

Alabama Respite Coalition

Results – Survey of Agencies and Respite Service Providers

Purpose and Methodology

Alabama Dept of Senior Services (ADSS) received an award from AOA to plan and implement respite services for family caregivers. Initial steps were establishing a statewide coalition of state and private agencies, compiling an inventory of available resources, and assessing unmet needs. ADSS contracted with The University of Alabama at Birmingham (UAB) and its Center for Educational Accountability (CEA) to conduct evaluation of Lifespan Respite Care. The UAB CEA serves as an external evaluator of a statewide service project to insure that objectives established by the AOA are met by the recipient agency in Alabama.

The evaluation addresses the five mandated priorities of the federal grant. The evaluation will be accomplished through a mixed-methods approach to gather qualitative and quantitative data from key information. Three goals will guide the evaluation:

1. Measure current capacity and improvement of Alabama Respite as perceived by family caregivers, agencies, and providers.
2. Identify needed enhancements to respite worker training and service delivery.
3. Identify facilitators and barriers to a coordinated system of lifespan respite care in Alabama.

Results of a statewide survey will enable Coalition members to more accurately identify respite provider needs, services available to family caregivers, and indicate areas for improvement. Evaluators are collaborating with members of the state Respite Care Coalition and its Assessment Committee to invite family caregivers and agency service providers to voluntarily complete surveys presented in written and online formats. The purpose is to determine current and unmet needs for family respite services.

The survey was developed by the Assessment Committee and evaluators, who solicited suggestions about content from Coalition members and service providers. In addition, we reviewed the helpful guide published by ARCH, "Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Care Program Managers," and shared drafts for comment.

The survey contains 41 items, of which five require open-ended responses. Items were grouped in five general categories: *demographics* (3 items); *respite agency (or organization) rules and service history* (17 items); *provider's perceptions of family caregiver expectations/needs* (15 items); *knowledge of other providers and agencies* (2 items); and *provider's training needs and other comments* (4 items). Estimated length of time to complete the survey is 30 minutes. Participants do not receive compensation. The UAB Institutional Review Board for Human Use granted expedited approval for survey protocol on April 02, 2010.

Those who require respite care represent a wide array of needs and abilities, for instance, individuals with developmental disabilities and those with a progressive physical illness. Eligibility to receive lifespan respite care is determined differently by each agency according to rules established by federal, state and private funders. For this reason, agency representatives invite their clientele and respite service providers to anonymously participate in the needs assessment through established service contacts.

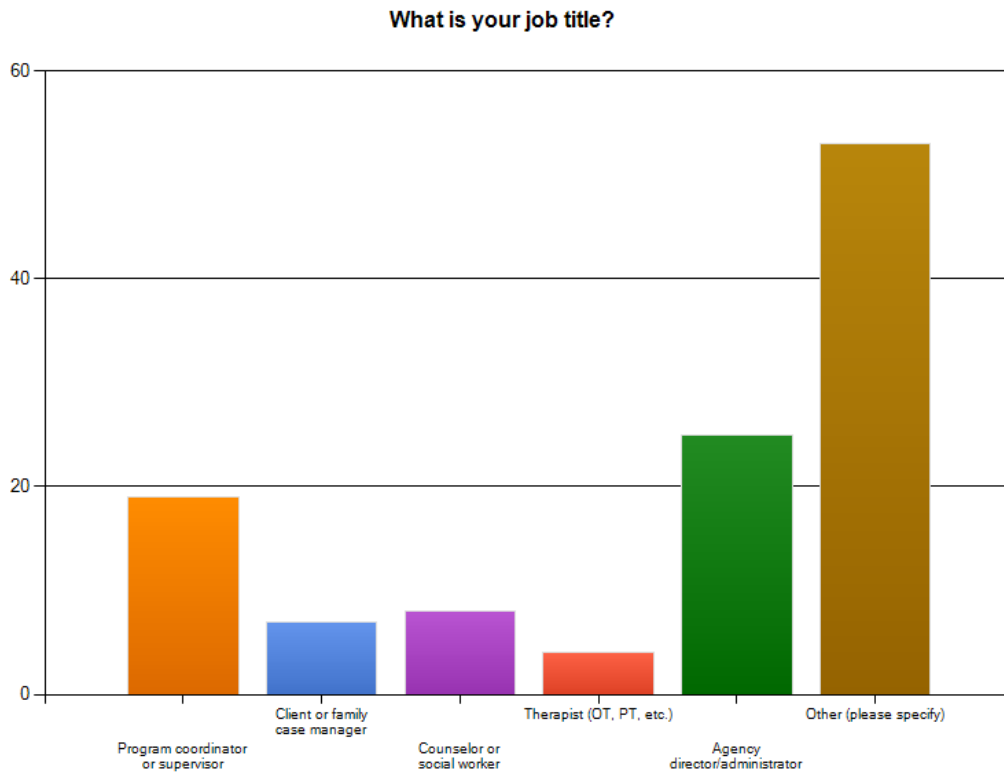
As of October 5, 2010, 1,408 copies of “Respite Services for Family Caregivers, a Survey of Agencies and Service Providers” were distributed and 122 completed surveys have been returned. Five agencies posted announcements plus links to surveys on homepages and two agencies included announcements about the survey in newsletters distributed statewide. Data collection is ongoing.

No respite service provider is obligated to participate in the statewide needs assessment. Those who decline to do so will not suffer penalties. Those who wish to discontinue participation may do so at any time. Those who desire physical assistance to participate may request this from an agency represented on the statewide Respite Care Coalition or the project evaluators.

