Sharing the Care:
An Innovative Model for Building Respite Awareness and Capacity Within Communities
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chapter one
Sharing the Care (STC) Toolkit

• Introduction •

Alabama Lifespan Respite Resource Network® (Alabama Respite) is pleased to present this Sharing the Care (STC) Toolkit as a part of our Technical Assistance resources for respite education, outreach, and expansion. STC is a community initiative of Alabama Respite that brings together family caregivers, service providers, and volunteers in targeted communities throughout the state to work towards the following goals: (1) Identify gaps and barriers to local respite care; (2) Provide education and public awareness about respite and its benefits; (3) Develop new and/or expand existing respite resources; and (4) Act as a grassroots advocacy group to educate federal, state, and local policymakers about the need for respite and family caregiver support services.

Part of Alabama Respite and its stakeholders’ vision is to have STC groups working in communities throughout our state – and beyond – to help ensure that family caregivers can get the breaks and supports they need to continue their important roles. To that end, this Toolkit has been designed with the dual purposes of; (1) Assisting current STC facilitators and leadership to conduct STC activities and events, and (2) Introducing the STC concept to communities outside of Alabama and providing tools needed for replication.

Alabama Respite hopes that you find the information and tools collected for this Toolkit to be useful in your efforts to expand respite awareness and resources for your community. This Toolkit is a living collection that our staff expects to evolve with time and experience. Moreover, the Toolkit can be customized to meet the specific needs of

HOW TO USE THE STC TOOLKIT

1. The STC Toolkit is available in e-book format for general reading and information, as well as printable pdf format on the Alabama Respite website, www.alabamarespite.org. You can access the printable version by visiting our website and clicking the STC Toolkit Button under the Resources tab.

2. The printable pages are formatted to fit a standard 3-ring binder. We recommend that you make tabs for each chapter of the Toolkit and place them in your binder. All the documents you will need to plan and carry out activities for your STC initiative are available for printing, so you have the flexibility to add or remove a resource or document as necessary when changes or additions are made.

3. Throughout each section, you will find web-based resources and links that you can print if you find useful to include in your binder. Remember that even great information found on a web resource may not be available indefinitely, so having a copy in your Toolkit may be useful later.

4. In addition to the chapter tabs, our staff recommends you make STC record keeping tabs in your 3-ring binder. Ideally, this Toolkit will serve not only as your how-to and idea guide but as your all-in-one STC record. At the back of the Toolkit, you may add sections for: Membership Lists, Committees, Minutes, and To-Do Lists.

5. Remember the Toolkit is a tool to help facilitate the activities of your STC initiative. As with any Toolkit, you may find that you do not need all the tools when you begin your STC, but they may be useful later. Just like a home improvement project, choose the tools that make the most sense in order to achieve the needed outcome. Once you gain experience, you may wish to add tools you need to your collection.
your own STC group. We welcome your comments and feedback as we work to make this the most effective set of tools possible. Please let our staff know which pieces work well for you, suggestions you have for improvements or additional tools, and your experiences in using the Toolkit in your community. We can be reached at info@alabamarespite.org or by calling 1-866-RESTALA (737-8252).

• Background Information •

When starting a new initiative such as Sharing the Care, it is important that potential volunteers and other stakeholders know who you are and what your organization does. The following is a brief history of Alabama Respite that our team uses as an introduction to the program.

Click www.alabamarespite.org/images/stctoolkitresources/orghistexample.pdf to download a copy of History of the Alabama Lifespan Respite Resource Network®

Who is Alabama Respite? Alabama Lifespan Respite Resource Network® (Alabama Respite) is a statewide program of United Cerebral Palsy of Huntsville and Tennessee Valley, Inc.(UCP). Alabama Respite’s mission is “to increase access to and availability of high quality respite resources for all caregivers in Alabama.”

What is Respite? Respite is temporary relief for family caregivers who are caring for individuals of any age who have disabilities, chronic or terminal illnesses.

What are our Services?
• Respite resource information, referrals, and vouchers for caregivers
• Education and public awareness
• State, local and federal advocacy
• Technical assistance for new programs including volunteer training
• Sharing the Care (STC) community initiatives

Alabama Respite’s website, www.alabamarespite.org offers information for caregivers and service providers wanting to learn about our activities and programs and hosts an interactive database of agencies that provide respite services specific to Alabama’s counties.

866-RESTALA (866-737-8252) is Alabama Respite’s toll-free number for caregivers and providers seeking additional information. The staff is available to provide information and education through presentations at conferences.
and to groups, organizations, churches and agencies that serve family caregivers. Alabama Respite staff may be contacted at info@alabamarespite.org.

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**Our History**

Alabama Respite began in 2000, working with a task force of approximately 45 volunteers from state agencies, both non- and for-profit organizations that serve people with disabilities, and consumers. The task force developed an initial Strategic Plan to identify the respite needs of caregivers in Alabama and the gaps and barriers they face accessing services.

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**Our Accomplishments**

- **HEARTS Voucher Respite Program**, first piloted in North Alabama by UCP in Huntsville in 1994, has successfully been replicated by all UCP affiliates throughout the state. The program serves caregivers of children up to age 19 and is funded by the Alabama Department of Child Abuse and Neglect Prevention.

- **Sharing the Care** is a community-based initiative that creates an opportunity for key stakeholders living in a specific area of the state to collaborate and develop respite resources and address funding needs unique to their community. Piloted in 2005 in Limestone County, the project has been replicated in Madison, Cullman, Blount, Jefferson/Shelby, Tuscaloosa, Walker, Marengo, Dallas, Etowah, Houston, Lee, Montgomery/Elmore/Autauga, Mobile/Baldwin, and Colbert/Lauderdale Counties. Alabama Respite has created training materials (a STC Toolkit) to begin STC projects in additional communities. Our staff presented this concept at the 2011 National Respite Conference at the request of ARCH, our National Respite Coalition.

- **Faith-based Volunteer Respite** is a low-cost method of service delivery, and many options for outreach ministries are available from which to choose. Alabama Respite has a special “module” included in the STC Toolkit that includes information and materials available for faith-based community leaders interested in learning more about this outreach ministry.

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“The Respite Ministry was established not only to give the caregivers some relief but as an outlet for those with dementia, Parkinson’s, and Alzheimer’s, hopefully to enable them to interact with others suffering from similar problems as well as the volunteers. It not only has done ALL of that, but it has been a tremendous blessing for EVERYONE participating. Being a volunteer is a breath of fresh air.”

—Glenda Yelverton
Respite Volunteer, First United Methodist Church, Montgomery, AL
♦ Our advocacy efforts with the Alabama Legislature resulted in Alabama Respite receiving state funding beginning in 2006. The funds are administered by the Alabama Department of Rehabilitation Services.

♦ Alabama Respite hosted the 2007 National Respite Conference in Huntsville.

♦ In 2007, the Alabama Department of Mental Health began contracting with Alabama Respite to manage voucher respite funding for caregivers of adults and children who have intellectual disabilities.

♦ In 2009, the Alabama legislature passed resolution HJR 170 to establish Alabama Respite “as the lead entity for lifespan respite coordination in the state of Alabama and designated Alabama Respite as the coordinator of the Alabama Respite Coalition.” From that effort, the Alabama Lifespan Respite Resource Network was passed into law in 2012.

♦ The Governor appoints our statewide coalition of stakeholders of about 30 individuals representing state agencies, organizations, and consumers. The Coalition collaborates with Alabama Respite to address gaps and barriers to current respite resources in a productive process and limits duplication of effort when possible.

♦ Alabama was one of the first of 12 states to receive a Federal Lifespan Respite Grant in 2009. The primary goal of the grant was for the Alabama Department of Senior Services (ADSS) to work in partnership with Alabama Respite to provide a statewide, comprehensive, and coordinated approach to providing lifespan respite care to all Alabama family caregivers regardless of disability, illness, age, income, race, ethnicity, special needs, or situation. Alabama Respite contracted with Alabama Department of Senior Services for a second capacity building grant during an 18 month period ending in January 2014.

♦ Alabama Respite staff participates as our state’s representative to the National Respite Coalition and on state and local committees, which address services related to caregivers.

Alabama Respite staff serves on the National Respite Coalition and as liaison for many state and non-profit agencies that are respite care stakeholders.

• Resources •

Organizational History
www.alabamarespite.org/images/stctoolkitresources/orghistexample.pdf

Building A Case for Respite
www.alabamarespite.org/images/stctoolkitresources/buildingcaseexample.pdf
The section will discuss how to get started with your STC Initiative including organizing your group and recruiting volunteers as well as how to keep your momentum going and ultimately become a sustainable community initiative.

**Getting Started**

*The First Meeting: Information and Organization* - Once you have made the decision to start a STC in your community, you will need to hold an informational/organizational meeting. Make sure you keep a list of caregivers and community stakeholders that you would like to invite to attend the first meeting. Likely you will have already given this some thought when you made the decision to start the initiative. Alabama Respite suggests that prior to the first meeting you take time to make personal visits and phone calls to individuals and groups you want to be represented at that first meeting. To help you consider who you may need to include, check out our “Who Do I Invite” Activity and complete it for yourself. Be sure to get suggestions from others you include about contacts they may have who are interested in participating. We have found that the most successful STC groups are the ones who understand early on the importance of engaging as many key stakeholders as possible. Recruitment is essential not only at this early organizational stage, but throughout the life of your STC initiative. Active, engaged participants are key to your group’s effectiveness and long-term sustainability.

Once you have your invitee list, you are ready for the next steps.

**What Do I Need to Do?**

1. **Find a meeting space and set a date.** You may already have a meeting space available and in mind, but if not, don’t worry. Your friends and potential partners are a great place to start when looking for a
space. Try to keep in mind a location that is easily accessible and convenient to as many caregivers and others you invite as possible. Make sure that you have enough space for everyone to be comfortable and accommodate any presentations or activities you have planned. If you are having trouble finding an appropriate place through your contacts, consider locations that can often be used by the public with as little as a phone call. Public libraries, universities, and other institutions often have meeting rooms available. Ask around, and you may be surprised how easy it is to find the perfect spot.

2. **Write a press release to send to local media outlets** such as newspapers, community calendars, and radio stations. A sample Press Release created by Alabama Respite for one of its initial STC initiatives is available in the Resource section of this chapter.

3. **Send out invitational flyers, e-mails, and make personal invitations whenever possible.** Sample invitations and letters are included in this Toolkit as models, but understand that your STC is unique. You can make your invitations look as simple or as elaborate or decorative as you wish. Also, no invitation, no matter how well-designed, can take the place of a personal phone call or visit when asking for participation.

4. **Be ready to get people motivated!** Door prizes and refreshments never hurt. A trip to your dollar store or dollar section of a department store can open up a lot of ideas for simple door prizes. One Alabama Respite staff member found garden kits at her favorite department store that included a pot, seed, and water-activated soil pod. These ended up not only working as fun and useful door prizes, but allowed her to discuss the parallels of planting a flower or herb seed and watching it grow to that of starting a new STC group. *Door prizes are completely optional. Not having them available does not mean that your group will not be successful.*

5. **Do not forget to have a sign-in sheet** to capture the names and contact information for those attending. A sample sign-in sheet is available for download in the Resource section.

6. **Set the agenda/provide good information.** A sample PowerPoint presentation designed by Alabama Respite staff for one of their STC organizational meetings is available in the Resource section of this chapter. Again, feel free to use this as a model or for ideas, but customize it for use in your community.

