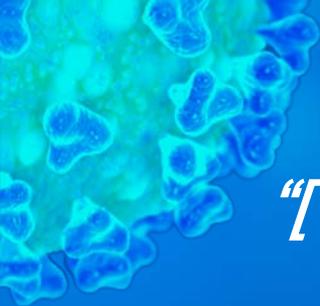
“Video calls with the children helps”

“We have provided some clients and foster parents with laptops in order to be able to make contact with them”



ADAPTED SERVICES – CHANGES IN SERVICE LOCATION

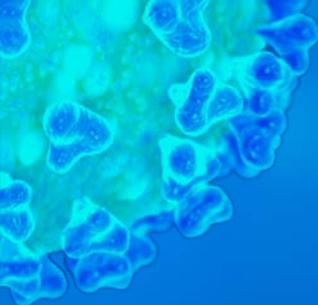
- ❖ Many agencies have changed ~~how~~ they provide respite.
- ❖ They have enforced strict ~~protocols~~ in order to continue services, have offered ~~in-home~~ services rather than center-based, and started providing services ~~online~~
- ❖ Many developed ~~online activities~~ such as online cognitive stimulation and online yoga classes



“[We] offered inhome aide support as an alternative to those funded families who are without day-program services.”

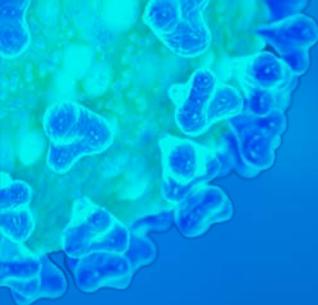
“We are developing communication and support opportunities done remotely and will be scheduling some activities through a YouTube channel”

“..live activities via Zoom...such as chair yoga, art, exercise, music, and more”



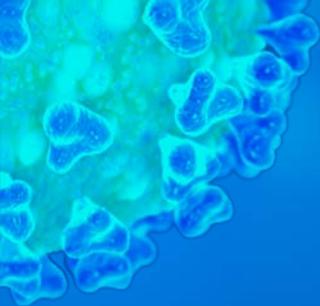
CHANGES IN FUNDING

- ❖ Programs and organizations are often, but not always, successful in *repurposing* funds
- ❖ Some programs have received ~~new~~ funding for initiatives
- ❖ A number of programs are using existing funds for *alternative service models* with funders' permission



CHANGES IN FUNDING

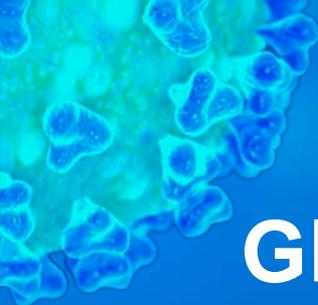
“[We offer] 'micro grants' to purchase a break of their choosing. These grants have been particularly useful during the pandemic as caregivers are using grants very creatively to purchase equipment or subscriptions that can help them look after their health and wellbeing and have a little time -out. Examples include: magazine or movie channel subscriptions, board games, home exercise equipment, items for crafts and hobbies....”



NEW SERVICES

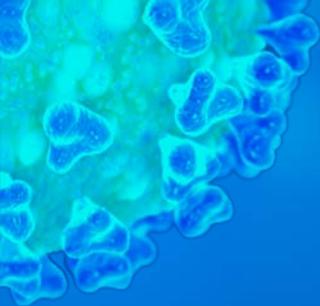
News services were developed in the following 4 areas:

- ❖ Delivery of food, supplies, and meals
- ❖ Use of internet platforms
- ❖ Caregiver support
- ❖ Innovative ideas



NEW SERVICES- DELIVERY OF GROCERIES, SUPPLIES, AND MEALS

- ❖ Delivery of *groceries, medications, supplies, and meals* was common among many organizations
- ❖ Utilized *volunteers and community partners* to shop and deliver to homes
- ❖ Offered meals to *caregivers* in addition to care recipients
- ❖ Delivery of *weekly packages* with a list of activities and supplies to do activities at home



“Most of these families do not have transportation or they should not be out in public due to their age and health conditions or the health conditions of their grandchildren/relative children... We are addressing this issue by delivering food and supplies (cleaning, diapers) to the families directly, enough to last 2 weeks.”