Survey Results

As of October 5, 2010, 122 individuals attempted and 120 completed a written or online *Survey of Agencies and Service Providers*. Seventy-one percent of respondents reported their race as White and approximately 30% as Black. Twenty-two percent reported their job title as “agency director/administrator,” while 16% reported “program coordinator/supervisor” as their job title as shown in Figure 1, below. In this case, *job title* is informally defined to account for relatives and acquaintances that provide respite care to disabled family members. Nearly half (46%) of respondents indicated they held a variety of other job titles, including mother, grandparent, companion, neighbor, therapeutic respite provider, volunteer, family support council member, and R.N.

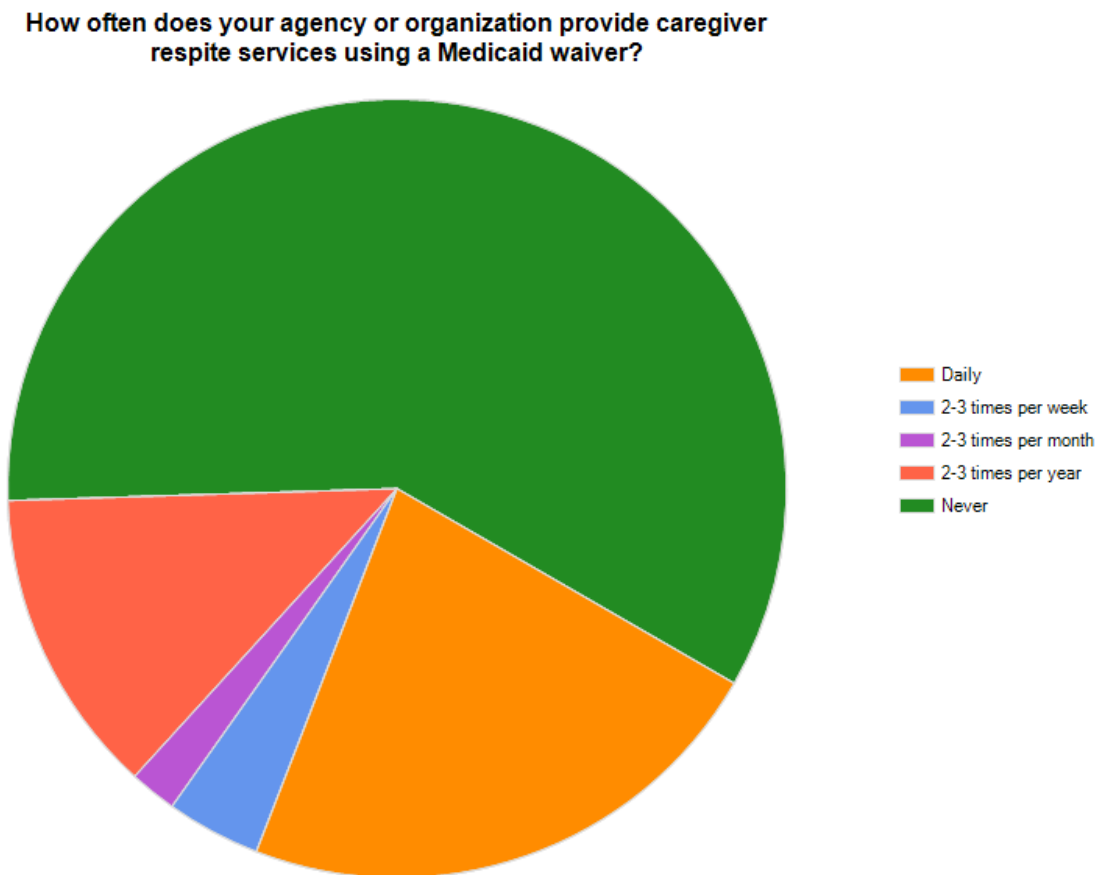
Figure 1. *Job Title* of Respite Service Providers (N=116).



One hundred and eleven service providers reported their agency or organization has provided respite services for an average of 8.82 years. The range of responses to this item was “0 or just began” to “50” years. Respite service providers indicated serving an average of 25.7 family caregivers during the past year. Five agencies provided services to 100 or more family caregivers during the past year; eighteen served between 50-99 families last year.

Forty-three percent of respondents do not accept Medicaid waivers for caregiver respite. Twenty percent were unsure. Perhaps this may be explained by the wide range of service providers, from individuals to agencies. Among 42 agencies and organizations that do accept Medicaid waivers, 23 provided daily respite services and 13 provided services 2-3 times per year, see Figure 2, below.

Figure 2. Frequency of Services Provided to Family Caregivers Using a Medicaid Waiver (n=102).



