



Ohio Respite Coalition

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# Lifespan Respite Strategic Plan

2013 - 2018

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## Executive Summary

The Ohio Respite Coalition (ORC) is a statewide collaboration among family members, caregivers, advocates, respite providers, agencies, community groups, and state and local government officials who believe all caregivers could use a break once in a while.

This strategic plan highlights the Ohio Respite Coalition's five-year approach to increasing the availability of respite services in the state. The coalition is supported by a three year (2011-2014) Lifespan Respite Program grant from the Administration on Aging (AoA) (now part of the Administration for Community Living (ACL), administered by the Ohio Department of Aging. The goals, strategies and tactics outlined in this plan will set a framework for how the Coalition will approach year three of the grant and beyond. More specifically, this plan includes the following:

**Section 1** highlights the Ohio Respite Coalition's Mission and Vision Statements and provides Ohio's definition of respite.

**Section 2** provides an environmental scan of national and Ohio-specific factors influencing the future direction of respite services. Key topics include existing respite services in Ohio, coordination of respite services and a summary from Ohio's regional summits.

**Section 3** outlines the top three strategic issues that emerged during Ohio's respite summits. These issues were further discussed during ORC's strategic plan development process and the group agreed that these issues would serve as the foundation for defining the strategic plan goals for this five-year plan. Participants at this meeting further fleshed out strategies and tactics to ensure successful completion of these goals.

**Goal 1:** By September 2017, develop high-quality training, education, and outreach materials for respite consumers, providers and the general public to promote clear and consistent messaging about respite and align respite service requirements across systems statewide.

**Goal 2:** By September 2015, expand the availability of respite services in Ohio, including development of a statewide respite system with a central access point for information and services.

**Goals 3:** By September 2014, develop and implement a business plan for the Ohio Respite Coalition to ensure sustainability through membership growth and infrastructure enhancements.

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# Mission, Vision and Respite Definition

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## ORC Mission

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To educate, advocate, and promote access to respite options for people who care for a loved one.

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## ORC Vision

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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.

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## Definition of Respite for Ohio

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Temporary relief from the responsibilities associated with caregiving.

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# Environmental Scan

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## Background

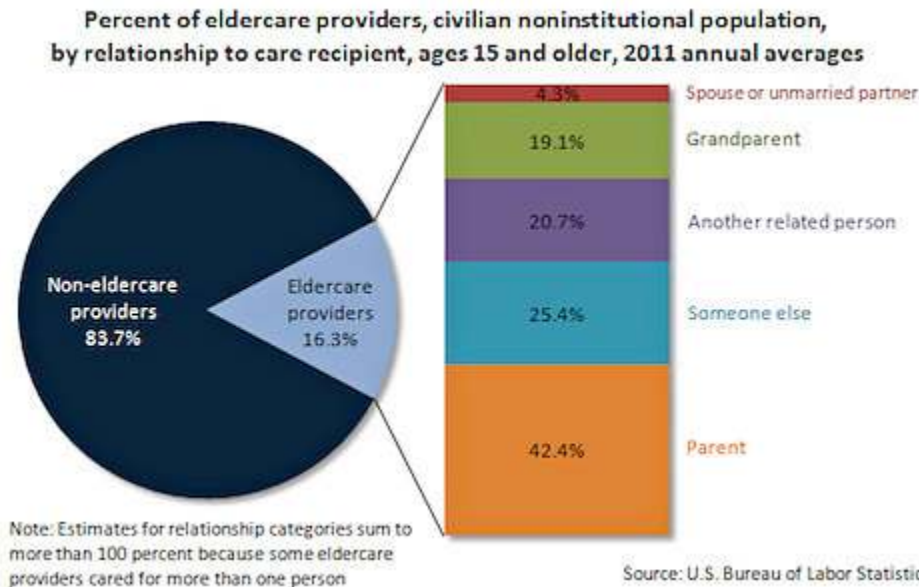
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As the U.S. population ages, demand for long-term services and supports is growing dramatically. Family caregivers of older adults are regarded as the backbone of the long-term care workforce (Noelker, 2001), and respite is an important resource for alleviating or preventing the stress they experience and for maintaining older adults in the community. In order to support and retain family caregivers in the caregiving role, a national panel of experts, convened in 2010 by the Benjamin Rose Institute on Aging under a cooperative agreement with the U.S. Administration on Aging, suggested that an increase in funding for caregiver services, particularly respite services with 24-hour availability, is critical (Noelker, L. S., Rose, M., Ejaz, F. K., Castora-Binkley, M., & Browdie, R. (2010)).

