

Respite Breakroom: *Engaging Family Caregivers*

A How-to-Guide for Faith & Community-Based Organizations

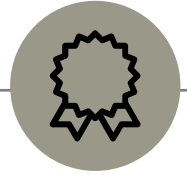


Developed by the:

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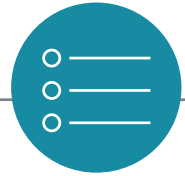
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- Mount Nebo AME Church, Awendaw, SC
- Hebron Zion Presbyterian Church, Johns Island, SC
- St Luke Presbyterian Church, USA, Orangeburg, SC
- Turner Lakeview Community Development Center, West Columbia, SC
- St. Paul United Methodist Church, Kingstree, SC
- Brown Chapel AME Church, Columbia, SC

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Introduction and Background



The South Carolina Department on Aging (SCDOA) is the Lifespan Respite grantee in South Carolina (SC) with the SC Respite Coalition (SCRC) as a subgrantee and partner in the Lifespan Respite projects. The SCDOA and SCRC also have partnered with Family Connection of SC and the Area Agency on Aging's Aging and Disability Resource Centers and Family Caregiver Support Programs to build a coordinated statewide lifespan respite system. Since beginning in 2009, this partnership has expanded respite options and increased accessibility to serve families, caregivers, and care receivers across the lifespan, regardless of the care condition or age of the care recipients. However, there is still much work to be done!

The Respite Breakroom model was developed as part of South Carolina's Lifespan Respite grant, partially funded by the Administration on Community Living, US Department of Health and Human Services with the aim to establish respite programs in faith communities. Both the SCDOA and SC Respite Coalition (SCRC) have worked extensively with faith-based programs. Caregivers often do not feel able to attend services and events at their faith home due to the care needs of their loved one, and therefore, experienced even greater social isolation. Caregivers often cite spiritual conflicts and disruption among the stresses of caregiving. They also cite faith and spirituality as a strength and a way to connect and find continued ability to provide care despite the demands on their time, energy, and emotions. Building on SCRC's previous work of developing respite programs in the faith communities, the Breakrooms were a way to assist caregivers to take a break while having the socialization and health benefits of connecting with others in their faith community and ensuring a safe, secure location on-site for their loved one who also would benefit from being in the presence of trained volunteers who can attend to their needs.

Respite Breakrooms began in faith-based programs and currently are being expanded to the broader community. Using a mini-grant process, faith-based organizations applied. SCDOA and SCRC selected five churches (one with a community center) to pilot the program. SCRC provided training and technical support to the selected programs to help them establish and successfully administer the Respite Breakrooms. Each program faced unique circumstances and progressed at different rates. Based on research, experience and the lessons learned, this guide is intended to provide strategies for replicating Respite Breakrooms as one model for faith and community-based respite programs.

The COVID-19 pandemic dramatically impacted this project as it paused with the closures of in-person gatherings at faith communities across the nation. Because of this experience, this guide also presents strategies addressing interruptions, necessary adaptations, safety precautions and how to maneuver around COVID going forward.

What is Respite?

Respite is a temporary, short break for family caregivers providing hands-on care for a loved one of any age who has a significant disability, special need or chronic illness. Respite gives time for family caregivers to do whatever they want to do with their respite time. They might use it to run errands, schedule doctor visits, read a book, take a nap or any other form of self-care. They also might use it to attend church services or other faith- or community-based programs, socially engage and connect with friends.

Caregivers are at a higher risk for health problems than non-caregivers, often a result of added stress and the physical demands of caregiving. Respite can relieve their stress, renew their energy and restore a sense of balance to their lives. It is an essential service that enables family caregivers to take a break and take care of themselves so they can continue to take care of their family member(s) at home for a longer period of time. This can delay and even prevent costly out of home placement.

Everyone benefits from respite. In addition to the caregiver, the person receiving care and the respite providers benefit as well. Care receivers report they need a break too. Many enjoy going different places, spending time with other people they know, different activities and some welcome a change in routine. Respite providers indicate they often learn new skills and information; and they enjoy the time with the person for whom they provide care and getting to know their families.

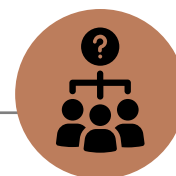
Why the Faith-Community?

For family caregivers, respite is one of the most frequently requested services. Family caregivers need regular planned respite in a safe environment with trusted caregivers. The need and number of family caregivers is far greater than the respite resources available. Faith communities offer a familiar place and familiar faces.

At the heart of faith-based groups is a desire to build a community and do good work. Faith communities have been vital in shaping and supporting the larger community. Depending on the size, they have various resources such as facilities, stable finances, volunteers, expertise, and a desire to help. Members bring a wide variety of professional and personal experience and skills as well as deep ties to the broader community.

As a model for faith-based and volunteer-led respite, Breakrooms can be especially valuable to caregivers in rural areas where resources, in general, are more limited. Families would be comfortable and familiar with their faith-community and other members, many of whom they have known for a long time. The Breakrooms provide a safe and known environment for caregivers and care receivers to attend and enjoy enrichment activities and social engagement. With many caregivers facing isolation, being able to engage to address their spiritual needs may allow them important time for self-care.

What is a Respite Breakroom?



A Respite Breakroom is a faith- or community-based respite model designed to give a family caregiver a break from their caregiving responsibilities so they can **rest, relax and recharge**. It is a respite site, a physical space, staffed primarily by volunteers, where family caregivers can bring their loved one with special needs to participate in activities and socialize with others in a safe, comfortable, and engaging place.

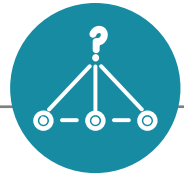
Respite Breakrooms are founded on the belief that respite provided in natural settings is accessible and appealing to the family caregivers and the family member needing care. It offers opportunities for the care receiver to visit with friends or make new ones as well as helping the caregivers expand their “circles of support.” Faith communities like churches, temples, synagogues, mosques, etc., are usually in the neighborhood or close to the family caregiver. Other community options include, but are not limited to, county recreation centers, senior centers, teen centers, etc., when otherwise not in use.

