MANUAL

Volunteer Respite Manual:
Creating Valuable Options for Family Caregivers

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Introduction

According to the National Alliance for Caregiving, nearly one-third of households include a person who is a family caregiver[1] (National Alliance for Caregiving (NAC), 2009). Many of us will be in the role of family caregiver at some point, either for brief or extended periods. Whether providing care for an older parent, a spouse, a child with disabilities, grandchildren, or even a friend or neighbor, the chances that our assistance will be needed are growing. Because of the added responsibilities and unique challenges of being a family caregiver, it is very important to provide support and respite options for caregivers so they can continue being successful in their caregiving roles.

The most significant barriers to family caregiver use of respite are the shortage of qualified respite providers and the cost of the service itself. Increasingly, programs are turning to the use of volunteers when available and appropriate to help provide respite services, curtail costs, and improve affordability for families. Volunteers are essential to families who may not be able to afford respite, who live in geographically isolated areas with fewer resources, or who face limited access to services because of a shortage of paid providers. Additionally, volunteers are assets to organizations because they are an unpaid source of labor; with volunteers, programs can stretch limited resources to provide services to more family caregivers and care recipients.

Another reason to use volunteers is to expand the caregiver's and care recipient's circle of relationships. Often, the only people in a care recipient's life are those paid to be there. Volunteers offer a unique aspect to respite, not because they are "free" but because their relationships are freely given.

However, keep in mind that volunteer respite is not free, and not every respite program has the need for or capacity to successfully organize and operate a volunteer program. Careful consideration of the resources required to successfully integrate volunteers into a respite program is key to building a sustainable program. Finding a few people willing to spend a few hours helping out will not guarantee success. Recruiting, training, supervising, and evaluating volunteers require ongoing staff time and resources.

What is Respite?

Respite is "temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs" (Tipler, 2010). Similarly, the Lifespan Respite Care Act of 2006 defines respite care as "planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult" (Administration on Aging, 2009). Although respite definitions vary among organizations and service delivery systems, they all share the main idea that respite allows family caregivers to take a short pause

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[1] In legislation authorizing the Lifespan Respite Program, family caregiver is defined as "family members, foster parents, or other adults providing ongoing unpaid care for an adult or child with a special need." Family caregivers will be used interchangeably with caregiver in this manual. However, both terms are meant to refer to family or non-family members who are the primary caretakers of an individual with a special need who do so without compensation or for a minimal government stipend.

from their continuous tasks as caregivers while their loved ones continue to be cared for at home or in safe, meaningful, and appropriate community settings.

According to the Lifespan Respite Care Act (P.L. 109-442), Lifespan Respite is defined differently from the commonly accepted concept of respite as a "service or program." Lifespan Respite is defined as "coordinated systems of community-based respite for family caregivers of children or adults regardless of special need." Using this definition, state grantee agencies, which are funded under the Lifespan Respite Program in collaboration with a State respite coalition, Aging and Disability Resource Center, and other stakeholders, are charged with

- Developing or enhancing lifespan respite programs at the state and local levels;
- Providing planned or emergency respite services for family caregivers caring for children or adults,
- Training and recruiting respite workers and volunteers,
- Providing information to caregivers about available respite services, and
- Assisting caregivers in gaining access to such services.

Read More:

For background on Lifespan Respite and its legislative history, see Lifespan Respite Care Act, Title XXIX of the Public Health Service Act (P.L. 109-442).
http://www.archrespite.org/images/docs/Lifespan_Respite_Act_2006.pdf

Benefits of Volunteering

Nationally, volunteering is quite prevalent. About 62.8 million people volunteered through or for an organization at least once between September 2009 and September 2010 (US Department of Labor, Bureau of Labor Statistics, 2011). Research has found that volunteering has many health advantages, including physical, mental, and social benefits. Individuals who volunteer describe their health as better compared with those who do not volunteer, they

suffer less from sickness, and they have lower death rates (Roland & Puymbroeck, 2007; Swinson, 2006). Furthermore, volunteers experience feelings of life satisfaction and well-being as well as enhanced social support because of the friends they make through volunteering. Other studies have found that volunteers are less likely to suffer from stress or depression and that helping others can even prolong one's life (Haupt, 2010). Thus, it is easy to see that engaging in volunteer work provides invaluable benefits for both the recipient and the volunteer.

Regardless of age, intergenerational volunteering in particular can have beneficial effects for each generation and for the community as a whole. According to Generations United, volunteering among engaged older adults can enhance their socialization, stimulate ongoing learning, increase emotional support, and improve health. Older adults who regularly volunteered with children burned 20% more calories per week, experienced fewer falls, were less reliant on canes, and performed better on a memory test than their peers. Older volunteers can dramatically improve outcomes for youth. In schools where older adults were a regular fixture (volunteers working 15 hours per week), children had improved reading scores compared with their peers. For youth, volunteering with older adults enables them to develop social networks, communication skills, problem-solving abilities, positive attitudes toward aging, and a sense of purpose and community service. Volunteering also promotes self-esteem (Generations United, 2007).

Using Volunteers in All Types of Respite

Respite can take place in a variety of settings and be delivered in many different ways. Respite can be provided in a person's home or elsewhere, depending on what is most suitable for the family at that time. Some family caregivers may prefer respite on a regular, planned basis for a few hours each week, while others may turn to respite only in emergency-type situations. Certain families prefer to drop off the care recipient at a center-based program, facility, or another provider's home for a few hours a day, overnight, or for an entire weekend so they can take a break from caregiving tasks to take time for themselves or fulfill other obligations, such as doing household chores or tending to other family members. Other families, or even the same family at a different time, may prefer in-home respite, which provides the benefits of a consistent setting for the care recipient and also avoids any problematic transportation issues.

Out-of-home settings where respite may occur include community or faith-based programs, center-based programs, adult day care centers, nursing homes, after-school programs, group or foster care homes, residential facilities, park and recreation programs, and even the respite provider's home. Respite can also be provided during certain scheduled activities or events or planned outings, such as mentorship programs in which volunteers are matched with care recipients, or through cooperatives where families take turns sharing caregiving responsibilities. Event respite involves scheduled activities that may take place periodically (monthly or weekly) on a planned or drop-in basis. For example, a day of horseback riding for children with autism or an occasional lunch program or weekend retreat for those with dementia can serve as respite for family caregivers and as a break for the care recipient who may benefit from a few hours or a few days in the company of others.

Volunteers can be used in virtually all of these settings, if adequately trained, supported, and supervised. Although many volunteer opportunities involve use of volunteers to provide direct services, volunteers can fulfill additional roles by providing administrative support, helping with fundraising, and promoting public awareness, or they can provide assistance with transportation, errand-running, and so on. The experience and skills that many volunteers possess by

virtue of their work or educational experiences (nurses, emergency medical personnel, special education teachers, therapists, or graduate students) also make them great resources for respite programs and may help determine what specific role they might play. Some may also have "real life" experience caring for or witnessing care for a family member that may influence what type of role they assume in a respite program. However, some volunteers may prefer to have a volunteer assignment that is not directly related to their ongoing work or personal experience.

Read More:

For more information on how volunteers can be used in various respite settings, see ARCH Fact Sheet 18: *Volunteer Respite: Valuable Resources*, Sept. 2010 at http://www.archrespite.org/images/docs/Factsheets/FS_18-Volunteer_Respite_FInal.pdf.

For more information about respite settings and types, see the *ABCs of Respite: A Consumer's Guide for Family Caregivers*, ARCH National Respite Network, 2010 http://www.archrespite.org/consumer-information.

Special Volunteer Considerations for Event Respite

A respite program that provides regular, consistent respite services may be able to provide the same respite volunteer in a direct service role to the same family each time respite is used. In contrast, Event Respite, a group respite opportunity that occurs monthly or even less often, may rely on a consistent pool of providers or may draw on different volunteers for each event.

Given that close to 90% of family caregivers are not receiving respite, every avenue for respite programming should be examined (NAC, 2009). To foster growth in the number of volunteers, respite programs may need to be sensitive to the time constraints and other responsibilities that individuals and families face, which may limit the number of hours they can volunteer. Although volunteering rates appear to be at a 30-year high, the last 20 years have seen some changes in how people volunteer. Episodic volunteering (serving 99 or fewer volunteer hours in a year) has increased since 1989. The overall increase in episodic volunteering since 1989 is largely driven by adults age 45 to 64 and teenagers. Episodic volunteering provides opportunities for individuals who are not able to commit extended time to volunteering but who still wish to serve (Corporation for National and Community Service, 2006).

This manual focuses on the use of the same respite volunteers on a consistent and regular basis, but special consideration should be given to recruiting, training, and supervising event respite volunteers, who may be available only for a one-time event. For examples of Event Respite, see text box descriptions of The Volunteer Respite Program run by the Children's Service Society of Wisconsin and Easter Seals' Family Friends Saturday Respite run by Easter Seals Greater Washington-Baltimore Region.

Purpose of the Manual

This manual draws on years of experience with volunteer services of National Easter Seals and its affiliates and of many ARCH member respite programs and services. Much of the groundwork for developing the manual was laid out in the ARCH National Respite Network and Resource Center's Fact Sheet Number 18: Volunteer Respite: Valuable Resources (http://www.archrespite.org/images/docs/Factsheets/FS_18-Volunteer_Respite_FInal.pdf)

The purpose of this step-by-step manual is to help community-based programs assess their individual needs, plan and implement volunteer respite programs, and assist state Lifespan Respite programs as they address the requirements in the Lifespan Respite Care Act to build respite capacity through volunteer training and recruitment. Interspersed throughout the document are text boxes with additional resources for reading further on that topic, highlights of National Volunteer Respite Initiatives, and examples of local volunteer respite programs. It is our hope that as state Lifespan Respite programs develop statewide systems of coordinated and accessible respite services, they will use this guide to help them directly or through their subcontracts with faith- or community-based organizations to pursue respite expansion by using volunteers in an array of respite care options for families.

Event Respite Example

Saturday Respite Event, Children's Service Society of Wisconsin, a member of Children's Hospital and Health System

Program Description

The program is supported by United Way, Northwestern Mutual Foundation, and the Respite Care Association of Wisconsin. With just 1.5 staff, the CSSW Volunteer Respite Program enabled more than 11,000 hours of repeated respite for the families of more than 450 children in 2010. It holds a Saturday day camp type 7-hour event for approximately 70 children in a donated space, such as a school or a church, about 18 to 20 times a year. The families, more than half of whom have incomes below the US poverty level, are not charged for the respite day, and they come from the four-county metro-Milwaukee region. About two-thirds of the children served have a special need or a mild to severe medical condition or disability, including behavioral disorders such as autism or attention deficit hyperactivity disorder (ADHD). The remaining one-third are siblings of these children, so respite care allows the parents or guardians to have a total break from caregiving for the day. The mix occurs naturally. Limits are not set for type of disability. The only children not accepted by the program at this time are those with trachea-vent needs, because a malfunction could be life threatening. Families ideally can attend six respite events a year at no cost.

Volunteer and Staff Responsibilities

One hundred twenty community volunteers age 15 and up are recruited to provide 1:1 or 2:1 supervision of children and for other supportive roles for the daylong event. CSSW staff are present and volunteer or paid nursing staff (usually volunteers from university programs attending with a professor for service learning) are responsible for all bathrooming, diapering, g-tube needs, medical needs, and dispensing of medication. One expense the program does entail is about $500 to hire five behavioral specialists to provide 1:1 supervision for children with significant autism or other conditions who might not otherwise have a good day with a "lay" volunteer.

Safety Precautions

To ensure safety, a home visit is done for each child prior to the event to establish a case file, which is updated regularly. The file includes the initial call-in sheet requesting respite, a signed HIPAA (Health Insurance Portability and Accountability Act) confidentiality agreement, photo release, release of liability statement, demographics for funders (2 full pages), medical emergency/care pages, and progress and supervision notes. Not only does this provide vital information regarding the needs of the child and family, but it also helps promote trust, which is a significant issue for families until they have attended once or twice.

Safety precautions for all nonmedical volunteers include never leaving a volunteer alone with a child; requiring sexual predator checks, photo ID carding, and criminal self-disclosure statements; and requiring a short safety orientation ½ hour preceding the all-day event. Full background checks are conducted on each nursing and behavioral staff member and include US criminal, caregiver/child welfare background checks, sexual predator checks, and WI Department of Transportation checks (even though volunteers don't provide transport).

Additionally, the nonmedical volunteers are emailed a confirmation letter with information prior to the event. Also prior to the event, nursing volunteers receive information about the children in care. If a child has special medical needs and is coming on transport, parental permission is obtained in advance to have the nursing staff call them for full details of care.

At the event, following their short orientation, the nonmedical volunteers sign a background disclosure statement (which is reviewed in advance and checked before children are matched with them), a confidentiality statement, and photo release. They then check in, get their child's name, move to a table with non-identifying (beyond name and birth year and month) information about the challenges, care, and likes and dislikes of the child for whom they will be providing care. They also receive a schedule and printed orientation. When the children arrive with their parents, the volunteers have been encouraged to ask them about care for the child for the day.

The parents, child, volunteer, and nursing staff all meet at check in. Parents sign in, indicate who is picking up the child (and sign out at day's end), and sign in medications and dosing with nursing staff. The nursing staff take notes regarding medical, dietary, bathrooming, wheelchair, and other care and have pocket sheets on ALL the children at the event. The children are color-coded to a nurse. At the back of each nurse's pocket lists are three grid sheets to note time and dose for medications, g-tube administration, and diaper changes. These records are kept throughout the day. Nursing staff and volunteers have medical notebooks with full information for EACH child; the pocket sheets have the child's name, birth date, parents' names, phone numbers for parents, doctor's contact information, and other basic emergency information. For each event, the information is updated for the returning child.

Volunteer and Family Recruitment

The volunteers are recruited mostly from large groups, including local companies, high school Key Clubs, Best Buddy groups, National Honor Societies, AmeriCorps, YMCA teen groups, and college or university groups. Attendance is usually modest at first, but those touched by helping families will return to work with leaders to bring a large event, at no cost, to their own campus, high school, or church and even raise funds for food or special activities for the day. By working with these select volunteer leaders as much as 3 months in advance, arrangements are made for parking, building use permits and activities. For example, if the event is to be held in a high school, CSSW obtains a certificate of insurance for the event, and the school donates the space. The space needs are rather specific, because they must be accessible and safe.

As illustrated, the program uses several tiers of volunteers, including key volunteer leaders who are in charge of acquiring space and food, developing arts and crafts projects, and managing other activities. Other volunteers make thank-you bags for all the volunteers who participate in the event. These volunteers, who do not have direct access to the children, may come from retirement communities, Girl Scouts under age 15, and corporate groups.

To recruit families, CSSW publicizes the events through flyers and community newsletters. Sign-up is first come, first served, although families who may be in crisis are called to ensure that they have a chance to use the respite service. Word of mouth is the best recruitment tool for both families and volunteers.

For Program-Specific Sample Forms and other material, see **Appendices pages A38 through A49**.

For more information, contact:

Ellen Anderson
Coordinator, Respite Programming
Children's Service Society of Wisconsin
4340 N. 46th St. Milwaukee WI 53216
(414) 444-5760 ext. 2225 • fax: (414) 444-5762

Before a program can start recruiting and retaining volunteers to provide respite, a plan must be developed and put in place for determining when, where, and in what capacity volunteers will be used and how funds will be obtained to start up and sustain the effort and evaluate and market the program.

Needs Assessment

When developing a volunteer program from scratch and identifying partners and funding sources, it is essential to establish a need or demand by conducting a market analysis or some type of needs assessment. Various agencies conduct a variety of needs assessments and many track unmet needs or requests for services that they cannot provide. For a new volunteer respite program, you may want to survey existing organizations to solicit input about the agencies and people they serve so you can answer the following questions:

- Define the target audience: Whom do you intend to serve?
- What are the existing assets and services in the community?
- What are the existing and emerging needs in the community among the target group?
- What are the real and potential funding opportunities for the program or services?
- Are there threats and opportunities in the external and internal environment that can affect the program's future? (Note how that information can be used to plan the program's future.)
- Have specific strategies been selected and developed to achieve your goals for the term of the plan?

Read More:

ARCH Fact Sheet 8: *How Fundraising Flows from Strategic Planning* at
http://www.archrespite.org/images/docs/Factsheets/fs_8-strategic_planning.pdf

ARCH Fact Sheet 27: *Sticky Figures: Using a Needs Assessment* at
http://www.archrespite.org/images/docs/Factsheets/fs27.pdf

ARCH, *Bringing Respite to Your Community: A Start-up Manual*. Chapel Hill: Author

ARCH, *Respite Programs for Adults and the Aging: A Start-up Manual*. Chapel Hill: Author

National Council of Nonprofits. How to Start a Nonprofit | Where to Find Assistance at
http://www.councilofnonprofits.org/resources/how-start-nonprofit/where-find-assistance

Infrastructure and Staffing

The process of determining need and market demand, programmatic goals, and intended outcomes, scope, and potential funding sources, generates a need for staff, board or advisory committee members, and volunteers with

various areas of expertise and skill sets. Roles for board members or advisory committees, leadership, program, respite, support staff, and volunteers should be carved out, and job descriptions should be drafted with proven business and staffing models in mind. The specific roles that volunteers will play and in what capacity they will serve must be delineated in advance. Orientation and training curricula must be planned and mapped out, policies and procedures must be researched and written, and supervisory roles must be defined. In some situations in which paid staff are also used within an organization as volunteers, it is vital to ensure that volunteer roles and responsibilities are separate from or not in conflict with those of paid staff. Specifics regarding volunteer recruitment, retention, and supervision are found in subsequent sections of this manual.

Read More:

For more information on nonprofit business and staffing models, see Strategic and Business Planning for Nonprofits at http://www.councilofnonprofits.org/resources/resources-topic/administration-and-management/business-planning-nonprofits.

Articles and links to additional websites can be found at Volunteer Management Resource Center at Idealist.org and at http://www.idealist.org/info/VolunteerMgmt/Additional.

Evaluation

Planning for and designing an evaluation before the program gets underway will save a lot of backtracking later. There are a number of approaches to evaluation that can help assess various aspects of a program.

- **Program evaluation** assesses the accomplishments of a program and can function as a management tool that feeds information back to the organization for the purpose of continuous improvement and program responsiveness.
- **Process evaluation** assesses the development and actual implementation of the program—whether strategies were implemented as planned and intended output was actually produced.
- **Outcome evaluation** assesses the extent to which an intervention (in this case, respite services) affects participants or individuals served—the degree to which changes occur in their knowledge, skills, attitudes, or behaviors as a result of the services provided.

Incorporating an evaluative component into the program serves a number of goals: capturing data and providing a way to analyze program and process improvement, assessing effectiveness of program services, and measuring whether and to what extent desired outcomes are being met. Building an intentional, systematic evaluation strategy into the program during the initial planning phase provides a mechanism for identifying the outcomes that the program intends to achieve upfront and allows related staff, internal and external expertise, expenses, and other items to be considered in budget development and strategic planning.

It may be valuable for the program to assess whether the frequency and dose of respite provision is consistent with the expectations and experiences of enrolled families. Once a qualitative and/or quantitative evaluation is completed, the information must be reviewed and interpreted accurately. The information from an evaluation should be used to inform respite practices through data-driven decision-making. Creating an internal process for reviewing and analyzing evaluation results informs programmatic adjustment and improvement. Evaluation is also vital in reporting valuable program and outcome information to funders and stakeholders.

Feedback Loop/Procedures

Soliciting feedback from the care recipients and their families, as well as respite volunteers and referral sources, is important to the integrity and quality of the services provided and can be an important component of evaluation. This can be done by using satisfaction surveys, comment cards, focus groups, and grievance procedures. One individual within the organization should be in charge of receiving and compiling all of this documentation as well as analyzing it and addressing voiced concerns.

Although evaluation can seem overwhelming if unfamiliar, it is a systematic process with a great deal of guidance and expertise available. Evaluation consultants and universities are also available to contract or partner with to help identify evaluation questions, measures and process, as well as data collection mechanisms and analysis. If budget is an issue, consider working with graduate students or interns with a background in research and/or evaluation.

Read More:

Senior Companion Performance Measurement Work Plan and Instruments, Respite Care Service Activity, includes a Performance Measurement Work Plan, Respite Caregiver Survey Instruments, and instructions for summarizing results. Developed by the Senior Companion Program Working Group with assistance from Project STAR (Rev 8/9/07) at http://www.nationalserviceresources.org/files/S-WP057_Respite_Care.doc

ARCH National Respite Network and Resource Center (2002). *Evaluating and Reporting Outcomes: a Guide for Respite and Crisis Care Program Managers.* Chapel Hill: Author.
http://www.archrespite.org/program-evaluation

Continued on next page

Valerie Cook, Office of Performance and Evaluation, Administration on Aging, US Department of Health and Human Services (2010). **Performance vs. Evaluation**. Presentation at Lifespan Respite Grantee Meeting in Baltimore, MD. http://www.lifespanrespite.memberlodge.org/Evaluation

Performance Measurement and Evaluation: Definitions and Relationships. This glossary describes and explains the relationship between two common types of systematic program assessment: performance measures and program evaluation. Based on Government Accountability Office (GAO) publications and program evaluation literature, it was first prepared in 1998. http://www.gao.gov/new.items/d11646sp.pdf

Minnesota Department of Human Services. (2009). ***Measuring the Difference Volunteers Make: A Guide to Outcome Evaluation for Volunteer Program Managers.***
http://www.energizeinc.com/download/Measuring_the_Difference2003.pdf

Identifying Costs and Potential Revenue Streams

Identifying costs is a critical process in program planning and budget development. Even volunteer-run programs incur expenses and require funding. Take time to determine infrastructure, fundraising, and service-related costs: direct and indirect costs such as insurance, workspace, utilities, website, equipment (e.g., computers, software, phones), as well as salaries and benefits, professional services, staff and volunteer development, evaluation, printing and marketing-related expenses, travel, other program development, and growth-related costs. Projections for earned and contributed income from the following sources must be determined and categorized to develop a budget: individual donations and payors, corporate, foundation, government, interest, billable services, sales, and others.

You still may need to charge for respite to cover at least some of the program costs, even if you are relying on volunteers. Client fees—whether billable, privately paid, sliding scale, donation based, or complementary—are predicated on actual costs and market-related influences such as state or regional funding and payroll rates. It is important to be tapped into provider networks and funding trends in order to anticipate and determine the availability of funding and the funding mix for the program.

Read More:

For more information about potential federal funding sources for respite, see the ARCH Lifespan Respite Toolkit Fact Sheet 2: ***Building Blocks for Lifespan Respite: Federal Funding for Adult's and Children's Respite*** at http://www.archrespite.org/images/docs/Lifespan_Summit_Docs/Building_Blocks_for_Lifespan_Respite.pdf.

Fundraising and Development

There are a multitude of private and public funding opportunities available to community-based organizations. Private funds are given by philanthropic organizations, foundations, corporations and individual donors, among others. Dollars from private organizations are often contributed to other organizations whose missions are aligned with their own and that help meet the goals of their funding agenda.

Public funding sources include state and local agencies, government entities, and others. Your state Lifespan Respite program can help you identify or leverage available funds. Before you develop messages and reach out to potential funders, be sure you have a good understanding of their funding priorities and target population. Work with established stakeholders and partner organizations to identify trends in local, state, and federal funding that might support the work of the program and pay for services or other aspects of the organizational infrastructure.

One-time or ongoing community or fundraising events, such as auctions, music events, walks or runs, and golf tournaments can be labor and resource intensive, but with the right support, they not only help raise funds, but they also engage the community and help recruit additional volunteers.

Read More:

The following links provide further information on fundraising and strategic planning:

For fundraising event ideas, see **Fundraising and Special Events**, Energize, Inc., at http://www.energizeinc.com/art/subj/events.html.

Many state respite coalitions, such as the Tennessee Respite Coalition, have been very successful at event fundraising. For more information on state respite coalition fundraising activities, see ARCH Compendium of State Respite Coalition Fact Sheets at http://www.lifespanrespite.memberlodge.org/Coalition_Factsheets.

ARCH Fact Sheet 6: *General Principles of Charitable Non-Profit Fundraising* at http://www.archrespite.org/images/docs/Factsheets/fs_6-general%20principles%20of%20charitable%20nonprofit%20fundraising.pdf

ARCH Fact Sheet 7: *Marketing for Charitable Nonprofit Organizations* at http://www.archrespite.org/images/docs/Factsheets/fs_7-marketing.pdf

ARCH Fact Sheet 8: *How Fundraising Flows From Strategic Planning* at http://www.archrespite.org/images/docs/Factsheets/fs_8-strategic_planning.pdf

ARCH Fact Sheet 10: *Creative Fundraising Activities* at http://www.archrespite.org/images/docs/Factsheets/fs_10-fund_raising-activities.pdf

Identifying and Engaging Potential Donors

Donations to a program or organization are largely determined by customer or client satisfaction since satisfied customers generally see the value of services and are willing to donate or pay to the extent of their ability. There are two kinds of potential donors: (1) those who both use the service programs and donate money, and (2) those who do not use the programs but donate their own money on behalf of others who need the services. Often the approach to each type of donor is different. Potential donors could be clients, clients' family members, friends, staff members, leadership volunteers and other volunteers, vendors, and others who work with the organization. All of these individuals are potential donors and can be helpful in introducing the organization to others who may be able to support the cause. The key component to identifying donors is to enlist staff members in the process. If the staff has interactions with the clients and their families, they are at the front line of engaging potential donors for the organization.

Building the Case

Develop a case statement or brochure that summarizes the needs addressed by the program and the strategies and services used to serve those needs. Include information about the program's achievements and the program's capacity to tackle its issues. Add a bit about the board or advisory committee and give an idea of the size of the program budget.

Stewardship

Properly and consistently thanking donors and communicating with them are often the most important aspects of relationship building within the development process. The time spent recognizing people for their contributions of time, talent, and resources is a great investment, and it seeds the opportunity for another or increased gift. Determine what the baseline will be for the stewardship program—What will the donor receive with some regularity? Newsletters, holiday cards, birthday cards, and annual reports are all examples of stewardship materials that a donor will pay attention to and appreciate receiving. However, you may want to take it up a notch for larger donors by having the CEO call and/or visit these donors and explain the impact they are having on the organization through their gifts.

Making it Easy to Donate

Making online and offline donations should be easy and joyful. Everywhere in the organization, there should be donor envelopes and readily available ways to give. For example, a service provider may mention during a session that a specific piece of equipment is needed. Why not make it possible for the donor to make a donation before they leave the building by having donor response envelopes displayed on the wall? Make sure that employees are aware of where donors can make their donations—the reception desk, a donation box, online. Many organizations use an online donation system on their website that uses PayPal or another online service to manage credit card donations.

A nonprofit organization can also partner with online entities that help raise funds. Some examples are:

- Facebook Causes at http://www.facebook.com/causes or Fundrazr.com at http://fundrazr.com/ that allow charitable organizations to raise funds for their cause.

• GoodSearch and GoodShop at http://www.goodsearch.com/ raise funds for you when your supporters download the GoodSearch toolbar, which uses the Yahoo search engine or becomes active whenever you shop from an affiliated website.

• Network for Good (http://www1.networkforgood.org/) uses the Web to help people get more involved in philanthropy and features nonprofit resources, online donation forms, and volunteer opportunities.

Read More:

Softduit Media has a step-by-step guide, How to Set Up PayPal for a Non Profit & Accept Donations via Facebook at http://softduit.com/how-to-set-up-paypal-for-a-non-profit-accept-donations-via-facebook/.

For more information on funding sustainability, see **Ten Nonprofit Funding Models**. Stanford Social Innovation Review, Spring 2009. http://www.ssireview.org/pdf/2009SP_Feature_Foster_Kim_Christiansen.pdf.

Example of Volunteer In-home Respite for Families With Children Who Have Disabilities

CareBreak at the Watson Institute, Sewickley, PA

Program Description

The Watson Institute, through its family of schools and services, helps children and youth with special needs achieve their fullest potential in all aspects of their lives. Watson strives to provide programs that serve the needs of these individuals. The Watson Institute provides respite that uses a volunteer respite model called CareBreak. The CareBreak program, in existence since 1998, is a volunteer respite model based on a foundation of values drawn from the concepts of community building, obtaining socially valued roles (known to some as social role valorization), and Citizen Advocacy. The CareBreak program uses volunteers to provide once weekly respite visits for 4 hours. CareBreak respite volunteers are recruited and carefully screened and trained by CareBreak staff, and they are then matched with a family caring for a child with a disability. The CareBreak respite typically takes place in the family's home and community by the volunteer who is asked to make a 6-month commitment.

The CareBreak Philosophy

CareBreak seeks to create relationships by reconnecting individuals with disabilities and their families who have become isolated from the ordinary community. CareBreak's practice of matching a volunteer or mentor to a person with a disability is based on Citizen Advocacy's premise that devaluation of a person or group by society has profoundly negative effects on their lives. Volunteers and individuals are brought together by a careful process of matching that includes similarities, strengths, and community, as opposed to time on a waiting list or other impersonal factors. Just as a Citizen Advocate is asked to represent the rights and interests of another person as if they were one's own, CareBreak volunteers are asked to build a relationship with the individual based on mutual interests and capacities, not just need and time availability. This process benefits the person receiving care, the family caregivers, and the individual volunteer. As a result, CareBreak volunteers provide a meaningful connection and greater access to the community. In return, the CareBreak volunteer's life is enhanced through the satisfaction of time well spent and of having a mutually beneficial relationship.