7. **Be ready with your action points and schedule the next meeting.** Remember – don’t let your participants leave without knowing what to do next! Alabama Respite staff has learned that one way to hurt the momentum of a new group is to get them very excited about the possibilities of the initiative at the organizational meeting, but then leave them unsure of what they can do right then (while their motivation is high) to move forward. Action points, quick assignments, or to-do lists are great ways to make sure people
connect with the purpose of the initiative and feel empowered to make a difference right away. Once you get started, seeing the outcomes and impact of your work act as motivation to keep going!

8. **Write up the minutes**, including the action steps, as soon as possible after your meetings. Minutes are always more complete when they are written with the information still fresh in your mind and the minds of the other participants. E-mail minutes to everyone on your list and follow-up on any action items due before the next meeting. Send final minutes to entire email list to keep everyone up to date.

9. **One week prior to your next meeting send out an e-mail reminder to everyone.** Call those who do not have e-mail or those you want to be sure to make an extra effort to invite.

• **Being Successful •**

**STC Structure and Leadership** - Your STC will bring together a diverse group of individuals and representatives of organizations who are respite stakeholders. Each brings with them great ideas and hopefully a passion for making a difference for caregivers in your community. That in itself sounds like a great recipe for success. But we have learned that there is another key ingredient that cannot be ignored – LEADERSHIP. Leadership is essential for any initiative to help provide organization and guidance towards group goals and objectives. From the very beginning, your group will need to decide how your STC will be structured and who will lead. There are several options for how this can be accomplished. A few of them are discussed below.

Alabama Respite currently has staff who serve as STC facilitators to help with the organization and leadership for the STC groups in a designated geographic area. The job description and responsibilities for this position can be found in the Resource section. Additionally, each group is expected to have a volunteer who acts as the STC chair. Some groups may choose to have a co-chair for the entire group.

The STC chair will be the person responsible for leading the meetings. A list of tips, "The Chair’s Guide to Meeting Success" is available in the Resource section of this chapter.

Your STC initiative will also need committees to help plan and carry out the activities of the group. This Toolkit includes chapters to help with planning and activities. Alabama Respite recommends that each group form at least two committees – a public awareness and advocacy committee and a resources and education committee. See the Resource

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“Caregivers can greatly benefit from being involved in a community STC group. Not only can they network with other providers, but it provides a platform for them to be able to participate in shared experiences and to help shape the outcomes of everyone involved. Most importantly, caregivers can find some peace of mind in knowing that they are not alone. As a caregiver myself, my spirits are always uplifted when I see the difference that STC members are making in the lives of caregivers and I am proud to be a part of this dedicated group of people.”

—STC Initiative Volunteer and Family Caregiver
section for a sample STC Committee Overview and Interest Form. Each committee will need a chair. We have found that many groups choose to have at least one co-chair on their committees as well. These individuals can work together to organize and carry out the activities planned for that committee.

To help your leaders with their important jobs, Alabama Respite has developed a list of tips available in the Resource section that we have found to be useful over the last several years. We encourage you to add to these tips as you learn from your experience as a STC leader.

• Long Term Success and Sustainability •

Continuity – Alabama Respite and its stakeholders sincerely desire that each community STC be successful in the goals and objectives developed for their unique group and enjoy long term success and sustainability. This Toolkit is intended not only to help start the group and provide guidance, but to be useful in ensuring the continuity of the group. By keeping a binder to hold key information and contacts, the materials in this Toolkit can be copied and used as a basic leadership manual. As new leadership is identified within the group, you will have a way to pass on to them (in the form of your Toolkit and binder) the information and resources they will need to move forward with the important work of the group.

In addition to the continuity provided by use of the Toolkit, the sustainability of your initiative will depend upon several factors, such as ongoing participation of stakeholders, recruitment of new volunteers and leaders, ability to adapt to the needs and changes in your community, collaboration with other organizations, and funding for ongoing activities.

Recruitment – One good source of information about increasing participation for community action initiatives comes from The Community Toolbox. The Community Toolbox has a number of additional resources and articles that you may find helpful for the overall success of your STC group. No one knows more about the needs of your community than the people who live and work there. However, it is important that your membership be representative of the diversity of people who live in your community so you can understand the whole scope of needs and resources.

To find and recruit great volunteers, all members of the STC will need to feel comfortable talking about the purpose of the group and inviting friends and colleagues to join. One way to do this is by developing what many people refer to as an “Elevator Speech” or “Elevator Pitch.” This is essentially a 45 second or less explanation of what STC is and why it is important. Alabama Respite recommends that all STC leadership have an elevator speech prepared and encourage all members of their group to do the same. You may even decide to spend some time at one of your meetings developing and practicing your pitch. Check out the Resource section for links and materials on how to develop your speech and ways to make this a fun group activity.
An elevator speech, or elevator pitch, is a brief way to introduce yourself and tell people about your community’s STC group. These speeches are generally anywhere from 10 to 45 seconds long and can be a useful tool to have ready when you talk to friends, caregivers, providers, and other people in your community about joining and/or supporting the activities of your group. The best part is that it only takes a few minutes to prepare and practice an elevator speech. Then you are always ready to recruit new people for your group! Are you ready to write your elevator speech? Here is how:

1. **Introduce yourself and “drop a hook” to get the listener’s attention.** Ex: “My name is Jane Doe, and I think family caregivers need a break!”
2. **Tell them who the caregivers are.** “Family caregivers provide care in the home to a person of any age who has a disability or chronic illness.”
3. **Tell them why respite is important.** “Respite gives caregivers the break they need to refresh them physically, mentally, and emotionally, so that they can continue to provide great care.”
4. **Say what STC does.** “STC is a group of volunteers who work to make respite resources more available and accessible to caregivers in our community.”
5. **Remember to keep it short and practice it so that it flows and feels natural!**

There are several variations on how you can conduct this activity with your STC group. Try one of these 3 ideas:

**Option #1:** You will need a chart or board to write the speech outline, strips of paper, and pens or pencils.

1. Write the instruction outline for how to develop an elevator speech on a chart. Remember:
   A. Introduce yourself and get your listener’s attention.
   B. Tell them what STC is and what it does.
   C. Tell them who family caregivers are.
   D. Tell them why respite is important. What is the ultimate impact of STC?
2. Have members write each part of their speech on strips of paper.
3. Give them time to rearrange their script strips to create a pitch with which they feel comfortable.
4. Have each member share their “pitch” with the group.
5. The group may provide constructive feedback to help further develop the pitch and give the person delivering the pitch experience that will increase their level of comfort in sharing.
6. Brainstorm together as a group places members could practice delivering their pitch. Who do they want to talk to about STC? What situations may they have during the next few weeks where they could use this pitch?

**Option #2:** You will need a clock or watch with a second hand; Elevator Speech outline; paper; pens or pencils.
1. Have each member develop their own elevator speech/pitch.
2. Break into groups of three members so people can practice and provide feedback to one another about their pitches.
3. Have people rotate and take turns giving their pitches to one another. You will need to time a rotation no longer than one minute for each person.
4. At the end of the exercise each person will have delivered their pitch twice. This is usually enough time for the person to feel comfortable with the speech OR to have a pretty good idea what they want to change about their original message.

Option #3: This activity has participants imagine that they are attending a social event such as a party or reception. You will need the activity sheet/speech outline, a way for people to write their speech, drinks and/or snacks. Members will mingle with one another, delivering their pitches while balancing their food or drink, and working an invitation to join the group into the conversation. This is an especially fun activity to try around holidays, when people will be more likely to have real life opportunities to share in the days and weeks following the meeting.

Volunteer Orientation – As your recruitment efforts pay off, you will continue increasing membership for your STC. This is very important for the vitality and sustainability of the group long-term. Therefore, you will want to make sure all volunteers are welcomed and brought up-to-date quickly on the purpose and activities of the STC. Creating a “Volunteer Orientation Packet” is a great way to make sure that all new and potential members get the information they need consistently and expeditiously. Alabama Respite recommends that leaders create a tab for their Toolkit Binders entitled, “Volunteer Orientation Packet,” where they keep “ready-to-copy” versions of the following documents:

- History of Alabama Lifespan Respite Resource Network®
- The Case for Respite in Alabama
- Establishing a *Sharing the Care*
- Respite Brochures
- Who Are the Caregivers?
- Principles for a Quality Respite Program
- Committees and Descriptions
- Membership and Contact List
- Suggested Activities

Collaboration – Collaboration with other groups that provide services and supports to caregivers and/or persons with disabilities or chronic illnesses, volunteer and information groups, faith organizations, and other community stakeholders are key to the success and sustainability of your STC initiative. Leaders should make a concentrated effort to connect with individuals and groups that have common interests and find innovative ways to work together for maximum impact to benefit the community.

Funding – The amount of funding needed to sustain your STC initiative will depend very much on its scope and structure. Many activities may be easily supported by volunteers, community groups, faith organizations,
or collaborations with other agencies and organizations. However, other STC initiatives may need more substantial funding based on the need for staff time or the type of activities that they plan to carry out. In these cases, many organizations seek grant funding. Grants are often available through community or private foundations, as well as state and national organizations. A variety of information is readily available through books, organizations, and the internet about how to locate funding sources and prepare grant proposals. Many local colleges and universities offer classes on grant writing. These classes are often offered at community centers and public libraries for a small fee. One resource you may find helpful is The Foundation Center at foundationcenter.org.

Conclusion – Starting a STC initiative in your community is an important first step to help meet the needs of the caregivers who live and work there. Managing and sustaining a successful STC initiative is hard work. But through the efforts and dedication of your volunteers and leadership, the possibilities for positive outcomes and change are unlimited. We hope that the information contained in this chapter, and throughout the Toolkit, will help you focus your energy on all of the opportunities that are positive and possible. As Margaret Mead once said, “Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it’s the only thing that ever has.”

• Resources •

Who Can I Invite Activity Sheet
www.alabamarespite.org/images/stctoolkitresources/whocaniinvite_activitysheet.pdf

Sample Press Release
www.alabamarespite.org/images/stctoolkitresources/pressreleaseinitialmeeting_example.pdf

Sample Invite Flyer
www.alabamarespite.org/images/stctoolkitresources/inviteflyer_example.pdf

Sample Invite Letter
www.alabamarespite.org/images/stctoolkitresources/inviteletter_example.pdf

Sample Agenda
www.alabamarespite.org/images/stctoolkitresources/inititalagenda_example.pdf

STC Power Point
www.alabamarespite.org/images/stctoolkitresources/stcpowerpoint_example.pdf

Sign-In Sheet
www.alabamarespite.org/images/stctoolkitresources/stcsigninsheet_example.pdf

Minutes Outline
www.alabamarespite.org/images/stctoolkitresources/minutesoutline_example.pdf

Job Description for STC Facilitator
www.alabamarespite.org/images/stctoolkitresources/stcfacilitatorjobdescription_example.pdf

Responsibilities of STC Chair
www.alabamarespite.org/images/stctoolkitresources/chairresponsibilitiesstc.pdf
Chair’s Guide to Meeting Success
www.alabamarespite.org/images/stctoolkitresources/chairsguidetomeetingsuccess.pdf

Top 10 Tips
www.alabamarespite.org/images/stctoolkitresources/top10tips.pdf

Sample STC Committee Overview
www.alabamarespite.org/images/stctoolkitresources/committeeedscriptions_example.pdf

Volunteer Orientation Packet– History
www.alabamarespite.org/images/stctoolkitresources/orghistexample.pdf

Volunteer Orientation Packet– Case for Respite
www.alabamarespite.org/images/stctoolkitresources/buildingcaseexample.pdf

Volunteer Orientation Packet– Who Are the Caregivers?
www.alabamarespite.org/images/stctoolkitresources/whoarecaregivers.pdf

Volunteer Orientation Packet– Principles for Quality Respite
www.alabamarespite.org/images/stctoolkitresources/qualityrespite.pdf

Volunteer Orientation Packet– Committees and Descriptions
www.alabamarespite.org/images/stctoolkitresources/committeeedscriptions_example.pdf

Volunteer Orientation Packet– Establishing an STC
www.alabamarespite.org/images/stctoolkitresources/establishinganstc.pdf

• Outside Resources •

Community Toolbox –Increasing Participation in Community Initiatives
ctb.ku.edu/en/tablecontents/sub_section_main_1078.aspx

Community Toolbox –Understanding Culture and Diversity in Building Communities
ctb.ku.edu/en/tablecontents/section_1168.aspx
Strategic Planning is the first major activity of your Sharing the Care (STC) group. Now that everyone has come together to meet and focus on the 4 major goals of the STC, it is essential to determine how you are going to work together to address these goals in YOUR COMMUNITY.

