



The BREAK Exchange

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 @exchange_break #BREAKexchange @ISBA_ShortBreak #ISBA2021

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Project Staff

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Overview

- Respite Research
- The BREAK Exchange
- Global Assessment of Respite
- Stay Connected



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An Inclusive Definition of Respite

“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* in the well-being of the caregiver, care recipient, and/or family system” (Kirk & Kagan, 2015)

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Why Research Respite Care?

- Understand and develop model practices
- Build the evidence-base for respite care
- Continuous quality improvement of existing services
- Improve the lives and well-being of caregivers and care recipients
- Advocate for the needs of caregivers and care recipients
- Use funding in the most effective way

*Slide content adapted from Raymond Kirk

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The BREAK (Building Respite Evidence And Knowledge) Exchange



- International group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care

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BREAK Exchange Partners



ARCH
National Respite Network
And Resource Center



ISBA



MARQUETTE UNIVERSITY
BE THE DIFFERENCE.



School of Nursing
UNIVERSITY OF WISCONSIN-MADISON




SHARED CARE
scotland

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BREAK Exchange Demographics

- Network of more than 180 people from 16 countries
 - Representation from individual to national authorities
 - People are served across the lifespan with any condition



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Benefits of Joining



CONNECT



LEARN



SHARE



COLLABORATE

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Purpose and Methods

- 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.
- 2-Part online survey
 - Supporting Caregivers During the COVID-19 Pandemic (March 31 - May 1, 2020)
 - Global assessment to gather more responses (May 1 - June 15, 2020)
- Quantitative and qualitative analysis

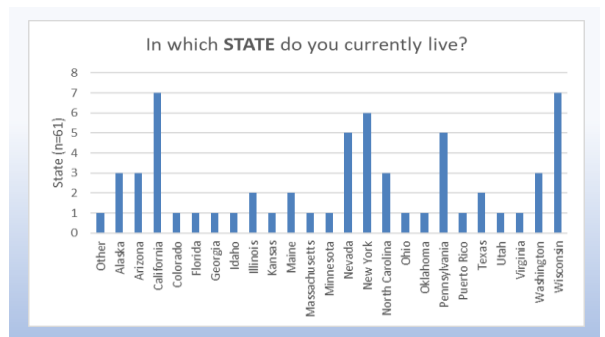
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RESULTS

- 68 total responses
 - 46 from COVID survey
 - 22 from Global Assessment

Country	Number
Australia	3
Canada	1
India	1
Spain	1
United Kingdom	1
United States	61

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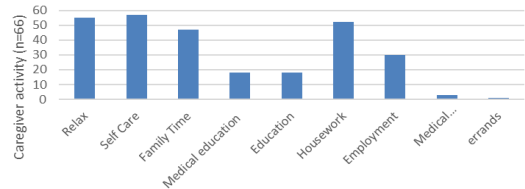
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Respite Overview

- Primarily funded by the government with some additional funds coming out of pocket and through charity
- Eligibility is mostly determined by the needs of the family, age, and diagnosis
- Respite is mostly provided by agencies
- Providers are typically trained by the agency
- Respite can be used on a regular basis or when needed
- Duration ranged from a few hours at a time to camps lasting more than a week

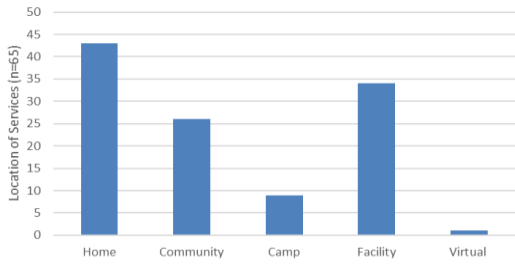
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What **ACTIVITIES** do caregivers typically do while receiving respite services?



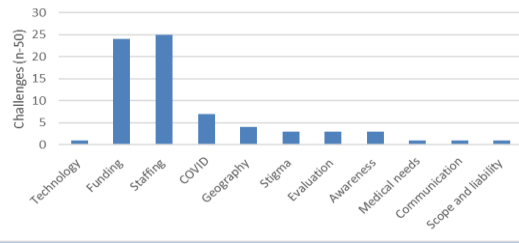
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WHERE are respite services typically provided?



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Please describe any **CHALLENGES** that exist in providing or receiving respite service



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Challenges Quotes

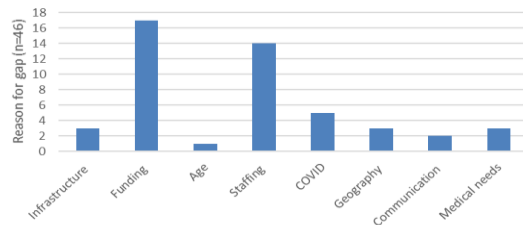
“Must address liability issues, training of respite caregivers, funding, documentation of program hours/families/outcomes met”

“Education that the service is out there and the eligibility requirements.”

“Care receiver reluctance to have someone in home. Caregiver reluctance to accept help”

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What are the **REASONS** there are not enough services to meet the demand for respite care?