CareBreak's Mission and Vision

CareBreak's mission is to offer a family-centered service that provides quality respite time for parents or primary caregivers of children with disabilities through meaningful experiences offered on a one-on-one, consistent, continuing basis in the child's home and community. CareBreak's vision is to promote interdependence and self-esteem for children with disabilities through creative and caring opportunities introduced by a volunteer. As a result of CareBreak, the child thrives, the parents get a much-needed respite, the volunteer feels the satisfaction of making a difference in the lives of a family, and the community as a whole benefits and grows stronger.

CareBreak's Guiding Principles

CareBreak provides the opportunity for individuals with disabilities to obtain socially valued roles. CareBreak respite volunteers are not typically human service professionals. They are bankers, realtors, engineers,

teachers, and other types of professionals. What they have in common is their socially valued roles and their desire to form a relationship with a person with a disability and provide respite to family caregivers through their gift of time.

- Individuals caring for family members with disabilities need a break in order to regroup, refocus, and re-energize.
- Individuals with disabilities need a break from their family caregivers.
- That respite break should be meaningful and valuable to the individuals with no strings attached (i.e., caregivers should not be required to attend groups or classes during the respite, and individuals with disabilities should not be required to engage in therapy or services during the break)
- The respite should be developmentally and socially appropriate and provided in as valued a manner as possible.
- The respite should be as person-centered and individualized as possible.

Providing Awareness and Leadership

The CareBreak Program, by the nature of its intimate design, is not able to serve all families and may not be a "fit" for families who are not comfortable with having services offered in their home and immediate community. In addition to offering the CareBreak model, the CareBreak coordinator works to ensure that respite needs of individuals across age and disability are effectively understood and met with appropriate resources.

Benefits of CareBreak

Through a foundation of values and a careful matching process, CareBreak is able to make connections that are meaningful to the individual with a disability as well as the family caregiver. The model lends itself to community building and inclusion because the CareBreak volunteers and person with a disability enjoy outings during which the individual can become understood and supported.

Volunteers

CareBreak volunteer respite providers are caring, compassionate people from all walks of life who enjoy children and want to make a difference. They understand that supporting a family in need is one of the most powerful ways to improve the quality of life in their community. CareBreak is valuable not because it is free but because the relationships between volunteer respite providers and families are freely given. By choosing to give their time, volunteers make a commitment to an individual and family—often being the first unpaid person in the family caregiver's life to do so.

The careful screening, training, and matching process used by CareBreak results in a high retention level and volunteer/client matches that far exceed the expected 6-month commitment. On average, university

student/respite providers continue their match for 3 years. Adult volunteer mentors older than age 24 who provide respite average a 5-year length of stay with their CareBreak family.

In addition to satisfaction surveys of respite volunteers and families, CareBreak also engages in continuous quality improvement (CQI) through outcome interviews and evaluations. This information is used to determine whether the frequency and dose of the CareBreak program is congruent with family caregiver needs and expectations. Information is gathered regularly and is used to modify and improve program function and to ensure that all changes to the program structure are based on data informed and data-driven decision-making.

Sample Application, Reference forms and Interview Questions can be found in **Appendices pages A31 through A36.**

For more information, contact:

Maryjo Alimena-Caruso
CareBreak at the Watson Institute
301 Camp Meeting Road
Sewickley, PA 15143
412-749-2863
maryjoa@thewatsoninstitute.org

Courtesy of Easter Seals

Recruiting dedicated and qualified volunteers is vital for community-based respite programs to meet the capacity-building requirements of a state Lifespan Respite program.. This may be a challenge for both new and well-established respite programs, but once recruited, respite volunteers can become committed long-serving volunteers. Most organizations have limited resources, so using volunteers is beneficial because it can provide more families with services or respite care options. Although training volunteers does have costs associated with it, ensuring that volunteers are satisfied with their work and that they remain in their roles is a worthwhile investment.

While many volunteers are seeking meaningful opportunities with long-term, clearly stated timeframes, an increase in episodic volunteering has emerged in the last decade. Recruitment is especially challenging today, because many volunteers are looking for flexible, short-term commitments, and projects of limited duration. This may suit the needs of event respite type programs, but it raises challenges for programs that would benefit more from volunteers who are willing to make a longer-term commitment. Programs may need to think more creatively about offering flexible schedules, having projects that offer both long- and short-term commitments, and providing opportunities for families or couples to volunteer together (Swinson, 2006).

Developing a recruitment plan is a critical step in determining how volunteers will be discovered and put to best use. It is important to cast a wide net in the search for suitable volunteers and to use various screening tools (e.g., job descriptions, application forms, interviews, and criminal history background checks) to increase the likelihood of making good matches.

An important note about marketing and recruitment is that there is no such thing as a recruitment season. To be effective, a volunteer respite program must commit to a 24/7 365-day-per-year approach. Because recruitment can be a large investment of time and energy, it is important to note how potential and/or trained volunteers actually come to you. Simple activities such as posting a regular, ongoing ad in a free newspaper or on a website may yield the best results. Partnering with other organizations also increases visibility. If you serve only children, consider partnering with a group that serves adults. Volunteers rarely join an organization the first time they hear about it. Typically, a multifaceted approach that combines media, community presence, and word of mouth will engage those interested in becoming respite volunteers.

There are several ways in which an organization can reach out and recruit volunteers for a respite program. Each local community will provide its own unique possibilities, but here are some suggestions.

Targeting Specific Groups

There are a variety of groups such as students, retired persons, baby boomers, individuals with disabilities, and civic groups that can be tapped when recruiting volunteers. When reaching out for potential volunteers, it is important to keep in mind that these people vary in the types of opportunities they may be seeking, and that their motivations are also likely to be different.

- *Students* often have volunteer work requirements through their high schools, colleges, or universities and may have to complete a set number of internship hours to be able to graduate. Developing relationships with educational institutions may provide a steady influx of volunteers. Other benefits of using students as volunteers are that they may have greater availability as opposed to people in other age groups who may have more commitments. Specifically, psychology, physical or occupational therapy, gerontology, social work, and nursing or allied health departments at a community college or university may be key contacts because their students may be interested in developmental, disability, or health issues for different age groups. Students can then be appropriately matched to provide respite to a population in which they are interested. At the same time, students benefit from serving as respite volunteers because it helps them meet requirements, earn course credits, and acquire experience that could be added to a résumé. Students in fields not directly related to providing care, such as communications or engineering, might find the appeal of providing volunteer respite to increase their marketability or to engage in an activity far removed from their day-to-day requirements. Students will typically be looking for short-term volunteer opportunities, and their motivation will rely mainly on completing school-related projects or requirements. However, student groups such as clubs or sororities and fraternities that embrace the mission of your organization, the population served, or the desire to help the community can also provide a long-term, steady stream of volunteers.

- *Retired persons and other seniors.* The Corporation for National and Community Service notes that the number of adults age 65 and older who volunteer has risen from 7.7 million in 2002 to 9.1 million in 2009. The most recent volunteer rate of older adults 65 plus is 23.9 percent for 2009 (Administration on Aging, 2011). Today's older adults are more educated and financially secure than they were in the past. The proportion of adults age 65 and older without a high school diploma has dropped almost 40 percentage points since 1974. Moreover, older Americans with college degrees are volunteering at a higher rate than in the past (Corporation for National and Community Service, 2006). Retirees typically have time available that they may want to allot to volunteering, especially since they may be looking for a meaningful way to contribute to society. They are valuable volunteers because of the expertise they possess from their years in the workforce. Older adults may

Ten Questions to Ask Before Recruiting New Volunteers

1. Why do we need volunteers?

    What would happen if we had none at all?

2. What role does our volunteer program play in our overall mission?

    Asking this question forces you and your staff to clarify your goals and explain the big picture.

3. Does our staff understand the pivotal role that volunteers play in our efforts?

    This question helps your paid staff appreciate the role that volunteers play in achieving your goals.

4. What are the benefits to the individual who volunteers in our organization?

    The answer to this question gives you an immediate recruiting and retention tool.

5. Are the placement opportunities for volunteers clearly defined? Do we have clear position descriptions? Are they flexible?

    You wouldn't want to show up for a volunteer position and not know what to do.

6. Whom do we want as a volunteer? When do we want them? What recruitment method would be best?

    The answers to these three "W's" give you a perfect recruitment strategy.

7. Who will do the recruiting? Are there skilled volunteers who can act as recruiters? Are we utilizing them?

    The answer to this question gives you the ability to put your plan into action.

8. Are we prepared to handle the response? Do we know who will interview, screen, place, train, supervise and evaluate our new volunteers? Do we include critical training about a volunteer's safety?

    Your game plan must be in place to welcome, utilize and keep volunteer capital safe and viable.

9. Do we need more advice? Should we form an advisory board of experts to advise us about our recruitment program?

    Have you contacted the local community colleges and universities and the non-profit organizations in your community to see if there are experts on volunteer management who can volunteer to work with you?

10. What would we do if we had an unlimited supply of skilled volunteers? Would we be ready to take advantage of their special talents? Do we understand how to gather credentialing information about volunteers?

    Think about these questions; be ready with a wish list of tasks that need to be covered in all phases of the activity.

    You may not be able to have a position description for everyone who shows up, but to the extent possible, you should try to be prepared with position descriptions for every skilled volunteer.

be able to apply their work experience directly to certain volunteer roles or they can seek out other volunteer opportunities if they are interested in pursuing something unrelated to their previous area of work. Retirees and seniors may be an invaluable resource because with their unfettered schedules, they have more time for volunteering for extended periods.

- **Civic groups** (e.g., Rotary Club, Men's Club, Women's Club, PTA, Chambers of Commerce, Girl Scouts, and Boy Scouts) are good places to seek out volunteers because the motivations of individuals involved in these groups revolve around serving their communities. Civic groups may comprise individuals interested in being engaged in volunteer opportunities for extended periods of time, since volunteering is central to their focus on community improvement.

- **Baby boomers.** Of the 77 million baby boomers (those born between 1945 and 1964) in the United States, about 33% volunteer on a regular basis. That is the highest rate of any generational group and four percentage points above the national average of 28.8%. In 2009, 22.8 million boomers gave 3.1 billion hours of service. Volunteerism in this age group has increased during the past few decades. The volunteer rate for young boomers, age 46 to 57, is 30.9%, significantly higher than the 25.3% recorded by the same age group in 1974 and the 23.2% recorded in 1989 (US Department of Labor, Bureau of Labor Statistics, 2011). The Edward M. Kennedy Serve America Act expanded opportunities for boomers to participate in AmeriCorps (http://www.americorps.gov) and provides a scholarship benefit that can be used by the volunteer or given to a child or grandchild. The American Association of Retired Persons (AARP) also launched Create the Good (http://www.createthegood.org) to facilitate volunteering among this population (Mercer, 2011).

- **Individuals with disabilities.** You might want to consider reaching out to disability organizations to recruit people with disabilities to serve as volunteers. Some effort will be involved in eliminating the programmatic, communication, and technological barriers that often exclude this population, but the results can be very rewarding. "When organizations work to eliminate these barriers and commit to being inclusive in their approach to recruitment, they benefit from the strengths of a diverse volunteer base." (North Carolina Respite Care Coalition, 2011).

The following are some additional examples of community-based organizations or state associations that might present opportunities for volunteer recruitment:

- Faith communities (e.g., churches, mosques, and synagogues), National Volunteer Caregiving Network (formerly known as Faith in Action programs), or other faith-based organizations are increasingly providing volunteers engaged in ministries to assist the disability and aging communities.

Courtesy of Easter Seals

- Local businesses or human resources departments from local corporations often help organize their employees to volunteer in the community.
- State or federal workers often form volunteer groups that dedicate their time to service.
- Professional associations such as the National Association of Social Workers or nursing associations may have state chapters that are involved in volunteer projects.
- Senior centers may provide a pool of seniors or retirees willing to volunteer their time.

Read More:

For more information on collaborating with the faith-based community to provide volunteer respite, see ARCH Fact Sheet 53. *Respite in the Faith Community*, 2010.

http://www.archrespite.org/images/docs/Factsheets/FS_53-Faith-Based_Fact_Sheet_5-27-10.pdf

National Volunteer Initiatives

The National Mentoring Partnership provides opportunities for a volunteer to spend time in the home, school, or community of a child with special needs through mentoring that child while providing respite to the family caregiver. In 2011, the US Office on Juvenile Justice and Delinquency Prevention announced a new one-time funding opportunity, the "Mentoring Youth with Disabilities Initiative." This initiative builds upon the foundation of evidence-based practices for effective mentoring and encourages communities to implement and enhance mentoring programs for youth with disabilities. For funding details of mentoring programs, see http://www.ojjdp.gov/funding/FundingDetail.asp?fi=231. For more information about the National Mentoring Partnership, see http://www.mentoring.org/ or the Partners for Youth with Disabilities mentoring project at http://www.pyd.org/national-center.

Corporation for National and Community Service (http://www.nationalservice.gov/Default.asp) is the nation's largest grant maker that supports service and volunteering. Through Senior Corps, AmeriCorps, and Learn and Serve America programs, the Corporation provides opportunities for Americans of all ages and backgrounds to help address critical community needs.

Cultural Diversity Considerations

Cultural diversity should be considered when recruiting volunteers. Many organizations promote diversity within their establishments and are committed to providing equal opportunities to volunteers without regard to their race, religion, sex, age, sexual preference, or disability. However, greater efforts should be undertaken to recruit minority volunteers, including older lesbian, gay, bisexual, and transgender (LGBT) individuals, individuals with disabilities, and other members of minority groups who do not feel welcome currently in many volunteer situations.

It is beneficial to be aware of the community surrounding your organization to determine specific needs of the population served. For example, there are respite programs that focus on providing services to Latino families so having a Spanish-speaking volunteer may be beneficial in this type of setting. Having a good understanding of the neighborhood in which your organization operates coupled with an awareness of the cultural makeup of those you serve may also help minimize barriers to care and services by those who may especially need them. (See Individuals with disabilities above).

Strategies for Recruiting Volunteers

One important way to get members of the community to volunteer is to ask. About 42.7% of volunteers became involved with their main organization after being asked to volunteer, most often by someone in the organization (US Department of Labor, Bureau of Labor Statistics, 2011). Just as important, get the word out that there is a tremendous need for respite volunteers, promote the program's mission, and demonstrate that your program is viable. About 41.6% of volunteers became involved on their own initiative; that is, they approached the organization (US Department of Labor, Bureau of Labor Statistics, 2011). Whenever possible, offer small incentives to volunteers such as recognition and a flexible program with a modest time commitment. Demonstrating the need for respite providers and asking for help can attract and engage volunteers in the program. Several marketing techniques are described below.

Word of mouth is a powerful way to make your program known. The volunteers serving your organization will be inclined to discuss with others what they are involved in, their experiences, and how they are treated by your organization. If volunteers are treated well and valued by your organization, they are most likely going to relay that information to their family and friends. Current volunteers can also let other individuals with whom they come into contact know that your organization is looking for great volunteers. Since most individuals tend to have friends with whom they share interests, the chances that current volunteers will have friends that are interested in volunteering is very likely. This word-of-mouth strategy works best when current volunteers begin to be vested in your program and naturally start to advocate for it. It costs nothing for the organization and is a great way to get others to learn about your volunteer opportunities.

Social media. Increasingly, more people are turning to social media and social networking sites for news, entertainment, and information gathering. Social media can be defined as websites that not only give you information, but also interact with you while giving you that information. Social media was once thought of as the way to reach "young people." But those older than age 65 are the fastest growing group of social media users. Social networking is a type of social media that allow you to interact by adding friends, commenting on profiles, joining groups, and having discussions. A recent

Nielsen study found that social networking takes up 23% of American's' online time. The top 15 most popular social networking sites can be found at http://www.ebizmba.com/articles/social-networking-websites.

In addition to those that we are most familiar with, such as Twitter (http://www.twitter.com/) or Facebook (http://facebook.com), the following are some additional examples that might be useful in recruiting volunteers, posting information about upcoming events or fundraisers, or simply raising awareness about respite:

- **TakePart.com** (http://www.takepart.com/) or Care2.com (http://www.care2.com/) are social action networking sites where you can find others who support your cause.

- **LinkedIn** (http://www.linkedin.com/) is a professional and business networking site. LinkedIn recently introduced a volunteer experience and causes section (http://www.linkedin.com/profile/edit-volunteering-combined) for its 120 million members.

- **Yahoo groups** (http://groups.yahoo.com/) allow you to set up your own group page to seek respite, share news, link respite providers to family caregivers, and recruit volunteers.

- **Ning** (www.ning.com) calls itself "The World's Largest Platform for Creating Social Websites."

- **Lotsa Helping Hands** (http://lotsahelpinghands.com) is a free-of-charge, private, web-based community for organizing family, friends, neighbors, and colleagues during times of need. You can easily coordinate activities and manage volunteers with the group calendar and communicate and share information using announcements, messages boards, and photos.

- **BlogTalkRadio** (http://www.blogtalkradio.com/) allows you to create your own radio show free of charge. You can develop a regular Internet radio show to talk about your program and recruit and highlight volunteers.

- **ARCH Event Pages or Discussion Forum** (www.archrespite.org) are open to members and others for posting upcoming events, including fundraisers and volunteer days.

Advertisements are great for letting potential volunteers know about opportunities they could become involved in. Several popular modes of advertising are briefly described below, although varying costs are associated with each.

- **Web site**. In 2010, nearly 77% of adults in the United States used the Internet (US Census Bureau, 2011). For an increasing number of people, the Internet is the first place they go to for information or assistance. If your organization has an online presence, a volunteer can easily learn about your organization and its mission and goals. For those with access to the Internet, a visit to your website can help familiarize potential respite volunteers with your work and with opportunities for volunteering. A website is also a great place to describe why volunteers are critical to the success of your organization. Volunteering opportunities as well as locations where volunteer work will take place can also be posted. Some websites have incorporated search portals that allow users to type specific criteria into designated fields, such as city or ZIP code as well as specific keywords. Clicking on the Search button then displays tailored results about volunteer opportunities.

- **Volunteer recruitment portals** are great to use in addition to your website, because having a strong online presence will help attract potential volunteers who may not have been aware of your organization. Volunteers who are not familiar with your organization might not find their way to your web site. Volunteer recruitment portals can help match volunteers with available opportunities based on region of interest and specific keywords. One example of a successful volunteer recruitment portal is VolunteerMatch (www.volunteermatch.org), which posts opportunities on behalf of organizations and acts as an intermediary between organizations and potential volunteers. HandsOn Network (www.handsonnetwork.org) is another.

- **Print materials** such as newspaper ads, community newsletters, brochures, and articles can be very informative, can be distributed in a variety of settings, and can also be personalized for specific communities. While print materials provide potential volunteers with necessary information, it is crucial not to overwhelm the reader with too much information all at once. Print materials should be well organized, concise, written in easy-to-read language, and contain contact information such as a phone number, website, or email address.

- **Public service announcements** (PSAs) are a different way to reach volunteers. They work by developing a marketing campaign that aims to inform the general public about a topic of interest (e.g., caregiving) and publicizing the campaign through various media outlets. PSA's can also be developed for specific points in time that coincide with nationally recognized months that honor certain individuals, events, or conditions (e.g., November is National Family Caregiver Month) and can be broadcast then. For more information on PSA development see http://www.psaresearch.com/bib9803.html

- **Local media** can keep potential volunteers informed of volunteering opportunities in their immediate area or neighborhood. Local media typically devote a certain amount of their time to PSAs. For more information, contact your local media stations and familiarize yourself with local newspapers and reporters.

- **Cable access channels** are another way to keep individuals abreast of what is happening in their communities and provide them with information on how to get involved in respite volunteer opportunities. Some cable channels offer 30-minute interview style infomercials of nonprofits or programs seeking volunteers. Bringing an articulate, enthusiastic volunteer to the interview helps program staff share their mission and volunteer responsibilities and also allows viewers to hear from a "satisfied customer" who can share their passion and joy for providing volunteer respite. Cable access is tailored to include information specific to each community. Contact your local community access station to learn how to post announcements.

- **Promotional items** bearing the program's name and phone number, such as pens, magnets, and chip clips, are relatively inexpensive and can be given away to family caregivers or used as small tokens of appreciation to volunteers. A baseball cap with "Thank you, Volunteer!" can express your appreciation and at the same time advertise the program. If people comment on these items, the volunteer then becomes a voice for sharing the value of the program with others.

Additional effective marketing techniques include disseminating literature about your organization and available volunteer opportunities, attending or partaking in speaking engagements, and attending volunteer fairs to advertise

the presence, scope, and mission of your organization. Volunteer "speed matching," an activity typically hosted by a community center or library, is patterned after speed dating. It allows potential volunteers to have a 5-minute conversation with representatives from as many as 20 nonprofits to gather information about each organization.

Targeted recruitment messages may involve specific incentives for recruiting each type of volunteer. For seniors, advertising the specific health benefits related to volunteerism (e.g., lower blood pressure or living longer) can serve as an effective recruitment strategy (Swinson, 2006; Corporation for National and Community Service, 2006). For many groups of seniors, receiving a small tax-free stipend allows them to more readily volunteer and also increases their personal investment and commitment to the volunteer effort. The volunteer programs Foster Grandparents and Senior Companion Programs, administered by the Corporation for National and Community Service, allow stipends to be waived when counting eligibility for public housing, Supplemental Security Income (SSI), or other federal supports for seniors. Even if a volunteer effort is not funded by the Corporation, it can waive the requirement that a stipend given to a senior for volunteer purposes must be counted as income when determining eligibility for certain federal supports.

Read More:

Volunteer-matching event to be held in Bethel Park. Pittsburgh Tribune-Review, Sunday, August 10, 2008.
http://www.pittsburghlive.com/x/pittsburghtrib/news/cityregion/s_582099.html#ixzz1SURQhiIL

Marketing for the Recruitment of Mentors: A Workbook for Finding and Attracting Volunteers. Ballasy, L. (2004). Portland, OR: Northwest Regional Educational Laboratory.
http://educationnorthwest.org/webfm_send/178/

Effective Practices Guide to Creating Inclusive and Accessible Days of Service. City Cares, Points of Light Foundation, and Youth Service America, 2002.
http://www.nationalserviceresources.org/filemanager/download/711/InclusiveAccessibleService.pdf

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Volunteer Engagement

Once you have identified potential volunteers, it is critical to ensure that the match between the volunteer and your program is a good one. Initially, it is important to make potential volunteers aware of the organization's mission and the need that exists in the community. This should be clearly explained in any discussion that ensues before an application is completed and again during the interview.

Job descriptions. Providing respite volunteers with rules and responsibilities is a proactive way to establish expectations up front and avoid misunderstandings. This also informs volunteers of their active and important role in the success of your program. Sample job descriptions can be made available online through

your organization's website or in print form so that potential volunteers have more information regarding their expected commitment. Job descriptions for respite volunteers should include the following elements:

- Time requirements (e.g., hours per week, days or weekends, daytime or evening),
- Location (e.g., neighborhood in which volunteer opportunities are available),
- Qualifications or special skills,
- Responsibilities, and
- Expected conduct.

For sample job descriptions, see **Appendices pages A13–A15**.

Application process. During the application process, potential respite volunteers will complete a form that contains personal information as well as their preferences for different types of volunteer opportunities, times, and locations. Sample application forms can be found in **Appendices pages A2–A5 and A32**.

A sample orientation checklist in **Appendices page A18** can be used to track which steps in the application process the volunteer has completed and which ones still need to be completed. The checklist is beneficial because it ensures that all steps of the application process have been addressed before volunteers begin their duties. All necessary forms and documents are collected from the volunteer after the checklist and signed agreements or policies between your organization and the respite volunteer are complete. Another benefit of using this checklist is that it helps standardize treatment across volunteers, thus ensuring a fair and consistent selection process.

Interviews. The applications submitted by prospective respite volunteers will need to be reviewed by a designated entity within your organization. The next step is to conduct interviews with applicants who meet the minimum requirements for becoming a respite volunteer so you can decide which applicants will be offered positions with your organization. Individuals who are not selected are notified. Those who are selected will undergo orientation and training where they will become familiar with what is expected of them in their new roles as respite volunteers. Additionally, those being brought on as volunteers should be notified that their acceptance into the program is subject to a criminal background records check, reference checks, and a driving record check should the volunteer's duties involve transporting clients. For sample interview questions, see **Appendices page A34**.

Criminal background and driving record check. To ensure the safety of your clients, criminal background checks should be performed for each respite volunteer before they begin interacting with any clients. If the volunteer is involved in any type of driving tasks for the client or their family, a driving record must be obtained. According to the Privacy Rights Clearinghouse (2008), the most common reasons for performing criminal background checks are

- Public safety,
- Compliance with legal requirements,
- Limitation of liability,
- Conditions of doing business,
- Protection of vulnerable populations,

- Customer assurance,

- Avoidance of loss of business, and

- Fear of business loss, or public or medical backlash over an incident caused by an individual with a past record.

For release of personal information for the Background Check Form, see **Appendices page A10**.

Reference checks. Volunteers should be asked to provide the names and contact information for at least three individuals who have known them for at least two years, are not a family member, and can speak directly to the individual's work ethic, experience with the specific population served, or ability to perform the volunteer respite function. A request for a completed references form should be sent from the volunteer coordinator directly to the potential volunteer; the completed form should then be returned to the volunteer coordinator and kept on file. All references should be verified via a telephone call from the volunteer coordinator. For a sample reference form, see **Appendices page A36**.

Read More:

For further information on background checks and who performs them, as well as tips for your organization, see the **Privacy Rights Clearinghouse** at http://www.privacyrights.org/fs/fs16d-volunteerscreening.htm.

Example of Out-of-Home Group Respite for Adults and the Aging With Memory Loss

The Gathering, A Faith-Based Volunteer Respite Program for Individuals with Early Memory Loss, St. Paul, MN

Program Description

Lyngblomsten, organized in 1906 by Norwegian women, is a nonprofit social ministry organization with the Evangelical Lutheran Church in America, providing quality care through its healthcare, housing, and outreach programs. The Gathering is one of the outreach programs in Home- and Community-Based Services and is offered in collaborative partnerships with churches that provide the facilities and host The Gathering to provide respite to caregivers of individuals with early memory loss. The Gathering was developed in partnership with Como Park Living at Home Block Nurse and Lyngblomsten Care Team Ministry at St. Timothy Lutheran Church in St. Paul, MN, in 2000 to support respite for caregivers. Lyngblomsten was awarded an Age Odyssey Policy Award for The Gathering from the Governor of Minnesota for its creative approach to meeting the needs of the frail elderly through agency and community group collaboration. Since then, The Gathering has spread to multiple church sites and church partners of eight different denominations. Each church hosts twice a month. Where there are churches working together, families can attend weekly by going to two sites if they desire. Churches are waiting to work with the program. In the Twin City area, The Gathering has 200 volunteers with varied backgrounds and has been a Brookdale grant recipient since 2005. Lutheran Services in America, based in Baltimore, MD, is expanding The Gathering nationwide through its Caregiver Suite initiative. The program is known as "First Circle Friends." For more information, including implementation, leader, and volunteer guides, as well as marketing materials, see http://www.lutheranservices.org/first_circle_friends.

Volunteer and Staff Responsibilities

Home- and Community-Based Services (Lyngblomsten) provides the staff of registered nurses and business specialists to support this quality programming. The volunteers plan and run the 5-hour respite day for 8 to 10 participants with early to mid-stage memory loss. There is one volunteer for every participant. Volunteer job descriptions ask for a 1-year commitment. Volunteers are trusted by the community and do not share their faith beliefs with families in the program. Under the guidance of a registered nurse (RN), the volunteers are specially trained to understand the distinctive needs of persons experiencing memory loss. Lyngblomsten trains and mentors the volunteers. The comprehensive training is conducted by the RN coordinator along with ongoing continuing education to remain current in meeting the needs of those with memory loss. Volunteers receive a 4-hour training that includes communication techniques and activity planning for those with memory loss. Lead volunteers receive a 4-hour additional training on best practices for a 5-hour day. All volunteers receive quarterly continuing education on the latest in memory care practices and current statistics showing the serious need for caregivers to receive respite.

Safety Precautions

The RN supervisor is always available to the volunteer in person or by cell phone if a challenging situation should arise. Questions are answered as quickly as possible—a nervous, unsure volunteer is not a satisfied volunteer. Non-hosting churches pay membership fees that cover the cost of criminal background checks for the volunteers.

Volunteer and Family Recruitment

Many sites have waiting lists of those in need of respite to get into the programs. An assessment by an RN

determines appropriateness of this social model program for the care recipient and the level of the caregiver and volunteer's commitment to attend. To maintain the integrity of the program's structure, The Gathering does not accommodate drop-ins or visitors. Volunteers are recruited from the faith community and are rewarded twice a year with special programs, continuing education, and food.