To start this process, Alabama Respite has found it useful to have your group complete a Strengths, Weaknesses, Opportunities, and Challenges (SWOC) Analysis of the respite resources and caregiver issues in your community. This section of your STC Toolkit includes a sample of a SWOC analysis based on one completed by the Montgomery Area STC at its first planning meeting in January 2011. While these assessments can be completed in a number of ways, the Montgomery Group met for 2 hours, using a facilitator to take notes and keep the activity on track. The information for the assessment came from members themselves as their roles as caregivers, professionals, and community members made them the “experts” on respite in their community. Remember, no one knows your community like the people who live and work there every day.

Using chart paper and markers, the Montgomery facilitator listed the 4 main goals of the STC and put the chart on the wall. She then placed four additional chart pages on the wall, one for each of the SWOC analysis areas of focus (Strengths, Weaknesses, Challenges, and Opportunities). Members worked together to describe each of these areas as they related to respite in their community. The answers were noted and used to progress to the next part of the planning meeting, which was determining what action steps were needed and identifying activities the group would like to accomplish that address the 4 main objectives of the STC in light of the unique SWOC just completed. Their input in this process became the initial strategic plan for this STC initiative. The document is contained in this Toolkit as an example.

Your STC group may use whatever model or tools for strategic planning you find most helpful. This may vary based on the interest and/or experience of the STC Facilitator or leadership. One model that many community groups have found helpful is MAP-IT. Information about that model is contained within this Toolkit and can be accessed in the Resource section below.

**Resources**

**MAP-IT**
[ctb.ku.edu/en/tablecontents/chapter2_section14_main.aspx](http://ctb.ku.edu/en/tablecontents/chapter2_section14_main.aspx)

**Sample SWOC**
[www.alabamarespite.org/images/stctoolkitresources/swocanalysis_example.pdf](http://www.alabamarespite.org/images/stctoolkitresources/swocanalysis_example.pdf)

**Sample Strategic Plan**
[www.alabamarespite.org/images/stctoolkitresources/strategicplan_example.pdf](http://www.alabamarespite.org/images/stctoolkitresources/strategicplan_example.pdf)
Chapter Four

Activity and Event Guides

• Introduction •

During your STC’s initial planning, you will have identified a number of potential activities and events that the group would like to host. This section will give you some examples of events carried out by STC initiatives throughout Alabama. In addition to the Event Guides, this section also contains information on activities that you may find useful for planning and use during your meetings. As your own STC group plans and hosts events, we hope that you will share your experiences with us at info@alabamarespite.org. Alabama Respite also encourages you to develop your own planning guides and add them to your binder. This will be very helpful when there is a change in leadership or committee members. Activity guides and good notes can help ensure that events hosted by your group are more effective each year.

• Suggested Planning Activity •

Strengths, Weaknesses, Opportunities, and Challenges (SWOC) Analysis

Overview – The SWOC is a guided brainstorming activity that allows members to discuss in-depth what the current status is in the community with regard to caregiver issues. The activity is usually conducted in the second or third meeting of a new STC as the first step in the planning process.

Preparation – As many community members as possible should attend the SWOC analysis activity, because the goal is to get a comprehensive view of what is actually happening in the community. The SWOC activity should be announced during the first meeting so STC participants have the opportunity to invite other colleagues and caregivers. A wide variety of professionals and caregivers should be personally invited to this meeting. The room should be arranged to encourage discussion. Large sheets of paper or a flip chart should be prepared ahead of time with a separate sheet for each category (Strengths, Weaknesses, Opportunities and Challenges). Assign a member ahead of time to write down what is said during the SWOC activity.

Materials:
• Large flip chart or poster boards (4)
• Markers (variety of colors is usually best)

Time: 1.5 to 2 hours (one STC meeting)
Procedure:
1. **Review the Goals of the STC.**
2. **Explain the Activity** – The purpose of the SWOC is to discuss and document what is currently available in your community, gaps or barriers that exist, and issues needing to be addressed. Strengths refer to areas in which your community is doing well in addressing the needs of caregivers. Weaknesses refer to areas in which your community needs to improve in order to more fully address the needs of caregivers, particularly in regards to respite care. Opportunities are external resources in your community that are available for the membership to use in order to meet the needs of caregivers. Challenges are external factors that might hinder your ability to further develop caregiver supports in your community. Giving examples of each area based on your community may be helpful.

3. **Facilitate Discussion** – The role of the facilitator is to keep the discussion going. Facilitator input should be limited and discussion encouraged from group members. The facilitator should lead the group through a discussion of each category. The assigned notetaker will write down what is said on the flip chart, large enough for participants to see what is written. Here are some possible questions to stimulate conversation:

   **Strengths**
   - What programs or services does each of your agencies offer that address caregiver needs?
   - What is going well in terms of addressing caregiver needs in your community?

   **Weaknesses**
   - What are some of the gaps in the services that we have in our community right now?
   - What keeps you from being able to fully meet the needs of caregivers?

   **Opportunities**
   - What partnerships could we develop in the community that would help us address caregiver issues?
   - What resources are we not taking advantage of in our community?

   **Challenges**
   - What do you anticipate keeping our STC from moving forward in meeting caregiver needs?
   - What are factors that will make it difficult for our group to be successful?

4. **Close Discussion** – Close by briefly summarizing the major themes of the discussion and restating that this is the first step in the planning process. The facilitator should provide contact information and encourage participants to send any additional ideas to the leadership after the meeting. The facilitator should state that the information gathered during this activity will be used at the next meeting to develop an initial plan of action.

5. **Write SWOC Report** – The facilitator will write a report listing each of the strengths, weaknesses, opportunities, and challenges discussed during the planning activity. This report will be shared with the group for editing and feedback prior to the next meeting. The final document will be the basis for developing the strategic plan for your STC initiative.
• Suggested Planning Activity •
Brainstorm BINGO

Overview – Brainstorm BINGO is a fun way to engage group members in coming up with ideas for STC group activities or events. This activity can be used in the STC group as a whole or by splitting the group.

Preparation – Make enough copies of the Brainstorm BINGO card for each member to have one.

Materials:
• Brainstorm BINGO card
• Pens/pencils for each member of the group
• Small prize (optional)
• Flip chart
• Markers
• Watch or timer

Time: 40-60 minutes

Procedure:
1. Split the STC into two equal groups. If you have a small group, you may choose to have a single group. If there are two groups, one will focus on Education and Resources and the other will focus on Public Awareness and Advocacy.
2. Start by reviewing the overall goals of Sharing the Care (STC).
3. Give each person a Brainstorm BINGO card and instruct them to put one idea for an event or activity in each square on the card. Give them 5-10 minutes to do this individual brainstorming.
4. The first person to fill up their card gets a small prize.
5. After 10 minutes of individual brainstorming, the facilitator will ask each person to share their favorite activity from their individual list, and the facilitator will write it on the flip chart. The same procedure will be used for their second and third ideas.
6. Have the group select their top three favorite ideas from the compiled list.
7. Ask the group to choose one idea of the three and begin discussing what would be involved in hosting that activity. Use the following questions to prompt discussion:
   A. What would be the main goal?
   B. Who would be the target audience?
   C. Who might be your collaboration partners?
   D. How would you get the word out about this event?
   E. What are some of the tasks you would have to complete in order to get this done?
   F. Are there any important ideas or tips that you would need to consider to do this in the most effective way?
   G. What would it cost in terms of money, time, and personnel?
8. If you have two groups, allow each to share their event or activity with the entire group.
   A. What are some of the barriers you may need to overcome in order to host this event or activity?
   B. What is the interest of the group in supporting this activity?
   C. What plan of action would need to be put into place in order to host the activity?
   D. What is the timeline for the activity if the STC membership decides to move forward?

9. The highest rated activities or events should be incorporated into your strategic plan and referred to the proper committees for action if applicable.

Event Guide
Respite Care Event in Collaboration with Local University

Description – When recruiting volunteers for your STC initiative, we highly recommended reaching out to local colleges and universities – particularly those with programs such as nursing or human services. In the Jefferson/Shelby Counties STC, two representatives from Samford University’s School of Nursing are particularly active and dedicated. As a result, the Education and Resources Committee worked with the University to support some unique respite opportunities for children with special medical needs and their families. The first opportunity sponsored by the University was a Saturday Respite Care Event. The success of this event, coupled with the vision and dedication of the teaching staff and volunteers, led to the development of an amazing week-long camp opportunity called CampUs.

Respite Care Event Example
Samford University, Birmingham, AL

1. Organize as a group to plan and develop a respite event.
2. Find a University that requires students to be involved in volunteering in the community. At Samford the program is called Samford Gives Back. Having employees from the university (faculty/staff) as active members of your STC is very helpful in planning this type of respite event.
3. Work through the coordinator of that program to advertise your event and get student volunteers. Students typically get some type of credit from the university for their service. Helping with the event could also be a specific class requirement for students.
4. Find a location to hold a respite event. If the university has a childcare center, ask if you can use the facility on a Saturday or Sunday (or evening). You could also ask churches or other daycare centers that are off campus (the event does not have to be on campus). Typically, a church, daycare, or university in the area will be a symbol of trust for parents.
5. Decide what age groups and types of disabilities your respite event will serve (we selected children).
6. Decide if siblings are welcome for the respite event. Allowing typically developing siblings is helpful for the caregiver and creates an all-inclusive environment.
7. **Decide how long the respite event will last.** Allow enough time so parents/caregivers can enjoy a meal and a movie, or go shopping, have a pedicure, etc. (3-4 hours is a good time frame to consider).

8. **Create a flyer about the event in order to recruit participants.** Send the flyer to local schools (particularly special education coordinators) if your target age group is children. If your target age group is older, send flyers to organizations that serve the age group you are targeting. Focus on the community where the respite care will take place in order to minimize transportation issues. On the flyer, include contact information for your selected registration coordinator. After the initial contact, if the participant is a good match for the respite event, a registration form can be sent to the caregiver (discussed further below).

9. **Add your respite event to the list of charities/activities available for the university students to select as their service event.** If the university holds a service fair to advertise the different options, be sure to participate and have information about your event. Also have *Sharing the Care* volunteers sign up to serve at the service fair and for the respite event.

10. **Ask the service coordinator with the university to help connect you with faculty from health science education related programs** (such as nursing, PT, OT, speech, pharmacy, social work, special education, etc.), as well as different social or service fraternities/sororities. This will help with some targeted recruitment of interested volunteers.

11. **Decide on enrollment numbers.** Base enrollment on the number of volunteers and the amount of space you have available. The ratio should be at least 1:1. Having a few additional volunteers is helpful for hall monitoring, preparing and delivering snacks, check-in and check-out, etc.

