



# Family Caregiver Survey 2019

*Preliminary results, compiled 8/2019 by Kristin Litzelman ([litzelman@wisc.edu](mailto:litzelman@wisc.edu))*

## Preface

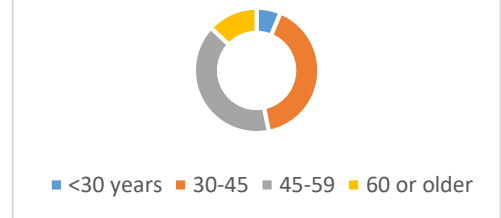
In June 2019 we invited family caregivers to participate in a survey to collect information about how they find and utilize resources to help care for themselves and their loved one. We remarkably heard from 514 family caregivers. The information contained in this report is what we learned as result. As promised at the beginning of the survey, we are sharing this information with state and other caregiver support agencies. While this is still a preliminary report, our goal is to develop recommendations to make it easier for family caregivers to learn about and access supports and services.

## Preliminary results: Caregivers of children or young adults (<30 years of age)

### Demographics

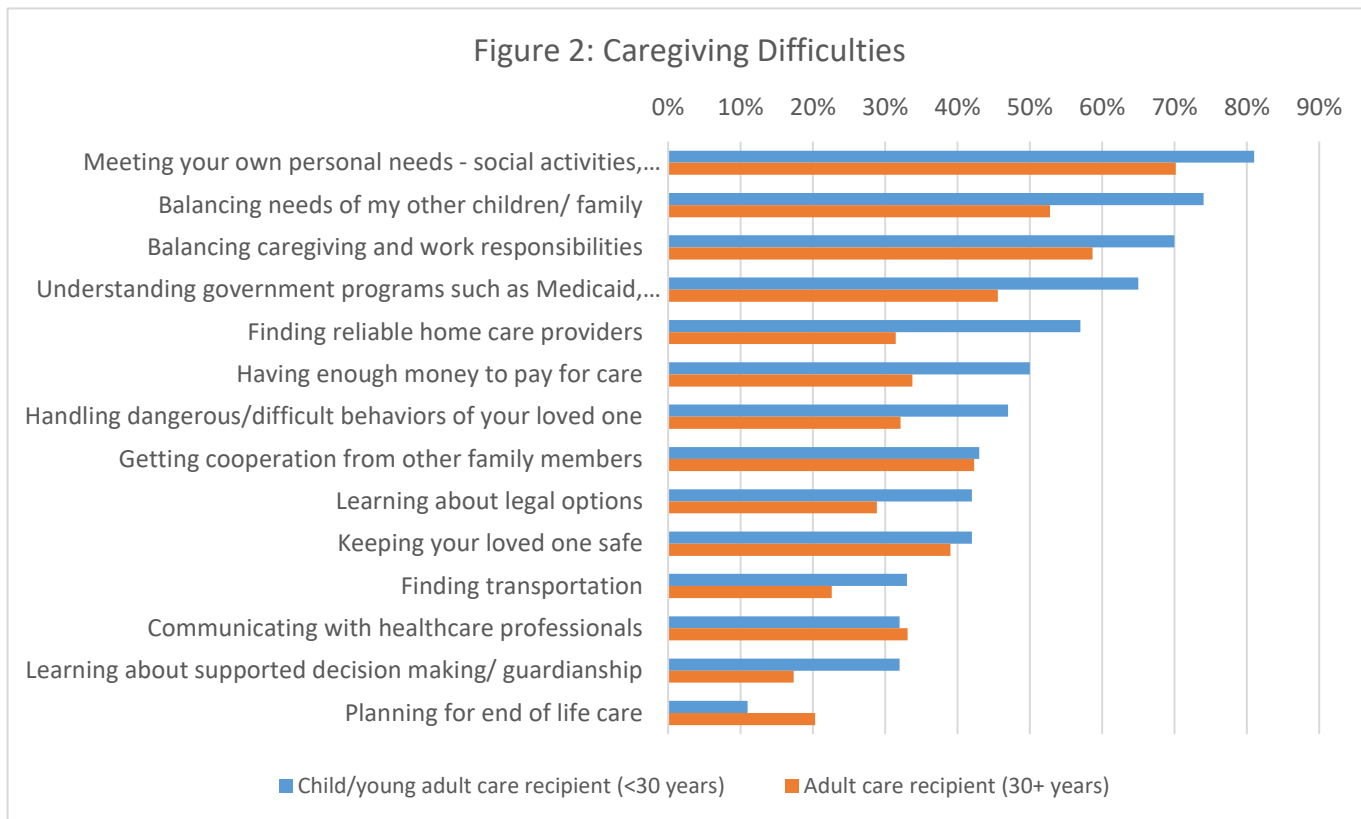
Forty percent of survey respondents were caring for a child or young adult (<30 years of age). These caregivers were primarily female (95%) and white (non-Hispanic) (90%). They ranged in age from young adults to older adults (**Figure 1**). A plurality (86%) was caring for their child and had been providing care for 5 or more years (88%). Most caregivers were providing care for someone with an intellectual or developmental disability (86%), and/or a physical disability (27%). Of interest, 7% were caring for someone with a mental health condition.