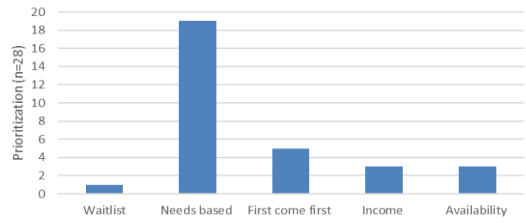
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Wait lists

- 51% of respondents reported having a wait list for services
- Mostly due to funding and staffing shortages

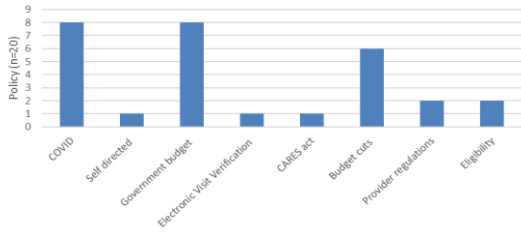
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How do you **PRIORITIZE** or **DECIDE** who gets services?



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Has there been any recent **LEGISLATIVE** or **POLICY** **CHANGES** that have impacted respite programs?



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New Policies and Opportunities

- Government budgets have a large impact on respite services
- “Can provide programs to participants across geographic barriers.”
- “Increased partnerships always present more opportunities...”

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Supporting Caregivers During the COVID-19 Pandemic

- 239 programs and providers responding to the COVID questions in the survey
- Only 12% were able to maintain existing respite services without alterations.
- Of the 42% of programs that initially discontinued in-person services, 73% rapidly adapted services or added new services.



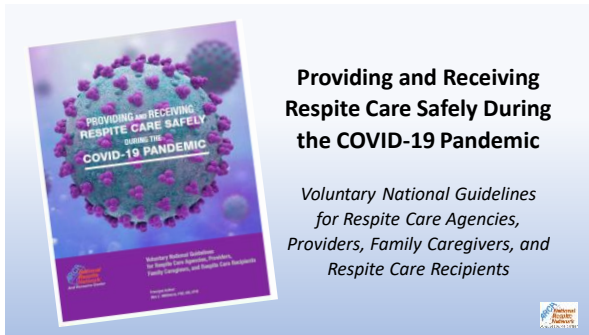
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Three Main Themes

- 75% of all programs surveyed created new or **ADAPTED AND ALTERNATIVE SERVICES** for caregivers and families.
- Programs relied primarily on **TECHNOLOGY** to deliver adapted or alternative services.
- Programs recognized the **STRESS** Covid-19 created for caregivers and families, and secondarily for program personnel, and worked to provide **SUPPORT** for both.



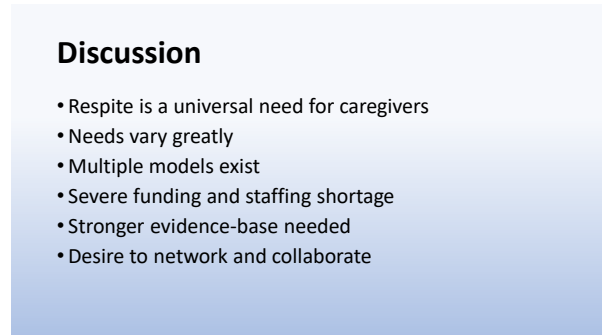
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Providing and Receiving Respite Care Safely During the COVID-19 Pandemic

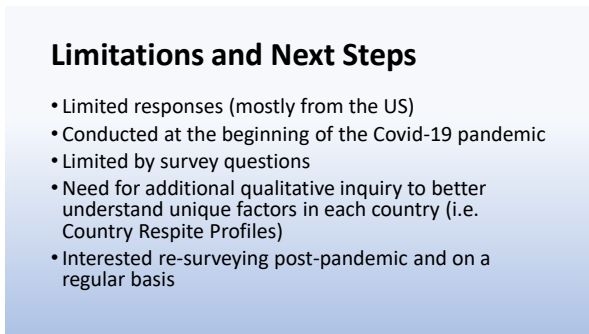
Voluntary National Guidelines for Respite Care Agencies, Providers, Family Caregivers, and Respite Care Recipients



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Discussion

- Respite is a universal need for caregivers
- Needs vary greatly
- Multiple models exist
- Severe funding and staffing shortage
- Stronger evidence-base needed
- Desire to network and collaborate



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Limitations and Next Steps

- Limited responses (mostly from the US)
- Conducted at the beginning of the Covid-19 pandemic
- Limited by survey questions
- Need for additional qualitative inquiry to better understand unique factors in each country (i.e. Country Respite Profiles)
- Interested re-surveying post-pandemic and on a regular basis



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Stay Connected!



- Like us on Facebook @ExchangeBREAK
- Join our Facebook Group called "The BREAK Exchange"
- Follow on Twitter @exchange_break
- Follow on Instagram @break.exchange
- Visit our website, join the email list, and complete your member profile at breakexchange.wisc.edu
- Email us at info@BREAKExchange.org



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"SELF CARE IS GIVING THE WORLD THE BEST OF YOU. INSTEAD OF WHAT'S LEFT OF YOU"

-Katie Reed