Research consistently shows that having respite time is the most desired and needed service reported by caregivers (Lund, Wright, Caserta, & Utz, 2006). A three-year research project conducted by the University of New Hampshire's Center on Aging and Community Living found that serving family caregivers through discretionary funding and emotional support helped them to maintain physical and emotional well-being even as their family members' health or abilities declined. (AUCDigest – July 2012; [http://www.aucd.org/docs/digest\\_2012/AUCDigest%20July%202012.pdf](http://www.aucd.org/docs/digest_2012/AUCDigest%20July%202012.pdf)). Moreover, caregivers who use respite report high levels of satisfaction with the service. Studies on the impact or outcomes of respite for caregivers, such as reduced caregiving burden and decreased depression, have shown mixed results. This phenomenon has been attributed to variations in research design and measures as well as to caregivers using too little respite, for too short a time period, or too late into the caregiving process. Consequently, respite service experts recommend that caregivers use respite early in the caregiving career, use it regularly, engage in personally meaningful activities during respite time, and use respite in conjunction with other services such as education and support groups (Lund et al., 2006).

Nationally, about 11% (3.7 million) of older Medicare enrollees received personal care from a paid or unpaid source in 1999. Recent data from the Bureau of Labor Statistics' 2011 American Time Use Survey showed that over a three-month period, 39.8 million people (aged 15 and older) provided unpaid care to someone over 65 "because of a condition related to aging." (Retrieved from: <http://www.bls.gov/news.release/atus.nro.htm>).

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The survey, which began in 2003, includes 12,500 respondents who are asked how they spent their previous 24 hours; starting last year, respondents were also asked about caregiving. Almost a third of respondents reported taking care of two or more older people, and 23% also had a minor child in their households.

Almost all community-resident older persons with chronic disabilities receive either informal care (from family or friends) or formal care (from service provider agencies). Over 90% of these older persons with chronic disabilities received informal care and/or formal care and about two-thirds received only informal care. About 9% of this chronically disabled group received only formal services. (*A Profile of Older Americans 2011*: [http://www.aoa.gov/AoARoot/Aging\\_Statistics/Profile/2011/docs/2011profile.pdf](http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/2011/docs/2011profile.pdf)).

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## Existing respite services in Ohio

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In Ohio, some 1,728 persons received caregiver respite services, and 879,058 service units were provided, according to the Administration on Aging's FY2010 Profile of State Older Americans Act (OAA) Programs. Title III expenditures were more than \$2.6 million, while total services expenditures exceeded \$2.7 million. These numbers served through the OAA represent a small portion of the estimated 1.31 million caregivers in Ohio in 2010 (*Caregiving Across the States: Publicly Funded Programs*, Family Caregiver Alliance. Retrieved from: [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1789](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1789)). Ohio provides respite through the National Family Caregiver Support Program, its PASSPORT HCBS Medicaid Waiver

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Program, and its state-funded Alzheimer's Respite Program. All three statewide programs administered by the Ohio Department of Aging offer respite in the form of adult day services and in-home personal care. Overnight and weekend/camp respite are offered by the Family Caregiver Support Program and the Alzheimer's Respite Program. Caregivers do not have to live with the care receiver to qualify for respite under any of these programs and there is no respite cap.

