

# Alabama Lifespan Respite Resource Network

## *Survey of Family Caregivers Results*

### Survey 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 role of the external evaluator is to insure that the recipient agency meets objectives established by the AOA.

The evaluation addresses the five mandated priorities of the federal grant. A mixed-methods approach to evaluation includes gathering qualitative and quantitative data from key informants. Three goals will guide the evaluation:

1. Measure current capacity and improvement of Alabama Respite Network 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 Network 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 Network and its Capacity Workgroup to invite family caregivers and agency service providers to 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 Capacity Workgroup and evaluators. We reviewed the helpful guide published by ARCH, "Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Care Program Managers." Network members and service providers offered suggestions about survey content and format.

The survey contains 49 items, of which eight require open-ended responses. Items were grouped in five general categories: *respite service needs and history of use* (28 items); *demographics* (13 items); *caregiver expectations and precipitating events* (5 items); and *identification of service providers and agency referrals* (3 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 4-02-10 and renewed the protocol on 12-31-11.

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. Each agency determines eligibility to receive lifespan respite care according to rules established by federal, state and private funders. For this reason, agency representatives invite their clientele and respite service providers to participate anonymously in the needs assessment through established service contacts.

As of January 2012, more than 3,000 copies of the *Survey of Family Caregivers about Respite Services* were distributed and 923 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.

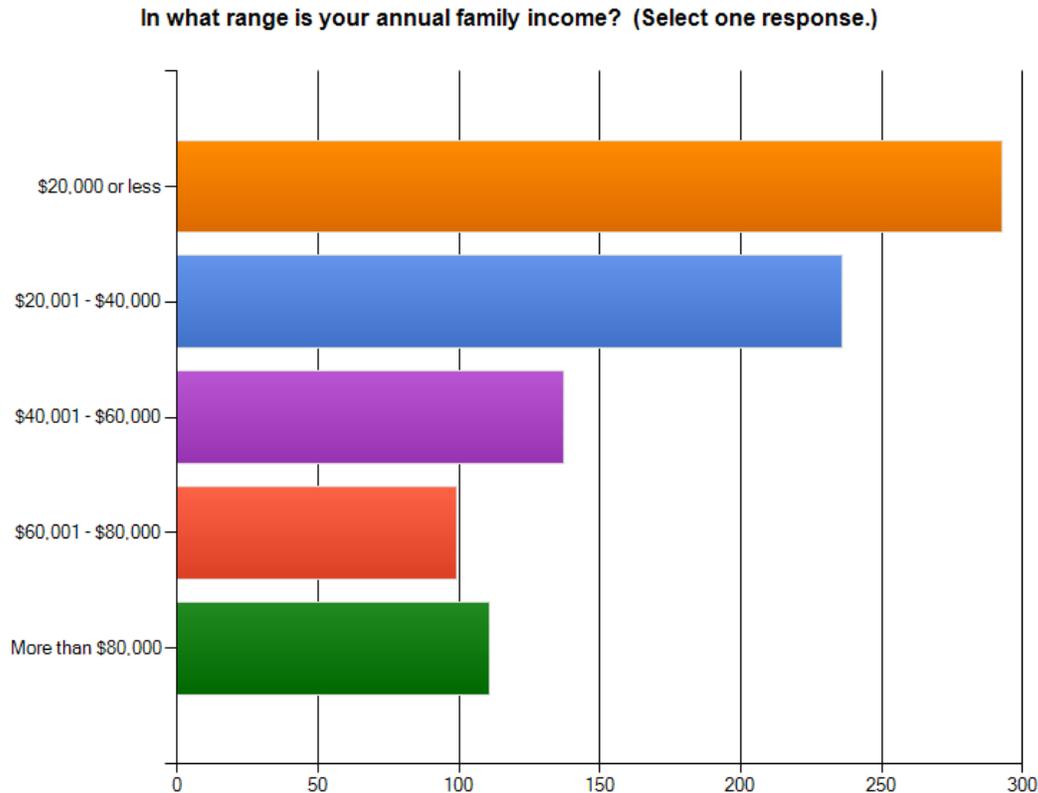
No family caregiver was obligated to participate in the statewide needs assessment. Those who decline to do so did not suffer penalties. Those who wish to discontinue participation did so without adverse consequence. Those who desire physical assistance to participate requested this from an agency represented on the statewide Network or the project evaluators.

## Survey Results

As of January 2012, 923 individuals attempted and 877 completed a written or online *Survey of Family Caregivers about Respite Services*. Two-thirds reported their race as White and nearly one-third as Black. Eighty-seven percent of participants are females. The average age of respondents is 51 years. Fifty-two percent are birth or adoptive parents of the person with a disability or chronic illness. Twenty-five percent of respondents are the son or daughter. Fifty-four percent of participants provide daily care for a female with a disability or chronic illness.