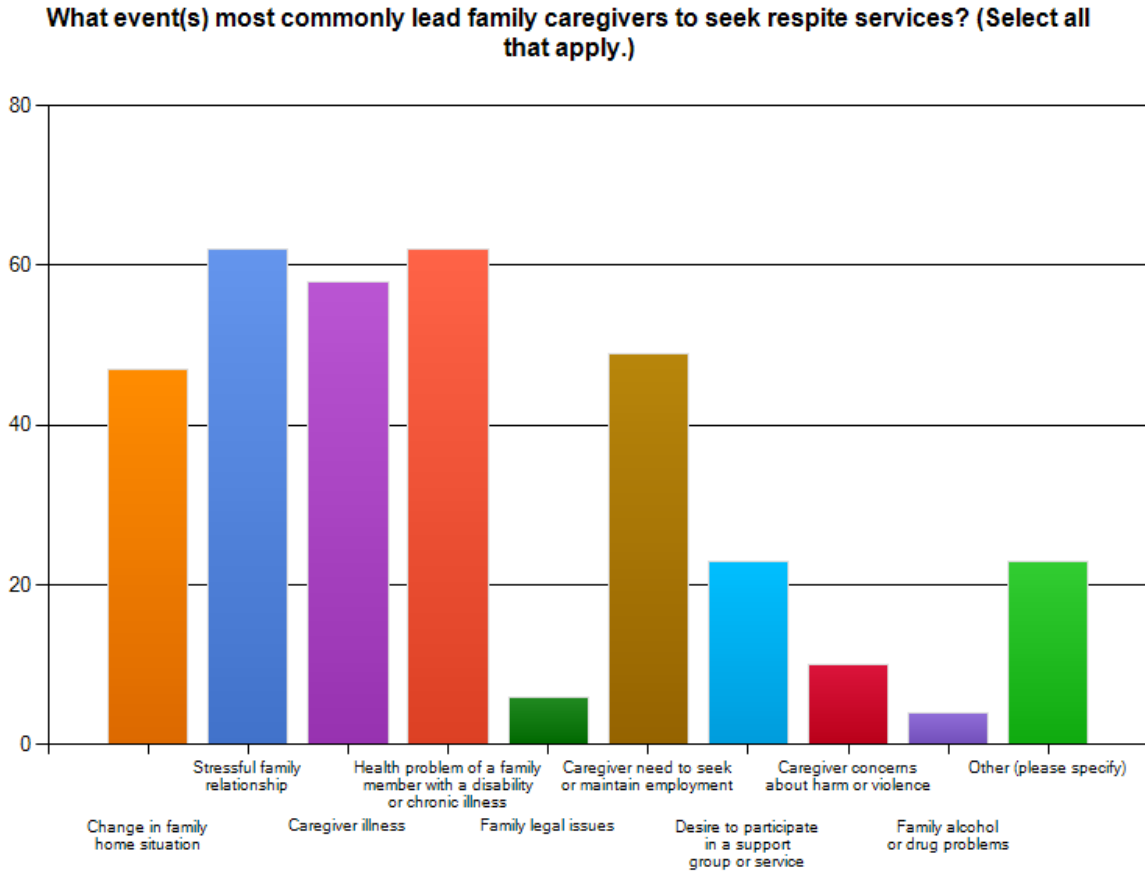
Seventy-four respite service providers identified an array of expectations among families for what respite can provide. A selection of responses illustrates perceived expectations:

- Non-medical in-home care for family members
- To help pay for services needed to care for family members when one does not have money on hand for that care.
- Companionship; light housekeeping; meal preparation, laundry assistance and bed linen changes; bathing, dressing & grooming assistance; transfer assistance; medication reminders; incontinence assistance
- Help to feed, play, bathe, medicate, change linen, wash linen, take out trash from patient, and wash dishes and cook meals.
- Provide quality care for a family member while family is away or unavailable
- Safe environment and caring people.
- Assistance with ADLs, light housekeeping, meal preparation, laundry, transportation, errands
- Support and encouragement when a new member moves into the home due to the death of the primary caregiver....to include time away from a new and more stressful home situation...respite for persons who are elderly or ill, have surgery, etc.
- In home "sitter services" if parent is working and a relative needs assistance
- Time away from the home situation – occasionally
- Time separate from their child/individual with special needs.
- 24-hour care as needed - food, bathing, etc.
- A break from care giving
- Relief from the daily task of caring for a developmentally disabled person
- Sitter services under nursing supervision so the family can have a night away from home

In Figure 3 is a summary of events identified by providers leading families to seek respite care. Sixty-one respite service providers noted one or more reasons why family caregivers seek services (a) *a stressful family relationship* (55% of respondents); (b) *health problem of a family member with a disability or chronic illness* (55% of respondents); (c) *caregiver illness* (51% of respondents); (d) *caregiver need to seek or maintain employment* (43% of respondents); & (e) *change in family home situation* (42%).

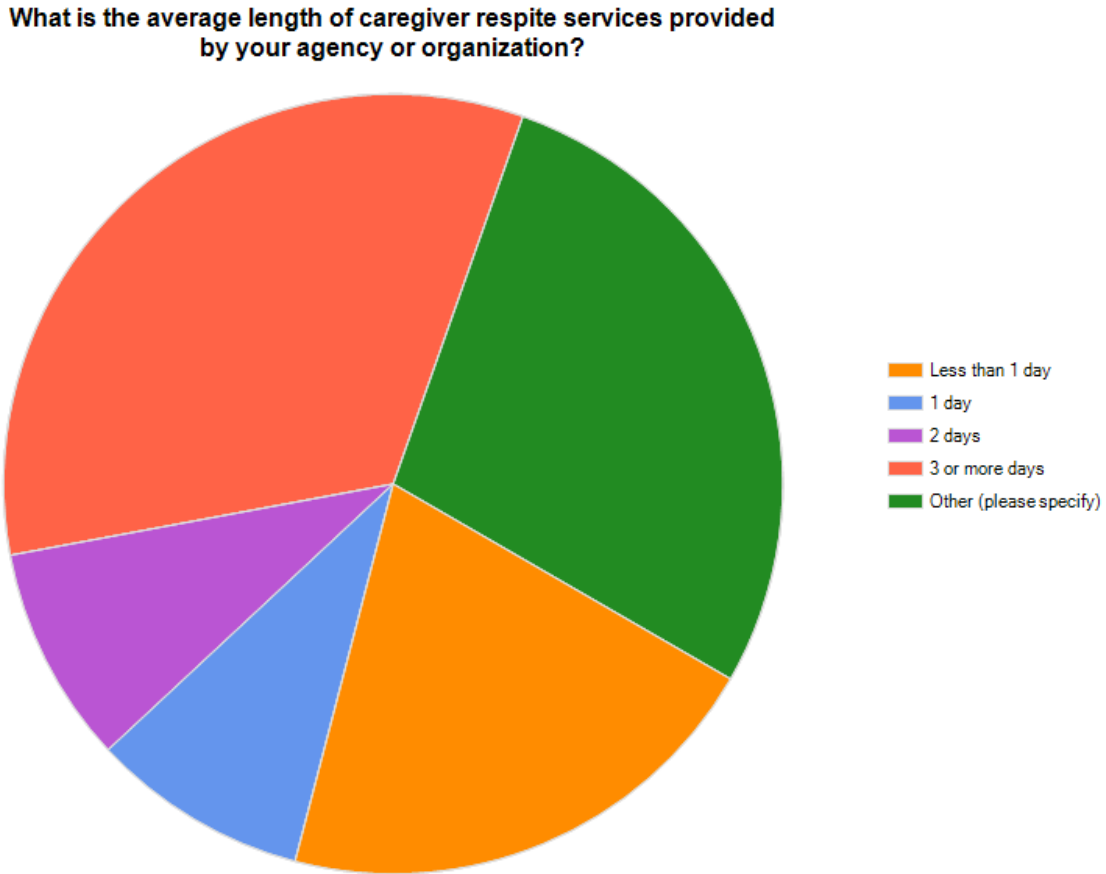
Twenty-three respite service providers indicated other reasons why families seek respite care: "aggressive behavior from the child," "resident/client needs to have more assistance than caregiver can provide for a short term before becoming stronger or more independent again," "person with a disability is unable to remain in the current placement/residence," "little support system" (available to family), need for "safe afterschool care," "caregiver fatigue," "unable to provide additional adequate care on the income the individual receives monthly...caregiver often must quit job or hire private sitter, for which there is no money." Multiple responses to this item were elicited.