Breakrooms can be in one faith group or they can be developed in partnership with other faith groups in the neighborhood. Likewise in the community, one organization (e.g., county recreation center, senior center, etc.) might take the lead providing the coordinator and physical space, then partner with other community organizations (e.g., local technical school or college for volunteers, EMS or nursing program for medical expertise, and disability organizations, memory care centers or other community resources to provide training or expertise in programming.

In South Carolina’s pilot project, no two Respite Breakrooms were identical, but the ability to recruit appropriate volunteers and participants were key elements that made Breakrooms successful. In general, mid-size to larger congregations likely will be more sustainable due to the larger pool of volunteers and families needing respite, but smaller faith groups can make it work too. One faith group built a strong relationship with a faith group across the street that provided volunteers who helped to prepare the space for opening. Another opened their Breakroom to families from other nearby faith groups. A couple Breakrooms had volunteer leaders who were nurses with extensive experience in senior center programming which allowed the site to open quickly and operate efficiently serving an older adult population. Another served children with disabilities and medical complexities in the congregation as well as seniors and adults with special care needs. One Breakroom was able to get media coverage in their regional congregational newsletters about the project to recruit volunteers and participants.

A Respite Breakroom IS NOT a childcare or adult day care program. These programs require state licensing and oversight. In SC, programs operating under four (4) hours in a day do not require licensing. As a place to provide a temporary break for family caregivers (less than 4 hours), Respite Breakrooms do not require licensing by a state or other governing body.

Key Elements to Establishing a Respite Breakroom



Although Respite Breakrooms may vary significantly in their size, partners, volunteers and who they serve, the following key elements are important to increasing the likelihood of success and sustainability.

Gain Leadership Buy-in and Support

To gain support for any new program, it is important to understand the leadership structure and decision-making body of the faith community with which you are working. Decision-making processes vary by faith (e.g., Christian, Jewish, Muslim, etc.) and even by denominations or sub-structures within the faith. Some may be simple while others have various committees and channels of approval through elders, advisors, staff, boards and sometimes state or regional decision-making bodies.

Gaining leadership support before beginning the project may avoid pitfalls along the way. Not having appropriate approval early can delay beginning work on a Breakroom. Approval may not only be required to begin new programs, but agreements may be required for each phase of the project including the decision on operational structure, volunteer program structure, space design, and beginning activities. The more people involved in a decision often determines the length of time needed to obtain approvals, depending on standing committees' meeting schedules and other church business.

Having a strong vision from the beginning will help gain buy-in at all levels. In South Carolina, we found that the Breakrooms able to serve the most families and open the fastest after the final decision was made had a strong vision of their Breakroom before beginning the effort. By sharing a clear vision, they were able to develop strong leadership buy-in as well as excitement from all levels and stakeholders in their faith community. In one case, the minister helped to recruit volunteers and participants because his mother used the Breakroom during services.

Lastly, prepare a clear proposal to present to leadership that can serve as a guide to development of the Breakroom. It should include:

- Vision statement of what the Respite Breakroom will do,
- Resources and support being requested such as financial support, staff and/or volunteers, space within the facility, etc.,
- The extent to which the program will need these resources,
- Resources the Breakroom has to offer, e.g., any external funding.

In our pilot, breakrooms with the most utilization were mid-size faith communities that had a great deal of leadership buy-in at the onset of the project, that already had thought through the logistics of establishing the space and planned for navigating any difficulties in the organizational approval process and governance structure.

Establishing a Breakroom Working Group

Having more than one Project Leader or Coordinator is critical to ensuring completion and continuation of the project. By establishing a Working Group of at least 2-4 people to share responsibility and workload, risks for delays or interruptions are minimized. Often in working with faith-based communities, there is one primary contact who is the visionary for the project. Obtaining approvals, having work begin in a timely fashion and progress on schedule is often dependent on the primary contact's life circumstances. It is critical to have at least one other person involved in the planning with detailed knowledge to be able to assist and step in if needed. The sites that were able to open quickly often had a team of volunteers who all shared key information and were able to be cross-trained and support each other with project management duties, recruitment, education, awareness, operational and other important activities. They supported the project from the beginning through design, implementation and operation of the Breakroom during open service times.

Educating

Begin to educate members of your faith community early in the process. Do not assume that people are knowledgeable about the needs of caregivers or even what respite is and why is it important. By educating early and often, you are garnering support and setting the stage to identify families needing respite and to recruit volunteers.

Some ways to educate about respite and caregiver needs are to:

- Ask to present at the beginning of a worship service to share information on caregiver needs for respite and the Breakroom project.
- Develop a series of articles on caregiving, respite and the Breakroom to include in the newsletter or bulletin.
- Ask to speak at small groups meetings such as church school classes, high school youth groups, young adult classes, Care Teams, specific mission groups, etc.
- Talk with ministerial and other staff or members who visit families in the hospital or at home about the importance of respite for family caregivers and the role of the Breakroom. Ask them to talk with families and encourage those who could benefit to use the Breakroom.
- Provide educational materials, such as brochures or factsheets available at www.screspite.org.

Identifying Population to Participate

To identify family caregivers in your congregation who may be interested in and would benefit from the Breakroom, use all forms of communication available to send information about caregivers, the Breakroom and what you are trying to do, and a brief survey to all families in the congregation. Be sure the survey goes to all members, not just those who physically come to worship. Those who stay at home may have the greatest needs.

Use some of the same tools listed above to reach all possible caregivers, including inserting the survey in a bulletin that is mailed or emailed to all members, sending the survey by itself via an email distribution list, distributing the survey at worship service, highlighting the surveys' availability on social media and putting it on the website. To assess the overall need, caregiver interest and to determine who you will serve in the Breakroom, you will need to know:

- If they or anyone in the home is an unpaid primary caregiver of a person with disabilities or special needs.
- If yes, for whom are they providing care (Relationship)
- Age of the care receiver
- Health condition of the care receiver (e.g., Alzheimers or dementia, autism spectrum disorder, Intellectual Disabilities, medically fragile condition, or Other condition).
- Are they able to attend worship services or events at their faith home (e.g., church, synagogue, mosque, or other appropriate term?)
- Would they be interested in having their loved one participate in an engaging program is a safe place while they attended services or other events?