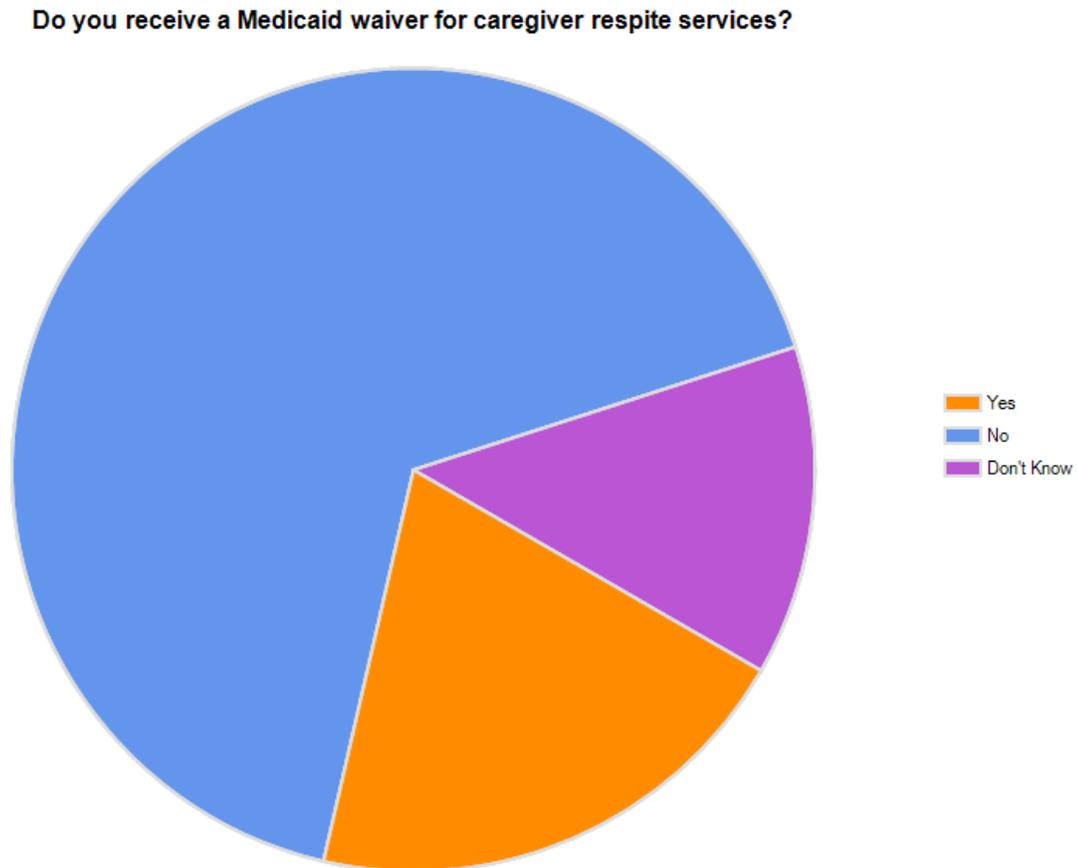
Sixty-four percent of participants are married, 16% are single and 10% are divorced. Range of annual family income is shown in Figure 1. Three-fourths reported annual family income of \$60,000 or less.

Figure 1. Annual Family Income Reported by Caregivers (n=876)



Only 20% reported receiving a Medicaid waiver for caregiver respite services as shown in Figure 2. Two-thirds of respondents have *never* accessed caregiver respite services using a Medicaid waiver. Thirteen percent did not know whether waivers were received.

Figure 2. Percent Reporting Receipt of Medicaid Waiver for Respite Services (n=903)



*Without the respite services, I would be in a mental hospital and my family would have fallen apart. My respite caregiver is a lifesaver and she loves my child. She only gets paid 8.00 an hour though and has three children of her own (single mom) and needs to find a job where she can earn more money – Alabama family caregiver*

A total of 686 caregivers stated expectations for how respite services will help their family. Responses were grouped into five categories for analysis: 1) Attending to family caregiver’s needs; 2) helping with activities of daily living; 3) caring for others in the family; 4) providing financial assistance to pay for respite; and 5) caregiver continuing education, providing therapies or medical treatment (listed in rank order). Many responses included multiple caregiver expectations for the benefits of respite.

Representative responses from families illustrate frequent expectations of respite care:

#### **Attending to Family Caregiver's Needs**

- *It would help provide much needed time to recharge my batteries and my spouse's. It is amazing how time consuming raising a child with a disability can be, no matter how mild or complicated their diagnosis.*
- *Could really use a couple of hours to get away from providing 24 hour care.*
- *I'm so stressed I'm contemplated suicide and I have screamed at my child. I expect it would be nice to do something for myself w/o feeling too guilty and that maybe I'd yell less and she'd be less clingy and less irritable. I could maybe catch up on some rest and be less cranky.*
- *Reduce stress by allowing relief from the constant responsibility of caring for a person with a disability.*
- *It allows me time to renew with a break. My child also loves the break!*
- *Help me by allowing me some time to myself and with my husband without the constant thought of my mother's needs. I need some time (more than a few hours) to relax and allow myself and my husband to renew. I am disabled with fibromyalgia and my husband is 72 with arthritis and high blood pressure. We just need some time to feel un-pressured.*
- *I would like to continue to work after my son turns 21. We have a homemaker that comes 10 hours per week. We have been told several times that there is a not a skilled respite provider in our area.*