12. **Use nursing care.** If a nurse is available to volunteer for the event, the nurse will be able to provide tube feeding, medication administration, and other related services if a participant needs skilled care during the event. These are the families that typically need respite the most because skilled nursing is a limited option during most events.

13. **Prepare a registration form that can be emailed to interested caregivers to complete and return.** Getting as much information as possible about the participants during the intake/registration process is very important. The forms should ask about diagnoses, medications, nutrition, toileting, behavior, favorite things, allergies, emergency contact information, etc. The registration form can also request a photograph of the participant, which further helps the volunteers to become familiar with the participants before the event. In order to prepare adequately and meet the needs of registered participants, it is typically not a good idea to allow walk-in participants the day of the event.

14. **Once participants are identified, you may need to collect additional information from the caregiver face to face or by phone interview.** You will be able to clarify any information from the registration form and get specific details that might be needed.

15. **Host a training a few days before the respite event.** Provide information about the registered participants, the schedule, the activities, and other important details, to the volunteers. Give a general overview about what to expect. Discuss basic disability training (such as people first language, behavior management, safety, respect, etc.). Emphasize safety as a top priority. Provide information about each primary diagnosis/disability. Allow volunteers to sign up for certain duties and areas (activities or age group). You might also want to
match participants and volunteers (or let them select), so they know who they are responsible for ahead of time.

16. **A week or more before the event email instructions and forms to parents/caregivers** (including directions, the schedule, and forms).

**Forms to Sign** – Have parents/caregivers sign a medical waiver/legal waiver form, as well as a photo release form if pictures will be taken during the event. You can distribute these ahead of time and have caregivers bring the forms to check-in, or you can wait and have caregivers sign forms at check-in.

**Optional** – Prior to the event, and depending on the space available, divide the registered participants into groups, based on age, abilities, space or other criteria determined by the STC. This keeps the group sizes manageable and helps reduce chaos during check-in/check-out time.

17. **At check-in, have at least 2-3 people working the check-in desk** to have forms signed (that are not already signed) and to place nametags on the children and their belongings. Have additional volunteers assigned to walk the families to their room. Allow parents/caregivers to stay and meet the volunteers and give any additional instructions. Family caregivers need to feel comfortable before leaving their loved one. Have a check-in and check-out sheet with at least time, date, and signature. Have the caregiver specify at check-in who will pick up the participant at the end of the event. You can assign numbers, tickets, bracelets, or other methods to match caregivers and participants if you have a large number of participants.

18. **Have a schedule prepared** (crafts, games, snack, story time, etc). However, know that some participants will not want to participate in all scheduled activities, so flexibility is necessary. Having the 1:1 ratio is important so that supervision and attention is available when a participant is not tolerating the planned activity or needs a break or change.

19. **Throughout the event, maintain safety as the top priority.** Have hall and door monitors to ensure that no one leaves or enters the facility without permission. Have someone responsible for checking food and environmental allergies that may affect participants’ safety during snack/mealtimes or activities.
**Overview** – The Tuscaloosa STC determined during their SWOC Analysis that a community strength was the expertise represented by their membership’s expertise, covering a number of topics, particularly related to the care of persons with disabilities, chronic illness, Alzheimer’s, and other memory disorders. A weakness identified was the lack of qualified respite care workers and volunteers to assist family caregivers with those individuals, as well as a need for family caregivers themselves to be trained in care provision. Therefore, Alabama Respite and the members of the STC partnered with Caring Days Adult Day Program to sponsor a two day training class designed to give family caregivers information about how to improve their ability to provide care to loved ones at home. Potential respite workers or sitters were trained to acquire skills and insight to better provide temporary care in order to give caregivers a break. Participants were charged $30 to help cover the cost of materials for the classes. Additional sponsors for the event came from the STC membership, including a local hospice organization and the local office of the Alabama Cooperative Extension System.

The training featured 10 sessions conducted over the two-day period. Each session was taught by an expert on a given topic, recruited through the STC membership and its collaborating organizations. At the end of the training, participants were requested to complete a program evaluation that asked for specific feedback on each session presented. The event was rated “Excellent” overall.

**List of Session Topics:**
- Understanding Memory Disorders
- Managing Behaviors
- Until Help Arrives
- Personal Hygiene
- Nutrition
- Feeding
- Physical Management
- Safety in the Home
- Activities
- Ethical Behavior in Someone’s Home: The Business of Being a Caregiver

**Description** – In August 2013, the Jefferson/Shelby Counties STC hosted their 4th Annual Legislative Event. This year’s event was entitled, “Connecting Awareness, Resources, and Relief.”

The purpose of this event was to educate local legislators, family caregivers, and community stakeholders from Jefferson and Shelby Counties about the numerous resources available to assist caregivers and give participants an opportunity to connect with policymakers. This year’s event had two major components, a health and resource fair with tables sponsored by local providers and a legislative education and advocacy discussion facilitated by the STC group volunteers.

“What makes this event successful is team work. The legislators who attend always want to come again, because they have the opportunity to interact with their constituents. It’s not just a speaking event, there is meaningful interaction.”

—Jefferson/Shelby County STC Member
During the event, discussions were led on the following topics: Funding, Gaps in Service, Respite, Stress and Burnout, and Transitioning of Services through the Lifespan. The discussions took place at round tables throughout the auditorium. Each table of caregivers, community stakeholders, and providers hosted a legislator with a STC member assigned to facilitate. After the discussions, the legislators were asked to participate in a panel discussion and state what they learned or what was discussed at their table. After the panel discussion, the floor was opened to questions or comments. Vendors and other stakeholders were available throughout the auditorium to share information with caregivers.

Planning Tips – The Public Awareness subcommittee of Sharing the Care Jefferson/Shelby Counties began meeting in May to plan this year’s event — their fourth annual. Many members of the committee have been involved since the first event. The involved members have learned what works well and how to improve each year. During the third year, the committee decided to hold table discussions in order to increase interaction between policymakers and attendees. This format has received the most positive feedback and maximizes the impact of the event.

The subcommittee met monthly until August before increasing the meetings to bi-weekly. The event activities were divided into categories: program, food, decorations, and invitations. Event sponsors were asked to provide refreshments. Each member of the subcommittee had a responsibility and was required to personally invite legislators to the event. Evaluations were collected from each participant at the conclusion of the event. The input received helped the staff and committee members plan for the next event.

**Event Guide • Faith Community Outreach**

**Description** – One theme that repeatedly emerges from the strategic planning process of many of our STC groups is the opportunity available for faith communities to reach out to caregivers through the use of respite and caregiver support ministries. In order to take advantage of that opportunity, many of the local STCs have held events that specifically reach out to local faith communities in order to make them aware of the needs of family caregivers, let them know ways they can help, and offer assistance in getting new programs started. Please see the information and materials available in our faith-based mini-module for examples of information to share with faith congregations in your own area.

“It [the Legislative Brunch] was an outstanding workshop, and the exposure and heightened awareness calls people to rethink the way we are doing things [respite and caregiver supports]. It is going to have to change because baby boomers are not going to settle for current status quo.”

—Alabama State Senator Linda Coleman
Checklist and Planning Tips:
Step 1: Decision to hold event.
Step 2: Identify planning committee and leaders.
Step 3: Determine format.
Step 4: Determine date, time, and location for event.
Step 5: Gather necessary supplies, support, and funding to carry out event as determined by planning committee.
Step 6: Advertisement and registration process for attendees.
Step 7: Attendance and follow-through.

Sample Format for Faith-Based Outreach Event:
• Register attendees and hand out materials
• Welcome
• PowerPoint Presentation
• Short (3-5 minute) presentation from a person involved in a local faith-based respite program
• Question and answer time
• Fellowship and arrangement for follow-up meetings and/or activities

• Event Guide •
Caregiver Advocacy Workshop

Overview - The Mobile Area STC determined there was a great need for advocacy and education about respite and the needs of caregivers in their community. However, many of the caregivers and other stakeholders involved as STC volunteers felt that they lacked the skills and confidence to be effective advocates. Several of the caregivers had attended advocacy training numerous times in the past, but reported leaving these trainings often feeling like they had wasted their time or were uncertain of the next step to take. In order to address these needs, STC members invited a number of caregivers and service providers to a meeting in which they shared their ideas on what worked well and what did not in previous trainings attended. Caregivers also shared what they felt was needed in order to feel prepared and confident in developing and using advocacy skills learned. Ultimately, caregivers reported that in order to maximize their effectiveness and the likelihood of following through with learned advocacy activities, they needed training in specific skills such as developing individual advocacy messages and contacting policymakers. However, the caregivers also needed a step-by-step plan that allowed them to work from strengths and follow-through with the support of a partner or group of people with similar interests.

Be sure to reach out to your local faith communities, missions groups, and Parrish Nursing Programs as you begin planning for this outreach event. One of these groups may be willing to provide a location for the event and/or other supports such as refreshments, help with publicity or event volunteers.
The STC leadership then moved forward in planning a series of workshops and events to enable caregivers to gain the maximum level of advocacy skills, confidence, and effectiveness. The primary purpose of the first workshop held was to assist family caregivers in developing their individual stories and advocacy messages. One of the tools used to facilitate message development was the “Telling Your Story” application (app) from Partners in Policymaking. The app is available on IOS and Kindle Fire formats free of charge. Participants with their own devices were encouraged to load the program prior to the workshop and bring the device with them. Alabama Respite collaborated with the Technology for Special Consumers (T.A.S.C.) program at United Cerebral Palsy (UCP) of Huntsville in order to borrow additional devices, including iPads and a Kindle Fire® for participants to use. T.A.S.C. also provided an attachment that allowed the facilitator to project the images on screen to explain how the program worked. Participants were e-mailed a link to Partners in Policymaking’s FREE advocacy web course prior to the event. Many of the caregivers went through the course prior to the workshop and reported they found the information presented to be very helpful in preparing for their next steps.

After introductions and review of advocacy tools and resources, participants worked in groups to develop their individual advocacy messages. The group format allowed them to receive feedback and experience pitching the messages.

During and after lunch, participants brainstormed concrete ways to put their messages into action. These “Next Steps” were recorded by the facilitator on a flip chart and incorporated into a plan for future activities and events centered on advocacy and education.

A sample of the next steps identified included: continuing to work individually and as a group to develop and practice advocacy and education messages; planning and attending a legislative forum to give participants an opportunity to deliver their messages at a group-supported event; creating a “buddy system” to visit legislators with a friend using a similar message to allow the caregiver to be able to feel more comfortable and supported; developing a “Caregivers of South Alabama” storybook that collects the advocacy and education messages of caregivers in Mobile and Baldwin Counties to share with policymakers and other stakeholders in the community; and teaming up with others in this group to do presentations and speaking engagements to groups throughout the community. Accomplish the group public awareness activity mentioned above by targeting service groups, churches, and other types of groups. The STC member or individual caregivers can make a list of groups which might be interested in having a speaker.

Participants were asked to complete an evaluation at the end of the event. Results were entered into surveymonkey.com and analyzed. In summary: 100% of participants would recommend this training to a friend. 100% said that as a result of the training, they feel like they are more likely to advocate for caregiver needs. Overall, 100% of participants rated the workshop as “good” or “excellent.”