The primary source of funding for respite services in Ohio is through Medicaid waivers. Medicaid waivers are programs offered through the Ohio Department of Job and Family Services (ODJFS), the Ohio Department of Developmental Disabilities (DODD), and the Ohio Department of Aging. For individuals with developmental disabilities, DoDD offers both the Individual Options (IO) waiver and the Level 1 waiver for some types of respite. The IO waiver covers informal respite provided by an approved independent provider or friend, up to 90 days of residential respite in an institution, and recently approved by CMS, community respite, which can take place in a variety of locations – camp, recreation centers or other places where an organized community program or activity occurs. Level 1 provides informal and residential respite. However, there are 27,000 people on the waiting list for these waiver services.

Custodial parents may be able to access respite services through the local mental health board if their county board provides funding for that service. The local county boards of developmental disabilities receive an annual allotment of Family Support Services dollars. These funds are then allocated to families who apply and can be used for respite service. The annual average family allotment in 2009 was \$869. This amount has been decreasing in each biennium budget.

The Ohio Home Care Program, through ODJFS, offers services through the Ohio Home Care Waiver and Transitions Waiver. These waivers are designed to meet the home care needs of people who have certain medical conditions and/or functional abilities that would qualify them for Medicaid coverage in a nursing home or hospital. Consumers may receive care and services at home, or they may choose to receive their care in a nursing facility. The Transitions Carve Out Waiver is designed to meet the needs of consumers who are age 60 and over but is not open to new enrollees. To qualify, consumers must first be on the OHC Waiver and be "transitioned" due reaching age 60.

There are over 92,000 Veterans with disabilities in Ohio. A new program in Ohio for Veterans with a skilled nursing facility level of care need called the Veteran-Directed Home and Community Based Services Program allows the Veteran to purchase respite services.

Individual provider organizations provide respite services to families, mostly through private pay. Many conduct fundraising to assist families with the cost of respite. Usually this financial subsidy is based on financial need. This additional source for providing respite services is critical to meet the needs of many more consumers who do not enroll in state or federally funded programs. It is difficult to capture the amount of funding and number of consumers covered through private pay options.

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## Coordination of respite

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Care coordination, an ongoing component of an effective system of care for children and youth with disabilities and special health care needs and their families, is not available to all families in Ohio. Even those families who receive services through one of Ohio's governmental systems are not always able to access care coordination due to the high costs associated with delivering this service. The researchers in "Caring for Children with Disabilities in Ohio" (Goudie, 2010) concluded that improved health care coordination and the delivery of family centered health care services for children with disabilities would help by offering prevention strategies related to family stress.

As part of this Lifespan Respite grant, the Benjamin Rose Institute on Aging has begun collecting information to help Ohio build a network of resources database.

To date, sources of information that have been identified include:

- ARCH National Respite Locator

<http://archrespite.org/respitelocator>

<http://archrespite.org/respite-locator-state-search/227-ohio-search>

Ohio – yields 192 results

- Connect Me Ohio (no longer in service)

Previous search for respite care yielded 54 results

- Ohio Respite Coalition Research Committee
    - Alzheimer's Association (Allison Gibson, Delaware County Social Worker) supplied respite provider lists for the Central Ohio, Cincinnati, Cleveland, Miami Valley/Dayton, and Northwest Ohio areas
    - Greene County (Renee Lammers, Family Stability Coordinator)
      - Family and Children First Council list of respite care resources and respite policy
      - Description of respite program availability/providers in the county
    - Mahoning County (Pam Petras, Help Hotline Crisis Center [www.helphotline.org], Special Navigator for Families with Special Needs)
      - Paper copy of 2012 "Respite and Summer Programs for Families with Special Needs"
  - Area Agencies on Aging  
Organizations, with contact information, that provide respite services under contract with the AAA or in its service network were supplied by four AAAs (4, 6, 7 and 10B) in conjunction with a survey of respite funding offered by Ohio Area Agencies on Aging.
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## Ohio's Regional Respite Summits

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During the March 2011 Ohio Respite Summit attendees identified lack of effective coordination of care as a primary weakness in Ohio's system of services. Related to this issue, the group recognized the lack of coordination within and across systems such that caregivers have to be their own care coordinators, that services are not consistent from one county to the next, that cross-agency cooperation is infrequent, that there is limited coordination and linking across funding silos, and that service coordinators are not universally informed about what's available and who's eligible for services.