In addition, survey pastoral care, congregational ministries and care teams to identify caregivers who might be homebound and not attending services or events due to caregiving responsibilities. This group can be an ongoing source of referrals for the Breakroom.

Recruiting Family Caregivers

While the initial survey of the congregation may have identified many families, you can utilize the same educational/awareness strategies described earlier to recruit family caregivers and volunteers. and to announce the opening of the Breakroom including:

- regular announcements and blurbs in bulletins and newsletters,
- passing information by word-of-mouth through the congregation,
- posting on the bulletin board and social media are great ways to announce the opening and spread the word of the Breakroom availability while highlighting the purpose of the Breakroom and encouraging members to use the space,
- having an open house to allow families to get a feel for the space and to generate enthusiasm, and
- continual and regular communication will be essential to identifying new families and maintaining the necessary levels of volunteers.

Ensuring Needed Policies are in Place

It is important that you have policies in place to protect those participating in the Breakroom as well as the volunteers. The two most important policies are: (1) prevention and reporting of abuse and neglect, and (2) privacy and confidentiality.

Prevention and reporting of abuse and neglect of children and vulnerable adults: Most faith communities with childcare centers, children and youth programs or ministries for people with special needs will already have established abuse and neglect policies. Review those policies to be sure they address issues in the break room. For example, if you have policies addressing child abuse and neglect, but the Breakroom is serving people with Alzheimers or adult with disabilities, they should be amended to address adult abuse and neglect as well.

If the faith group does not have set policies, it is recommended that you develop policies and have them in place to provide appropriate guidance and training before opening the Breakroom. Having a member on your working group or leadership team who is a social worker or has experience in child or adult abuse and neglect would be helpful in developing these policies. See Appendix A for links to sample Abuse and Neglect policies developed for faith communities.

Privacy and Confidentiality: Everyone working in the Breakroom, whether staff or volunteers will have access to information about the families and the participants that is personal and should be kept private. Additionally, information related to participants' health conditions is considered health protected information and must be kept confidential. This information should not be shared with anyone without permission. Have all volunteers and staff sign a confidentiality agreement attesting to their understanding of confidentiality and responsibilities to not share information about participants and families. More on Confidentiality and HIPAA is included in Section IV.

Staffing and Volunteers

Staffing of the Breakroom should be designed to meet the needs of the participants being served in the breakroom based on their ages and care needs. Programs with the greatest opportunities for success will be able to recruit a large pool of volunteers with the range of skills needed including knowledge about universally designed and accessible space to best prepare the Breakroom for programming, and skills for recruiting participants, providing care, planning program activities appropriate to the needs of the participants, recordkeeping and ensuring sufficient staffing on respite days.

Recruit volunteers with a variety of skill sets to support the needs of the participants. Current and former caregivers, members with experience caring for children and/or adults with disabilities or medically complex conditions, and older adults challenged by aging or Alzheimers/dementia bring critical knowledge and skills to share. Professionals such as nurses, EMTs, social workers, special education teachers or aides, physical or occupational or speech therapists, childcare or adult daycare workers, and architects with knowledge of universal design provide expertise to address a range of needs.

In SC, a couple Breakrooms had volunteer leaders who were nurses with extensive experience in senior center programming which allowed the site to open quickly and operate efficiently serving an older adult population. Another served children with disabilities and medical complexities in the congregation as well as seniors and adults with special care needs.

Possible sources of volunteers outside of the faith group are from local universities and technical colleges in their human services, social work, nursing assistant and nursing programs. These may also be a consideration for future community partnerships in order for students to engage in service learning while providing valuable respite to family caregivers.

For operations of the Breakroom, the following general guidance is recommended:

- *Designate a Site Coordinator* – This person may be a paid staff person or volunteer. Often in faith communities, this person is the visionary behind the project. Whether paid or volunteer, thought, it is critical to have at least one other person with detailed knowledge of the procedures and plans from week to week to assist or serve as a back-up, when needed.
- *Recruiting:* Use a standard application to gather needed information like contact information, special skills and experience, available time, etc. Appendix B provides a sample volunteer application.
- *Background Checks:* For all volunteers who will have direct contact with care receivers, checks should be completed of the national sex offender registry, and state or national background checks. In South Carolina, state background checks are provided by the South Carolina Law Enforcement Division (SLED). Non-profits can obtain background checks for a discounted fee. National background checks are conducted by the FBI. The results of these checks should be kept in a file for each volunteer in the faith group's locked human resources files.
- *Scheduling:* When Breakrooms are open, schedule enough volunteers trained to support the onsite participants with a 2:1 ratio (2 volunteers for each participant) so that no volunteer is left alone to care for any participants, for safety reasons.
- *Scheduling:* Schedule more volunteers than you expect to need or have designated backup volunteers secured in the event any primary volunteers are unable to attend. This ensures enough volunteers for the Breakroom participants to be well cared for and preventing the need to limit capacity or turn away family caregivers and care receivers.
- Schedule volunteers to be onsite at least 20 minutes before starting and ending times to give families time to arrive to get settled before faith-community activities begin and for pick-up and cleaning the area after use.

Training Staff and Volunteers

Training is an important part of preparing volunteers to provide engaging, safe and quality respite care. Whether volunteers are from within the faith group or are community partners, retaining volunteers is made easier by having clear roles and responsibilities, training and supervision to support their learning needs and performance, valuing and recognizing their service, creating positive supportive environments for volunteers as well as the families being served, and helping volunteers connect their service to their personal mission statements, purpose, and values.