Figure 3. Events Leading Family Caregivers to Seek Respite Care (n=113).



Of 111 respondents, 33% indicated their agencies provide caregiver respite services an average of 3 or more days as shown in Figure 4, below. Twenty-one percent replied, less than 1 day. Thirty-one service providers offered other responses to this item: “it depends on the care plan and funding,” services are provided “as specified by the governing agency,” “four hours weekly,” “a few hours each month,” “anywhere from 5 hours per week to 30 days at a time in our Respite Home,” “only a couple of hours” (per service), “client attends our center between 2-5 days/week, for as long as their condition can be cared for by us,” and “its up to the family. We pay \$100 per quarter for respite at a fee no more than \$10 per hour.”

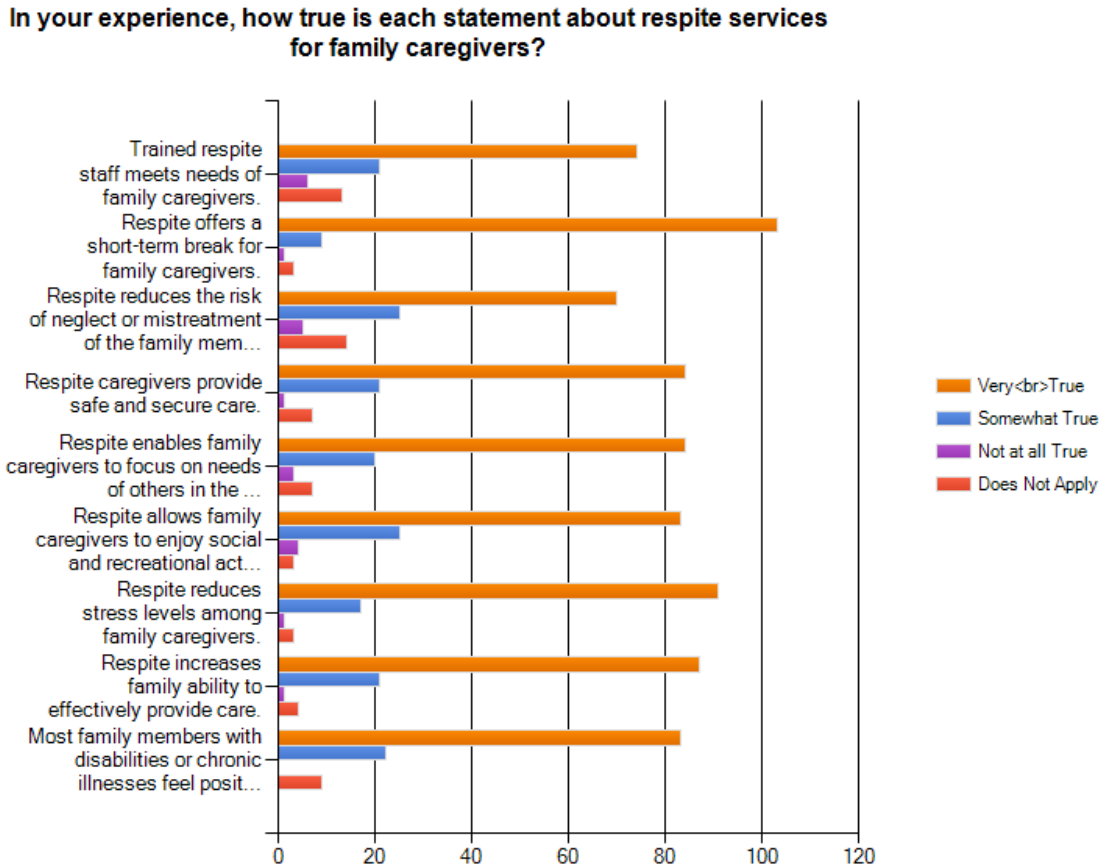
Figure 4. Average Length of Services Provided (n=111).



Forty-one percent of 116 providers noted that caregiver respite services *are* sufficient to meet current need. One-third disagreed, replying that respite services for families are *not* sufficient, while 25% felt unsure. Fifty-two of 114 respondents (46%) are able to identify other agencies and organizations that provide respite services to families. Forty-one (36%) cannot do so.

