

Lifespan Respite for All Ages: Priorities for Improving Respite Services in Ohio

Miriam Rose, M.Ed.

Linda S. Noelker, Ph.D.

Katz Policy Institute
Benjamin Rose Institute on Aging
Cleveland, Ohio

Presented at the 15th National Lifespan Respite Conference
Boston, MA
October 17, 2013

PLEASE DO NOT CITE, QUOTE, DUPLICATE, OR DISTRIBUTE THIS DOCUMENT WITHOUT THE AUTHORS'
PERMISSION

Presentation Objectives

- To describe the challenges and barriers to respite use by families and agencies providing respite to care recipients of all ages.
- To understand the importance of lifespan respite systems and strategies to improve these systems.
- To apply the information learned to efforts to improve the availability and quality of respite services in your locale.

Ohio's Lifespan Respite Grant Partners (2011-2014)

- Ohio Department of Aging
- Ohio Respite Coalition
- Family & Children First Cabinet Council
- Aging & Disability Resource Network
- Benjamin Rose Institute on Aging
(research & evaluation partner)

Respite and Ohio Caregivers

- Estimated 1.31 million caregivers (of persons age 18+) in Ohio provided 1.41 billion hours of care in 2007 (AARP)
- Respite defined as: “Planned or emergency care that provides temporary relief to caregivers who are caring for a child or adult of any age requiring daily assistance.”
- Video: In the caregivers’ words...
“Respite for Caregivers Across the Lifespan: Family Members Tell Their Stories”