Suggested topics for training include:

- Mission of Your Breakroom
- Any relevant policies (e.g., abuse and neglect, confidentiality)
- Relevant procedures and guidelines (e.g., welcome, sign-in procedures, and sign-out procedures)
- Safety
- Developing emergency plans and/or guidelines under what circumstances the caregiver may want to be notified to return to the Breakroom should a difficult behavior or need arise
- Specific disability, health conditions and care needs

Although training in specific disabilities and/or health conditions is important, every person is an individual. A useful tool for assisting volunteers in learning the care needs of the Breakroom participants is for the family caregiver to complete appropriate sections of the booklet, "What You Need To Know About Me," which provides details about the care receivers' likes, dislikes, care needs, and information about their strengths and abilities. This provides specific information about the care receiver beyond the general educational information. Completing select portions of this booklet also may allow the family caregiver to feel more comfort in the care receiver attending the Breakroom program while the caregiver attends activities in another part of the faith community. This booklet is available to download from the SCRC website at: <https://www.screpite.org/resources/publications/>. The information in this booklet should only be shared with people providing care for this care receiver. After review, it should be kept in a locked drawer or cabinet with other confidential information so that it will not be seen by others in the Breakroom who do not need to know the information.

Alzheimers Disease Training Resources

Since most of the Pilot Breakrooms serve people who had a diagnosis of dementia, we have included some basic information on Alzheimer's Disease as well as links to more extensive in-person and on-line training.

Dementia Dialogues® provides the most current and practical information about how to care for people with dementia. This 5-module, evidence-informed nationally registered training course is designed to educate community members and caregivers for persons who exhibit signs and symptoms of ADRD, free of charge. Dementia Dialogues® is available as an in-person class, on-line or in a self-paced training format:

- To participate in the Dementia Dialogues® training in-person or on-line, contact the Office for the Study of Aging's (OSA) Program Coordinator at the University of South Carolina or the identified state designee provided below.
- If you are unable to participate in a training offered by a certified instructor online or in-person, you may complete a self-paced training. This training is accessible at [this website](#). If you have any questions about the online learning format, please contact the OSA Program Coordinator, Megan Byers, Arnold School of Public Health, University of South Carolina, at E-Mail: OSAInfo@mailbox.sc.edu

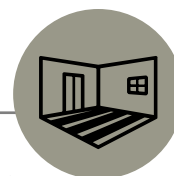
Additional on-line training resources for understanding and caring for people with Alzheimers' are available at the Alzheimer's Association website: www.alz.org. Selected topics are listed in Appendix C.

Respite Education and Caregiver Coaching

Breakrooms have an opportunity for increased respite education and caregiver coaching to establish greater "respite plans" for caregivers beyond just using the Breakroom. In that way, Breakroom volunteers can be a great first respite experience for caregivers who have limited opportunities or access to respite. These caregivers may need coaching to expand their circles of support for informal respite or learn to access other formal respite opportunities.

Breakroom volunteers who have been trained to coach caregivers can assist caregivers who may be unfamiliar with how to access other resources, by facilitating contact with other services and supports to learn about eligibility and the process for applications or receiving needed services. Breakrooms can also serve as a first line of dissemination with referrals sheets and resource guides as well as information and education on respite. In the SC Breakroom pilot project, volunteers were encouraged to refer caregivers to the Area Agencies on Aging for additional supports, as well as to SCRC for respite education, and to Family Connection of SC if they were parents of children with disabilities or other special needs. Links to key service providing agencies and organizations are provided in Section VI.

Preparing The Breakroom Physical Environment



Design a specific space. Respite Breakrooms should be established for just this purpose with proper safety precautions and activities. Your breakroom needs to be the place where visitors who are aging or have disabilities or other special needs can freely be themselves without any fear that behaviors or noises will be disrupting to others.

Oftentimes, the faith group has a purpose for most spaces, possibly a faith education class or other meeting area, that now is designated for the Respite Breakroom. The space will need to be repurposed. The space must be cleared to ensure there was enough open and unobstructed floor space to prevent falls and allow for ease of movement of volunteers and the care receivers to ensure for safety.

In designing the room, it is important to ensure the comfort of all seating in the room, and ensuring it is easy to change positions, prevent falling or sliding from chairs, and that it provides adequate support for comfort and being able to rise from the seated position as well for people with differing levels of muscle tone and balance.

The furniture in the Breakrooms need to be thoughtfully arranged to allow for the safety of the participants, and to allow for universal use independent of any care needs of the care receivers, so that the room was welcoming, accessible, and functional for anyone who may use it.

It also is important to ensure the Breakroom is close to an accessible restroom. As there will be different care conditions of the participants, it also is important to have “zones” within the room, where possible, to allow for freedom from distractions and quiet reverie, should a participant be overstimulated by other group activities.

Universal Design is very important when thinking about the layout and arrangement of the Breakroom to address the issues above and to ensure true accessibility for all participants. The seven principles of Universal Design, as outlined here, are: <http://universaldesign.ie/what-is-universal-design/the-7-principles/> :

1. Equitable use: Equity in use centers on not isolating or segregating individuals because of their abilities and that any needs for security, safety, and privacy are available to everyone who uses a space.
2. Flexible use: Flexibility in use pertains to the space being able to be used by a range of people regardless of their abilities, disabilities, and are easily adaptable to the needs of the Breakroom participants.
3. Simple and intuitive use: A space that is simple and intuitive to use will mean that regardless of literacy level, cognitive abilities, or memory, it is easy to use and manipulate the furnishings and environment.
4. Perceptible information: Having perceptible information in an environment means that regardless of the sensory capabilities or limitations of any of the participants, people are able to receive information and instructions related to use of the space.

5. Tolerance for error: A “tolerance for error” means that the environment has removed as many hazards as possible and that the most used areas of a space are the safest. Any hazards have been appropriately reduced and isolated from common use areas.
6. Low physical effort: Spaces with low physical effort are vital for participants who may have disabilities or physical limitations. They reduce repetitive motions necessary to comfortably use the space.
7. Size and space for approach and use: Allowing size and space for approach and use means that for participants using assistive and adaptive devices and walking aids, they are able to comfortably walk through the room, be seated, and see other components of the room unobstructed.