Figure 1. Caregiver age (care recipient <30 years of age)



## Difficulties

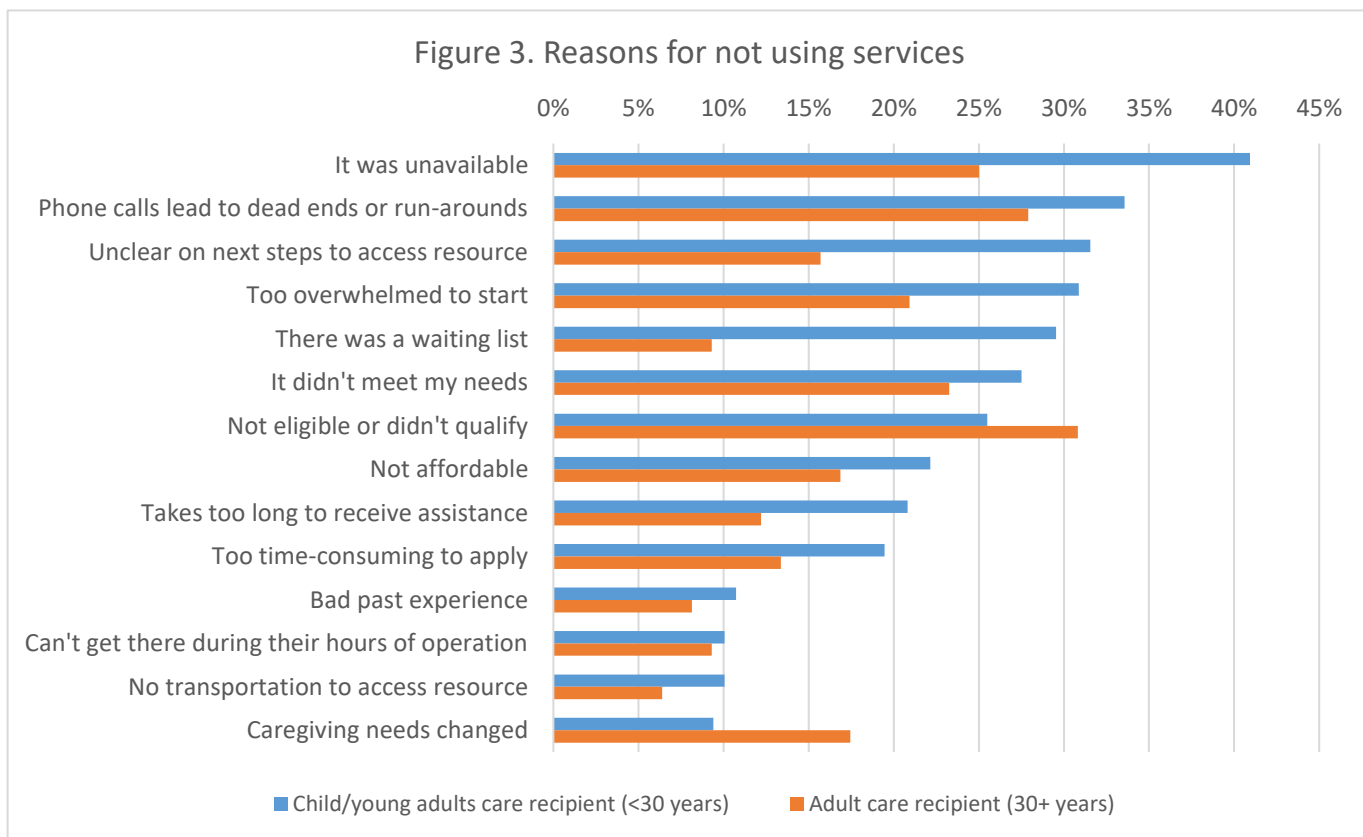
Among these caregivers, meeting their own personal needs was the top-ranked difficulty (81%), followed by balancing needs of the other children/family in the household and balancing caregiving and work (endorsed by 74% and 70% respectively). Understanding government programs, finding reliable home care providers, and having enough money to pay for care were also top-ranked difficulties (65%, 57%, and 50% respectively). **Figure 2** depicts the percent of caregivers endorsing each provided category (note: this figure and many subsequent figures display the results for caregivers of both children/young adults [blue bars] and older care recipients [orange bars]). A narrative description of the survey results for caregivers of adults [ages 30+ years] starts on page 7). In addition, caregivers specified other difficulties including challenges with accessing resources (e.g., “Enforcing school accommodations”; “Accessing



FAPE”) and obtaining high-quality or specialized services (e.g., “accessing specialized care, particularly qualified psychiatric care for a non-verbal patient”). Figure 2 also demonstrates different focus of caregiving concerns as care recipients age. This is discussed in more detail on page 7.

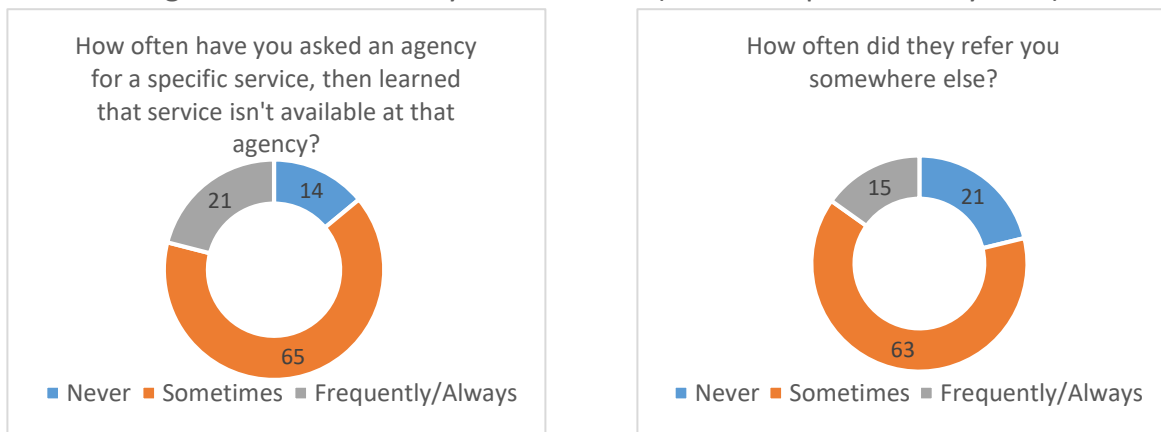
### Service use in the past year

Sixty-three percent caregivers of children or young adults under 30 had applied for services in the past year, and 83% had received services. More than three in four had contacted an agency about services or resources in the past year. The most commonly reported agency was Hospitals and Clinics (including doctors, nurses and hospital social workers) (64%), followed by an IRIS or Family Care Consultant (47%). Among caregivers who contacted an agency, most reported being comfortable knowing what to ask (64%), although more than one in five reported being uncomfortable (21%). Caregivers often used the suggested resources emerging from these contacts (sometimes: 37%; frequently: 51%; always: 11%). The most frequently endorsed reason for not using suggested resources was that the service was not available (41%). Approximately one third endorsed that they did not use services because phone calls lead to dead ends or run-arounds (34%), they were unclear on next steps to access resource (32%), or they were too overwhelmed to start (31%). **Figure 3** depicts the proportion of caregivers endorsing each reason for not using services.