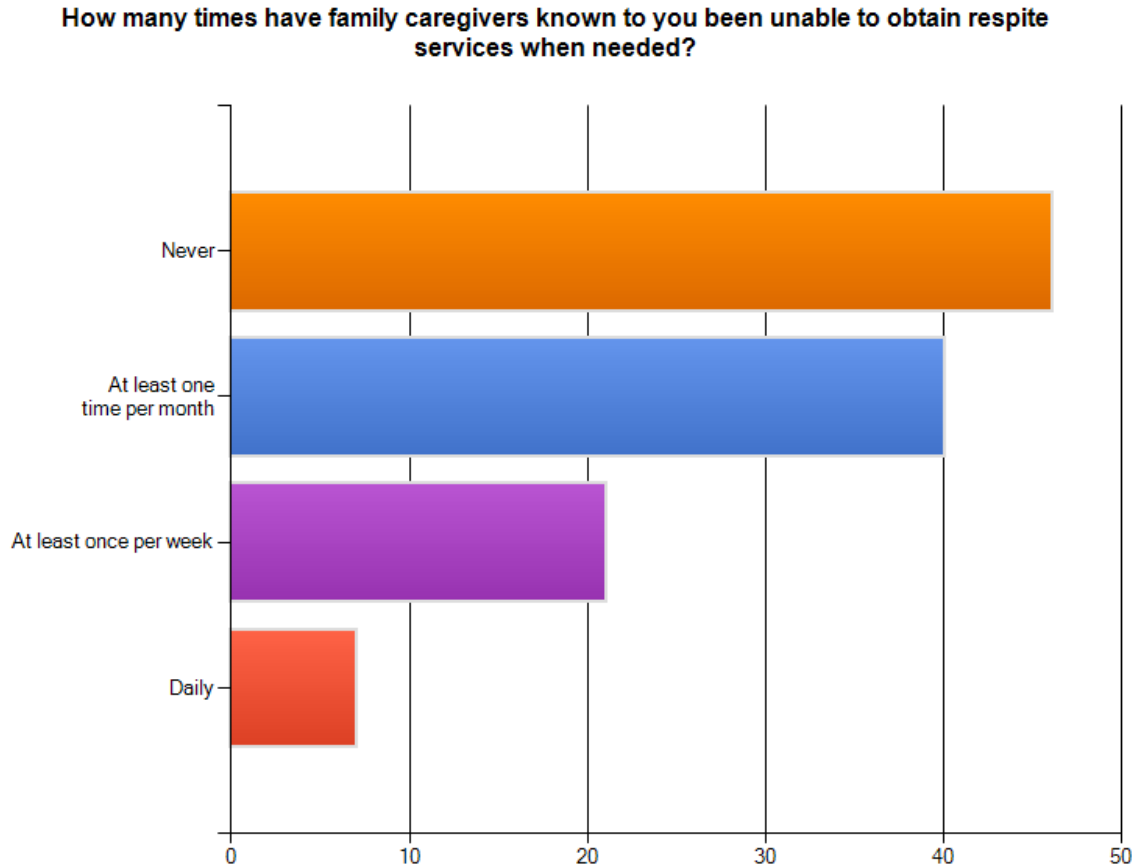
Respite service providers were asked to rate a group of statements about respite services for family caregivers. Ratings were based on a three-point scale and ranged from *Very True* to *Not at all True*, as well as an option *Does Not Apply*. One hundred and sixteen providers responded to one or more of these items as shown in Figure 5. A majority replied *Very True* to several items: (a) “respite offers a short-term break for family caregivers” (89%); (b) “respite reduces stress levels among family caregivers” (81%); (c) “respite increases family ability to effectively provide care” (77%); (d) “respite caregivers provide safe and secure care” (74%); & (e) “respite enables family caregivers to focus on needs of others in the household” (74%). One statement received lower ratings from the sample of service providers, i.e. “respite reduces the risk of neglect or mistreatment of the family member with a disability or chronic illness.” Seventy of 114 respondents (61%) rated this statement as *Very True*.

Figure 5. Respite Service Providers' Opinions Regarding Family Caregiver Services (n=116).



In Figure 6 are responses to the item, “How many times have family caregivers known to you been unable to obtain respite services when needed? Sixty percent of 114 service providers knew of occasions when family caregivers could not find respite care. Forty replied, “at least one time per month” and 21 replied, “at least once per week.”

Figure 6. Frequency when Family Caregivers Could Not Obtain Needed Respite as Rated by Service Providers (n=114).



In addition, service providers were asked to report the average wait for family caregivers to receive respite. Forty-three percent of 105 providers responded, *less than one week*; however, 38% indicated average waiting time was *three weeks or more*. Nineteen percent indicated between 1-2 weeks waiting period.

One hundred and sixteen respite service providers identified “how families learn about respite services available in your community” as shown in Figure 7. Providers selected all options that applied to their community. Forty-seven percent indicated families were recommended by social contacts. The same number of providers indicated that families *call a federal state or local agency for help*. Fifty-two (45%) providers reported that families were recommended for respite by a support group. Forty-two percent indicated that physicians referred families to respite care.

Figure 7. Service Providers' Knowledge of How Families Learn About Available Respite Care (n=116).