<http://youtu.be/9iqAf1ZFxzA>

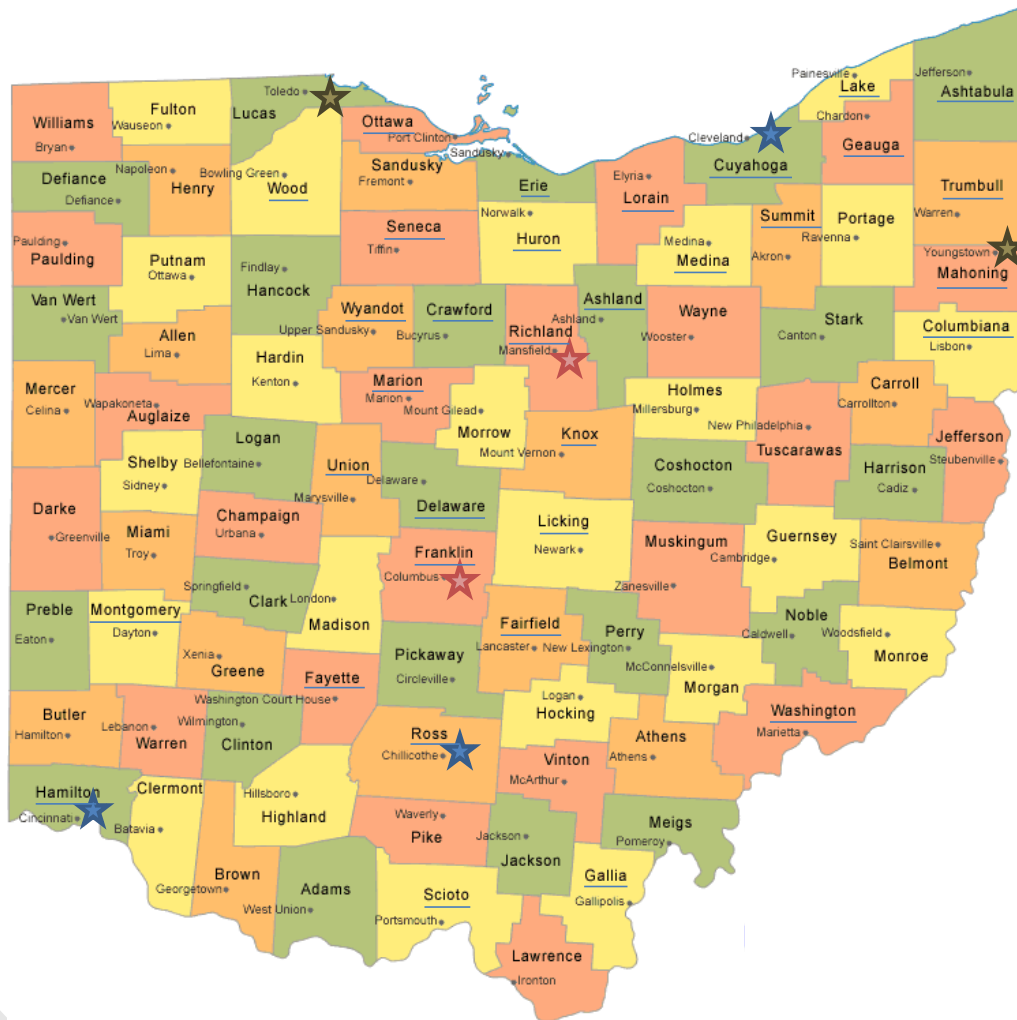
Ohio Respite Coalition

- Statewide collaboration of family members, caregivers, advocates, respite providers, agencies, and public sector members
- Mission: To educate, advocate, and promote access to respite options for people who care for a loved one.
- Vision: All caregivers regardless of location or circumstances have access to quality, person-centered respite services and are able to use them in a timely and effective manner.

Description of Ohio Respite Coalition

- Led by volunteers, including the Steering Committee and these subcommittees:
 - Membership
 - Stakeholder Education
 - Research
 - Government Relations
- Two statewide respite summits have been held in the state capital, Columbus
- Current membership totals 150
- Website: www.ohiorespite.com

Regional Respite Summit Locations 2011-2013



Description of Regional Summits

- Total of 335 attendees from 33 Ohio counties (representing 64% of the population)
 - Professionals
 - Family caregivers
 - Provider staff
 - Government agency staff
 - Advocates
- Agenda at each summit included similarly structured roundtable discussions

Questions for Roundtable Discussions

- What is your connection to respite?
- In your experience, what are the successes of respite care in this area?
- In your experience, what are the challenges of respite care in this area?
- In your opinion, what should be the priorities for improving respite for caregivers in our area?
- Can you recommend any strategies or approaches to improve respite here?
- Are there people or organizations that aren't here and should be?

Methods

- Six of the regional respite summits produced reports with varying levels of detail that addressed results of the roundtable discussions
- Content relating to challenges or barriers and recommendations for improvement were extracted from the reports and categorized by two independent raters
- The number of summits where each unique theme was mentioned was tallied

Access to Respite: Challenges

- Services difficult to access (4)
- No single point of contact, website or comprehensive provider list for respite services (4)
- Waiting lists (2)
- Lack of transportation (2)
- Less available and accessible for caregivers of disabled children and younger adults, especially those who are medically complex and technology-dependent, and few home health providers for children (2)
- Other challenges related to:
 - More availability of respite for caregivers of older adults but also an insufficient number of adult day centers
 - Physicians who are gatekeepers but lack awareness of respite
 - Educators who lack knowledge to identify children with special needs

Access to Respite: Recommendations

- Centralized point for accessing respite services with capabilities including “no wrong door” and search by county (5)
 - 2-1-1 feasibility
- Comprehensive respite service inventory, resource list or registry for the lifespan (3)
- Other recommendations related to:
 - Respite referral system for physicians
 - Improved transportation to respite centers
 - No waiting lists

Advocacy for Respite

- Challenge:
 - Case managers do not advocate on behalf of families (2)
- Recommendations:
 - Advocacy to increase legislator awareness of the importance of respite and to improve legislation affecting respite (5)
 - Support networks/advocacy groups for parents of all populations, promoting efforts to “keep loved ones home”; small groups who need respite could be matched with a mentor (3)