#### **Helping with Activities of Daily Living**

- *I hope it would provide me with the assurance of qualified individuals caring for my terminally ill grandmother as I attended my own medical appointments, ran errands essential to meeting both of our basic needs, and occasionally have short term periods to rest and rejuvenate-also essential to my ability to meet our basic needs.*
- *I cannot go anywhere unless my husband is home; I cannot even get her meds at the store or buy groceries unless my husband is home. Our entire family revolves around my daughter's illness - how we live, where we work, and my son's life is significantly affected as well. I cannot go to a doctor unless my husband is home.*
- *Respite services are provided so that a caregiver may attend to other areas of his or her life during the respite period, for example, grocery shopping or taking another child to a movie.*
- *My husband and I have not had a moment of time away from our daughter since she was born 5 yrs ago. It would be nice to be able just to go out and sit down for dinner or a movie...it would also be amazing just to be able to grocery shop.*
- *Respite allows me to work and care for my mother. With respite, I'm able to visit my children and friends, to go shopping, and to participate in other activities.*
- *I could use someone to look after my wife while I go to the grocery store, get a haircut, cut the grass and other things I have to do.*
- *Provide care via voucher (to pay) for sitter (so that) caregiver (can) shop and go to doctor's appointments, and/or training in specific area of educational sessions.*

#### **Caring for Others in the Family**

- *For times when I have to focus on my other son. When I have gaps in coverage between my work and school. When in need of a real break so my husband and I can go out for a few hours.*
- *Give me the time to get out and do things with my other child.*
- *Receiving this enables me to spend more time doing special things for my husband.*

- *Having help with my son allows me to spend more quality time with him. It reduces stress. I am able to care for other members of my household better when receiving respite care. There are not enough hours in the day to care for a special needs child and take care of others. When a home health aide comes to the house, I am freed up to do other caregiving that gets pushed aside. For example, if a home health aide bathes and feeds my son, I can do other housework that frees me up on the weekend to spend time doing much needed therapy with my son.*
- *Relieve me to continue school and taking care of two kids and being a single parent.*
- *Gives me time to spend with my husband, sons, daughters-in-law and seven grandchildren, as well as providing me some time for myself.*
- *Allow me time with my 4 other children without having to be totally focused on my son. Allows a break to help me refocus on my son's needs.*

#### **Providing Financial Assistance to Pay for Respite**

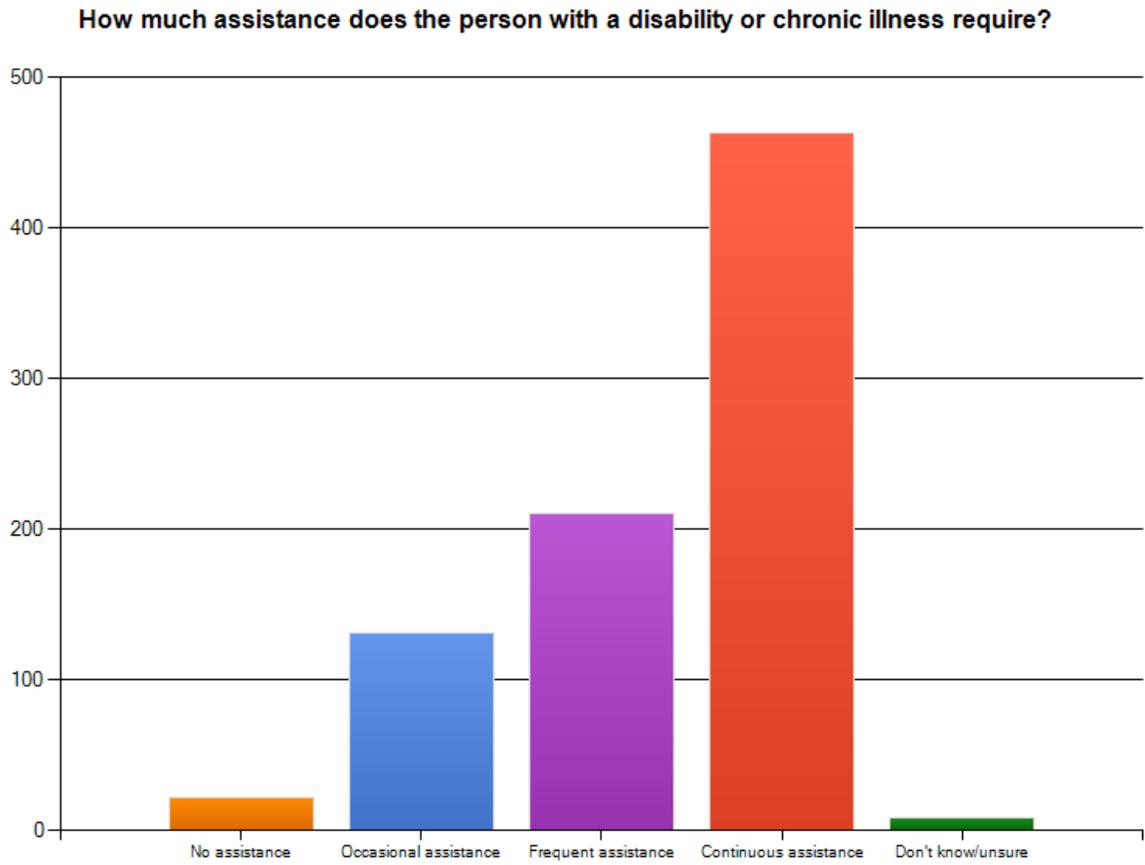
- *We are unable to pay anyone for help. That we badly need.*
- *With the cost of caring for our needs as we age and also for our adult daughter with a disability, there never seems to be enough dollars left over for hiring an individual to care for our loved one; and we feel very fortunate that we have been able to access the respite reimbursement for a few days away the past several years. Thank you!*
- *Finding a provider that we could trust is the first step. Funding for her time goes hand in hand. You can't have one without the other.*
- *Helps me to pay someone to stay with my loved one while I work.*
- *To be given more respite days when the funds are available.*
- *They paid for someone to sit with my son for 10 hrs. - I got a good break. I did not have enough income on my own to pay for this service.*
- *Help with more respite money. \$100 for every three months is not enough money. We have private insurance and have a lot of medical bills.*