For more information, contact:

Carolyn Klaver RN
The Gathering Coordinator
Lyngblomsten Services, Inc.
Home- and Community-Based Services
1415 Almond Avenue
St. Paul, MN 55108
cklaver@lyngblomsten.org
see http://www.lyngblomsten.org/services/supportive/gathering

National Volunteer Initiative

National Volunteer Caregiving Network (formerly Faith In Action National Network)

The Robert Wood Johnson Foundation (RWJF) funded a number of faith-based initiatives between 1983 and 2008, to support interfaith volunteer caregiving. The project brought together congregations, social service organizations, and others to engage and organize volunteers for providing services. Among the volunteer services provided were friendly visitors, shopping, transportation, home repair, and respite. Individuals received assistance included the frail elderly; those with physical disabilities, Alzheimer's disease or dementia; the terminally ill; and people with developmental disabilities and mental illness. As a result of the RWJF funding, the Faith In Action model emerged. Coalitions made up of groups of congregations representing the communities' various faiths came together to establish a single caregiving program, drawing their volunteers from participating congregations. The key to their success was having a paid coordinator to administer the program. To maintain the interfaith character of the program, the model required that there be no religious proselytizing by the volunteers, thus making services more acceptable to those in need of care who might not share their beliefs. During the course of the initiative, projects were established in every state, Puerto Rico and the Virgin Islands. Even though RWJF funding has ended, more than 600 local programs continue to provide volunteer caregiving services for their neighbors in need. Many of these programs have created a national membership network with a Web site where you can find local programs. For more information about the **National Volunteer Caregiving Network**, call 304-907-0428, or visit http://www.nvcnetwork.org. You can download a free copy of the **Developing an Interfaith Volunteer Caregiving Program: A Start-up Guide** at http://www.nvcnetwork.org/index.php/publications/developing-an-interfaith-volunteer-caregiving-program-a-start-up-guide.

Volunteer Orientation and Training

During the development phase of your program, make sure to draft a plan that will address when training will take place and what type of and how much training your volunteers will need, depending on the various roles they will assume and how much of a time commitment they are making. Your program should offer an orientation or pre-service training for all volunteers, more in-depth training related to specific roles the volunteers may assume, and regular in-service training for volunteers who have made or are considering making longer-term volunteer commitments. For Event Respite, the training approach you use will have to be condensed but effective for a broad array of volunteers. The key is knowing in advance the levels of and types of training you plan to offer and to whom. It is also a good idea to research and select proven training curricula appropriate to the levels and types of training you plan to offer. If your program plans to develop its own training materials or revise other curricula, you need to allow sufficient time to field test the training protocol in advance by using current staff for feedback and suggestions for revision.

Orientation

Once the application process, interview, and reference and background checks are complete, all volunteer applicants who qualify should be notified about their new status with the organization and provided with a date and time when they can attend an orientation. Even if they were engaging in a one-time respite event, some mechanism for sharing the information below would be beneficial, especially if you would like them to return to assist with additional events. For this type of **Event Respite**, an orientation could be condensed into 1 hour preceding the event. Alternatively, the information could be made available in print form and shared with volunteers when they arrive or sent to them by mail prior to the event. By signing off on the material, they would indicate that they had read and understood the expectations.

The way in which the information is shared during an initial orientation and subsequent training illustrates as much about your organization as the type of information does. "Do volunteers feel welcomed and valued the moment they come through the door? If possible, is the session planned so that more than one method of training is used to in order to meet the needs of various learning styles? Is the session reasonable in length, with time allowed for questions and breaks?" (North Carolina Respite Care Coalition, 2011).

Content for an orientation might include the following topics:

- History of your organization
- Introduction to following broad topics:
  - Family caregiving
  - Disability/chronic illness
  - Aging issues

- Diversity, and
- Recognizing and reporting neglect and abuse, and
- Volunteer roles and responsibilities.

Consider creating a volunteer handbook that can serve as an important part of orientation and as a convenient reference tool. You may want to include summaries of policies and procedures; general information, such as office locations and contact information; a welcome message from the program director; definition of terms or acronyms, sample forms, timesheets (importance of reporting hours), volunteer rights and responsibilities, and information for volunteers with disabilities, including inclusion, accessibility, and accommodations.

Read More:

For more information on creating a volunteer handbook, see Creating a Volunteer Handbook, Corporation for National and Community Service Resource Center, Tools and Training for Volunteer and Service Programs at http://www.nationalserviceresources.org/practices/17451.

An example of a volunteer handbook developed by the National Wildlife Federation can be found at http://www.councilofnonprofits.org/sites/default/files/Vol%20Handbook%20policies%20and%20proc%20sample.pdf.

History of Organization

During the orientation process, respite volunteers should be provided with background information about your organization and its history. The mission, values, goals, and structure of your organization are important elements to communicate to volunteers because they may be curious about these aspects or even want to share more with others about how great your organization is and their involvement with you. Possible topics for discussions include

- When the program was founded,
- How it has expanded throughout the years and its current status,
- The nature of the programs and services,
- Organizational structure (number of employees and volunteers), and
- Number and kinds of individuals served through the respite program.

Sharing information about your organization and how respite volunteers fit into its structure and how invaluable their services are to your operations will help volunteers feel welcomed and more closely connected to the work of the organization. It is important to emphasize the importance of volunteers in helping your organization achieve its goals, thank respite volunteers for their commitment, and guarantee your support in helping volunteers succeed in their new roles (Volunteers of America; Volunteer Handbook: Supervisor Curriculum, 2010).

Introduction to Topics in Volunteering

While more in-depth training will follow, depending on the respite role the volunteer assumes, some examples of topics that might be introduced during orientation are (1) the demographics, benefits, consequences, and types of

family caregiving; (2) an introduction to **disabilities and chronic conditions,** including demographics, the use of person-centered language, disability etiquette, and overarching medical concerns that may affect people with different disabilities such as seizure disorders; (3) an overview of **aging issues,** such as normal emotional, physical, and cognitive changes, as well as dementia and related conditions; (4) **diversity and cultural sensitivity;** and (5) responsibilities regarding recognizing and reporting **abuse and neglect.**

Volunteer Roles and Responsibilities

The respite volunteer will need clear guidelines that specifically describe what their role will encompass. Having clear expectations will ensure that volunteers understand what is required of them in order to successfully perform their duties. Guidelines also help protect vulnerable individuals, ensure their safety, and minimize the likelihood of any potential problems. It is expected that respite volunteers will

- Keep all client information confidential;
- Treat their clients and their families with respect;
- Show up on time for all previously arranged commitments;
- Respect client and family decisions and instructions;
- Perform their respite duties to the best of their abilities;
- Follow all policies and procedures as established by the program;
- Complete all necessary documentation and reporting;
- Contact immediate supervisor with any issues, questions, or concerns and
- Be aware of their rights as volunteers, including the ability to turn down requests made by the organization or care recipients and family caregivers if it is not part of their initial agreement.

To ensure that volunteers are clear about their roles and responsibilities and are on track throughout their volunteer careers, it is important to use a service agreement. A volunteer service agreement is also an excellent risk management tool, and it provides the basis for holding volunteers accountable. Volunteers want to succeed, and by being explicit about your requirements and rules, you are empowering them to succeed and serve safely. Implementing volunteer service agreements is also a critical step because your organization will want to ensure that volunteers are committed to their future functions before it invests time, money, and energy into their training and supervision.

The volunteers should be trained on the volunteer service agreement in a group setting so they can ask questions and to ensure that the agreement is understood. Once respite volunteers have been introduced to the volunteer service agreement and have had ample opportunity to read through it on their own, they will need to sign it, thereby indicating that they understand and agree to the outlined terms. Copies should be provided for volunteers to take with them, and the original signed papers should be placed in their file. The signed paperwork serves as an agreement to the job assignment and lets the volunteer know what is expected from him or her in order to be successful. For sample volunteer service agreement, see **Appendices pages A6–A7**.

Training

Some of the topics that you might include in pre-training for committed volunteers were mentioned in the Orientation section. This section is in no way inclusive in its references to available or appropriate training curricula nor does it contain an exhaustive list of training topics you may want to cover, depending on your program, the needs of the care recipient and family caregiver, and the learning styles of your volunteers. Instead, we have included summaries of generally recommended training topics for your respite volunteers. Depending on the roles and responsibilities the volunteers will be assuming and depending on who they are providing care for, you may want to include some or all of the following topics or add your own:

- Family Caregiving "101",
- Disability and Chronic Care Issues,
- Community Integration and Person-Centered Planning,
- Aging Related Changes,
- The Volunteer's Routine Caregiving Responsibilities,
- Diversity and Cultural Competency,
- Basic Medical Training,
- Communication,
- Maintaining Confidentiality
- Ethical Issues, including Reporting Abuse and Neglect,
- Documentation and Reporting Expectations, and
- Policy and Procedure Review.

Once a volunteer is matched to a family caregiver and a care recipient, more individualized in-depth training may be necessary, depending on the needs of the care recipient and family caregiver.

Family Caregiving "101"

As described in the Introduction, a family caregiver is any person providing care on an ongoing basis for no or minimal compensation for an individual who may need assistance. Often, caregivers are family members who have many other roles and responsibilities in addition to their caregiving tasks (e.g., working full time outside the home or raising children). The majority of caregivers—about three-quarters of them—happen to be women caring for their aging parents. However, a family caregiver may be a friend, neighbor, or foster parent who provides ongoing care and support. Caregiving can take many forms and may include any of the following elements (Family Caregiver Alliance, 2009):

- Cooking, cleaning, doing laundry or going grocery shopping for someone,
- Driving someone to medical appointments, the pharmacy, or the store,
- Handling someone's finances and scheduling their appointments, and
- Helping with one or more activities of daily living, including feeding, helping someone get into and out of bed, dressing, bathing, and transporting.

Because being a caregiver is so time-consuming, family caregivers often spend less time taking care of themselves than they normally would and ultimately end up neglecting their own health. Caregivers suffer from stress, anxiety, and depression as well as a number of chronic conditions at higher rates than noncaregivers (Family Caregiver Alliance, 2006; Schulz and Sherwood, 2008; NAC, 2009). Given the above reasons, it is easy to understand why respite is crucial and why respite volunteers are invaluable resources who greatly benefit not only care recipients, but their caregivers as well.

Read More:

For more information about family caregiving, see the Family Caregiver Alliance at http://caregiver.org; the National Family Caregivers Association at http://nfcacares.org; and the National Alliance for Caregiving at http://www.caregiving.org/.

Disability and Chronic Care Issues

The Americans with Disabilities Act (ADA) defines disability as "a physical or mental impairment that substantially limits one or more of the major life activities of an individual." There are different types of disabilities that can be categorized as sensory (e.g., visual, hearing), cognitive, developmental, or physical. Some conditions in both children and adults are related to mental health disorders. Disabilities exist from birth in some cases, as a result of injury, or from a disease. When an organization is serving individuals with a specific disabling or chronic condition, or if a volunteer has been matched with someone with a specific condition, then the specifics of that condition would be provided in additional follow-up training opportunities for the volunteer. For introductions to a limited number of disabilities and chronic care issues developed by Easter Seals, refer to **Appendices pages A53–A63**. You can find information on neurological conditions, including amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), brain injury, spinal cord injury and epilepsy in **Appendices pages A64–A67**. For individuals with mental health conditions, see **Appendices A68–A70**. For children with other chronic health conditions, see http://cshcn.org/diagnosis-information.

Read More:

When working with individuals with disabilities, a volunteer should treat them with dignity and respect. For etiquette techniques that have been developed by Easter Seals, see http://www.easterseals.com/site/PageServer?pagename=ntl_etiquette.

For more information on respite for specific populations, see ARCH Fact Sheets at http://www.archrespite.org/productspublications/arch-fact-sheets.

Community Integration and Person-Centered Planning

Volunteers should be made aware of the broader context of the long-term services and support systems in which they are participating. Because of the costly nature of long-term care (e.g., nursing home stays) as well as national policy that permits individuals with disabilities the right to live and work in the least restrictive environment, there is currently an increased effort to support individuals with disabilities or chronic illnesses to live and work in their communities for as long as possible by providing them with necessary supports. Because of these policy changes, coupled with the growing population of older adults, there will be an increased need for respite volunteers to assist family caregivers who provide the majority of long-term services and supports in the United States.

At the same time, an increased focus on person-centered planning has helped change society's view of individuals with disabilities and the aging population as being dependent to individuals who have a right to live as independently as possible. Person-centered planning is an ongoing problem-solving process that can be used to help people with disabilities and older individuals plan for their future. According to the Pacer Center, the Minnesota Parent Training and Information Center, funded by the US Department of Education's Office of Special Education Programs, the purposes of person-centered planning are to

- Look at an individual in a different way;
- Help the focus person in gaining control over his or her own life;
- Increase opportunities for participation in the community;
- Recognize individual desires, interests, and dreams; and
- Develop a plan, through team efforts, to turn dreams into reality.

Respite volunteers should be sensitized to person-centered planning and engage in activities and discourse with the care recipient that respect and help promote the concept.

The Aging Process & Related Health Changes

Age-related changes are inevitable and are bound to occur as individuals get older. Not everyone experiences these changes in exactly the same way, but it is important to note that older adults may not be able to function as they once did and may require additional assistance with everyday tasks. Changes may include impaired hearing (inability or lowered ability to detect certain pitches or frequencies), changes in vision (e.g., longer time to adapt to change from light to dark environment, decreased acuity, and lowered ability to read small text), slowed reaction time to environmental cues (e.g., taking longer to apply the brakes in case the car needs to stop suddenly), and decreased mobility or ambulatory ability.

Respite volunteers should be aware of these changes so they can have more effective interactions with their family caregivers and care recipients. For example, older adults may be self-conscious about these changes that they simply cannot control and may be resistant to relying on others for assistance. Respite volunteers need to be sensitive to this self-consciousness and will need to assist older individuals without compromising their dignity and by not taking away their remaining independence in doing some of the things they are still able to do for themselves. Similarly, volunteers should be educated about strategies that they could use to help make up for some of these sensory

declines (e.g., speaking more slowly and more clearly, using a louder tone of voice, and standing closer to someone who may have hearing issues).

Older adults may compensate for some of these changes by using hearing aids, using glasses (bifocals or trifocals) or magnifying devices for reading small type, by ordering large-type reading materials, and by driving only during the day. It is critical to note that the older adult population is the most diverse of all populations and also that not all older adults are affected in the same way by these natural age-related health changes, and certainly not to the same degree. Respite volunteers should be aware that these processes occur but should not make any assumptions about any care recipient's functional ability level. It is best to ask family members or the care recipients themselves what they are having trouble with or if they have noticed any changes in themselves, which may be affecting their health or well-being.

Read More:

For a detailed reading on age-related health changes, see the **American Psychological Association's** website at http://www.apa.org/pi/aging/resources/guides/older-adults.pdf.

For in-depth training on an Overview of the Aging Process and its Impact on the Family (Chapter 2), see **Caring to Help Others: A Training Manual for Preparing Volunteers to Assist Caregivers of Older Adults** at http://www.caringtohelpothers.com/pdf/Caregivers_section_02.pdf.

The Volunteer's Routine Caregiving Responsibilities

A respite volunteer's caregiving responsibilities will depend on who the care recipient is and on the care recipient's strengths and abilities. Some care recipients may need assistance with getting dressed, eating, getting up, or moving from place to place, while others will be able to perform some or most of these tasks on their own. Caregiving responsibilities are also dictated by the care recipient and their family caregiver's needs and preferences. Some family caregivers may feel comfortable having volunteers administer medication, for example, while others may not. In addition to care recipient and family preferences, your respite program may have certain policies that will need to be followed in regard to allowing or prohibiting certain caregiving tasks. The following list includes a number of responsibilities respite volunteers may be expected to perform during their visits with care recipients:

- Keeping a care recipient company and engaging in conversation;
- Providing supervision;
- Engaging the care recipient in activities of their choosing (e.g., watching a movie, listening to music, looking through photographs, reading, attending worship, gardening, playing games, emailing friends or family, and maintaining social activities and connectedness);
- Providing help with food, help with meal preparation, or help with eating;
- Helping the care recipient use the bathroom;
- Assisting the care recipient with dressing or changing clothes; and
- Assisting the care recipient in getting up and moving around.

As previously mentioned, the best way for a respite volunteer to be sure they are performing all the tasks and duties that are expected of them is to communicate clearly and openly with family members about their needs and preferences and with respite program supervisors to determine which respite activities are permissible.

> **Read More:**
>
> For in-depth training on Primary Caregiver Responsibilities, the Basics of Caregiving (Chapter 6), see **Caring to Help Others: A Training Manual for Preparing Volunteers to Assist Caregivers of Older Adults** at www.caringtohelpothers.com/pdf/caregivers_section_06.pdf.

Diversity and Cultural Competency

Diversity refers to the individual differences found among family caregivers and care recipients a respite volunteer might come into contact with or serve. It is critical for a volunteer to understand that diversity can refer to a number of factors including, but not limited to, the family caregiver's or care recipient's

- Age;
- Gender;
- Race/ethnicity, religion or culture;
- Disability, medical condition, or diagnosis;
- Social support and relationships;
- Sexual orientation; and
- Family composition (e.g., single heads of households, grandparent or other relative as head of household, or LGBT families).

There are differences between older and younger adults, as well as variations within an identified population. In addition, individuals diagnosed with the same condition may experience it in completely different ways. It is important to be mindful of the diversity that exists among care recipients and treat each care recipient as an individual. A respite provider's lack of knowledge and understanding about the culture of those they serve, including traditions, history, values, and family systems, can hamper the optimal delivery of services (Smedley, 2003).

Factors such as socioeconomic status, familial interdependence, level of acculturation, immigration status, and fear of stigma in response to a disease or physical disability may influence minority group members' experiences of caregiving. Those factors might also make those caregivers less likely to receive social and professional support services, potentially causing them to suffer levels of distress that are much greater than those documented in samples of nonminority caregivers (American Psychological Association, 2011). For example, because of previous experience with hostility or harassment, many LGBT older adults are reluctant to access mainstream aging services, which increases their social isolation and negatively affects their physical and mental health (Movement Advancement Project, 2010). Moreover, cultural experiences define how care recipients and caregivers receive information and how they make choices. By learning the core cultural values of the major ethnic and other minority groups represented in the community, volunteers can provide better care (Webb, 2008).

While cultural competence is vital, it is not a replacement for getting to know the family caregiver and care recipient. Information obtained at an assessment or intake should be focused on identifying personal preferences, values, and support needs. For example, for an in-home service setting, it may be helpful to ask the family to envision the type(s) of volunteer that would be most compatible with their household and family members. This information along with cultural considerations may help you achieve a higher level of match, satisfaction, and service longevity of volunteers.

Cultural competency is an important concept because it posits that in order for respite volunteers to perform their work in the most effective way possible, they must have an understanding of care recipient's and the family caregiver's needs and values. As important, volunteers should be recognized for their own cultural values, and equal time should be allowed for getting to know them in order to support quality service and good matching between the volunteer, the care recipient and the family caregiver.

There are training materials available for enhancing cultural competence among volunteers. Interactive materials that allow an individual to relate to someone who is not in the "dominant culture" seem to be most effective. Presenting an opportunity to assess their own cultural biases may help volunteers identify areas where they need to improve. For a training exercise to assess cultural bias, see **Appendices page A17**.

Read More:

See the following for more detailed information and resources regarding cultural competency:

- The **Office of Minority Health** website at
  http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=1&lvlID=3

- **National Center for Cultural Competence**, Georgetown University, Center for Child and Human Development at http://www.gucchdgeorgetown.net/NCCC/journey/

- Health Resources and Services Administration, US Department of Health and Human Services website has training resources on **Culture, Language, and Health Literacy** at
  http://www.hrsa.gov/culturalcompetence/index.html

- **Cultural Competence**, National Resource Center on LGBT Aging at
  http://www.lgbtagingcenter.org/resources/resources.cfm?s=4

For practical applications for serving family caregivers in culturally responsive ways, see American Psychological Association, Caregiver Briefcase, **Variations for Practice for Culturally Diverse Groups** at http://www.apa.org/pi/about/publications/caregivers/practice-settings/cultural-issues/index.aspx.

Basic Medical Training

Respite volunteers should receive general medical training for their own benefit as well as that of the care recipients. Although medical care is not necessarily to be provided to care recipients by the volunteer and depends on the

family's wishes in combination with your program's policies, volunteers may find themselves in a rare emergency situation where some training would be greatly beneficial.

Your program therefore should decide if it will provide any type of training such as cardiopulmonary resuscitation (CPR) or infection control so that volunteers are prepared if they have to face life-threatening emergencies. CPR on is performed when an individual stops breathing or when their heart stops beating by delivering either chest compressions or coupling those compressions with rescue breaths. Infection control, or strategies for decreasing the likelihood of spreading infectious disease, may be another worthwhile training topic. Volunteers should be educated about the invaluable benefits of washing hands regularly, especially if they come into contact with care recipients whose health is compromised. Similarly, exposure to blood or other potentially infectious materials can pose a hazard for volunteers. Training should be provided so that volunteers can perform their duties in a safe way while minimizing their risk of exposure. In addition, check state laws and requirements regarding medication administration and any other restriction related to provision of direct medical or emergency care.

Read More:

For more information about **CPR classes and certification**, see www.redcross.org. A reference sheet compiled by the American Red Cross with steps involved in hands-only CPR is available at http://www.redcross.org/www-files/Documents/pdf/training/HandsOnlyCPRsheet.pdf.

Another resource is the University of Washington's School of Medicine website, which contains detailed **step-by-step CPR information** as well as video demonstrations as a free public service at http://depts.washington.edu/learncpr/.

To learn more, see **Infection Control from Medline Plus**, a service of the US National Library of Medicine at http://www.nlm.nih.gov/medlineplus/infectioncontrol.html.

For more information about **blood-borne pathogens**, your organization's legal responsibilities, and possible solutions or tips on how to devise a safety protocol, see the US Department of Labor, Occupational Safety & Health Administration (OSHA) website at http://www.osha.gov/SLTC/bloodbornepathogens/index.html/.

For more tips on how to prevent the spread of the disease, see *ARCH Respite Fact Sheet 42: Preventing the Spread of Disease* at http://www.archrespite.org/images/docs/Factsheets/fs_42-preventing_spread_disease.pdf. Although this Fact Sheet focuses on children, it may provide useful information regardless of the age of the care recipient.

Communication and Interaction

Care recipients interests and goals. In order to help care recipients preserve their dignity, respite volunteers should realize the importance of involving care recipients in decisions. Instead of assuming that a care recipient will need help with certain tasks, it is better to be open and ask them to let you know when or in what ways they may require your

assistance (e.g., not everyone will need help using the bathroom, changing their clothes, or eating). Depending on others for help with activities of daily living can be very difficult for many, especially for a care recipient whom the volunteer has just met and who still regards the volunteer as a stranger. In order to build a good relationship, volunteers should be respectful and never make assumptions about their care recipient's needs. Volunteers can inquire about a care recipient's favorite activities or how they would like to spend their time together. Instead of assuming someone wants to watch TV, asking the care recipient about their activity of choice demonstrates respect for the care recipient's independence. Following a schedule that the care recipient is comfortable with allows them to feel in control of their day and routine and will foster a positive relationship with the volunteer.

Training should also address the way in which volunteers interact with individuals with disabilities or with the aging population. Such individuals are entitled to the same courtesies you would extend to anyone, including personal privacy and respect. This concept was expounded on by Wolf Wolfensberger who coined the term social role valorization (SRV) and follows the principles of normalization. The major goal of SRV is to create or support socially valued roles for people in society, because if a person holds a valued social role, that person is highly likely to receive from society those good things in life that are available (Osburn, 2006; Wolfensberger, 1998). There are excellent training curricula for a more in-depth understanding of these concepts.

Read More:

For more information on social role valorization and training materials, see http://www.socialrolevalorization.com/training/index.html.

Establishing boundaries. A respite volunteer must clearly express to care recipients, family caregivers, and their family members what their availability is at the onset of their partnership. Volunteers must express, in advance, what their weekly hourly commitment will be, in case something comes up and the family requests additional services beyond the capacity of the volunteer. Establishing boundaries is critical for avoiding volunteer burn-out. Volunteers should feel as though it is okay to say no to extraneous commitments beyond what they have previously agreed to and they should be made aware of the rights of the family caregivers and care recipients to be able to express their needs and desires. The volunteer's supervisor can play a vital role in helping maintain boundaries between the family caregiver, care recipient, and the volunteer if the situation becomes challenging.

Person-centered or person first language eliminates the use of antiquated negative terms, such as birth defect and handicapped. Most importantly, person first language always puts the person first, and if it is necessary to speak of a person's disability, that is always secondary. An individual is always a person first, that is, a person with a disability.

Expectations of volunteer in the caregiving role. It is imperative to have clear communication about what is expected of respite volunteers in their caregiving roles. The personal needs and preferences of the family caregivers

and care recipients should be made known to volunteers at the outset. Clearly defined expectations will help volunteers stay on track and be sure that they are performing the duties specifically asked of them. A key point is that a discussion about family needs and preferences should occur between the volunteer and the care recipient's family. This discussion will include a family's expectations of what duties or tasks a volunteer should be performing in their absence.

Volunteers, of course, must listen and honor care recipient and family needs and requests, as long as they are consistent with general guidelines established by the respite program. In the event that changes in relationships or family roles occur, volunteers should be notified. If these new relationships concern volunteers in some way, how the change is affecting the care recipient or family caregiver (or volunteer) should immediately be discussed with a respite program supervisor.

Maintaining Confidentiality

While optimal communications between volunteers and families are encouraged, respite volunteers should be made aware at the outset that they are not to share any information about the individuals they work with or their families. The respite program will most likely provide volunteers with sensitive information about the care recipient, usually including their medical history, routines, and personal preferences. Respite volunteers will also learn about individuals as they spend time with them and it is very important that trust and confidentiality are developed and maintained between volunteers, care recipient and family caregivers. For sample confidentiality policies, see **Appendices pages A8, A9, and A21–A23**.

At the same time, volunteers should be encouraged to share their positive experience with others by addressing their role and volunteer satisfaction with the organization and not by naming the care recipient or providing identifying information such as address or status. Training should cover this issue, and certain safeguards should be put in place at this time, such as a confidentiality agreement, which will describe what is expected of the volunteer. For sample confidentiality agreements, see **Appendices page A9**.

The Health Insurance Portability and Accountability Act (HIPAA), was signed into law in 1996. A main component of HIPAA aims to ensure that medical information of care recipients who are receiving medical care remains private. Volunteers should be informed of HIPAA during training and are expected to sign a HIPAA agreement. A copy of aHIPAA agreement is included in

Appendices page A8. Volunteers should review this material and sign the form to demonstrate that they have read and understood HIPAA requirements.

Ethical Issues

When respite volunteers are performing their duties, there is the rare possibility that they will be faced with ethical issues. For example, they may learn that the care recipient has been neglected by family members. This poses the question of what the volunteer's ethical obligation is toward the care recipient, family, and the volunteer program. It is important to emphasize that respite volunteers should maintain an open line of communication with their direct supervisor and immediately discuss any concerns. The program should develop documentation tools to be completed by the volunteer and future steps to be undertaken by the respite program, such as reporting this or other matters to proper authorities. For a sample Incident Form, see **Appendices page A11**.

Recognizing and reporting neglect and abuse. Your organization will be responsible for educating volunteers to recognize neglect and abuse and understand their obligation to report it. There are many types of abuse including physical abuse, neglect, sexual abuse, exploitation, and abandonment. Children and adults with disabilities as well as the aging are often at higher risk for abuse or neglect, so issues regarding identification and reporting of abuse should be introduced here. Without adequate family supports, children with disabilities are almost four times more likely to be victims of neglect, physical abuse, or emotional abuse, and almost three times more likely to be victims of sexual abuse than children without disabilities (Sullivan & Knutson, 2000). About 30% of children in foster care have severe emotional, behavioral, or developmental problems, requiring foster families to look to respite for support and a necessary break from caregiving (American Academy of Child and Adolescent Psychiatry, 2005).

Although it is known that in 90% of all reported elder abuse cases, the abuser is a family member, it is not known how many of these abusive family members are also caregivers. Researchers have estimated that anywhere from 5% to 23% of all family caregivers are physically abusive. Most agree that abuse is related to the stresses associated with providing care (National Center on Elder Abuse, 2002).

It is also important to understand and clearly communicate your state's child abuse and neglect reporting procedures to volunteers. Identifying and reporting suspected abuse or neglect should be addressed by local, county, or state authorities who can give specific reporting protocol for that volunteer's particular area. This step would include identifying mandated reporting procedures, anonymous reporting, and permissive reporting (in states where that is

Read More:

For more information about recognizing and reporting child abuse and neglect, see the Child Welfare Information Gateway, **Identification of Child Abuse & Neglect** at http://www.childwelfare.gov/can/identifying/.

For information about abuse and neglect among the aging population, contact the **National Center on Elder Abuse/NCEA** c/o University of Delaware Center for Community Research and Service, Newark, DE 19716 or see www.ncea.aoa.gov; ncea-info@aoa.hhs.gov.

an option). In addition, it is vital to share and review any internal agency Confidential Incident Reports that need to be completed as a result of any reporting.

Documentation and Reporting Expectations

To ensure the safety of volunteers and care recipients, respite volunteers should be clear about what is expected of them in terms of reporting and documenting a variety of issues that may arise. Volunteers have certain rights, as well as obligations, to protect their own and their care recipient's well-being. Therefore, all volunteers should be familiar with their duties, as well as the program's guidelines for reporting various incidents, including suspected abuse and neglect, incident or accident reporting, and emergency procedures. Aside from the process a volunteer must follow when documenting events, volunteers must also be trained on logistical issues, including where to get the necessary forms, when and how to fill them out appropriately, and who the completed forms should be delivered to. For a sample Incident Form, see **Appendices page A11**.