Immediately following the workshop, attendees received a copy of the “Next Steps” developed at the meeting and were contacted by the STC facilitator to attend the next work meeting to practice their advocacy messages. The leadership also worked to collaborate with other local non-profits and the League of Women Voters to participate in a Legislative Forum.
Description
One of the events sponsored by the Montgomery Area *Sharing the Care* (STC) was a Family Caregiver Forum. In the initial strategic planning meetings for the group, numerous needs and opportunities were identified. In order to prioritize those needs and opportunities, the group decided to hear directly from a cross-section of family caregivers in the community, many of whom were unable to attend the group meetings previously held due to their caregiving obligations. STC members worked together to: plan the format, select a location to host the event, identify and recruit caregivers from across the lifespan and disability diagnoses to act as panelists for the event, develop the forum questions, and advertise and provide necessary supports for the event. The forum was a successful event with very positive feedback from panelists, other caregivers in attendance, and the STC volunteers. The information shared by participants in the forum was used to set the Montgomery STC agenda for the year.

Checklist and Planning Tips:
Step 1: Decision to hold event.
Step 2: Identify planning committee and leaders.
Step 3: Determine questions, format, and panelists.
Step 4: Determine date, time, and location for event.
Step 5: Gather necessary supplies, support, and funding to carry out event as planned by the committee.
Step 6: Advertisement and registration process for attendees.
Step 7: Attendance and follow-through.

Sample Panel Questions from Event:
- What is your name? For whom do you care?
- What is a typical day like in your home?
- What services and supports do you receive? What kind of supports do you need?
- Through your contacts with different service organizations, agencies, or other groups to which you belong? Has anyone ever talked to you about respite care?
- Have you ever used respite care in order to take a short break from your caregiving duties?
- What kind of respite services have you used? In-home? Out of home? Voucher respite?
- What was your experience using that service?
- What are some of the things that someone else could do for you as a caregiver that would take some of the load off of you? Mow the yard once a week? Cook and deliver a meal to you? Help with grocery shopping or errands? Call to check in on you?
- What kind of respite options would you most like to see developed in our area?
- How do you feel caregiving has affected your own health and well-being?
- Are there people in your family or support circle on which you can count? Who are they? Do you feel comfortable asking them for help?
• Resources •

Brainstorm Bingo Card
www.alabamarespite.org/images/stctoolkitresources/brainstormbingo_activitysheet.pdf

Link to an article written by a person attending the event:
www.al.com/opinion/index.ssf/2013/08/opinion_from_kathy_hollowell_u.html
Advocacy is one of the core objectives of a STC initiative. Remember that your STC volunteers represent a grassroots initiative of family caregivers and other respite stakeholders who share a vision about the types of support that need to be available and accessible within their community for caregivers of persons across the lifespan and across disability or chronic illness diagnoses. This group will work together to educate the community and policymakers about the need for respite and caregiver supports, and advocate for meaningful systems change.

In order to accomplish these goals, members of your STC and caregivers throughout the community will need to acquire key advocacy skills, and have an opportunity to put those skills into practice. The Activity and Event Guides section of this Toolkit will provide you with a few examples of activities that your STC can host to facilitate advocacy and systems change goals. However, your group may have other ideas and activities that you would like to support, and we at Alabama Respite encourage you to do so! Our staff members have been involved in advocacy and education with policymakers since Alabama Respite’s earliest days, and we know that there is still much work to be done. Many policymakers are still unaware of the number of family caregivers represented in their district, the important role they play, or the need for respite and other essential caregiver supports. In fact, many policymakers and members of the community at large have no idea what the word RESpite even means. As we have heard many times – “I am not sure exactly what respite means – but I know I need a break!”

The purpose of this section is to provide you with some key documents and tools that you can share with members of your STC initiative. We hope that you will find them to be useful as you move forward with your advocacy objectives. If you locate additional tools or documents that you find important in your work, add them to your binder for this section. Also, let us know what worked well for your group by e-mailing us at info@alabamarespite.org.

Setting the Stage and Presenting the Facts

As mentioned previously, one of the largest barriers to effective advocacy when it comes to respite and family caregiving is a basic lack of education and awareness. Therefore, one of the very first steps you will need to take is to develop a list of facts and talking points. ARCH, the national respite organization, has some good information available at www.archrespite.org.

In addition to your general facts and talking points, it will be important to show the impact of the statistics and give them a personal face – connect them with real people who live and work in your community. In order to do this, we recommend that members of the STC each develop their story and advocacy message. The activity guide has information about a STC sponsored workshop that focused on this step using tools available from Partners in Policymaking. Your group may have other tools or ideas for developing an advocacy message. Whichever method you find to be the most helpful is fine. The important thing is that the message is succinct, personal, and powerful, and that the person delivering it feels comfortable and confident. This will come with practice and encouragement.
• Know Your Audience •

Once advocates have their talking points and message developed, it is time to get to work delivering it. But who should they deliver it to? Advocates need to know who their policymakers are and how to contact them. In Alabama, individuals can look up their state representatives by entering their zip code on the legislative website. The legislative site also has links where you may find current district maps for the state house and senate, as well as your U.S. congressmen. Many communities have information available through their county commission or chamber of commerce. Alabama Respite recommends that a STC leader print a list of the policymakers who cover your area (national, state, and local) with their contact information and place it behind a tab in your binder. This will become an important document to reference and a valuable handout at your advocacy trainings and events.

Personal relationships are key to effective advocacy. You must work to get to know your policymakers. Visit or call them and get to know members of their staff by name. When they think about caregiver issues and respite in their area, you want them to think about you. As a STC leader or volunteer advocate, you will be an expert on respite issues in your community!

For more tips on developing positive relationships with your policymakers and becoming an advocate, download “Becoming an Advocate: Seven Keys for Effective Legislative Advocacy.” This document was developed by Alabama Respite staff from a publication written by Nebraska Senator Dennis Byars. Additionally, Alabama Respite staff developed a “Guide for Effective Communication with Your State and Congressional Leaders” (page 29) that has several good tips for calling and meeting with your legislator.

Many times, we have found that caregivers and other members of the STC initiatives like to see example letter outlines or have some direction on what to say if they e-mail or call a policymaker. Hopefully having developed their advocacy message will help them to know what to say. However, sometimes people can be intimidated by not knowing the forms or procedures they need to follow in order to contact a policymaker. In those cases, you may find it helpful to share examples such as these:

- Sample letter outline from self-advocate
- Sample letter outline from provider
- Call to action – phone call

• Specific Issues •

At times, your STC group may find the need to rally advocacy support around a very specific issue. For example, one of Alabama Respite’s most popular programs is a voucher respite program that allows family caregivers to self-direct their funding and hire a respite provider of their choice. In recent years, budget cutbacks have threatened to eliminate or severely reduce that program – much to the disappointment of many of our caregivers. As a result, Alabama Respite and the STC initiatives sent e-mails and letters to people who had received vouchers in the past, asking them to help us advocate for continued funding of the program. To help get as many responses as possible, we provided them with a basic outline of what we wanted them to share with our policymakers.

Alabama Respite and its staff wish you and your STC initiative volunteers much success in your advocacy efforts. With organization, dedication, and perseverance, you will have a positive impact for caregivers in your
community and your state. Remember, “If you think that you are too small to have an impact, try going to bed with a mosquito in the room.”

• Resources •

Developing Grassroots in Your Community
www.alabamarespite.org/images/stctoolkitresources/developinggrassrootsadvocacy.pdf

Seven Keys to Legislative Advocacy
www.alabamarespite.org/images/stctoolkitresources/7keysadvocacy.pdf

Guide for Effective Communication with Your State and Congressional Leaders
www.alabamarespite.org/images/stctoolkitresources/effectivecommunicationadvocacy.pdf

Legislative Letter Outline
www.alabamarespite.org/images/stctoolkitresources/letterstolegislatorsoutlineadvocacy.pdf

Sample Letter from Family Member/Self-Advocate
www.alabamarespite.org/images/stctoolkitresources/letteroutlinefamilymemberadvocacy.pdf

Sample Letter from Provider
www.alabamarespite.org/images/stctoolkitresources/letteroutlinelprovideradvocacy.pdf

Call to Action
www.alabamarespite.org/images/stctoolkitresources/calltoaction.pdf

E-mail for Support

Letter Asking for Support
www.alabamarespite.org/images/stctoolkitresources/caregiverrequestletteradvocacy.pdf
Public Awareness is one of the four core objectives of STC initiatives, and is key to maximizing solutions for solving the gaps and barriers caregivers encounter when seeking respite services and caregiver support. If key stakeholders, policymakers, and the public are unaware of the issues of caregiving and respite, then they are unlikely to act towards creating additional resources in the community. The activity and event guide section of this Toolkit offers several suggestions for events that can be hosted to promote awareness of respite and caregiving issues. However, those suggestions are only a start.

There are numerous things that your STC initiative can support to promote public awareness year-round. STCs are also encouraged to plan at least one major public awareness event each November in recognition of National Family Caregiver Month and Respite Awareness Month in Alabama. Alabama Respite and its STC initiatives have hosted a number of events over the years to spotlight Awareness month, including local outreach events, press conferences, and statewide educational and legislative events. In 2010, Alabama Respite was able to host an awareness event that featured both of the current gubernatorial candidates in Alabama, each speaking about their own experiences with caregiving. This event was very exciting, especially considering that it took place only days before the general election. Additionally, the Governor issues a proclamation each year in recognition of Respite Awareness Month.

Public awareness events are a great way to reach out to your community and spread awareness about respite and caregiver support needs. When considering the opportunities available in your community, you will need to look at all of the media sources noted below.

Media Sources

To locate individuals who may have an interest in working with your STC to promote its efforts, several media sources that may be useful are: print, television, radio and social media. With these sources, always begin at the grassroots, local level.

Distribute your informational brochures and flyers:

- **Chamber of Commerce**
- **Local Libraries**
- **Doctor and Dentist Offices**
- **Schools**
- **Local Magazines** – Most communities have local magazines that highlight hometown activities and organizations. Be sure to contact magazines that cover all age groups since respite and caregiving are lifespan topics.
• **Newspapers** – Identify the writer for the “Local Area” section. Find out if there is a “Health Section” and contact that writer. Write an Op Ed piece and submit for publication. Many times, particularly in small towns, you may meet with the Editor of the local paper. Your STC initiative may even be interested in creating a “Letter to the Editor” campaign.

• **Newsletters** – Oftentimes members of the local STC group are associated with organizations and agencies that produce newsletters. Church newsletters could have a great impact on getting the word out about STC. These newsletters may be online, print, or both.

• **Radio** – Almost every town has a radio station that needs information to fill air space. Public Service Announcements (PSAs) can be produced and given to the station for airing. Some stations also have talk shows that are looking for topics to present. These are particularly effective in reaching rural residents who could benefit from an event you are planning. Check the yellow pages for listings of stations, or ask the local Chamber of Commerce for contact information.

• **Television** – As with radio, even small towns may have local TV stations that are willing to run a PSA. Some have local talk shows that will allow you to present information about your program or an upcoming event. Cable networks almost always have one station devoted to local news and information. Check yellow pages for local listings.

• **Social Media** – In today’s world, nearly all organizations have a website, or at least access to the internet and social media websites such as Facebook, Twitter, Pinterest, and Instagram. Posting information on these sites gets your message out immediately to an audience of people who are interested enough in your topic to follow you and allows them to share that information with their own networks. There is something very exciting about the potential for one of your messages to go “viral” and reach more people than you ever imagined. Best of all, these formats are free to use.

• **Digital or Traditional Billboards** – Some agencies are given billboard space as a public service. Investigate the potential of partnering with those organizations to produce a message that will benefit you both.

• **Additional Resources and Links**

As your STC initiative works to promote awareness of respite and caregiver issues, you may need some additional tips and information on topics such as creating a communication plan, developing a press release, or arranging a feature story. Below are links to comprehensive information on each of those topics from healthypeople.gov and The Community Toolbox, as well as a photo release. Make sure that you have written permission before including any information or image of a caregiver or volunteer involved with your STC initiative before submitting to any media source, including your own website or social media accounts.