#### **Caregiver Continuing Education, Providing Therapies or Medical Treatment**

- *It helps me by letting me know how and what kind of exercise to do with my son to help him get better.*
- *Help me to learn how to help my grandchild grow and develop.*
- *To give me opportunity to attend conferences to learn more about helping my child and to have time away from home to refresh myself.*
- *My son is 3 years old now, so he's not being seen like he was for speech therapy, but the people in Huntsville, AL have helped me in other ways by answering any questions I might have. I really love and appreciate them.*
- *It will give me the opportunity to do things I otherwise would be unable to do. Also allows me to be able to have the time to learn more about the children's conditions.*

A total of 834 family caregivers indicated the level of assistance required by the family member with a disability or chronic illness as shown in Figure 3. Fifty-five percent need continuous assistance, 25% require frequent assistance, and 16% need occasional assistance.

Figure 3. Assistance Required by Relative with a Disability or Chronic Illness (n=834)



Eight hundred and fifty four family caregivers indicated events that led to the most recent request for respite care services. The four most common responses were to “relieve stress” (73%), “care for myself” (46%), “care for personal business” (31%), and “improve relationship with my spouse or partner” (30%).

More than 600 family caregivers responded to the item, “tell how members of your household were affected by the event leading to the most recent request for respite services.” Selected quotes from family caregivers represent the types of responses to this completion item.

### **Relieve Family Caregiver Stress**

- *Not having time to relieve stress of daily life, leads to more stress which in turn leads to not being able to function properly as a parent and caregiver.*
- *Our entire family life revolves around my daughter's needs and issues. We are in her room full time or she is on an electronic monitor, even at night, when we sleep, we check the monitor constantly and check on her if she is seizing or calls for help.*
- *I recently was laid off from work, and am acting as his full time caregiver; it is difficult for me to search for work, interview, etc. I can go nowhere without him, and he has a very difficult time seeking help from anyone but me. I enjoy caring for him, but I still need an income.*
- *Amazing! We are able to have a more normal life now. I have a 6 month old and he actually gets a little attention. I seriously would have had a nervous breakdown by now had I not had Vanessa (respite care giver).*
- *Can't leave house unless I have these services. Need to get groceries. Also have trouble controlling Blood Pressure. Trip to store gives a little relief.*

### **Care for Myself**

- *(I have a) hard time getting to doctor appointments.*
- *I want to make sure she is safe and so I can care for myself.*
- *I had to become a stay at home mother...we lost health care and 1/2 of our income.*
- *Without help, sometimes my family members stress me out. I don't have time to care for myself...(I am) looking out for my husband's safety when I have to leave him alone.*
- *I was able to get more rest.*

### **Care for Personal Business**

- *My sister has to lose time and pay at work and travel several hundred miles to spend a few days here, so I can have a brief time apart for either personal business or recovery. As a consequence, my sister ends up needing respite care because she has NO down time.*
- *Well, it frees me up to take care of personal business that only I can take care of. Also, it helped me deal with some anger issues and a lot of depression over my loss.*
- *She can't be left alone so we couldn't go do things we needed to do. Getting run down.*
- *I can pick up a granddaughter from school, run errands. (I) couldn't cook supper here alone with (my loved one for whom I care).*
- *He has someone to sit with him while I run my errands or get some rest.*