Keeping the seven principles at the forefront of designing the Breakroom is not difficult and means that the care receivers utilizing the space will have the most benefit, and the best chance of having peace, comfort, and relaxing interactions while away from their family caregivers, and simultaneously promoting positive experiences for the Breakroom volunteers.

In addition to the physical design elements of the Breakroom are the environmental considerations. The room should contain elements of a healthy environment (air, water, nourishment, light, fitness, comfort, mind) that address all of the senses: sight (vision); hearing (auditory); smell (olfactory); touch (tactile); vestibular (movement); and proprioception (position).

Appendix D provides additional items for consideration when modifying space for a Breakroom.



Programming and activities should be designed to be age and ability appropriate for the participants in the Breakroom. Volunteers with related experience can be a tremendous help in creating engaging and appropriate activities. Considerations in programming and some suggested activities are provided for potential Breakroom participants.

Activities for people with Alzheimers or other dementia

The focus of activities in the Breakroom should be on comfort and familiarity, and not teaching new things. Choices should be limited to avoid sensory overload. Do not insist attendees participate in activities, assume their intent, correct them, or single them out.

- Focus on calming activities, such as sensory manipulatives, reviewing family or faith group photo albums, applying hand lotion, or resting,
- Simple arts and crafts projects,
- Play soothing music, or
- Watch the service if they so choose and you have remote viewing capabilities.
- Look for activity supply catalogs for people with limited range of motion or those specifically for seniors for other ideas and materials.

NOTE: It is especially important for participants with dementia that you schedule volunteers as teams (at least 2 volunteers to 1 participant). Different individuals often will be able to soothe the participant in various ways if they become agitated or disoriented.

Activities for Older Adults who are aging/elderly (SC Physical Therapy Association)

- Fingernail painting
- Jigsaw puzzles
- Memory game
- Ceramics, Mosaics
- Gardening (small potted plants/herbs)
- Greeting card decorating
- Collage (tearing magazine pictures and gluing to posterboard)
- Pet therapy (volunteer animal training groups bring dogs to locations)
- Bingo
- Poetry readings
- Name-That-Tune game
- Read daily headlines and discuss happenings
- Look for activity supply catalogs for people with limited range of motion or those specifically for seniors for other ideas and materials.

Activities for Children and Youth - (SC Physical Therapy Association)

- Establish an age-appropriate routine for the respite time slot (i.e., Wash hands, sit on circle, sing a welcome song together, etc.)
- Provide group activities that allow for independent working alongside peers
- Provide 2 activity options with pictures or actual finished product available to observe
- Possible activities include:
 - Painting ceramics
 - Making slime
 - No-bake cookies, cupcake/cookie decorating
 - Parachute game
 - Balloon volleyball
 - Jigsaw puzzles
 - Making sock puppets
 - Sticker books
 - Making musical Instruments (e.g., with beans, toilet paper rolls, etc.)
 - Simon Says
 - Holiday themed crafts
 - Gardening (small potted plants/herbs)

Documentation and Measuring Success

It is important to document who participates in the Breakroom every time it is open. Establish a process where families/participants sign-in when they arrive and sign-out when they leave the Breakroom. Appendix E provides a sample “Sign-In” sheet. This is important for safety, but also enables you to quantify how many people are using the Breakroom. This will be important information to report the leadership regularly, but this is only one measure of how the Breakroom is doing.

Periodic surveys of caregivers and participants are recommended to better understand their experiences and how satisfied they are with the Breakroom services. The information tells you how well the Breakrooms is doing and can help you make changes, if needed, to ensure their comfort and that their needs are being met.

Survey volunteers as well to get feedback and engage them in making the Breakrooms the best they can be.

Initial Costs

In our pilot, the average amount needed to open a Breakroom and establish the space for comfort and function was around \$3,500. This covered furniture such as lift chairs, ergonomic seating that was safe, unlikely to tilt or tip, and solid enough to support weight on the arms for people to push to a standing position. Examples of other supplies included technology and equipment to view the service, entertainment materials, first aid kits, chuck pads, simple decorations, etc. Funds needed for capital expenses, physical modification, paid staff, and food would be additional costs.



Everyone in a Respite Breakroom will be exposed to very personal information about care receivers and families. You will be trusted to keep this information private and confidential. One of the best ways to show them they can trust you is to protect their privacy by not sharing their personal information with anyone.

If you are a family member or friend or member of a faith group who will be providing respite care, keeping things private may seem to be a little harder to do, especially where other family members are concerned. Regardless, it will be just as important for you to respect the family's privacy and understand the importance of keeping their private information safe.

What is confidentiality and why is it important?

The word "confidentiality" simply means to keep secret or private. Confidentiality and privacy are important to all of us. They are things that we all expect concerning our own lives and personal information. The same is true of the families whose loved ones come to the Breakroom.

For example, when we talk with our doctors, we expect them not to share details about our medical concerns or any of our other personal information with others. By not doing so, our doctors protect our confidentiality.

This is the same in Respite Breakrooms. Do not share any information about care receivers with anyone who is not providing care for them in the Breakroom unless you have written permission. Keeping their trust is critical to having a good relationship with them for a long time.

What is HIPAA and protected health information (PHI)?

HIPAA stands for the *Health Insurance Portability and Accountability Act*. It is the Federal law that protects the privacy of everyone's health and medical information, called "**protected health information,**" "**personal health information,**" or "**PHI.**" This includes basic personal information items like names and social security numbers. It especially protects the confidentiality of health or medical information including future health plans.

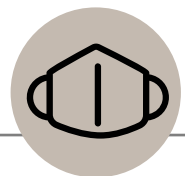
Knowing what information to keep private

The best way to approach what information is confidential and protected is to remember that as a respite caregiver, ALL information about the care receivers and families is considered confidential.

It is OK to share PHI **ONLY** when the primary family caregiver or the care receiver authorizes it. Keep in mind that sometimes even if the care receiver you are supporting gives permission to share information, you should **not** share it. The best way to know is to get written permission from the family caregiver.

