

# **Lifespan Respite Grant**

*Caregiver Needs and Provider Survey Report*



Aging Services  
and  
Office of Performance Outcomes and Accountability

09/02/2016



# Lifespan Respite Grant

## Caregiver Needs and Provider Survey Report

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## Introduction

In 2013 the Oklahoma Department of Human Services received a grant from the Administration for Community Living to enhance the support available to people who care for others across the lifespan. Two separate surveys were conducted to address the goals of this grant. Both surveys were administered electronically through the Business Enterprise Survey Tool (BEST), the online survey software tool used by the Oklahoma Department of Human Services.

The first survey was completed by caregivers and aimed to learn more about the available resources and unmet needs of caregivers in Oklahoma. Participation invitations for the Caregiver Survey were extended via email to 261 individuals who attended caregiver conferences, workshops or support groups, or applied for caregiver services. The survey link was activated on June 2, 2016 and remained open until June 20, 2016. Paper copies of the survey were also distributed to caregivers at caregiver workshops provided by the Alzheimer's Association and Oklahoma Healthy Aging Initiative. In total, 132 caregivers completed the survey.

The second survey was completed by caregiver service providers and aimed to learn more about the availability and capacity of caregiver support services in Oklahoma. Participation invitations for the Provider Survey were extended via email to 99 employees of caregiver support agencies/organizations. The survey link was activated on June 15, 2016 and remained open until July 15, 2016. Paper copies of the Provider Survey were also made available. In total, 67 service providers completed the survey.

It should be noted that there are several limitations to the survey results. The first of

these limitations could be a selection bias with regards to the Caregiver Survey. The Caregiver Survey was completed by caregivers who attended caregiver conferences, workshops or support groups, or who applied for caregiver services. Since these individuals may differ from caregivers who did not attend events or applied for services, without further information, the results of the Caregiver Survey should not be considered representative of all caregivers in Oklahoma. Additionally, it would be possible for one individual to take the survey multiple times if that individual attended more than one event or attended an event and applied for services.

The second limitation lies in the sampling of respondents for both surveys. Though every effort was made to reach caregivers and agencies across the state of Oklahoma, responses indicate that not all Oklahoma counties are represented. This means that these results should not be considered representative of all caregivers or all caregiver support service providers in Oklahoma.

A third limitation lies in the interpretation of the questions in the Provider Survey. The survey questions were asked on an agency level, for example “Does your Agency/Organization provide Respite Services?” However, survey respondents were asked verbally to answer the questions on behalf of their program area within their agency. This discrepancy may cause the results, such as the services available to caregivers, to be inflated depending on how the question was interpreted.

With these limitations in mind, the results of the Provider Survey should be interpreted with caution and should not serve as the sole basis for decision-making.

SECTION 1

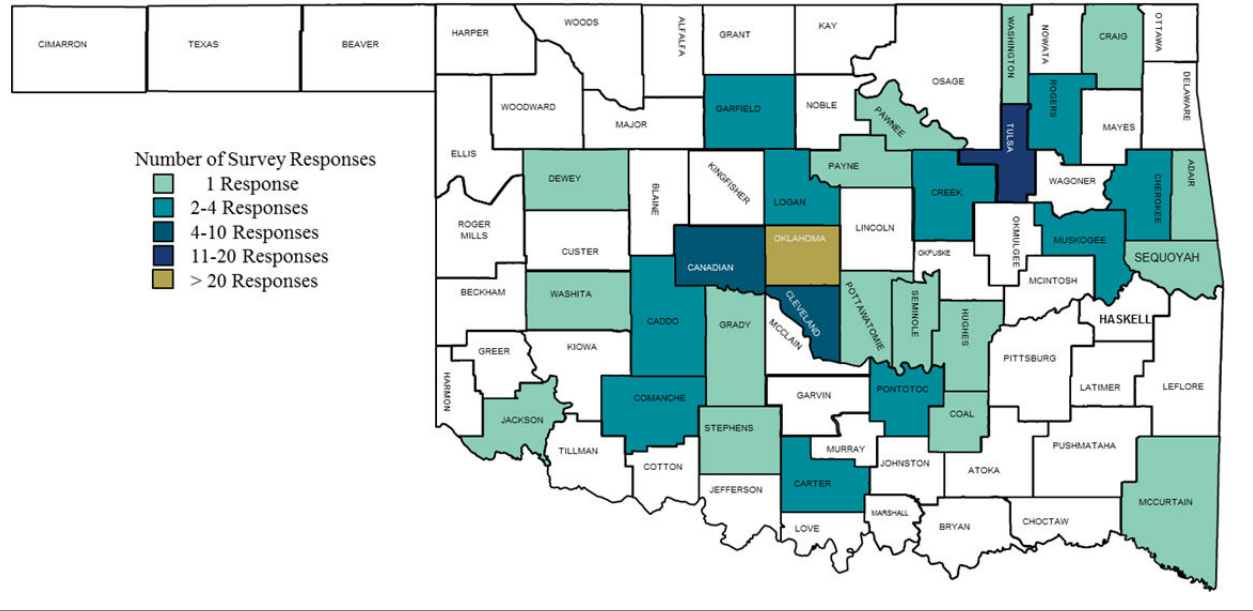
Caregiver Needs  
Survey Results  
*Lifespan Respite Grant*

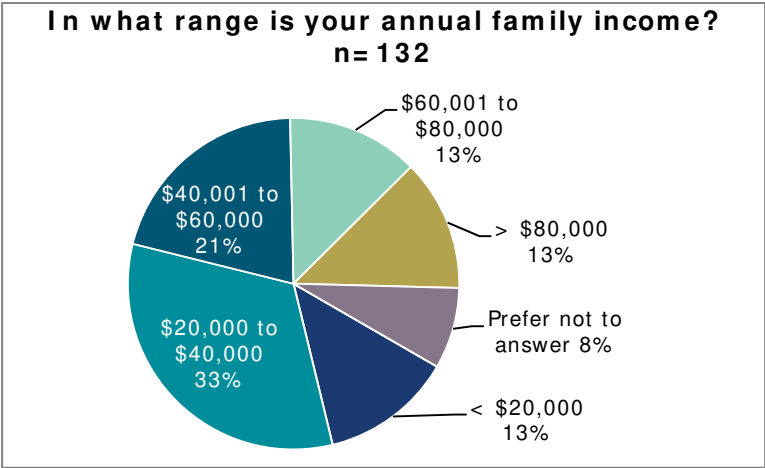
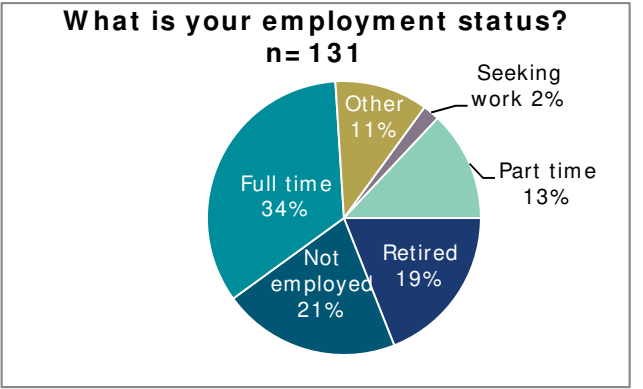
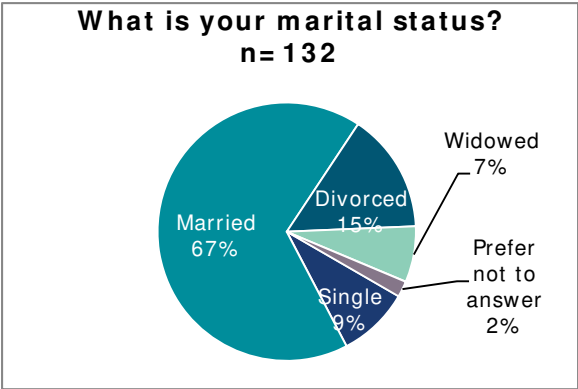
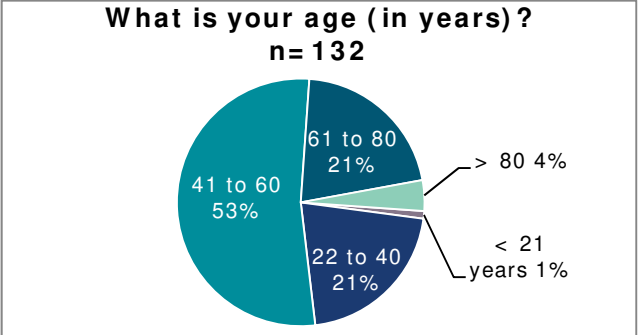
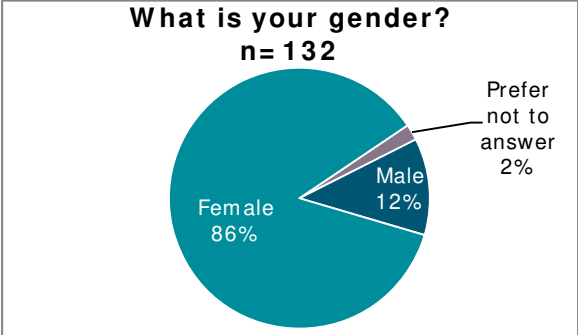
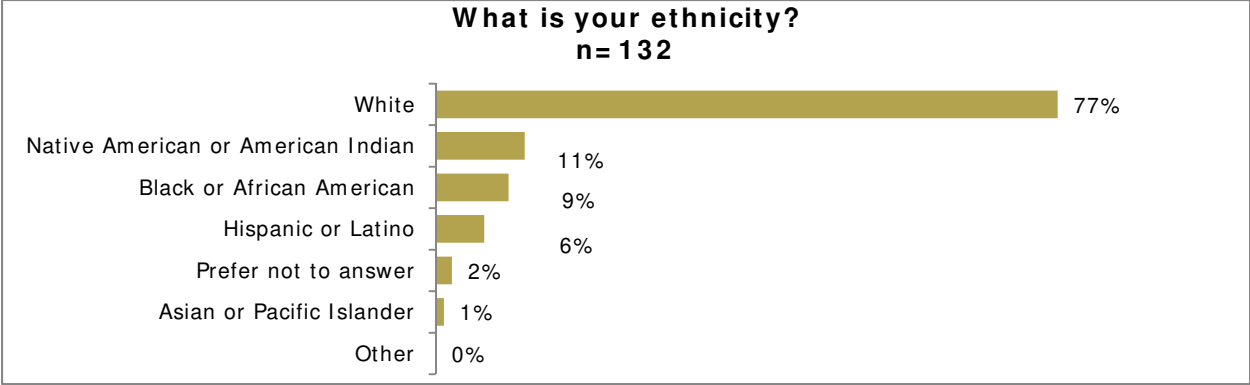
The Caregiver needs survey was completed by caregivers and aimed to learn more about the available resources and unmet needs of caregivers in Oklahoma. Caregivers were asked demographic questions, questions about the type of care they were providing and to whom, and what services they currently receive and would like to receive.

A typical respondent to this survey is that of an adult white female (77%) in Oklahoma County between the ages of 41 and 60 (53%), who is married (67%), does not work full-time (66%), and has a household income between \$20,000 and \$60,000 (54%).

**RESPONDENT CHARACTERISTICS**

To help us identify the unmet needs in your area, please select the county where you live.

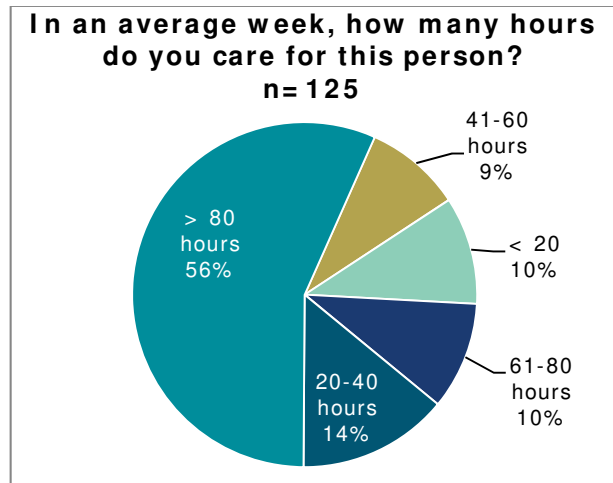
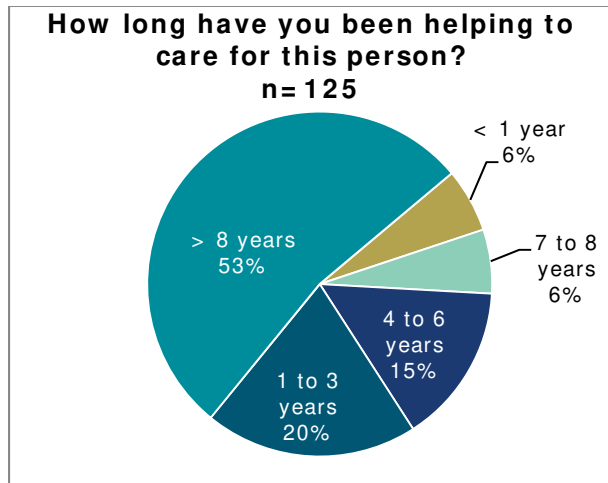
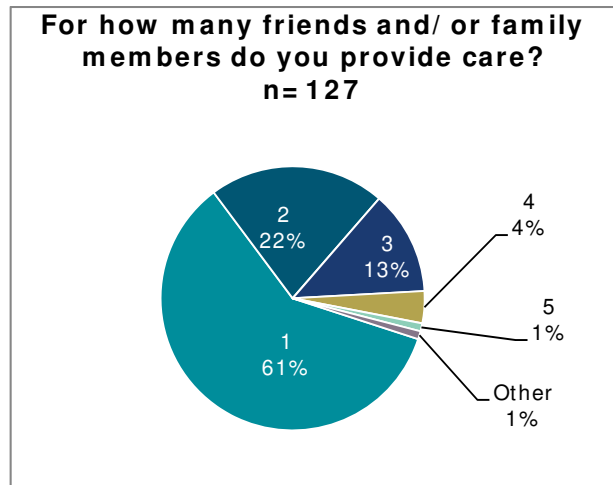
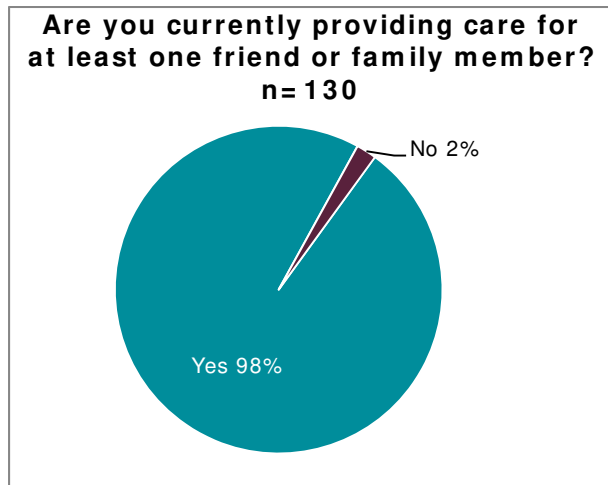




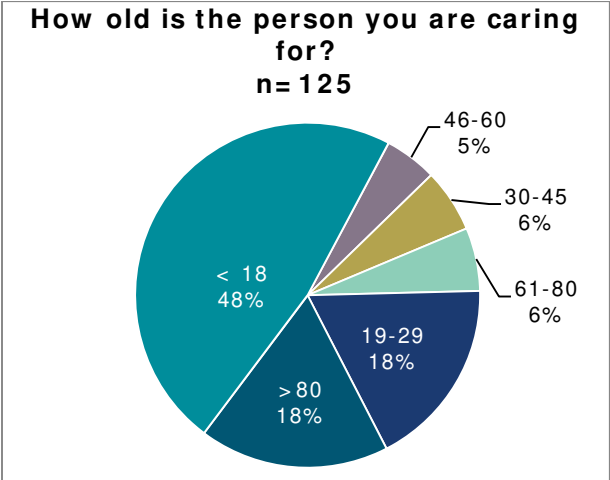
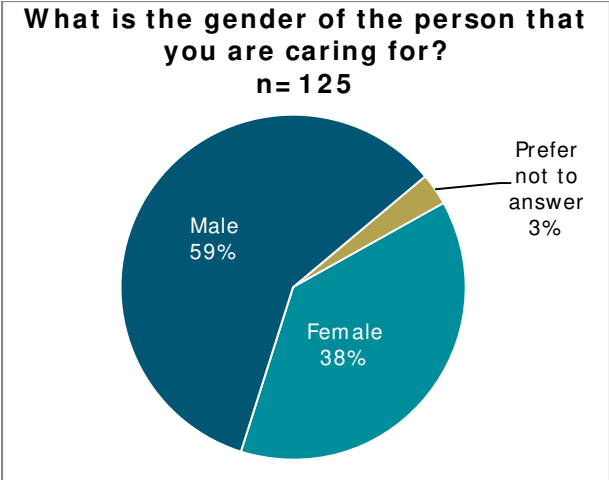
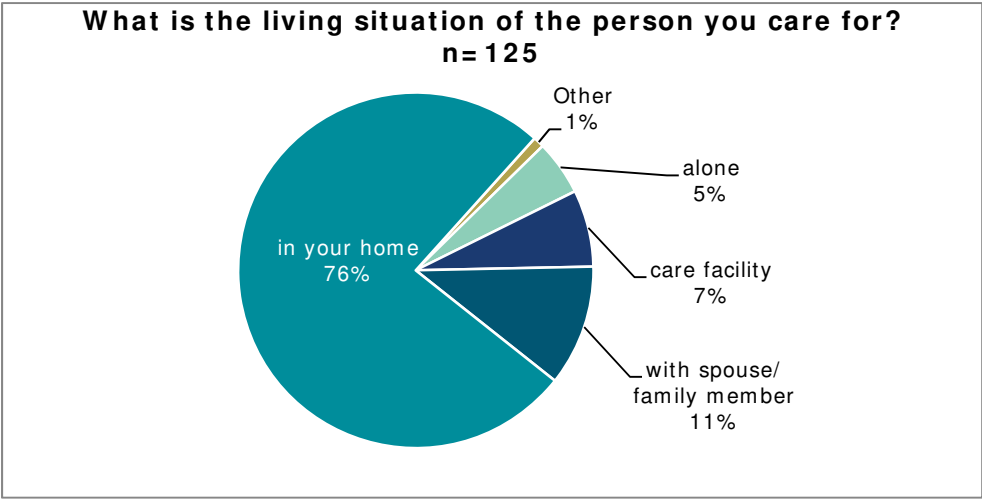
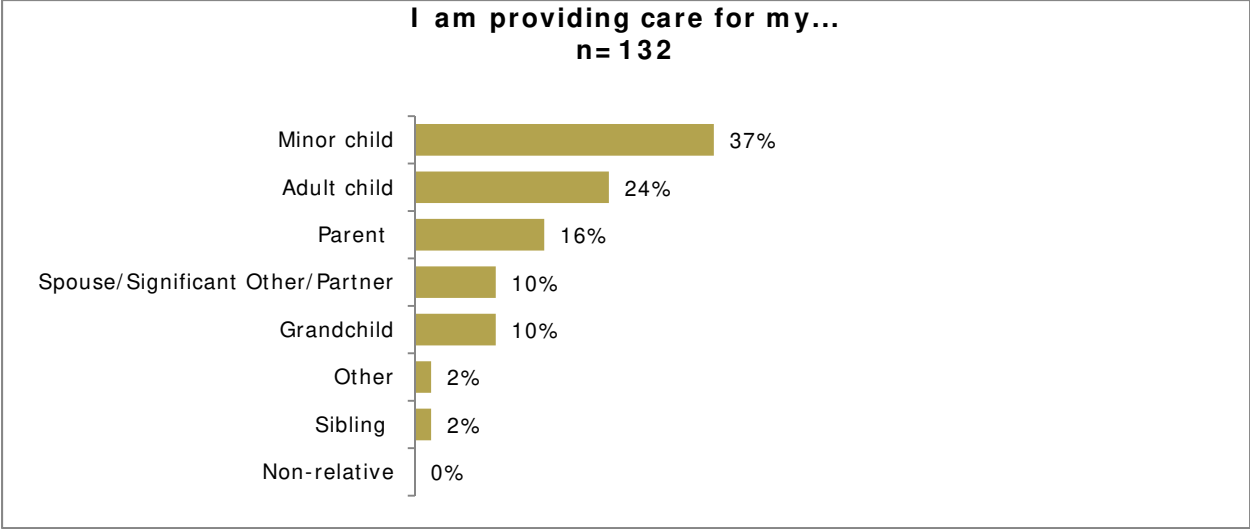
**CAREGIVER AND CARE RECIPIENT INFORMATION**