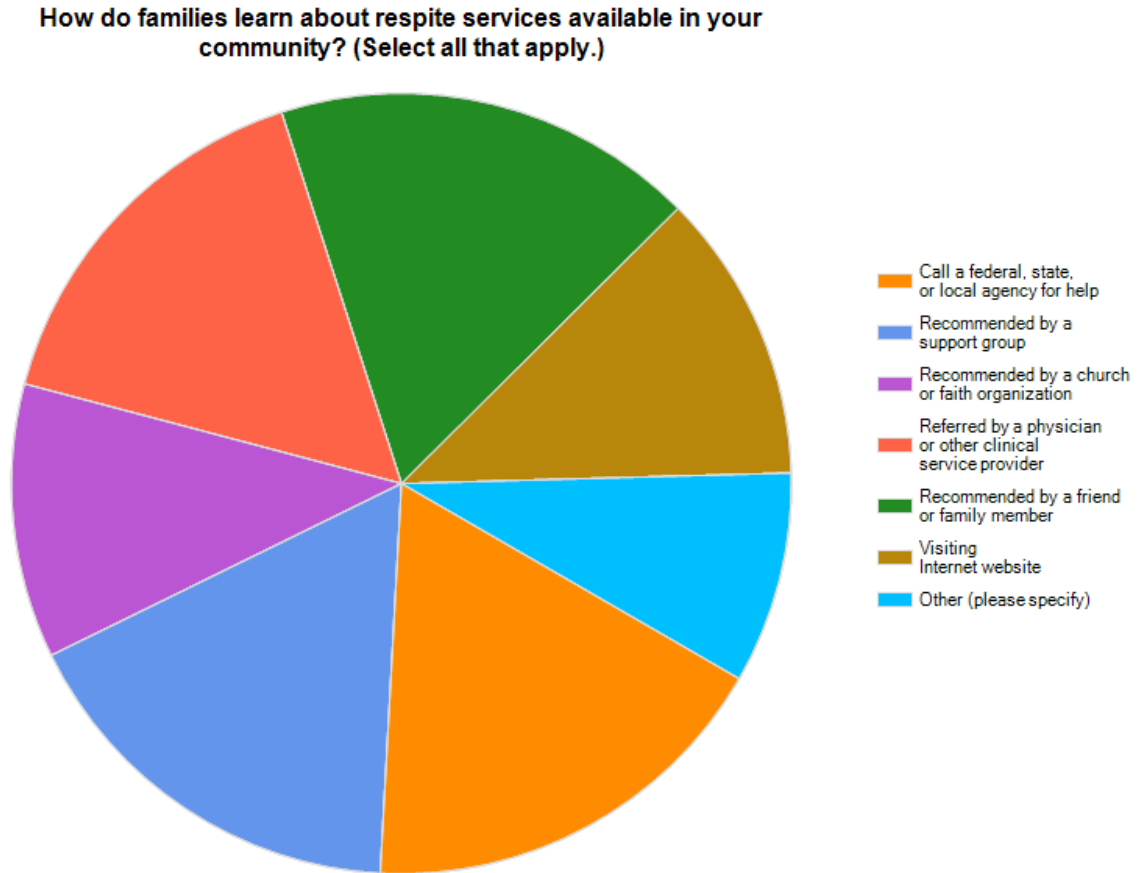
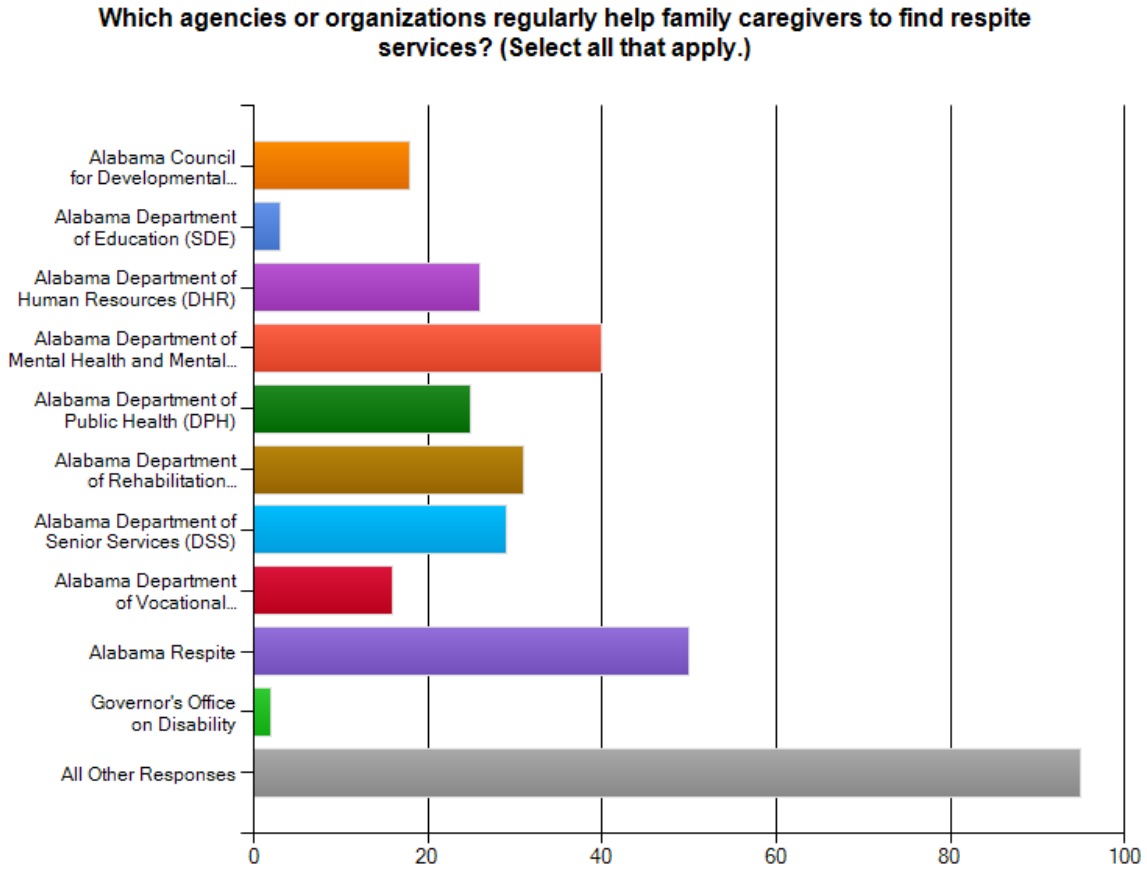