Policy and Procedure Review for Volunteers

When the training of respite volunteers is complete, a final review of policies and procedures should be conducted before the volunteers meet care recipients, family caregivers and their families (see Policies and Procedures section). At this point, it is important that volunteers are knowledgeable about and comfortable with their new role and that they feel confident to meet the respite program's expectations. Remind your volunteers that a supervisor is always available to provide support and that they are not alone if they have any concerns. When initial training is completed,

- Answer any further clarifying questions volunteers may have.
- Provide volunteers with all necessary documentation (e.g. Policies and Procedures, Service Agreement, Training Reading Materials, Volunteer Handbook).
- Collect all necessary signed documentation (e.g. Service Agreement, HIPAA and confidentiality agreement(s), Policies and Procedures, Background Check Form)
- Provide volunteers with detailed contact information for their immediate supervisor and encourage open communication throughout the duration of their respite volunteer role.
- Provide volunteers with contact information for the care recipients and family caregivers as well as what their schedule will be; if matches are yet to be made, explain the process to the volunteers and tell them when they should hear back from you with an assignment.

Volunteer Management

Once respite volunteers with great potential are selected for your program, the next step will be to match them carefully and deliberately with care recipients and family caregivers, provide guidance and support to maintain the relationships that develop, provide expert and ongoing supervision in all areas of volunteer management, and be respectful of the scheduling needs of the volunteers.

Volunteer Assignment: Matching Volunteers With Family Caregivers and Care Recipients in Your Program

Matching volunteers with care recipients and family caregivers is based on factors such as their interests and skill sets, their schedule and availability, and whether they can effectively meet the needs of the family looking for support. Some respite volunteers have a certain preference for the population they would like to be engaged with (e.g., children, older adults, individuals with disabilities). Taking these preferences seriously and tailoring experiences to volunteers' preferences will make them feel as though they are an important part of your organization and may help keep volunteers satisfied in their roles for longer periods.

In addition to honoring preferences, it is important to keep in mind that volunteers usually have some type of working experience. Drawing on their previous experience can be very helpful with volunteer assignments. For example, people who have experience in teaching, nursing, social work, physical or occupational therapy, or health care have special training and are likely used to interacting with those who have more serious disabilities or health conditions and really enjoy working with them. Students in these disciplines are also great resources. The benefit of using volunteers with this type of prior experience is that they already understand the many factors associated with providing care. However, making use of the valuable experiences of other individuals from different vocational backgrounds, coupled with the proper training and orientation, will prepare them to excel in their respite volunteering roles as well.

One critical component of creating matches is being aware of the volunteer's, care recipient's and family caregiver's schedules and being able to coordinate them. For example, if a volunteer has time available in the mornings, but a family caregiver needs them in the evenings, this type of arrangement will not work out. Similarly, the days of the week during which respite could be provided by volunteers should be compatible with the family's needs. In addition, the amount of time volunteers can devote to their respite role should be taken into account when creating matches with families. Volunteers have lives of their own full of other responsibilities and will probably be able to fulfill their role as a volunteer for only a limited amount of time (a set number of hours per week). These time limitations should match up with the family's need for support. For example, if a volunteer can dedicate 4 hours each week

for respite work, but a family needs someone to provide relief for 6 hours, different arrangements should be made. Perhaps a different volunteer would be more suitable for that specific family, or if the respite program and the family allow, two volunteers can contribute to meeting respite needs.

Schedules are only one criterion on which a match should be based. An organization should have a matching policy that also includes criteria for evaluating the match from the volunteer's, care recipient's, and family caregiver's perspectives (e.g., geography, gender of care recipient, commonalities, ability to perform the tasks related to the care, and energy level or activity expectations of the care recipient).

How the match will be made should also be thought out in advance and included in program policy. The following are examples of questions that should be addressed in advance:

- Are volunteers assigned?
- Do they get to choose from a pool of potential care recipients and their family caregivers?
- Do family caregivers and/or care recipients choose from a pool of providers?
- Should the volunteer expect to read any profiles of waiting care recipients and their family caregivers?
- Should the family caregivers and/or care recipients expect to read volunteer profiles?
- Are volunteers likely to be matched with care recipients they would be friendly with in other circumstances?

National Volunteer Initiative

The Brookdale Foundation's National Group Respite Program.

The Brookdale Foundation's National Group Respite Program is a social adult day care model that provides dementia-specific group activities for participants and respite time for caregivers. The Brookdale Foundation funds 15 programs annually. Grants are for $7,500 in the first year, and $3,000 in the second year. Applicants must be nonprofit organizations or public agencies seeking to provide dementia-specific day services. Programs must be based on a social day service model and provide caregiver services. Services must be available for at least 4 hours a week. Programs must be staffed by at least one paid professional staff member who is responsible for the supervision of program assistants, including trained volunteers and students.

Sponsoring organizations must provide 100% matching funds in either cash or in-kind support. Applicant organizations must demonstrate that a concrete fundraising plan has been established to sustain ongoing services. Most programs operate on annual budgets of $15,000 to $20,000. Information about delivering a package of core services using the Brookdale model and the grant application process can be found on the Brookdale Foundation Group National Group Respite Program website (http://www.brookdalefoundation.org/Respite/respiteprogram2008.html). Contact: Evelyn Yuen, Technical Assistance Resources Manager, Phone: (510) 540-6734, Fax: (510) 540-6771 or e-mail: ey@brookdalefoundation.org.

- How does the volunteer actually match?
- Does a staff person accompany them for the first visit?
- Is it a cold call?
- Does the match take place in an agency setting?
- Is there a process or procedure for addressing compatibility?
- What are the steps if the match is not a good fit?

Unlike in a work situation in which people are assigned, the volunteer and family must feel as though there is a good fit in order for the volunteer to return to the assignment on an ongoing basis. Are there guidelines established for both the volunteer and the family to indicate at the time of the initial match that it would not be conducive to further interaction?

Your program should emphasize that if volunteers are unhappy with a match that was made, it is their responsibility to raise that issue with their immediate supervisor. Similarly, if care recipients, family caregivers or their families are dissatisfied, they must be told whom they should contact to discuss their concerns.

The Volunteer's Relationship with the Care Recipient and Family Caregiver

After your organization has created a match between a respite volunteer and a care recipient and family caregiver, the volunteer work begins. To facilitate a good working environment and create a mutually respectful relationship, it is imperative that your volunteers establish good rapport with those they are serving (see Communication under the section on Training). Family members often entrust volunteers with their home, belongings, and a fellow family member. Respite volunteers are initially strangers and trust must be earned, which is why it is critical to start building positive relationships right away. Volunteers can develop rapport by

- Showing care recipients and family caregivers that they are dependable by showing up for respite commitments,
- Being punctual so that family members can see that the volunteer is a dedicated individual and honors his or her commitments,
- Listening to and following the preferences and needs of care recipients and family caregivers,
- Having a positive attitude and being enthusiastic, and
- Performing duties to the best of their ability.

If volunteers are unsure of what the family requires, they should be told that it is okay to ask. Family caregivers will appreciate that volunteers want to respect their wishes. Volunteers need to be sensitive to family roles and dynamics and not overstep their boundaries. Relationships are different from family to family, as are family interactions, which is why volunteers should pay attention to the ways in which roles manifest with the care recipients and families they are working with. These interactions, roles, and dynamics should be respected and not judged or corrected by the volunteer according to their own beliefs, expectations, or experiences. Additionally, certain negative interactions may be indicators of abuse or neglect. If volunteers witness or suspect abuse or neglect, it is their responsibility to document and report the incident(s) to their immediate supervisor.

Event Respite Example

The Volunteer Respite Program, Family Friends Saturday Respite, Easter Seals Greater Washington-Baltimore Region

Program Description

Easter Seals' Family Respite Services provides much-needed relief care and support for family caregivers of children with intellectual disabilities through a diverse group of carefully selected and well-trained volunteers interacting with the children who have intellectual disabilities and their siblings. The Program offers inclusive hands-on educational and therapeutic activities that address fine and gross motor skills designed to reinforce children's individual educational goals and stimulate social and emotional developmental skills.

The Respite Program hosts monthly Saturday respite care events at Easter Seals Inter-Generational Center (IGC) in Silver Spring, MD, and on Community Respite Trips throughout the area. During in-center respite events, children with intellectual disabilities were provided with stimulating activities while they interacted with other children and engaged in such things as arts and crafts, cooking activities, and outdoors play. The Community Respite Trips provide enriching experiences to various community locations, including museums and educational centers such as the Maryland Science Center, Port Discovery, the zoo, petting farms, and pumpkin patches.

Volunteer and Staff Responsibilities

The Program started its volunteer base with a group of volunteers 55 years and older, but now it maintains a group of about seventy volunteers ages 15 and up. Volunteers are recruited to provide 1:1 attention for children with and without disabilities during our Saturday events. Easter Seals staff are present and aid volunteers with children's toileting, diapering, g-tube needs, medical needs, and dispensing of medication.

Safety Precautions

To ensure safety, all families fill out a "Getting to Know My Child" (GTKMC) form for all children participating in the program and discuss any additional concerns and/or needs with Easter Seals staff. Family files includes the GTKMC form, signed HIPAA confidentiality agreement, photo release, release of liability, emergency contact (medical and family), release form, and any additional notes. Safety precautions for all volunteers include requiring a background check, never leaving a volunteer alone with a child, and a short safety orientation during the half hour preceding the event. The orientation includes safety precautions, plans for the day (verbal and printed), as well as detailed information about the child they will be matched with. Information includes the child's name, age, disability or special need, likes and dislikes, schedules, triggers, and other information necessary for quality care. In addition, all volunteers are required to sign confidentiality agreements, liability releases, photo releases, and emergency contact information. When the families arrive, each volunteer is encouraged to ask parents about care for their child. Once the parents are ready to leave, Easter Seals staff remind them of the pickup time and confirm who will be picking up the child(ren) at the end of the event.

Volunteer and Family Recruitment

The volunteers are recruited mostly from local colleges and universities, Boy Scouts, churches, other volunteer organizations, other Easter Seals programs, pro bono Gazette ads, and by word of mouth through current volunteers.

Families are recruited through fliers in schools, pro bono Gazette ads, and by word of mouth from current families. Sign-up is first come, first served for each event. If an event fills up, a waitlist is created in case additional slots open up. Both family and volunteer information is also on our website, but word of mouth is definitely the best way to recruit.

Sample Volunteer Screening Form, See **Appendices page A51**

For more information, contact:

Daun Payton
Respite Outreach Coordinator
Easter Seals Greater Washington-Baltimore Region
1420 Spring Street, Silver Spring, MD 20910
(301) 920-9712 fax: (301) 920-9770
http://gwbr.easterseals.com

Dealing with Relationship Losses

After spending time with a care recipient, family caregiver, and possibly the family, getting to know one another, and building and maintaining a relationship, it could be devastating to the respite volunteer when that relationship is over, whether it is because of a change in the care recipient's condition or loss of independence, but especially if it is because a care recipient has passed or is dying. It would be advantageous to discuss in advance the appropriate ways to support the family, and at the same time, share with volunteers how they can expect to be supported by the program if such an event were to occur.

Read More:

For more information, see Family Caregiver Alliance Fact Sheet on Grief and Loss at http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=404.

Supervision

Expert and ongoing supervision provides the best opportunities for managing issues that will inevitably arise. Respite volunteers should have supervisors in place who, at a moment's notice, can address any concerns from the volunteers or from care recipients and family caregivers, and who can resolve these matters in an effective and expedient fashion. Supervisors also evaluate volunteers to make sure they are meeting the expectations set forth by the organization and respite program. Some volunteers will need gentle reminders about critical policies and procedures, while others may require greater and more frequent clarification of certain rules. Most importantly, a supervisor's role will be to offer support, encouragement, and praise for volunteers who are doing a good job, and offer motivation and guidance to those who are

struggling. In rare instances, a volunteer may be unable or unwilling to follow the policies the program has established for the protection of everyone involved. Supervisors must understand that their responsibility to the mission of the organization and the goals of the program may, at times, necessitate the termination of a volunteer.

Scheduling

To have a successful volunteer who is comfortable as well as successful and efficient in their role, the program will need to provide continuing support along the way. One way your respite program can do this is through the way volunteers are scheduled. For volunteers who are matched with an individual family to provide ongoing service, it is resource efficient to provide them with a way to schedule directly with the family on a weekly basis. It is essential to provide ongoing supervision and contact to both the family and volunteer to ensure the successful follow-through of scheduling and supervision. In addition, a standard with an appropriate benchmark about scheduling, canceling, or rescheduling should be addressed at the match and reinforced throughout the provision of service.

Whenever possible, respect volunteers' scheduling need by allowing them to choose their own time commitment and the hours they will be available. Set limits for the number of hours or days that can be volunteered each week and be sure that your volunteers know that saying no to a request is okay, if it was not previously planned or if it is outside the expected number of hours they are supposed to contribute for that week. The program should ensure that your policies and procedures allow volunteers to decline requests or tasks that make them uncomfortable or that they have not been trained to do.

Sign-up sheets, master calendars, and phone calls can all serve to remind your volunteers of their commitments. Other valuable tools include volunteer scheduling software, which can be found online for a nominal fee or may even be complimentary for some charities. WhenToHelp includes ways for volunteers to enter their availability, what shifts they would prefer to work, methods for trading shifts or requesting time off, and improved modes of communication through automatic text messages, emailing, and schedule reminders. WhenToHelp is available free for approved charities and also for a monthly premium based on the number of volunteers using the software (http://www.whentohelp.com). VolunteerSpot is another way to manage and schedule volunteers online. The website has complimentary software with features such as automated email reminders, an activity organizer, sign-in sheets, and calendar summaries; there is also the option of monthly subscriptions for a fee, which include extra features such as advanced reporting (http://www.volunteerspot.com/getstartednow). A nonprofit organization called TechSoup.org also has software for volunteer management either free or at a very low cost.

Volunteer Retention

Making certain that respite volunteers are happy and satisfied in their roles is essential. If volunteers are satisfied, they are more likely to remain engaged and be productive in their volunteer roles over longer periods. Retaining volunteers, in turn, decreases volunteer turnover, which can be costly because of the recruitment, training, and supervision invested in current volunteers. Retaining respite volunteers is often a matter of designing your program to be as clear about expectations and as accommodating and supportive of volunteers as possible, while still meeting the program's needs and safety requirements. There are a variety of mechanisms and supports that describe ways in which volunteers can be retained.

Recognizing Volunteers

Since volunteers are not recognized for their efforts with a paycheck each week, it is very important to find other means of acknowledging their hard work and valuable contributions. Recognizing respite volunteers is of utmost importance and can ultimately reinvigorate volunteers and help them continue to feel connected to the cause for which they are donating their time. It can also serve as a motivating factor for their continued dedication to your organization and clients. The method of recognition your program chooses may depend on both your budget and on the volunteers you are working with. The following are some formal methods for providing recognition:

- Certificates of appreciation;
- Ceremonies or other forms of public acknowledgment;
- Annual dinners or special events for volunteers;
- Thank you letters, cards, or notes; and
- Promotional Items, such as pens, caps, or magnets with the program's name and number.

A small token of appreciation does not need to be expensive to be meaningful. A $5 or less gift card to a local or chain coffee shop can thank volunteers and remind them to take a "coffee break" for themselves. A $5 gift card to a gas station chain may thank the volunteer for the countless times they have driven to and from the volunteer site.

Informal ways of recognizing volunteers, for example through verbal praise and encouragement, are also critical. Research has shown that volunteers who provide services in the nonprofit sector may actually respond better to informal modes of recognition (Culp, Schwartz, & Campbell, 2005). Simply spelling out the number of hours they contributed acknowledges that their time is highly valued. For example, "Your group helping on June 25th enabled 658 hours of respite for families!" or "By volunteering for 12 days this year, the Smith family was able to regroup for time equal to a week of vacation."

It is also important to recognize changes in the lives of volunteers and respond accordingly. Celebrating births or expressing sympathy for a death can be ways to acknowledge and reinforce the value of the volunteers within your

organization. According to the Ohio State University Extension Service, "Because volunteers are motivated to serve by different stimuli, no single means of recognition will be appropriate in all situations or for all volunteers. An effective volunteer administrator will develop a broad-based recognition program which is ongoing, diverse, and fulfills a variety of needs and expectations." A list of 139 ways to thank and recognize your volunteers is available at http://www.four-h.purdue.edu/downloads/ext_ed/pdf/131and139.pdf.

Recognition Award Ceremonies

Your community may participate in the Jefferson Awards, a prestigious national recognition system for honoring community and public service in America (http://www.jeffersonawards.org/). The Jefferson Awards are presented on two levels: national and local. They began in 1972 to create a Nobel Prize for public service. Today, their primary purpose is to serve as a "Call to Action for Volunteers" in local communities. In addition, local chapters of the National Association of Women in Business Organizations (NAWBO) annually recognize volunteers in their community who have been brought to their attention by volunteer agencies.

Ongoing Support and Supervision

Responsive and expert supervision is probably the single most important factor for retaining volunteers. Supervision provides a structure for the volunteers so they know who they should turn to when a difficult or challenging issue comes up or an incident occurs while they are providing care. It is through supportive supervision combined with the experience of making a difference in someone's life that will produce volunteer commitment to the program.

Continued support for respite volunteers can help ensure that volunteers have the necessary resources and tools to perform their duties well. Holding meetings on a regular monthly basis, for example, can be beneficial for the respite program as well as the volunteer. Volunteers can keep you abreast of new developments and have an opportunity to bring up potential issues, concerns, or difficulties they are faced with. This gives the program an opportunity to intervene and potentially provide needed support and guidance to volunteers who are struggling in their volunteering tasks. Hosting regular meetings is important to becoming aware of how volunteers are performing in their roles, giving them a chance to voice their concerns, and solving problems to prevent volunteer burnout or, even worse, having volunteers resign from their position. These meetings are also a great time to praise volunteers for their continued efforts and hard work and motivate them to stay on task.

Ongoing support may also encompass an educational or training component for respite volunteers that promotes awareness and acquisition of skills from various resources, special topics (e.g., seasonal flu and pandemic

preparedness), stress management, performance enhancement, documentation and reporting, and review of policies, procedures, protocols, and guidelines for interacting with certain clients.

Volunteer Networking and Peer Support

Connecting your respite volunteers with each other creates a system of support and may help keep volunteers successfully involved in their roles. By being in contact with others who are engaged in similar tasks, respite volunteers will feel as though they are not alone in the work they are performing and in their experiences. Volunteers will have the opportunity to share stories and resources and to connect with others, which is beneficial for their well-being and in minimizing their risk of burnout.

It is helpful to start this process in the beginning by introducing a "seasoned" volunteer to volunteers in training. The experienced volunteer can answer questions and offer a genuine level of honesty about the volunteer experience that exceeds what a staff person can offer. In addition, linking experienced volunteers through social media or one-on-one provides ongoing mentoring and support. Networking events with a "purpose", such as a guest speaker, can also stimulate conversation that generates feelings of support and belonging.

Event-type respite may use different groups of volunteers each week from a workplace, civic, or student group for single events that repeat weekly or monthly. Valuing your volunteers' time and staying in touch with them might encourage them to help out more often than just once a year. Many groups cannot do regularly scheduled respite but may be willing to help out two or three times a year, and they will want to keep in touch and be notified about volunteer opportunities. This provides the program with a list of groups to count on throughout the year.

Volunteer Evaluation as a Retention Tool

Evaluation of the volunteer's performance is a critical component of volunteer retention because it is a perfect opportunity to see how volunteers are performing in their respite roles. Periodic evaluation of your volunteers provides an opportunity to assess progress, discuss and address concerns and needs, and provide any additional support, training, information, or intervention. Your organization can also decide whether a respite volunteer is performing satisfactorily or meeting expectations by taking into account feedback from care recipients and their family members and deciding whether they should continue in their roles. Providing volunteers with an opportunity to evaluate their own activities and the support of the program reinforces the value you place on their role and involvement. For volunteer evaluation forms, see **Appendices pages A28–A30.**

Preventing Volunteer Burnout

Providing care can be stressful and demanding at times. Research shows that although engaging in volunteer work has definite benefits, being involved in too much caregiving can lead individuals to neglect their own health.

In order for your organization to be supportive and ensure that your respite volunteers remain healthy and productive, it is essential to be aware of their limits and check in with them regularly. Your organization should communicate clear volunteer expectations with realistic outcomes. Expecting more than what is feasible from a volunteer can leave them feeling as though their contributions are not making a real difference. The number of hours a volunteer can commit to should be monitored each week to prevent exceeding a level the volunteer is not comfortable with.

Volunteers who have been serving the organization in just one capacity for a period of time may be more vulnerable to burnout, especially if they are providing direct services. The supervisor may talk with such volunteers about moving to another role. A needs assessment and/or interest survey may be used to help determine that new role. Using flexibility and sensitivity in dealing with the volunteer staff will allow people to move from one role to another and remain with the organization for a longer period of time.

As previously mentioned, by recognizing volunteers and praising their efforts, as well as providing expert supervision, maintaining close relationships with them, and checking in regularly, your respite volunteers will feel as though they have proper supports in place to be successful in their roles.

Policies and Procedures

In order to create a good working environment, ensure the safety of volunteers and care recipients, and minimize issues that may arise during a volunteer's time with your organization, it is imperative to develop and enforce program policies. Volunteers should be made aware of these requirements during orientation. You may want to consider having them sign off on documentation that indicates their consent to following your organization's policies and procedures before they begin their volunteer assignments. It would be especially helpful to compile these policies and procedures into a volunteer handbook that volunteers can readily refer to.

It is important to note that the ultimate effectiveness of policies and procedures is related to the following factors:

- The degree to which the policies and procedures are communicated to people who "need to know,"
- Whether the policies and procedures are understood,
- Whether the rationale for your policies is clear because volunteers often want to know "why" in addition to "what," and
- The commitment of supervisors to hold volunteers accountable for adhering to policy.

Several policies and procedures common to other volunteer organizations are described below. Many of the sample policies were adapted either from 2010 Volunteers of America, Volunteer Handbook (supervisor curriculum), or the Interfaith Caregiving Network Volunteer Handbook. For sample policies and procedures, see **Appendices pages A19–A27**.

Eligibility Requirements

You may want to specify certain program requirements that must be met for an individual to be eligible to become a respite volunteer, such as completing orientation and necessary training and having criminal background checks and driving records that are in good order.

Confidentiality Policies

To protect care recipients and families, a primary policy should reflect the need to maintain confidentiality. A clear and concise confidentiality policy, including HIPAA requirements, should be included in your policies and procedures manual. For examples of confidentiality policies, see **Appendices pages A8, A9 and A21**.

Minimum Commitment

Information about availability will also help effectively match volunteers with family caregivers on the basis of days and times when family caregivers have a need for respite. Unless this is a single respite event rather than an ongoing series of respite visits, it is usually best to have a policy in which the volunteer agrees to serve in their respite role a minimum set number of hours per week or month. Many organizations also ask their volunteers to commit to at least one year in their position. The rationale for the time commitment should be clearly expressed. This step allows the potential volunteer to explore how an incomplete commitment might have a negative impact on a care recipient, especially if the special support need is exacerbated by transition or frequent changes. A clear rational also helps individuals understand how their ongoing role assists the caregiver and care recipient.

Even for event respite, asking a group of volunteers to commit to helping out at an event two or three times a year rather than just once a year will let them know their time is valued and will make it easier for the program to schedule events.

Drug-Free Work Place

In order to be in accordance with laws and promote safety for the organization, family caregivers, care recipients, and fellow employees and volunteers, a zero-tolerance policy for alcohol and drug use should be in effect. While volunteers are on duty, they must remain drug and alcohol free so that their judgment is not impaired and they can adequately perform their duties without putting others at risk. For a sample drug-free workplace policy, see **Appendices page A25**.

Code of Conduct

All volunteers should be expected to follow a code of conduct that is intended to ensure their well-being and that of people who are served by the program and the overall organization. Unacceptable conduct may include insubordination, dishonesty, harassment, theft, and failure to maintain care recipient and family caregiver confidentiality. For a sample code of ethics document, see **Appendices page A20**.

Accommodations for Volunteers With Disabilities Policy

An accommodations statement is an effective way to convey your program's commitment to volunteers with disabilities and to demonstrate that volunteers with disabilities will receive equal opportunity. Having a policy in place will help the program establish precedence for accommodation when there are requests. For sample policy on providing accommodation for volunteers with disabilities, see **Appendices page A24**.

Absentee Policy

If volunteers miss days they have committed to, it can be problematic for care recipients and their families who may be counting on those respite volunteers. To ensure the relationship and continued support the organization and the volunteer provide for the care recipients and family caregivers remain in good standing, volunteers should be prepared to honor their commitments. It is important for your organization to devise policies regarding absenteeism. The absentee policy should specify how a volunteer should notify the care recipient and family caregiver and his or her supervisor when the volunteer must miss a scheduled appointment. In the extraordinary event of an emergency, it is the duty of the

Policy Checklist

Which of the following are items for which you have a written policy in your agency?
For which do you need to have a policy?

	Have	Need	Don't Need
1. Reference checks	☐	☐	☐
2. A valid driver's license	☐	☐	☐
3. Valid car insurance	☐	☐	☐
4. Volunteers covered by liability insurance	☐	☐	☐
5. Confidentiality Statement	☐	☐	☐
6. Trial period	☐	☐	☐
7. Reasons for dismissal	☐	☐	☐
8. Grievance procedures	☐	☐	☐
9. Nondiscrimination	☐	☐	☐
10. Expense reimbursement	☐	☐	☐
11. Background checks	☐	☐	☐
12. Drug-free workplace	☐	☐	☐
13. Timesheets	☐	☐	☐
14. Notification of absence from volunteer duty	☐	☐	☐
15. Training requirements	☐	☐	☐
16. Dress code	☐	☐	☐
17. Use of telephone	☐	☐	☐
18. Other	☐	☐	☐

From Kentucky Commission on Community Volunteerism and Service, www.volunteerKY.ky.gov

volunteer to contact a supervisor immediately. Preferably, this should be done before the volunteer's scheduled respite visit so other arrangements can be made.

Grievance Procedure

One mission of your organization should be to promote an environment with desirable working conditions. In the event that problems arise, volunteers are encouraged to share their concerns and be assured that these concerns will be addressed appropriately without delay. It is important to note that volunteers will not be penalized in any way for complaints they make, but volunteers should maintain a professional demeanor while the matter at hand is being investigated and resolved. A sample procedure for addressing complaints is outlined in **Appendices page A27**.

Policy on Harassment

Your program may want to commit itself to creating a comfortable work environment free of harassment for all respite volunteers. Such a policy should prohibit harassment on the grounds of gender, age, race or ethnic background, religious preferences, sexual orientation, or disability. Sexual harassment such as unwanted sexual comments or advances should also be strictly prohibited. A sample harassment policy is included in **Appendices page A26**.

Abuse, Neglect, and Incident Reporting

It is the volunteers' duty to report concerns and discuss those concerns with their supervisor immediately after an incident such as abuse or neglect or an accident has occurred. Volunteers should be required to complete an Incident Report describing, in detail, what had taken place, where, and how, and then submit the report to their supervisor. For an example of an Incident Report form, see **Appendices page A11**.

The supervisor may then take the report to higher state authorities, such as child or adult protective services, for further investigation. Ultimately, a police report may need to be filed. These authorities will investigate and take action to correct or remedy the situation. It is also important to note that certain professionals are mandated to report suspected abuse, neglect, exploitation, or abandonment of children or older adults who have a functional, mental, or physical inability to care for or protect themselves, although these requirements vary by state.

If any volunteers are engaged in abusing or neglecting their clients, they are subject to immediate termination as well as further legal action. (See also Training – Ethical Issues page 48.)

Emergency Policy

Although rare, it is possible that emergencies could occur. If volunteers are in any of the following situations, they should be sure to act accordingly and then be sure to complete an Incident Form (as above).

- Fire: In the event of a fire, evacuate the premises immediately, with the care recipient. Leave all belongings behind, and focus on getting to a safe place with the care recipient. As soon as you have reached safety, call 911. Be sure to follow all directions and do not re-enter the building until specifically instructed to do so. It is also the duty of the volunteer to immediately contact the care recipient's family member(s) to inform them of the emergency situation (Easter Seals, 2006).

- Unconscious care recipient: First, it is critical to not move the care recipient from the place and position in which they were found, because moving a person who is unconscious could result in dangerous complications. The only acceptable time to move an unconscious care recipient is if there is a fire or some other imminent threat. The volunteer should immediately call 911. After doing so, it is the volunteer's duty to call the care recipient's family member(s) and tell them what has taken place. It is expected that volunteers will contact your program and get in touch with their supervisor, detailing the events that took place. In addition, there will be paperwork such as the Incident Report Form that the volunteer will be responsible for completing (Faith in Action, 2010).

- Conscious care recipient: If the care recipient is conscious, again, it is imperative that the care recipient is not moved. Call 911 and inform the responder of the care recipient's symptoms. After help is on the way, volunteers are expected to contact the care recipient's family member(s) and then their immediate supervisor at (your organization's name) and tell them what has taken place (from Faith in Action, Volunteer Caregivers Orientation Manual). As previously mentioned, the Incident Report Form should be completed, documenting the day's events.