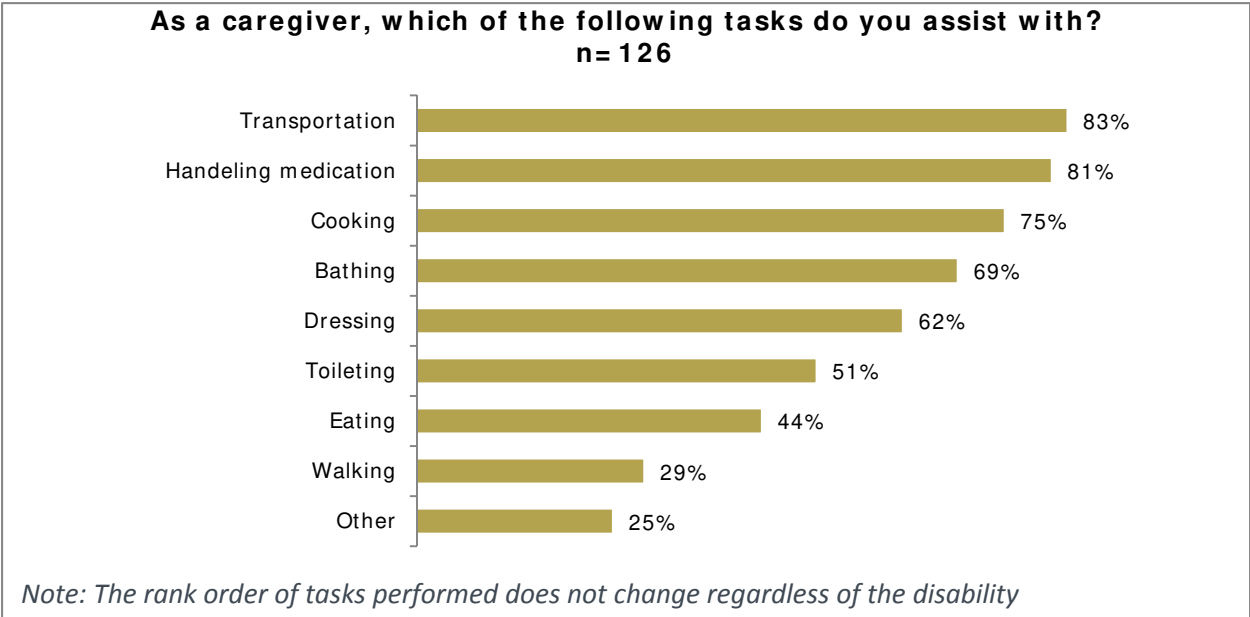
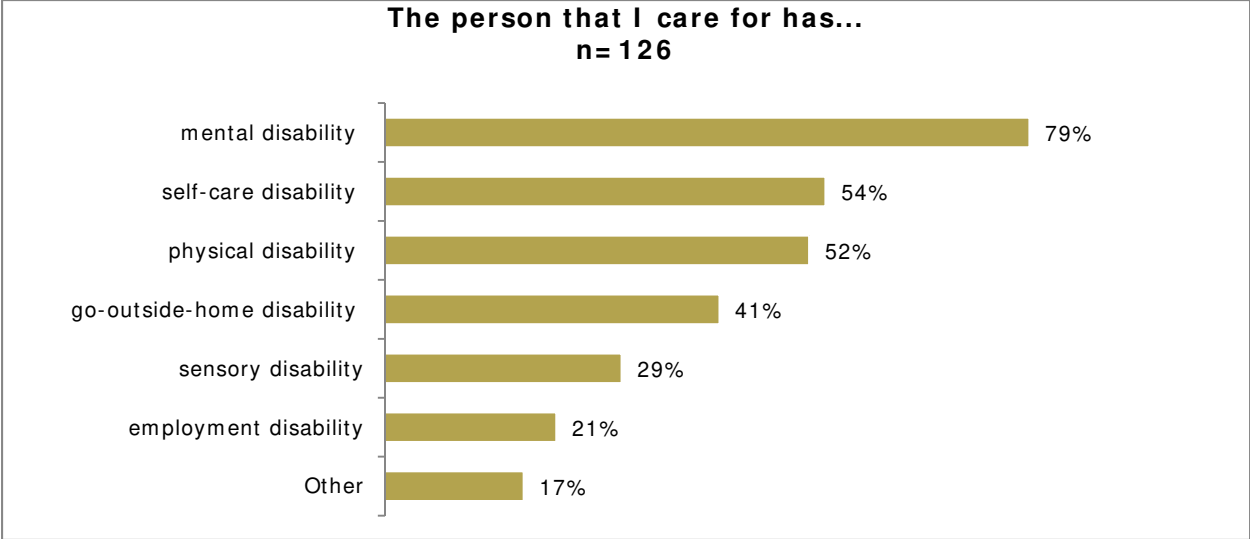
A typical respondent to this survey provides care for only one family member (61%) for more than 80 hours a week (56%), and has done so for more than 8 years (53%). The care recipient is a male (59%) adult or minor child (61%) living in the home (76%). Almost half of the respondents were caring for an individual under the age of 18 (48%).

The most common disability indicated was mental disability (79%), followed by self-care disability (54%) and physical disability (52%). Over half of the respondents indicated assisting with the following tasks: transportation (83%), handling medication (81%), cooking (75%), bathing (69%), dressing (62%), and toileting (51%)







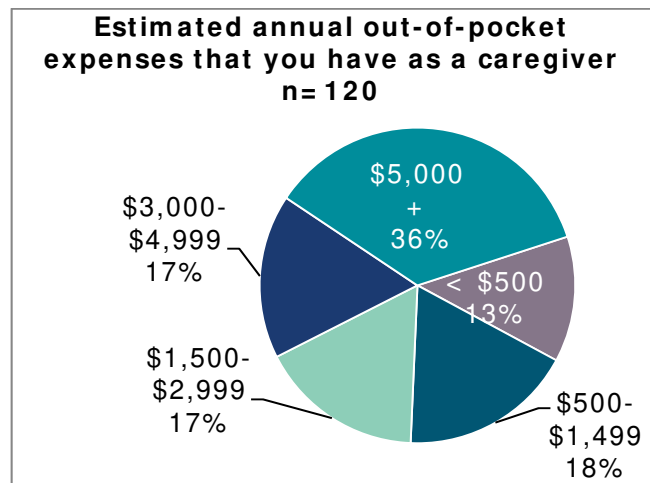
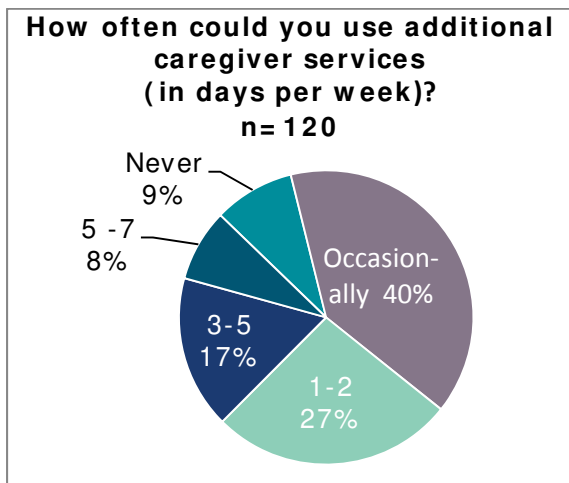
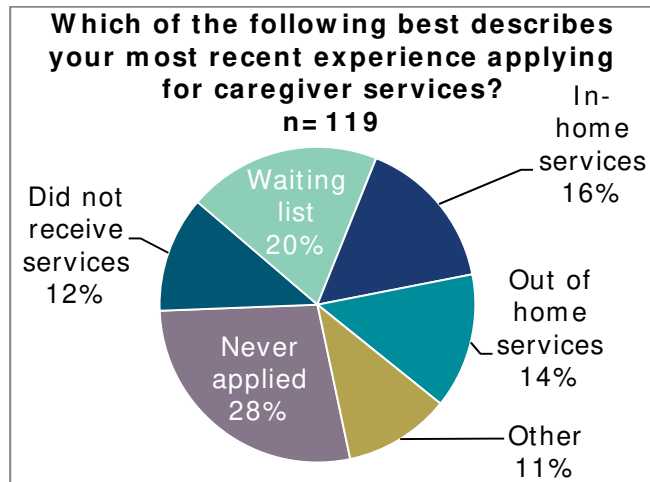
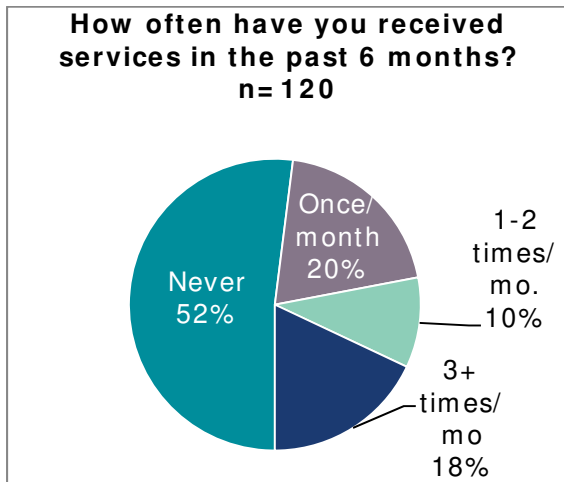


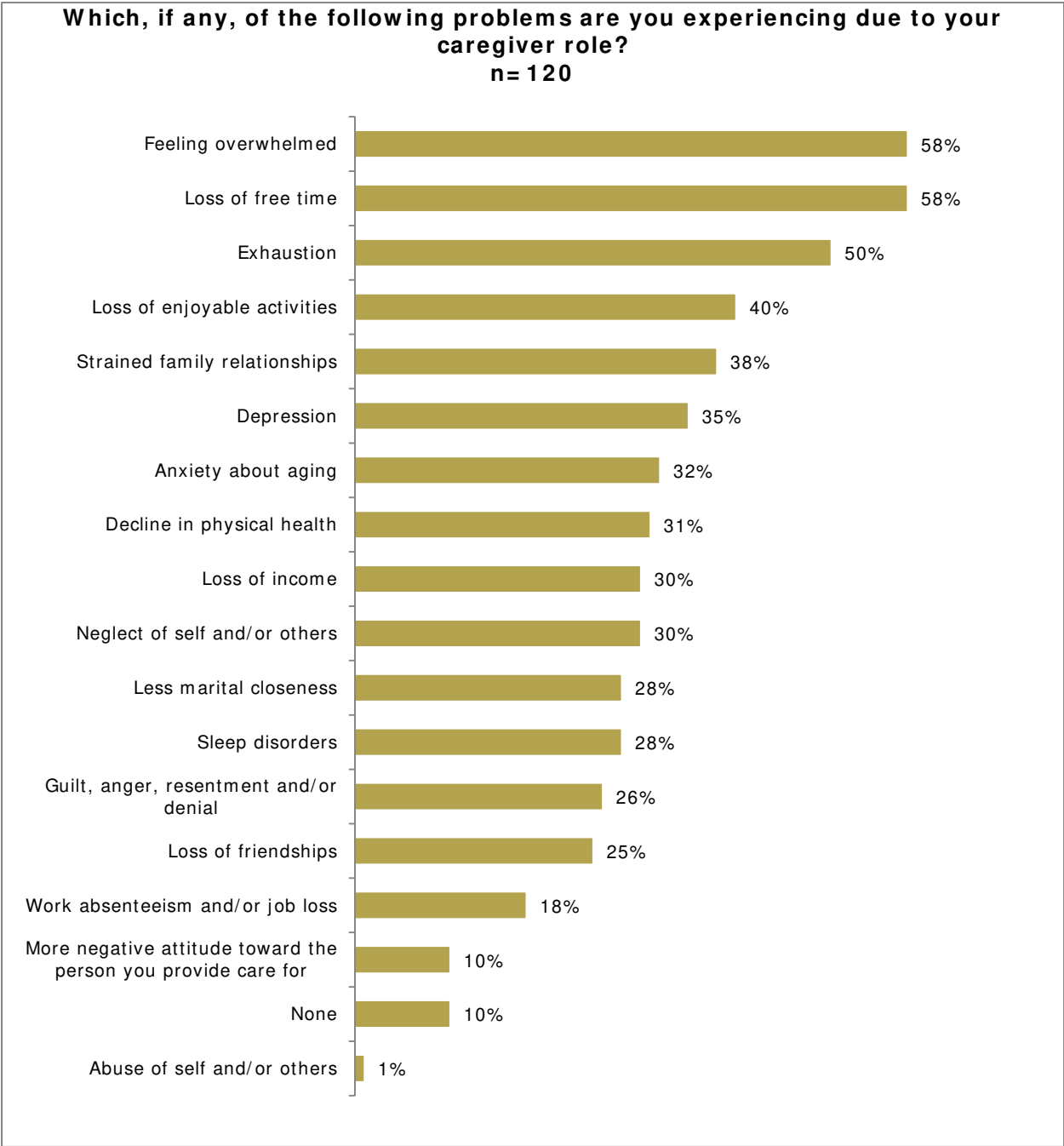
**SERVICES AND RESOURCES**

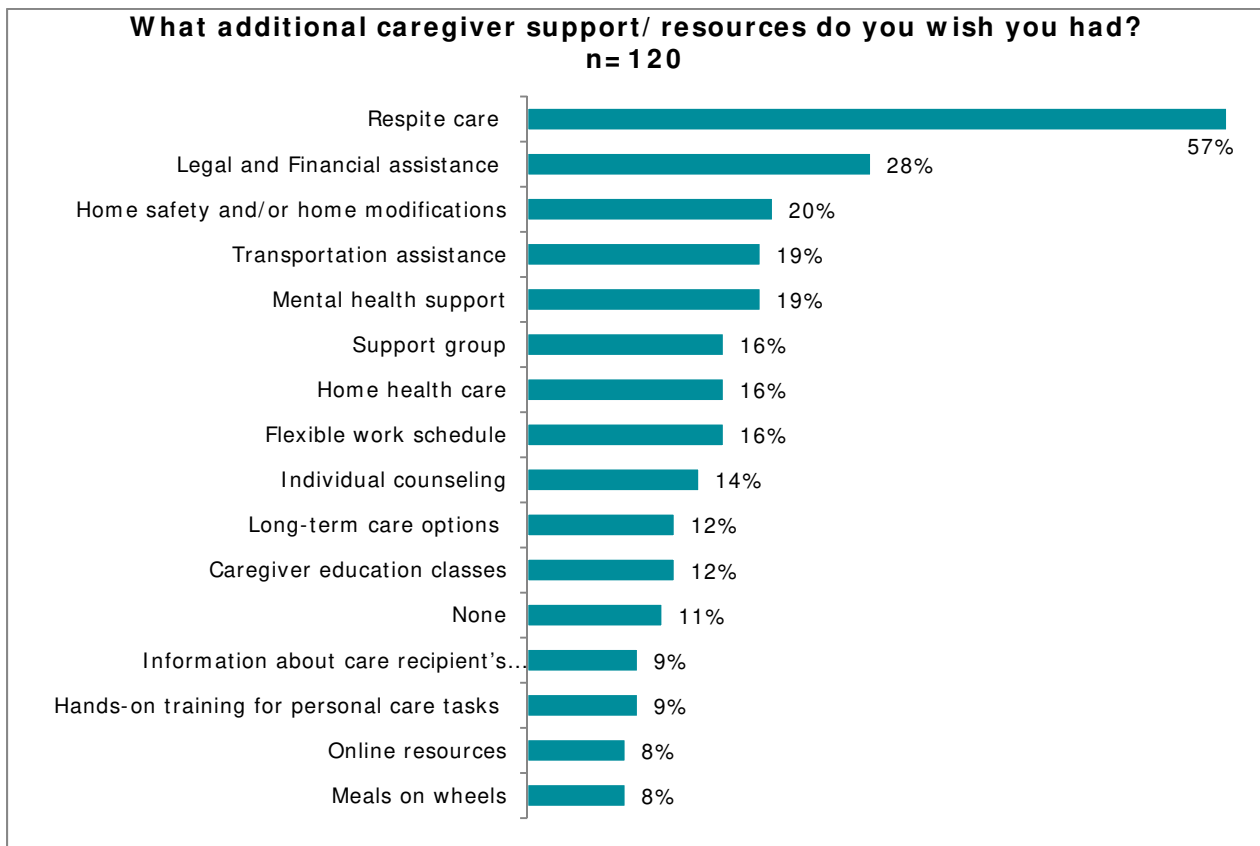
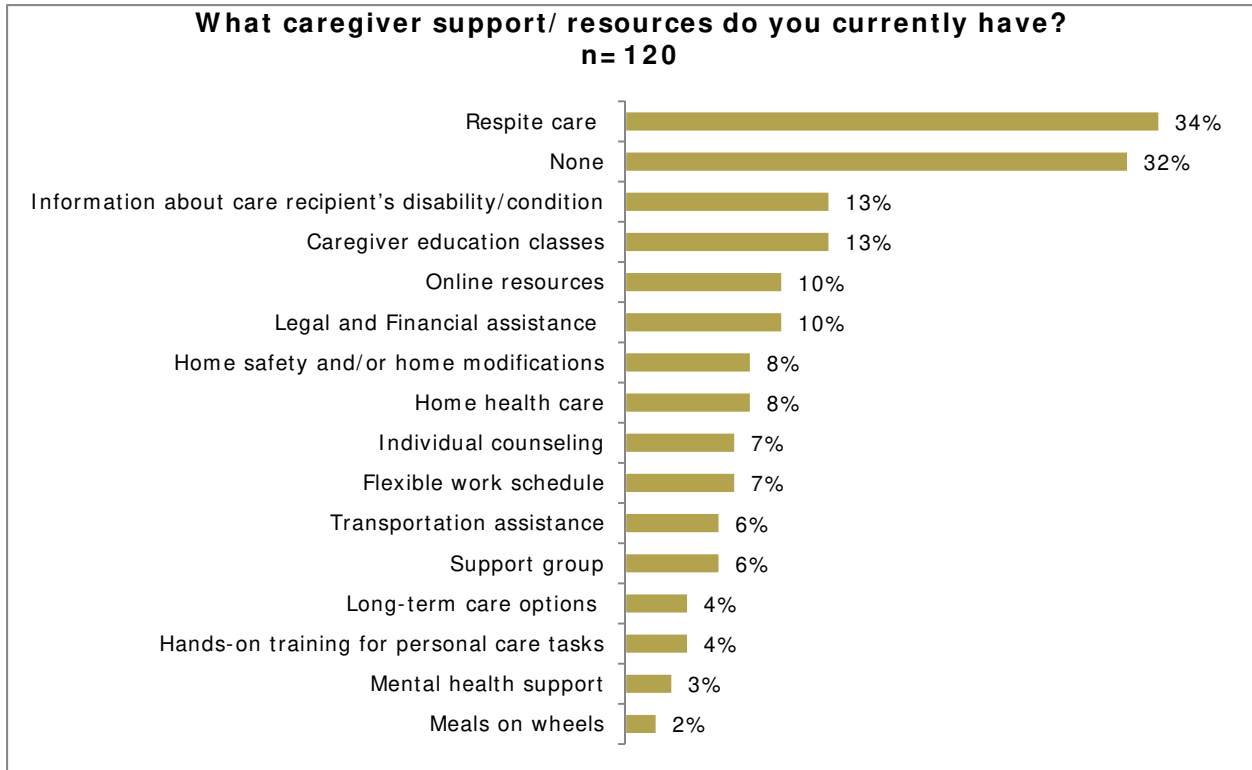
A typical respondent to this survey spends more than \$5,000 per year in out-of-pocket expenses providing care and did not receive caregiver services in the past 6 months (52%). Only 41% of respondents indicated receiving services in their most recent experience applying for services. Almost half of respondents indicated only needing additional caregiver services occasionally (40%).