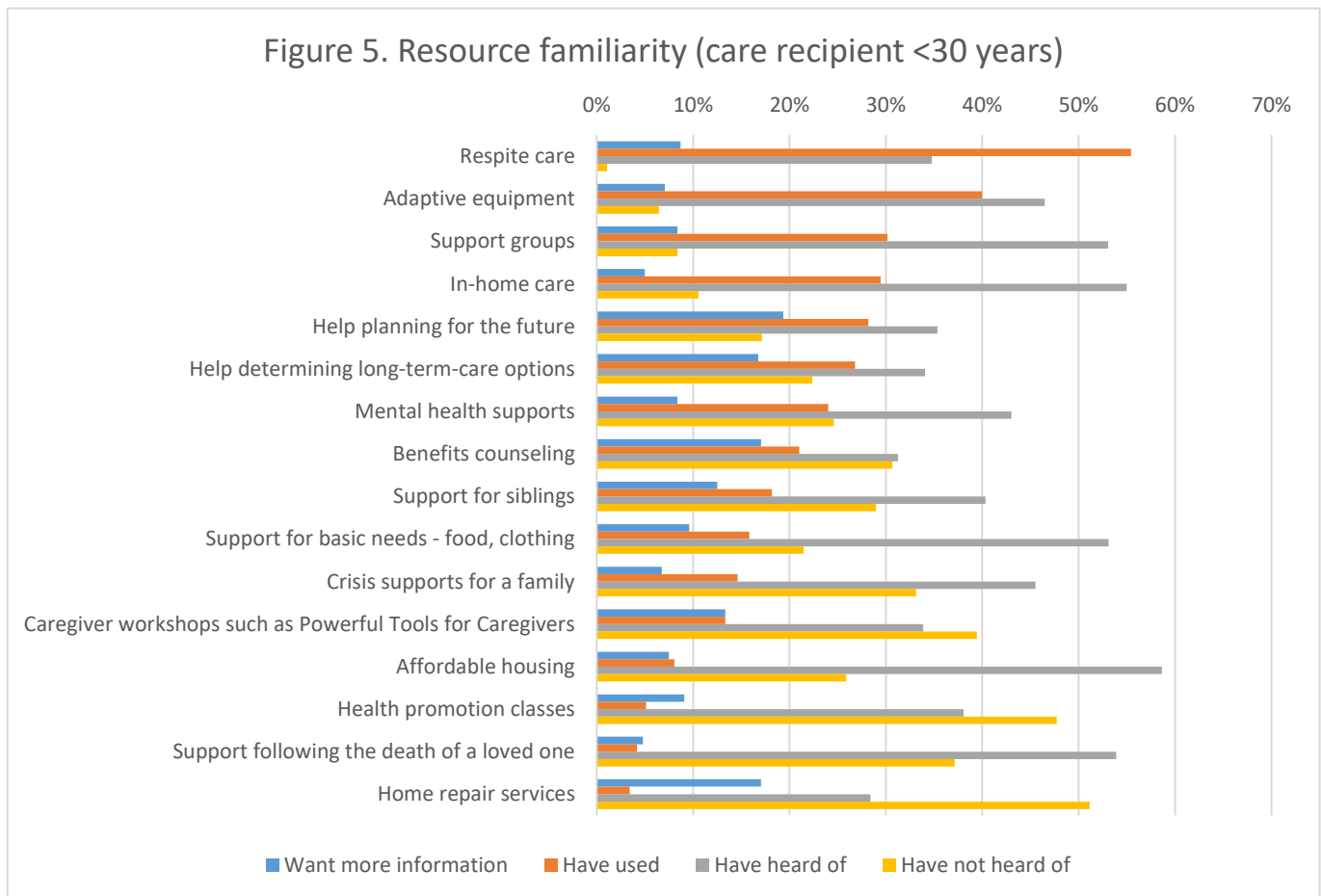
One in five caregivers of children/young adults reported asking for a specific service that then wasn't available at that agency (21% "frequently" or "always"; **Figure 4**), and one in five indicated that they were never referred somewhere else when they were asked about a service that wasn't provided by a given agency (21%). **Of note, nearly three in four caregivers of children/young adults reported that they never asked about help for themselves as a caregiver in these conversations (74%).**

Figure 4. Availability of services (care recipient <30 years)