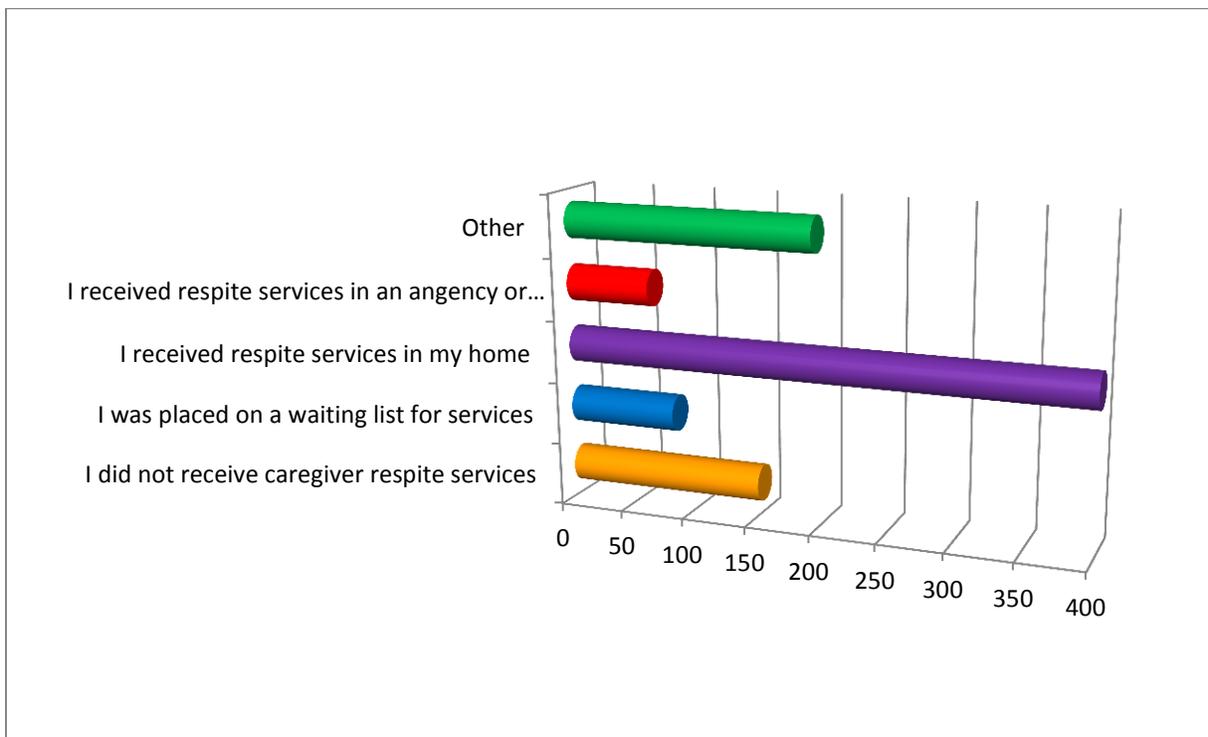
### **Improve Relationship with My Spouse or Partner**

- *(His) daughters have been traveling from out of state to help out, but have exhausted leave time. Everyone worries, and stress and exhaustion lead to errors and bickering.*
- *I feel like I neglect other members because all I do is work and take care of my mom. My daughter has Type 1 diabetes and she needs my help too.*

- *Allowed relaxation time and a chance for my spouse and I to have time out.*
- *Respite relieves stress because my mother wanders off when she is by herself. It also improved my relationship with my spouse by giving us time with each other.*
- *Spouse benefits (from respite) as we are able to be away and recipient is being cared for.*

In Figure 4 are responses from 838 family caregivers who indicated the outcome of the most recent application for caregiver respite services. Forty-eight percent received respite services in their home. Eight percent received respite services in an agency or community setting. Eighteen percent did *not* receive caregiver respite services. Examination of responses to the “other” category revealed that these family caregivers do not know how to request respite services and are concerned about finding a qualified caregiver.

Figure 4. Outcome of the Most Recent Application for Caregiver Respite Services (n=838)



Of 749 family caregivers, 239 (32%) were unable to find caregiver respite services when needed on three or more occasions. Sixty-five caregivers (9%) could not find respite services on two occasions when needed. The same number could not find respite services on one occasions when needed. The majority (74%) of 813 respondents are *not* on a waiting list for caregiver respite services.

Of 775 respondents, 240 (31%) indicated that the most recent caregiver respite service lasted for one day or less. Fifty-two caregivers (6.7%) received two days of respite services and 139 caregivers (18%) received three or more days of respite services. Forty-five percent of 741 caregivers said the most recent respite service was *not* enough to meet their needs.

Responses to the item, “how would you feel if caregiver respite services were not available?” are shown in Figure 5. The most frequent response among 781 caregivers was *extremely stressed* (54%), followed

by *moderately stressed* (24%). As indicated in Figure 6, family caregivers learn about respite services from a variety of contacts including recommendation from a friend or family member (24%), referral from a federal, state or local agency (22%), referral by a physician or other clinical service provider (18%), or recommendation from a support group (15%). Participants named other service providers, programs, meetings and media, including Children’s Rehabilitation Services, an area agency on aging, Early Intervention, homebound school teacher, social worker, hospice agency, CASA of Madison County, Central Alabama Aging Consortium, Senior Citizens Center, Alabama Lifespan Respite Resource Network billboard advertisement or web site, flyer, radio or newspaper.