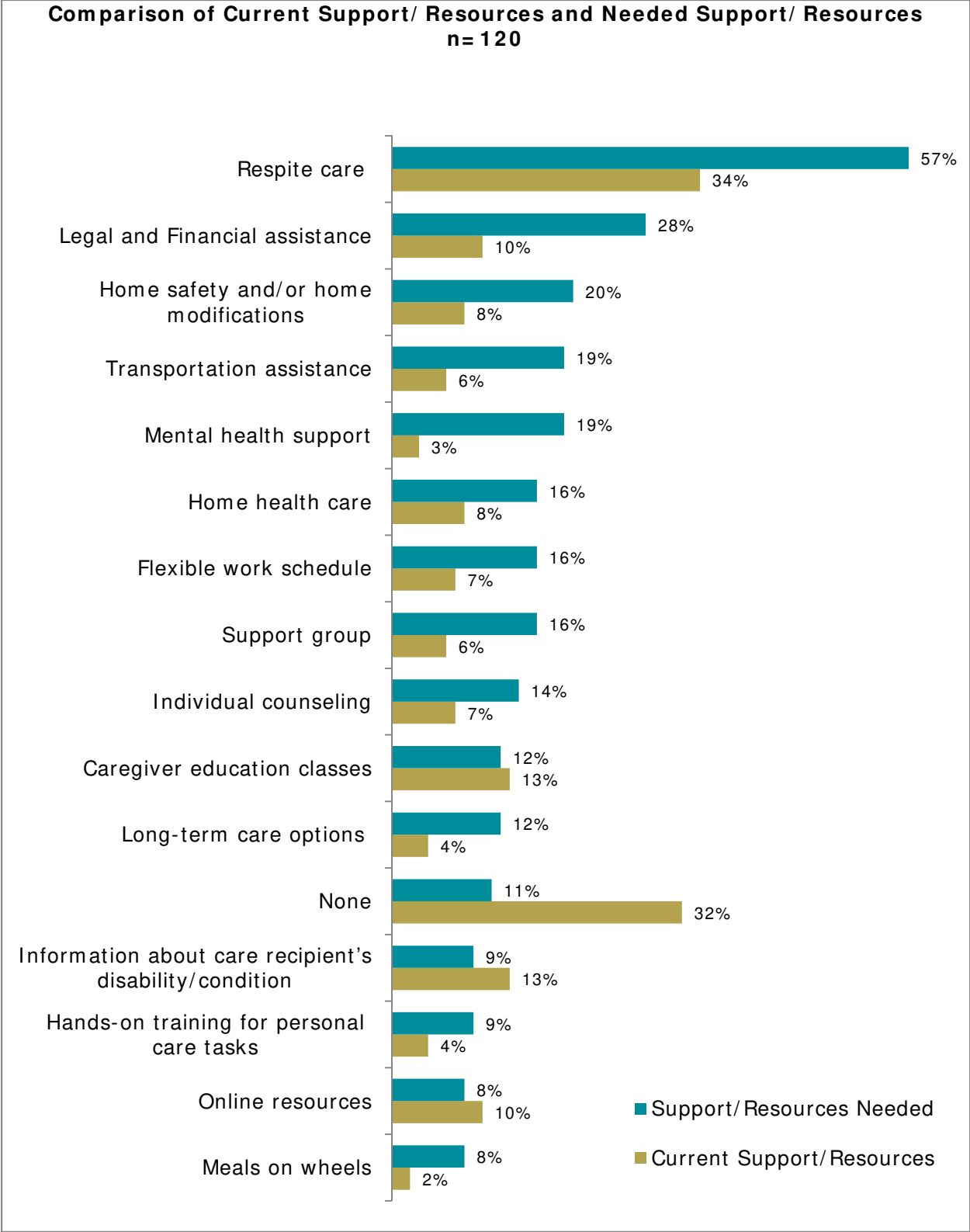
Over half of respondents indicated experiencing feeling overwhelmed (58%), loss of free time (58%) and exhaustion (50%). One-third of respondents indicated either currently receiving respite service (34%) or receiving no support/resources (32%). Over half of the respondents indicated the most desired support or resource they could receive is respite care (57%).

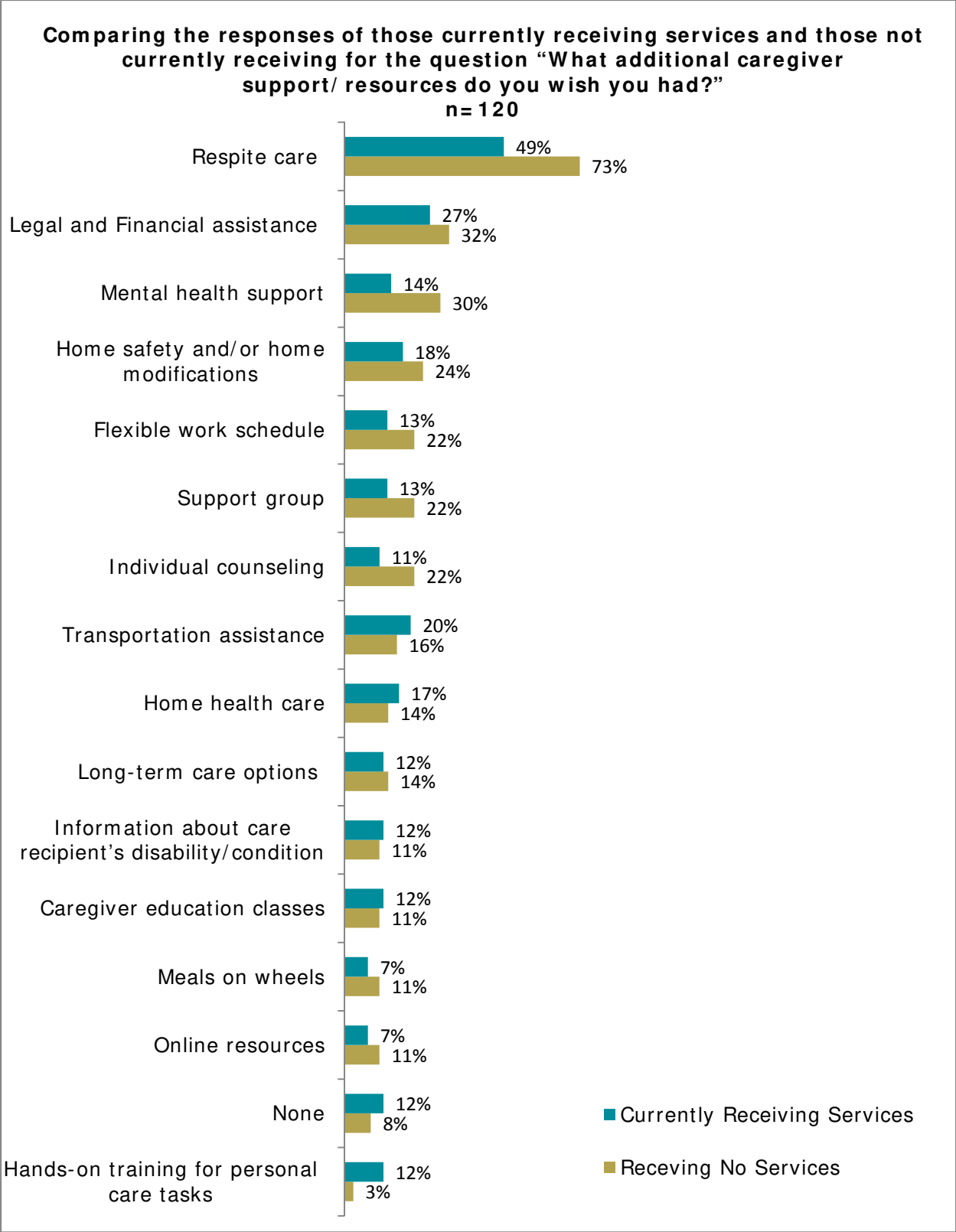
When comparing the responses of those currently receiving services with those who are not for the question, “What additional caregiver support/resources do you wish you had?”, the biggest needs were seen in respite care (57%), followed by legal and financial support (28%).













## Provider Survey Results

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*Lifespan Respite Grant*

The Provider Survey was asked of caregiver service providers and aimed to learn more about the availability and capacity of caregiver support services in Oklahoma. Providers were asked questions about their specific agency/organization, individual services offered, and what services they feel caregivers need.

Slightly less than half of respondents (44%) indicated serving all 77 counties in Oklahoma. Half of the respondents categorized themselves as non-profit (53%) and indicated that their agency/organization served over 250 caregivers per year (48%). The vast majority indicated they provided information and referral services (94%).

Caregivers will generally qualify for services from the provider via methods other than interviews on the phone or in-person, or via an online application. These methods include, but are not limited to the following: paper applications, assessments, intake forms, referrals, or no eligibility requirements. The most common form of funding for caregiver services provided by the respondent organization is grants (43%).

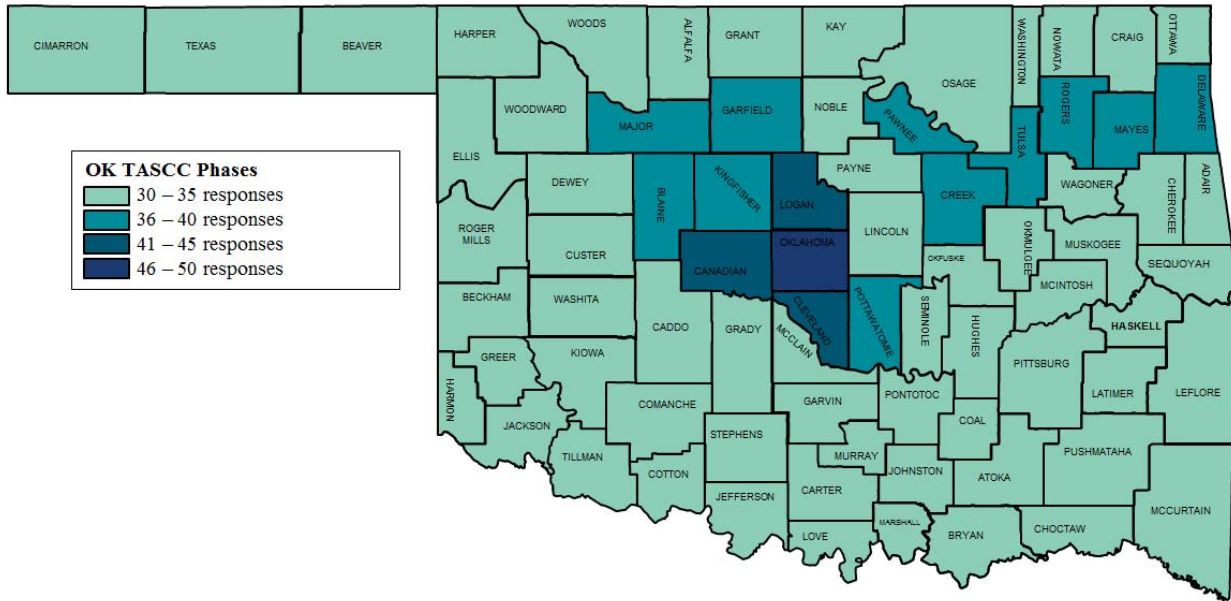
Over half of respondents indicated the reason for seeking services was because of a change in family home situation (64%), a stressful family relationship (60%), or a health problem of the care receiver (55%). Respondents indicated caregivers typically hear about the organization's services via other (91%), word of mouth (85%), through the organization itself (72%), or via public presentations (70%). Other responses included, but were not limited to the following: health care providers, community events or organizations, or social media.

When asked what support/resources caregivers need the most, almost all respondents indicated respite care (93%). Caregiver education classes (43%) and Legal and Financial Assistance (42%) were the next most common responses.

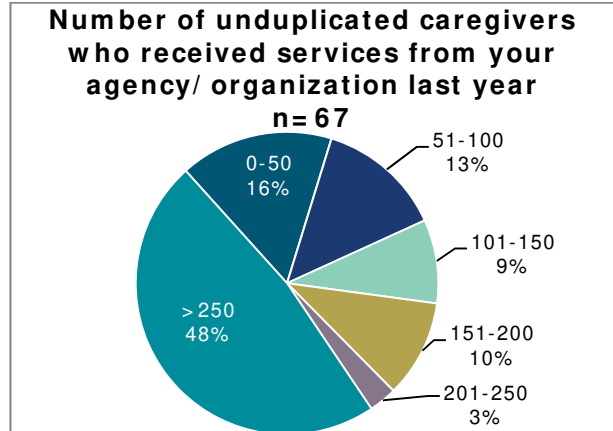
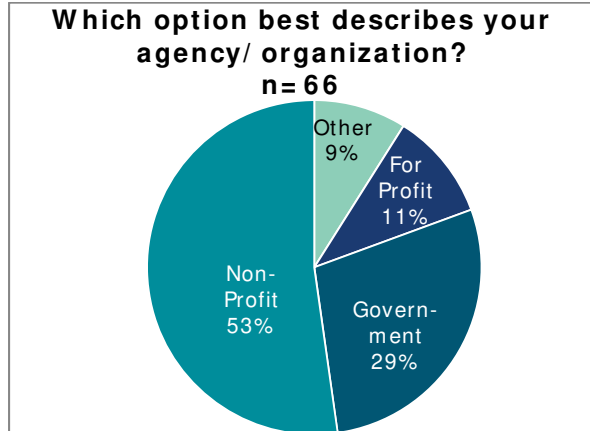


**RESPONDENT CHARACTERISTICS**

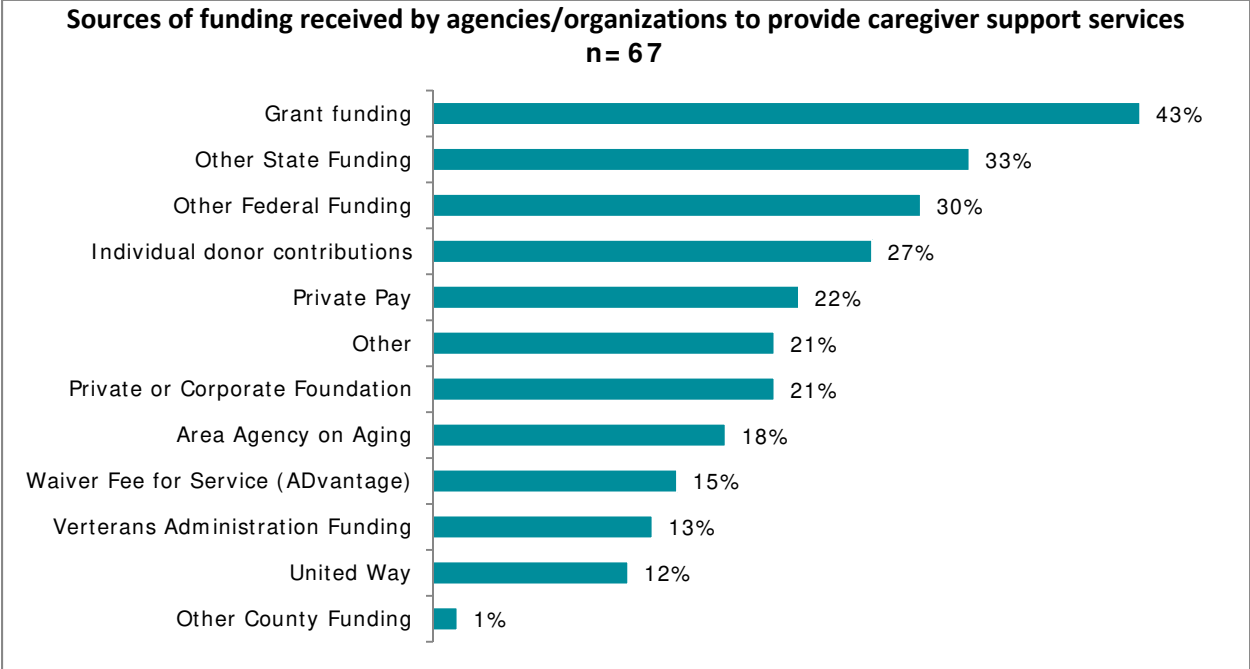
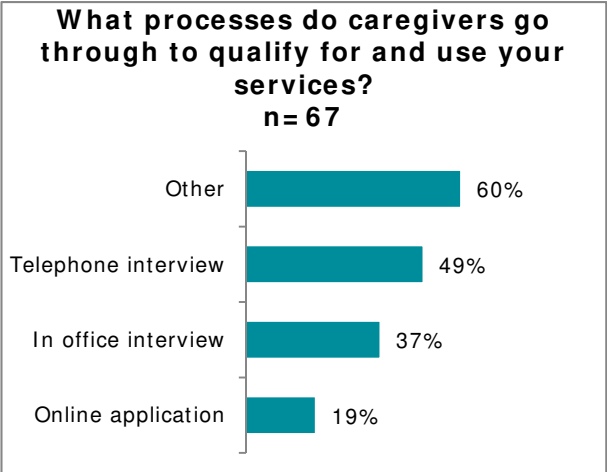
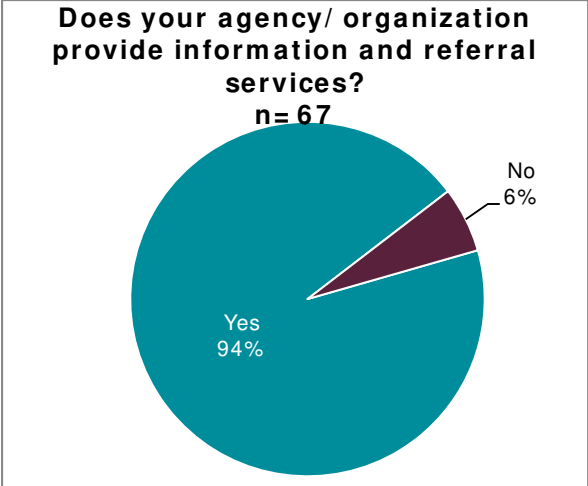
Please indicate the Oklahoman counties that your agency/ organization serves