The volunteer should refrain from transporting the care recipient to the hospital if a need for medical care arises and call 911 instead (Faith in Action, 2010).

Dispensing Medication

Medical care for the care recipient will be provided as outlined by the family. In the event that the care recipient needs to be given medication when they are in the care of a respite volunteer, giving medication is permissible only if the family has previously authorized it and state law allows it with the family's permission. If a family wants such authorization, an agreement must be signed by the care recipient and/or their family caregiver and the volunteer indicating that permission is granted to the volunteer to give medication to the care recipient on the schedule set forth by the family (Easter Seals, 2006). Volunteers need to know that administering any type of medication to the care recipient without consent from their family member(s) and a signed contract acknowledging this agreement is prohibited.

Read More:

For more information on policies and procedures to adapt for respite volunteer programs, see **Effective Strategies for Providing Quality Youth Mentoring in Schools and Communities: Generic Mentoring Program Policy and Procedure Manual** (2007). This sample manual, developed by The Hamilton Fish Institute on School and Community Violence &The National Mentoring Center at Northwest Regional Educational Laboratory provides a comprehensive guide helpful for developing policies and procedures for new or existing respite programs. http://www.mentoring.org/downloads/mentoring_205.pdf

Bringing Respite to Your Community: A Start-up Manual and *Respite Programs for Adults and the Aging: A Start-up Manual* both include chapters on needs assessment, the planning process, program models, budget, collaboration, marketing, funding, administrative policies and procedures, staffing, daily operations, and evaluation. Included are sample forms, policies, job descriptions, and other resources, which can help existing programs reevaluate the design of their current services. Order online at:
http://www.archrespite.org/productspublications.

ARCH's *National Respite Guidelines* (2011) provide further guidance on best practices for safety, program content, and administration.
http://www.archrespite.org/productspublications/products-and-publications#Guideline2011

Liability and Insurance Issues

A common question asked by insurance underwriters is, "Does the insured have volunteers?" If the answer is "yes," a red flag may go up. Other questions an insurance underwriter might ask are

- What do the volunteers do?
- What are their ages?
- How many hours are volunteered?
- Does the insured tell them when to work, where to work, and what work to do?
- Do the volunteers drive the insured's vehicles?
- Do the volunteers drive their own vehicles on behalf of the insured?
- Do the volunteers receive any fringe benefits, such as meals, lodging, or transportation expenses?

All of these questions must be answered to the underwriter's satisfaction if a nonprofit agency is to obtain insurance. Insurance companies must control the risks they take, and many underwriters believe that control diminishes substantially when volunteers are introduced into the equation. Those of us familiar with the nonprofit world know that many organizations would be unable to provide valuable services without volunteers. For this reason, we must strive to educate underwriters and allay their fears. To correct misperceptions on the part of a carrier, you must establish a dialogue with your insurance professional to explain the management of volunteers and the duties they perform. You must also be organized in your approach to managing volunteers. Lack of procedures and controls can jeopardize your chances of getting insurance (Montgomery, B., rev 2002).

Identifying and Managing Liability Risks

The fear of being sued is pervasive in all volunteer organizations. Some leaders are more fearful or risk averse than others. While it is true that "anyone can sue an organization for any reason," the fear of being sued can ultimately have positive effects on an organization. Concern about "what could go wrong" can inspire practical steps to either reduce the likelihood of harm or reduce the ultimate cost of harm or loss. Thinking about "what could go wrong" should also help identify steps the organization will take if something does go wrong, such as carefully documenting incidents or "near misses," or investigating and/or following up on all complaints made by recipients of care, primary caregivers, or respite volunteers. For example, respite volunteer programs can preemptively think about how a lawsuit could derail their community-serving missions and take steps to both minimize the likelihood of a lawsuit against the organization and plan the organization's response to a legal threat before it occurs. Although it is impossible to eliminate the possibility of a lawsuit, every organization can take steps to achieve the above outcomes.

Hand-wringing and simply hoping for the best are poor choices for the volunteer program manager who believes his or her organization's mission is worthwhile. Yet managing liability risks need not be as complicated or costly as many people believe. The following steps suggest a way to get comfortable with liability risks that won't bankrupt your organization or draw too much time away from your community-serving mission. One way to begin this process is to

The Risk Management Process

- **Step 1— Consider the Context.** During this first step the team involved in brainstorming the environment in which the respite program operates, including its:

  - History of lawsuits, claims and losses—for example, has the organization ever faced claims alleging negligence providing respite care?

  - The perspective of the board of directors of the organization; Are they fearful or especially concerned about certain types of losses?

  - The perspective of the insurance providers for the organization—has the organization's coverage been cancelled or curtailed in any way due to specific operations? Have insurance providers recommended changes in operations or practice in order to reduce premiums or provide coverage?

  - The program's relationship to other programs or organizations, such as the parent entity, a partner organization, or a funding provider.

- **Step 2—Identify Risks.** During Step 2 the team discusses the risks associated with the organization. What could possibly happen to derail the mission of the program? What events might impair the ability of the program to deliver uninterrupted services?

- **Step 3—Prioritize Risks.** During Step 3 the team reviews the list of risks and ranks them according to their seriousness and importance to the organization. There is no single way to approach this task. The goal is to develop a priority-order list of issues that the team will tackle with policies, procedures, practice or training.

- **Step 4—Decide What to Do.** During Step 4 the team chooses a subset of the list—perhaps the top 10 most likely or potentially significant risks—and decides what actions the organization can take to (1) reduce the likelihood of the risk materializing; and (2) prepare to deal with the consequences of the risk materializing. For some teams it's helpful to list the selected risks on a two-column worksheet and list risk issues in the left hand column and possible action steps for each risk in the box to the right of the risk. Examples of action steps include adding a safety component to the volunteer orientation, implementing safety policies, and encouraging volunteers to come forward with any concerns they have about their personal safety, the safety of clients, or the safety of the overall respite program.

- **Step 5—Follow-up and Adjust.** The final step calls for the review of the actions taken to determine whether they should be continued, revised or disbanded. For example, is the new policy requiring the use of a service contract being followed consistently? Policies and action steps that are not serving the program's interests should be changed or abandoned.

* Adapted from the No Surprises Volunteer Risk Management Tutorial developed by the Nonprofit Risk Management Center. http://www.nonprofitrisk.org/tools/volunteer/intro/1.htm

schedule a series of brainstorming sessions involving representative stakeholders in the respite program. Be sure to seek the input and advice of your insurance agent.

Read More:

ARCH Fact Sheet 17: Risk Management (revised 2002) at
http://www.archrespite.org/images/docs/Factsheets/fs_17-risk_management.pdf

Risk Management is a guidebook prepared for the ARCH National Respite Network that includes potential resources, an annotated bibliography, numerous overheads and handouts, and suggested exercises for use in training. Order online at http://www.archrespite.org/productspublications.

Risk Management and Liability Waivers

Federal and state mandates protecting volunteers. Individuals who volunteer for a nonprofit may express concern about their exposure to personal liability resulting from their volunteer service. Therefore, in addition to understanding the steps the program and organization have taken to guard against harm or loss, volunteers should also be aware of the protection they enjoy under various federal and state "volunteer protection" statutes. Your respite volunteer program should be prepared to address these concerns and direct volunteers to resource material for additional guidance. For instance, with respect to liability claims, a respite volunteer program should urge its volunteers to review information on the state's volunteer protection law as well as the Volunteer Protection Act of 1997.

These laws provide a defense for volunteers acting within the scope of their responsibilities for a nonprofit organization. While this protection varies from state to state, it is generally limited to instances when the volunteer has been "simply negligent" (fails to do something a reasonable person would do under the circumstances or does something a reasonable person would not do under the circumstances) versus "grossly negligent" (outrageous or intentional conduct that contravenes community standards).

Liability waivers. A waiver is a type of liability shield—a contract that seeks to protect an organization against liability claims by obtaining a promise from persons accepting the agreement to assume full responsibility for any harm they suffer and not to hold the nonprofit responsible. Liability shields come in various forms and are used by nonprofit organizations for a variety of purposes. The most common form of liability shield in the nonprofit world is a waiver and release of liability offered by a nonprofit to a participant or volunteer who is asked in advance of an activity or event to waive his rights to sue the nonprofit.

Liability shields can be executed before a loss or injury occurs or after a loss. Technically, a liability shield executed before the loss or harm is referred to as a waiver, while a liability shield executed after harm has occurred is called a release. A release executed after a loss—after the injured party has had an opportunity to survey the damage or

reflect on his injuries—is most likely to be upheld when contrasted with a waiver executed before the loss or harm has occurred. For a sample Release and Waiver Form, see **Appendices page A12.**

While an indemnification policy has the potential to protect your organization from liability in some locations, it may not be protective in all states or settings. Ultimately, a waiver does not protect anyone from a lawsuit. Families may sue volunteers and volunteers may sue families or agencies in a state or federal civil suit. Organizations that provide volunteer respite care should discuss this issue with their insurance provider and do an assessment of risk. This assessment will address how their policy addresses volunteer services. Volunteers are a human resource to an organization, and an organization, if properly screening, training, and supervising a volunteer, should be prepared to support them as an extension of their paid staff. Often, careful documentation of screening, training, supervision, and hours of service are necessary to ensure that volunteers are covered by an organization's insurance policy. This action also protects volunteers if they are injured (e.g., by lifting an individual) while acting within the role they were prepared for and assigned to perform. It is also important to learn from your risk insurance provider whether there are any roles or actions that your volunteer CANNOT perform within their assignment. Examples may include dispensing medication or providing care related to medical technology. It is important to identify such actions to avoid putting a volunteer or care recipient at risk of harm.

Agencies have the ultimate responsibility for protecting their volunteer human resources and families whom they serve. An indemnification policy is not a replacement for careful screening, training, matching, and supervision; it can often serve as a deterrent to potential volunteers and should be entered into cautiously.

Read More:

Nonprofit Risk Management Center is a nonprofit resource center that provides free technical assistance to nonprofit staff members, volunteers, and leaders on a wide range of risk management, liability, and insurance topics. The Center also offers risk management software; practical publications on safety, insurance, and liability topics; and numerous training opportunities. To access the Center's technical assistance programs, visit the Advice section at www.nonprofitrisk.org or call 202-785-3891.

State Liability Laws for Charitable Organizations and Volunteers is a free resource that describes and compares the various state liability laws as well as the federal law (http://www.nonprofitrisk.org/library/state-liability.shtml).

Cost of Insurance Coverage

Organizations that run respite volunteer programs may purchase a variety of types of insurance coverage that address varying exposures. The limits of liability, deductibles, policy terms, and policy types selected by each organization vary, depending on

- The availability of coverage under a parent organization's insurance program;
- The availability of coverage and policy terms desired by the program (in some cases, an organization may wish to purchase a limit of liability that no insurance provider or carrier is willing to provide); and
- The organization's ability to afford the coverage it seeks (in many instances, an organization must make difficult choices between the coverage it would like to buy and what it can reasonably afford at the time the coverage is purchased).

The average cost of insuring volunteers can vary. The average cost of coverage for each volunteer per year is $10 to $15 (Tipler, 2010). Some companies such as CIMA provide insurance for volunteers involved with nonprofit organizations at a cost of $12 per volunteer per year. The CIMA website contains all documentation such as application materials, coverage details, discussion of benefits included, policies, forms, and costs of services. For example, CIMA provides three

Type of Coverage	Cost per Year
Medical Expense Reimbursement	$3.94
Volunteer Liability Insurance	$1.72
Automobile Liability Insurance	$6.34
Total cost (per year) for all services:	**$12.00**

different types of coverage that could be purchased separately or in combination. The three coverage types and their associated costs are listed in the table above (http://www.cimaworld.com/htdocs/volunteers.cfm).

Read More:

Volunteers Insurance Service (VIS) describes in detail the coverage types listed in the table. For a complete, printable brochure see http://www.cimaworld.com/files/brochure.pdf.

Types of Insurance Coverage That Protect Programs and Participants

The paragraphs below describe the most common and arguably most important liability policies that a volunteer respite program should consider. Note: these coverages can be purchased separately or in coverage "packages." In all cases, your respite program should seek advice and counsel from a professional insurance agent or broker concerning your insurance requirements and preferences. Consultation with an attorney may also be advisable to ensure that volunteers who are "working" for your agency are adequately covered.

- **Commercial General Liability (CGL)**—The CGL is a more comprehensive version of "general liability" coverage, which is designed to cover the liability exposures that are common to all organizations, from large corporations to small nonprofits. The policy is a combination of three separate coverages, each with its own insuring agreement and exclusions:

  – Coverage A—General Liability (bodily injury and property damage) covers liability for claims alleging bodily injury and property damage caused by an accident, except for liabilities that are specifically excluded. Exclusions include liabilities more properly covered under a separate policy, such as automobile and workers' compensation and liabilities considered uninsurable. Some of the liabilities covered under CGL policies include injuries arising from your premises, injuries to care recipients under the agency's supervision, injuries to volunteers while working for you, injuries to participants at special events, injury caused by products you sell or manufacture, fire damage to your landlord's building, and damage to property not owned by you or in your possession.

  – Coverage B—Personal Injury and Advertising Injury Liability covers exposures that do not involve bodily injury or property damage, are not caused by an accident, and therefore are not covered under Coverage A. These liabilities are libel, slander, false arrest, malicious prosecution, wrongful eviction, wrongful entry, violation of privacy, infringement of a copyright, and unauthorized use of an idea in advertising.

  – Coverage C—Medical Payments coverage is not liability coverage per se but rather accident coverage, with a standard maximum limit of $5,000 per person. It covers injuries from accidents at your premises, or at your activities off-premises, regardless of your legal responsibility for harm. Medical Payments insurance excludes injuries to employees and those arising from automobile accidents and athletic activities.

- **Directors' and Officers' Liability (D&O)**—D&O policies provide coverage for '"wrongful acts."' The major difference between the CGL policy and the D&O policy is that nonprofit D&O policies exclude bodily injury and property damage. The most common claim filed under a nonprofit D&O policy is a claim alleging wrongful employment practices. Other examples of claims include those from donors alleging misuse of funds, claims from advocacy groups for the disabled alleging ADA violations, and from for-profits alleging unfair trade practices. Make certain that your D&O policy includes coverage for a wide range of employment-related claims. Other key considerations in choosing a D&O policy include making certain that the policy has a broad definition of "insured" that includes the nonprofit itself, and that common exclusions such as '"insured vs. insured"' and '"emotional distress"' have been deleted.

- **Professional Liability**—Many nonprofits are exposed to claims alleging negligence in the delivery of professional services, such as counseling, nursing/medical services, referral services, and more. A respite program should discuss its need for this type of coverage with a competent insurance professional (agent, broker, or consultant).

- **Accident Insurance**—Accident policies are relatively inexpensive policies that finance the cost of medical treatment for individuals (volunteers and/or participants) who are injured while delivering services for or receiving services from an organization. These policies usually pay the costs of emergency room services and follow-up treatment to predetermined limits based upon the kind of injury. For example, a broken leg may have a limit of $2,500, while an

eye injury might be limited to $1,500 unless the injury resulted in the loss of sight in the eye, in which case the limit might be $15,000 (these amounts are hypothetical and intended for illustrative purposes only). Usually these policies do not have deductibles. Note: an accident and injury policy does not respond to illness nor does it protect the organization from liability for the injury. One distinctive feature of an accident policy is that it will pay a claim regardless of who is at fault. These policies are generally written as "excess insurance," meaning that they pay only after other available insurance—generally, the claimant's personal health insurance—is exhausted. If the volunteer or participant were uninsured, the accident policy would "drop down" and become primary coverage for the injury. Accident policies provide affordable coverage for an organization concerned about volunteers or participants who may be uninsured or underinsured for injuries sustained while volunteering.

- **Business Auto Coverage**—The "business auto policy," also called the "business auto coverage form" or "commercial auto policy," provides liability coverage and physical damage coverage. Respite programs that own vehicles should purchase coverage for their owned vehicles, while organizations that rely on vehicles owned by employees and/or volunteers should purchase "non-owned" auto coverage. Non-owned and hired auto liability coverage is typically the only auto coverage a nonprofit will require if it does not own any vehicles. It's important to remember that when volunteers or program staff members are driving their own vehicle on the organization's behalf and are involved in an at-fault accident, the volunteer or staff member's personal insurance (on the vehicle being driven) will respond first. The organization's non-owned auto policy will respond when the limits of the driver's personal auto coverage have been exhausted.

Although developing materials and websites can be costly and time-consuming, it is critical to incorporate a marketing plan and a marketing budget into your business model. Look to your board or advisory committee to donate time and resources, and try connecting with a local college or university to identify design students looking for projects and opportunities to build their résumés. An accomplished marketing plan for the overall program can also be an excellent strategy for recruiting volunteers.

Establishing Trust in the Community

Gaining the trust and confidence of your community involves more than honesty and transparency. Trust is also fostered by dependability and responsiveness. As you begin to identify partner organizations and volunteers to build and lead your respite efforts, it is important to vet them carefully on the basis of history, mission, and track record, as well as perception within the community. This is especially true when serving vulnerable populations and families with heightened need for support.

The following are methods that can be used to market and establish trust:

- Convene a panel of stakeholders (e.g., advisory committee or board) of established and trusted leaders, influencers, and individuals or organizations who are well connected with the population you intend to serve.
- Be thoughtful in defining your services (don't say you can provide a service that you don't have the capacity to provide).
- Feature well-established and trusted partners in your marketing materials.
- Highlight experienced and well-respected leaders and or volunteers.
- Share success stories and testimonials.

Identifying and Building Relationships with Stakeholders

A key to success for any community-based program is thoughtful planning, marketing, and relationship building with stakeholders. Stakeholders include individuals and entities that have a stake in an organization—who are affected by or can affect the organization's actions, objectives, or policies. For volunteer respite programs, this includes the individuals and families whom you serve, donors and funders, policy makers, referral sources, and others.

Potential Referral Sources

Look to existing providers in your community—perhaps agencies and organizations you have historically collaborated with—to explore and identify referral sources. Identify where family caregivers turn for information, support, and services, including their health care providers, Family-to-Family Health Information Centers, Aging and Disability Resource Centers, Area Agencies on Aging, state respite coalitions, and state Lifespan Respite Programs. Consider reaching out to less traditional referral sources such as faith communities, local employers and human resource professionals, disease- and condition-specific organizations (e.g., Autism Society of America, MS Society, Alzheimer's

Association), and park districts. Take time to learn about their needs and the needs of the individuals they serve when developing your program and services. Work with them to make the referral and intake processes streamlined and user friendly.

Collaborating with agencies, local transportation organizations, faith communities, businesses, health providers and/or service organizations in your community can help build a strong and sustainable program. Through both collaborations and formal coalitions, differing perspectives can effectively be united by a common vision, cause, and leadership. This is also a compelling way to engage stakeholders within your community. Furthermore, such groups often bring experience and expertise to the table and frequently provide referrals or volunteer recruitment opportunities to meet their member or care recipient needs. While identifying groups to work with, you may discover others in your area who are also interested in or are currently operating similar or compatible programs. Through collaborations, duplication can be avoided and expertise can be shared.

National Volunteer Initiative

VA Volunteer Support In-Home Respite Program

The Department of Veterans Affairs Voluntary Service (VAVS) and the Office of Care Management (OCM) have joined to form the Caregiver Support Network. The Respite program is designed to help provide compassionate support to those caregivers who give care to America's veterans in their homes. Twelve pilot sites were established throughout the United States. The pilot programs are training small groups of volunteers and matching them with veterans age 18 and over living in their neighborhoods. The volunteer support caregiver provides respite to a veteran's family caregiver. The sites are in Augusta, GA; Baltimore, MD; Lexington, KY; Los Angeles and San Francisco, CA; Richmond, VA; Minneapolis, MN; Seattle, WA; St. Louis, MO; Syracuse, NY; Temple, TX; Tucson, AZ. Contact: Laura Balun, National Director of Voluntary Service, US Veteran's Administration at laura.balun@va.gov

Policy Makers

Invite local and state policy makers to the table. Help acquaint them and their staff with the respite needs and services (or lack thereof) of family caregivers who live in the local district. The following are some steps to identify and build relationships with key policy makers:

- Identify those members that sit on key committees or who hold leadership positions that are critical to your program.
- Use existing networks to identify members that may have a personal interest or experience that makes them likely to support your issue.

- Invite members to come and see your programs in action or to meet with care recipients and families. It is especially useful to be sure to invite them to special events and to give them an opportunity to speak.
- Take time to attend town hall meetings and other public events and make yourself known to members by introducing yourself and/or asking a question in an open forum.
- Regularly communicate with the members and their staff about issues of importance to you through meetings, letters, and phone calls.
- Put members and their staff on your mailing lists for things like newsletters and other communications that are published on a regular basis.
- Offer to assist members with constituent services (a possible source for referrals).
- Regularly and publicly thank members who help you by sponsoring legislation, getting out the votes, speaking out on your issue, or anything else of importance.
- Join your state respite coalition or start one and use it to advocate for improved respite programs and policy.

Developing the Appropriate Marketing Messages

Methods for developing and delivering messages to advertise your volunteer respite program should be deliberative and purposeful. Marketing is more than just raising awareness. To be most effective, identify specific groups in your community that you plan to target (e.g., aging caregivers, parents of children with special needs, caregivers of adults with chronic conditions, and other community-based or faith-based agencies) and develop a message specifically targeting their unique needs and concerns. More than one message and strategy for delivering those messages will probably be necessary.

Read More:

For more information on marketing respite see the ARCH Webinar: **Marketing Respite to Family Caregivers, Moving Beyond Awareness** with Alicia Blater, NC Lifespan Respite Project, July 26, 2011, at http://www.archrespite.org/ta-center-for-respite/webinars-and-teleconferences/webinar-marketing-to-family-caregivers.

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  http://www.womenshealth.gov/aging/caregiving/caregiver-stress.cfm

Federal and State Resources on Volunteerism

US Administration on Aging (AoA), Civic Engagement Initiative. Volunteers have always been the backbone of programs administered under the Older Americans Act. Each year about ten million older people use Older Americans Act services, whose delivery largely depends upon the efforts of half a million volunteers. Volunteers help the aging network in many other ways, including assisting at group meal sites and delivering meals to home-bound elders; escorting and transporting frail older persons to health care services and grocery shopping; weatherizing the homes of low-income and frail older persons; counseling older persons in a variety of areas including health promotion, nutrition, legal and financial concerns; detecting and preventing health care fraud; and helping during disasters. For more information about the wide variety of rewarding volunteering opportunities to benefit older Americans, see AoA's Civic Engagement section at http://www.aoa.gov/AoARoot/AoA_Programs/Special_Projects/Civic_Engagement/index.aspx#resources.

Engaging Volunteers in the Aging Network: A National Resource Center. In 2010, AoA funded the National Association of Area Agencies on Aging (n4a) for a 3-year project to create "Engaging Volunteers in the Aging Network: A National Resource Center" (the Center). The Center will help AoA and the Aging Network use volunteers more effectively, especially baby boomers; develop AoA's and the Aging Network's leadership in civic engagement; and expand the Aging Network's use of volunteers. The Center is a partnership of n4a, the AARP Foundation, the National Association of State Units on Aging and Disabilities, Senior Service America Incorporated, the Council for Certification in Volunteer Administration, and the University of Michigan.

National Council on Aging. AoA is funding a 3-year project with the National Council on Aging (NCOA) to provide technical assistance and other support to local programs that can become national multigenerational and civic engagement models for using older volunteers in meaningful direct services as well as administrative, technical, or developmental activities. Projects will focus on three target populations: (1) older relatives caring for grandchildren, (2) families caring for children with special needs, and (3) caregivers of frail elderly. Nineteen local grants have been awarded since 2008. This project is funded in partnership with the Corporation for National and Community Service, the Atlantic Philanthropies, and MetLife Foundation.

Corporation for National and Community Service. The Corporation is the nation's largest grantmaker supporting service and volunteering. Through Senior Corps, AmeriCorps, and Learn and Serve America programs, the Corporation provides opportunities for Americans of all ages and backgrounds to address critical community needs.

State Service Commissions. The Commissions manage, monitor, and evaluate AmeriCorps programs and are also charged with encouraging volunteering in their states. They often administer special volunteer initiatives. See http://www.nationalservice.gov/about/contact/statecommission.asp.

State Lifespan Respite Programs. More than half the states are funded by the AoA to develop or enhance statewide Lifespan Respite systems to coordinate community-based respite for family caregivers caring for anyone of any age with a special need. The grantees and their partners are charged with recruiting and training respite workers, including volunteers. For contact information for each state program, see ARCH at http://www.archrespite.org/lifespan-programs.

Volunteer Training Resources

Caring to Help Others: Training Manual for Preparing Volunteers to Assist Caregivers of Older Adults, sponsored by Eisei, Inc. The purpose of this manual is to help community-based organizations prepare volunteers to more effectively assist primary caregivers of older adults. It is meant to be used by organizations involved in volunteerism and in support and outreach services to older people and their primary caregivers. http://www.caringtohelpothers.com/html/about.htm

Generations & Autism Connect is a ready-to-use modular training curriculum that will assist volunteer coordinators with their training responsibilities in preparing individuals who will be volunteering with children with autism. Each module contains a PowerPoint presentation, a script for the presentation, and supporting handouts. Module topics include (1) Overview of Autism, (2) Families, (3) Communication, (4) Behavior, (5) Community Integration, and (6) Socialization. Contact: Patricia Wright, 233 S. Wacker, Suite 2400, Chicago, IL 60606; 312-551-7226; pwright@easterseals.com

CareBreak Model Development Training is a comprehensive training and curriculum to replicate a home- and community-based volunteer program based on an established frequency and dose of service. The Model Replication Training walks interested parties through the entire process, which includes every step from startup, recruiting, screening, training, and matching the volunteer mentor; referral, intake, and assessment of families; and retention, quality assurance, and outcome measurement. The Model Replication process also provides every form, document, piece of paperwork, and quality monitoring tool used by CareBreak to run the program and promote the health and safety of participants. This model, which had been replicated in other states that support individuals of different ages and disabilities, has an evidenced informed base of practice. Contact: MaryJo Alimena Caruso, CareBreak at the Watson Institute, 301 Camp Meeting Road, Sewickley PA 15143; 412-749-2863; maryjoa@thewatsoninstitute.org

Caregiver Support Network Volunteer Training Manual. U.S. Department of Veterans Affairs Voluntary Service (VAVS) and the Office of Care Management (OCM) have joined to form the Caregiver Support Network to prepare volunteers to more effectively assist veterans' primary caregivers. This training manual is designed to help community organizations and volunteers provide compassionate support to those offering care to America's veterans in their homes. http://www.kofc.org/un/en/resources/military/serve/vavs_caregivers.pdf

PHI Training Curricula. Training and Organizational Development Services. PHI is a national nonprofit organization whose mission is to transform the delivery of eldercare and disability services. PHI offers both home- and facility-based providers the skills to manage change and create dynamic relationship-centered organizations that better serve elders, people with disabilities, and their families. They provide a series of curricula on topics such as adult abuse and neglect prevention, fall prevention, and personal care service. http://phinational.org/training/resources/phi-curricula/

Energize, Inc. Especially for Leaders of Volunteers. An onsite resource that provides materials on every aspect of volunteer management, including funding, evaluation, training, and useful software at http://www.energizeinc.com/index.html.

National Council of Nonprofits. The Council has valuable resources on managing volunteers at http://www.councilofnonprofits.org/resources/resources-topic/volunteers. Their state associations frequently offer workshops and webinars on topics relating to volunteer management and may know of local nonprofits looking for assistance. To find an affiliated state association on nonprofits, see http://www.councilofnonprofits.org/find-your-sa.

Idealist is a clearinghouse of nonprofit and volunteer resources. http://www.idealist.org/

**Volunteer
Management
Resources**

Appendices

Appendices

Sample Forms

Volunteer Applications

Service Agreements

Confidentiality Agreements

Background Checks

Reporting Forms

Release and Waiver Forms

Easter Seals Delaware and Maryland's Eastern Shore

61 Corporate Circle | New Castle, DE 19720-2405 | Ph (302)324-4444 | Fx (302) 324-4480

VOLUNTEER INFORMATION FORM

Last Name	First Name	Mid. Initial	Date

Title (please indicate Mr., Mrs., or Ms.)   **Nickname**   **Sex**   **Male** ☐   **Female** ☐

Home Address

Street

City   **State**   **Zip Code**

Home Phone (please include area code)   **Cell Phone**

Business Phone   **Date of Birth** (mm/dd/yyyy)

E-mail

Have you ever been convicted of a misdemeanor or a felony? Yes ☐   No ☐   If yes, please explain fully below:

Are you at least 18 years old? Yes ☐   No ☐

Current Employment

Organization Name   **Position**

Street Address

City   **State**   **Zip Code**

Business Phone (include area code)   **Does your employer Match Gifts?** Yes ☐   No ☐

Does your employer Match Volunteer Hours? Yes ☐   No ☐

Previous Employment/ Volunteering

Organization Name Position

City   **State**

Education

Are you currently in High School? Yes ☐   No ☐   **If no, did you graduate from High School?** Yes ☐   No ☐

Highest Level of Post High School Education Completed:

School Name   **What was your major or area of study?**

Type of School ☐ Community College ☐ Technical School ☐ University ☐ Post–Graduate   **Did you graduate? Yes** ☐   **No** ☐

If no, please give date you entered   **Date you left**

If yes, what date did you graduate?   **What kind of degree did you get?**

Type of Work Desired (please check all items that you are interested in)

☐ **Direct Interaction with Adults** ☐ **Office Work** ☐ **Marketing**

☐ **Public Speaking** ☐ **Fair Exhibits** ☐ **Research**

☐ **Training** ☐ **Sharing skills/ talents/ interests** ☐ **Special Events**

☐ **Other**

I'm interested in the above interaction as it relates to adults/children (check one). OR

I prefer administrative work.