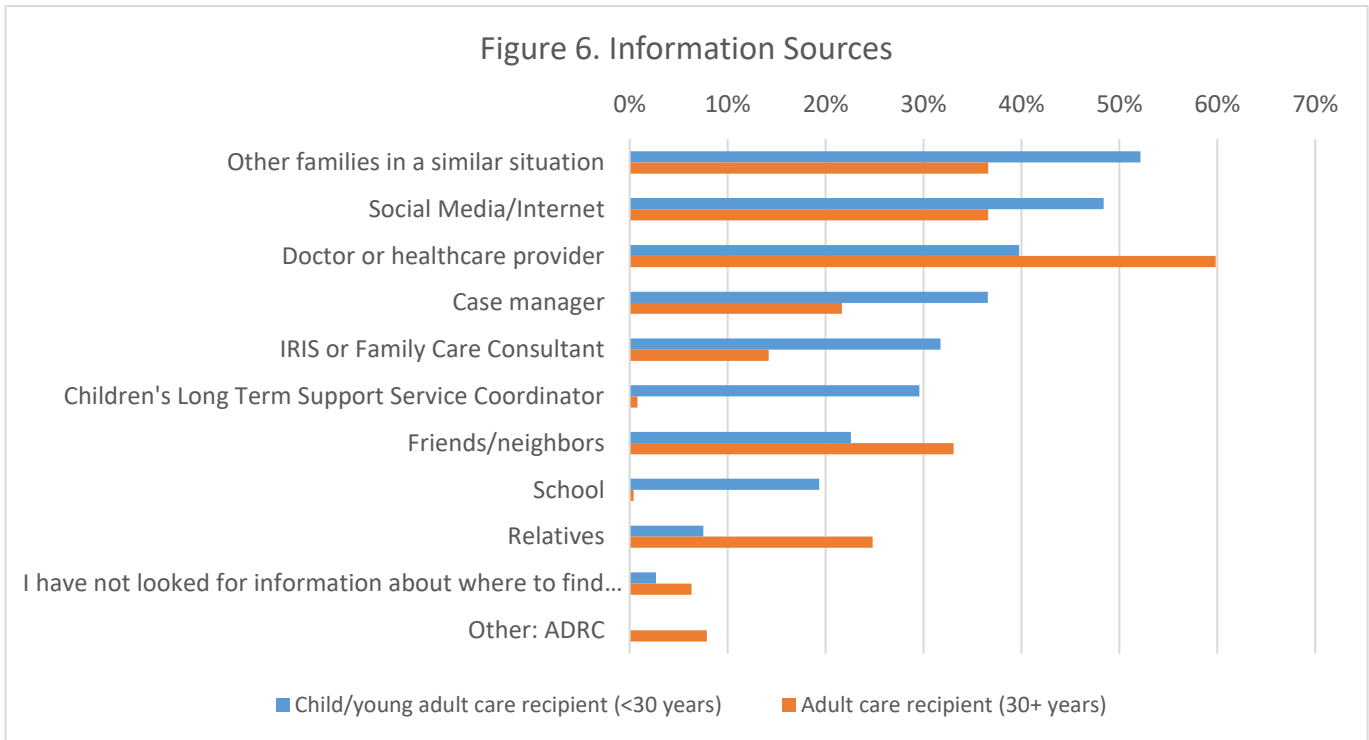
Caregivers had varying familiarity with an array of resources (**Figure 5**). More than half of caregivers in this group had used respite care (55%). More than a third reported that they had not heard of several services, including home repair services (51%), health promotion classes (48%), caregiver workshops such as Powerful Tools for Caregivers (39%), or crisis supports for families (33%). More than one in six indicated they wanted more information about help planning for the future (19%), benefits counseling (17%), home repair services (17%), and help determining long-term-care options (17%).

Figure 5. Resource familiarity (care recipient <30 years)

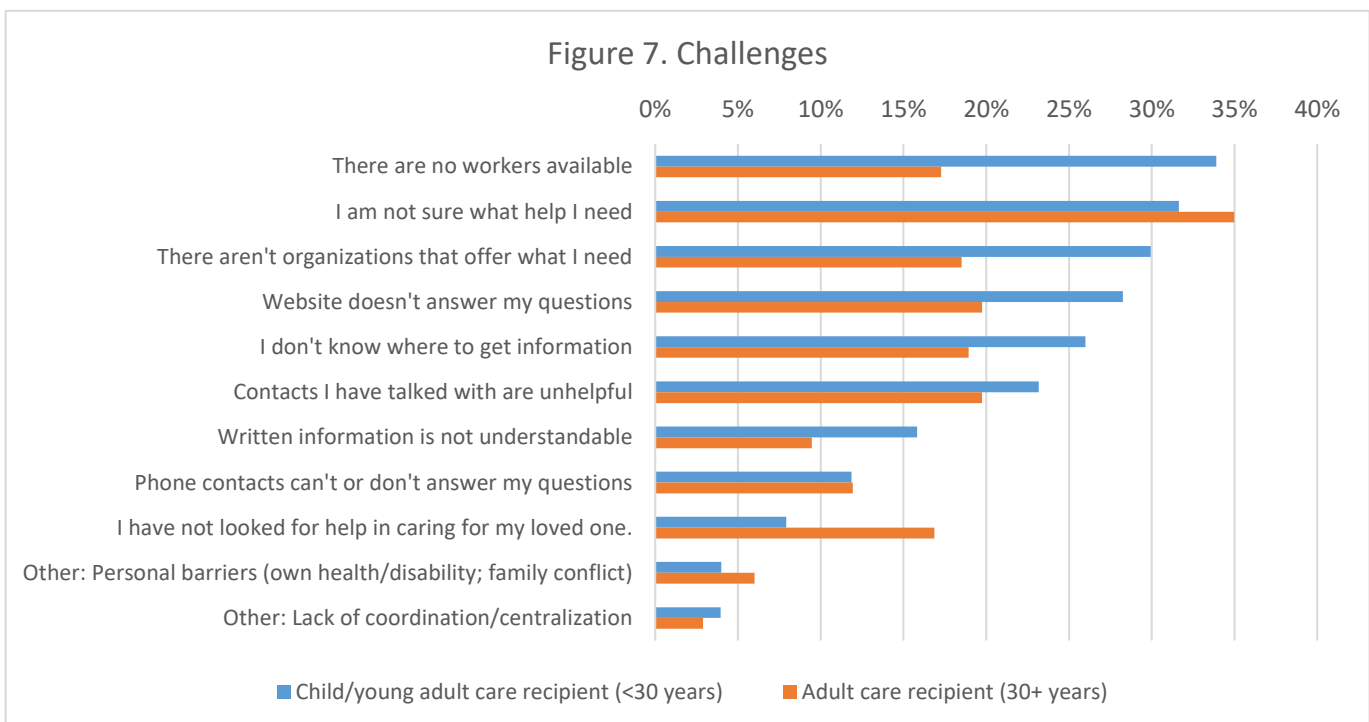


Information sources

Caregivers reported they accessed a variety of sources of information (**Figure 6**). Caregivers of children and young adults most frequently reported getting information from other families in a similar situation (52%), social media or the internet (48%), or a doctor or healthcare provider (40%).