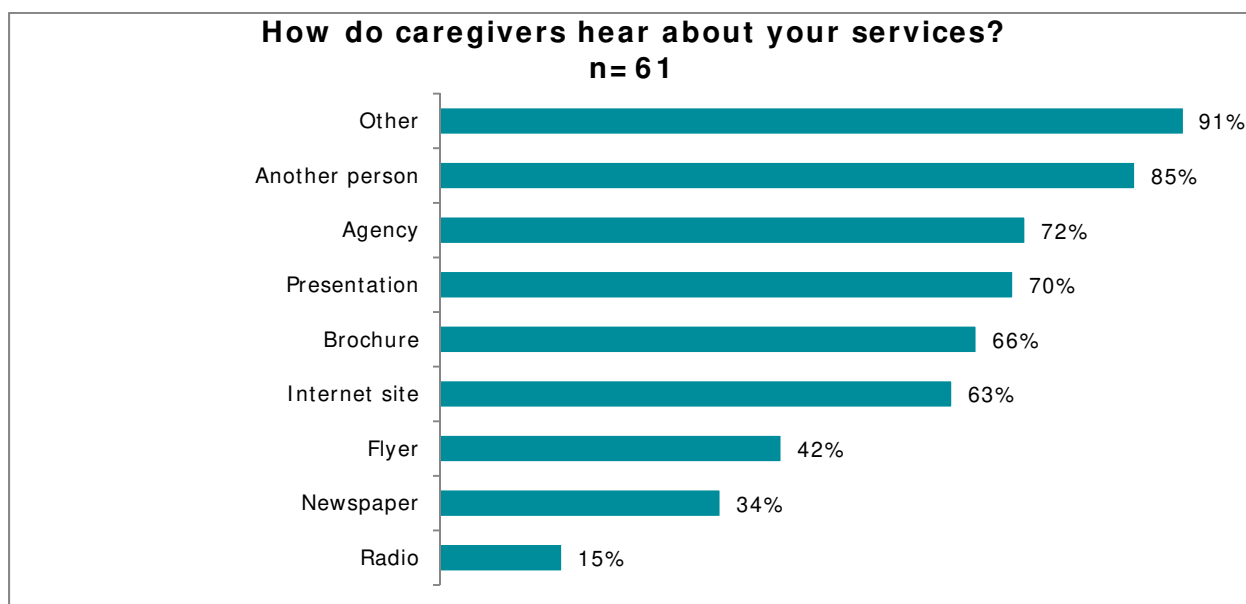
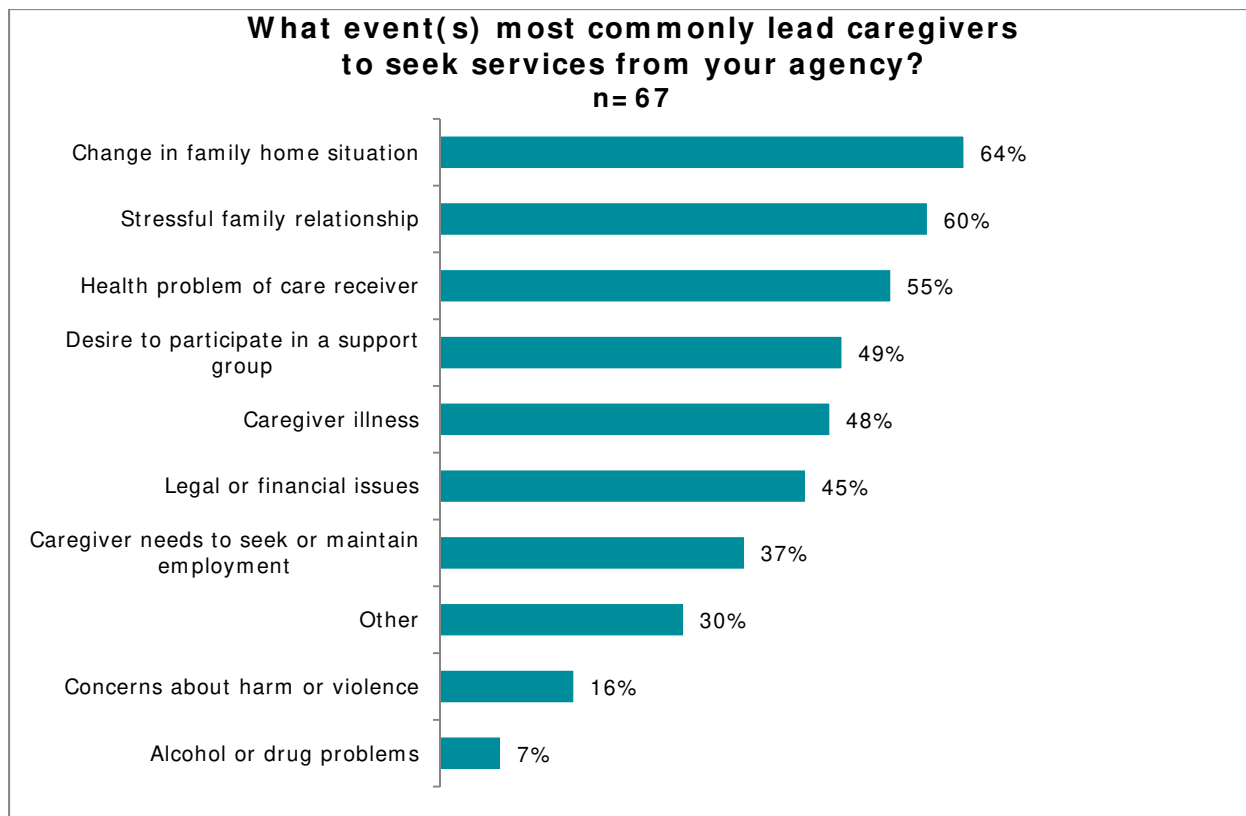
\* It should be noted that the map reflects the number of individual respondents who indicated each county, which does not necessarily reflect the number of agencies/organizations providing services in each county.



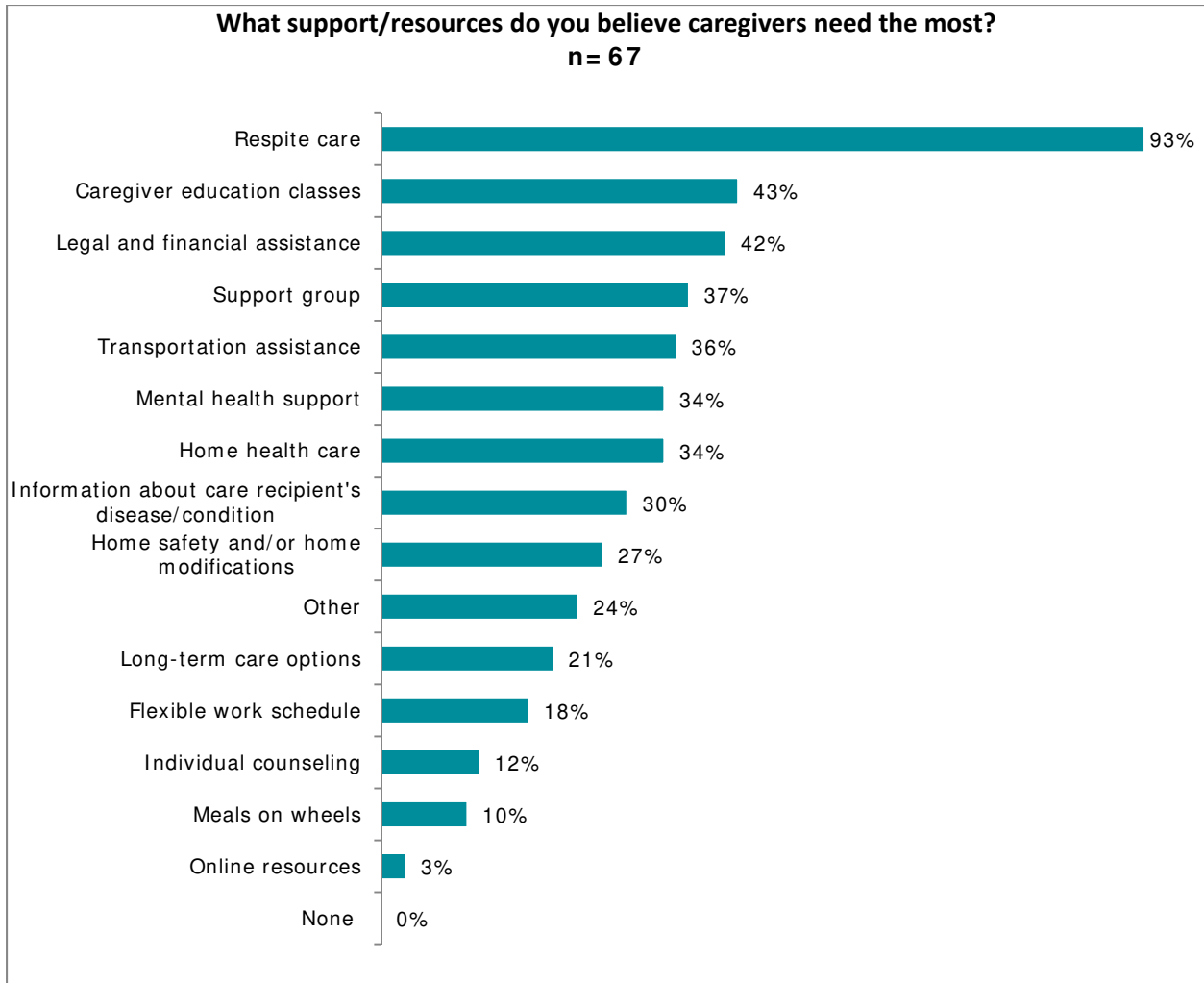
**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers



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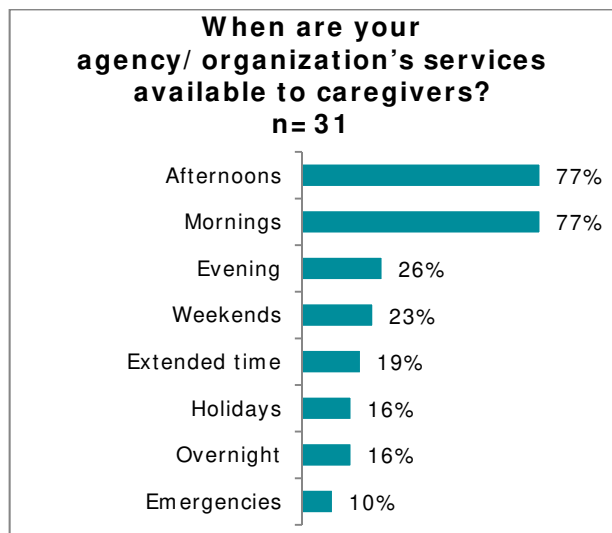
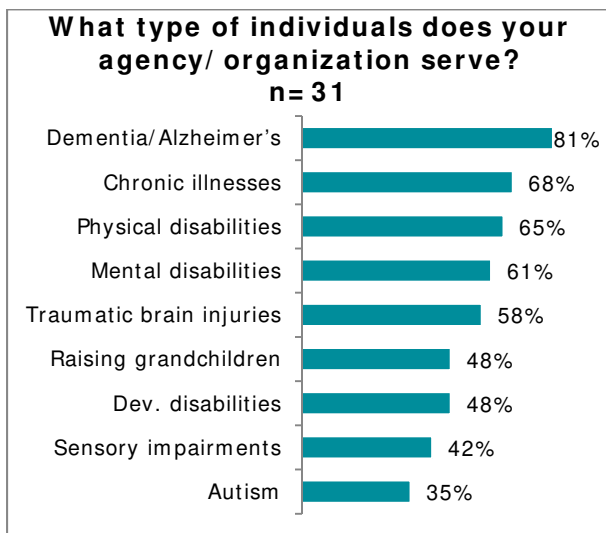
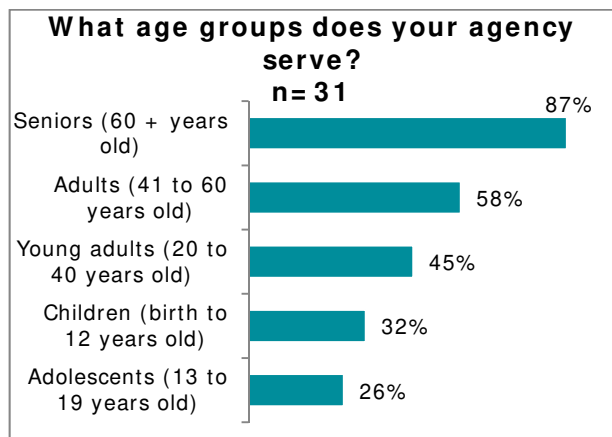
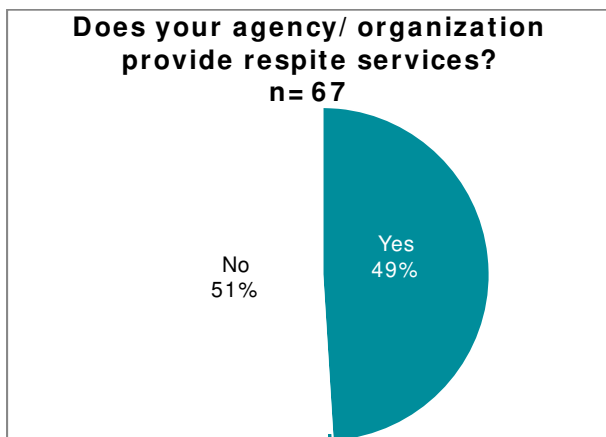


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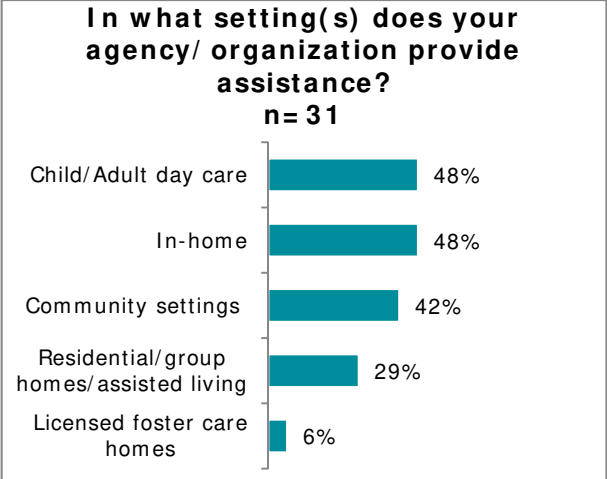
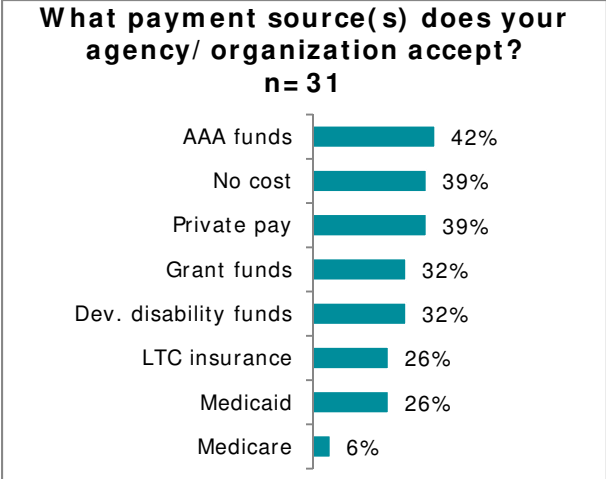
**RESPITE SERVICES**

All respondents were asked if their agency/organization provides Respite Services. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Half of the respondents indicated their agency/organization provides respite services (49%). Of those organizations that do provide respite services, their typical client is 60 years of age or older (87%) and has dementia or Alzheimer’s disease (81%), chronic illnesses (68%), physical (65%), mental or emotional disabilities (61%), and/or traumatic brain injuries (58%). Respondents indicated their agency/organization provides services mainly in the morning (77%) or afternoon (77%). The agency/organization also accepts payments from a variety of sources with the chief source coming from the local Area Agency on Aging (42%). Likewise, the agency/organization provides services in a variety of settings but the most common settings are in Child or Adult day care (48%), or in the client’s home (48%).



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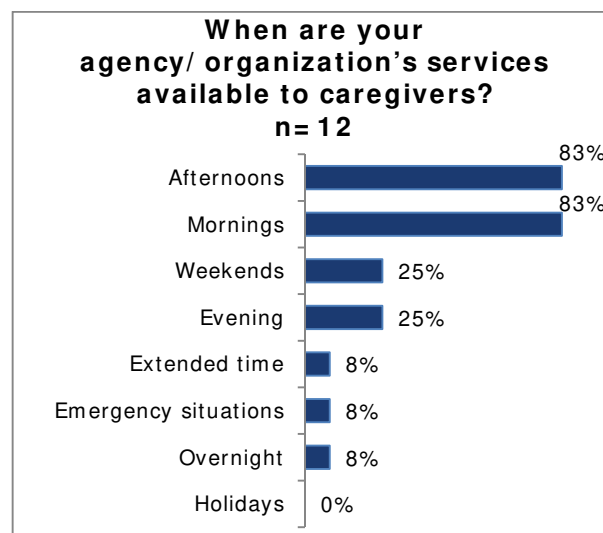
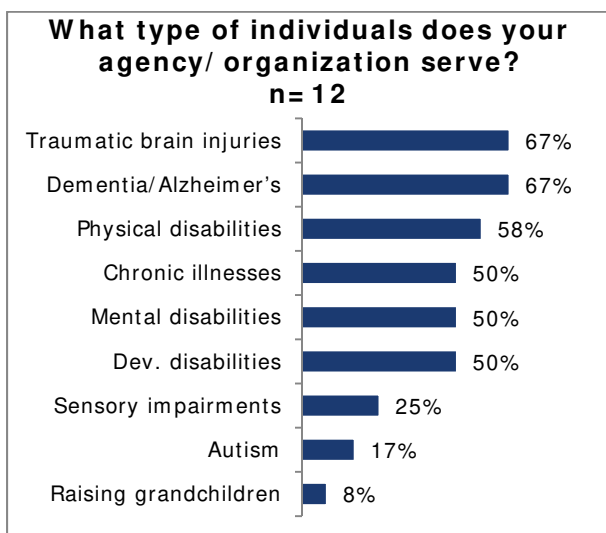
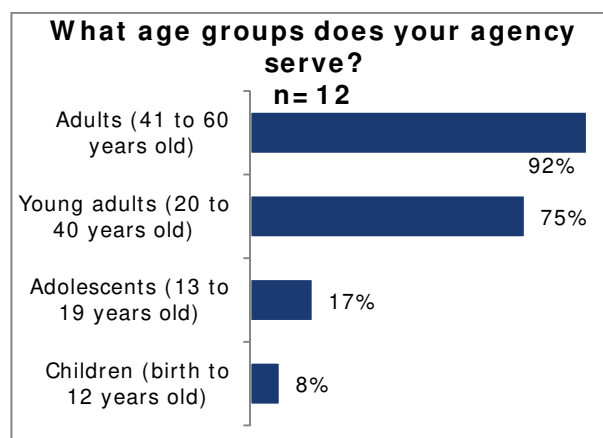
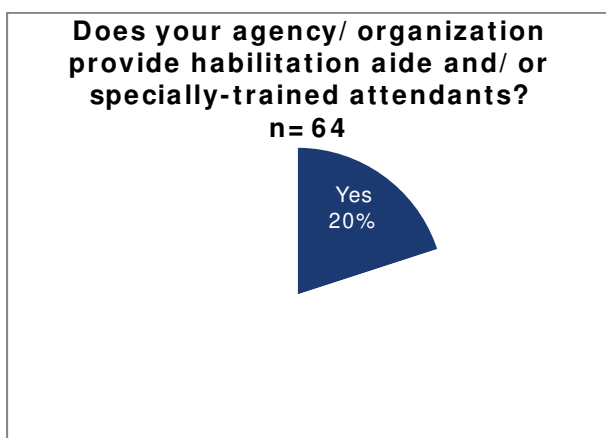


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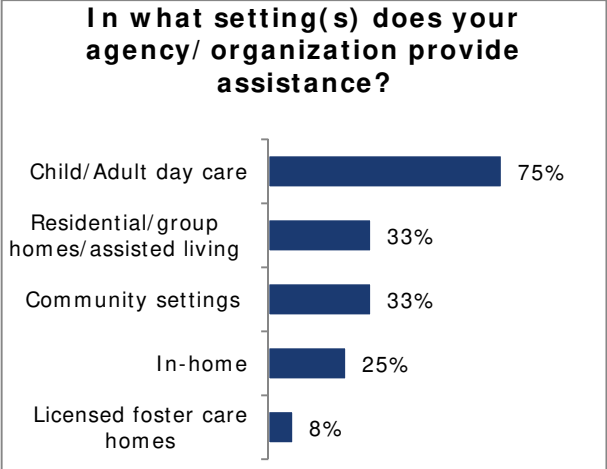
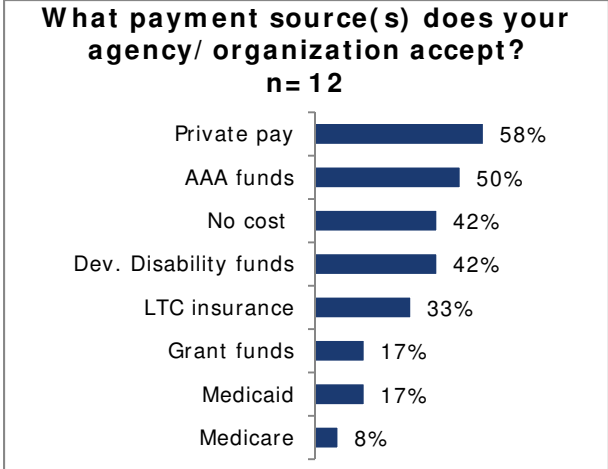
**HABILITATION AIDE AND/OR SPECIALLY TRAINED ATTENDANTS**

All respondents were asked if their agency/organization provides Habilitation Aide and/or Specially-Trained Attendants. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Less than one-fourth of respondents indicated their agency/organization provides habilitation aide or specially-trained attendants (20%). Of the organizations that do provide these services, the typical clients are between the ages of 20 to 40 (75%) and 41 to 60 (92%) and have a traumatic brain injury (67%), dementia or Alzheimer’s disease (67%), and/or a physical disability (58%). Services to clients are generally available in the morning (83%) or afternoon (83%) with most clients paying for services privately (58%) or through the local Area Agency on Aging (50%). Additionally, services are provided primarily in Child or Adult day care settings (75%).