Figure 8 presents responses to the question asked of respite service providers, *which agencies or organizations regularly help family caregivers to find respite services?* The most frequent responses were: Alabama Respite, Mental Health/Mental Retardation (MHMR), United Cerebral Palsy (UCP), Department of Rehabilitation Services (DRS), and Department of Senior Services (DSS), listed in rank order. Seventeen providers indicated a variety of other agencies, including: SARCOA, an Area Agency on Aging (n=4); Autism Society of Alabama; The ARC; M4A, an Area Agency on Aging; & Alzheimer's of Central Alabama.

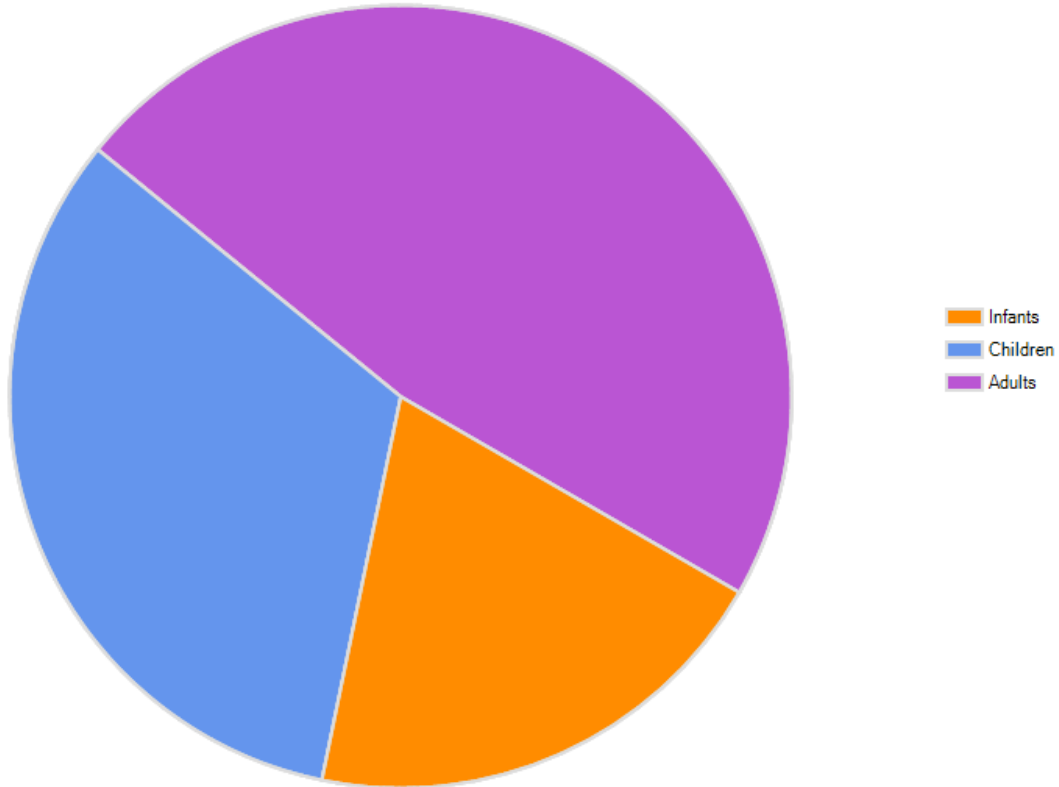
Figure 8. Identification of Agencies of Organizations that Help Families Find Caregiver Respite (n=112).



One hundred and nine respite service providers indicated age groups of individuals with chronic illness or disabilities are eligible for family caregiver respite services as illustrated in Figure 9, below. The majority (85%) indicated caregivers of adults are eligible, followed by caregivers of children (56%) and infants (36%).

Figure 9. Age Groups of Individuals with Chronic Illness or Disabilities Eligible for Family Caregiver Respite Services (n=109).

Which age groups of individuals with disabilities or chronic illnesses are eligible for family caregiver respite services? (Select all that apply.)