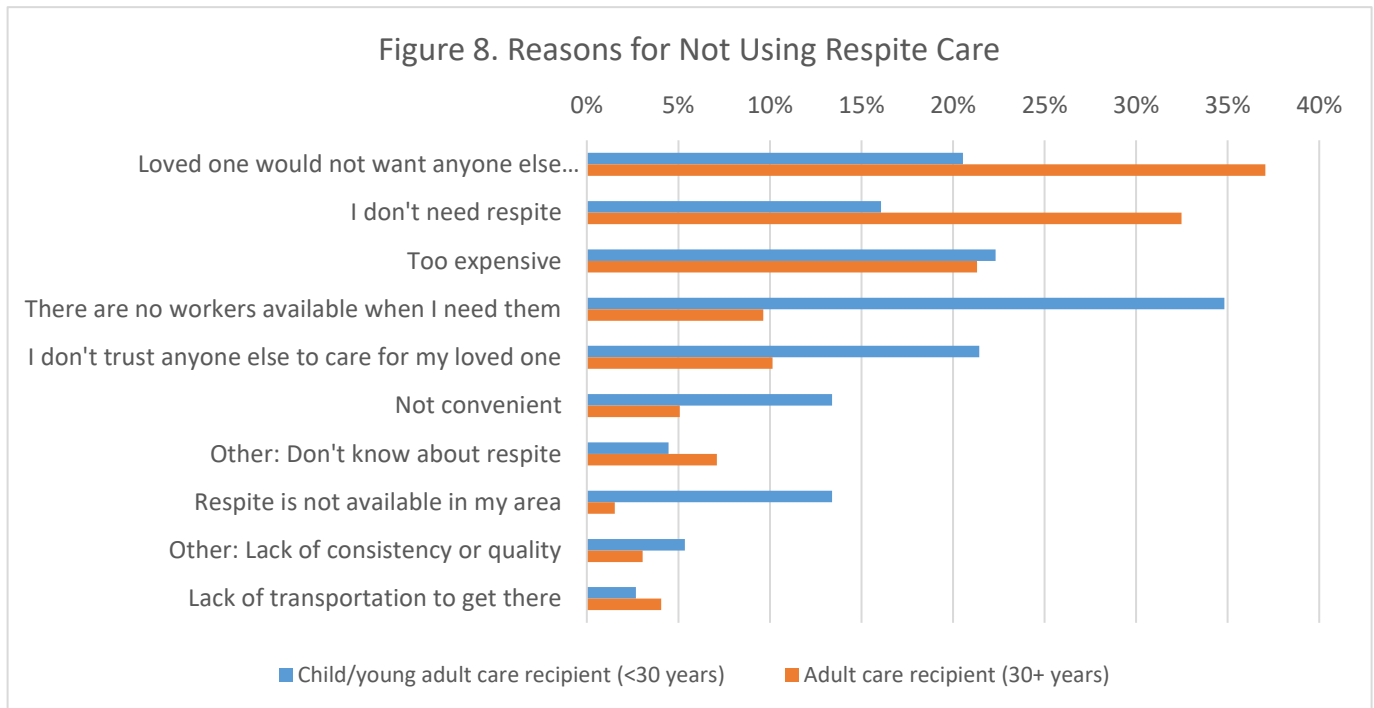
More than three in ten reported key challenges around finding available workers (34%), not being sure what help they need (32%), or organizations not offering what they need (30%). **Figure 7** depicts the proportion of caregivers endorsing each challenge type. Other themes that emerged included the lack of centralization or coordination of services, for example: "information is spread out and different resources



are only mentioned in some places, not others” as well as personal barriers such as lack of time, for example “It is difficult to find the time to research this while working a full time job and caring for my son.”

### Respite Care Utilization

More than half of caregivers in this group reported ever using respite care (56%). The most commonly endorsed reasons for not using respite care was that there were no workers available when needed (35%), it was too expensive (22%), they don’t trust anyone else to care for their loved one (21%), and their loved one would not want anyone else caring for them (21%). **Figure 8** depicts the array of reasons caregivers endorsed for not using respite care.

