

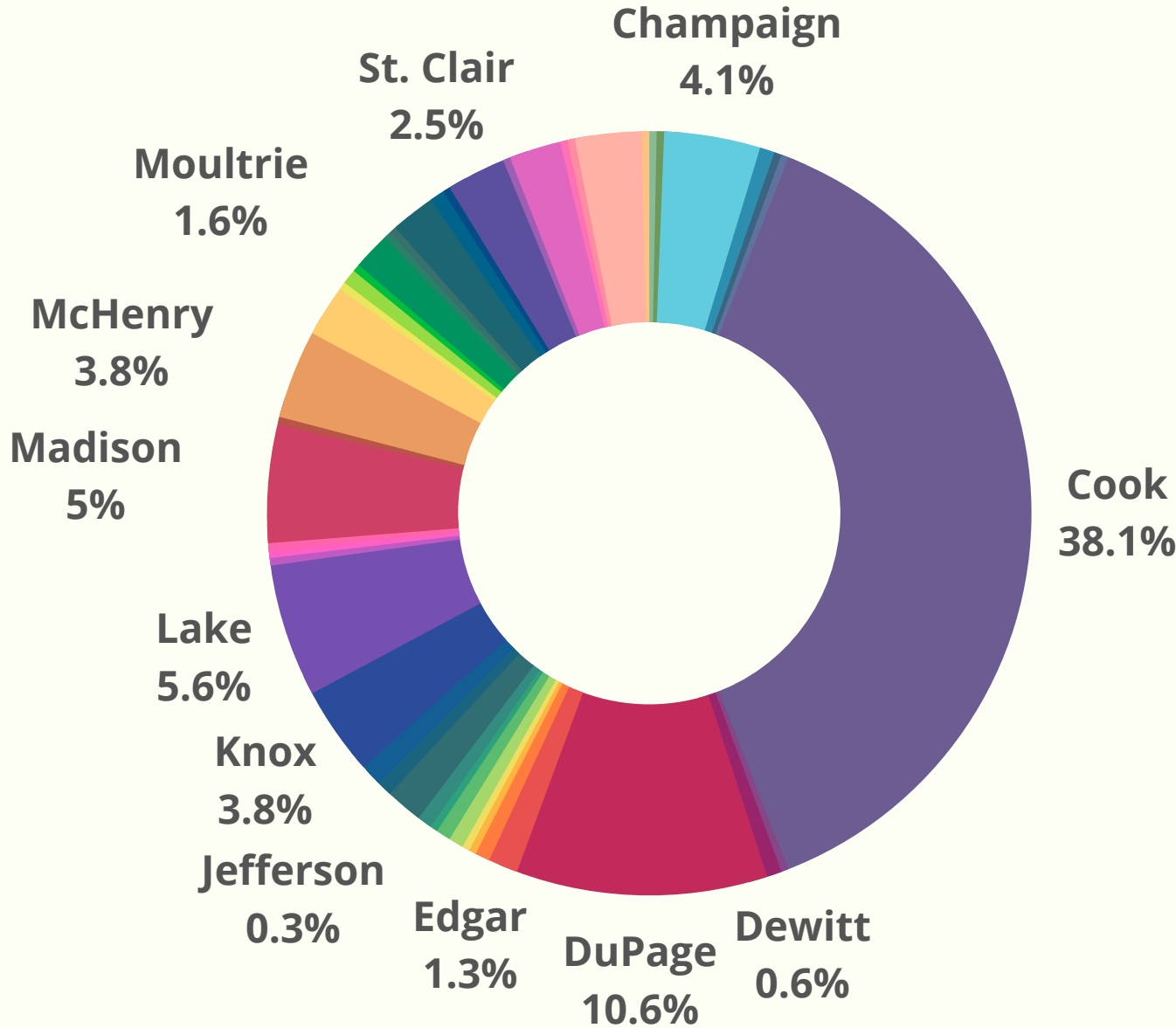
ILLINOIS CAREGIVER SURVEY

The following graphs represent the responses from caregivers across the state and lifespan.

This data represents responses from 373 caregivers and therefore needs to be considered in context from the group surveyed.