Throughout 2011 and 2012, Ohio held regional respite summits in Chillicothe, Cincinnati, Mansfield, Columbus, and Cleveland. In all, 247 attendees, including professionals, family caregivers, provider agency and government staff, and advocates, from 30 counties participated. A list of organizations that participated in the regional summits is in the [Contributors](#) section starting on page 16.

The most critical need areas discussed included education, training and outreach, and a statewide respite services network. Consistent feedback from participants focused on the following areas:

- Improve respite training curricula and programs with certification for providers (paid, unpaid, and volunteer)
  - Provide specialized training for serving consumers with special needs (e.g., on vents, behavioral disorders, autism)
  - Develop public awareness campaigns for families and professionals (including physicians and legislators) on the need for and how to access respite
  - Develop education and outreach campaigns for consumers with attention to caregiver age differences and emphasis on wellness
  - Develop advocacy campaigns to increase funding for respite
  - Create single point of entry into respite services
  - Develop a statewide inventory or clearinghouse of respite services for caregivers
  - Increase funding through advocacy and policy changes
  - Standardize access to respite across programs and counties, including rural areas
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- Eliminate waiting lists
  - Create a coordinated statewide system of care
  - Coordinate respite with other health and social services
  - Address caregiver/client guilt and mistrust through education and improved respite workforce
  - Address age eligibility requirements that create service gaps
  - Standardize assessment of caregivers and their respite needs
  - Systematically monitor caregiver satisfaction with and outcomes of respite use
  - Conduct cost-benefit analyses of respite service programs
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# Strategic Goals & Objectives

On July 15, 2012, the Ohio Respite Coalition held a Strategic Plan Retreat to develop Ohio's priorities over the next five-years. There were representatives present from multiple disciplines including state government, local providers, and consumer advocates. The group focused on the following three goals for this strategic plan period:

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## Goal 1: Training, Education, Outreach

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By September 2017, develop high-quality training, education, and outreach materials for respite consumers, providers and the general public to promote clear and consistent messaging about respite and align respite service requirements across systems statewide.

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### Strategies & Tactics

- I. Review existing training programs for commonalities and facilitate communication among systems
    - a. Develop common curriculum or adapt existing curriculum with a goal of having the state adopt a common certification for respite providers
    - b. Develop dissemination approaches for curricula (web-based, train-the-trainer, mechanisms in place to share resources)
  - II. Develop specific training packages for unique populations
    - a. Identify what is existing and what is needed and add stackable certificates
    - b. Establish PATHS program for direct service providers in DD adult community
  - III. Outreach
    - a. Develop marketing campaign and messaging targeting I&R, 2-1-1, ADRN, etc.
    - b. Motivate/educate providers, caregivers, and general public on respite, benefits of respite, how to access (wellness strategies conveyed using respite as a communication strategy)
    - c. Understand and develop marketing message to address why an individual might not want to be a respite provider. Establish federal/state/local forgiveness for nursing students who work in home health providing nursing services to pediatric patients.
    - d. Using a variety of vehicles, inform people of the needs and opportunities, and create awareness of respite
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- e. Develop websites, printed materials, PSAs, media placements, and add to story bank
- f. Develop advocacy campaign to increase and sustain funding for respite
- g. Develop a respite roadshow / speakers bureau
- h. Develop consistent message for marketing materials

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## Goal 2: Develop a statewide respite system with central access point

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By September 2015, expand the availability of respite services in Ohio, including development of a statewide respite system with a central access point for information and services.