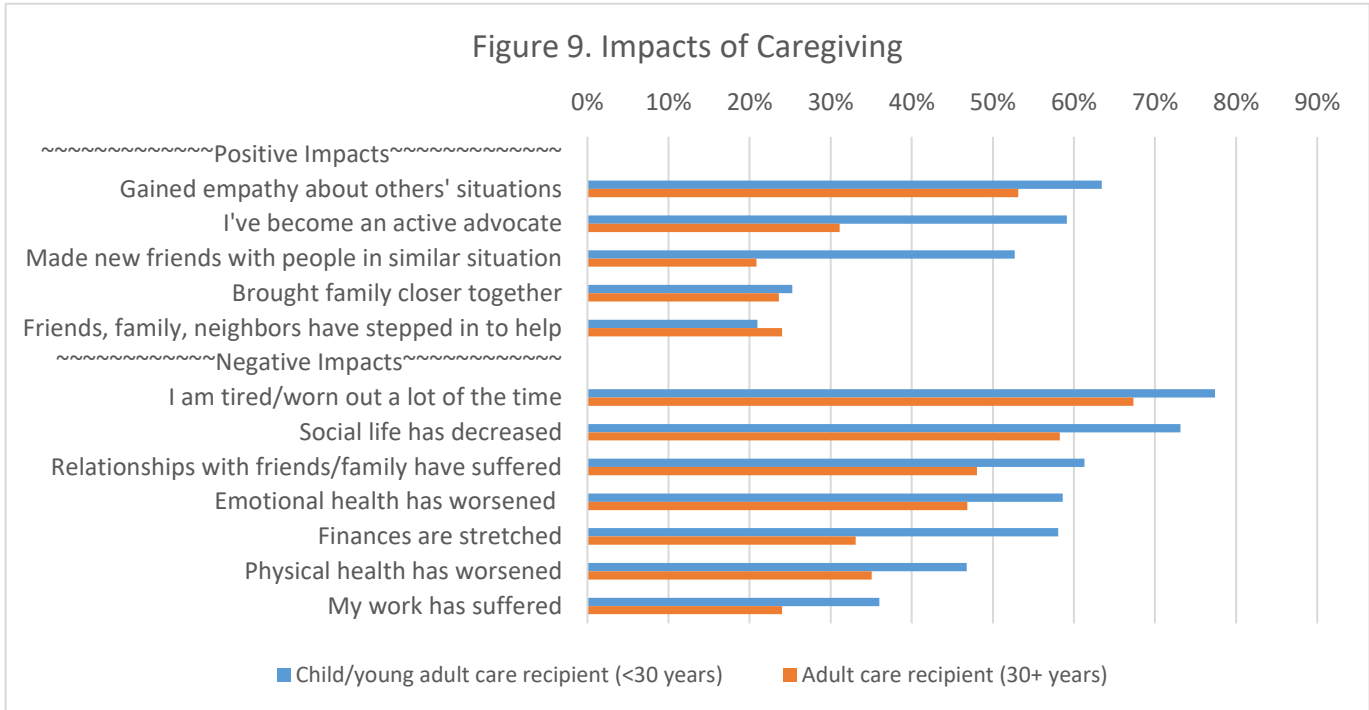


When caregivers were given the opportunity to list other reasons for not using respite care, several themes emerged. Several caregivers noted that a lack of consistency or quality of care was a barrier, for example: “They come and go, and my loved one began having abandonment issues and acting out when I tried to find new workers” as well as emphasizing the importance of finding the *right* person to provide care, for example “I don't trust just anyone with my son”; “Complex needs require familiarity”; “Very difficult to find someone our son will spend time with.”

A small minority of caregivers of children or young adults indicated that they were unfamiliar with respite care (4%) or that they didn’t qualify for respite services (4%). Several others indicated that agency-related issues kept them from accessing respite care, for example: “...our child was approved for the long-term and community support waivers, but there is a long waiting list in our county - we've been on the waiting list for over a year and a half and we've heard nothing and never been contacted by the county”; “Asked not to return to respite because of behaviors.”; “We've been trying to apply, but are having problems getting help with the paperwork. CLTS case manager doesn't call me back!”

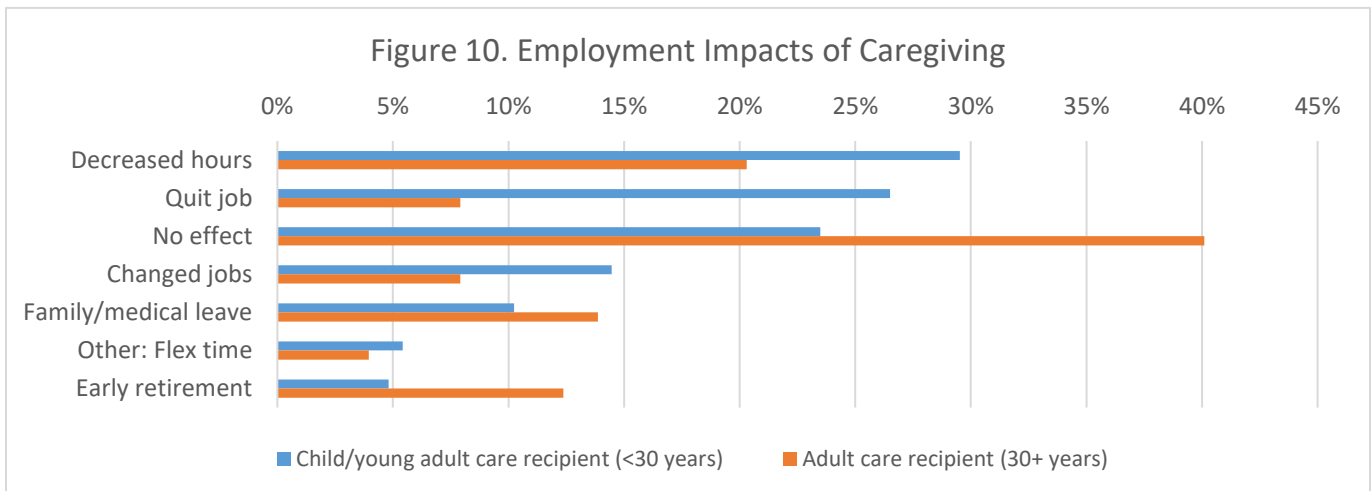
### Impacts of Caregiving

Caregivers in this group noted a wide array of impacts (**Figure 9**). Importantly, four in five caregivers endorsed one or more positive impacts such as gaining empathy about others' situations (58%), becoming an active advocate (43%), making new friends with people in similar situations (34%), and bringing family closer together (24%). However, nearly nine in ten reported at least one negative impact, most commonly being tired or worn out (72%), social life decrease (65%), that their relationships have suffered (54%), or that their emotional health has worsened (52%).



### Impacts on Employment

Two-thirds of caregivers in this group were employed outside the home. Nearly a quarter of employed caregivers reported no impact on their work (23%). However, three in ten reported decreasing their work hours (30%) and more than a quarter reported quitting a job (27%) because of caregiving duties. **Figure 10** depicts the employment changes endorsed by caregivers. Encouragingly, employed caregivers reported that their supervisor was accommodating when the caregiver needed to leave work unexpectedly (73% reporting supervisor was accommodating “always” or “most of the time”).