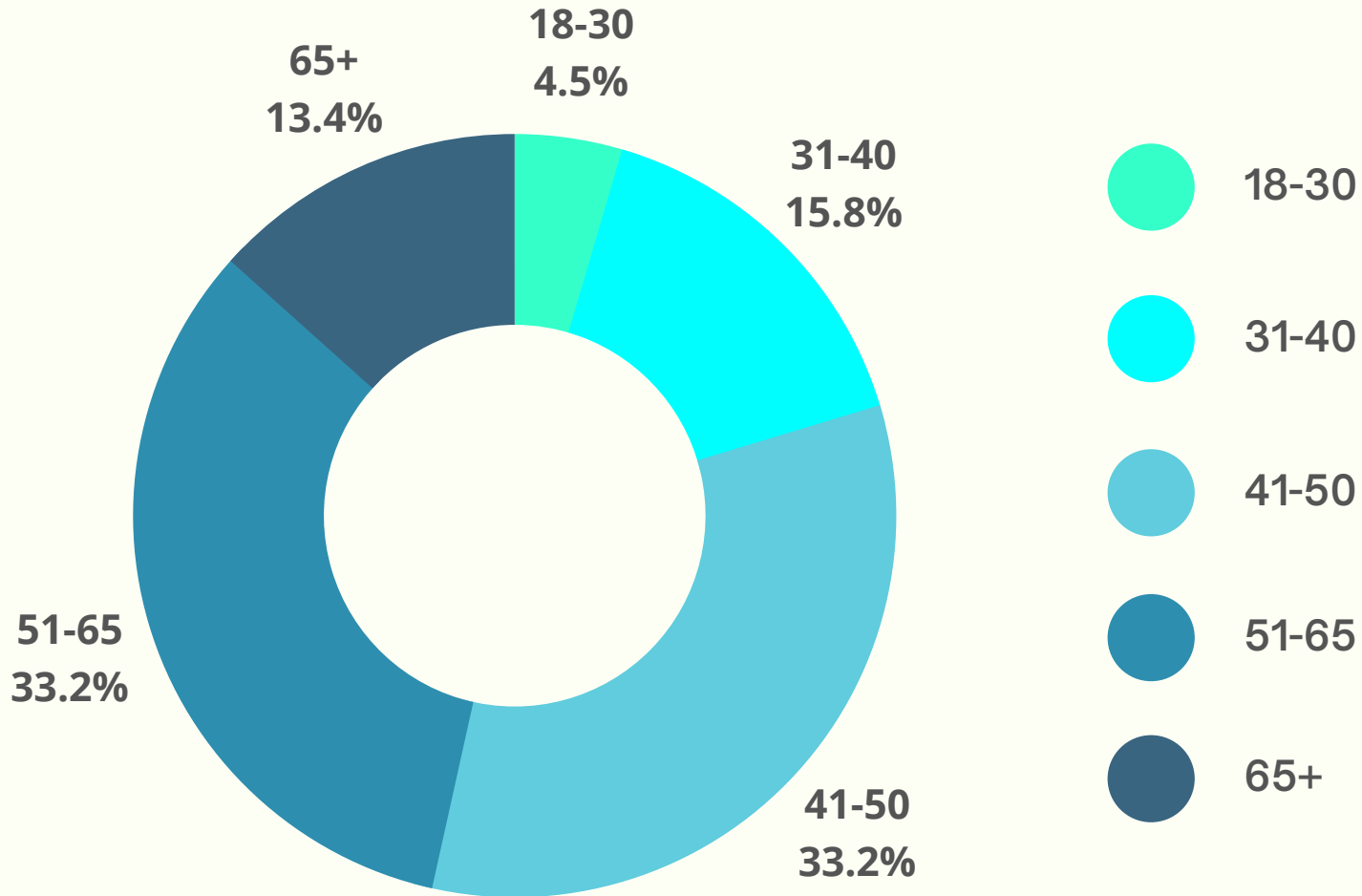
Caregiver Counties

Counties Represented

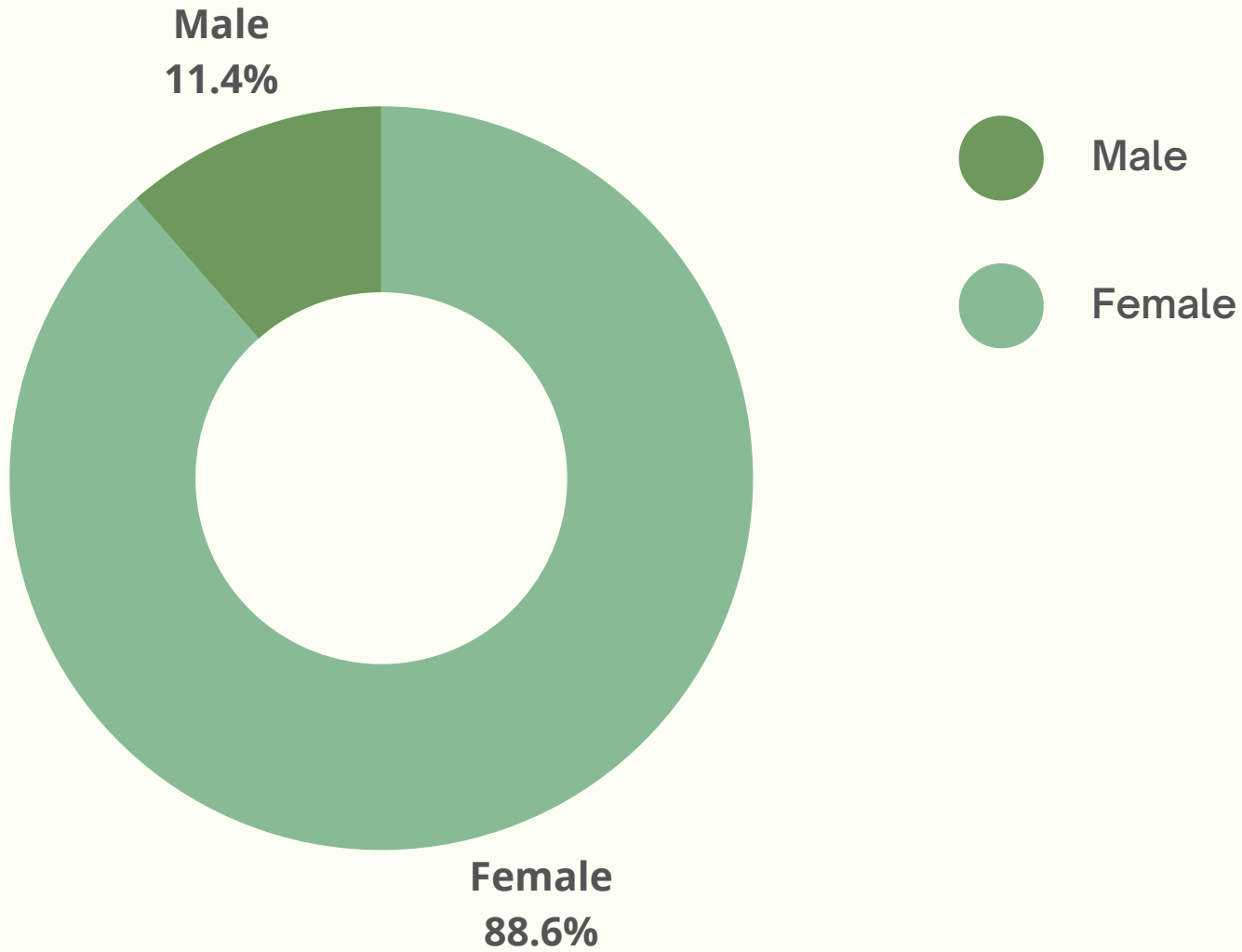


- Bond
- Bureau
- Champaign
- Christian
- Clinton
- Coles
- Cook
- Dekalb
- Dewitt
- DuPage
- Edgar
- Franklin
- Hendersen
- Henry
- Iroquis
- Jackson
- Jefferson
- Jersey
- Kane
- Kankakee
- Kendall
- Knox
- Lake
- LaSalle
- Macon
- Macoupin
- Madison
- McDonough
- McHenry
- McLean
- Monroe
- Montgomery
- Morgan
- Moultrie
- Ogle
- Oswego
- Peoria
- Piatt
- Randolph
- St. Clair
- Stephenson
- Tazewell
- Union
- Warren
- Will
- Woodford

