The BREAK Exchange

Presented by:
Tyler Engel, BS
BREAK Exchange Staff
Barrier Buster Designs
Kim E. Whitmore, PhD, RN, CPN
BREAK Exchange Director
Assistant Professor, College of Nursing
Marquette University

Project Staff
• Danielle Ortmann, BSN, RN
• Rachel Sobiesk, BSN, RN, DNP Student
• Grace J Leonard, Instructional Technologist

School of Nursing University of Wisconsin – Madison

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Overview
• Respite Research
• The BREAK Exchange
• Global Assessment of Respite
• Stay Connected

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)

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

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
BREAK Exchange Partners

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

Benefits of Joining

CONNECT  LEARN  SHARE  COLLABORATE

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

RESULTS

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

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In which STATE do you currently live?
**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

**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”
Wait lists

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

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...”

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.

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.
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

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

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

Stay Connected!
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- 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

"SELF CARE IS GIVING THE WORLD THE BEST OF YOU, INSTEAD OF WHAT’S LEFT OF YOU"
Katie Braid