Personal pictures or video or audio recordings of the participant, family, or anything that might identify them are also confidential. Do not take pictures of the care receiver or share them on Facebook, in the bulletin or on your phone without the written permission of the care receiver or family. Many will be happy to have their pictures taken to share the good work of the Breakroom, but others may be less comfortable. It is always best to ask and be sure the caregiver and care receiver know how the picture will be used and agree to its use.

Infectious Disease and Personal Protective Equipment (PPE) Use



While COVID-19 has heightened our awareness and sensitivities to infectious diseases, everything we learned and practiced related to COVID-19 are good strategies to prevent the flu and common cold as well. Infectious diseases are particularly dangerous to older adults and people with disabilities. Seniors have weaker immune systems due to their age and can become even more susceptible to infection when they are ill.

To prevent the spread of all infectious diseases and protect everyone in the Breakroom, here are a few suggested infection control practices:

- Wash hands frequently. Hand washing is still one of the best ways to reduce the spread of infectious diseases.
- Place alcohol-based hand sanitizers (ABHS) at all entry points and other high activity areas of the in and around the Breakroom.
- Assist participants and visitors with hand hygiene, if necessary.
- Adhere to respiratory hygiene and cough etiquette. Cough in the crook of your arm, or a tissue and not on your hand.
- Wear masks when in close contact.
- Have participants and volunteers stay home when experiencing symptoms of illness.
- Routinely clean all frequently touched surfaces within the facility (e.g., doorknobs, light switches, handrails, bathroom fixtures, countertops, tables, chairs, elevator buttons, workstations, chairs, tables, books, etc.).
- Continue checking the official DHEC COVID-19 Web Page, or your local public health department, to stay updated on all current guidance and memos.

Provide education on proper hand hygiene, respiratory etiquette, how to wear a mask, and social distancing as recommended by your local public health agency.



Resources in South Carolina

- GetCareSC www.GetCareSC.com
Provides a search tool for seniors, caregivers, and adults with disabilities to find providers and available services, like respite care, assisted living, transportation, and insurance -- and if you need help and you don't know where to start. The GetCareSC website is maintained by the South Carolina Department on Aging, helping connect you to local resources and find help in your community.
GetCareSC Toll Free: 800-868-9095
- Local Area Agency on Aging can help you find services in your area.
<https://www.getcaresc.com/about/area-agencies-aging>
- SC Department on Aging <https://aging.sc.gov/programs-and-initiatives>
The SCDOA works with a network of regional and local organizations to develop and manage services that help seniors remain independent in their homes and in their communities.
- SC Respite Coalition <https://screspite.org>
Statewide non-profit organization working to expand quality respite opportunities in South Carolina throughout the lifespan for families who have a member with special needs.
- SC Chapter, Alzheimers Association <https://alz.org/SC>
The AASC has many virtual offerings including education programs, caregiver support groups, early stage social engagement programs and advocacy trainings. It also has a 24/7 around-the-clock care and support Helpline at 1-800-272-3900.
- Family Connection of SC <https://www.familyconnectionsc.org/referral/>
FCSC's Family Information Center (FIC) staff are highly trained professionals who are parents themselves, and provide information, support, education and referrals to meet the individualized needs of families who have children with special needs.

National Resources

- ARCH National Respite Network has downloadable factsheets on a variety of respite topics including respite for a wide variety of special populations:
<https://archrespite.org/productspublications/arch-fact-sheets>
- Family Caregiver Alliance <https://www.caregiver.org/>
Has a variety of resources to help family caregivers and and the people who receive their care.



- A. Sample Policies for Faith Communities
- B. Sample Volunteer Application Form
- C. Links to Training for Alzheimers
- D. Modifying a Space and Environmental Considerations for a Breakroom
- E. Sample Sign-in Sheet

Appendix A: Links to Sample Policies for Faith Communities

Sample Policies for Abuse and Neglect

- SafeChurch – Child Protection Policy for Churches:
<https://www.guideone.com/sites/default/files/sr-child-protection-policy-church-pdf.pdf>
- Small Membership Church – Sample policy:
<https://nccumc.org/christianformation/files/Small-Membership-Church-Sample-Policy.pdf>
- Child/Youth/Vulnerable Adult Protection Policy 2020, Presbyterian Church:
https://www.google.com/search?q=vulnerable+adult+protection+policy+church+template&client=firefox-b-l-d&biw=1275&bih=843&ei=BN8jYtnaK5aNwbkP_52lqAc&ved=0ahUKEwjZ7PbN_a_2AhWW_RjABHf9ODXUQ4dUDCA0&oq=vulnerable+adult+protection+policy+church+template&gs_lcp=Cgdnd3Mtd2l6EAW6BwgAEecQsANKBAhBGABKBAhGGABQxQpYhhIgs0FoAXABeACAAXCIAboKkgEEMTUuMZgBAKABAcgBCMABAQ&sclient=gws-wiz
- SAFE Sanctuaries Policies – Smaller Membership Congregations:
<https://s3.us-east-1.amazonaws.com/gbod-assets/generic/09-2020-Safe-Sanctuaries-Smaller-Membership-Congregations.pdf>
- A Resource Packet for Creating Safe Sanctuaries Guidelines for your Small Membership Church – United Methodist Church:
https://www.eocumc.com/safe-sanctuaries/_pdf/SafeSanctuaries-Small-Churches-0517.pdf

APPENDIX B
(Sponsoring Organization's Name)
RESPIRE BREAKROOM VOLUNTEER APPLICATION

We encourage the participation of volunteers who support our mission. If you are willing to be interviewed and trained in our procedures, we encourage you to complete this application.

The information on this form will be kept confidential.
 Thank you for your interest in volunteering in our Breakroom.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Email: _____

Employer: _____ Position: _____

Any special talents or skills you have that you feel would be a benefit?