• **Photo Release**
• **Communication Plan Template**
• **Arranging News and Feature Stories**
• **Preparing Press Releases**
• **Example of News Story from Alabama Respite**
• Resources •

Link to website on National Family Caregiver Awareness Month
caregiveraction.org/national-family-caregiver-month/

Governor’s Proclamation
www.alabamarespite.org/images/stctoolkitresources/governorproclamation_example.pdf

Photo Release
www.alabamarespite.org/images/stctoolkitresources/photorelease_example.pdf

News Article Example
www.alabamarespite.org/images/stctoolkitresources/storyonstcexpansion_example.pdf
A Faith-Based Respite Network

• Introduction •

An estimated 31% of households in the United States are involved in caregiving at any given time. In Alabama, that translates to 1,463,221 Alabamians providing full-time care for a loved one in their home. A 2013 Pew research report estimates that 39% of the population will provide care for a loved one at some point during the year. There are many caregivers in your family, neighborhood and faith community. For those individuals, caregiving can be a very rewarding experience, but it can also be mentally, physically, emotionally, and financially stressful.

Fortunately, there are many ways that the faith community can help. One key way that congregations can get involved is through respite. **Respite is temporary relief for family caregivers who are caring for an individual of any age who has disabilities or chronic/terminal illnesses.**

**Benefits of Respite** – Research demonstrates that respite has a number of benefits for both the caregiver and the care recipient. Respite reduces the stress and fatigue associated with caring for a family member. When the caregiver is refreshed, his or her attitude improves toward the care recipient and the overall functioning of the family unit improves. The improved attitude and family functioning that comes with a short break helps prevent unintentional abuse and neglect.

Caregivers are more likely than the general population to experience health problems of their own. Stress and the physical demands of caregiving are often the root cause of these problems. Respite provides an opportunity for caregivers to address their own health and well-being. This allows the caregiver to continue providing care for a loved one in their home for a longer period of time, and delays out-of-home placement in a medical facility.

**Why the Faith Community?** The number of family caregivers and the need for quality respite care in our state is significant. However, current resources are limited, expensive and often difficult to access. Caregiving families are often so focused on the task of providing around-the-clock care that they become isolated. Often, families drop out of the faith community at the time when support is most needed.

A respite ministry can be a great way to bring caregivers back into the faith community and demonstrate a commitment to supporting them. Faith-based groups may already have a foundation of trust within their community, and this can give caregivers reassurance that their loved ones will be properly cared for in their absence. Involvement in a respite ministry often gives church members a new-found awareness of the barriers that people with disabilities or health issues face that prevent them from fully participating in the congregation. With this understanding comes the possibility of a more inclusive community that is welcoming to people with special needs and their families. These families are thus able to participate more fully and feel a sense of belonging.

Faith communities have a lot to offer in terms of their capacity to provide respite and caregiver support. Limited resources are available for respite programs. Faith communities already have many of the resources that are needed. Availability of facilities, stability of finances, and a wealth of volunteers make faith communities a good option for
respite programs. Most likely congregants provide a source of untapped talents that can be put to good use through a respite ministry. Starting a respite program need not be expensive.

This faith-based guide will provide your faith community with some tools to begin a caregiver ministry and/or a respite ministry. Alabama Respite is committed to working alongside your faith community and providing the assistance, training and encouragement needed to develop and sustain a ministry of this type. Please contact Alabama Respite at (256) 859-4900 to learn more!

What Can Our Congregation Do Right Now?

• Teach caregivers that they may be on a long journey. Encourage them to take a break as they continue.
• Surround them with support before a crisis!
• Encourage them to ask for help from family, friends, and their faith community.
• Call the caregivers in your congregation and listen to their concerns.
• Ask caregivers how you can help.
• Look at how your current ministries can be adapted to include caregivers.
• Create a “respite fund” from which caregivers can draw to pay for respite.
• Make accommodations to include the caregiver and their loved one in church activities.
• Prepare a list of ways to help out with everyday activities that can be difficult for caregivers to find time or energy to do. Volunteer to assist the caregiver with these activities.

• Starting a Faith-Based Caregiver Ministry •

1. Start with your own congregation.
   A. There may be caregivers in your congregation that you do not even know about!
   B. Be sure to follow up with members who have stopped coming to church. Often, caregivers who have been consistent members of the faith community drop out when a loved one becomes ill or disabled.

2. Let the caregivers tell you what they need.
   A. You can speak personally with caregivers or use a questionnaire to determine what caregivers need and want in a caregiver ministry.
   B. A church meeting or forum is another way to find out what caregivers need.

3. Look for ways to link new caregiver ministries with programs you already have.
   A. A caregiver program can be a natural extension of ministries such as visitation or special needs ministries the church is already doing.
   B. Volunteers who are already working with these programs may also be interested in caregiver needs as well.

4. Find out what others are doing for caregivers in your community.
   A. Speak to other churches about what kind of programs they offer for caregivers. You may be able to partner with other churches to recruit a larger group of volunteers.
   B. Speak to community organizations that may be involved in caring for caregivers. There may be an opportunity to reach out to individuals outside your church who are being served by these organizations!
5. Educate your faith community about caregiving and caregiver needs.
   A. Use bulletins and newsletters to share information about caregivers and their needs.
   B. Have a special prayer or service for caregivers.
   C. Allow caregivers to speak about their caregiving experiences.
   D. Provide a resource table with information about caregiving.

6. Prioritize.
   A. You will likely feel overwhelmed with the needs you find within your community.
   B. Choose two or three small goals to work towards.
   C. Start with something that you know can be done with your current time, volunteer base, and resources.

If you would like more information about how to get started with a faith-based caregiver support program, please contact Alabama Respite by e-mail at info@alabamarespite.org or call (256) 859-4900.

Caring Days is a day program for adults with Alzheimer’s and other memory disorders, located in Tuscaloosa, AL. It is a program of Caring Congregations. Clients attending the program participate in specially designed activities to encourage the continued use of social, language, motor and cognitive skills. The goal of Caring Days is to provide quality of life to all clients by making sure they laugh and smile each day.

In 1994, members of the local First Presbyterian Church recognized the need for adult day care for those experiencing memory loss. Currently, 23 congregations of various denominations work together to provide this program. They incorporated into a group called Caring Congregations. Their first project, Caring Days Adult Day Care, opened on March 10, 1997.

In 1998, Caring Days won the prestigious LOTUS Award. This award is presented annually by the Women’s Committee of Spain Rehabilitation Center in Birmingham, Alabama. It is given in recognition of outstanding contributions toward improving quality of life for people with disabilities. In 2000, Caring Days proudly became an agency of United Way of West Alabama.

In October 2012, Caring Days moved into their new Mal and Charlotte Moore Center—a specially designed facility that allows for plenty of room to accommodate individuals of various levels of ability and offers activities such as art therapy. On a typical day, the program serves an average of 25-32 individuals—and 52 total individuals throughout the month.

For more information or to let them know you would like to support the program, please contact Vicki Kerr at (205)752-6840.

www.caringdays.org
www.facebook.com/caringdaysadultdaycare
• Faith-Based Respite Planning Guide •

Step 1: Educate

The first step in the planning process is to educate your congregation about caregiving and the need for respite. Do not assume that your congregation is knowledgeable about the needs of caregivers. Alabama Respite has found that many who care for a loved one in their home do not identify themselves as “caregivers” until someone points out that they serve in that role. Here are several ways you can provide education about respite:

- Provide educational materials, such as brochures or rack cards to your congregation (available through Alabama Respite).
- Include a series of articles on caregiving in your newsletter/bulletin.
- Have a caregiver service or prayer.
- Have a guest speaker at your worship service – please contact Alabama Respite if you would like to request a speaker.
- Have a caregiver from your own congregation share about how caregiving has affected his/her faith journey.

Step 2: Establish an Advisory Board/Group

Often educational activities within your congregation will spark an interest among members about caregiver issues. As interest develops within your congregation, it is a good idea to establish an advisory board or committee that will work on these issues. This group will be responsible for the rest of the planning process. Here are some ideas about individuals who should be invited:

- Caregivers in your congregation
- Care providers in your community
- Lay leadership – Lead member of your outreach team, disability coordinator, etc.
- Clergy – In situations where there are multiple clergy, you should ask who the appropriate clergy is for that particular ministry
- Disability professionals
- Caregivers in your community
- Clergy from other churches
- Members of Alabama respite or your local Sharing the Care

Sharing the Care (STC) is a community initiative that brings together a group of volunteer community stakeholders whose goal is to strengthen caregivers by increasing the availability and accessibility to local respite resources. Activities of STC groups include public awareness, training, technical assistance, and resource development. Currently numerous STC groups are active in Alabama. Please contact Alabama Respite at info@alabamarespite.org if you are interested in becoming involved!
Step 3: Assess Needs and Assets

Your advisory committee should take the lead in assessing the needs of caregivers that you expect to serve. This committee will need to decide whether the program will be primarily for current members of the faith community or will include the community at large. If you will only be addressing caregivers in your congregation, the needs and assets assessment should focus on identifying caregivers in your congregation and determining their needs. Assess the needs and assets of caregivers within your faith community and/or your community at large (depending on the intended scope of your program).

First, you should identify caregivers in your congregation (or community). Members of the board may be able to brainstorm and develop a list of known caregivers in the congregation. Remember to include those who are homebound or have left your congregation because of the demands of caregiving.

**Needs:** A questionnaire or interview format may be used to assess the needs of caregivers. Alabama Respite or the local STC can assist in locating or developing instruments that fit the needs of your congregation.

**Assets:** Determine what caregiver supports already exist within your community. Contact other churches and ask what they are doing for caregivers. There may be an opportunity to partner to assist more caregivers. Also contact local non-profit organizations that work with caregivers to determine what resources they may be able to offer.

Step 4: Develop a Plan

Once you have determined the needs and assets of your congregation/community, it is time to set priorities and make decisions. Identified needs and assets should be the basis of your plan. If you would like assistance in planning your program, please contact Alabama Respite at (256) 859-4900.

The advisory board should make a detailed plan that addresses the following questions:

- **Who will be your target population?** Adults, children or both
- **Types or severity of disability or chronic illnesses.** Do you plan to serve people with physical or cognitive impairments? Specific disabilities such as Alzheimer’s or Autism?
- **What are your priorities?** Choose one or two priorities based on assessment and then set one to three goals.
- **How will you measure success?**
- **What type of program will you have?** Examples include drop-off respite nights, benevolence funding, voucher programs, adopt-a-family programs, and in-home respite.
- **How will your program be funded?** Initial funding to get it started, on-going funding to ensure the program continues.
- **How will volunteers be recruited and coordinated?**
- **What training will be required of volunteers?**
- **What documentation will be needed?**
- **Who will develop this documentation and how will it be developed?**
- **Who will be responsible for each aspect of the program?** Write each aspect out in detail to ensure everyone knows what is expected.
- **What other faith communities or organizations would you consider if developing a partnership?**
- **What will each partner’s specific role be?**
Aaron’s Staff is a non-profit organization dedicated to providing respite for parents and guardians who have children with special needs. The ministry is made up of volunteers from area churches, schools and individuals who give of their time to provide quality care for the children and their siblings while the parents take time for themselves. Their mission is to help “lift the load” and meet the needs of the family on a physical, emotional and spiritual basis.