NEW SERVICES – USE OF INTERNET PLATFORMS

❖ YouTube

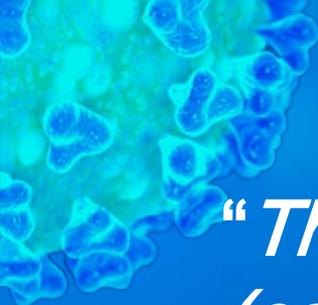
- ❖ Videos related to *providing care*
- ❖ Videos with *activities*

❖ Blog Posts/Websites

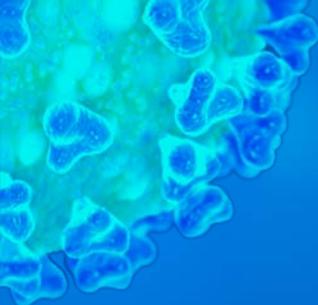
- ❖ Provide *information* about COVID-19
- ❖ Provide *resources* related to caregiving

❖ Social Media

- ❖ Support groups via social media for caregivers to *share experiences*
- ❖ Social media campaign addressing *fear* surrounding COVID-19

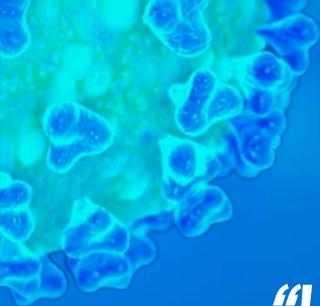


“ The [Center] is also providing free programming (cognitive and physical stimulation) on Facebook Live three times a day at 10:30am, 12:30pm and 2:00pm Monday-Saturday. These videos of word games, trivia, sing-a-long, and chair exercise are then posted on our YouTube channel and ~~web~~ for caregivers to watch with their loved ones with Alzheimer's and dementia when they please”

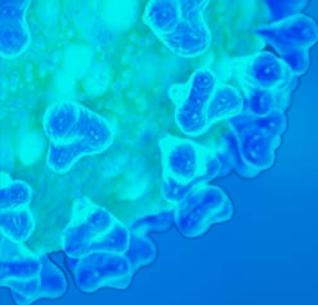


NEW SERVICES – CAREGIVER SUPPORT

- ❖ *Carepackages* for caregivers with resources, supplies, and self-care items
- ❖ *Grants* for caregivers to purchase equipment or subscriptions for activities
- ❖ *Weekly checkins* with caregivers via phone
- ❖ Increased efforts for *appreciation and recognition* of caregivers and employees

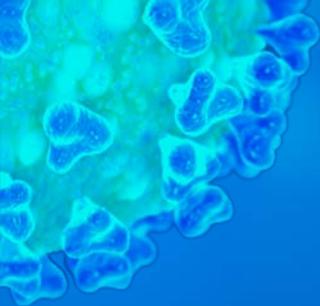


“We are currently sending caregivers a weekly sheet of activities that they can do with their loved one at home. These have been well received. We also have a team of volunteers calling each caregiver once per week to see how they are coping.”

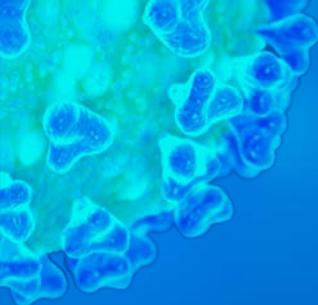


NEW SERVICES – INNOVATIVE IDEAS

- ❖ *Raising money* to help support families financially during this time
- ❖ *Making face masks* for consumers and their families
- ❖ *Online music therapy* for care recipients with dementia
- ❖ *Emergency programs* allow consumers to hire caregivers in emergency situations
- ❖ *E-pets* and robotic animals to help with isolation

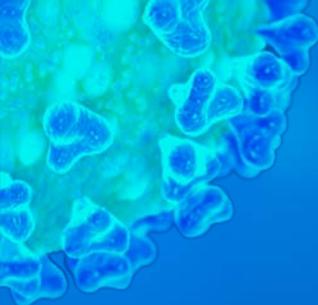


“[We are] offering the idea of purchasing electronic pets for those in nursing homes who cannot have their caregivers and family members visit.”