Interests: Please tell us in which areas you are interested in volunteering

- _____ Administration/Coordination of Respite Breakroom
- _____ Communication/Recruitment/Education
- _____ Respite Breakroom Care provider (Caring for the participants)
- _____ Training Breakroom volunteers
- _____ Fundraising
- _____ Deliveries



Please indicate days and times you could be available:

| Mon | Tues | Wed | Thurs | Fri | Sat | Sun |
|-----|------|-----|-------|-----|-----|-----|
| | | | | | | |
| | | | | | | |
| | | | | | | |

Any physical limitations? _____

In case of emergency contact: _____ Phone: _____

As a volunteer of this Respite Breakroom, I agree to abide by the policies and procedures of the supervising organization. I understand that I will be volunteering at my own risk and that the organization, its employees and affiliates, cannot assume any responsibility for any liability for any accident, injury or health problem which may arise from any volunteer work I perform for the organization. I agree that all the work I do is on a volunteer basis and I am not eligible to receive any monetary payment or reward.

Signature: _____ Date: _____

Appendix C: Links to Training for Alzheimers and Autism

Alzheimer's

The Alzheimers Association has a series of free on-line training videos related to Alzheimers disease and caring for someone with Alzheimers disease including:

<https://training.alz.org/products/4053/understanding-alzheimers-and-dementia> - Alzheimer's disease is not a normal part of aging. Learn about the impact of Alzheimer's, the difference between Alzheimer's and dementia, stages and risk factors, current research and treatments available for some symptoms, and Alzheimer's Association resources.

<https://training.alz.org/products/4036/effective-communication-strategies> - Communication is more than just talking and listening – it's also about sending and receiving messages through attitude, tone of voice, facial expressions and body language. Explore how communication takes place when someone has Alzheimer's, learn to decode verbal and behavioral messages delivered by someone with dementia, and identify strategies to help you connect and communicate at each stage of the disease.

<https://training.alz.org/products/4038/healthy-living-for-your-brain-and-body-tips-from-the-latest-research> - For centuries, we've known that the health of the brain and the body are connected. But now, science is able to provide insights into how to make lifestyle choices that may help you keep your brain and body healthy as you age. Learn about research in the areas of diet and nutrition, exercise, cognitive activity and social engagement, and use hands-on tools to help you incorporate these recommendations into a plan for healthy aging.

<https://training.alz.org/products/1019/living-with-alzheimers-for-caregivers-early-stage> - In the early stage of Alzheimer's disease, families face new questions as they adjust. What does the diagnosis mean? What kinds of plans need to be made? What resources are available to help? This 3-part program provides practical answers to the questions that arise in the early stage. Hear from those directly affected and learn what you can do to cope with the changes that come with an early-stage diagnosis.

<https://training.alz.org/products/1023/living-with-alzheimers-for-caregivers-middle-stage> - In the middle stage of Alzheimer's disease, those who were care partners now become hands-on caregivers. This 3-part series has caregivers and professionals discussing helpful strategies to provide safe, effective and comfortable care in the middle stage of Alzheimer's.

<https://training.alz.org/products/1024/living-with-alzheimers-for-caregivers-late-stage> - In the late stage of Alzheimer's disease, caregiving typically involves new ways of connecting and interacting with the person with the disease. In this 2-part series, you'll hear from caregivers and professionals about resources, monitoring care and providing meaningful connection for the person with late-stage Alzheimer's and their families.

<https://training.alz.org/products/1025/living-with-alzheimers-for-younger-onset-alzheimers> - When someone under 65 is diagnosed with Younger-Onset Alzheimer's disease or related dementia, the first reaction is often shock or denial. This doesn't happen to someone so young...does it? What does the diagnosis mean? What kinds of plans need to be made for everyone? What about work? What resources are available to help? Get answers to questions that arise for people concerned about Younger-Onset Alzheimer's disease or a related dementia. Hear from those directly affected and learn what you need to know, what you need to plan, and what you can do to ease the impact throughout the course of the disease.

<https://training.alz.org/products/4037/understanding-and-responding-to-dementia-related-behavior> - Behavior is a powerful form of communication and is one of the primary ways for people with dementia to communicate their needs and feelings as the ability to use language is lost. However, some behaviors can present real challenges for caregivers to manage. Learn to decode behavioral messages, identify common behavior triggers, and learn strategies to help intervene with some of the most common behavioral challenges of Alzheimer's disease.

<https://www.helpforalzheimersfamilies.com/learn/alzheimers-education/> - Free five course training that covers understanding Alzheimer's, minimizing symptoms, encouraging engagement and safety.

<https://www.wehelpcaregivers.com/education/> - PDFs on caregiving, understanding Alzheimer's, understanding memory loss

<https://training.mmlearn.org/caregiver-training-videos/topic/alzheimers> - 12 videos that cover topics as listed above but also a five video series that empower caregivers.

APPENDIX D: Modifying a Space & Environmental Considerations for a Breakroom

Jennifaye V. Brown, PT, PhD, NCS

A Breakroom is intended to be a place of respite – a temporary break for individuals with special needs/disabilities and their family caregivers. Therefore, the room should contain elements of a healthy environment (air, water, nourishment, light, fitness, comfort, mind) that address all of the senses: sight (vision); hearing (auditory); smell (olfactory); touch (tactile); vestibular (movement); and proprioception (position).

| HEALTHY ENVIRONMENT | |
|----------------------------|---|
| AIR | <ul style="list-style-type: none"> • Well-ventilated with easily accessible vents to open/close as a method to control room temperature • Adjustable speed-controlled ceiling fans • Digital thermometer secured and locked in a see-through container <p>Note: Individuals should have a light blanket or layered clothing to adjust to room temperature</p> |
| WATER | <ul style="list-style-type: none"> • Room temperature bottled water is appropriate for hydration or to have if medications need to be taken or feeding tubes need to be drained <p>Note: Individuals should have their thickener to add to water if there are swallowing precautions</p> |
| NOURISHMENT | <ul style="list-style-type: none"> • Any healthy food item that can be used to immediately raise blood sugar or to eliminate behavioral agitation due to hunger. • Healthy: No added sugars such as high fructose corn syrup or salt • Simple: crackers • Individuals should bring their preferred snacks <p>Note: Be aware of any food allergies and make sure they are eliminated from the room.</p> |
| LIGHT | <ul style="list-style-type: none"> • Adjustable (dimmer switch) and in zones <p>Note: Bright light is a stimulant and can be a trigger for behavioral outbursts</p> |
| FITNESS | <ul style="list-style-type: none"> • Any activity that can quickly absorb the energy of movement, thus causing the person to fatigue and reduce the unwanted behaviors <p>Note: A simple rope pulley system attached to a wall or door or a table-top punching bag can engage the arms</p> |
| COMFORT | <ul style="list-style-type: none"> • Upholstered water-resistant cushioned seating systems that have different height or shapes for the ease of sitting and standing and comfortable when sitting as not to irritate the skin/body parts • Upholstered water-resistant cushioned mat for someone that needs to lay down to relieve pressure on the body from sitting in the wheelchair • Chairs should have arms to assist in standing <p>Note: A twin sized mat that attaches to the wall and can be folded down when needed conserves space</p> |
| MIND | <ul style="list-style-type: none"> • Perception is everything: the space should be designed for universal engagement so that everyone thinks the space is for individuals with and without special needs/disabilities • The space can be used for other functions |