The founders of Aaron’s Staff, Rhoda and Tim Trimble, can identify with the parents and guardians of these children. For 27 years, they took care of their son Aaron, who was the first of their five children and had cerebral palsy. They faced many challenges, one of which was difficulty in obtaining rest. For years they dreamed of being able to help families in similar situations. In March 2010, the foundation for Aaron’s Staff was set in motion and the ministry was launched in June of that same year. The ministry has grown by leaps and bounds over the past three years and is making plans to expand their services more in the future.

On a typical respite night, parents and family caregivers enjoy a much needed evening out, while their children and siblings enjoy an evening of fun with their peers and are encouraged to participate in activities according to their individual abilities. Activities include arts and crafts, music therapy, pet therapy, story time, movies, and much more. Care is provided for children from infancy to age 21 with a wide variety of disabilities, including Autism, Cerebral Palsy, Cystic Fibrosis, seizure disorders, Spina Bifida, Traumatic Brain Injury (TBI), and visual or hearing impairments. Meals and snacks are provided at the events, donated courtesy of various local restaurants. Aaron’s Staff does not charge families any fee for their services, but reservations are required. These can be made on their website or by calling and reserving a spot.

Aaron’s Staff currently provides respite care one evening a month. They hope to someday be able to provide counseling services (which are now available on a limited basis), small group support, summer day care (which began on a one day basis in 2011) and a year-round daily program. Their personnel are thoroughly trained, CPR certified, and have completed an application, interview process, and cleared criminal background checks. Medical personnel are also on site at each respite night event.

aaronsstaffrespite.org
www.facebook.com/pages/Aarons-Staff-Respite-Care-Ministry/112969048765341

Video:

Windows: video1.adph.state.al.us/alphtn/tapings/Respite/RespiteV3.wmv.asx
Real Player: video1.adph.state.al.us/alphtn/tapings/Respite/RespiteV3.ram
The options for respite ministry are as varied as the congregations themselves. Alabama Respite is willing to work with you to determine what type of ministry will work best for your congregation and the specific needs of your community. This section will discuss common types of respite ministries: benevolence funding, respite sites, adopt-a-family programs, family caregiver cooperatives, trained respite providers, and collaborative respite programs.

**Benevolence Funding** – A benevolence fund is a sum of money set aside for a particular cause or activity. In this case, benevolence funds can be set up through the faith community and set aside specifically to help pay for respite for caregivers or to support an existing respite program. Faith communities may choose to use the money to reimburse the caregiver or directly pay the provider of respite services.

Benevolence funding may work well when the congregation does not wish to start an independent respite program. This may be a good choice if the faith community lacks the facilities, funding, and/or volunteer base to start their own program but wishes to support caregivers through respite. An already existing mission fund can also be used for this purpose. Generally, this type of funding will need to be established through the leadership of the faith community. For sample benevolence funding policies or other information about benevolence funding, please contact Alabama Respite at (256) 859-4900.

**Respite Site** – Faith communities may wish to open their church to provide respite. There are a number of ways that a respite site can be developed. One of the most popular models of site-based respite is a “respite night” or “day out.” The congregation provides care and activities at their facility while enabling the caregivers a break.

Alternately, the congregation may wish to support a respite ministry by allowing an outside group to use their facilities for the purpose of respite. The respite site option may be good for faith communities that have some type of childcare facilities or senior centers that are only used on a part-time basis.

In order to be a respite site, it is important that the facility be accessible for the target group receiving respite. If an outside group will be using your facility, it is important to have a signed agreement regarding how and when the facility is to be used. Address issues such as maintenance of the facility, replenishment of supplies and time schedules prior to starting the respite program.

**Adopt-A-Family Program** – In adopt-a-family respite programs, a family in need of respite is matched with another family who can provide respite for the caregiver. The program requires careful planning, and care must be taken in matching families to ensure that both parties are comfortable and the needs of the care recipient...
are met. Faith communities that have families interested in providing respite, but lack the resources to sustain a large-scale respite program, may find that this type of program best meets their needs.

**Family Caregiver Cooperatives** – In a cooperative, several caregiving families needing respite trade off keeping each other’s loved ones. Cooperatives are usually arranged with children but can benefit seniors or other populations. Additionally, caregivers may utilize respite volunteers from the faith community.

The faith community can help organize and connect families that are in need of respite, provide appropriate facilities for respite, and coordinate volunteers. A caregiver cooperative would work best when there are a number of caregivers for the same age group in your church or community. This service can be provided in the individual’s home or in a church facility.

**Trained Respite Providers** – Another approach to respite ministry involves training volunteers to provide respite care to a particular population. A registry of volunteer or paid respite providers can be created and maintained. Volunteers can then be matched to appropriate families.

A registry may work well where the population being served requires special equipment/care that is only available within the family home. Organization and careful matching of volunteers with care recipients are required. Alabama Respite provides training for faith communities interested in providing trained providers.

**Collaborative Respite Programs** – Collaborative respite programs involve partnerships among several faith communities, families, community programs, universities and/or government organizations. A collaborative program allows faith communities to draw upon outside resources that may not be available within one’s own congregation. If your faith community already has existing partnerships within the community, this may be a good option to fully meet the needs of caregivers.

**Conclusion** – As you can see, there are numerous approaches to starting a respite program in your faith community. If you are interested in any of these types of respite programs or creating a respite program all your own, Alabama Respite would appreciate the opportunity to share with you the tools and knowledge to move forward. Please contact us at **(256) 859-4900** for more information.

**Available Training** – Alabama Respite has free training available for caregivers and faith-based communities. Respite Education and Support Tools (R.E.S.T.) is a comprehensive, 8-hour training for volunteer respite providers. Alabama Respite has staff members certified to teach this program. In addition, Alabama Respite offers shorter, targeted trainings:

- Basic Caregiving
- Basic Respite Care
- Crisis Intervention
- Volunteer Orientation
- Universal Precautions
- Disability Awareness
- “People First” Language
- Accessibility Audits
- Dealing with Behaviors
- Assisting with Care
- Stress Management for Caregivers
- Planning for a Crisis
- Education About Specific Disorders/Disabilities
- Child Development
- First Aid and CPR
- Confidentiality
- Adapting Activities to Specific Populations
- Sensory Processing and Communication
- Documentation
- Developing Policies and Procedures
- Program Planning and Evaluation
If you are interested in any of these training opportunities or would like us to develop a training not listed, please contact Alabama Respite at info@alabamarespite.org.

- Resources -

**General Caregiver/Respite Information**

Explanation of Respite  
[www.youtube.com/watch?v=nnU9UIrnCbE](https://www.youtube.com/watch?v=nnU9UIrnCbE)

AARP Caregiving Resource Center  
[www.aarp.org/home-family/caregiving](https://www.aarp.org/home-family/caregiving)

ARCH Fact Sheets  
[www.archrespite.org/productspublications/arch-fact-sheets](https://www.archrespite.org/productspublications/arch-fact-sheets)

Information About Disabilities that may be Served  
[www.caregiverslibrary.org/caregivers-resources/grp-disabilities.aspx](https://www.caregiverslibrary.org/caregivers-resources/grp-disabilities.aspx)

Caregiver Stress FAQ  

Caregiver Action Network  
[www.caregiveraction.org/resources/agencies](https://www.caregiveraction.org/resources/agencies)

REST Ministries, Inc. (Chronic Illness Support Ministry)  
[www.restministries.com](https://www.restministries.com)

Dementia Education for Caregivers  
[www.phoebe.org/education-for-caregivers](https://www.phoebe.org/education-for-caregivers)

PBS Caregiver Resources  

Caregiver Support Network Volunteer Training Manual  

PBS Video about Alzheimer’s Caregiver  

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**Faith-Based Respite**

Faith-Based Respite – ARCH webinar  

Disability World Article about Faith-based Respite  
General Info about Faith-Based Respite (radio broadcast)
www.blogtalkradio.com/makingroom/2010/10/10/faith-based-respite-care

Faith-Based Mental Illness Support

Program Examples

Developing a Respite Program – Nathaniel’s Hope
www.youtube.com/watch?v=XhwNvz6aOTQ

Aaron’s Staff
www.aaronsstaffrespite.org

Pure Ministries – Respite Guide

Planning Resources

Care Ministry Program Guide – Leader’s Toolbox
www.caregiverslibrary.org/caregiving-ministries/care-ministry-program-guides-article.aspx

Caregiver Needs Assessment
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695

Building Capacity to Support Family Caregivers – Data Report

Disability Awareness Sunday Resources (United Methodist)
www.umdisabilityministries.org/2800.html

Disability Ministry Resources
www.joniandfriends.org
Baldwin County

Fairhope United Methodist Church
Shepherd’s Place
155 South Section Street
Fairhope, Alabama 36532
251-928-1148
Age: 65 and above memory challenged, limited physical disabilities
Monday and Wednesday, 8 a.m. to 3 p.m., Tuesday and Thursday, 9 a.m. to 1 p.m.
Contact: Leisa Richardson
Email: Shepherdsplace@fairhopeumc.org

Gulf Shores United Methodist Church
Day Break Senior Day Care
1744 Gulf Shores Parkway
Gulf Shores, Alabama 36542
251-968-2411
Age: 55 and above with dementia
Monday and Wednesday, 10 a.m. to 2 p.m.
Contact: Terry Fowinkle, Director
Email: terryfowinkle@hotmail.com

Calhoun County

Anniston First Baptist Church at McClellan
851 Morton Road
Anniston, AL 36205
256-847-0230
2nd Friday of each month, 6:00 p.m. to 10 p.m.
Contact: Dean Pearce
Email: dpearce@annistonfbc.com or
Contact: Sherry McCune
Email: sdelozier@annistonfbc.com

Word Alive
122 Allendale Road
Coldwater, AL 36203
256-831-5280
Age: 0-21
Takes place during 11:15 a.m. church service
Email: Kidzalive@wordalive.org

Etowah County

Christ Central Methodist Church
Central Friends
409 W. Grand Avenue
Rainbow City, AL 35906
256-442-6625
Age: 3 – up
4th Friday of the month, 6:00 p.m. to 10 p.m.
Contact: Jeri Shoulter

Jefferson & Shelby Counties

Oak Mountain Presbyterian Church
Sunday Morning Buddy System
5080 Cahaba Valley Trace
Birmingham, AL 35242
205-981-4325
Contact: Gwen McLeod
Email: gwenmcleod@hotmail.com

St. Mark United Methodist Church
2901 Columbiana Rd
Vestavia Hills, AL 35216
205-444-4696
Age: 0-21
1st Friday of the month
Contact: Susan Lee
Email: SLee@shelbyed.k.12.al.us
Email: info@saintmarkumc.org

First United Methodist Church of Alabaster
Aaron’s Staff
10903 Alabama 119
Alabaster, AL 35007
205-261-9915
Age: 0-21
3rd Saturday of the month, 5 p.m. to 9 p.m.
Contact: Rhoda Trimble
Email: rho413@att.net
McCoy Methodist
*Adult Day Care Center*
730 8th Avenue West Suite 102
205-251-2178
Age: Adults
Fee begins at $30/day
7 A.M. to 5 P.M.
**Contact:** Betty Lee, Director
**Email:** umseniors@att.net

South Highland Adult Day Center
*Special Connections Program*
2035 Highland Avenue South
Birmingham, AL 35205
205-933-0790
Adults with dementia/memory disorders
Full day $40, Half day $ 25
7:15 A.M. to 5:30 P.M.
**Email:** myork@southhighland.org

Briarwood Presbyterian Church
2200 Briarwood Way
Birmingham, AL 35243
205-776-5291
www.briarwood.org
Sunday A.M. and P.M. Worship; Wednesday Night Bible Study
**Contact:** June Cork
**Email:** jcork@briarwood.org