Advocacy for Respite: Other Recommendations

- From a public health perspective, promote respite as a preventative/wellness intervention that enables caregivers to continue to care for their loved ones, ultimately saving money for government-subsidized programs (2)
- Improve communication and collaboration among policymakers, providers and stakeholders (2)
- Promote workplace policies that accommodate the needs of employed family caregivers



Care Coordination Related to Respite

- Challenges:
 - Lack of communication/coordination among organizations, service providers and caregivers (4)
 - No coordination of respite services with other needed services (2)
- Recommendations:
 - Effective coordination of respite with other services (e.g., health care and social services) used by care recipients (2)
 - Assessment and service coordination for the family as a unit and not just the care recipient, as well as assessment of caregiver needs (2)

Caregiver Issues Related to Respite: Challenges

- Caregiver resistance to respite—until there is a crisis (2)
- Caregiver guilt
- Parents fear that custody issues could be raised if they admit to need for respite
- Growing demand for respite care as caregiving needs and number of caregivers needed grow

Caregiver Issues Related to Respite: Recommendations

- Make acceptance of help palatable to caregivers and decrease the stigma of respite use by caregivers (2)
- Give caregivers a more central role as a partner in the care receiver's health care
- Educate caregivers about respite early, before they are in crisis

Evidence Related to Respite: Recommendations

- Research evidence about the need, use and cost of respite in relation to potential savings; also, research other states where respite is working well (2)
- Gather statistics on services and users (2)
- Record personal stories (2)

Evidence Related to Respite: Other Recommendations

- Identify successful respite service models for younger families
- Systematically monitor caregiver outcomes and satisfaction with respite
- Conduct cost-benefit analyses of respite services for evaluation, quality improvement and advocacy

Respite Provider Issues

- Challenges:
 - Inadequate training/certification of providers (3)
 - Hard to find qualified caregivers (3)
- Recommendations:
 - Increase network of qualified respite providers, particularly in rural areas of great need (3)
 - More training for case managers about respite
 - Encourage college students to become respite providers
 - Promote retention of quality workers



Respite Workforce: Recommendations

- Develop curriculum for respite workers/volunteers and provide (specialized) training (4)
- Monitor performance of workers to ensure quality of care (2)
- Address recruitment of and financing training for workers (2)
- Improve content, design, and delivery of respite training programs and curricula

Public Awareness of Respite: Challenges

- Low public awareness of respite options in general, and especially among legislators, employers, insurance companies and physicians (5)
- Limited information available about respite services (3)
- Other challenges related to:
 - Difficult to reach caregivers
 - Term “respite” is off-putting, needs to change its image

Public Awareness of Respite: Recommendations

- Develop education programs and informational and advocacy materials in language that is understandable for caregivers, providers, legislators, the general public, and medical and allied health professionals (6)
- Public education and marketing campaign, including information about the value of family caregivers and the hours they devote to caregiving (3)
- Use the term “day care” instead of “respite” and shift marketing terminology away from “caregiver” (2)

Public Awareness of Respite: Other Recommendations

- Identify and include other key stakeholders that should be involved
- Find a “celebrity” spokesperson
- Use multi-media approaches (print, radio, TV, PSAs) to educate families about how to access respite services

Respite Options

- Challenges:
 - Lack of emergency/temporary respite (2)
- Recommendations:
 - Flexible/volunteer/faith-based/informal/creative respite programs, e.g., teach families how to use people they know (4)
 - Provide emergency placements (2)
 - Establish co-op system for parents
 - Increase use of adult day care

Respite Rules & Regs.: Challenges

- Different respite rules and programs in different counties (3)
- Age eligibility requirements result in service gaps (2)
- Provider regulations are financially and legally burdensome (2)
- Other challenges related to:
 - Provider regulations are punitive in audits and denials despite acting in good faith
 - Lack of flexibility in care plans