| PHYSICAL SPACE | |
|-----------------------------------|--|
| ENTRY | <ul style="list-style-type: none"> • Door way has clearance on right and left side for wheelchair placement if pulling action will occur • Area of clearance should have a sight line in/out of room; anyone can see if a person/object is in the path of the doorway • 36 inch wide door recommended • 32 inch doorway clearance at minimum • Door opens to 90 degrees (allowing 32 inch clearance) or 180 degrees • ADA compliant door handle (horizontal) that is 34 inches from floor; no more than 5 pounds of force required to open/close the door |
| ROOM CONFIGURATION & CONSTRUCTION | <ul style="list-style-type: none"> • Five feet of turning space clearance for a wheelchair • Non-skid flooring – NO throw rugs; if carpeted: <ul style="list-style-type: none"> ○ low/short pile nylon fiber and if on a slab include rubber padding, or ○ commercial grade carpet to make it easy for wheelchair propulsion <p>Note: Avoid placement of cords in the pathway of locomotion (walking or use of wheelchair)</p> • Muted wall colors <p>Note: Bright colors with defined bold objects provide increase visual stimulation which may trigger unwanted behaviors such as agitation</p> • Landline phone for emergency use or require that all patrons have a cell phone <p>Note: Check room for cell phone signal and provide a cell phone charging station.</p> • ADA compliant light switches 15-48 inches from floor which are flat panel or motion sensor <p>Note:</p> <ul style="list-style-type: none"> • 48 inch height is not accessible to an individual with quadriplegia in a power wheelchair • Clearance to approach light switch: 30 inches from front; height no greater than 48 inches • Clearance to approach light switch: 48 inches from side; height no greater than 54 inches • Light switch should be operable with one hand not requiring fine motor coordination of fingers/thumb (grasp/pinch) or twisting of wrist <ul style="list-style-type: none"> • No more than 5 pounds of force required to turn light switch on/off • Electrical outlet height from floor no less than 15 inches |
| ROOM CONTENT | <ul style="list-style-type: none"> • Adjustable height table to accommodate wheelchairs • Cabinets at bottom: depth (maximum 6 inches), height (maximum 9 inches) to allow for toe clearance for individuals in wheelchairs. <p>Note: Cabinet with code locking mechanism for food items and another cabinet for cleaning supplies to include gloves for anti-bactericidal products.</p> • Upholstered water-resistant cushioned seating systems which can accommodate anyone and be easily cleaned after use. <p>Note: Verify if anti-bactericidal does not impact upholstery, e.g., color change</p> • End tables next to seating systems that have rounded edges – avoid |

| | |
|--|--|
| | <p>furniture with sharp edges</p> <ul style="list-style-type: none"> • Plastic pillows with cloth pillowcases – plastic pillows can be wiped with anti-bactericidal agent after use • Laundry basket for pillowcases/Hoyer slings • Paper towel dispenser • Manual or electric Hoyer to transfer dependent individuals to/from wheelchair and mat that attaches to the wall and can be folded down when needed conserves space • Hoyer slings (2 minimum that accommodates Hoyer chosen) <p>Note: Individuals may be seated in wheelchairs with Hoyer sling in place</p> |
| SPECIAL CONSIDERATIONS FOR THE SENSES | |
| SIGHT | <p>Visual impairment</p> <ul style="list-style-type: none"> • For those who use walls for way finding cues (known as shoreline), items need to be within cane sweep (27 inches height maximum) and provide minimum head room clearance of 80 inches minimum from floor along wall; items above 80 inches can protrude out any distance • A soft sound doorbell/buzzer can be used to detect door opening/closing |
| AUDITORY | <p>Hearing Impairment</p> <ul style="list-style-type: none"> • A light can come on/off to detect door opening/closing • Strobe (flashing) light when alarm sounds <p>Note:</p> <ul style="list-style-type: none"> • Eliminate unnecessary noises that provide multiple sensory stimuli e.g. television or sound system to hear service • Use of soft melodic music without words to provide relaxation and decrease agitated behavior |
| VESTIBULAR | <ul style="list-style-type: none"> • Slow down speed of wheelchair as fast movement during turns may cause agitated behavior or a startle reflex. • A rocking chair at slow oscillations (movement) can reduce agitated behavior. |

| OTHER CONSIDERATIONS | |
|-----------------------------|--|
| Cleaning Supplies | Avoid aerosols. Should not be pungent or leave residual odor as this can exacerbate allergies or lead to agitated behavior. |
| Small Portable Fans | To cool individuals who may experience autonomic dysreflexia, *check for a coiled urine drainage tube or pressure on skin (check position in wheelchair or item applying pressure against skin) may cause autonomic dysreflexia or agitated behavior |
| First Aid Kit | Consult Health Ministry to provide a basic first aid kit for room |
| Fire Extinguisher | Know the location of the closest fire extinguisher and escape route |

Prologue

The Breakroom should address all seven senses and have elements of a healthy environment and universally designed to reflect the culture of the community with the intent of being a temporary respite place during service. This list is not all-inclusive; and you may benefit from consultation with a professional experienced in ADA compliant environmental modifications.