Figure 5. Caregivers’ Perceptions about Feelings if Respite Services Were Not Available (n=781)

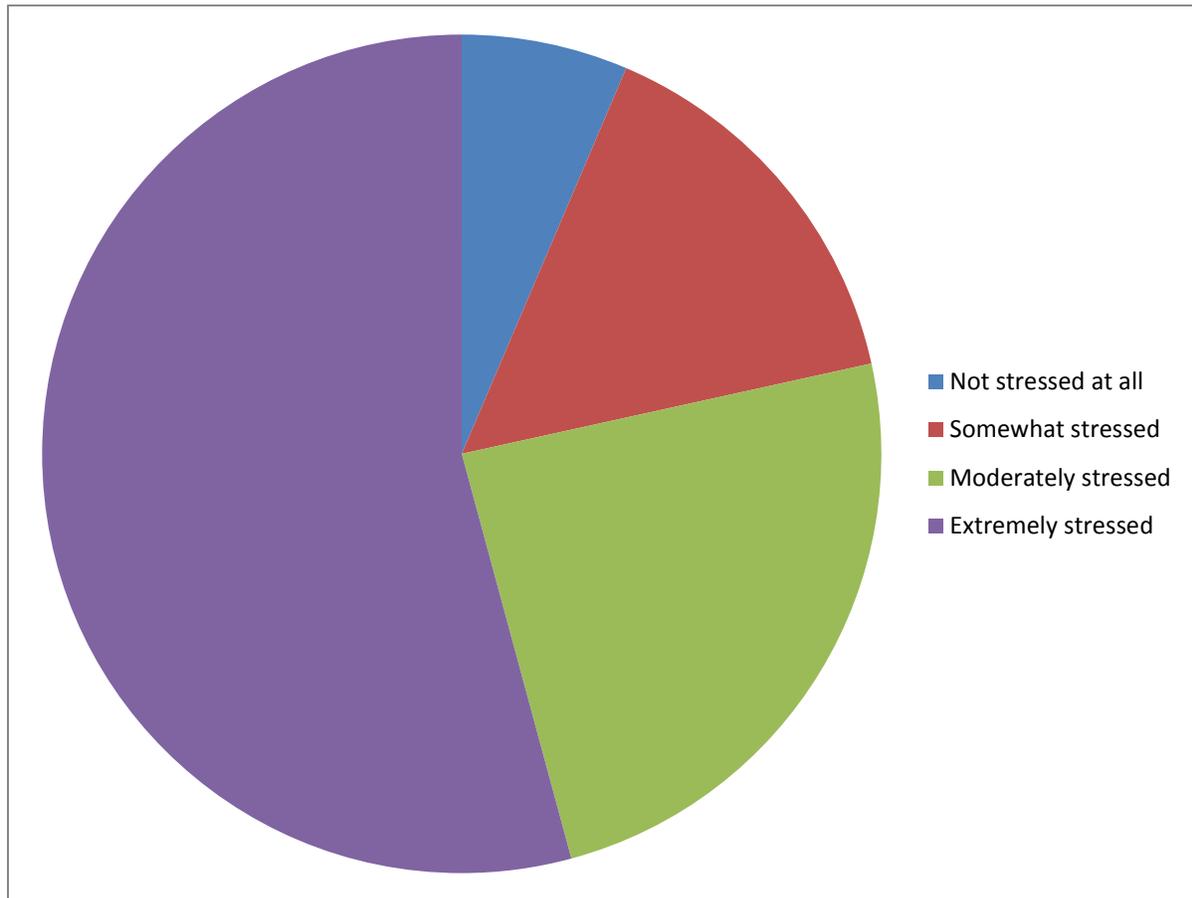
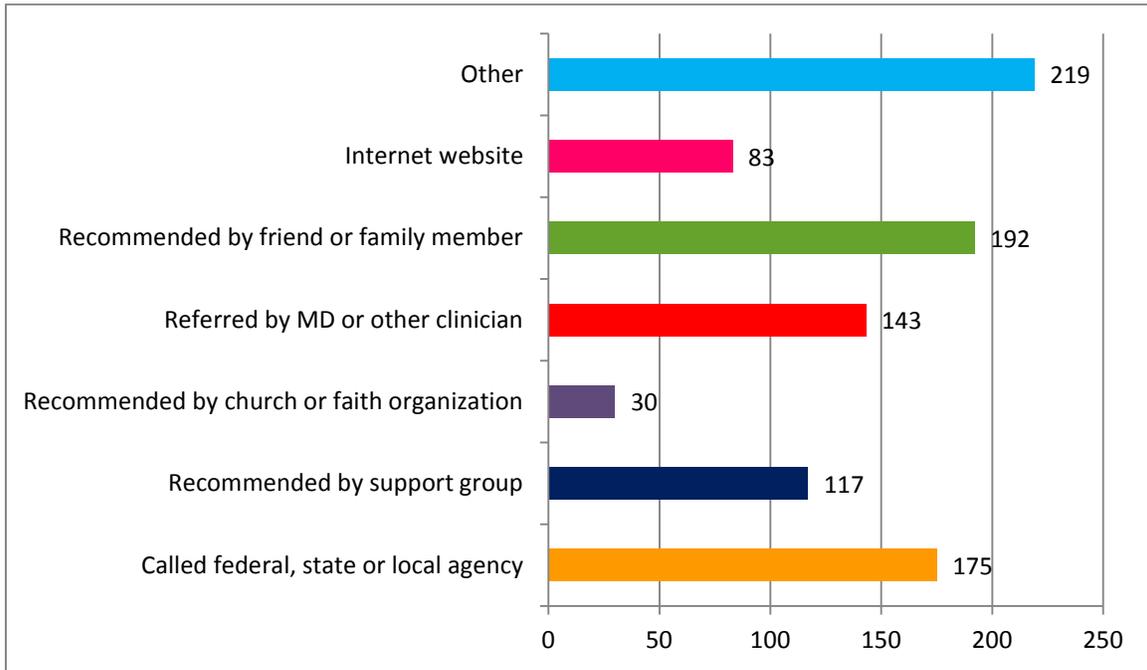