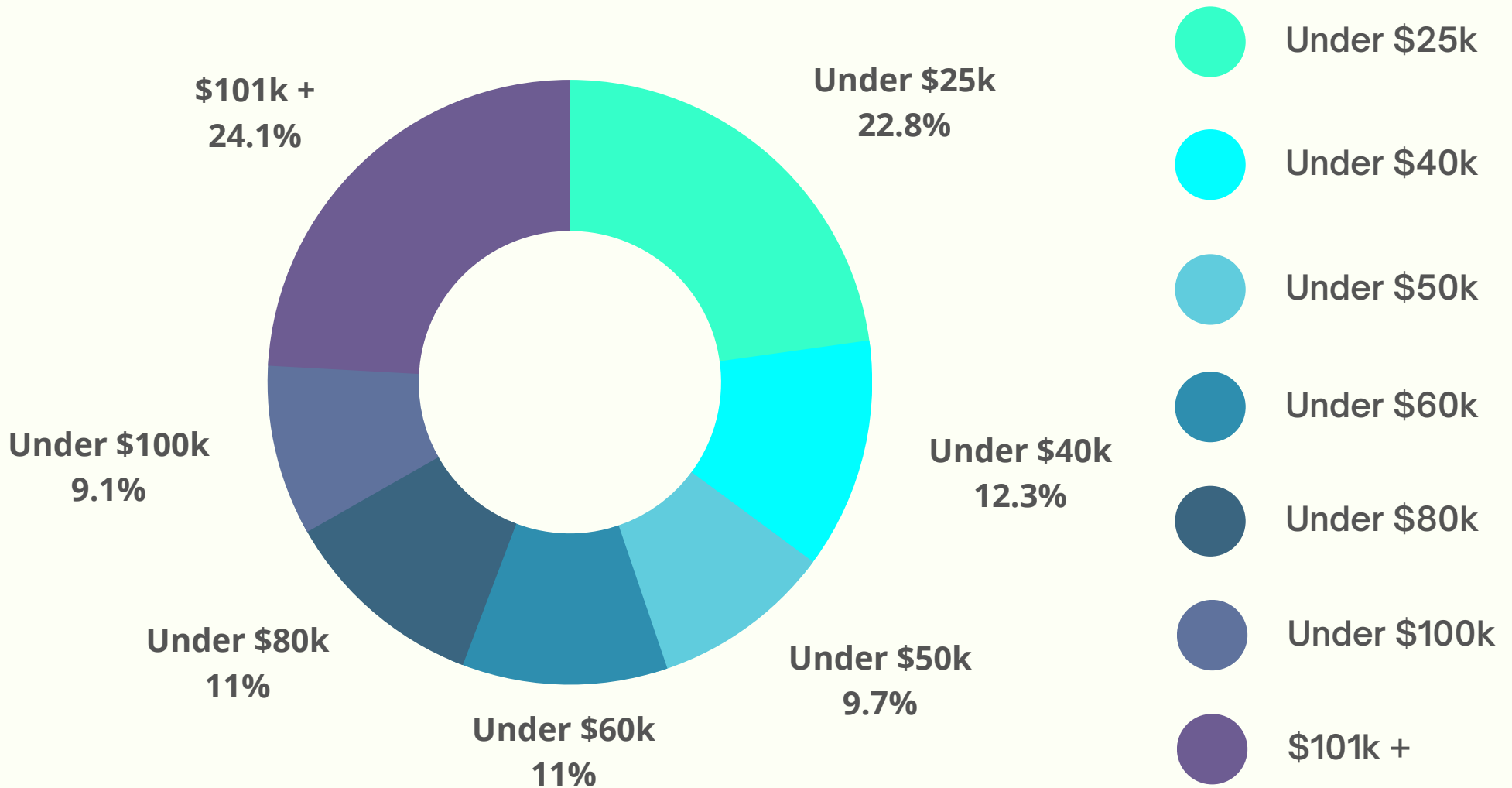
Caregiver Ages



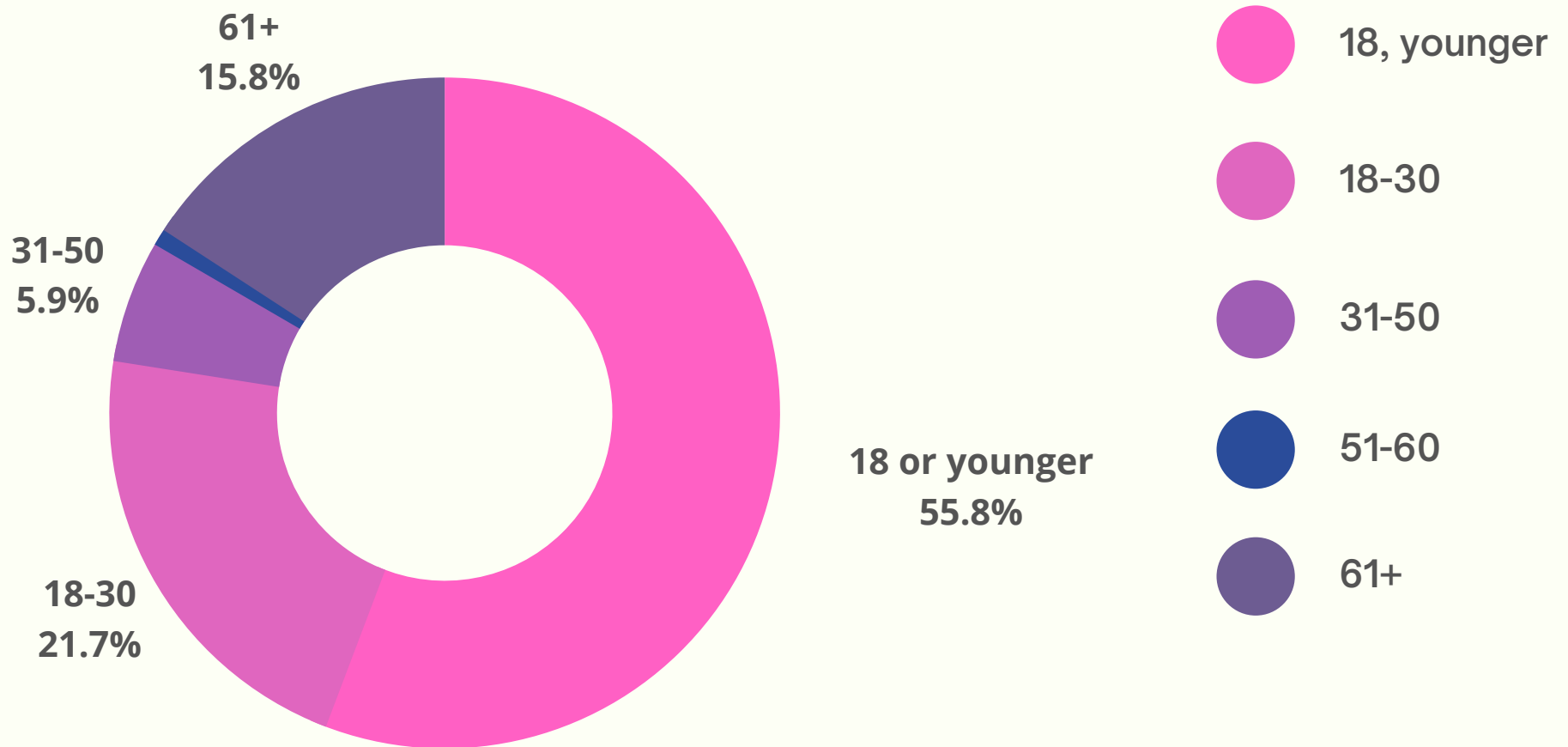
Caregiver Gender



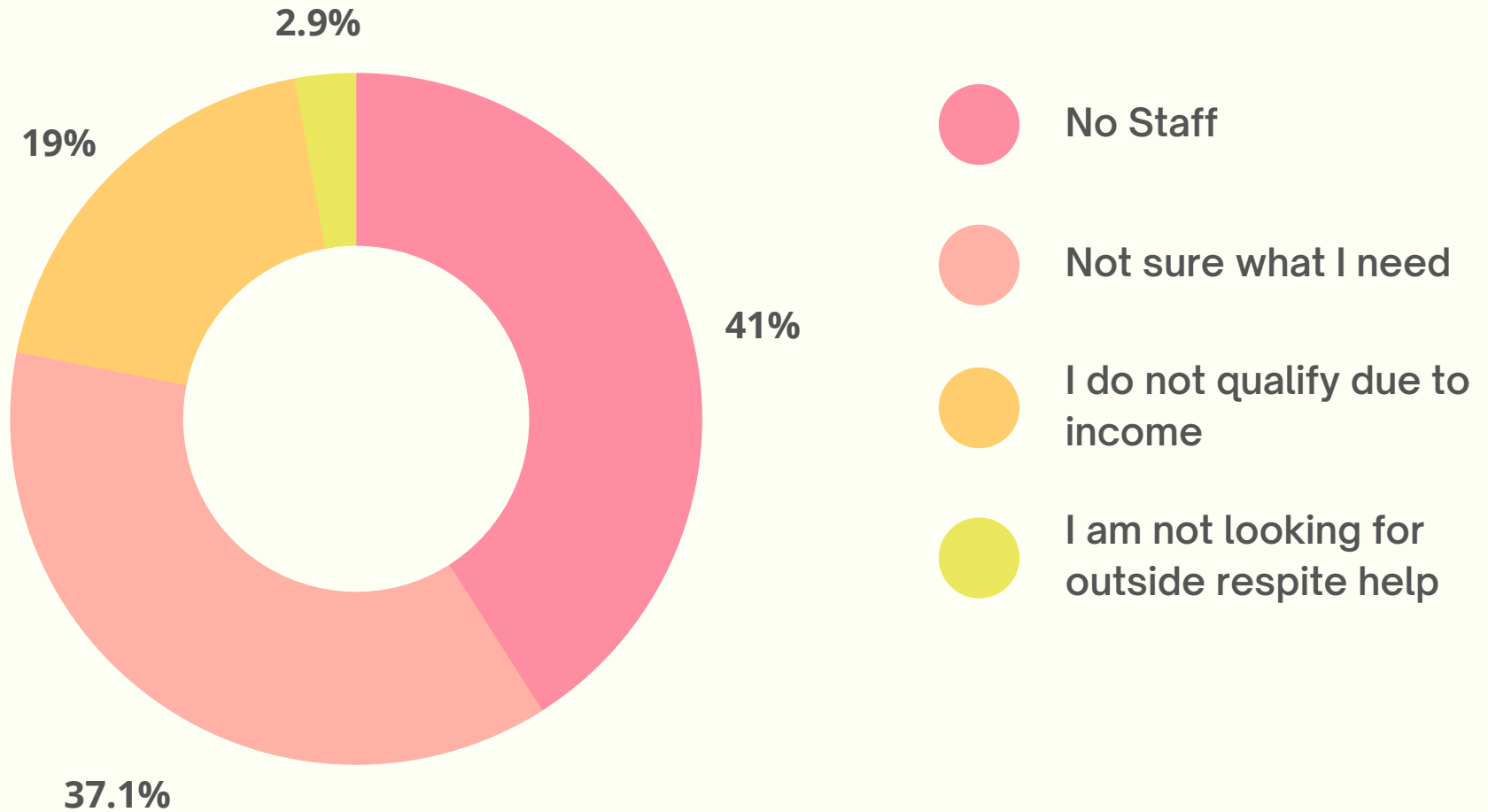
Caregiver Income



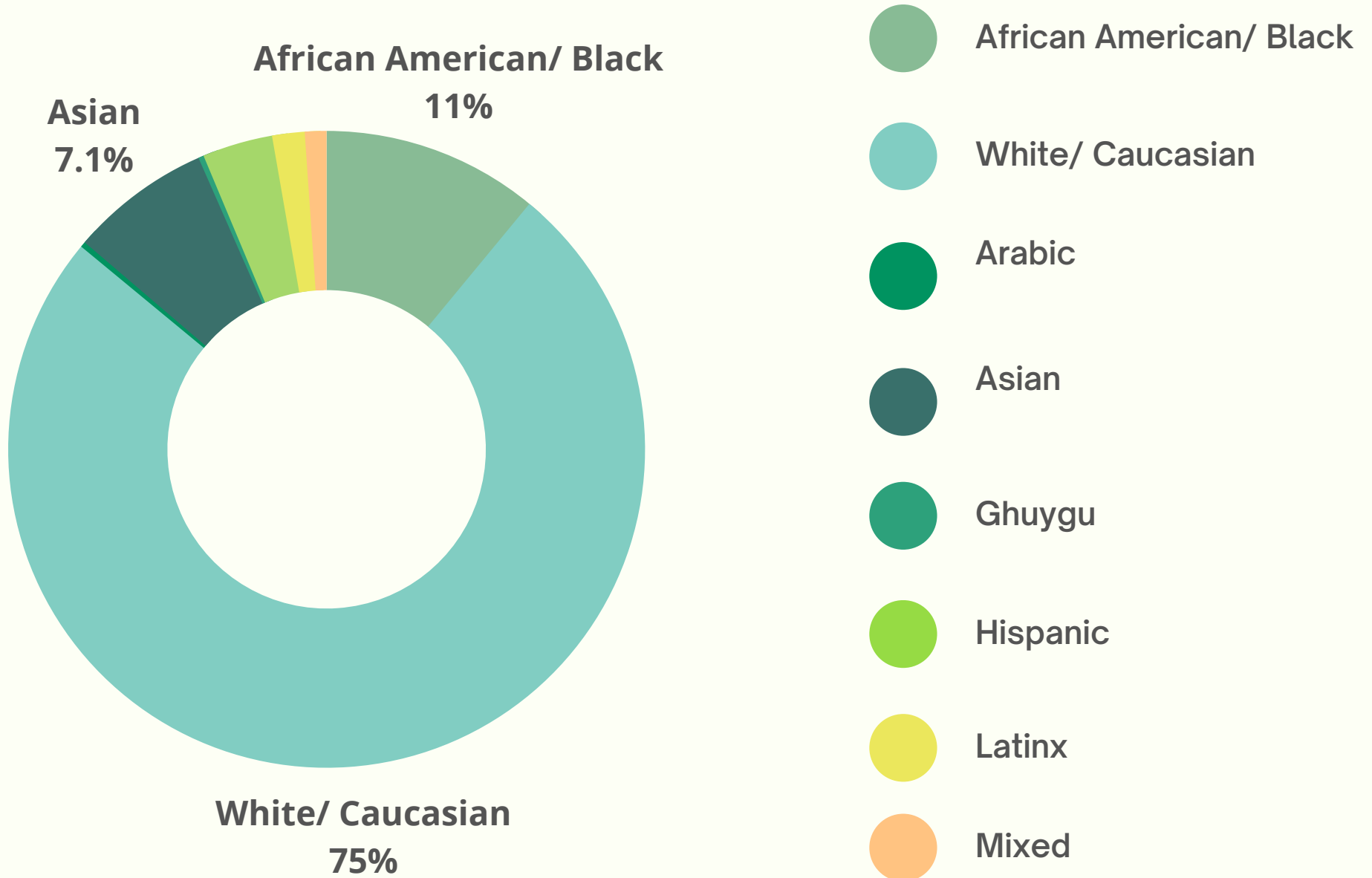