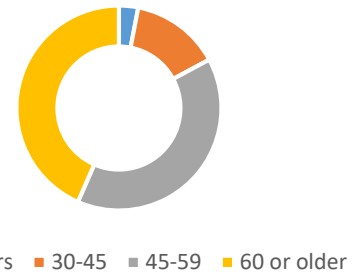


## Preliminary results: Caregivers of adults 30 years of age and older

### Demographics

Sixty percent of the caregivers surveyed were caring for an adult loved one (30 years of age or older). Respondents were primarily female (89%) and white (non-Hispanic) (88%). They ranged in age from young adults to older adults (**Figure 11**). Nearly half were caring for their parent or in-law (42%) and nearly one in four was caring for their spouse or partner (24%). Nearly half of caregivers had been providing care for 5 or more years (45%). One in three were caring for someone with Alzheimer's disease or dementia (33%), while more than a third were caring for someone with a physical disability (36%), three in ten were caring for a frail elder (28%) and one in five were caring from someone with an intellectual or developmental disability (20%).

Figure 11. Caregiver age (care recipient 30+ years)



### Difficulties

Among these caregivers, meeting their own personal needs was the top-ranked difficulty (70%), followed by balancing caregiving and work and balancing needs of the other children/family in the household (59% and 53%, respectively). See **Figure 2**, page 2. Understanding government programs and getting cooperation from other family members were also top-ranked concerns (46% and 42%, respectively). In addition, caregivers specified other difficulties including challenges with accessing resources (e.g., “Finding health care providers that accept payment from govt. Programs closet have a 4-hour drive”) and obtaining high-quality or specialized services (e.g., “Lack of quality care in assisted living facilities.”) Older adult caregivers reported lower levels of difficulty than caregivers of children/young adults across most items. Notably, they were considerably less likely than caregivers of children/young adults to note difficulties with finding reliable home care providers, understanding government programs, and having enough money to pay for care, and more caregivers of adults noted difficulties with planning for end of life care than caregivers with younger care recipients.

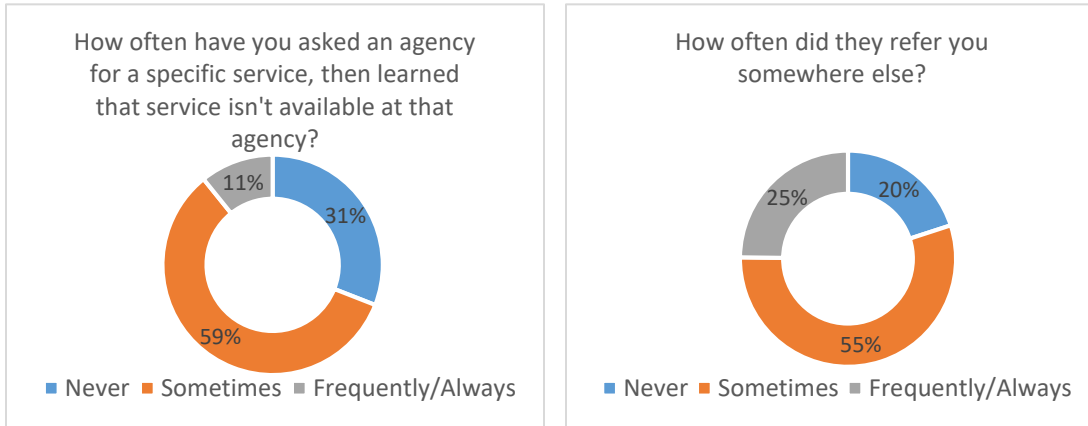
### Services used in the past year

Forty-five percent caregivers of adults (30+ years) had applied for services in the past year, and 53% had received services. More than six in ten had contacted an agency about services or resources in the past year (63%). The most commonly reported agency was Aging and Disability Resource Centers (69%), followed by Hospitals and Clinics (including doctors, nurses and hospital social workers) (52%), and home health care agencies (34%). Among caregivers who contacted an agency, most reported being comfortable knowing what to ask (74%), although nearly one in five reported being uncomfortable (18%). Caregivers often used the suggested resources emerging from these contacts (sometimes: 41%; frequently: 33%; always: 12%). The most frequently endorsed reason for not using suggested resources was that the family was not eligible or did not qualify (31%). More than one in four reported that phone calls lead to dead ends or run-arounds (28%) or that suggested resources weren't available (25%). (See **Figure 3**, page 3).