Figure 6. How Caregivers Learned About Community Respite Services (n=795)

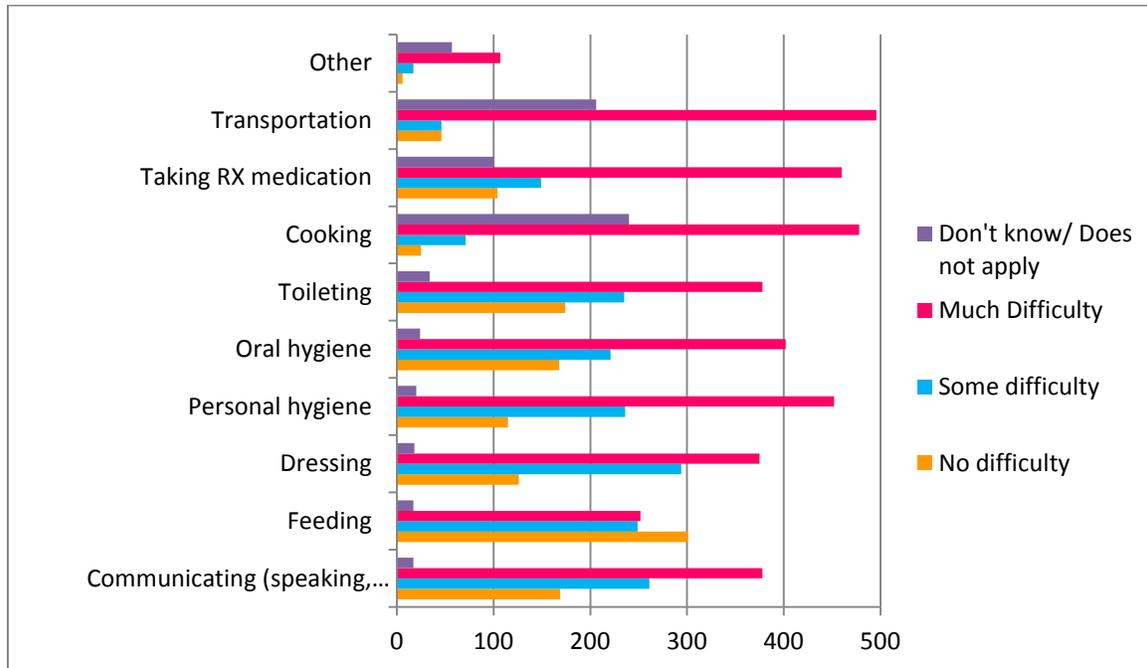


A total of 850 family caregivers indicated level of difficulty for 10 life skills among relatives with disabilities or chronic illness. Among these skills are taking medication as prescribed, transportation, bathing and hand washing, and caring for mouth and teeth. The most frequent response about level of difficult for 9 of the 10 skill areas was *much difficulty* (range between 46% – 62%), with the exception of feeding as shown in Figure 7. Caregivers perceived least difficulty for the life skill of feeding among persons with disabilities or chronic illness (37% have *no difficulty*).

One hundred and fifty five family caregivers responded *Other*, indicating their loved one needs constant care or has sensory disabilities. Caregivers replied:

- *My daughter has cerebral palsy and is wheelchair bound and cannot verbally tell you what she needs. Needs constant supervision and help to do normal activities. Such as toiletries and feeding.*
- *He requires total care.*
- *She is totally dependent (on care from others).*

Figure 7. Level of Difficulty with Life Skills Among Persons with Disabilities and Chronic Illness (n=850)



Finally, 475 caregivers offered additional comments concerning respite care that were grouped into four categories: Benefits to the Caregiver and Family Members; Unmet Needs for Respite; Awareness about Respite; Confidence and Trust in the Respite Provider. Selected comments from family caregivers represent their thoughts and needs.