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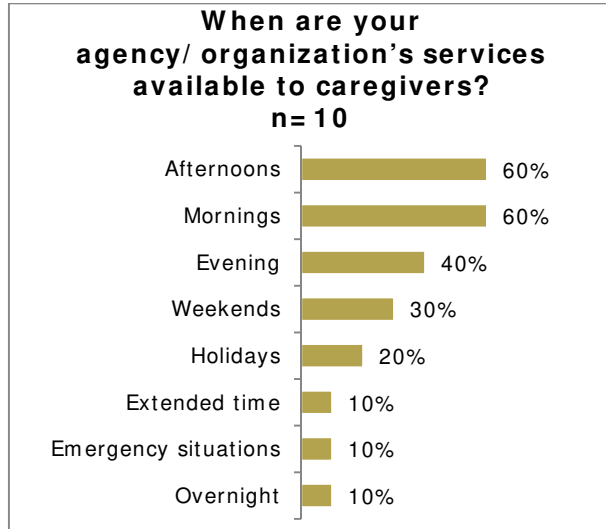
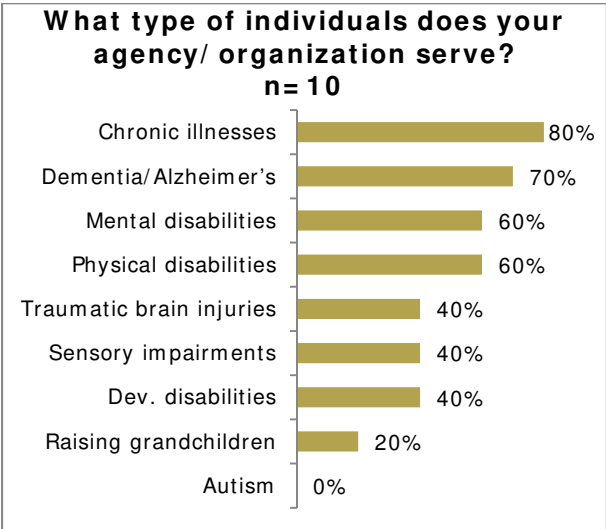
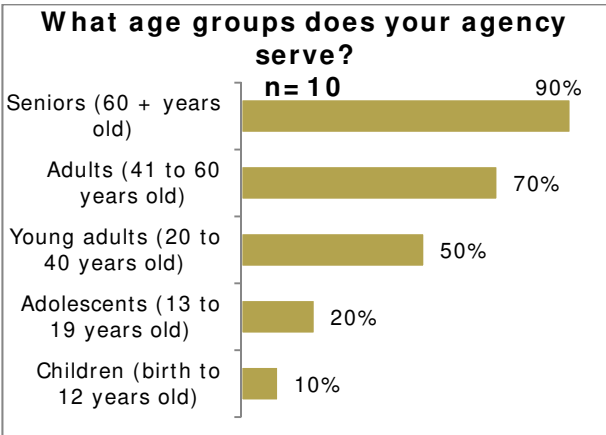
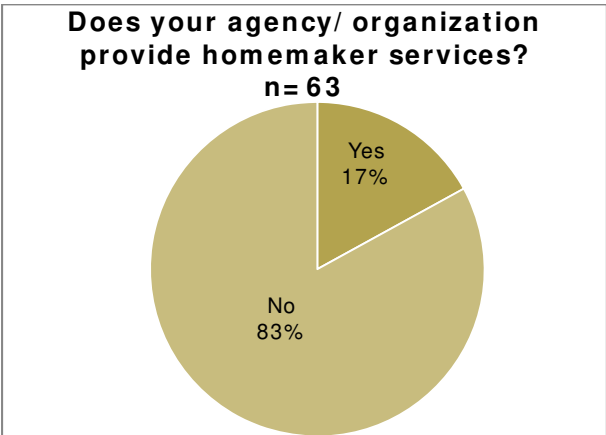
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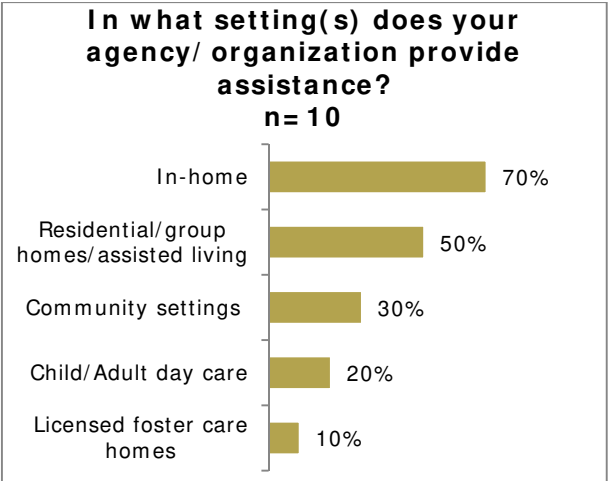
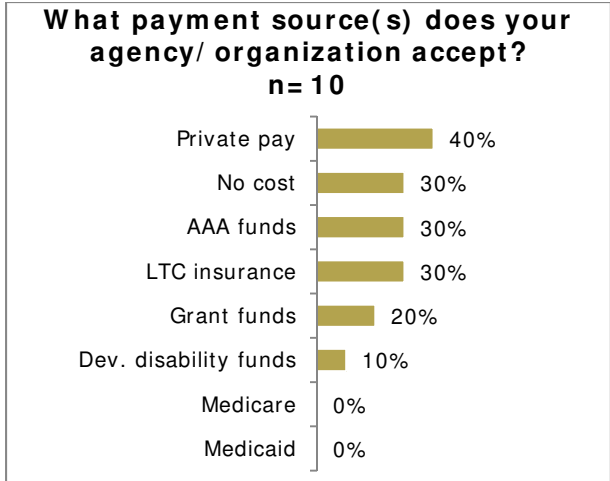
**HOMEMAKER SERVICES**

All respondents were asked if their agency/organization provides Homemaker Services. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Less than one-fourth of respondents indicated their agency/organization provides homemaker services. Of the organizations that do provide these services, their typical clients are 41 year of age or older, and have chronic illnesses (80%), dementia or Alzheimer’s disease (70%), and/or have mental, emotional or physical disabilities (60%). The organization provides services primarily in the morning (60%) or afternoon (60%). Clients pay from a variety of sources with the most common being private pay (40%). Additionally, the most common setting for providing these services is in the client’s home (70%).



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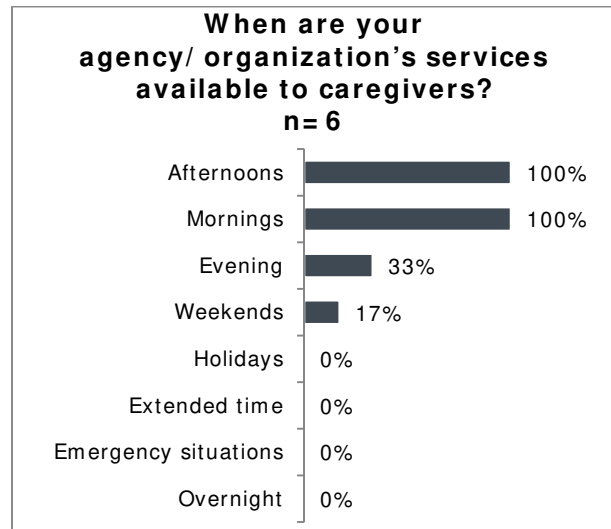
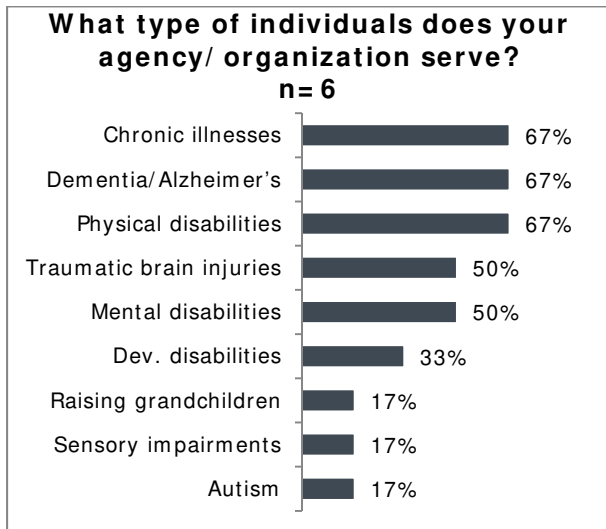
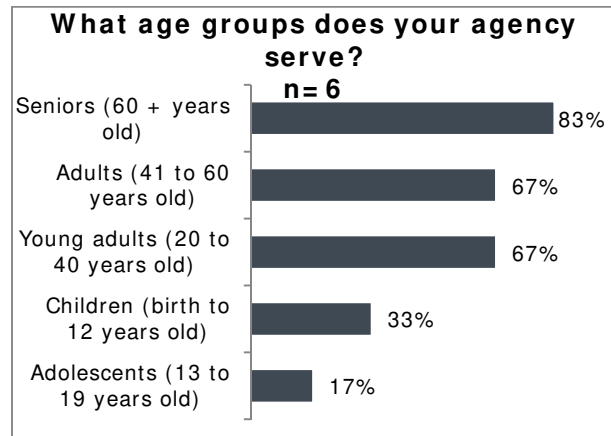
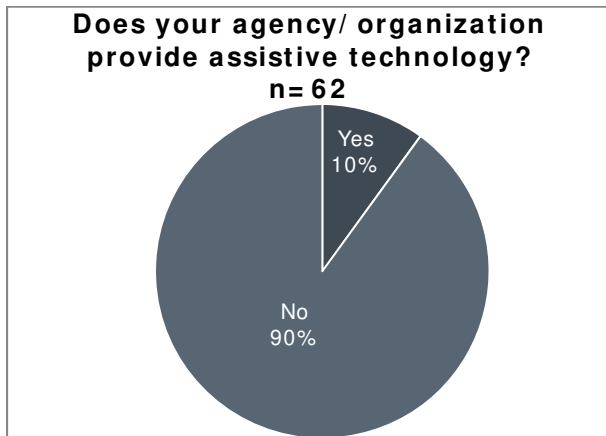


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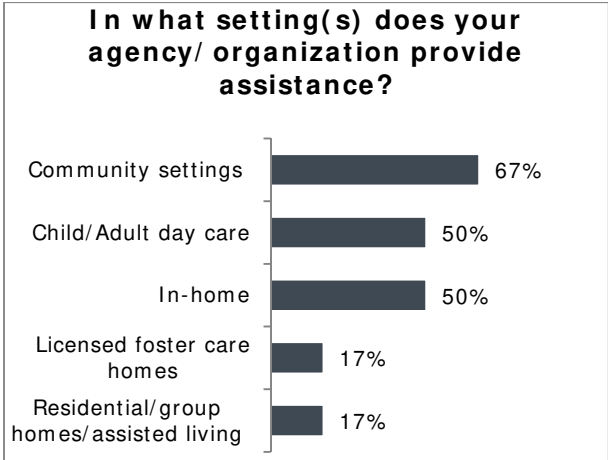
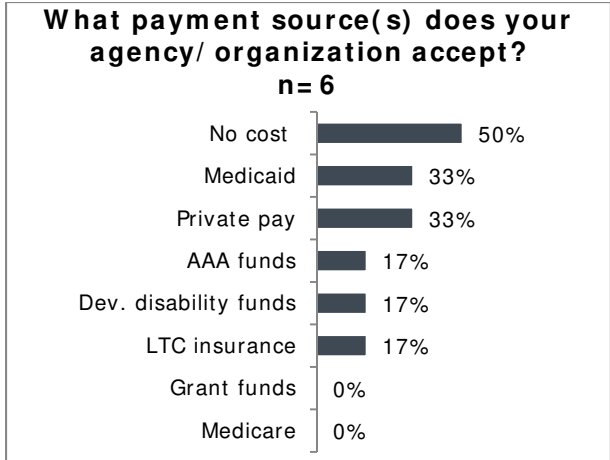
**ASSISTIVE TECHNOLOGY SERVICES**

All respondents were asked if their agency/organization provides Assistive Technology Services. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Only 10% of respondents indicated their agency/organization provides assistive technology. Of those that do provide these services, their typical client is 20 years of age or older and has chronic illnesses (67%), dementia or Alzheimer’s disease (67%), and/or physical disabilities (67%). The typical organization provides these services in the morning (100%) or afternoon (100%) and half are free or no cost to those who are eligible (50%). Additionally, the most common setting for providing these services is community settings (67%).



**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers

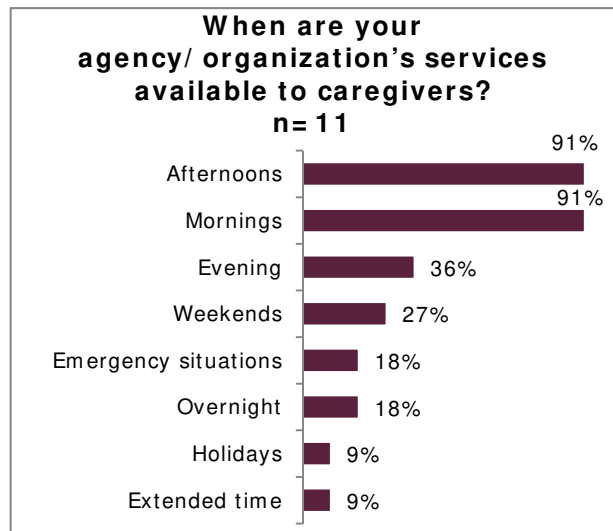
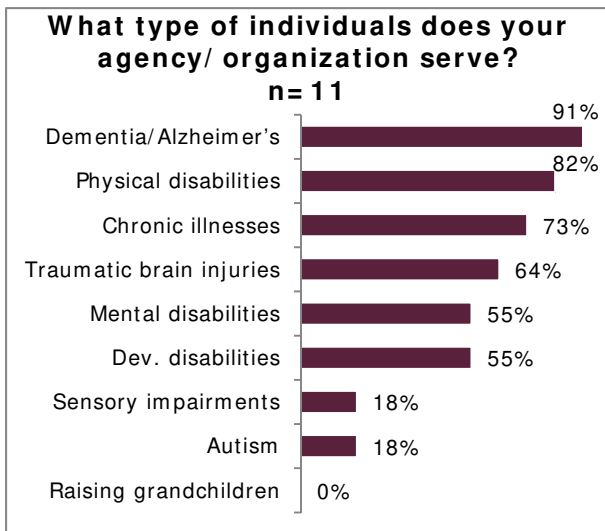
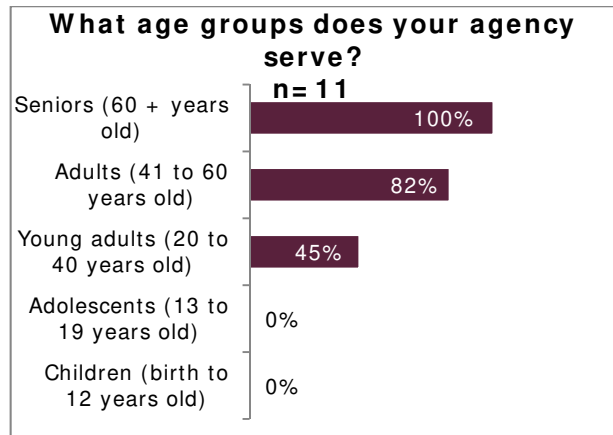
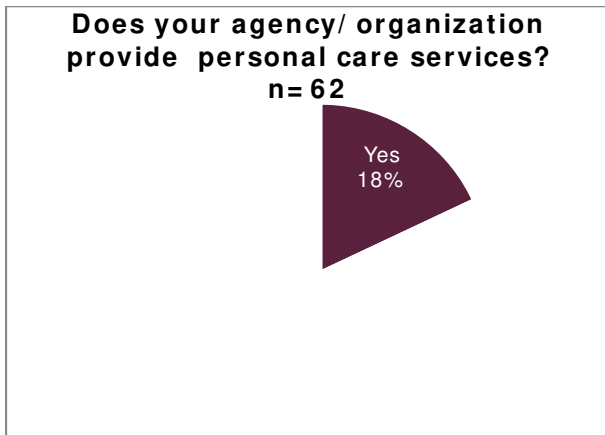


**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers

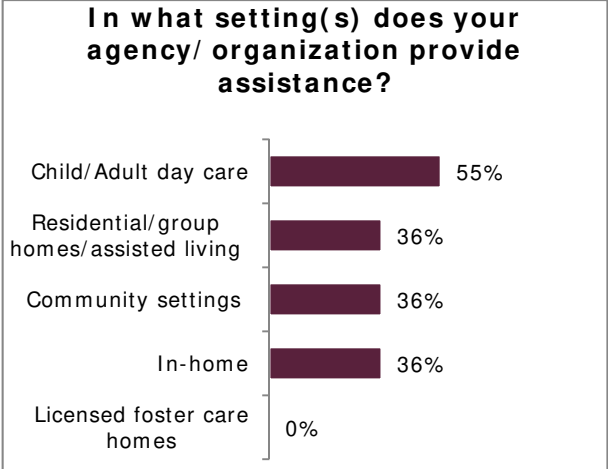
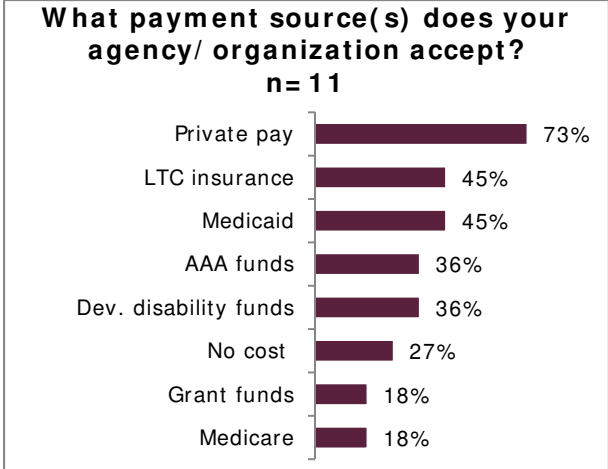
**PERSONAL CARE SERVICES**

All respondents were asked if their agency/organization provides Personal Care Services. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Less than one-fourth of respondents indicated their agency/organization provides personal care services. Of the organizations that do provide these services, their typical client is 41 years of age or older, and has dementia or Alzheimer’s disease (91%), physical disabilities (82%), chronic illnesses (73%), and/or traumatic brain injury (64%). The typical organization provides these services in the morning (91%) or afternoon (91%), and clients pay for these services with private pay (73%). Additionally, the most common setting for providing these services is Child or Adult day care settings (55%).