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### Strategies & Tactics

- I. Develop central access point/website as promotional/education/resource tool
    - a. Develop education materials for each target audience (consumers, providers, etc.)
    - b. Include linkages to available resources (services, training opportunities)
    - c. Use existing access points (Red Tree House, ADRN, 211, I&R, etc.)
    - d. Develop and use common data system that includes inventory of respite providers
    - e. Gather information on funding
    - f. Gather information on how to become a provider
    - g. Review what other states are doing regarding central access point
  - II. Expand Ohio's Statewide Respite Network
    - a. Determine what services can be used for respite
    - b. Develop provider inventory/gap analysis
    - c. Engage in advocacy with funders for common definition/use of terminology
    - d. Define role of unpaid respite providers
    - e. Allow respite searches at Central office for those not connected to the web
      - i. Data tracking capability
      - ii. Personal service for those who need it
      - iii. 1-800#
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- f. Locate advocates in existing system who can help direct individuals to services/care/support
  - i. Identify those with skill, interest, experience
  - ii. Use Listserv for information sharing
- g. Offer resources to build skills to provide respite as a career
  - i. Link to Direct Service Workforce initiative through Governor's Office of Health Transformation (OHT)
  - ii. Advocate to add curriculum for respite providers
  - iii. Develop Train-the-Trainer curriculum
  - iv. Integrate Curriculum/How-to manual from ARCH
- h. Develop Volunteer Respite Network that connects to volunteer agencies/organizations
  - i. Develop a coalition road show on respite
- III. Develop legislative advocacy team (funding, awareness, policy/rules)
  - a. Develop and implement sustainable funding strategies
  - b. Determine appropriate oversight of certification process

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### Goal 3: Develop an ORC Business Plan to Ensure Future Sustainability, Growth and Succession Plan

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By September 2014, develop and implement a business plan for the Ohio Respite Coalition to ensure sustainability through membership growth and infrastructure enhancements.

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#### Strategies & Tactics

- I. Submit Lifespan Respite legislation with funding appropriation
    - a. Develop planned strategy for ongoing advocacy to continue appropriation
    - b. Identify specific legislators who have influence and interest
    - c. Establish a budget for appropriation
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- d. Identify hard objective data available that establishes evidence of need for respite and for a coalition
  - e. Determine philanthropic opportunities
  - II. Develop membership recruitment and retention plan
    - a. Develop strategic plan for the coalition
    - b. Seek regular contact among members of the coalition
    - c. Establish what is needed of members
    - d. Develop recognition program for those who participate and contribute
    - e. Provide/establish virtual presence for networking and sharing of information (regularly)
    - f. Recruit affiliate sponsors with related mission
  - III. Determine governance structure with leadership responsibilities and succession plan
    - a. Explore most appropriate organization type (e.g., 501(c)(3), LLC)
    - b. Establish organizational structure
    - c. Consider a stand-alone or part of something larger
    - d. Address logistics (office locations, staff, website maintenance, support services, etc.)
    - e. Research outside experts who could help with business plan
  - IV. Develop / purchase data tracking system to support accountability of the coalition and sustainability
    - a. Gather baseline data
    - b. Determine hardware and software requirements
    - c. Identify key elements
    - d. Incorporate in-house research capabilities or hire research consultant
    - e. Establish valid measurement tool
    - f. Demonstrate cost savings to system
    - g. Measure caregiver satisfaction
    - h. Develop measurable respite outcomes
  - V. Determine need for financial support beyond appropriation
    - a. Develop a membership program -- identify benefits for members
    - b. Develop a donation program -- financial support structure (e.g., PayPal)
    - c. Identify and apply for grants from philanthropic entities
    - d. Determine appropriate in-kind support from sponsoring organization(s) or like-minded entity(ies)
    - e.
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- VI. Support for delivery of services
    - a. Establish how appropriations can used
    - b. Determine role of coalition in distributing new funds
    - c. Establish central office/regional offices
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## Contributors