### Benefits to the Caregiver and Family Members

- *Respite services for the caregiver are very important. One person cannot handle 'around the clock' care.*
- *It enables families to keep their children at home instead of placing in nursing homes due to total care*
- *These services are very necessary for me to be able to go to doctor, dental appointments, get groceries, and being able to get out of the house for some time for myself. I don't know what I'd do without this help to care for my mom. My family members are not any help at all. They work and just cannot help with our everyday activities. The stress that comes from taking care of my mom 24 / 7 would be unbearable without Caring Days giving me that break for a few hours.*
- *Respite really aids in providing a more normal life for my 20-year old son with Duchenne Muscular Dystrophy. We were the only caregivers until (name) was 18 years old. My husband and I are so happy that we can all be home together. It is crucial for us to have a break...*
- *They are needed so family members can stay at home and it improves the health of the caregiver.*
- *Wonderful service. Everybody needs a break, whether physically or mentally.*

## **Unmet Needs for Respite**

- *Respite is a wonderful service, just need more of it.*
- *Respite services being received are extremely helpful, but we could certainly use more hours of care and more flexibility. We are very appreciative of services; however, more hours would be a great benefit. The individual for whom services are authorized requires continuous care and supervision.*
- *As aging parents, we have the need for respite care on a continual basis. We have to make arrangements far ahead of actual dates that we need respite. Our schedule has to be arranged around the needs of our child. The maximum amount we receive will not even cover a 24-hour period. During hospitalization, we pay out of pocket for a sitter when family members are not available.*
- *Have been denied respite services, Medicaid waiver and SSI benefits based solely on income. Faith based respite care available for my child in the area is inadequate to care for his needs (in my opinion). We have no respite care unless family volunteers or we pay.*
- *Would like to have services to free-up caregivers on weekends, nights, or on a weekly basis (24-hour care), so caregivers can have extra time for themselves or to take vacations. Would like to have more weekend and holiday services, or a person to come and help caregivers on weekends. Would like to see respite services have a night shift for those who work at night. (I hear this a lot.) To have more adult day care in Tuscaloosa County.*
- *Social services for caregivers of, and for disabled children, need to be more accessible. I am so frustrated and know that good people give their money to help children like mine; yet the services never actually get to the people with greatest need. Management in this area does a serious disservice to the disabled and the people who willingly donate their money to them.*
- *It would be very helpful if assistance was provided on need vs. hours. It would be nice to have someone fill in as a companion as well as giving help to a patient. It is very difficult if you do not have the finances to hire the help you need.*

## **Awareness about Respite**

- *I have never been given a list for caregivers. I have to find my own. I get to buy groceries every three months. Because I have no help. I do everything myself. I have to beg people to sit with my son to go and buy food. I get really depressed and upset because I can't leave my house. I need help.*
- *I've never been offered such services, but I would be very grateful for any help offered. Thank you.*
- *I'd like to know if there are additional services out there that can assist the elderly*
- *I would like to find out how to apply for respite care services in my area.*
- *We need more information on where we can receive respite money or services. My husband is a 100% disabled veteran. Would this make us available for any respite monies from VA? Camp ASCCA costs a lot; is any money available for camp? What is a Medicaid waiver respite service?*
- *The most difficult thing for me has been finding caregivers. Regular babysitters are not qualified to take care of my son. Direct payment to agencies is cost prohibitive. We need affordable (\$10 or under) hourly caregivers available in the home. We have yet to find a good list of caregivers. Even many daycares do not provide care for special needs children. We particularly need a daycare in unincorporated Jefferson County that accepts special needs children for after school care 3 days a week.*

- *I really need some help with respite care and no one seems to know in Mobile, AL how I can obtain this.*
- *Would like to know more about them. Would like to be a respite caregiver myself.*

#### **Confidence and Trust in the Respite Provider**

- *The respite service I receive works very well for me and my situation. I was able to pick and train whom I wanted to stay with my child. This worked out well as my child already knew this person and she is a well qualified CNA at a local nursing home. I am a very protective parent. I would never leave my child in the care of a total stranger. This gives me a few hours per month to leave her with someone I know, so that I can have peace of mind when I leave her.*
  - *It would be great to have any qualified respite services. I don't need people here who are not trained or who don't want to be here.*
  - *It'd be nice to know there was a qualified caregiver who'd passed a background check that you felt confident was safe. I feel I would benefit from having respite 5 or more hours a week...*
  - *I need access to a safe place whereby if I have to go out of town I know that my child can be left there and be well taken care of.*
  - *She feels the respite care givers are untrained and unprofessional. I opt to pay for respite service so that I can hire someone I trust who is trained appropriately to care for my child.*
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