Person To Contact In Case Of An Accident or Emergency

Name _____ **Relationship To You** _____

Address _____

Street   City   State   Zip

Phone (Daytime): _____

Availability

From Date mm/yy	To Date mm/yy	Day of Week	Start Time	End Time
		Monday		
		Tuesday		
		Wednesday		
		Thursday		
		Friday		
		Saturday		
		Sunday		

Qualifications Describe your qualifications and why you think you can make a contribution to Easter Seals.

Courses/Training List any special courses or training that can be applied to volunteering at Easter Seals. (i.e. CPR, First Aid, Lifeguarding)

Course Name	Start Date	End Date	Instructor	Certification	Expires	Comments

---

Personal Reference

Name _____ **Phone** _____ **Relationship to you:** _____

Address _____ **City** _____ **State** _____ **Zip** _____

It is the policy of Easter Seals Delaware and Maryland's Eastern Shore to afford equal opportunity to all qualified persons regardless of race, age, national origin, disability, color, religion, sex or other artificial barrier.

With my signature, I authorize Easter Seals Delaware and Maryland's Eastern Shore to obtain criminal background check(s) and verify any information regarding my past work history, my character, or my academic performance, as required of my potential position.

Volunteer Signature: _____ **Date:** _____

VOLUNTEER APPLICATION

Personal Information

Last Name:	First Name:	Middle Initial:
Address:	City:	Zip Code:
Home Phone:	Work Phone:	Cell Phone:
Emergency Contact – Name:	Emergency Contact – Relationship:	Emergency Contact – Phone:
Email:	*DOB:	*SS #:

*Date of Birth and Social Security Number are requested to complete required background checks.

Have you lived outside the State of Wisconsin in the past three years? ☐ Yes ☐ No

I am a student ☐ Yes ☐ No If Yes, school name:

Occupation:/Field of study: Employer/Teacher's Name:

Background Information

Special Skills/Interests ☐ Musical Instrument ☐ Singing/Dancing ☐ Drama ☐ Clowning

☐ Arts/Crafts ☐ Public Speaking ☐ Athletics ☐ Other

Why are you interested in volunteering for Easter Seals?

Have you volunteered with Easter Seals before? ☐ Yes ☐ No If Yes, when?

Have you ever been convicted of a crime? ☐ Yes ☐ No If yes, list the offense:

Were you referred to Easter Seals by anyone? ☐ Yes ☐ No If yes, referral source:

Do you need any special accommodations to volunteer? ☐ Yes ☐ No If yes, what?

Optional Information
(For statistical purposes only)

Gender: – Marital Status: – Ethnic Background: –

Do you have a disability or impairment? –   If yes, type of disability/impairment:

Availability:

Please check all days you may be available to volunteer:

☐ Monday   ☐ Tuesday   ☐ Wednesday   ☐ Thursday   ☐ Friday   ☐ Saturday   ☐ Sunday

Please check all times you may be available to volunteer:

☐ Morning   ☐ Afternoon   ☐ Evening

Area(s) of Interest:
(Please check all that apply)

☐ Administrative Work
(Milwaukee, S. Milwaukee and Waukesha)

☐ After School & Summer Respite Programs
(Various locations)

☐ Workforce Training and Development
(Located in Waukesha)

☐ Education Programs
(Various groups and locations)

☐ Adult Recreation Programs
(Holler Park, Wil-O-Way Parks, or in the Community)

☐ Adult Day Services
(Locations in Kenosha, S. Milwaukee, Wauwatosa, Waukesha)

☐ Summer Day Camp
(Wil-O-Way Parks and Waukesha)

☐ Special Events / Fundraisers
(Walk With Me, and 75th Anniversary)

Liability Release

I certify that the statements made in this volunteer application are true and correct, and have been given voluntarily.

I understand that I will not be paid for my services as a volunteer for Easter Seals Southeast Wisconsin.

I consent to Easter Seals Southeast Wisconsin using any audio-visual programs, photographs or public relation references. These may be used for any purpose Easter Seals Southeast Wisconsin deems appropriate.

I give Easter Seals Southeast Wisconsin permission to use the above information in its statistical reports. I understand that information that identifies me (i.e., name, address, phone number, email address, employer, etc.) will be kept confidential. Additionally, I waive any and all causes of action, claims, rights, liabilities or obligations that may now or in the future arise from volunteering in any Easter Seals Southeast Wisconsin program, service or event.

I acknowledge and agree that Easter Seals Southeast Wisconsin may investigate my criminal record, if any, and that Easter Seals Southeast Wisconsin may refuse my application if such investigations reveal matters that may indicate my unsuitability as a volunteer, at the sole discretion of Easter Seals Southeast Wisconsin.

_____   _____
Volunteer Signature   Date

_____   _____
Parent/Guardian Signature (if volunteer is under 18)   Date

FOR OFFICE USE ONLY	
Date initial contact made: _____	Date background check done: _____
Date application received: _____	Area of interest: _____
Date orientation scheduled: _____	Date of first volunteer job: _____

Photocopy of Photo Identification: _____	Signed HIPAA Forms:_____

Sample Agency/Volunteer Agreement

This agreement is intended to indicate the seriousness with which we treat our volunteers. The intent of the agreement is to assure you both of our deep appreciation of your services and to indicate our commitment to do the very best we can to make your volunteer experience here a productive and rewarding one.

I. Agency

We, _____ (agency), agree to accept the services of
_____ (volunteer) beginning _____ and we commit to the following:

1. To provide adequate information, training, and assistance for the volunteer to be able to meet the responsibilities of his/her position.
2. To ensure diligent supervisory aid to the volunteer and to provide feedback on performance.
3. To respect the skills, dignity, and individual needs of the volunteer, and to do our best to adjust to these individual requirements.
4. To be receptive to any comments from the volunteer regarding ways in which we might mutually better accomplish our respective tasks.
5. To treat the volunteer as an equal partner with agency staff, jointly responsible for completion of the agency mission.

II. Volunteer

I, _____ agree to serve as a volunteer and commit to the following:

1. To perform my volunteer duties to the best of my ability.
2. To adhere to agency rules, policies, and procedures, including record-keeping requirements and confidentiality of agency and client information.
3. To meet time and duty commitments, or to provide adequate notice (one week minimum) so that alternate arrangements can be made.

III. Agreed to

_____   _____
Volunteer   Staff Representative

_____   _____
Date   Date

This agreement may be canceled at any time at the discretion of either party, but it will expire automatically on _____ unless renewed by both parties.

From NC Handbook of Volunteer Management, 1991
As printed in North Carolina Respite Care Coalition, Lifespan Respite: An Information Guide for Developing, Recruiting, Training and Retaining Volunteers, 2011

EASTER SEALS DELAWARE & MARYLAND'S EASTERN SHORE

Volunteer/Student Service Agreement

This agreement does not represent a legally binding contract nor constitutes an offer of employment. The intent is to assure you both of our appreciation and to indicate our commitment to do the very best we can to make your volunteer experience a productive and rewarding one.

I. EASTER SEALS DELAWARE AND MARYLAND'S EASTERN SHORE

Easter Seals, agrees to accept the services of _____ and we commit to the following:

1. To provide adequate information, training, and assistance for the volunteer to be able to meet the responsibilities of the position.

2. To ensure diligent supervisory aid to the volunteer and to provide feedback on performance.

3. To respect the skills, dignity and individual needs of the volunteer, and to do our best to adjust to these.

4. To be receptive to comments from the volunteer regarding ways in which we might mutually better accomplish our tasks.

5. To treat the volunteer as a partner jointly responsible for completion of the Agency's mission.

II. THE VOLUNTEER

I,   (Volunteer Name)   , agree to serve as a volunteer, without compensation, in the capacity of

   (Volunteer Assignment)   and commit to the following:

1. To perform my volunteer duties to the best of my abilities and strive towards Agency performance standards.

2. To adhere to Agency rules and procedures, including record-keeping requirements and confidentiality and privacy policies dictated by HIPAA.

3. I will not attempt work that is beyond my abilities, or for which I have not been trained or authorized.

4. To meet schedule commitments and/or provide adequate notice so alternate arrangements can be made.

I understand the risks of volunteering with Easter Seals and acknowledge that neither Easter Seals nor any employee or volunteer will assume any financial liability for any injury or illness, that I might incur while performing my volunteer service. I understand that I am not eligible for Workers Compensation.

III. TERMINATION

The volunteer relationship at Easter Seals is "at will" and may be terminated, upon notice by either party, at any time, with or without cause. Easter Seals my terminate the volunteer immediately, and without notice, for dishonesty, violation of any law or regulation effecting volunteer's duties or responsibilities, or in the event that Easter Seals determines, in its sole judgment, that an employee's continued service presents an unreasonable or immediate risk of injury or damage to any Easter Seals participant or employee or facility, or may cause disruption of the orderly operations of the organization.

IV. AGREED BY:

_____   _____   _____   _____
Volunteer   Date   Staff Representative   Date

_____   _____
Parent/ Guardian if under 18 years of age   Date

Easter Seals DE & MD's Eastern Shore is committed to affirmative action, equal opportunity, and the diversity of its workforce. Revised 1/8/10

EASTER SEALS
DELAWARE & MARYLAND'S EASTERN SHORE

HIPAA CONFIDENTIALITY POLICY AGREEMENT FOR VOLUNTEERS

My signature below acknowledges that I have received and reviewed a copy of the Confidentiality Policy pursuant to the HIPAA regulations. This policy explains my responsibility to safeguard the protected health information of the people we serve at all times.

I agree to abide by the terms of the Confidentiality Policy at all times.

_____   _____
Volunteer Signature   Date

_____
Print Name

4/01/03

Volunteer Confidentiality Agreement

I have been made aware of the issues regarding strict confidentiality about information available to me in the position of volunteer for the (**insert organization name**). All information obtained will be strictly for the purpose of executing my responsibilities as a volunteer. All information obtained will be kept confidential. This agreement applies to all information regarding personnel and client matters. Violation of this confidentiality agreement will result in my dismissal.

_____
      Signature of Volunteer

_____
Date

WITNESSED:

_____
Volunteer Coordinator

EASTER SEALS DELAWARE & MARYLAND'S EASTERN SHORE

APPLICANT'S AUTHORIZATION FOR THE RELEASE OF PERSONAL INFORMATION

TO: *JAIME WILSON, Payroll Specialist/H.R. Assistant*   *FAX: (302)324-4480*

FROM: _____

RE: CRIMINAL BACKGROUND AND / OR DEPARTMENT OF MOTOR VEHICLE CHECK

I, _____/ _____/ _____

| First Name (Please Print) | Middle Name | Last Name |

.....do authorize the release of any information and/or review of the full disclosure of all records or any part thereof concerning myself by and to, CLIENT, or its authorized agents, whether the said records are public, private, or of a confidential nature. The intent of this authorization is to give my consent for full and complete disclosure of the records of institutions, employment and pre- employment records, complaints or grievances filed by or against me, records of complainant, arrest, trials and/or convictions for the alleged or actual violations of law, including criminal and/or traffic records; records of complaint of a civil nature made by or against me, wherever so located.

It is my specific intent to provide access to personal information, however personal or confidential it may appear to be required to comply with 11 Del. C. Sections 8560-8562, and the sources of information specifically enumerated above is not intended to deny access to any records not specifically intended herein.

I understand that any information obtained by a personal history background investigation, which is developed directly or indirectly, in whole or in part, upon release CLIENT will consider authorization in determining my suitability for employment.

CURRENT INFORMATION:

_____   _____

Social Security Number   Address

_____   _____

City, County, State, Zip Code   Date of Birth

_____   _____

Driver's License Number   State

PREVIOUS INFORMATION:

Please provide the following information, as applicable, to the past seven (7) years:
(If more room is needed, please attach separate page.)

_____

Maiden Name/Previous Last Name/Alias (es)

From: To:

_____ /_____ / _____ /_____ /_____ / _____ _____
Previous Address #1   City   County   State   Zip   Date   Date

_____ /_____ / _____ /_____ /_____ / _____ _____
Previous Address #1   City   County   State   Zip   Date   Date

_____   _____

Signature   Date

YOUR ORGANIZATION'S NAME

INCIDENT REPORT FORM

Date of incident: _____ Time: _____ AM/PM

Name of injured person: _____

Address: _____

Phone Number(s): _____

Date of birth: _____Male _____Female _____

Who was injured person? (circle one)   Client   Lifespan Respite Volunteer   Other

Type of injury: _____

Details of incident: _____

_____

_____

_____

_____

_____

Injury requires physician/hospital visit?   Yes   No

Name of physician/hospital: _____

Address: _____

Physician/hospital phone number: _____

_____
Signature of injured party   Date:

*No medical attention was desired and/or required.

_____
Signature of injured party   Date:

Return this form to your immediate Supervisor or Lifespan Respite Program Manager within 24 hours of incident.

EASTER SEALS
DELAWARE AND MARYLAND'S SHORE
RELEASE AND WAIVER FORM

1. I, the undersigned, hereby Release and agree to Hold Harmless Easter Seals Delaware and Maryland's Eastern Shore and their representatives individually and collectively, from and against any claims, demands and/or liabilities for any injuries, harm, loss, inconvenience or other damages resulting from my participation in the following Volunteer Activity   _____.

2. I have been advised of and acknowledge the risks involved in this activity. I understand that volunteers are not considered employees of Easter Seals and therefore, are not eligible for workmen's compensation or any other insurance coverage.I will conduct myself in a safe and prudent manner while participating

3. I hereby consent to authorize emergency treatment in the event of injury or illness while participating in this activity.

4. I agree to keep privileged and private information confidential.

5. I consent to use my name and any photographs taken of me during the activity in any promotional materials or publications.

I CERTIFY THAT I HAVE READ THE RELEASE AND WAIVER AND UNDERSTAND THAT I GIVE UP SUBSTANTIAL RIGHTS BY SIGNING IT, AND SIGN IT VOLUNTARILY.

Volunteer Signature: _____

Volunteer Name- Print   _____ Date _____

Address: _____

e-mail: _____ phone number: _____

Any volunteer who is under 18 is required to have a parent or guardian sign below

Signature of parent or guardian: _____ Date _____

Sample Job Descriptions

[These are only samples. Projects are encouraged to customize as appropriate]

Senior Companion Position Descriptions

Homebound Clients

Under the direction of the Senior Companion Project Director and the assigned Volunteer Station Supervisor, the Senior Companion will carry out the following duties, providing service to homebound seniors to help them live independently.

Responsibilities

a. Visit up to 3 to 6 homebound senior citizens once a week for 3 to 5 hours each.

b. Provide transportation assistance to each client for medical appointments, grocery shopping, basic errand running, and needs of daily living.

c. Offer companionship and socialization, which may include reading, playing games, talking, listening, participating in recreational activities or providing assistance with filling out forms or other paperwork.

d. Provide respite care relief in certain assignments.

e. Advocate for the client when appropriate to assist the client in obtaining necessary community resources or services that prolong independence and improve the quality of life.

f. Provide light meal preparation or light housekeeping when appropriate.

g. Submit monthly time sheets and client report forms, and, as applicable, mileage and meal reimbursement forms, to the main office in a timely manner.

Qualifications

a. Companion must be 60 years or older and determined through a physical examination to be capable of fulfilling the responsibilities required of the program as stated above without detriment to self or the client served.

b. Companion must be willing and able to volunteer between 15 to 40 hours per week.

c. Companion must have reliable and safe means of transportation.

d. Companion should have compassion for people with a kind and friendly attitude.

e. To receive a stipend, annual income must be within federally established guidelines.

From Senior Companion Program Handbook, 2008
http://www.nationalserviceresources.org/sc-scp-handbook

Adult Daycare Center

FUNCTION: Performs one-on-one volunteer services for assigned clients, including elderly individuals and those with disabilities.

SUPERVISION RECEIVED: Serves under direct supervision of Activities Coordinator or Assistant.

EXAMPLES OF SERVICES PERFORMED

• Assist in exercises by helping assigned clients participate to the best of their ability, or by doing passive exercises on those clients who may not be able to move on their own.

• Create and assist in craft classes by helping assigned clients to work with their craft projects and to give client a sense of self-worth by encouraging them to feel good about the things they accomplish in this area.

• Assists clients with serving snacks and noon meal.

• Assist with moving assigned clients from one location to another, as activities require.

• Assists assigned client with bathroom needs and personal hygiene.

• Talking with and interacting with clients, other staff, and volunteers.

• Abiding by the rules regarding the right to privacy in the client's best interest.

EXPERIENCE AND TRAINING: No experience is needed. A real love for people is a must. Orientation and monthly training is provided. Volunteers may travel as a group to other facilities for a learning experience, on occasion.

QUALIFICATIONS: Age 60 years or older. To receive a stipend, annual income falls within Federally established guidelines. Willing and able to volunteer 15 to 40 hours per week. Health, as determined by physical examination, must be adequate to meet the demands of the position without detriment to self or client served.

From Senior Companion Program Handbook, 2008
http://www.nationalserviceresources.org/sc-scp-handbook

Orientation

Activity: Assessing Your Cultural Competence

Highlight the awareness on each line that best represents you.

I know my own cultural background.

Very Aware	**Somewhat Aware**	**Need Awareness**

←————————————————————————————→
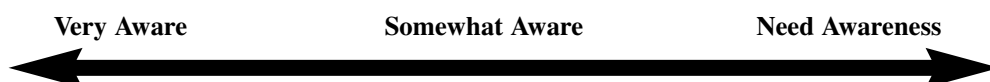
I am aware of many of the cultural influences that have shaped my worldview.

Very Aware	**Somewhat Aware**	**Need Awareness**

←————————————————————————————→
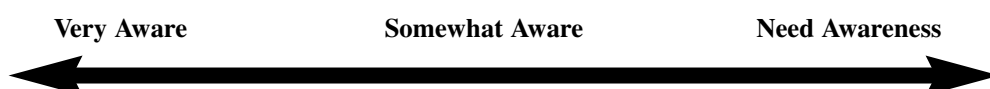
I can describe the influences of culture and cultural identity on children's development.

Very Aware	**Somewhat Aware**	**Need Awareness**

←————————————————————————————→

I understand how prejudice and discrimination impact children's development from an early age.

Very Aware	**Somewhat Aware**	**Need Awareness**

←————————————————————————————→
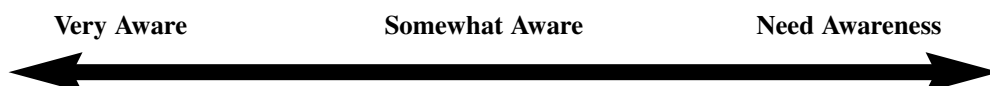
I understand how prejudice and discrimination can impact a family.

Very Aware	**Somewhat Aware**	**Need Awareness**

←————————————————————————————→
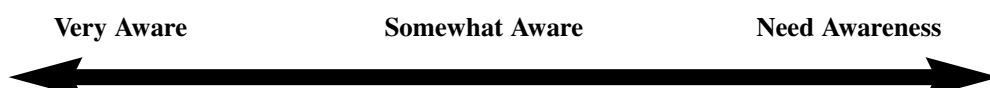
I am clear about my own attitudes regarding culture and race and the impact these will have on children in my care.

Very Aware	**Somewhat Aware**	**Need Awareness**

←————————————————————————————→
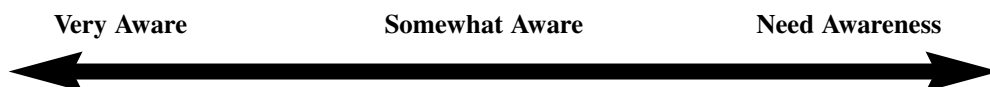
I know how to provide culturally competent advocacy to the children I serve and culturally competent support to their families.

Very Aware	**Somewhat Aware**	**Need Awareness**

←————————————————————————————→

Easter Seals
DISABILITY SERVICES
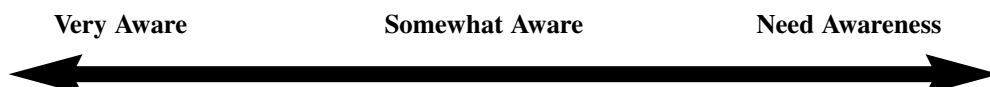
Name _____ Program/Department _____

The following checklist applies to volunteers and students making an ongoing commitment.

VOLUNTEER/STUDENT PAPERWORK AND ORIENTATION CHECKLIST		
	Completed date/initials/	Comments/ Not Applicable
Paperwork - To be completed prior to second day		
Information form		
Confidentiality Policy Acknowledgement		
Waiver		
Criminal Background Authorization		
Adult Abuse Registry Authorization		
Child Registry Authorization		
PPD results if applicable		
Service Agreement		
Position Description		
MISCELLENOUS-Verbal		
Introduction to department staff/supervisor		
Sign in/Sign out procedures		
Break room/vending machines/rest rooms etc...		
Smoking designated areas		
Easter Seals Overview		
History/Programs/Services		
Dress Code		
Attendance		
Facility Tour		
Parking		
To be completed within first month		
PROGRAM/DEPARTMENT SPECIFIC ORIENTATION		
SAFETY ORIENATION		
Fire extinguisher locations		
Emergency/evacuation plans, procedures		
Participant rights		
Infection control		
DEPARTMENT SPECIFIC TRAINING		
Orientation to roles and responsibilities		
Introduction to staff		
Place to put personal items		
Breaks (breakfast/lunch/snacks)		
WORKSPACE/OFFICE EQUIPMENT		
Preparation of workspace		
Office and program supplies		
Computer access and training if applicable		
Policy on use/misuse of e-mail and internet		
Copier codes		
Fax machine		
Phone System		
Communication with participants and families		
INTEROFFICE COMMUNICATION		
Staff directory		
Mailboxes and mailing		
FINANCIAL (if applicable)		
Preapproved expenses/preapproved mileage		
MISCELLANEOUS		
Cell phone/texting/IPods		
Meetings/introductions with key personnel		
Requirements of academic institution		
Other		

Revised 1/12/10

Sample Policies and Procedures

Code of Ethics:

This code of ethics governs the performance of the (Sponsoring Organization's) officers, employees, board members, volunteers, and agents, (representatives) engaged in the administration of contracts supported by Federal assistance. Any employee in violation of these policies is subject to disciplinary action as outlined in the Employee Handbook. Any officer or board member who violates these policies will be subject to disciplinary action as determined by a majority vote of the Board of Directors. Any volunteer who violates these policies will be subject to disciplinary action as determined by the Manager of the program in which the person volunteers.

1. **Gifts:** Representatives shall not accept gratuities, favors, gifts, or anything of monetary value (over $5.00) from present or potential contractors or sub-recipients.

2. **Personal Conflict of Interest:** Representatives who participate in the selection, award, or administration of a contract supported by Federal funds are prohibited from a real or apparent conflict of interest. Such a conflict would arise when any of the parties below has a financial or other interest in the entity selected:

   a. A (Sponsoring Organization) representative;
   b. Any member of his or her immediate Family;
   c. His or her partner;
   d. An organization that employs, or is about to employ, any of the above.

3. **Organizational Conflict of Interest:** The (Sponsoring Organization) is prohibited from real or apparent organizational conflicts of interest. Such a conflict when the nature of the work to be performed under a proposed third party contract may, without some restrictions on future activities, result in an unfair competitive advantage to the third party contractor or impair its objectivity in performing the contract.

4. **Bonus or Commission:** The (Sponsoring Organization) affirms that it has not paid, and agrees not to pay, any bonus or commission for the purpose of obtaining approval of its application for Federal financial assistance.

5. **Restrictions on Lobbying:** The (Sponsoring Organization) agrees to comply with the provisions of 31 USC 1352, which prohibits the use of Federal funds for lobbying any official or employee of any Federal agency, or member or employee of Congress. In addition, even though no Federal funds are use, the (Sponsoring Organization) agrees to disclose any lobbying of any of any official or employee of any Federal agency, or member or employee of Congress in connection with Federal assistance and to comply with USDOT regulations "New Restriction on Lobbying," 49 CFR Part 20.

6. **Employee Political Activity:** The terms of the "Hatch Act," 5 USC Section 1501 through 1508, and office of Personnel Management regulations, "Political Activity of State or Local Officers or Employees," 5 CFR Part 151, apply to supervisory employees of the (Sponsoring Organization).

7. **False or Fraudulent Statements or Claims:** The (Sponsoring Organization) acknowledges that it will not make a false, fictitious, or fraudulent claim, statement, submission or certification in conjunction with any program supported by Federal assistance. The (Sponsoring Organization) is aware that Federal penalties could be imposed for making a false, fictitious, or fraudulent claim, statement, submission or certification in conjunction with any program supported by Federal assistance.

My signature below acknowledges understanding of the (Sponsoring Organization's) Code of Ethics:

Signature: _____ **Date:** _____

Sample Confidentiality Policy

The right of all clients to confidentiality of information is very important and is protected by both State and Federal laws. An agency that violates the data privacy law is liable to a person who suffers any damage as a result of the violation, and the person damaged may bring legal action to cover any damages sustained, plus costs and reasonable attorney fees. In the case of willful violation, an agency is liable for between $100 to $10,000 per violation. Any person who willfully violates provisions of Minnesota Statutes 13.0213.09 is guilty of misdemeanor, while willful violation by an employee, including volunteer staff, constitutes just cause for suspension or dismissal.

However, more important than any possible willful violation of the data Privacy Act by staffs the fact that all people have an inherent right to privacy regarding their particular problems and circumstances, but even to the fact they are clients of the Faith in Action Transportation Program.

Therefore, it is most important in a staff position, be it volunteer or salaried, that we treat all information received during the course of our activity at the agency, as confidential. Such may be shared among fellow staff when it is appropriate and legal to do so, but we must always be on guard against repeating information to anyone outside of the volunteers or the Program Coordinator in the Faith in Action Transportation Program. Even the sharing of details of a particular situation without using names of places can be a breach of confidentiality, as others who overhear may be in just the right position to figure out who you may be discussing. The world is smaller than we sometimes think.

If asked what you do as a volunteer staff person, describe your responsibilities in general terms. Avoid commenting on a client's capabilities or circumstances. If asked why a passenger is receiving a ride, for example, you might simply say, "There can be many reasons, and it would not be appropriate for me to comment." To those who continue to probe for details or examples of a personal nature, one can always say something like,

"I'm sure you can understand it is unprofessional for me to give specific information. You would expect the same privacy if you were in need of help." Should you meet an acquaintance while with a client you are assisting, introduce the client as you would any friend. "This is my friend, (give first name only); we're on our way to the library (or whatever place or general activity it is)." Be as normal as the situation calls for.

Source: Minnesota Faith in Action Transportation Program

EASTER SEALS

DELAWARE and MARYLAND'S EASTERN SHORE POLICY

NAME: **CONFIDENTIALITY POLICY**

APPLIES TO: All people we serve, employees and volunteers

POLICY STATEMENT: It is the policy of Easter Seals to maintain the highest level of confidentiality for the people whom we serve, our employees and our volunteers at all times and under all circumstances, and in compliance with all HIPAA policies and regulations.

POLICY STANDARDS:

Client / Participant Information:

1.   All client or participant protected health information is strictly confidential and can be shared only with those who have a "need to know" in the due course of business and operations, and only in a secure area. The "need to know" is defined as that which is necessary for one to perform one's specific job responsibilities adequately.

2.   Each client or participant will be treated with respect and provided privacy when receiving services at Easter Seals. Discussions about a client / participant will be confidential and conducted discreetly. Persons not involved in the service delivery will not be permitted to be present during discussion unless the client has given informed consent.

3.   Clients or participants from whom confidential information is elicited will be informed of Easter Seals' policy and purposes for collecting the information.

Confidentiality Breaches:

1.   "Carelessness" is defined as a breach that occurs when a volunteer unintentionally or carelessly accesses, reviews or reveals himself/herself or others without a legitimate need to know the client / participant protected health information. Carelessness is a minor infraction. Some examples of carelessness include, but are not limited to, volunteers discussing client/participant protected health information in a public area, employees leaving a copy of client / participant protected health information in a public area, employees leaving a computer work station unsecured. A public area is any unsecured area or an area of public access.

2.   "Curiosity or Concern" is defined as a breach when one accesses, reviews, discusses client / participant protected health information for purposes other than care of the client / participant. This is considered a major infraction. Some examples of curiosity or concern include a volunteer looks up birthdates, addresses of friends or relatives; accesses and reviews a client / participant record out of concern or curiosity; reviews a "famous " or public person's record.

3.   "Personal Gain or Malice" is defined as a breach when a volunteer accesses, reviews, discusses client protected health information for personal gain or with malicious intent. This is a "critical" infraction.