Ages of Caregiver's Loved One



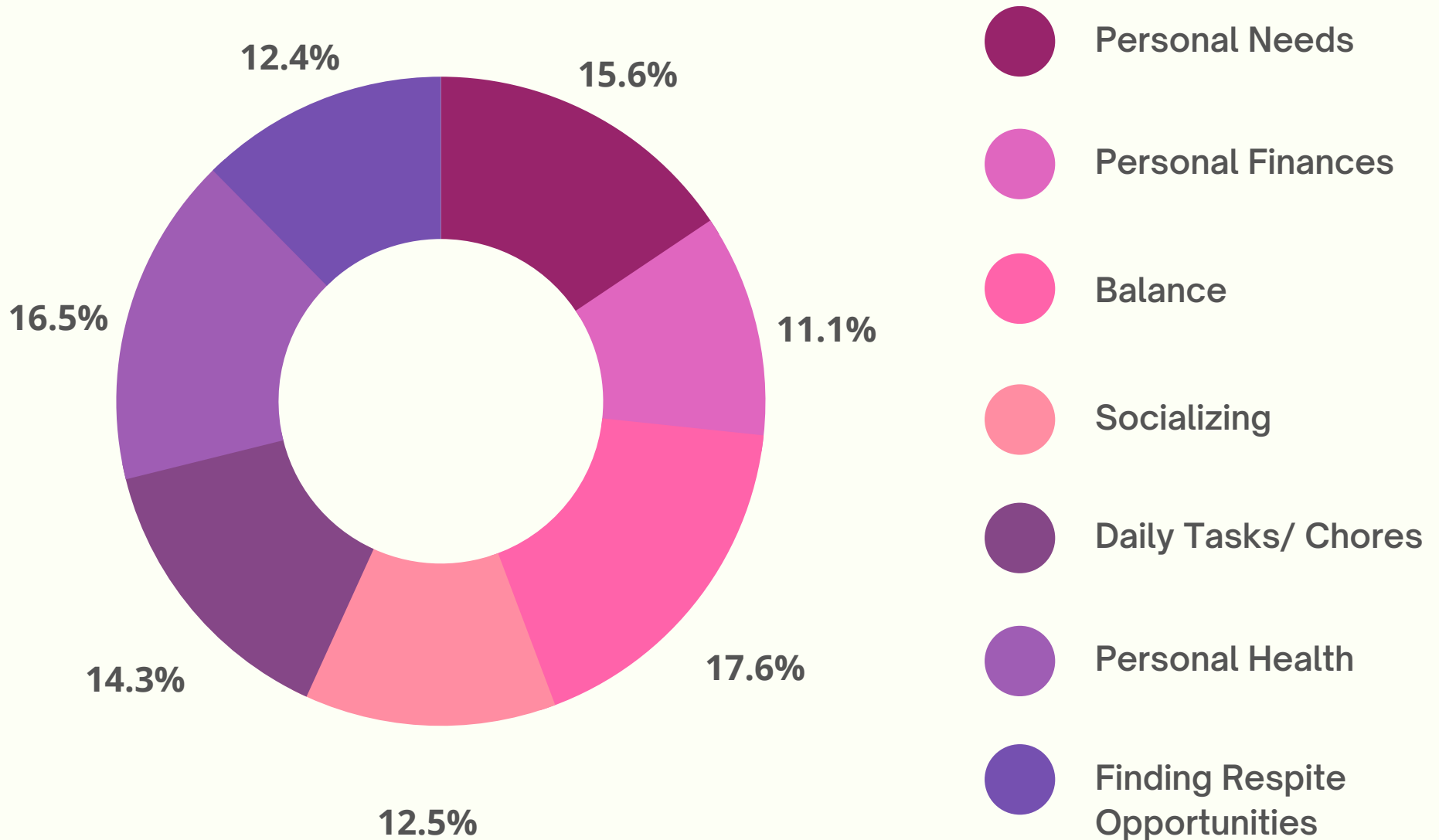
Applied but not receiving services because...



Caregiver Race



The most difficult part of caregiving



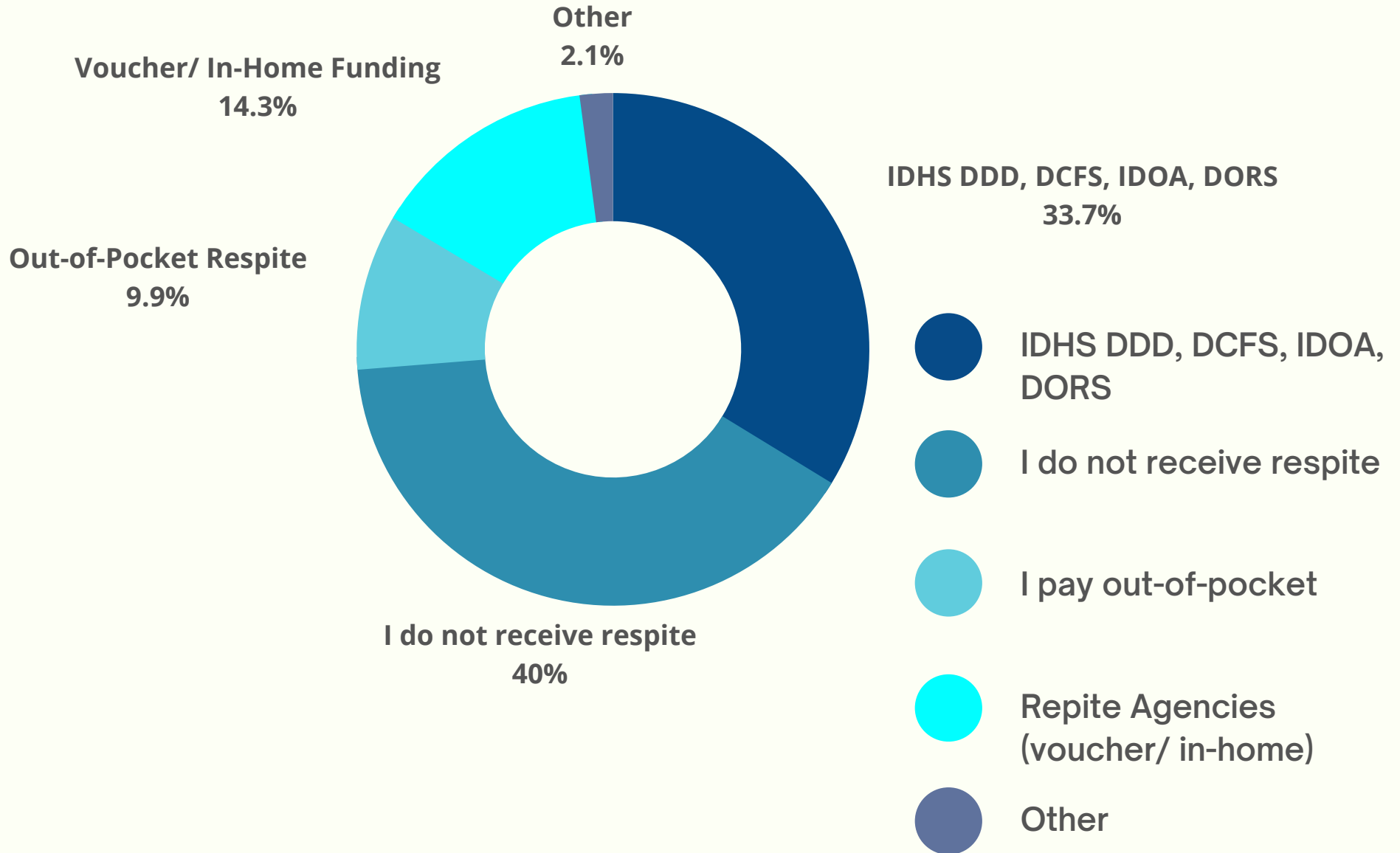
The Most Difficult Part of being a Caregiver

We gave options and allowed caregivers to select all that applied. Nearly every caregiver selected more than one option, and many selected every option.