Respite Rules & Regs.: Recommendations

- Decrease/simplify paperwork (2)
- Standardized respite rules and programs across counties
- Make regulations more manageable for providers

Special Populations and Respite

- **Challenges:**
 - Lack of respite services for medically complex and technology-dependent children and young adults (2)
 - More providers and respite options needed for those with mental health needs
 - Gaps in service in rural communities, where there are few out-of-home respite options
- **Recommendations:**
 - Specialized care for specific populations, e.g., Alzheimer's, autism, mental health (2)
 - Needs assessment for disabled children that delineates their medical needs in relation to appropriately designed and staffed respite programs

Other Respite Issues

- Challenges:
 - Trust issues for the care recipient
 - Risk to health and safety of care recipients without adequate respite availability
- Recommendations:
 - Increase use of technology in delivery of respite services

Funding Respite: Challenges

- High cost of respite, especially for middle-income families, and inadequate funding (6)
- Funding sources difficult to find (4)
- Gaps in service for middle-income caregivers (3)
- Low reimbursement rates (2)
- Other challenges related to:
 - Unsure of who pays for what with so many different waivers
 - State doesn't pay for evaluation or assessment
 - Families consider institutionalization purely for financial reasons or reduce their income to qualify for subsidized care

Funding Respite: Recommendations

- Secure adequate funding, through advocacy and a public information campaign (5)
- Advocate for flexible funding, regardless of income, and caps on rates (3)
- Other recommendations related to:
 - Provide insurance coverage for respite
 - Provide tax credits to caregiving families
 - Make respite more affordable via spend-downs, sliding scale

Ohio State Government Respite Funding

Departments of:

- Aging
- Developmental Disabilities
- Job and Family Services
- Medicaid
- Mental Health and Addiction Services
- Youth Services

Department of Aging

Alzheimer's Respite Program

- Family caregivers 18+; care receiver 60+ with Alzheimer's disease or related disorder.
- Funds used for specific services such as personal care, homemaking, adult day care and visiting.
- Alzheimer Associations use the funds for caregiver training, support groups, family care planning meetings, telephone helpline, family education, public education, professional education, newsletters and the Safe Return program.
- Respite Reimbursement: new consumer-driven program, offering a reimbursement (stipend) to persons living with and providing care to someone with Alzheimer's Disease who could benefit from respite and meet certain other eligibility criteria. Caregivers may choose to receive service from any established service provider. Families contribute to the cost of the service too.
- Accessed through AAAs.

Department of Developmental Disabilities

Family Support Services

- State-funded reimbursement program (family co-pays) for approved providers; local service facilitators
- For families caring for a person (any age) with intellectual or development disabilities at home
- Eligibility through county Boards of DD

Department of Job and Family Services

Family Centered Services and Supports Program

- Purpose: maintain children (0-21) at home using non-clinical HCBS funded by multiple federal and state streams
- Target population: children/youth with multi-system needs (e.g., DD, abuse, behavioral)
- Apply through local Family and Children First Council
- Respite services allowable if included in individualized family service plan (respite was second most used service in FY2012)
- Sliding fee scale

Department of Medicaid

HCBS Waivers with Respite Services

- Any age with ICF-MR level of care need:
 - Individual Options
 - Level One
 - Self-Empowered Life Funding
(participant-directed model of care)
- Ohio Home Care (age 0-59 with nursing facility-based level of care need)
- Transitions Developmental Disabilities (ICF-MR level of care need) transfer from Ohio Home Care Waiver if need is re-evaluated from intermediate or skilled level of care
- Transitions Carve-Out (nursing facility-based level of care need) transfer from Ohio Home Care Waiver at age 60

Resources

ARCH National Respite Network

www.archrespite.org

National Alliance for Caregiving

www.caregiving.org

Family Caregiving 101

www.familycaregiving101.org/

Family Caregiver Alliance

www.caregiver.org

Thank you!

Questions or comments



mrose@benrose.org

Inoelker@benrose.org

www.benrose.org