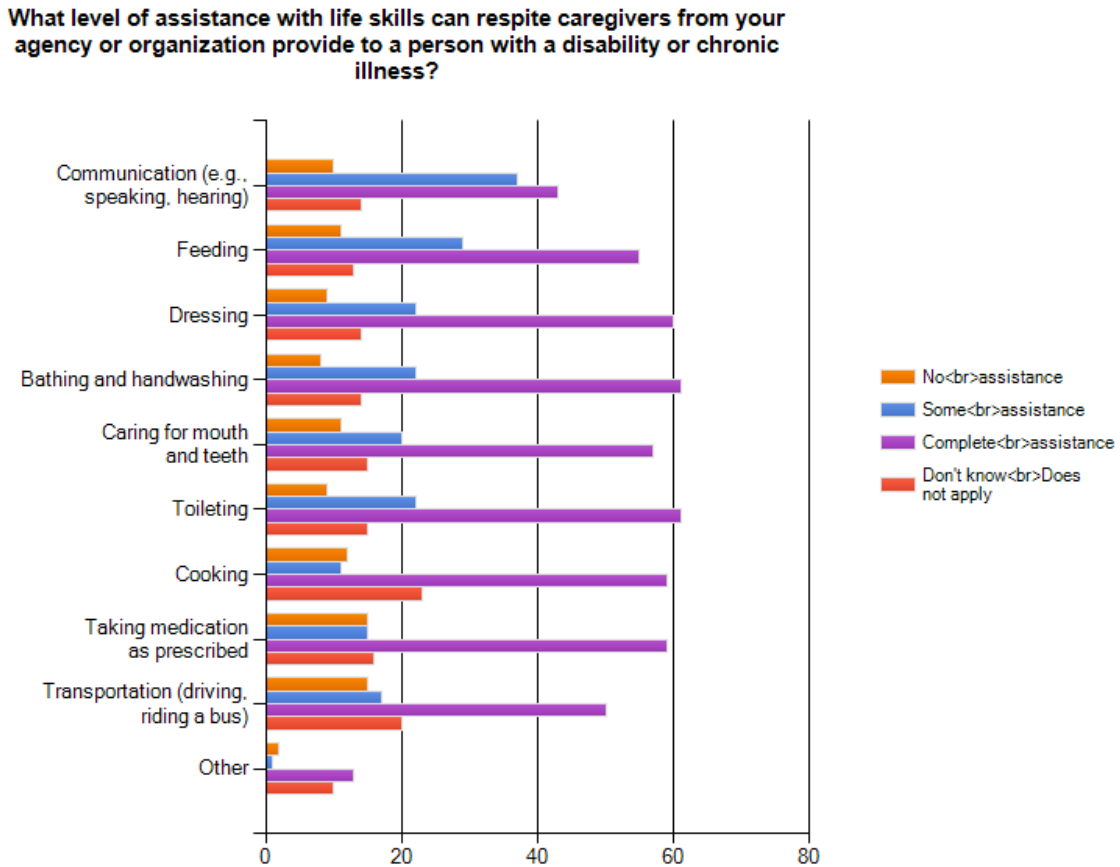
Eighty-nine percent of 105 service providers indicated that the individual with a disability of chronic illness must reside in the parent or guardian’s home in order to receive caregiver respite. Sixty percent replied that caregivers may receive respite if the eligible family member lives with another family member, while 47% said caregivers may receive respite even if the family member lives in his or her own apartment or home.

When asked what level of supervision the service provider’s organization can provide to individuals with disabilities or chronic illness during caregiver respite, 37% of 101 respondents replied, *continuous supervision*. Twenty percent chose *frequent supervision* and 13% said *occasional supervision*. It is interesting to note that 31% replied, *don’t know/unsure*; explanations were provided by 15 of these respondents: “no supervision, we are a cash reimbursement program for families needing respite”; we provide supervision 7:00 a.m. – 6:00 p.m. on weekdays; provide “Registered Nurse supervision.”

One hundred and ten service providers indicated the level of assistance with life skills that may be provided during caregiver respite to an individual with a disability or chronic illness as shown in Figure 10, below. *Complete assistance* was the most frequent responses across nine categories of life skills

including bathing and handwashing, toileting, dressing, taking medication, cooking, feeding, oral hygiene, transportation, and communication. Two life skills were more often identified as having *no assistance* available during caregiver respite, i.e. transportation (17%), and taking medication as prescribed (14%).

Figure 10. Level of Assistance with Life Skills Available During Respite Care for Individuals with Disabilities or Chronic Illness (n=110).



Seventy-eight respite service providers identified the most important training needs of their agency or organization to provide respite to family caregivers. The *first priorities* for training are: Behavior management/modification (n=6); first aid and CPR (n=6); bathing and lifting (n=5); effective communication with families and individual with disability or chronic illness (n=5); handling forms, documents and legal issues (n=5); managing emotions/upset feelings (n=4); dementia/Alzheimer’s Disease (n=3); specific procedure, such as tube feeding (n=3); and medication management (n=2), listed in rank order.

When asked to indicate *second priorities* for agency training, respite providers replied: Disability-specific training, e.g. ASD, dementia, seizure disorder (n=6); bathing and lifting (n=5); providing emotional

support, particularly to family caregivers (n=5); first aid, home safety, emergency response (n=5); cooking, feeding and household chores (n=4); referrals to other social service and respite agencies (n=4); communicating with the individual with a disability or chronic illness and families (n=3); managing medications (n=3); legal issues, such as responding to suspected neglect or abuse (n=3); specific procedures to serve individuals with disabilities, such as handling equipment and implementing agency rules (n=3); and offering social support for family caregivers when needed (n=2), listed in rank order.

Finally, 54 service providers offered additional comments about family caregiver respite. A selection of verbatim comments illustrates nature of feedback received in response to this question:

Support programs keep clients in their homes. This is more cost effective than nursing home placement.

There is a need for respite care due to so many people wanting to stay at home. Community services along with Home Health and Hospice allow a person to stay at home with their family.

They don't have enough financial support for the family caregiver.

I think the best thing that ever happened to caregivers is people offering respite services for the help.

I think Respite Services are good because it lets people (clients) try out a different environment.

These services help with relief for the caregiver even though (name) does receive skilled care, she needs these respite hours to help the parent with other needs for the family due to no other support system in the family.

There is tremendous need for more respite services to be made available to caregivers. The stress level of caregivers is extremely high and unless you are fortunate to have a waiver program, there are very few resources available for respite in this area.

Respite helps to preserve the caregiver's mental and physical health, adds stability to the entire family unit, and affords the client due dignity.

It is a great program and we enjoy the opportunities that we have to share with families that need the service.

I am a pediatric neurologist at Children's (Hospital of AL). There is a HUGE unmet need for respite care for families in Alabama.

I feel respite services are a good thing. My mom, who is the primary caregiver, needs time for doctor appointments and social time.

Just wish there was a respite service that (name deleted) could be with the same staff person every time she is there.

Respite providers can be trusted.

For more information on the survey or results, please contact:



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