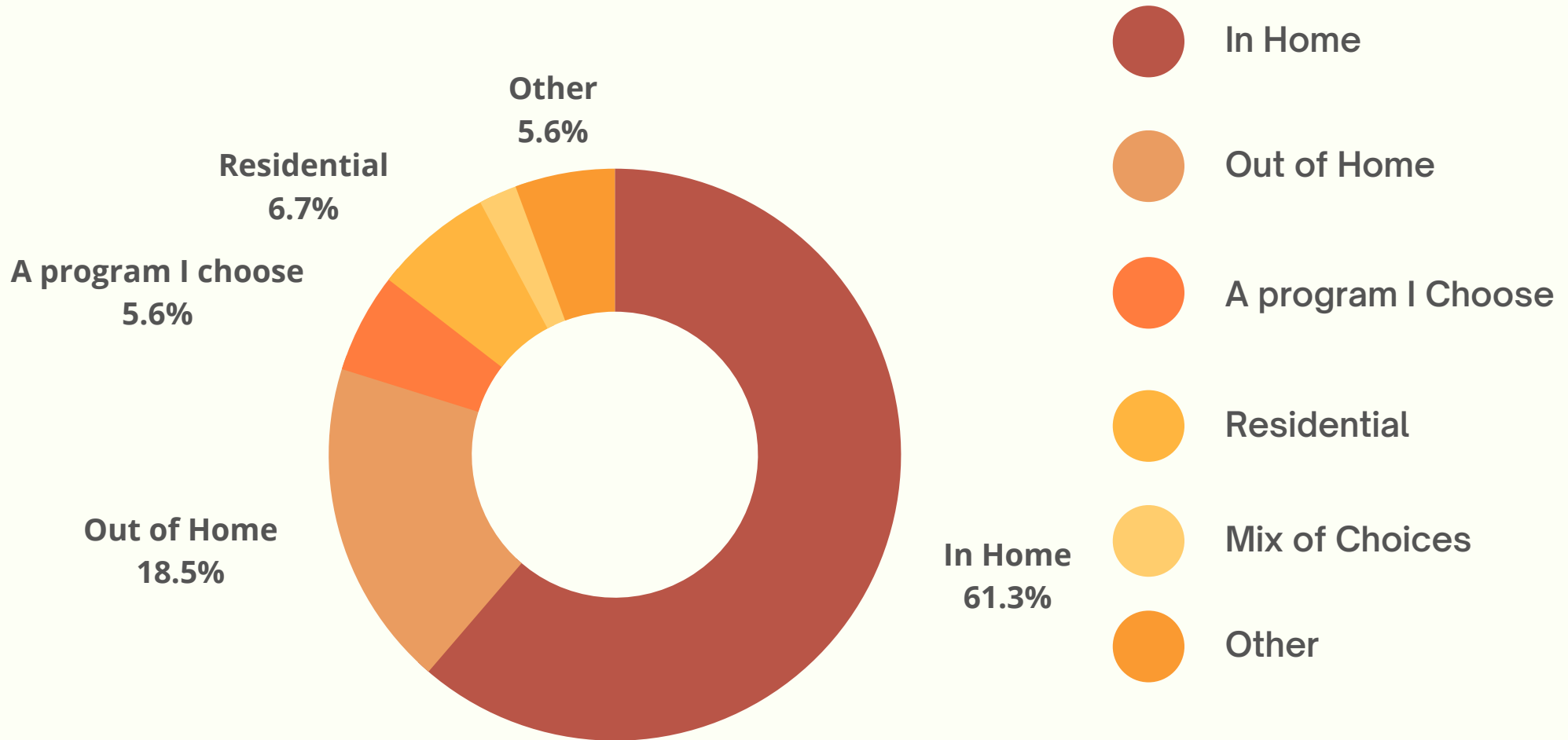
The options were as follows:

1. meeting personal needs
2. personal finances
3. balancing, family, work are caregiving duties
4. spending time with other loved ones
5. completing daily chores/ tasks
6. managing personal health/ mental health
7. knowing what other resources are available