Ohio Respite Coalition  
Benjamin Rose Institute on Aging  
Easter Seals of Ohio

### Organizations that participated in Regional Respite Summits during 2011-2012

Achievement Centers for Children, Camp Cheerful  
Akron Children's Hospital  
Akron Rotary Camp for Children with Special Needs  
All Care Services  
Alzheimer's Association, Cincinnati/KY  
Alzheimer's Association, Greater East Ohio Area Chapter  
Alzheimer's Association, Central Ohio Chapter  
Alzheimer's Association, Cleveland Area Chapter  
Alzheimer's Association, NW Ohio Chapter  
American Cancer Society  
American Red Cross  
ARC Southwest Ohio  
Area Agency on Aging - PSA5  
Area Agency on Aging - PSA6  
Area Agency on Aging - PSA7  
Area Agency on Aging - PSA8  
Area Agency on Aging - PSA10A  
Ashland University/Help Me Grow & Family and Children First Council  
Associated Healthcare of Ohio  
Beech Brook  
Benjamin Rose Institute on Aging  
Brain Injury Association of Ohio  
Brooks House Assisted Living Community  
Camp Allyn for Children with Special Needs  
Campbell Group  
Catholic Charities (SWO)  
Cincinnati Children's Hospital Medical Center/Perlman Center/UCEDD  
Cincinnati Public Schools  
Cleveland Clinic Children's Hospital for Rehabilitation  
Compassionate In-Home Care, Inc.  
Connections  
County (Delaware) Council for Older Adults  
County (Licking) Aging Program  
County (Union) Senior Services  
County (Wyandot) Council on Aging

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Crestwood Care Center  
DD Board, Delaware County  
DD Board, Huron County  
DD Board, Knox County  
DD Board, Licking County  
DD Board, Ross County  
DD Board, Union County  
DD Services, Butler County  
DD Services, Hamilton County  
Department of Job and Family Services, Geauga County  
Department of Job and Family Services, Richland County  
Down Syndrome Association of Greater Cincinnati  
Easter Seals Northern Ohio, Inc.  
Easter Seals (Goodwill) Miami Valley  
Elmwood Assisted Living  
Epilepsy Foundation of Greater Cincinnati  
Family and Children First Council, Butler County  
Family and Children First Council, Crawford County  
Family and Children First Council, Cuyahoga County  
Family and Children First Council, Dayton  
Family and Children First Council, Gallia County  
Family and Children First Council, Scioto County  
Family and Children First Council, Vinton County  
Family Voices of Ohio  
Firstlight Home Care of Columbus  
Franklin Woods Nursing Rehab.  
Griswold Special Care  
Hearth Consultants LLC  
Home Instead Senior Care  
Hospice of the Western Reserve  
Inner-Circle Communities  
Joyful Acres  
Judson at University Circle (Judson Park)  
Kindred Transitional Care & Rehabilitation - Newark  
Linking Employment, Abilities & Potential (LEAP)  
Long Term Care Ombudsman, Cuyahoga County  
Mental Health Services for Homeless Persons  
Michael Carter Group  
Mid-Ohio Board for an Independent Living Environment  
Mill Run Place  
Montefiore/The Weils  
Mount Carmel Health System/Hospice  
NAMI, Richland County

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National Church Residence/Ashland University  
National MS Society, Buckeye Chapter  
National MS Society, Ohio Valley Chapter  
Nationwide Children's Hospital  
New Avenues to Independence  
Northwest Counseling Services  
Ohio Care Planning Council  
Ohio Center for Autism and Low Incidence  
Ohio Department of Aging  
Ohio Federation for Children's Mental Health  
Ohio Senior Health Insurance Information Program  
Partners of Marion Care & Rehab.  
Providence Baptist Church, Alzheimer's Support Group  
Providence House  
Rehab & Nursing Center @ Firelands  
Rehab Center, The  
REM Ohio  
Resident Home Corporation (RHC)  
Richland Newhope  
Rose-Mary Center  
Senior Independence Home Health and Hospice  
Silver Lining Group  
Southeastern Ohio Center for Independent Living  
Southwest General Health Ctr. Hospice, Geriatric Assessment, and Home Health Services  
St. Augustine Health Ministries  
St. Catherine Manor of Washington Court House  
St. Joseph Home of Cincinnati  
Stepping Stones Respite Center  
T. C.'s Helping Hands Inc.  
University Hospitals Case Medical Center  
Visiting Nurse Association of Mid-Ohio  
Vitas Innovative Hospice Care of Columbus  
Wesleyan Village  
Willow Brook Christian Communities  
Winchester Place Nursing and Rehabilitation Center  
Wingspan Care Group/Applewood Centers, Bellefaire JCB  
Zangmeister Center

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