**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers

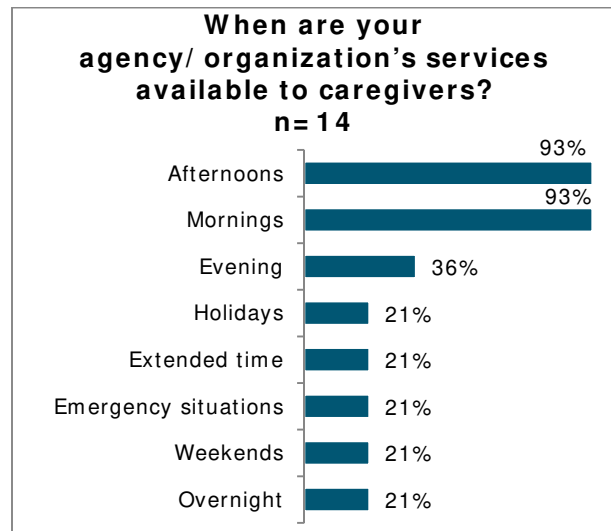
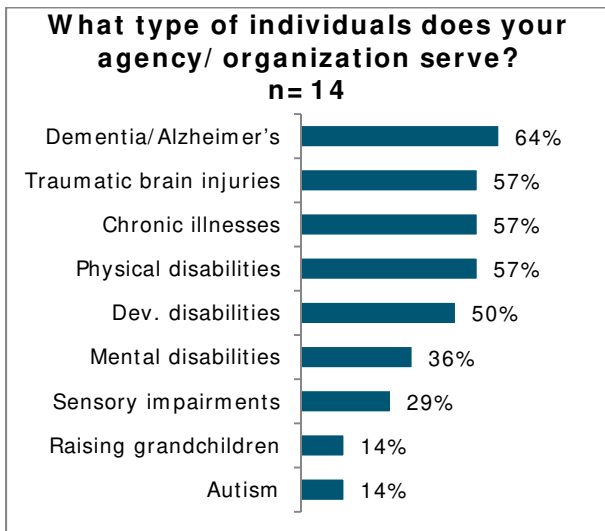
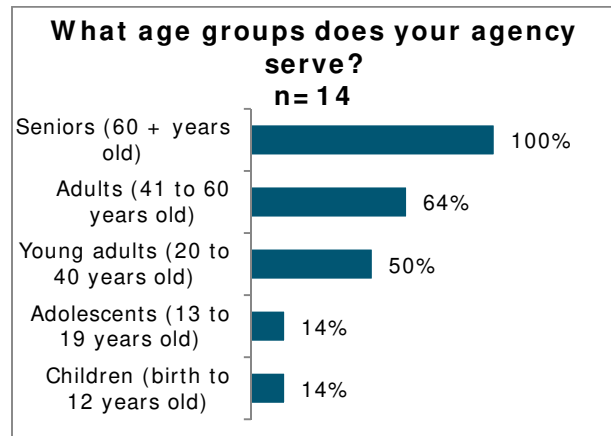
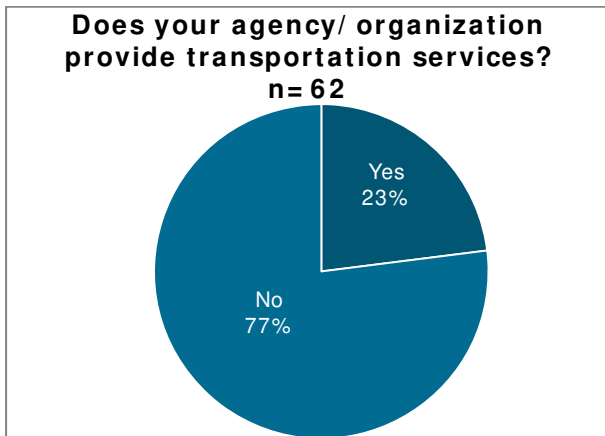


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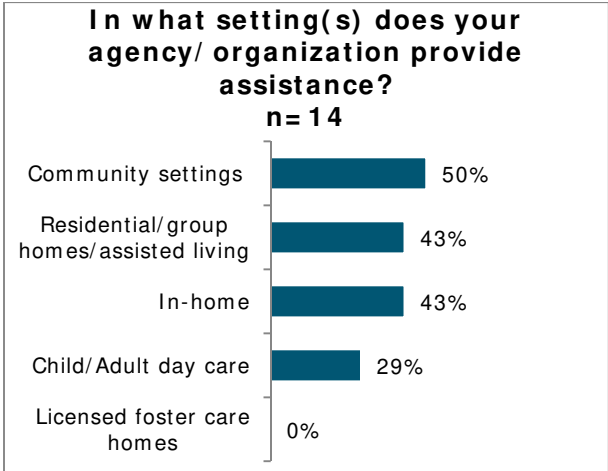
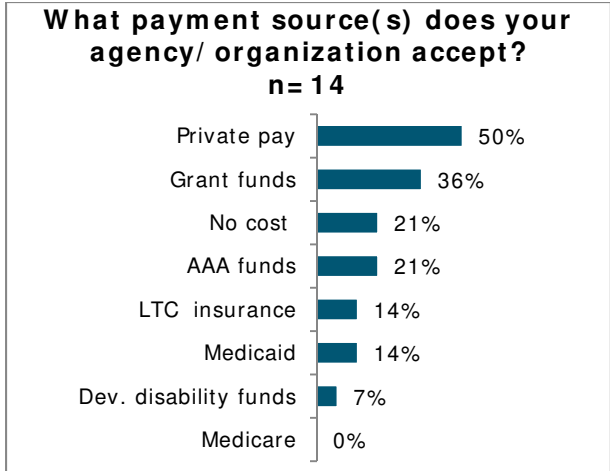
**TRANSPORTATION SERVICES**

All respondents were asked if their agency/organization provides Transportation Services. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Less than one-fourth of respondents indicated their agency/organization provides transportation services. Of the organizations that do provide these services, the typical client is 41 years of age or older and has dementia or Alzheimer’s disease (64%), traumatic brain injury (57%), chronic illnesses (57%), and/or a physical disability (57%). Services are typically provided in the morning (93%) or afternoon (93%) with clients paying through a variety of sources but most commonly through private pay (50%). Additionally, services are delivered in a variety of settings but most commonly in a community setting (50%).



**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers



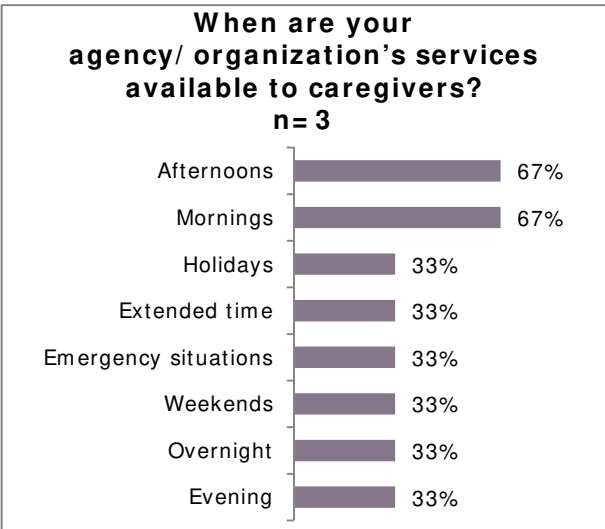
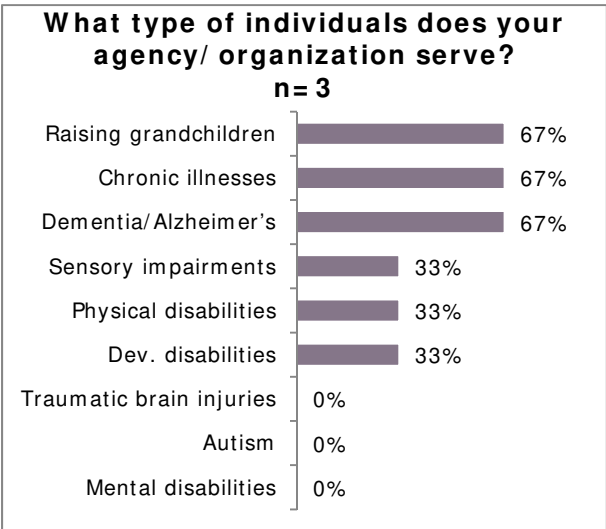
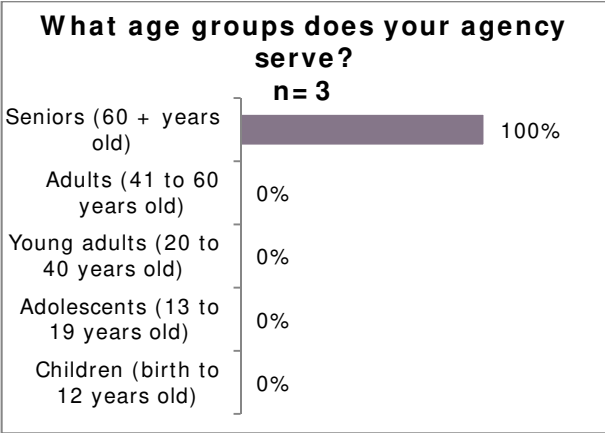
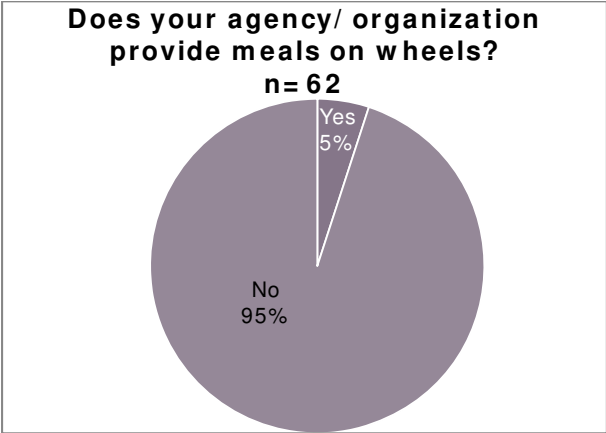
**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers



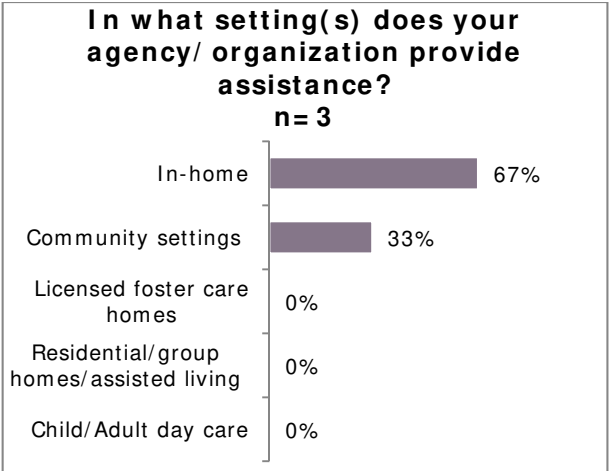
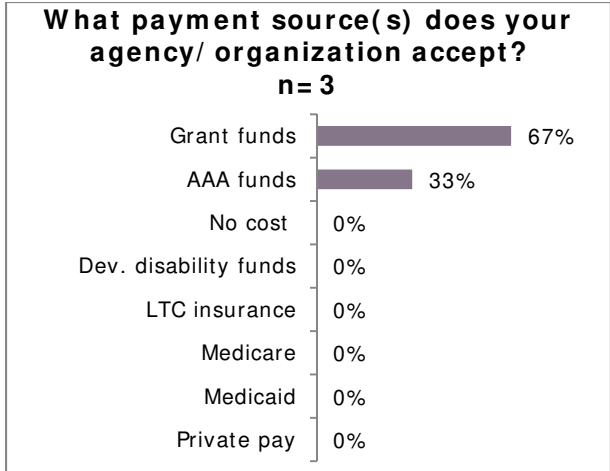
**MEALS ON WHEELS SERVICES**

All respondents were asked if their agency/organization provides Meals on Wheels Services. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Only 5% of respondents indicated their agency/organization provides meals on wheels. Of the organizations that do provide these services, only 60 years of age or older clients are served. The typical clients are grandparents raising grandchildren (67%), have chronic illnesses (67%) and/or dementia or Alzheimer’s disease (67%). The typical organization provides these services in the morning (67%) or afternoon (67%) and services are primarily paid through grant funds (67%). Additionally, the most common setting for providing these services is in the client’s home (67%).



**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers

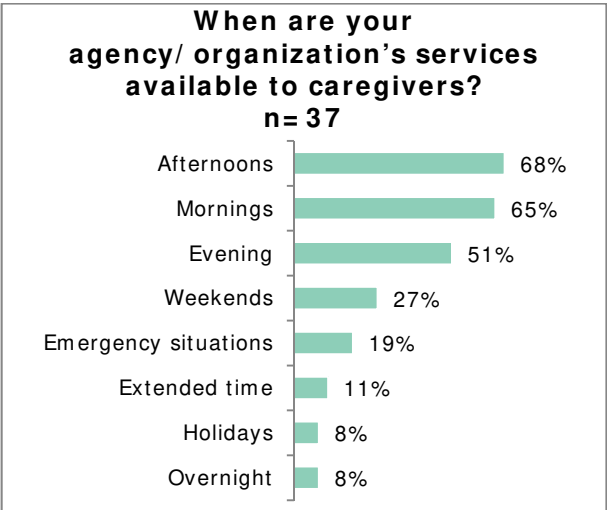
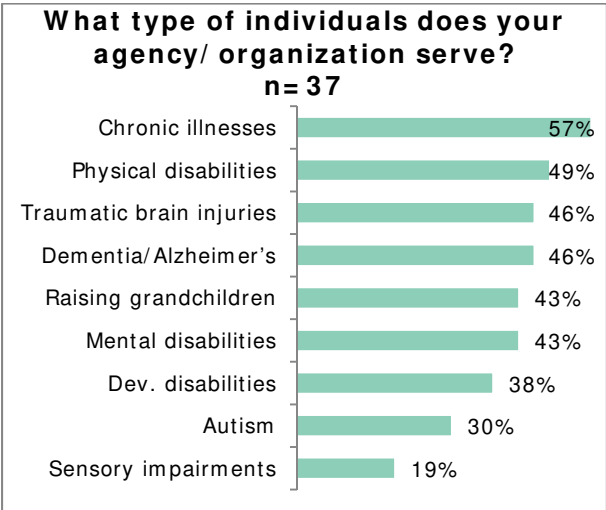
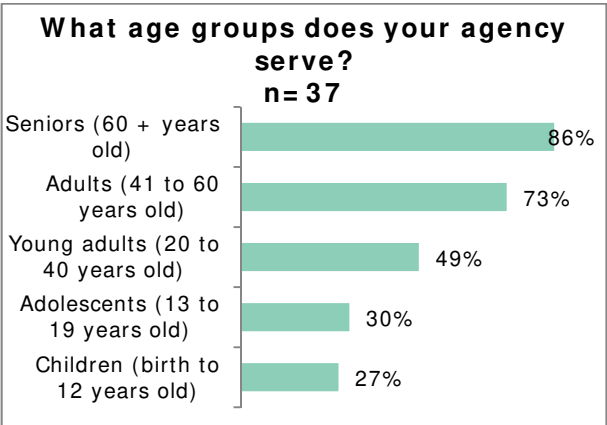
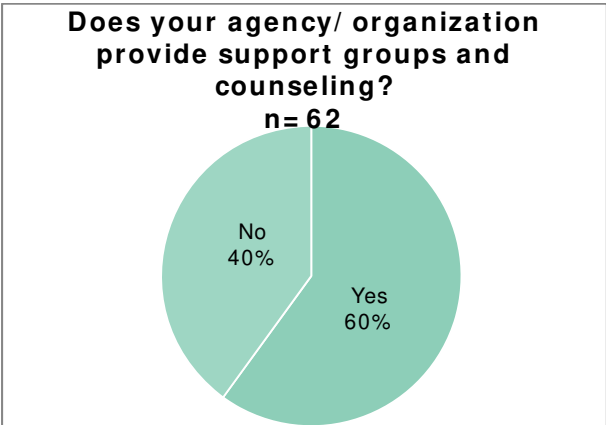


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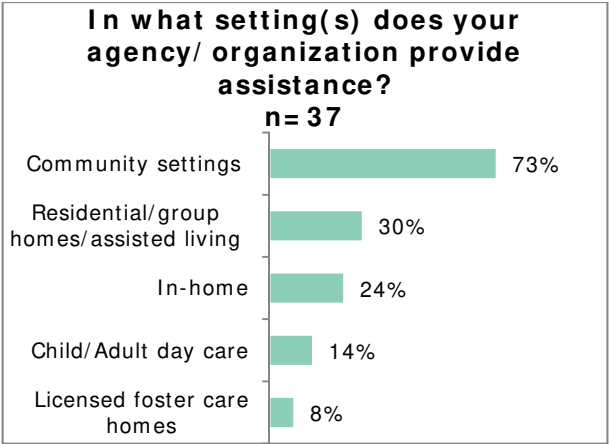
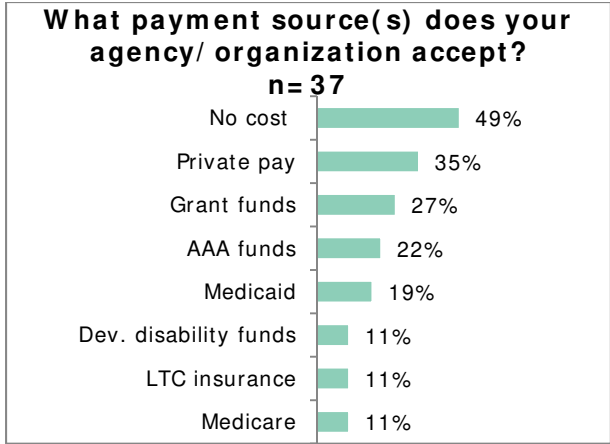
**SUPPORT GROUPS AND COUNSELING SERVICES**

All respondents were asked if their agency/organization provides Support Groups and Counseling Services. For those indicating providing the service, a series of questions was asked about age groups served, types of individuals served, when services are available, what payment sources are accepted, and in what settings services are provided.

Over half of respondents indicated their agency/organization provides support groups or counseling. Of those who do provide these services, their typical client is 41 years of age or older and has chronic illnesses (57%). Services are generally provided in the morning (65%), afternoons (68%) or evenings (51%) and are paid through a variety of sources but are most commonly free or no cost to those who are eligible (49%). Additionally, the most common setting for providing these services in a community setting (73%).