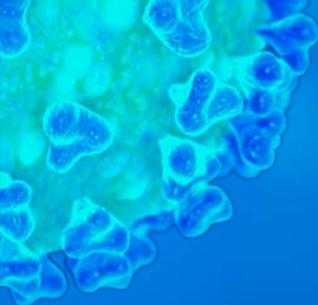
RESOURCES

- ❖ Respondents shared helpful resources, such as:
 - ❖ *Public Health Department Information*
 - ❖ *COVID-19 Information from National Associations*
 - ❖ *Mental Health and Wellness Information*
 - ❖ *YouTube Videos/Trainings*
- ❖ Full list of resources will be available on our website



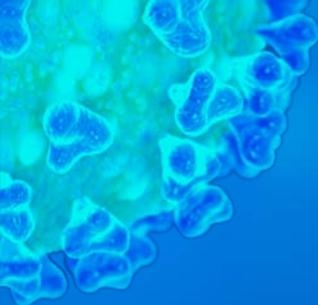
IMPLICATIONS

- ❖ Despite numerous challenges, many organizations have been able to adapt services or create new services to continue to help support caregivers
- ❖ Most organizations prioritized supporting basic needs and mental health of caregivers, families, and staff
- ❖ Organizations that were most successful were able to plan and adapt quickly and appeared to have good leadership and support



LIMITATIONS

- ❖ These are preliminary results
- ❖ Survey responses were collected at a single point of time and the impact of the pandemic may have varied based on the location of the respondent
- ❖ Majority US responses
- ❖ Limited openended questions



DISCUSSION

Please complete the **FEEDBACK SURVEY** at:

[bit.ly/ SurveyResultsFeedback](https://bit.ly/SurveyResultsFeedback)

DISCUSSION

- ❖ What information **SURPRISED** you?
- ❖ What information **CONFIRMED** what you already know?
- ❖ What **QUESTIONS** do you have that this survey doesn't answer?
- ❖ What stands out as the **MOST IMPORTANT** findings?
- ❖ **WHAT SHOULD WE DO** as a result of knowing this information?
- ❖ **WHO** should we share this information with?
- ❖ What is the **BEST WAY** to share this information with others?
- ❖ Do you think organizations are **CONTINUING** to experience challenges/adaptations?
- ❖ Should we **RESURVEY**? If so, what questions should we ask?
- ❖ What **OTHER** questions or comments do you have?

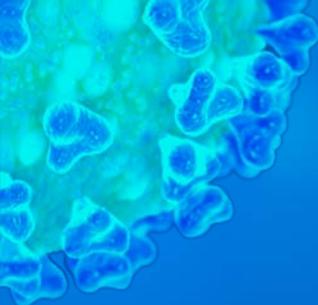
Development of National Guidelines

- ARCH has formed a Workgroup to help develop National Guidelines for Providing and Receiving Respite Care Safely During the COVID-19 Pandemic
 - ❖ Once complete, they will be available online at archrespite.org
- ❖ Example Topics
 - ❖ Planning to safely re open services
 - ❖ PPE, sanitation, and food safety guidelines
 - ❖ Special considerations for special populations
 - ❖ Redefining respite
 - ❖ Legal considerations

#CaregivingDuringCovid Challenge

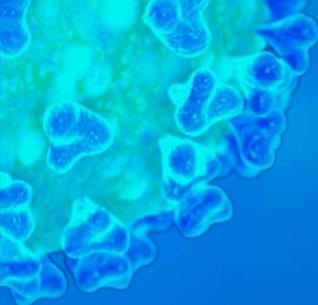
- ❖ Take a picture that demonstrates how caregiving looks for you during this time
- ❖ Post and tag the BREAK Exchange on social media
- ❖ The picture with the most “likes” by June 15, 2020 will receive a \$100 Giftcard





Global Assessment of Respite Survey

- ❖ Purpose: to conduct a global assessment of the state of respite care. Survey responses will be summarized and shared with respite care partners to help identify best respite care practices and opportunities for improving respite systems.
- ❖ Please complete by *June 15, 2020* online at https://uwmadison.co1.qualtrics.com/jfe/form/SV_1KTcdYjt5qu7IFv



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You can't
pour
from an empty cup.
Take care
of yourself
first!