Sanctions:

1. If a supervisor or manager believes a breach has occurred by a volunteer, after investigation, the progressive discipline process will be followed (see Sanction Policy.) Scope and severity of the outcome will assist in determining what level of progressive discipline is utilized, up to and including termination.

2. The volunteer who is sanctioned for breaching the confidentiality policy will be required to re-certify the Confidentiality and Compliance policies with the Human Resources Department.

3. If applicable, the incident will be reported to the appropriate licensing board.

4. If an individual observes a breach of confidentiality, he or she shall report it to his/her immediate supervisor, the Vice President of Human Resources or Easter Seals Privacy Officer (VP, Finance). Failure to report a breach of confidentiality will result in disciplinary action.

5. Submitting a false report of a breach of confidentiality in bad faith or for malicious reasons will result in disciplinary action.

6. Tampering with incoming or outgoing mail, mail that has been distributed or any communication that is marked as confidential is prohibited. All interdepartmental mail of a confidential nature is to be placed in a secure, confidential envelope and is to be opened by the addressee only.

Employee Information:

1. Employee records and confidential Human Resources materials are strictly confidential.

2. Employee files are to remain in Human Resources secured in a locked cabinet with restricted access.

3. Employee files cannot be removed from the Human Resources Department without written authorization from the Administrator.

4. Employee records and health information are to be treated with the same respect and in the same confidential manner as client or participant information.

5. Breaches in employee confidential matters are the same as violating client or participant confidentiality and are grounds for disciplinary action up to and including termination following the same formula as for "breaches" of client confidentiality.

ORIGINATION DATE: 01/03
ANNUAL REVIEW MONTH: January
MOST RECENT REVISION (# and date):

Provision of Accommodations to Volunteers with Disabilities

The following is a sample policy on providing accommodations to volunteers with disabilities. This policy is intended as a guide for programs. An accommodation statement is an effective way to convey your program's commitment to volunteers with disabilities and to demonstrate that volunteers with disabilities will receive equal opportunity; this policy will help you establish procedures for accommodations when they are requested.

Upon a volunteer's self-disclosure of a disability and a request for an accommodation, the program will engage in the following process:

1. The volunteer manager or other program staff will ask the volunteer to suggest several accommodations and to show how these accommodations allow the volunteer to complete his or her essential duties and participate in the program.

2. The volunteer manager or other program staff will explain possible accommodations the program could provide the volunteer. Accommodations the program could offer include, but are not limited to: modifying policy and procedures, removing structural barriers, providing assistive devices, restructuring service descriptions, modifying service schedules, and substituting alternative learning experiences in place of educational requirements for qualified volunteers.

3. The volunteer manager or other program staff and the volunteer will jointly determine the costs of each suggested accommodation and assess the impact of the accommodation on the service environment.

4. The volunteer manager or other program staff and the volunteer may invite outside experts to offer ideas and resources on potential accommodations.

5. With the input of the volunteer, the program will procure and accommodation option that allows the volunteer to effectively complete his or her duties and participate in the program without causing the program an undue financial burden or altering the fundamental nature of the service duties or the program. The program reserves the right to select an accommodation option that is equally as effective as the volunteer's recommendation but less costly.

6. The volunteer manager or other program staff and the volunteer will meet at least once after the accommodation(s) is in place to review its effectiveness and make any changes necessary to ensure that the volunteer can participate fully in program activities.

7. The program recognizes that the provision of accommodation(s) is an ongoing process that may require occasional reevaluations to ensure volunteers with disabilities are fully included in all aspects of service. The program will engage in reevaluations of accommodation(s) on a periodic basis, or when the volunteer requests a reevaluation.

8. If the volunteer is dissatisfied with the decision of the program, the volunteer may file a grievance using the established grievance procedure in the Program Policy Manual.

9. All information about a volunteer's accommodation(s) is confidential. Documents about accommodation(s) will be placed in a locked file separate from the volunteer's application, evaluations, etc. Information regarding accommodation(s) may not be released without the volunteer's informed consent.

Sample Drug Free Workplace Policy:

1. The (Sponsoring Organization's) employees and volunteers are prohibited from the unlawful manufacture, distribution, dispensing, possession or use of a controlled substance at any of the (SO) facilities and/or during any of the programs offered by the (SO).

2. Any violation of the prohibitions in #1 will be considered to be "Just Cause" for suspension and/or discharge under the procedures of the (SO).

3. As a condition of employment or registration as a volunteer each employee or volunteer will:

   a. Abide by the terms of #1 above and;

   b. Notify the (SO) in writing of any criminal drug status conviction for a violation occurring in the workplace no later than five calendar days after such conviction.

4. The (SO) will notify grantor agencies in writing within ten calendar days after receiving notice under #3B as referred to above, with respect to any employee or volunteer who is so convicted and will:

   a. Take appropriate personnel action against such an employee, up to any including termination; or

   b. Require such an employee to participate satisfactorily in drug abuse assistance or rehabilitation program approved for such purposes by Federal, State, or local health, law enforcement or other appropriate agency.

5. The employee and/or volunteer acknowledges by signature below that he/she has:

   a. Been given a copy of this policy statement;

   b. Reviewed this policy statement, and;

   c. Understood the policy statement.

A copy of the policy will be maintained in the volunteer's Personnel File.

I have read and understand the above Policy.

Signature: _____ Date: _____

Adopted by the (Sponsoring Organization) on this date:

Policy on Harassment:

It is the policy of the (Sponsoring Organization) that it will not tolerate verbal or physical conduct by any employee or volunteer which harasses, disrupts, or interferes with another's work performance or which creates an intimidating, offensive, or hostile environment.

1. All forms of harassment are prohibited but it is the (SO's) policy to emphasize that sexual harassment is specifically prohibited. Each supervisor has a responsibility to maintain the workplace free of any form of sexual harassment. No supervisor is to threaten or insinuate, either explicitly or implicitly, that an employee's refusal to submit to sexual advances will adversely affect the employee's employment, evaluation, wages, advancement, assigned duties, shifts, or any other condition of employment or career development. In addition, no supervisor is to favor in any way any applicant or employee because that person has performed or shown willingness to perform sexual favors for the supervisor.

2. Other sexually harassing conduct in the workplace, whether committed by supervisory or non-supervisory personnel, is also prohibited. Such conduct includes:
   a. Sexual flirtations, touching, advances, or propositions;
   b. Verbal abuse of a sexual nature;
   c. Graphic or suggestive comments about an individual's dress or body;
   d. Sexually degrading words to describe an individual; and
   e. The display in the workplace of sexually suggestive objects or pictures, including nude photographs or illustrations.

3. Any employee who believes that the actions or works of a supervisor or fellow employee constitute unwelcome harassment has a responsibility to:
   a. Tell the supervisor or fellow employee that their action or words are unwelcome and are considered harassment;
   b. Report or complain as soon as possible to the appropriate supervisor or to the President of the Board of Directors if the complaint involves the Director.

4. All complaints of harassment must be investigated promptly in a manner that is as impartial and confidential as possible. If the employee is not satisfied with the handling of a complaint or the action taken by the Manager then the Grievance Procedure should be followed.

I have read and understand the above policy and signing below constitutes an agreement to adhere to this policy.

Signature: _____ Date: _____

Sample Grievance Procedure

Resolution of Problems

When problems or grievances arise, the following steps are suggested in order to enable the [Name of Organization] to promptly resolve disputes. [Name of Organization] will protect the confidentiality of parties involved to the extent possible.

1. When a volunteer or care receiver wishes to bring an unresolved problem or concern to the attention of [Name of Organization] we ask that they first discuss the problem or concern with those involved in order to reach a mutually agreed upon solution. If there is no resolution, the volunteer or care receiver is asked to proceed to steps 2,3,4.

2. The volunteer or care receiver should discuss the problem with [Name of Organization] staff. The staff member will gather information about the matter from relevant sources, including the person filing the grievance.

3. The persons involved, including the person filing a grievance will work together to formulate a plan of action, which will include checkpoints and a time frame for completion.

4. On the completion date, if the plan of action has not been successful, a determination will be made by the Director regarding further action.

Evaluation Forms

Performance Evaluation of Volunteer

Volunteer _____ Position _____

Period covered by evaluation _____ Date of Evaluation _____

Position Duties and Responsibilities:	Not Met	Satisfactory	Superior
1. _____	1	2	3
2. _____	1	2	3
3. _____	1	2	3
4. _____	1	2	3
5. _____	1	2	3

Work Relationships:	Needs Improvement	Satisfactory	Superior
1. Relations with other volunteers	1	2	3
2. Relations with staff	1	2	3
3. Relations with service recipients	1	2	3
4. Meeting commitments on time	1	2	3
5. Initiative	1	2	3
6. Flexibility	1	2	3

Comments by supervisor regarding above areas:

Comments by volunteer regarding above areas:

Overall, how does the volunteer feel about this position?

What else can be done to support the volunteer in this position or to move the volunteer to a new position?

_____   _____   _____   _____

Supervisor   **Date**   **Volunteer (optional)**   **Date**

Scheduled date of next evaluation _____

From NC Handbook of Volunteer Management, 1991
As printed in North Carolina Respite Care Coalition, Lifespan Respite: An Information Guide for Developing, Recruiting, Training and Retaining Volunteers, 2011

Volunteer Evaluation of Assignment

Name _____ Work Area _____

Circle the appropriate answer:
3-Excellent, 2-Good, 1-Satisfactory, 0-Unsatisfactory, NA – Does not apply

1. Personal satisfaction with present job assignment.	3	2	1	0	NA
2. Job description complies with present duties.	3	2	1	0	NA
3. Adequate orientation and training.	3	2	1	0	NA
4. Supervisor's instruction adequate for day-to-day activities.	3	2	1	0	NA
5. Comfortable relationship with co-workers.	3	2	1	0	NA
6. Cooperative and positive relationship exists with staff.	3	2	1	0	NA
7. Cooperative and positive relationship exists with supervisor.	3	2	1	0	NA
8. Receive adequate recognition for services.	3	2	1	0	NA
9. Receive adequate support from staff.	3	2	1	0	NA

10. Any additional comments (Please include any feelings, problems, etc. about your volunteer involvement):

11. Any suggestions for improving the volunteer program:

12. If exit interview, please state reason(s) for leaving.

_____   _____
Volunteer's Signature   Supervisor's Signature

_____   _____
Volunteer Administrator's Signature   Date

CareBreak
Forms

(copied with permission

from CareBreak at

The Watson Institute)

CAREBREAK AT THE WATSON INSTITUTE
VOLUNTEER APPLICATION

NAME: _____ DATE: _____

ADDRESS: _____ APT. _____

HOME PHONE: _____ CELL: _____

EMAIL ADDDRESS: _____

ARE YOU OVER THE AGE OF 18?   YES   NO

EMPLOYER: _____ WORK PHONE: _____

IS IT OKAY TO CALL YOU AT WORK? YES   NO

BRIEFLY STATE YOUR BACKGROUND, INTEREST AND/OR EXPERIENCE IN WORKING WITH CHILDREN WITH DISABILITIES:

_____

_____

EDUCATION (HIGH SCHOOL, COLLEGE, OTHER):

YEAR(S)	NAME	CITY & STATE	DIPLOMA/DEGREE
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

ARE YOU CURRENTLY A STUDENT?   YES   NO   IF YES, WHERE: _____

EMPLOYMENT (LAST THREE YEARS):

DATE	EMPLOYER	ADDRESS	POSITION
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

SPECIAL SKILLS / TRAINING: CERTIFICATE RECEIVED:

_____   _____

_____   _____

DO YOU HAVE A CURRENT CPR CERTIFICATION?   YES   NO   INFANT /CHILD CPR?   YES   NO

CERTIFICATION DATES: _____

LIST ANY VOLUNTEER EXPERIENCE YOU HAVE HAD (INCLUDE DATE, AGENCY/INSTITUTION AND ACTIVITY/POSITION):

_____

_____

LIST YOUR INTERESTS AND HOBBIES (INCLUDE ANY/ALL HOBBIES OR INTERESTS):

_____

_____

COMPLETE THIS SENTENCE: I'M THE TYPE OF PERSON WHO _____

_____

EMERGENCY CONTACT: WHO SHOULD WE CONTACT IN AN EMERGENCY SITUATION:

NAME: _____   PHONE (HOME):   _____

ADDRESS: _____   PHONE (WORK):   _____

_____   RELATIONSHIP: _____

DO YOU HAVE A CAR OR DO YOU RELY ON BUS TRANSPORTATION? _____

I GIVE MY PERMISSION TO THE CAREBREAK PROGRAM AT THE WATSON INSTITUTE TO CONTACT THE REFERENCES LISTED BELOW AND EMPLOYERS/PLACES VHERE I HAVE VOLUNTEERED FOR ROUTINE INQUIRY INTO SUCH MATTERS AS MY CHARACTER, GENERAL REPUTATION AND PERSONAL CHARACTERISTICS. THE INQUIRY WILL BE USED BY THE WATSON INSTITUTE TO EVALUATE MY APPLICATION. THE NATURE AND SCOPE WILL BE MADE KNOWN TO ME UPON WRITTEN REQUEST.

I UNDERSTAND THAT ANY FALSIFICATION OF INFORMATION RENDERED IN CONNECTION WITH MY APPLICATION AS A VOLUNTEER TO THE WATSON INSTITUTE CAN RESULT IN AN IMMEDIATE TERMINATION AS A REPRESENTATIVE OF THE WATSON INSTITUTE AND CAREBREAK. I HAVE READ THE VOLUNTEER POLICY AND AGREE TO COMPLY WITH ALL POLICY STATEMENTS.

_____   _____
APPLICANT'S SIGNATURE   DATE

THE CAREBREAK PROGRAM AND THE WATSON INSTITUTE REQUIRES THAT YOU SUBMIT THREE WRITTEN REFERENCES. IT IS YOUR RESPONSIBILITY TO SOLICIT THESE REFERENCES BEFORE YOU ARE MATCHED. WE WILL PROVIDE FORMS FOR YOU TO DISTRIBUTE TO YOUR REFERENCES AND WILL CONFIRM ALL REFERENCES BY MAIL OR BY PHONE. YOU MUST HAVE KNOWN EACH REFERENCE FOR AT LEAST ONE YEAR, AND PREFERABLY LONGER. PLEASE -- NO FAMILY MEMBERS.

PLEASE LIST YOUR REFERENCES BELOW AND THEIR DAY/EVENING TELEPHONE NUMBERS.

NAME	DAY PHONE	NIGHT PHONE
_____	_____	_____
_____	_____	_____
_____	_____	_____

RETURN TO: CAREBREAK VOLUNTEER COORDINATOR / THE WATSON INSTITUTE
301 CAMP MEETING ROAD / SEWICKLEY, PA 15143

<table>
<tr><td>For Students
University:
Years of study:
Major:</td><td>**THE CAREBREAK PROGRAM
INTERVIEW QUESTIONS**</td><td>Contact information:
Telephone:
Cell phone:
Email:</td></tr>
</table>

Applicant s Name _____   Interview Date _____

Interviewer _____   Recommended for training? _____

1. Why are you interested in volunteering?

2. Why The CareBreak Program?

3. What makes you interested in volunteering with children? (What about children makes you interested in volunteering with them?)

4. What do you hope to gain from your volunteer experience?

5. Have you ever interacted with a person with disabilities before?

6. How much and what kinds of experience do you have working with children?

7. Have you ever had to discipline a child? What did you do, or what would you do?

8. What type of child would you be interested in working with? (e.g., gender, age, ability, energy level)

  Are there special needs that you are uncomfortable or unable to accommodate (i.e. seizures, lifting / positioning)

9. What kinds of activities do you like to do with kids?

10. How will a child benefit from your CareBreak efforts?

11. What benefit do you hope to provide to the parents/caregivers?

12. When are you available to volunteer?

13. How far would you be willing to travel? What type of transportation do you use?

14. Describe the CareBreak child and family you envision being matched with.

Interviewer Comments: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

CareBreak at The Watson Institute
Volunteer Reference Form

Applicant's Name: _____

Reference Name: _____

Reference Address: _____

_____

CareBreak program volunteers provide respite to families with children who have a disability. Once matched with one particular family, the volunteer goes into the family's home on a weekly basis and cares for the child (or children) while the parents take a break. Our volunteers develop relationships with both child and family; they
are a consistent help to the parents and a dependable friend to the child.

Please keep this information in mind as you answer the following questions.

1. How long have you known the applicant?

2. In what capacity have you known the applicant?

3. How would you describe the applicant?

4. Have you ever seen the applicant interact with children and their families? If so, how would you describe the interaction? Also, if you have children, do you (or would you) allow the applicant to care for them?
5. In your opinion, what would the applicant bring to the position of CareBreak volunteer and what would he/she bring to a CareBreak program family and child?

6. CareBreak Program families rely on their volunteers to be reliable and dependable in their visits. In your opinion, would the applicant be able to provide this dependability?

7. Is there anything else which would be helpful to us in placing the applicant with the family, which would be best, suited to him/her?

_____   _____
Signature   Date

A CareBreak staff member will be calling you to verify this recommendation.
Please give us your phone number and the best time to reach you:

_____

Please return this form to: CareBreak Coordinator
                                      The CareBreak Program at The Watson Institute
                                      301 Camp Meeting Road
                                      Sewickley, PA 15143

Thank you very much for taking the time to complete this reference. You have been a great help to us in making a good match between an enthusiastic volunteer and a grateful family. If you have any questions, please call the CareBreak Program at (412) 749-2862 / 749 2863 or (866) 893-4751.

For office use only
Date:
Comments:

Signature:

Children's Service Society of Wisconsin Event Respite Sample Forms

(copied with permission from

Children's Service Society

of Wisconsin)

Children's Service Society of Wisconsin

Volunteer Respite Event Registration
Saturday July 9th, 2011
Wil'O'Way Park 10602 Underwood Parkway, Wauwatosa
Event is from 8:00 a.m. to 3:00 p.m.

> **To register email your name, address, phone #, birthday, emergency contact & their phone# ~ or this form to: Ellen Anderson ellen.anderson@cssw.org**

~ register early!~

Volunteer Name: _____

Your phone _____

Company, School etc.: _____

Address w/zip: _____

Birthdate _____

Email: _____

> All Attendees: Background disclosures (any criminal or caregiver incidents)
> will be required to be signed at the event before participating.

Emergency contact for you:

Name: _____

Relationship to you: _____ Phone: _____

Preference of child to care for:

Child w/special need _____ Sibling _____

Have you had experience caring for a medically or behaviorally challenged child (nurse or other training)?

> If volunteer is under 18 years old… Parental Consent needed:
>
> I hearby give permission for my son/daughter _____
> To serve as a volunteer for Children's Service Society of Wisconsin Volunteer Respite Program.
>
> Signature of
> Parent/Guardian: _____ Date _____

Children's Service Society of Wisconsin
Volunteer Respite Program
4340 N. 46th St. Milwaukee, WI 53216
(414) 444-5760 ext 2225 Fax (414) 444-5762
We cannot accept day-of-event registrations

Children's Service Society of Wisconsin
A member of Children's Hospital and Health System.

Date completed: _____

Date Updated: _____

1212 S. 70th Street, Milwaukee, WI 53214
Ph: (414) 453-1400 Fax: (414) 453-2538

Volunteer Respite Program
MEDICAL EMERGENCY FORM (date)

Parents/Caregivers:
BRING THIS TO RESPITE EVENT; AND NOTE ANY CHANGES~

Child's Full Name: Child's SSN #   Birthdate:

Parent/Guardian with whom child resides:

Home Address: (*Street, City, State, Zip*)   Email:

Emergency Contact of Parent/Guardian: Phone #:   Other Phone:

Alt.Contact Name: Phone: Relationship to child:

In case of medical emergency involving the above named child, I understand the following procedure will be followed: A reasonable effort will be made to contact me and secure my consent for any medical services. If I cannot be located within a reasonable time, the respite provider has my permission to contact the child's physicians/ get emergency help.

Dr.:   Phone: Dr.:   Phone:

Hospital Preference for emergency treatment:

Insurance policy # and ph# / Medical Asst.:

Child Height: Child Weight:

Glasses: Contacts: Hearing Aids:

Prosthetic: If so, describe, and note any special care needed:

History of Seizures?: If yes, describe in detail:

Feeding Challenges? If so, describe, and include feeding requirements:

Speech challenges? If so, how do we best communicate with your child?

Walking or Mobility challenges? If so, please describe. What assistance is required?

Special toileting needs? If so, how should your child be helped/cared for?

Any help with dressing needed? If so, describe:

Any other personal care assistance needed? (Include dental hygiene, hair care, etc.)

P. 2 Medical Emergency Form/ Volunteer Respite Program

This child is allergic to:

This child is currently taking the following medication(s):

Medication: **Taken for:**   **Dosage:**   **Time:**   **How dispensed:**

Existing Diagnosis:

Signature, Parent/Guardian _____ Date: _____

Children's Service Society of Wisconsin

Saturday Respite Event
Child Information Sheet for Volunteer

PLEASE DO NOT LEAVE YOUR CHILD/MATCH UNATTENDED AT ANY TIME

Child name: _____   Age: _____

Siblings attending (and ages)
Description of special needs for volunteer:

_____
_____
_____
_____
_____

Behavior issues and what to do:

_____
_____

Things that might distress/frighten this child:

_____

What comforts/calms this child?:

_____

Favorite activities:

_____

This child will be using the nursing staff for:

_____
_____
_____

Dietary issues:

This child is the sibling of a child with special needs. Siblings attend to give the parents a day truly to themselves. Siblings often don't get much one to one attention due to other demands of parents/caregivers. He/she will love this special day with you.

Notes: _____
_____

VOLUNTEER:
PLEASE RETURN THIS FORM TO THE REGISTRATION TABLE BEFORE YOU ARE MATCHED WITH YOUR CHILD, IN THE MORNING.

_____2006_____2007_____2008

Dear Respite Care Family,   June 15, 2011

This letter confirms your registration for the Respite Event at:

> ## WilOWay Park 10602 Underwood Parkway, Wauwatosa, WI
> ## Sat. June 25th, 2011   8:30 am to 3:00 pm

We are excited to spend a fun day with your child/children! When you meet the volunteers spending the day with your child/children at the beginning or end of the day, please thank them, as a kind word means a lot, and encourages them to help us again! They have dedicated their day to the care of your child, so you can have respite time.

- At the event, check in with nurse assigned to your child(ren) and volunteer assigned to your child; give them all information they will need for your child's care and safety.

- This is an Outdoor/Indoor event; put on sunscreen or bug spray as desired. We do not provide this.

- Sign in, indicate in writing who is picking up the child(ren) then sign out at pick up time.

- Bring with you any supplies or equipment that your child/children may require, ie. change of clothes, diapers, g tube feeding, special care products, with their name on the bag.

- If your child has special dietary restrictions, you are welcome to pack a lunch and snacks. A regular kid-friendly lunch and pm snack, and water will be served.

- If your child needs medicine during the event, please send only the dose(s) needed in the original container. You can store the rest up high/locked up somewhere safe at home. This prevents accidental mis-dosage or forgetting of important meds at the Event. Be sure and collect the container at the end of the day. Your pharmacist will give you an extra container (for school or events) if you ask!

- Please mark backpacks/supplies etc. with their name. Kids won't need their own toys.

- It will be a fun day including outdoor padded playground, Drum Circle with Tom Gill, disc golf, canvas painting, table games, arts & crafts, face painting, movies, bingo and more!

- Enclosed is a Child Emergency Data Sheet; please fill out and SIGN and bring to the event. We will be updating our files after the event with this information, to help keep your children safe. We have their previous info that day.

We look forward to seeing

_____!

KEEP THIS NUMBER~ PHONE where we can be reached <u>AT THE EVENT</u>: 414-559-2490

Ellen Anderson, Coordinator Volunteer Respite Program, Children's Service Society of Wisconsin
This event hosted by Hales Corners Lutheran Church
And made possible in part by United Way and The Respite Care Association of Wisconsin

Diaper Check Chart MUST be checked every hour; initialize. Note BM or U for urinated

Child Name	8:30-10	10-11	11-12	12-1	1-2	2-3

G-Tube Feeding/med Chart MUST be initialized and specified WHAT administered/meas. and When.

Child Name	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial

MEDICATION Admin Chart

Child Name	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial	Time & What Given; Initial

Schedule

8:00-8:30	Volunteer Sign-in, orientation, breakfast snacks
8:30-9:00	Kids Sign-in~ Meet your friend
All morning:	gym time w/balls, table games, arts & crafts incl. beading, playdoh, friendship bracelet making, pipecleaner projects, drawing & more; table games, book nook, and movies
9:00	Rotate out by nametag color to Fire & Police Activities! (Survive Alive House, using the fire hose, touring a MPD squad, fire truck, emerg. vehicle etc.; groups going all a.m. and from 12:30-2; we will call you by groups)
10:00	Snack available
11:30-12:30	Lunch
All Afternoon:	Arts & crafts, table games, book nook, gym time, movies face painting, BINGO with prizes
2:00-3:00	Snack available/ fruit wrinkles
2:30	Help clean Up. Thank you!
3:00	Children get picked up

No one is to leave the designated areas or to be alone with a child at any time.

You and your child can choose what activities to do throughout the day. If a crowd or loudness disturbs your child, feel free to do arts and crafts, read books or find a quiet spot. If they are too wound up, take them to movies or other quiet areas. Feel free to ask for help.

Respite Event

At: Wil'O'Way Park
10602 Underwood Parkway, Wauwatosa
Saturday, June 25th, 2011 8am-3pm

Thank you so much for signing up to help families with kids with special needs!
We are looking forward to a fun filled, exciting day. Check in for the children will begin at 8:30 AM and we would appreciate it if you arrive by 8:00 AM. We will have a brief orientation to the facility and the child you will be working with. We do our best to match everyone up, but some absences due to illness etc. are inevitable, and some switching at the last minute may occur. Most children are brought by their parents. We encourage you to ask them directly about the child's care and needs for the day.

- Volunteers are matched up with a child with special needs, or their sibling for the day, and you decide what you want to do together. This is a very special event as it is outdoor/indoor. We have the entire fenced park to ourselves (w/padded playground, basketball court and more, AND an air-conditioned field house. We will have a drum circle as an option for you and your child in the a.m. with large drums from around the world. Available all day are arts & crafts, table games, quiet area/book nook, music area and gym activities. In the afternoon we'll also offer face painting and bingo with prizes. All activities are optional.
- Lunch and snacks throughout the day are provided for you and the children.
- Nursing staff and behavioral specialists are on hand and do ALL medical, diapering/toilet, or medicinal needs the children may have during the day (for liability, volunteers DO NOT help with toileting or medical needs). Just take your child to the toilet area to get a nurse to help, or find a nurse as needed. Please help us make sure the nursing staff also assigned to the child also meets the parents before they go. Getting the child's information is important.
- **We will be checking DRIVER'S LICENSES, School photo IDs OR VALID STATE IDs; please put in a pocket.** Please leave purses or other valuables home or locked in your car as we don't have a secure place for them
- It is playtime, so wear comfortable jeans or other casual clothes!
- Please no cell phone photos or other photos of the children without our permission. Some may be victims of abuse by local perpetrators and we do not want their images out.
- Unfortunately we cannot accept any late or day-of registrations.

We look forward to a very busy and fun time, and couldn't do it without you!
THANKS AGAIN for your participation- while we are having fun, the parents/ caregivers of these children are <u>very appreciative</u> of your gift of much needed time to re-group.

Ellen

Ellen Anderson
Coordinator, Volunteer Respite Services
Children's Service Society of Wisconsin
Part of Children's Hospital and Health System
4340 N. 46th St. Milwaukee WI 53216

This event is hosted by Hales Corners Lutheran Church.
Programming funded in part by United Way and the Respite Care Association of Wisconsin

Children's Service Society of Wisconsin

⌘⌘⌘ Stay Safe and HAVE FUN! ⌘⌘⌘

– **Name Tags:** Children's Nametags names have a stripe of COLOR designating their nursing staff (red, green, blue, yellow, purple, white or black). The color matches the apron/or top, and/or nametag ofthe nursing assistant assigned to your child match.
– **Nursing Assistant:** are the only ones to take a child into the bathroom. Take your child to the bathroom area and a nurse will be there to help. They also will do any diapering (remember to have your child checked for changing through the day, if in diapers) and any medication/g tubes etc. They can also help with any medical questions/issues. In an emergency get the closest nurse!
– **CELL PHONES:** Do not take/make calls/messages while with your child; they need your love and attention! No Cell phone pictures of the kids, please.
– Please do not carry children on your shoulders or backs.
– Clean up: help keep it clean during the event, and to pack up/clean up at 2:30. Thank You !
– Volunteers must stay in the designated areas with the group, which include the public areas of the field house and the fenced park behind the field house.

<u>Thank you SO MUCH on behalf of the parents you are giving a much needed break to!</u>
BE SURE AND GET A VOLUNTEER THANK YOU GIFT BAG AND A
CERTIFICATE OF VOLUNTEERING BEFORE YOU GO!

> **Your Child Match: DO NOT LEAVE YOUR CHILD UNATTENDED!**

Easter Seals Family Friends Saturday Event Respite Sample Form

(copied with permission

from Easter Seals)

Family Friends Respite Screening

Respite Trip Volunteer

Date of Contact: _____

Name: _____Age: _____

Address: _____

City: _____State: _____Zip: _____

Phones: Home _____Cell   _____

Email Address: _____

Each volunteer will be matched with 1 child and will work with a team of volunteers. All volunteers must attend a pre-trip training session and provide their own transportation to our office to catch the bus.