**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers

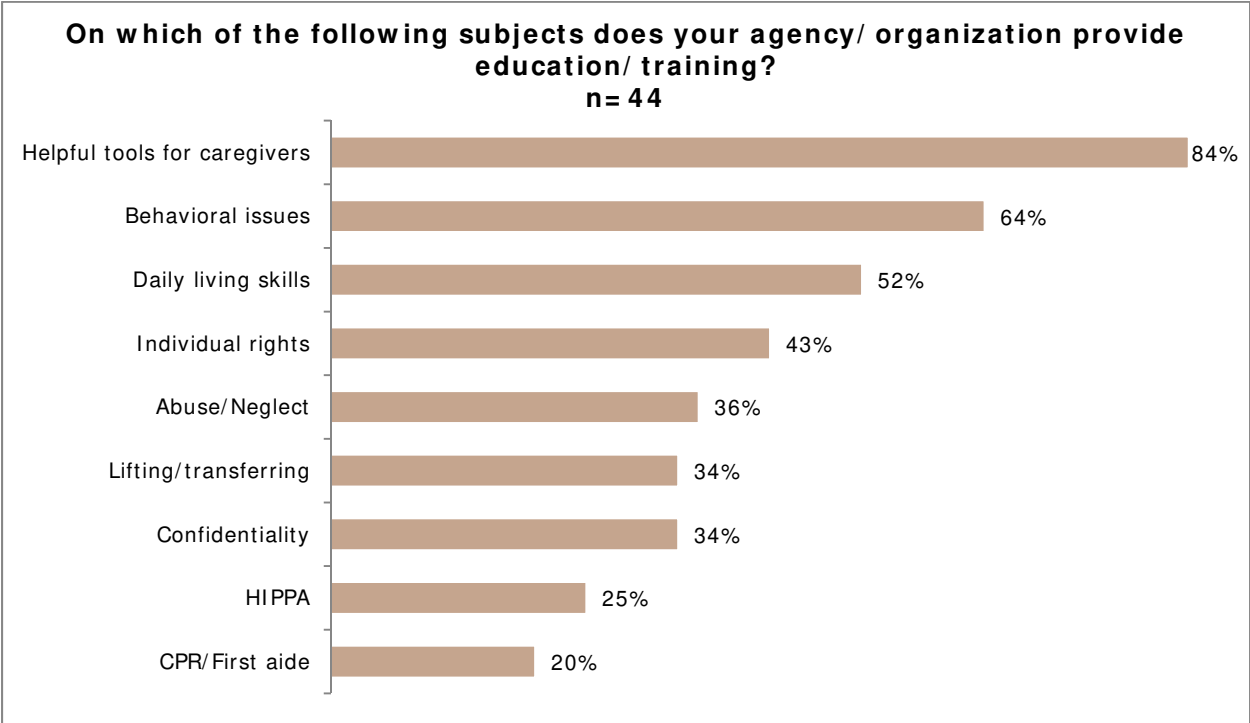
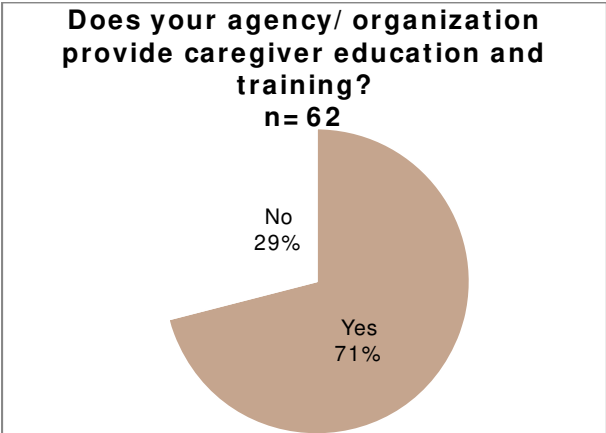


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**CAREGIVER EDUCATION AND TRAINING SERVICES**

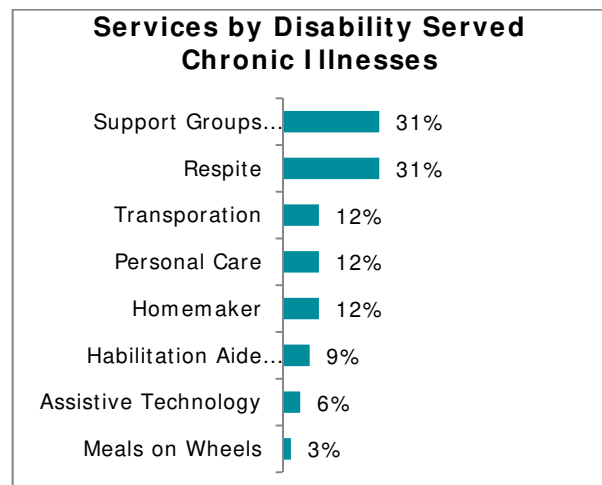
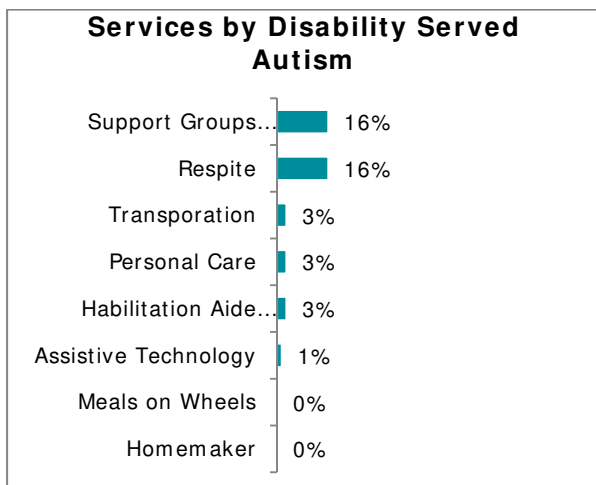
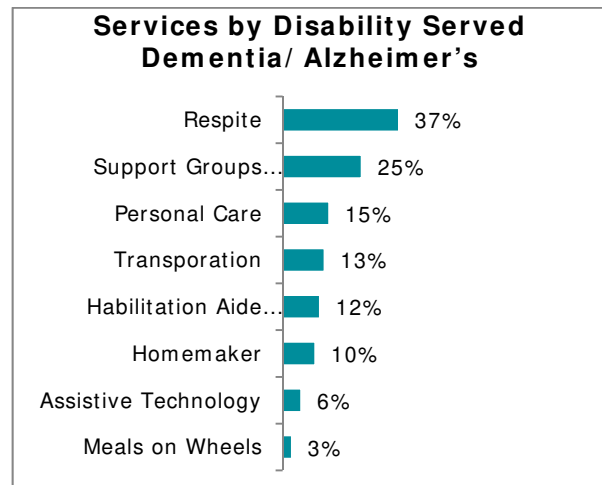
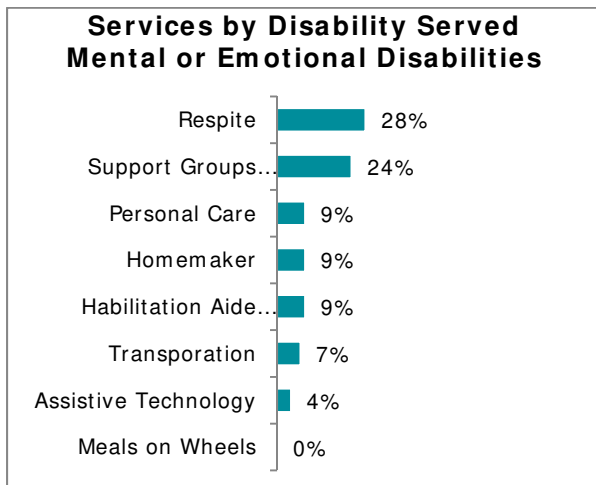
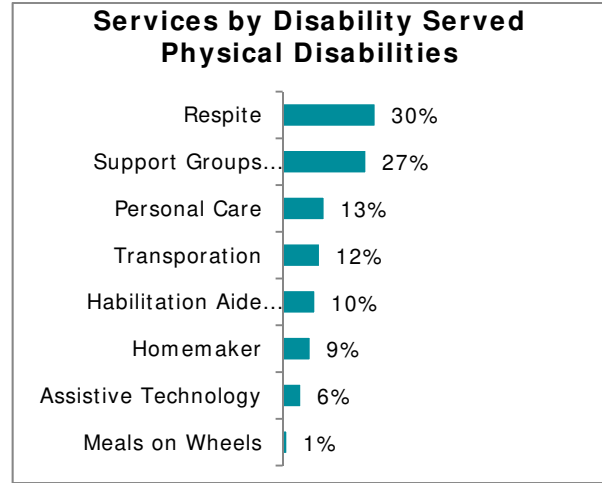
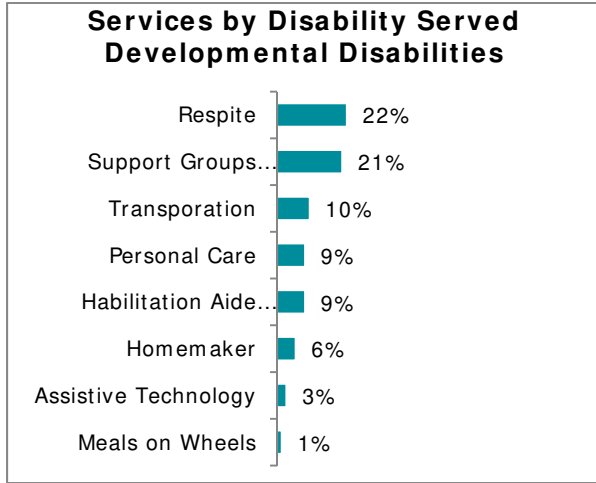
All respondents were asked if their agency/organization provides Caregiver Education and Training Services. For those indicating providing the service, a single question was asked about the subjects of the education/training their agency/organization provides.

Over half of the respondents indicated their agency/organization provides caregiver education and training (71%). Of those who provide these services, they will most commonly cover the subjects of helpful tools for caregivers (84%), behavioral issues (64%), and daily living skills (52%).



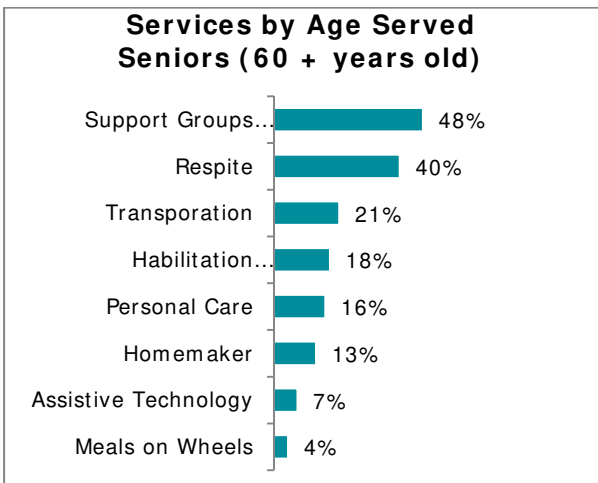
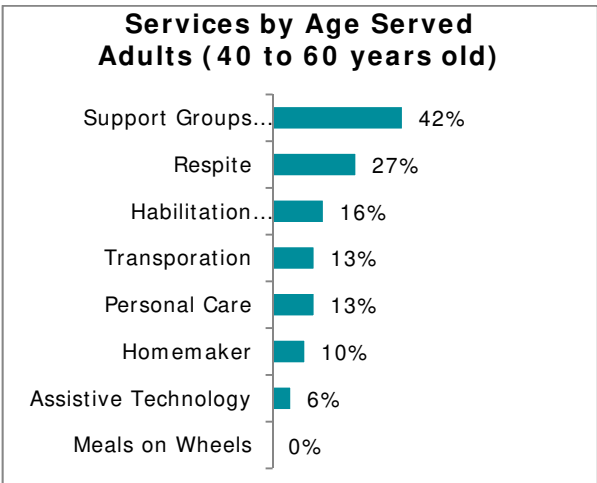
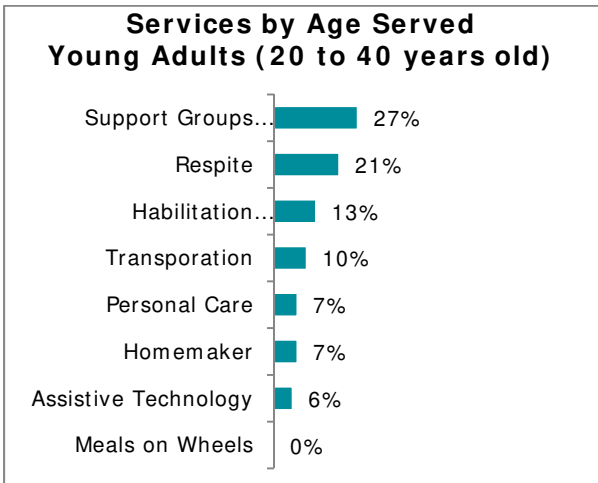
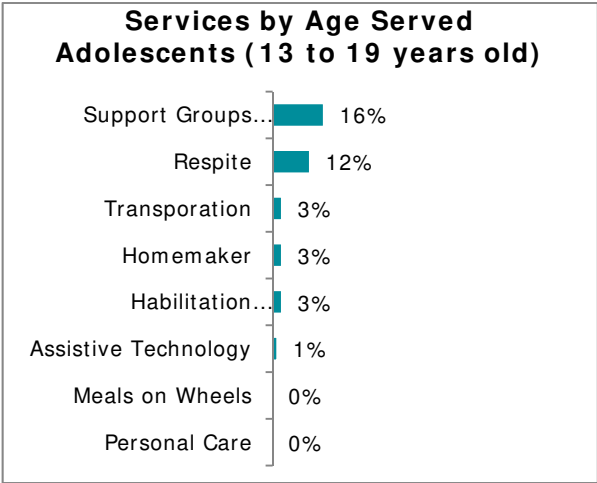
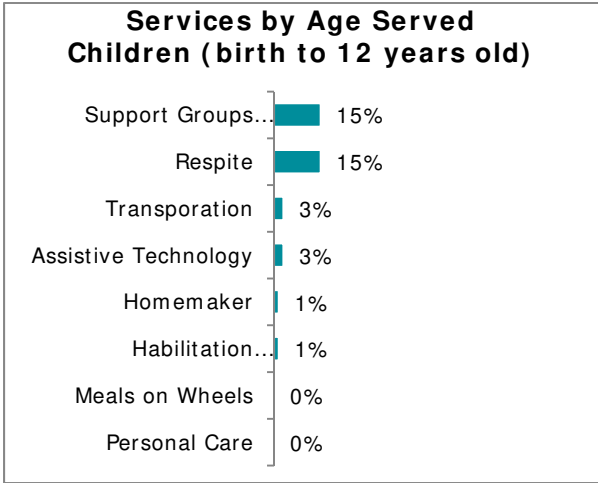
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**SERVICES BY TYPE OF DISABILITY SERVED**



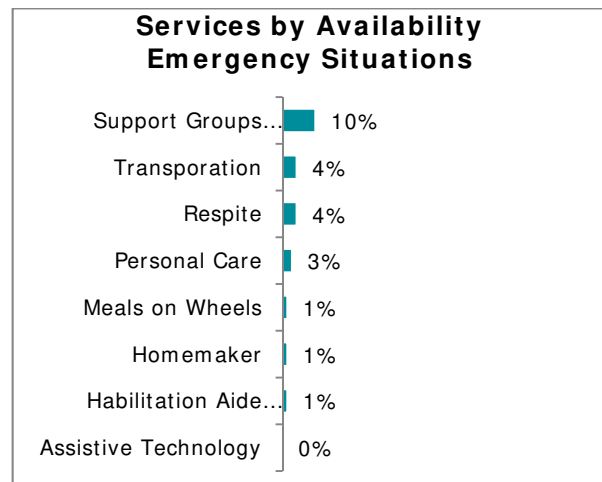
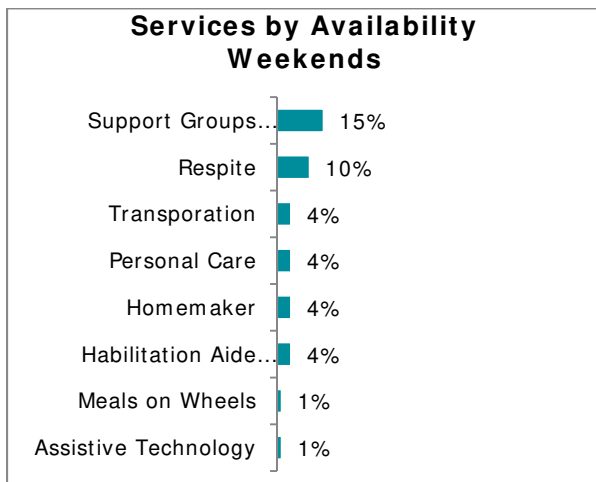
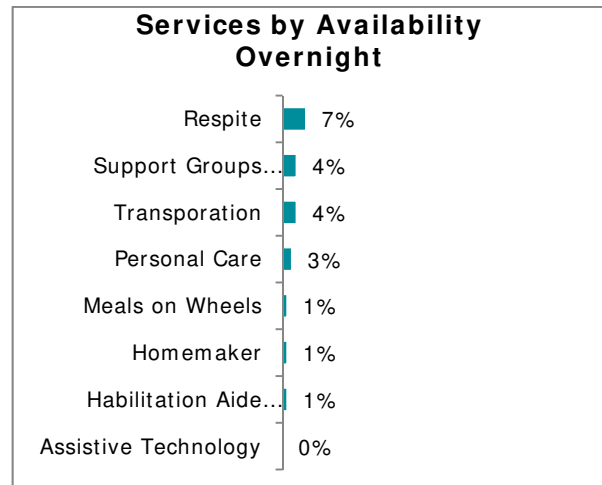
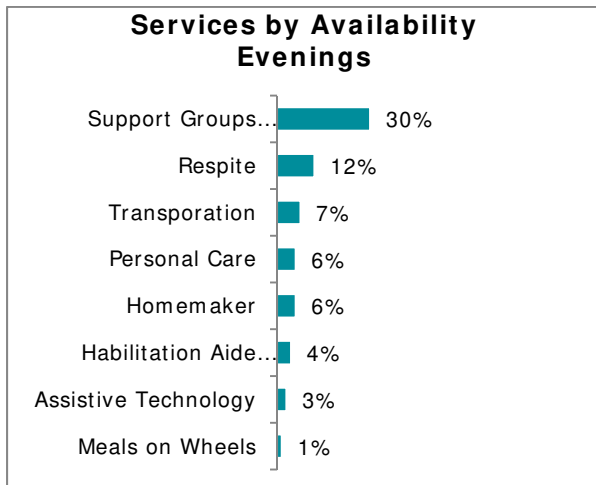
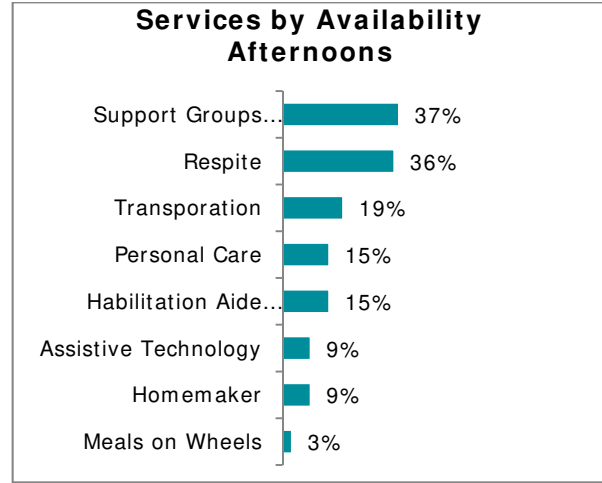
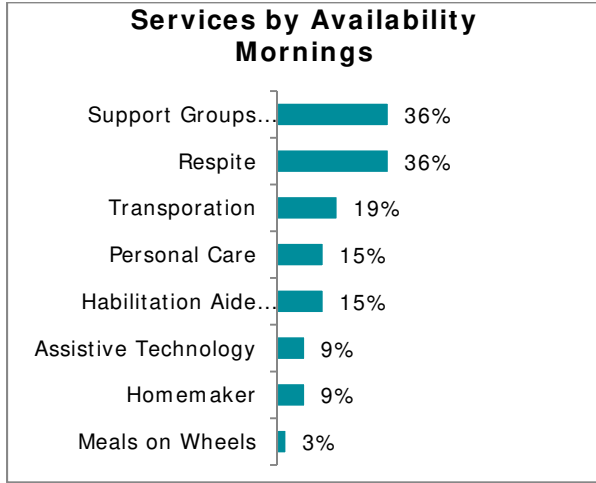
**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers