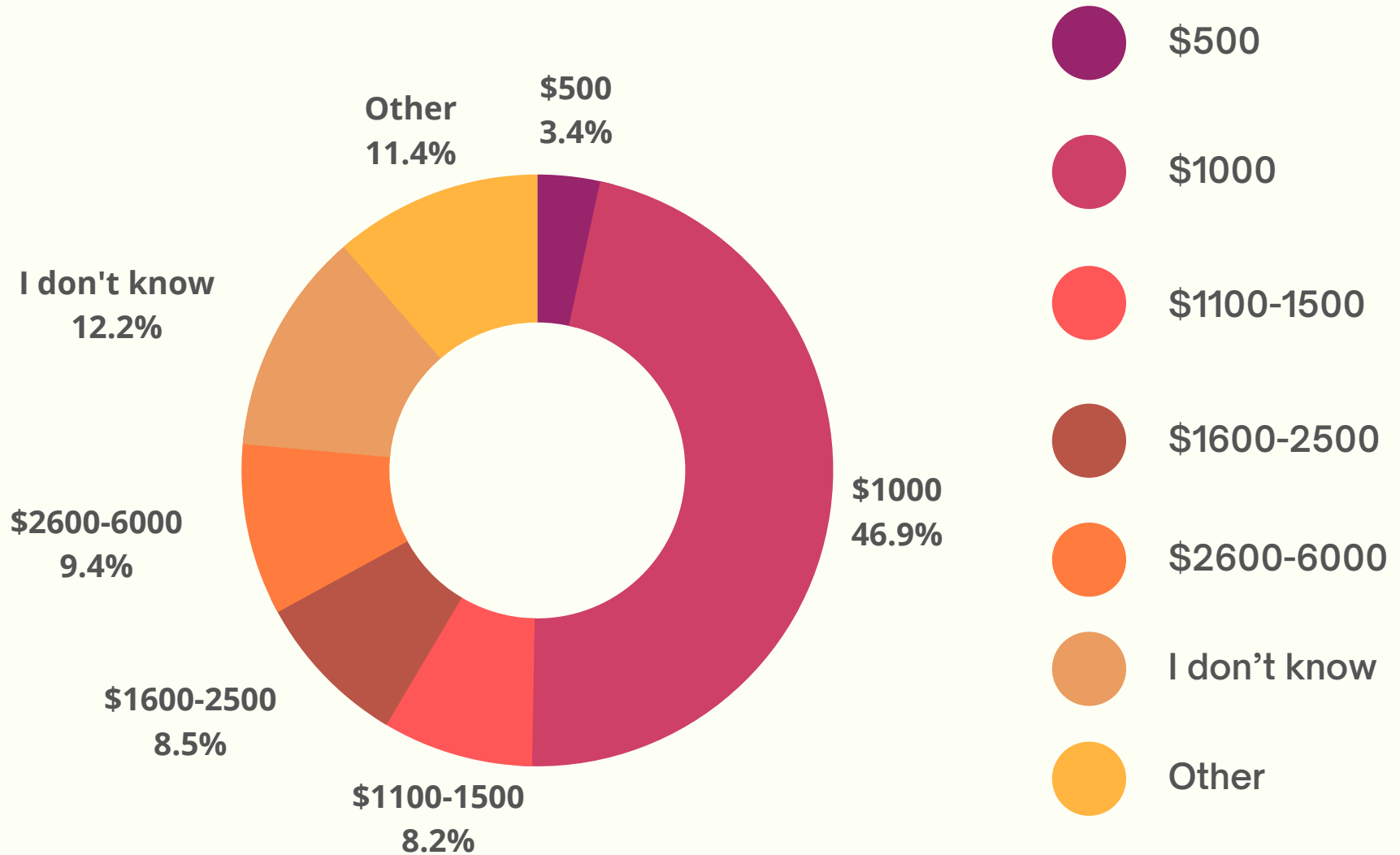
Where I receive Respite



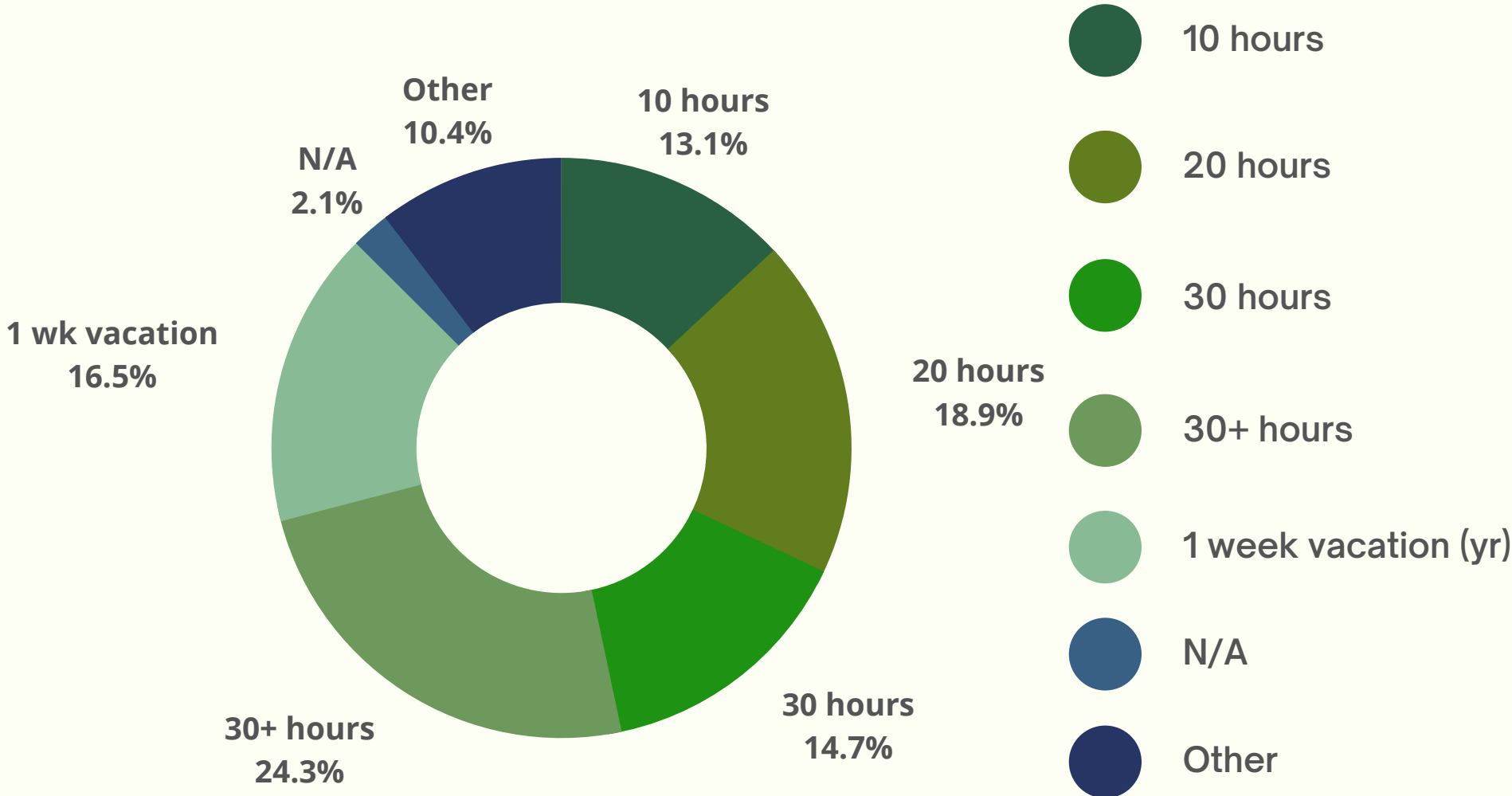
Preferred Caregiver Respite



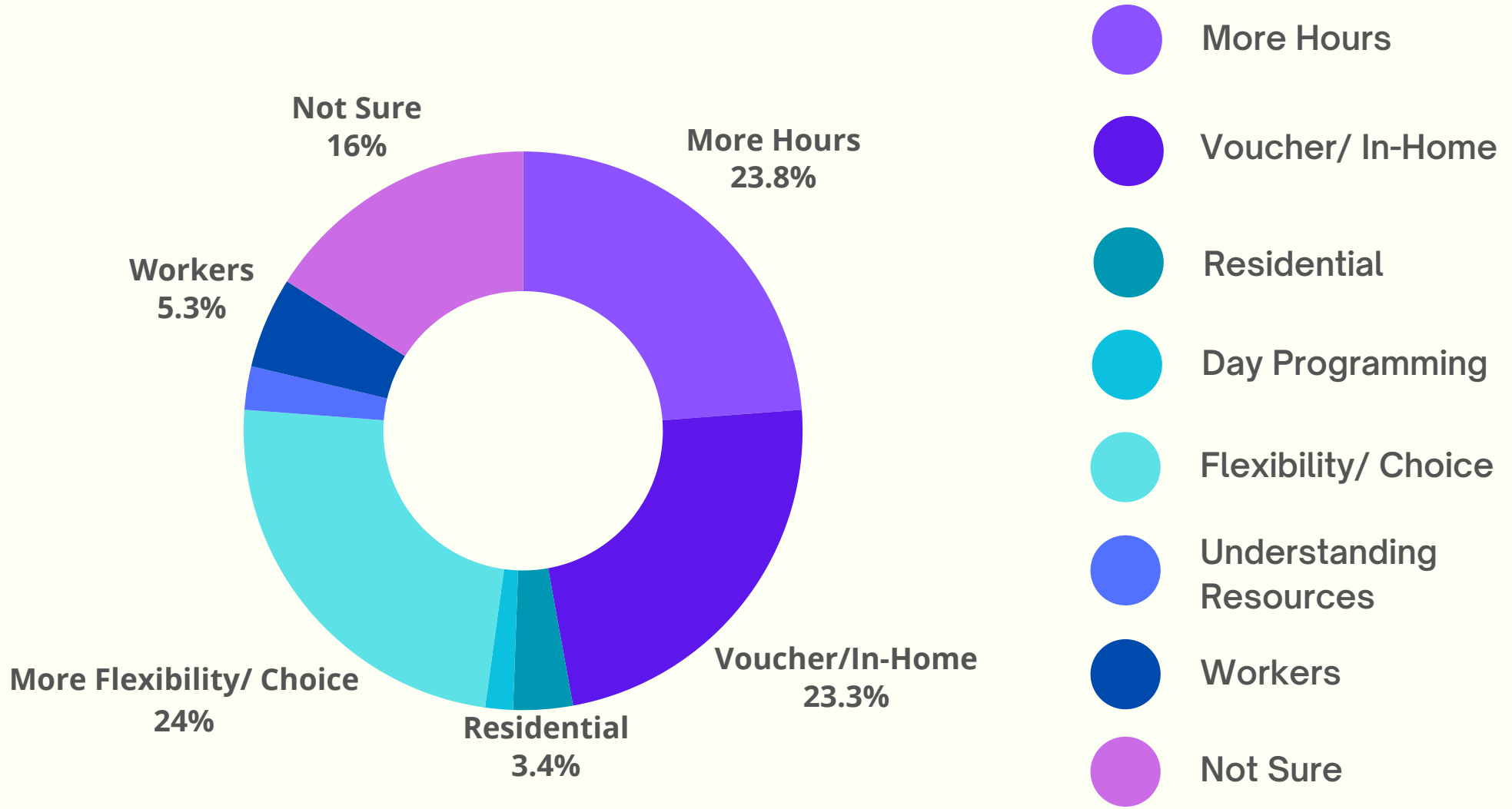