**Lauderdale/Colbert County**

Faith Church
*Shoals Respite*
3601 Florence Boulevard
Florence, AL 35630
256-767-4711
1 Friday/month (call for dates)
**Contact:** Crystal Magruder

**Limestone County**

Friendship United Methodist Church
16479 Lucas Ferry Road
Athens, AL 35611
256-232-7207
Age: No limitations
3rd Friday of the month, 6:00 P.M. to 9 P.M.
**Contact:** Dean Morgan
**Email:** Dmorgan@al-rsvp.com

Lindsay Lane Baptist Church
1300 Lindsay Lane
Athens, AL 35613
256-232-7202
4th Friday of the month, 6:00 P.M. to 9 P.M.
**Contact:** Dean Morgan
**Email:** Dmorgan@al-rsvp.com

Clements Baptist Church
8690 US Hwy 72
Athens, AL 35611-9081
256-232-7207
Age: No limitations
2nd Friday of the month, 6:00 P.M. to 9 P.M.
**Contact:** Dean Morgan
**Email:** Dmorgan@al-rsvp.com

Isom’s Chapel Methodist Church
16230 Mooreville Road
Athens, AL 35613
256-232-7207
Age: No limitations
2nd Friday of the month, 6 P.M. to 9 P.M.
**Contact:** Dean Morgan
**Email:** Dmorgan@al-rsvp.com

**Madison County**

Faith Presbyterian Church
5003 Whitesburg Drive SE
Huntsville, AL 35802
256-881-4811, 256-682-8886, 256-468-5371
Age: Children any age
3rd Friday of every month except December
**Contact:** Holly Wilkes or Linda Rass
**Email:** holly54!@knology.net
Weatherly Heights Baptist Church
1306 Cannstatt Drive SE
Huntsville, AL 35803
256-881-6882
Age: Call for ages
1st Friday of the month, 6:00 p.m. to 10 p.m.
Contact: Pat
Email: Pat@weatherly.org

First Baptist Church
225 Hunt Drive
Hazel Green, AL 35750
256-828-4479
Age: 0-21
4th Friday of the month, 6:00 p.m. to 10 p.m.
Contact: Misty McCleary
Email: Misty.McCleary@hazelgreenfbc.org

Good Shepherd Catholic Church
S.N.O. (Special Needs Night Out)
13550 Chaney Thompson Rd SE
Huntsville, AL 35803
256-883-5183
They take siblings as well
Does not provide any medicine
Age: 0-21
2nd Saturday, September through May
Contact: Karrie Bajoras
Email: Bajoras@comcast.net
Contact: Beth Sparkman
Email: Goodshep@hiwaay.net

First Baptist Church
600 Governors Drive SW
Huntsville, AL 35801
256-428-9400
Special needs building accessibility
Worship enhancement

Buddy Ministry
Special Needs Sunday School
Age: 0-21
Email: Joy@sbc.hsv.org

Montgomery County

First United Methodist Church
Joy for Johnny
2416 W. Cloverdale Park
Montgomery, AL 36106
334-239-9887
For children with disabilities and their siblings
2nd Saturday of the month, 4 p.m. to 8 p.m.
Contact: Susan Hunt
Email: joyforjohnny@gmail.com

Respite Care Ministry
334-834-8990
For people with memory loss
Contact: Daphne Johnston
Email: Djohnston@fumcmontgomery.org

Frazier United Methodist Church
Dementia Daycare
6000 Atlanta Highway
Montgomery, AL 36117
For Alzheimer's
Age: Seniors
Thursday 9:30 a.m. to 12 p.m.
Contact: Donna Anderson
Email: jjshoulter@bellsouth.net

Tuscaloosa County

North River Church
North River Respite
4215 Rice Mine Road NE
Tuscaloosa, AL 35406
205-344-4044
Age: call for ages and dates for respite
Contact: Holly Glasgow, NRC Respite Coordinator
Email: hglasgow1228@gmail.com
Covenant Presbyterian Church
Arts N’ Autism
113 Hargrove Rd.
Tuscaloosa, AL 35401-5033
205-799-7032, 205-247-4990
After school program
Contact: Jan Sikes
Email: artsnautism@gmail.com

Worship without Worry
205-758-1193
Care for children with autism
(may take other diagnoses)
Sunday school to Worship 9:30 a.m. to 12 p.m.
Contact: Greg Sanders

Caring Days Adult Day Care
943 31st East
Tuscaloosa, AL 35405
205-752-6840
For adults with memory disorders
Monday through Friday, 7:30 a.m. to 5:30 p.m.
Contact: Vickie Kerr, Executive Director
Email: vicki@caringdays.org
A good evaluation forces us to ask what IMPACT our activities have in regards to our stated goals. We must question, “Did we make a difference?”; “What kind of difference did we make?” and “How much of a difference did we make?”

This section features examples of evaluations for different events held by STC initiatives throughout Alabama. You may be interested in using one or more of these examples to develop evaluations for your own activities and events. As new evaluations and activity procedures are developed for overall STC performance, the documents will be made available on the Alabama Respite website under “Toolkit Resources.”

This section also contains a summary of a statewide survey conducted by the University of Alabama at Birmingham (UAB) in collaboration with Alabama Respite and the Alabama Lifespan Respite Coalition.

Information is provided in this section concerning Alabama Respite’s Voucher Program. STC facilitators within our state should keep contact information and forms under this tab for easy reference and distribution. Areas outside of our state interested in developing a voucher respite program may use this information as a model for replication. If you have any questions regarding the Voucher Program and how it works, please contact us at info@alabamarespite.org.

The last page of this section is a Quality Improvement Form for the STC Toolkit. Please use this form to document your feedback on the Toolkit and submit your comments to our team at Alabama Respite.
• Resources •

Event Evaluations – Advocacy Workshop
www.alabamarespite.org/images/stctoolkitresources/evaluationexample_advocacyworkshop.pdf

Event Evaluations – Building Stronger Caregivers Workshop
www.alabamarespite.org/images/stctoolkitresources/evaluationexample_buildingstrongercaregiversworkshop.pdf

Event Evaluations – Caregiver Training Class
www.alabamarespite.org/images/stctoolkitresources/evaluationexample_caregivertrainingclass.pdf

UAB Surveys - Survey of Respite Providers

UAB Surveys - Survey of Family Caregivers
www.alabamarespite.org/images/stctoolkitresources/finalresultssurveyoffamilycaregivers.pdf

Voucher Program Description
www.alabamarespite.org/images/stctoolkitresources/voucherrespiteexplained.pdf

Quality Improvement Form
www.alabamarespite.org/images/stctoolkitresources/qualityimprovementformstctoolkit.pdf
chapter nine

Resources

• Introduction •

The purpose of this section is to give STC leaders and members a place to put informational documents that they would like to have available at their fingertips, as well as a place for us to include web resources and links that we at Alabama Respite think will be helpful to you as you lead the STC initiative in your community.

• National Caregiver and Respite Resource Networks •

ARCH National Respite Resource Network – The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums. They offer a number of services including the National Respite Locator, which helps caregivers and professionals locate respite services in their community; a list of members of the National Respite Coalition which advocates for preserving and promoting respite in policy and programs at the national, state, and local levels; and the Lifespan Respite Technical Assistance Center which is funded by the Administration for Community Living, Administration on Aging (AoA) and the US Department of Health and Human Services. A catalog of ARCH products such as fact sheets and archived webinars can be accessed at this link. Alabama Respite recommends that STC leaders print this catalog of products for easy reference.

Caregiver Action Network (CAN) – formerly the National Family Caregivers Association provides education, peer support, and resources for family caregivers. The Caregiver Action Network serves a broad spectrum of family caregivers ranging from the parents of children with special needs to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS to adult children caring for parents with Alzheimer’s disease. Many of the resources and links available can provide good information for use in STC activities and orientation for members.

Caregiver and Volunteer Online Community Programs – These services allow caregivers to create online communities and make care arrangements with their personal support circles.

- LotsaHelpingHands
- Caring Bridges
- Caring Connections
• Alabama Caregiver and Respite Resource Networks •

**AARP Caregiving Resource Center** – (Alabama Chapter and National) A ton of information and a variety of tools are available for caregivers through AARP on its website and through the AARP iPad application. While much of it is geared toward caring for individuals 50 and over, some resources can be used across the lifespan.

**The Aging and Disability Resource Center (ADRC)** promotes easier access to community resources for seniors, caregivers, and adults with severe and persistent mental illness, providing information about long-term care services, public assistance programs, and private businesses.

**Area Agencies on Aging in Alabama** are the designated managers for state service and planning areas. A service and planning area is a geographic area of the state with more than 100,000 people and containing a significant number of elderly over the age of 60 who can be effectively served by the area agency under the Older Americans Act.

**Family Voices of Alabama** aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through their national network, they provide families with tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care. This organization also has a number of tools and resources available, including a Care Notebook and information on transitioning from child to adult services.

> “True genius resides in the capacity for evaluation of uncertain, hazardous, and conflicting information.”
> —Winston Churchill

**• Other Related Topics •**

- **Abuse and Neglect Prevention**
- **Recognizing Child Abuse and Neglect**
- **Elder Abuse Prevention Toolkit**
- **Disability Awareness and Advocacy**
- **Alabama Legislature** – The Zip Code Look Up feature allows residents to determine the names and contact information for their legislators. This is an important resource for in-state advocacy activities. Other states should contact their state legislature for information on similar features.
• **List of Disability Awareness Months** – Information on various disability awareness days, weeks, and months.

• **Partners in Policymaking® from Minnesota Governor’s Council on Developmental Disabilities** – A training program developed by the Minnesota Governor’s Council on Developmental Disabilities to teach parents and self-advocates the power of advocacy to change the way people with disabilities are supported, viewed, taught, live, and work. Since 1987 this program has developed numerous training tools and has several things available via its website that can be helpful in supporting the advocacy work of STC groups, including a free online training course and some new apps on helping advocates develop their story. The apps are available for download in iPad, iPhone/iPod Touch, and Kindle Fire formats.

• **People First Language** – Language a society uses to refer to persons with disabilities shapes its beliefs and ideas about them. Words are powerful; old, inaccurate, and inappropriate descriptors perpetuate negative stereotypes and attitudinal barriers. When we describe people by their labels of medical diagnoses, we devalue and disrespect them as individuals. In contrast, using thoughtful terminology can foster positive attitudes about people with disabilities. One of the major improvements in communicating with and about people with disabilities is “People First Language.” People First Language emphasizes the person, not the disability. By placing the person first, the disability is no longer the primary, defining characteristic of an individual, but one of several aspects of the whole person. People First Language is an objective way of acknowledging, communicating, and reporting on disabilities. It eliminates generalizations and stereotypes by focusing on the person rather than the disability.

• **Strategic Planning** Each of the following resources may be useful for assistance and information on the strategic planning process:
  • **Mind Tools** – Using a SWOT Analysis (Strengths, Weaknesses, Opportunities, and Threats)
  • **Community Toolbox** – SWOT Analysis
  • **Questions To Ask During A Non-Profit SWOT**
  • **Developing Strategic Plans** – A tool for community- and faith-based organizations

• **Video Caregiving** – From Terra Nova Films, a visual education center for family caregivers, numerous videos are available on this site that relate to training for caregivers and for Alzheimer’s Disease.
chapter ten

Record Keeping

• Introduction •

Alabama Respite recommends that STC leaders use this section of your Toolkit to keep important records. Placeholders are provided for Membership Lists and Committees, Minutes, and To-Do Lists. Tabs should be created for each of these categories and placed in your Toolkit three-ring binder.

- Membership lists
- Minutes
- To do list
Sharing the Care is an initiative of Alabama Respite
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