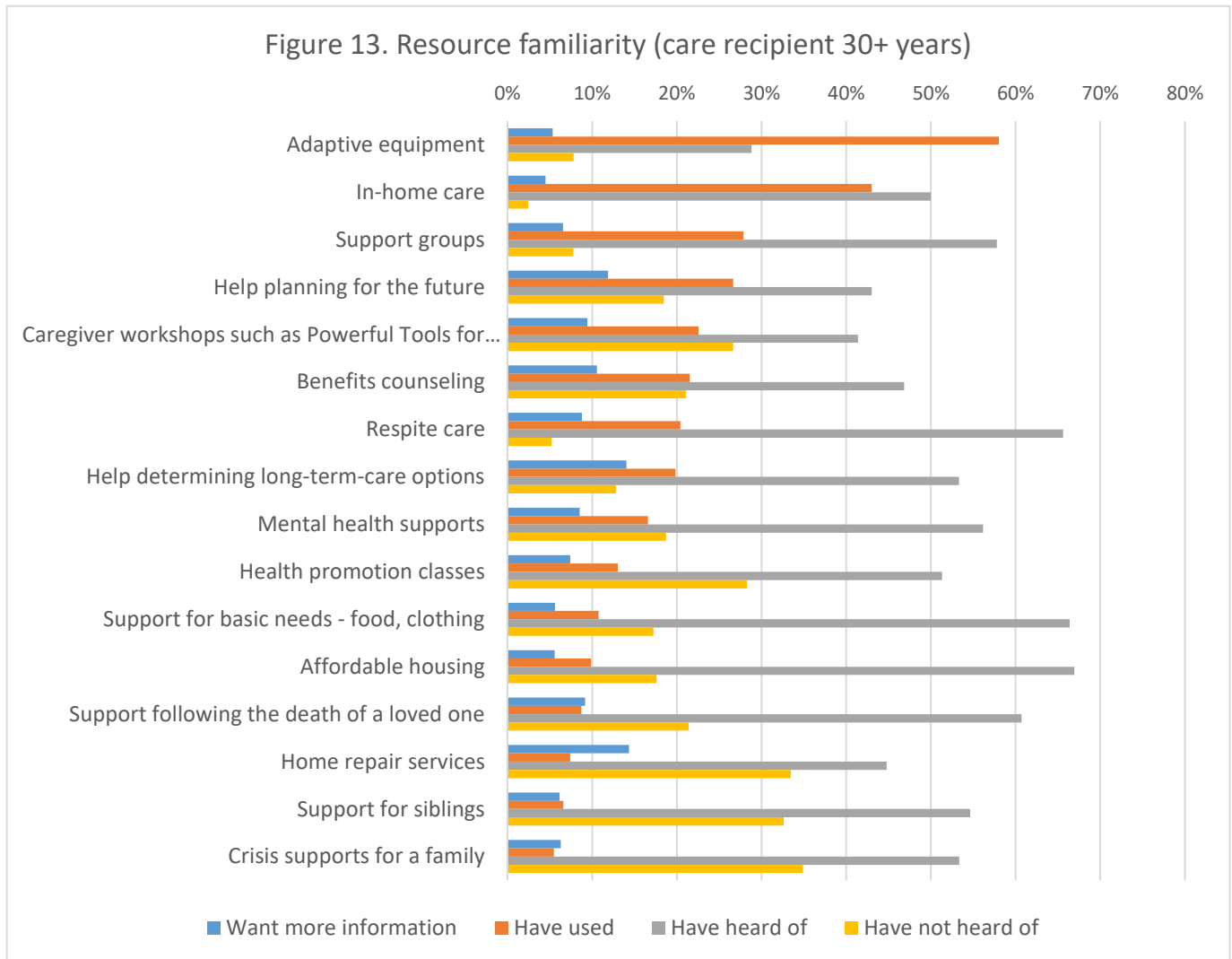


More than two-thirds of caregivers reported that they had at least sometimes asked for a specific service that then wasn't available at that agency (59% "sometimes"; 11% "frequently" or "always"; **Figure 12**), and one in five indicated that they were never referred somewhere else when they asked about a service that wasn't provided by a given agency (20%). **Of note, two-thirds of caregivers reported that they never asked about help for themselves as a caregiver in these conversations (66%).**

Figure 12. Availability of services (care recipient 30+ years)



Caregivers of adults (30+ years old) had varying familiarity with an array of resources (**Figure 13**). More than half of caregivers in this group had used adaptive equipment (58%) and four in ten had used in-home care (43%). Only one in five had used respite care (20%). A third or more reported that they had not heard of several services including crisis supports for families (35%) and home repair services (33%). Nearly one in six indicated they wanted more information about help determining long-term-care options (14%) and home repair services (14%).



### Information sources and challenges

Caregivers reported a variety of sources of information (see **Figure 6**, page 5). Caregivers of adults (ages 30+) most frequently reported getting information from a doctor or healthcare provider (60%), social media or the internet (37%), or other families in similar situations (37%).

More than one in five report key challenges around not knowing what help they need (35%) and struggling to get useful information (Contacts I have talked with are unhelpful – 20%; Website doesn't answer my questions – 20%). See **Figure 7**, page 5. Other themes that emerged from open ended responses included personal barriers such as caregivers' own health problems, lack of time, or family conflict (for example: "I do not have enough time to review & follow-up on the information provided to me"; "My spouse is unwilling to have help in the home") and the lack of centralization or coordination of services (for example: "too many agencies each offering bits and pieces not the whole picture"; "Rules

seem to be constantly changing and workers don't understand them"; "too much info can be confusing, conflicting info, scenarios differ, timelines change, health changes").

### Respite Care Utilization

Only one in five caregivers in this group reported ever using respite care (22%). The most commonly endorsed reasons for not using respite care was that the loved one would not want anyone else caring for them (37%) or that they don't need respite (32%). Respite was also seen as being too expensive (21%). See **Figure 8**, page 6. When caregivers were given the opportunity to list other reasons for not using respite care, several themes emerged. A sizable subset of caregivers in this group volunteered that they didn't know about respite care or needed more information (7%). Several also noted that they relied on family or friends to provide informal respite.

### Impacts of Caregiving

Caregivers in this group noted a wide array of impacts (see **Figure 9**, page 7). Importantly, four in five caregivers endorsed one or more positive impacts such as gaining empathy about others' situations (53%), becoming an active advocate (31%) and bringing family closer together (24%). However, nearly nine in ten reported at least one negative impact. Two-thirds reported feeling tired or worn out a lot of the time (67%) and half or nearly have reported social life decrease (58%), that their relationships have suffered (48%), or that their emotional health has worsened (47%).

### Impacts on Employment

Seven in ten caregivers in this group were employed outside the home (71%). Four in ten employed caregivers reported no impact on their work (40%). However, one in five reported decreasing their work hours (20%) and more than one in ten reported taking family/medical leave (14%) or quitting a job (12%) because of caregiving duties. See **Figure 10**, page 7. Encouragingly, employed caregivers reported that their supervisor was accommodating when the caregiver needed to leave work unexpectedly (69% reporting supervisor was accommodating "always" or "most of the time").