**SERVICES BY AGE**



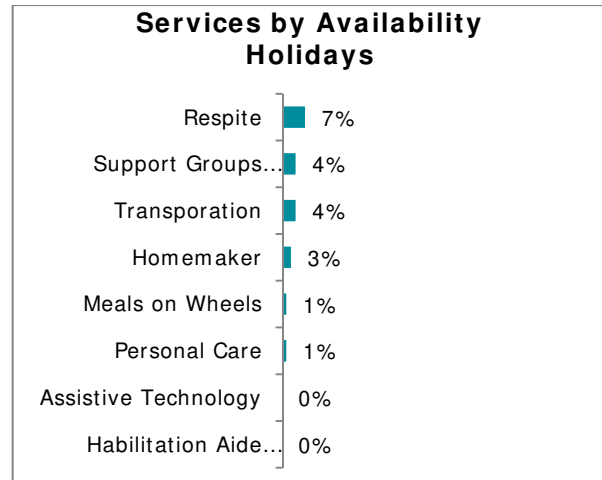
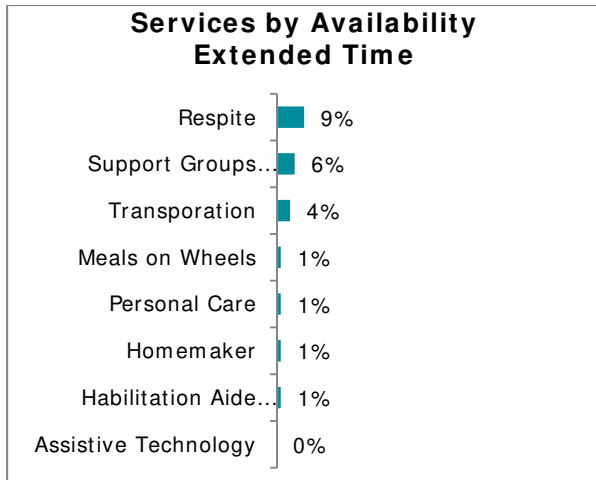
**Footnote:** It should be noted that percentages may represent multiple individuals from within the same agency, meaning that results may overestimate the number of services available to caregivers

**SERVICES BY AVAILABILITY**



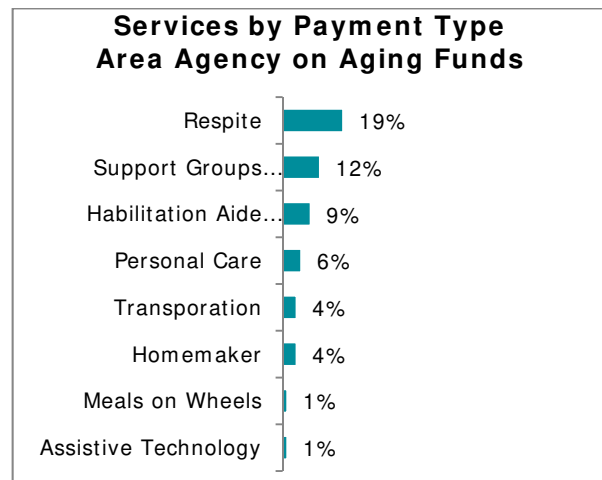
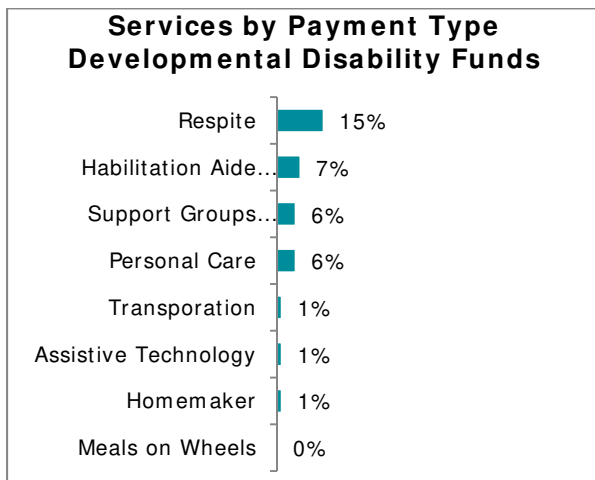
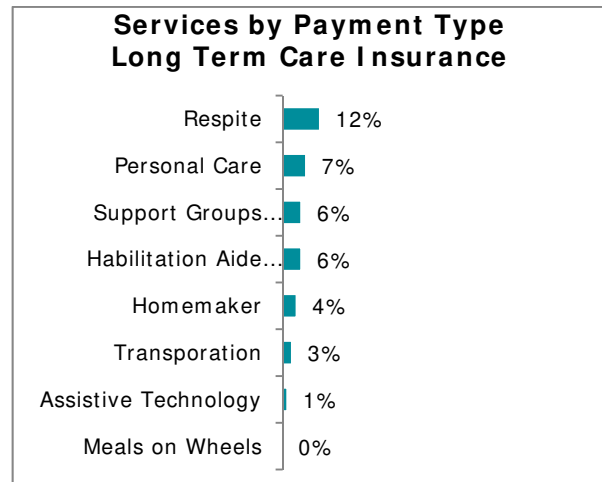
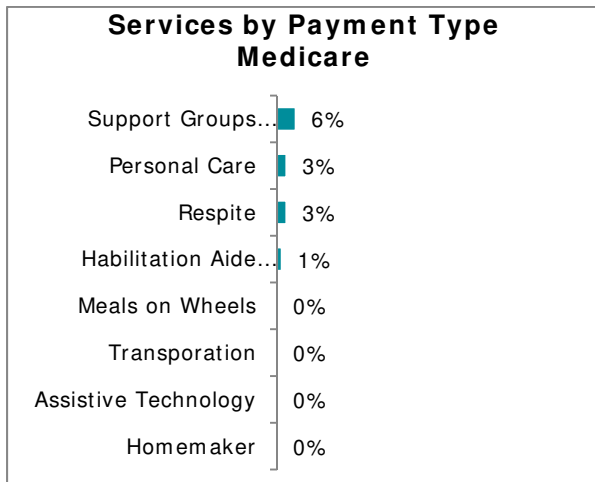
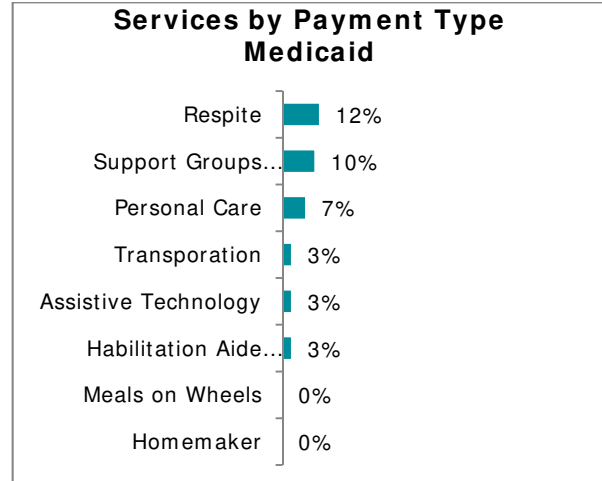
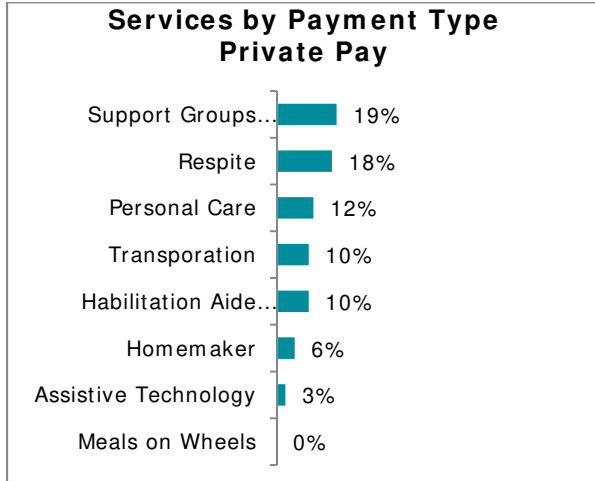
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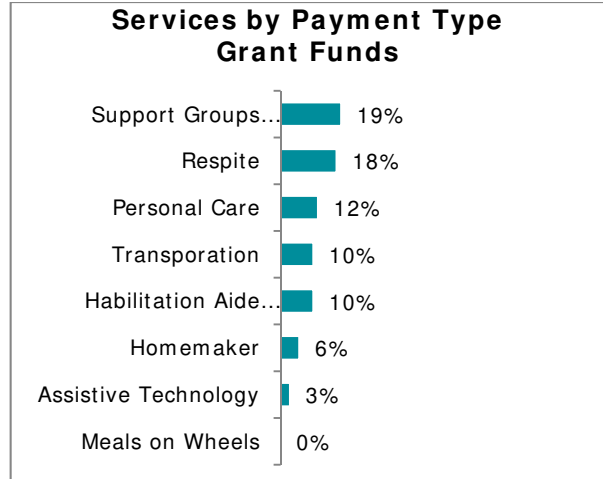
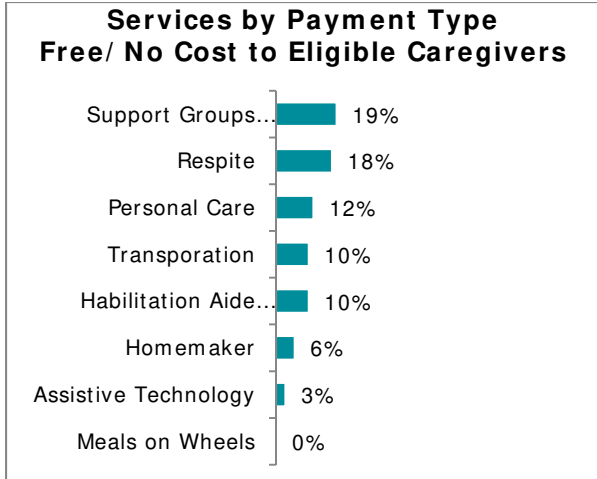


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**SERVICES BY PAYMENT TYPE**

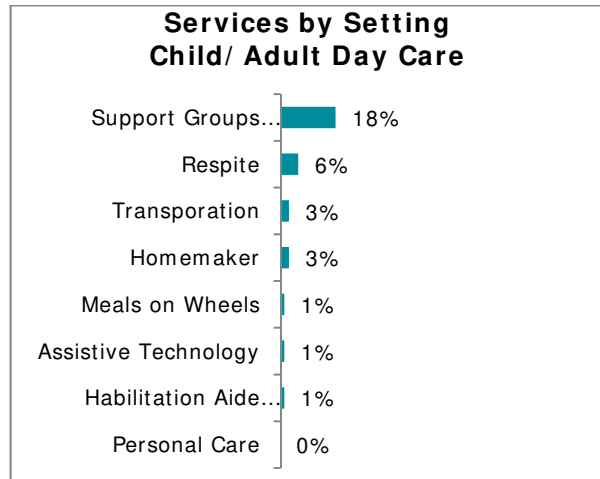
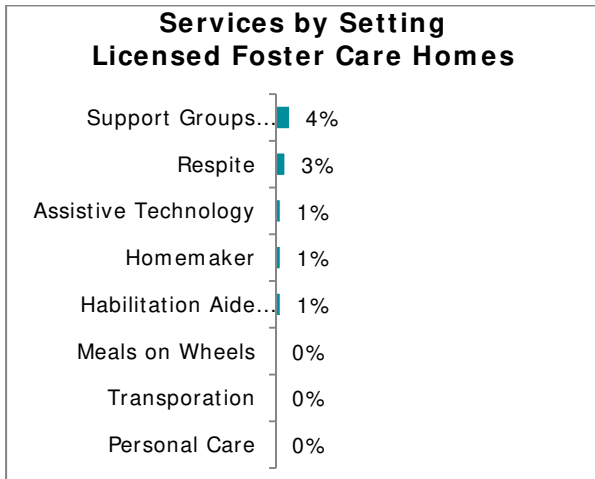
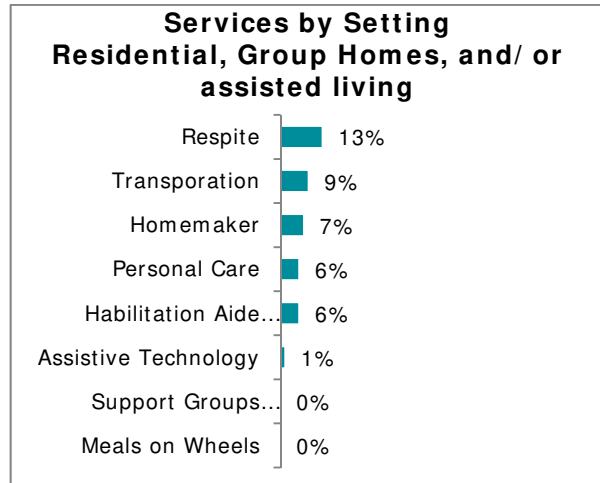
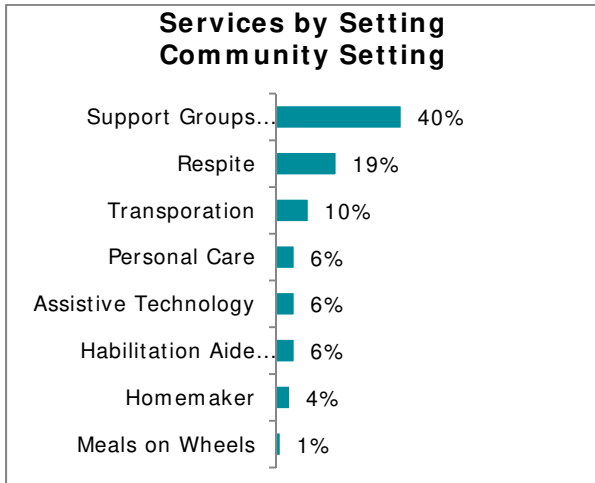
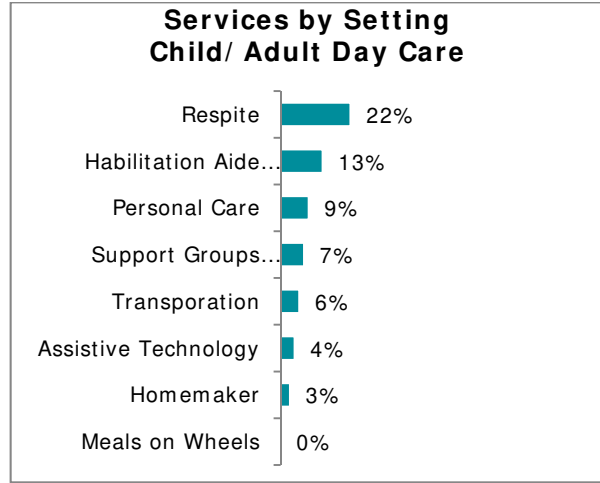
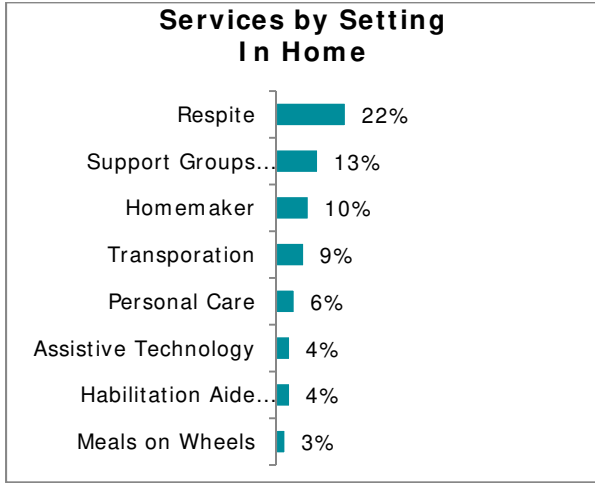


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**SERVICES BY SETTING**



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## Comparison of Survey Results

### *Lifespan Respite Grant*

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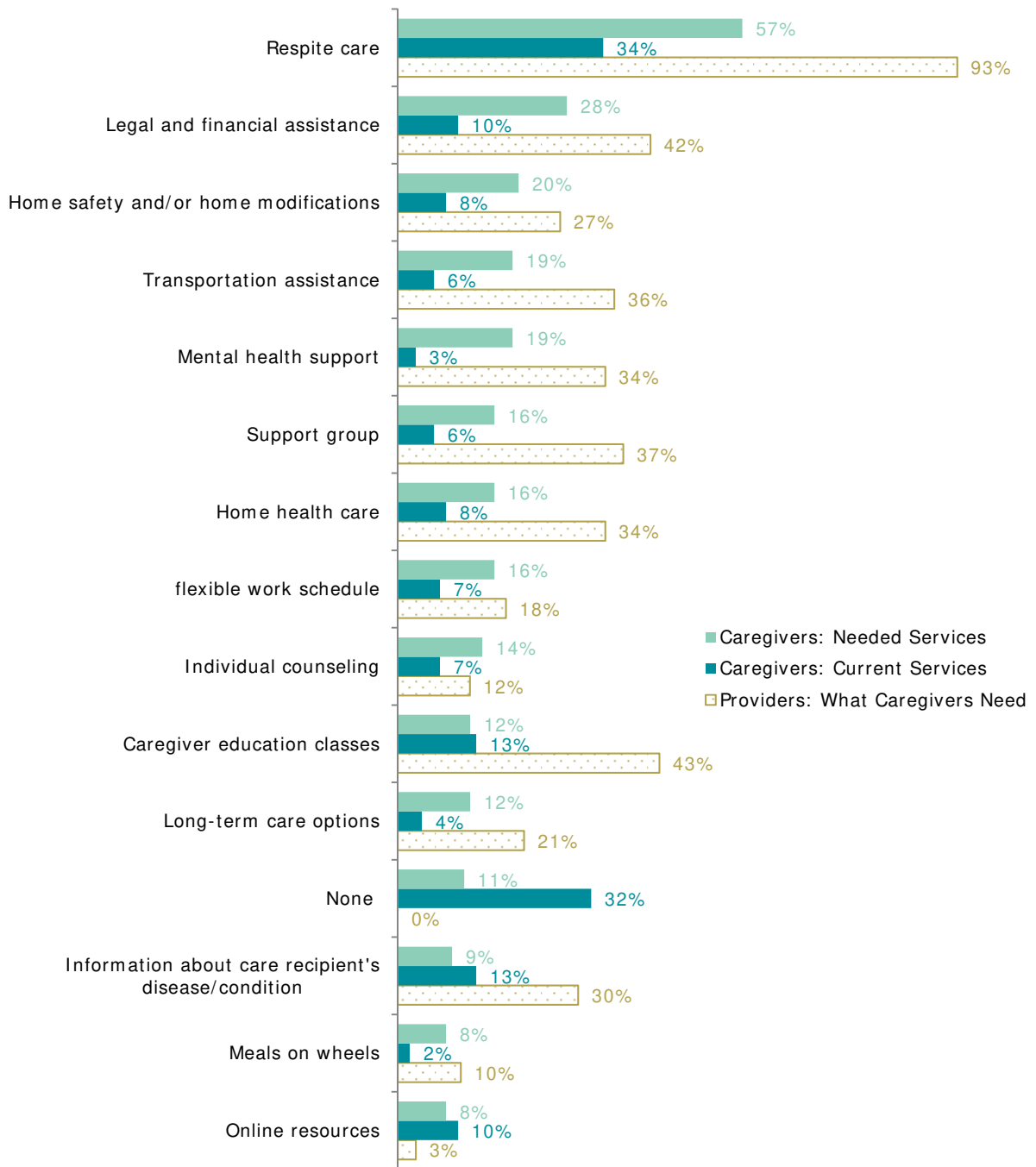
The chart below compares the services caregivers currently receive, services caregivers indicated they wished they had, and services that providers indicated that caregivers need. For both caregivers and services providers, respite is the most used and needed service. Legal and financial assistance received the second highest responses for services caregivers wished they had.

It should be noted that caregiver education classes is the most provided service based on Provider Surveys. Caregiver Educations Classes received the second highest responses from Providers indicating which services they felt caregivers needed. However, these services ranked much lower for the services caregivers currently receive and services they wish to receive.

It should also be noted that 48% of caregivers indicated caring for an individual under the age of 18; however the agencies/organizations providing services indicated serving primarily individuals over the age of 20.

Overall, providers indicated caregivers needed more services than caregivers indicated they needed.

**Comparison of Caregiver Current Support, Caregiver Resources Needed, Provider Opinions of What Services are Needed**



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