1.) How did you hear about this opportunity?

2.) Do you have any experience working with children?

3.) Do you have any experience working or spending time with people with disabilities?

4.) Is there any type of disability you would not be comfortable with (i.e. non-verbal, wheel chair)?

5.) Would you be comfortable working with an active child (i.e. quick on his/her feet, high energy level)?

6.) Do you have any preferences that would help us select the best child for you (age, gender, disability)?

7.) Trips may require extensive periods of standing & walking. Are you comfortable with that?

8.) Will you be available to ride on the bus to and from the event location?

9.) Would you be interested in additional training (training on autism, etc)?

10.) Do you know of any friends, family, co-workers, etc who may be interested in the Program?

11.) Any additional comments, questions, or concerns you may have?

Please provide us with the name, phone number and/or email address of at least 2 references.

Name: _____Name: _____

Phone: _____Phone: _____

Email: _____Email: _____

Introduction to Select Disabilities and Conditions

Understanding Autism

Autism is a developmental disability that typically appears during the first three years of life. A result of a neurological disorder that affects the functioning of the brain, autism impacts the normal development of the brain especially in the areas related to social interaction and communications skills.

The condition traditionally called "autism" is part of a set of five closely related conditions which all share symptoms and fall under the broad diagnostic umbrella of "Pervasive Developmental Disorders." They each share three primary symptoms of impaired social interaction, impaired communication, and characteristic behavior patterns. Following is a brief summary of the conditions:

- Autistic Disorder – occurs in males four times more than females and involves moderate to severe disturbances in communication, socialization and behavior.

- Rett's Disorder – diagnosed primarily in females who exhibit typical development until approximately 18 months when children begin to regress especially in terms of motor skills and loss of abilities in other areas. A key indicator of Rett's Disorder is the appearance of repetitive meaningless movements or gestures.

- Childhood Disintegrative Disorder – involves a clear regression in multiple areas of functioning including motor skills, bladder control and social skills following two years of normal development.

- Asperger's Disorder – typically diagnosed later in life than other disorders on the spectrum, persons with Asperger's Disorder usually function in the average to above average intelligence range and have no delays in language skills. Deficits appear most often in the areas of social skills, concentration and coordination.

- Pervasive Developmental Disorder - Not Otherwise Specified – includes children that do not fully meet the criteria for the other specific disorders or those that do not have the degree of impairment associated with those disorders.

Understand…

Individuals with autism interact with others differently. They often appear to live a life of isolation, have difficulty understanding and expressing emotion, and may express attachment in a different manner.

Approximately 40 percent of individuals with autism do not speak. Others have echolalia, a parrot-like repeating of what has been said to them. Persons with autism often have difficulty understanding the nonverbal aspect of language such as social cues, body language and vocal qualities (pitch, tone and volume).

Individuals with autism typically have difficulty relating to objects and events and a great need for "sameness" which makes them upset if objects in their environment or time schedules change. Children with autism may not "play" with toys in the same manner as their peers and may become fixated to specific objects.

Persons with autism may greatly overreact to sensory stimuli that they see, hear, touch, feel or taste. They may also not react at all to various stimuli from the environment.

Children with autism often have a different rate of development especially in the areas of communication, social and cognitive skills. In contrast, motor development may occur at a typical rate. Sometimes skills will appear in children with autism at the expected rate or time and then disappear.

Autism is a lifelong disability that is generally diagnosed before the age of three years old. However, often children are misdiagnosed or not diagnosed until later in life.

For more information, see National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/autism/detail_autism.htm

Understanding Cerebral Palsy

More than 500,000 Americans have some degree of cerebral palsy. Three thousand people are born with the condition each year, and approximately 500 others acquire cerebral palsy in early childhood.

Cerebral palsy ("cerebral" refers to the brain and "palsy" means to deprive of action or energy) is not a disease, but a condition caused by damage to parts of the brain that control muscle coordination, balance and purposeful movement. Most commonly, injury occurs to the developing brain of a fetus or newborn. Preventive measures are increasingly possible, and include ensuring the well-being of mothers prior to conception, adequate prenatal care and the protection of infants from accidents and injuries.

Individuals with cerebral palsy may be affected differently, depending on the specific areas of the brain that have been damaged. Muscle tightness or spasm, involuntary movement, and disturbance in gait and mobility are common effects. Individuals also may experience abnormal sensations and perceptions; sight, hearing or speech impairment; seizures; and mental retardation. Related problems may include difficulties in feeding, bladder and bowel control, difficulty breathing due to posture, skin disorders from pressure sores, and learning disabilities.

Infants in the high-risk category for cerebral palsy can be tense and irritable, experience difficulty eating and lag in developing muscle control. Early identification – often possible through routine physical examinations – is important for children with cerebral palsy. With support and care from informed parents and the help of a variety of professionals (physicians, physical and occupational therapists, speech-language pathologists, nurses, social workers, teachers and others) children with cerebral palsy can actively participate in their schools and communities.

Understand…

- Cerebral palsy is not communicable or progressive. With the exception of a very rare type, cerebral palsy is not inherited.

- Although cerebral palsy cannot be "cured," professional medical supervision, appropriate therapy and adequate training can control many of its effects. Since each person with cerebral palsy is different, support program must be tailored to the individual.

For more information, see National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/cerebral_palsy/cerebral_palsy.htm

Understanding Down Syndrome

Each year, approximately one in every 800 to 1,000 babies is born with Down syndrome, a condition that may delay a child's physical and mental development.

Down syndrome is a chromosomal disorder that occurs when an extra chromosome — chromosome 21 — is present in either the sperm or the egg at conception. There is no standard profile of a person with Down syndrome and not all people who have the disorder have severe mental retardation. Most people with Down syndrome have mild to moderate mental impairments and are able to live productive and satisfying lives in their communities.

In the past, children with Down syndrome were often placed in institutions because it was believed they would never be able to participate in society. But, today children with Down syndrome can grow up to be productive, independent members of their communities, thanks to the care and support of informed parents and professionals.

Understand…

Down syndrome is not caused by any action of the child's mother or father, during or before pregnancy, but the chances of having a baby with Down syndrome increase significantly with maternal age or if one parent is a translocated cell carrier.

There are three types of Down syndrome:

- Trisomy 21 or Nondisjunction: an extra 21st chromosome is replicated in every cell in the body. This faulty cell division is the cause of 95 percent of all Down syndrome cases.

- Translocation: part of the 21st chromosome breaks off during cell division and attaches itself to another chromosome. This happens during or immediately after conception, and accounts for only three to four percent of Down syndrome cases. In about one-third of translocation cases, one parent is a translocated chromosome carrier.

- Mosaicism: a very rare form of Down syndrome, accounting for only one to two percent of all cases. Nondisjunction of the 21st chromosome takes place in one of the initial cell divisions after fertilization. This creates a mixture of two types of cells, some with 46 chromosomes and some with 47.

For more information, National Down Syndrome Society Helpline | 1.800.221.460

Understanding Learning Disabilities

A learning disability means having one or more related problems that affect specific areas of learning and behavior. Some people may have many overlapping learning disabilities; others may have a single, isolated learning disability that has little impact on other aspects of their lives.

Learning disabilities may affect many areas of a person's life: school, work, family life and even friendships. A child with a learning disability may have difficulty with written or spoken

language such as reading, writing, spelling and math; with skills such as speaking clearly, putting thoughts down on paper or remembering; and with such abilities as coordination, paying attention and sitting still.

Understand…

- Each child with a learning disability is different; all people learn and remember in different ways.

- Learning disabilities are more common in boys than girls.

- Having a learning disability is not the same as having mental retardation; most children with learning disabilities have average or above-average IQs.

- Learning disabilities are not the result of emotional disturbance. However, emotional problems can be the result of frustrations that arise from learning disabilities.

- The earlier a learning disability is detected, the greater the chance for improvement.

For more information, see National Institute of Neurological Disorders and Stroke

http://www.ninds.nih.gov/disorders/learningdisabilities/learningdisabilities.htm

Understanding Post-Polio Syndrome

Post-polio syndrome (PPS) is a condition that affects polio survivors, years after they've recovered from their initial bout with the disease. An interval of 30 to 40 years usually elapses before the first PPS symptoms occur, but intervals as short as eight years and as long as 71 years have been documented. Modern rehabilitation may restore individuals with post-polio to their regular level of functioning; it may also require that they return to or begin using braces, crutches, canes, wheelchairs and a variety of adaptive equipment.

Weakness is the general symptom of post-polio syndrome. Muscle strength decreases when the nerve supply to the muscle is reduced. Symptoms can appear in the muscles that were affected at the time polio was contracted or in previously unaffected areas. Most new pain problems in polio survivors result from repetitive strain injuries to weakened muscle fibers and muscular tissues.

Understand…

- Post-polio syndrome is not a recurrence of the virus.

- The rest necessary to resolve pain and inflammation often leads to further weakness and atrophy. Thus, a vicious cycle of increasing weakness, increasing pain and increasing disability can result.

- Shrinking of muscle size and decreasing strength occurs very slowly, at a rate of 1 percent of muscle strength per year.

- Individuals with post-polio have less muscle reserve and may need more time to resume normal activity after surgery or severe illness.

Family and friends should be supportive of lifestyle changes, accept the survivor's physical limitations and assist polio survivors in taking responsibility for their own care.

For more information, see National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/post_polio/post_polio.htm

Understanding Spina Bifida

Spina bifida ("open spine") is a birth condition characterized by an incomplete closure of the spine. Children born with spina bifida may have varying degrees of muscle paralysis, bladder and bowel problems, loss of skin sensation and spine and limb problems.

Spina bifida is not rare. It occurs in one of every 1,000 children born. However, with help from parents and a team of doctors, therapists, teachers and others, individuals with spina bifida can achieve independence and participate fully in their communities.

Although spina bifida occurs in different forms and has varying degrees of effect, most babies born with the condition will require surgeries to correct spinal, foot or leg problems; shunt surgery to drain fluid from the brain; application of techniques to control bladder and bowel function; and braces and other equipment to assist in walking. Nevertheless, advances in treatment and management have made it possible for children born with spina bifida to live long and productive lives.

Understand…

There are three broad types of Spina bifida:

• Lipomeningocele: A lipoma or fatty tumor is covered by skin and located over the lumbosacral spine.

• Meningocele: The protective covering of the spinal cord is pushed out in a section of the spinal column.

• Myelomeningocele: The most common and most severe form, in which both the spinal cord and its coverings are out of position.

Most babies with spina bifida develop hydrocephalus, an accumulation of fluid in the brain. If fluid is not drained, the pressure buildup can cause brain damage, seizures or blindness.

Parents who have one child with spina bifida, or have spina bifida themselves, increase their chances of having a child with spina bifida.

For more information, see National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/spina_bifida/spina_bifida.htm

Understanding Stroke

Each year, an estimated 600,000 Americans experience a new or recurrent stroke. Specifically, men are at greater risk than women, but more women have fatal strokes.

A stroke occurs when the blood supply to the brain is suddenly interrupted or a blood vessel in the brain bursts, spilling blood into the spaces surrounding the vessels. A stroke may bring weakness or paralysis to parts of the body and can result in problems with vision and speech, as well as fear, confusion and disorientation.

The blockage of, or hemorrhage from, the blood vessels to the brain that occurs during a stroke can cause either temporary or permanent brain damage. In either case, rehabilitation is of the utmost importance to the recovery of the stroke survivor as it is designed to help him or her return to independent living.

Understand…

- One side of the body may be affected by stroke - usually the one opposite to the side of the brain affected.

- Remember to stand at the person's "good" side.

- Inability to speak well does not mean an inability to understand or loss of mental capacity.

- The way a person acts, looks, and feels immediately following a stroke is no indication of how the person will act, look or feel later.

- A person who has had a stroke may tire easily, show frustration and anger suddenly or feel depressed at times. The person may cry or laugh unexpectedly and be unable to remember well or pay attention very long.

- It is important to be casual, courteous and respectful if the person cries, acts, depressed or swears. He/She may not be aware the behavior they are exhibiting is inappropriate. Alarm, embarrassment or fear will aggravate the behavior.

- Use simple words when talking to a stroke survivor and the same words or instructions when asking him or her to do the same thing. Be sympathetic, but always encouraging. Instead of pity, give the person reassurance that they are loved and useful.

- Remember that despite the changes, the stroke survivor is the same individual you knew before the stroke occurred.

- Treat adults as adults, not children.

For more information, see National Institute of Neurological Disorders and Stroke
http://www.ninds.nih.gov/disorders/stroke/stroke.htm

Dementia

Dementia is a condition affecting 6.8 individuals in America (National Institute of Neurological Disorders and Stroke). However, it is important to note that it is not a part of the normal aging process although dementia incidence increases with age.

Dementia affects one's cognition, memory, judgment, behavior, and functional ability. During the progression of this disease, individuals will require increased levels of care. There are many forms of dementia, although Alzheimer's Disease is the most common type. Most types of dementia, including Alzheimer's, are progressive and irreversible, with no present day cure. Individuals with dementia often times exhibit memory loss, impaired judgment, behavioral changes and may be agitated or confused (Family Caregiver Alliance, Dementia). Dementia manifests itself differently from individual to individual and no two persons with dementia exhibit identical behaviors as a result of this disease.

Respite workers should be aware if their client is experiencing dementia. When working with individuals with dementia it is critical that respite volunteers ensure their safety, and have patience when interacting with these clients because repetitive questions or actions are common among individuals with dementia. It is also important that the client is comfortable, and in a familiar setting with familiar items. Family members are a great resource that can identify what their loved ones prefer and the types of actions, questions, or behaviors that may elicit agitated behavior.

For more information about the different types of dementia please visit:
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=569

For specific information about Alzheimer's Disease please visit:
http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp?type=more_information

For more information about the care of an individual with dementia, see National Institutes of Health at
http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm

What Kind of Care Does a Person with Dementia Need?

People with moderate and advanced dementia typically need round-the-clock care and supervision to prevent them from harming themselves or others. They also may need assistance with daily activities such as eating, bathing, and dressing. Meeting these needs takes patience, understanding, and careful thought by the person's caregivers.

A typical home environment can present many dangers and obstacles to a person with dementia, but simple changes can overcome many of these problems. For example, sharp knives, dangerous chemicals, tools, and other hazards should be removed or locked away. Other safety measures include installing bed and bathroom safety rails, removing locks from bedroom and bathroom doors, and lowering the hot water temperature to 120°F (48. 9°C) or less to reduce the risk of accidental scalding. People with dementia also should wear some form of identification at all times in case they wander away or become lost. Caregivers can help prevent unsupervised wandering by adding locks or alarms to outside doors.

People with dementia often develop behavior problems because of frustration with specific situations. Understanding and modifying or preventing the situations that trigger these behaviors may help to make life more pleasant for the person with dementia as well as his or her caregivers. For instance, the person may be confused or frustrated by the level of activity or noise in the surrounding environment. Reducing unnecessary activity and noise (such as limiting the number of visitors and turning off the television when it's not in use) may make it easier for the person to understand requests and perform simple tasks. Confusion also may be reduced by simplifying home decorations, removing clutter, keeping familiar objects nearby, and following a predictable routine throughout the day. Calendars and clocks also may help patients orient themselves.

People with dementia should be encouraged to continue their normal leisure activities as long as they are safe and do not cause frustration. Activities such as crafts, games, and music can provide important mental stimulation and improve mood. Some studies have suggested that participating in exercise and intellectually stimulating activities may slow the decline of cognitive function in some people.

The emotional and physical burden of caring for someone with dementia can be overwhelming. Support groups can often help caregivers deal with these demands and they can also offer helpful information about the disease and its treatment. It is important that caregivers occasionally have time off from round-the-clock nursing demands. Some communities provide respite facilities or adult day care centers that will care for dementia patients for a period of time, giving the primary caregivers a break. Eventually, many patients with dementia require the services of a full-time nursing home.

For respite model ideas and activities for individuals with dementia please visit:
http://www.archrespite.org/images/docs/Factsheets/fs_55-alzheimers.pdf.

Neurological Conditions

This list provides information on a few of the more commonly-occurring neurological impairments in the United States. For information on other specific conditions and diseases, see the website of the National Institute of Neurological Disorders and Stroke at http://www.ninds.nih.gov/disorders/

Degenerative disorders

There are many disorders which begin or become symptomatic in adulthood. Individuals with these disorders experience increasingly severe symptoms over time, although the course of these diseases are widely variable and generally unpredictable. In addition to the four listed below, examples of other degenerative neurological disorders include Alzheimer's disease, Friedreich's ataxia, Lewy body dementia, and spinal muscular atrophy.

Multiple sclerosis (MS) is believed to be an autoimmune disease with an as-yet unknown environmental trigger, with symptoms generally appearing between the ages of 20 and 40. It is a chronic disease of the central nervous system (brain, spinal cord, and optic nerve). Symptoms may vary from mild muscle weakness to partial or complete paralysis, and may include vision or hearing impairment, numbness, prickling sensations, pain, speech impediment, tremors, dizziness, depression, and mild cognitive impairment. There is no cure, but symptoms may remit spontaneously; physical therapy and drug therapies can be helpful. There are about 400,000 people with MS in the U.S., with more than 200 new diagnoses each week.

For more information:
National MS Society
733 Third Ave
3rd Floor
New York, NY 10017
Phone: 800-344-4867
Email: http://www.nationalmssociety.org/ContactUs.aspx
Website: http://nationalmssociety.org/

Parkinson's Disease (PD) is one of a group of disorders that stem from the loss of dopamine-producing brain cells. Primary symptoms are tremors of the hands, arms, legs, jaw, and face; rigidity of the limbs and trunk; slowness of movement; and impaired balance. Symptoms usually occur after age 50 and become progressively worse. Patients may experience wide variation in severity, from mild to severe disability. There is no cure, but there are drug therapies that may help with symptoms. More than one million people in the U.S. have been diagnosed with PD, and 50,000-60,000 new cases are diagnosed each year.

For more information:

National Parkinson Foundation

1501 N.W. 9th Ave/Bob Hope Rd

Miami, FL 33136-1494

Phone: 800-4PD-INFO (473-4636) Helpline

305-243-6666/ 800-327-4545 (Headquarters)

Fax: 305-243-6073

Email: contact@parkinson.org

Website: http://www.parkinson.org

Michael J. Fox Foundation for Parkinson's Research

Church Street Station

P.O. Box 780

New York, NY 10008-0780

Phone: 800-708-7644

Email: info@michaeljfox.org

Website: http://www.michaeljfox.org/

Amyotrophic lateral sclerosis (ALS), commonly called Lou Gehrig's Disease, is a rapidly progressive, fatal disease that attacks the nerve cells which control voluntary muscles. Patients lose the ability to use their muscles, which then weaken; eventually they lose the ability to move at all. When muscles in the chest and diaphragm fail, the person must rely on a ventilator to breathe. ALS does not affect the individual's ability to see, hear, smell, or taste, or think. There is no known cause, and no cure. Most individuals with ALS die within three to five years of the onset of symptoms, although about 10% live for 10 years or more. ALS usually occurs between the ages of 40 and 70. About 30,000 Americans have the disease at any given time.

For more information:
ALS Foundation
1275 K Street NW, Suite 1050
Washington, DC 20005
Phone: 202-407-8580
Fax: 202-289-6801
Email: alsinfo@alsa-national.org
Website: http://www.alsa.org

Huntington's Disease (HD) is a genetic disease in which brain cells degenerate over time, causing uncontrolled movement, loss of intellectual functioning, and emotional disturbance. The individual progresses at an unpredictable rate, but always results in the patient's inability to care for him/herself. Anyone who carries the gene for HD will develop the disease; children of those with the disease have a 50/50 chance of inheriting the gene. Onset usually

occurs between the ages of 30 and 50. About 30,000 people in the U.S. have HD, and another 150,000 are "at risk" because one of their parents has the disease.

For more information:
Huntington's Disease Society of America
Email: http://www.hdsa.org/contact-us.html
Website: http://www.hdsa.org

Traumatic brain injury (TBI) results when the brain is damaged, as in a sudden and violent blow to the head, or an object pierces the skull and enters the brain. Symptoms can be mild to severe, depending on the extent of the damage, and may last for a few seconds or be life-long. Resulting disability depends on the location and severity of the injury, as well as the individual's age and health status. Common problems include difficulty with cognition, communication, or ability to process sensory input, changes in behavior or personality, and mental health issues. Serious TBI can result in coma or vegetative state. It is estimated that 1.7 million people in the U.S. sustain a traumatic brain injury each year. The vast majority, 80%, are treated and released from an emergency hospital visit; 275,000 are hospitalized; and 52,000 die. More than 80,000 individuals with TBI suffer a permanent disability of some type. The leading causes of TBI are falls (35%), motor vehicle accidents (17%), being hit or colliding with an object (16%), and assaults (10%) (Faul, Xu, Wald, & Coronado, 2010). In addition, veterans of the wars in Iraq and Afghanistan have suffered traumatic brain injuries at a higher rate than in previous conflicts, with an estimated 212,742 TBI in the 10-year period ending in March 2011. Of these, 2,235 were classified as severe, resulting in confusion or disorientation lasting more than 24 hours, loss of consciousness for more than 24 hours, and memory loss for more than seven days; and 3,573 were classified as penetrating, in which an object enters the brain (DOD, 2011).

For more information:
Brain Injury Association of America
1608 Spring Hill Road, Suite 110
Vienna, VA 22182
Phone: 703-761-0750
Fax: 703-761-0755
Email: info@biausa.org
Website: http://www.biausa.org

Spinal cord injuries occur when the spine is damaged by a sudden blow in which bone fragments or other material bruise or tear into spinal cord tissue. The resulting disability may allow for recovery or be permanent, depending on the severity of the injury and the emergency treatment received. Loss of mobility is connected to the location of the injury on the spine. An injury may be incomplete, in which case the individual retains some motor or sensory function below the injury. In a complete injury, all motor function and sensation is lost. Patients often have medical complications including chronic pain, bladder and bowel dysfunction, and increased susceptibility to respiratory and heart problems. There are over one million people living with paralysis due to a spinal cord injury in the U.S. Of these,

35% reported "a lot of difficulty" in moving and 16% said they were "completely unable to move." (Christopher & Dana Reeve Foundation, 2009).

For more information:
Christopher & Dana Reeve Foundation
636 Morris Turnpike
Suite 3A
Short Hills, NJ 07078
Phone: 800-225-0292
Email: prc@ChristopherReeve.org
Website: http://www.christopherreeve.org

Epilepsy is a brain disorder in which nerve cells have a disturbed pattern of activity, which can cause strange sensations or emotions, as well as muscle spasms, convulsions, and loss of consciousness. It can be caused by abnormal brain development, disease, or injury. For the majority of individuals with epilepsy, medication or surgery can control seizures.

For more information:
Epilepsy Foundation of America
8301 Professional Place
Landover, MD 20785-7223
Telephone: 1-800-332-1000
Fax: 1-301-577-2684
Spanish Speakers Only: 1-866-748-8008
Email: ContactUs@efa.org
Website: http://epilepsyfoundation.org/

Mental Health Conditions

Adults with Mental Health Conditions

Mental disorders are "health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning" (U.S. Department of Health and Human Services, 1999b). The U.S. Surgeon General estimates that 26.3% of American adults aged 18 and older have a di¬agnosed mental health disability and 6% of adults have a serious mental illness (Kessler, Chiu, Dem¬ler, &Walters, 2005; National Institute of Mental Health, (2008). Some of the most common disorders among adults in the United States are mood disorders (9.5%) such as major depressive disorder, dysthymic disorder, and bipolar disorder; anxiety disorders (18.1%) such as social phobia, post-traumatic stress disorder, and generalized anxiety disorder; and personality disorders (9.1%) such as avoidant personality disorder, borderline personality disorder, and antisocial personality disorder (National Institute of Mental Health, 2010). A unique population includes those with co-occurring disorders. The prevalence in the US of persons with intellectual/developmental disabilities and a co-occurring mental illness is estimated to be over 3 million (North Carolina START, 2010).

The Impact of Mental Disorders on Health, Employment, and Interpersonal/Social Relationships

Mental disorders can have a significant impact on an individual's health and well-being, employment, and social and familial relationships. Individuals with mental disorders are five times more likely to experience a co-occurring health condition such as diabetes, heart disease, or cancer, as compared to those without mental disorders (Parks, Radke, & Mazade, 2008). Mental disorders are the leading cause of disability in the United States among those 15-44 years of age (World Health Organization, 2008). The main burden of illness is concentrated in about 6% of the population (1 in 17) that has a serious mental illness (Kessler et al., 2005). Individuals with mental illness often become the focus of family life (Mental Health America, 2010). Those with mental disorders can experience impaired functioning in their interpersonal relationships (Robinson, Rodgers, & Butterworth, 2008). Evidence suggests that some mental disorders are associated with marital dissatisfaction (Whisman & Bruce, 1999) and the likelihood of marital breakdown (Mendlowicz & Stein, 2000; World Health Organization, 2008; Kessler, Walters, & Forthofer, 1998).

Services and Supports for those with Mental Disorders

With appropriate treatment, many individuals with mental illness can learn to cope or recover (Mental Health America, 2010). Unfortunately, research suggests that a large proportion of adults with mental disorders in the United States delay or do not receive treatment for their disorders (Wang, Lane, Olfson, Pincus, Wells, & Kessler, 2005). Among the reasons reported for not receiving mental health treatment include cost or insurance issues, not feeling a need for treatment, feeling that they could handle the problem on their own, and concerns regarding the stigma associated with mental health problems (Substance Abuse and Mental Health Services Administration, 2006). Studies show that people who have a dual diagnosis of mental illness and intellectual/ developmental disability are at greater risk for institutionalization than people diagnosed with an intellectual/developmental disability alone. In addition, overuse of community emergency departments and long stays in psychiatric facilities have been documented in this population (North Carolina START, 2010).

For more information:

American Psychological Association

www.apa.org

(202) 336-5500

Mental Health America

www.mentalhealthamerica.net

(800) 969-6642

National Alliance on Mental Illness (NAMI)

www.nami.org

(800) 950-NAMI (6264)

Children with Serious Emotional Disturbance

The federal definition of children who have serious emotional disturbance used by the Substance Abuse and Mental Health Services Administration (SAMHSA) is "children and youth from birth to 21 years of age (with) an emotional, socio-emotional, behavioral or mental disorder diagnosable under the DSM-IV or its ICD-9-CM equivalents, or subsequent revisions.

Children with SED may have a variety of diagnoses, including

- anxiety disorders (high level of fear);
- bipolar disorder (swings in mood from very "high" to sad and hopeless);
- conduct disorders (trouble following rules, aggressiveness, lying, stealing);
- eating disorders (eating too much or too little, concern about body image);
- obsessive-compulsive disorder (recurring unwanted thoughts, repeating behaviors such as handwashing or counting); and
- psychotic disorders (not in touch with reality, hearing or seeing things that are not there, false beliefs).

It is difficult to identify the number of children in the United States with SED; estimates vary 5 to 26 percent (Brauner & Stephens, 2006). Based on a reported population estimate of 72.3 million children under age 18 (Meyer, 2001), this would mean at least 3.6 million children and youth and their families are affected by serious emotional disturbance. SAMHSA (2011) estimates that 4.5 to 6.3 million children and youth in the United States suffer from a serious mental health condition (about 10%) and 20% have a diagnosable mental disorder; about 65% to 80% of these children and youth do not receive the specialty mental health services and supports they need.

Characteristics

The National Dissemination Center for Children with Disabilities (NICHCY, 2010) has identified the following characteristics and behaviors as typical of children with emotional disturbances:

- Hyperactivity (can't sit still very long, has problems paying attention, seems careless and disorganized, doesn't finish projects and schoolwork);

- Aggression (has temper tantrums, picks fights, doesn't cooperate);

- Self-injury (hurts him/herself);

- Withdrawal (failure to interact with others, retreat from exchanges or social interaction, excessive fear or anxiety);

- Immaturity (acts younger than his/her age, cries a lot, has temper tantrums, doesn't cope well with change);

- Learning difficulties (doesn't do well at his/her grade level at school).

It is important to note that many children who do not have an emotional disturbance may display some of these behaviors at different points in their development. The fundamental difference is that for children who have a serious emotional disturbance these behaviors continue over a long period of time, demonstrating the child's inability to cope with the environment or peers.

For more information:
The **Maternal & Child Health Library at Georgetown University** offers an extensive Knowledge Path on Emotional, Behavioral, and Mental Health Challenges in Children and Adolescence that contains resources from the fields of health, education, social services, and juvenile justice for families, schools, health professionals, program administrators, policymakers, and community advocates.
http://www.mchlibrary.info/KnowledgePaths/kp_Mental_Conditions.html

National Federation of Families for Children's Mental Health
9605 Medical Center Drive
Rockville, MD 20850
Phone: 240-403-1901
Fax: 240-403-1909
Email: ffcmh@ffcmh.org
Website: http://ffcmh.org/

National Technical Assistance Center for Children's Mental Health
Georgetown University Center for Child and Human Development
Phone: 202-687-5000
Fax: 202-687-1954
Email: childrensmh@georgetown.edu
Website: http://gucchdtacenter.georgetown.edu/in

Notes