Desired Yearly Voucher Stipend



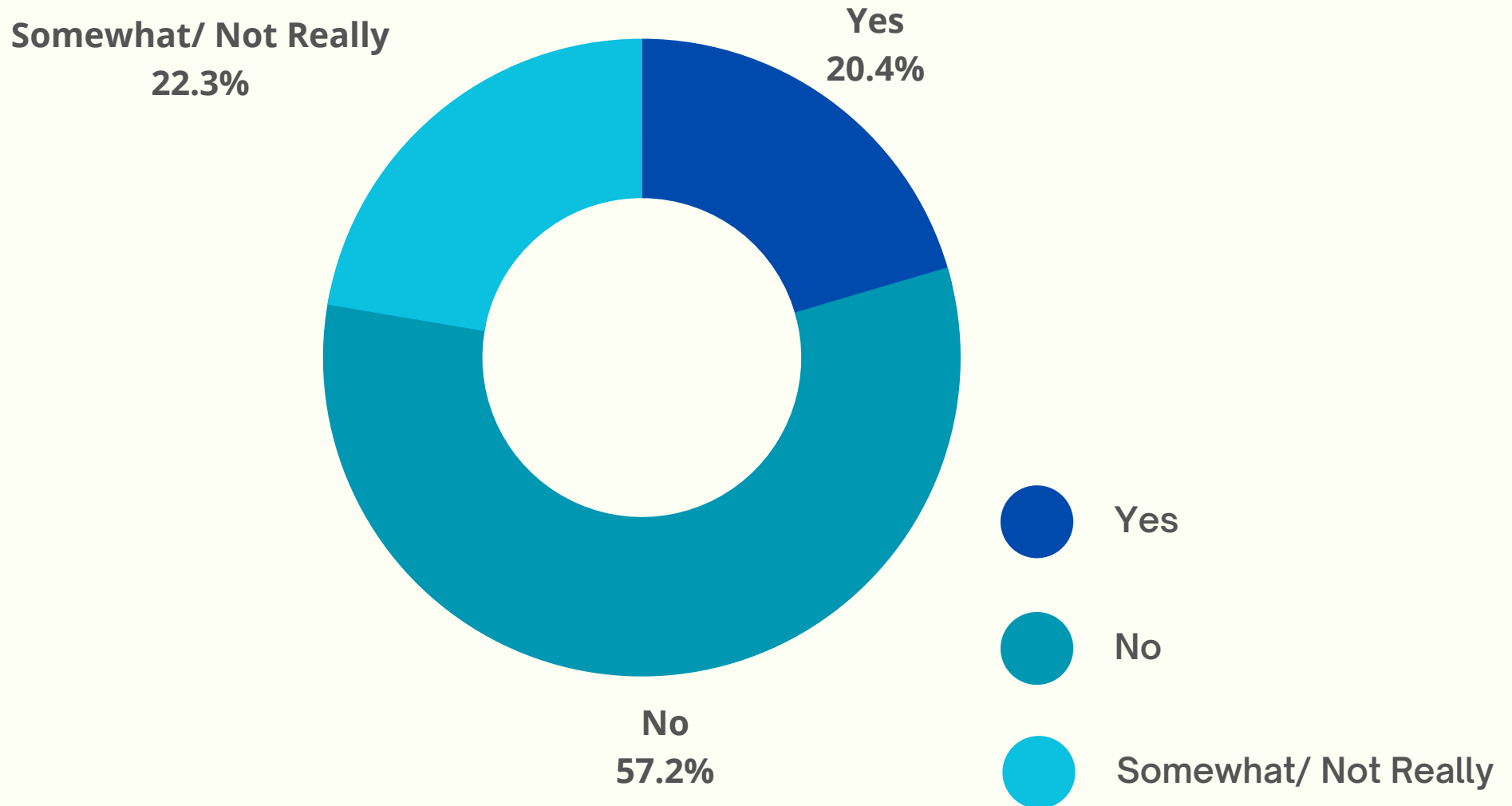
Monthly Hours to Keep Individual In-Home



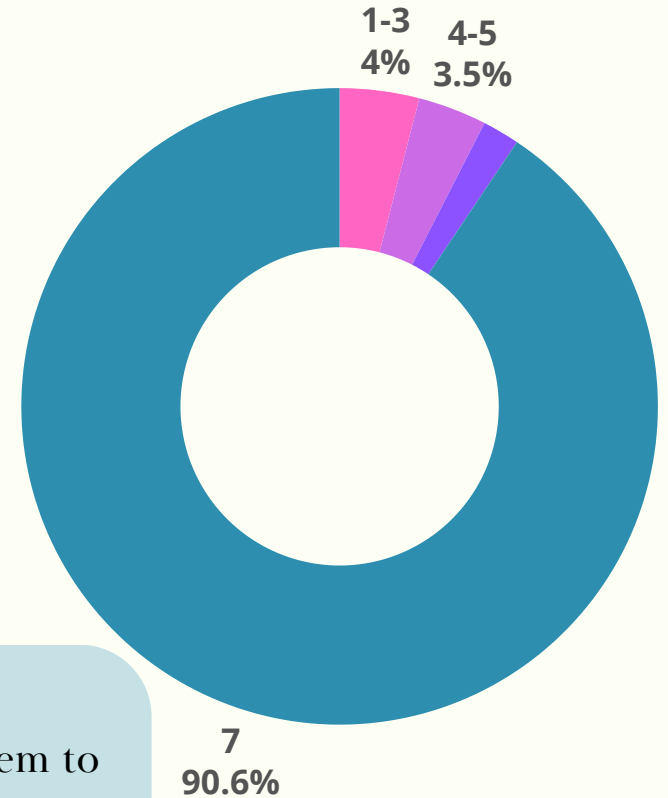
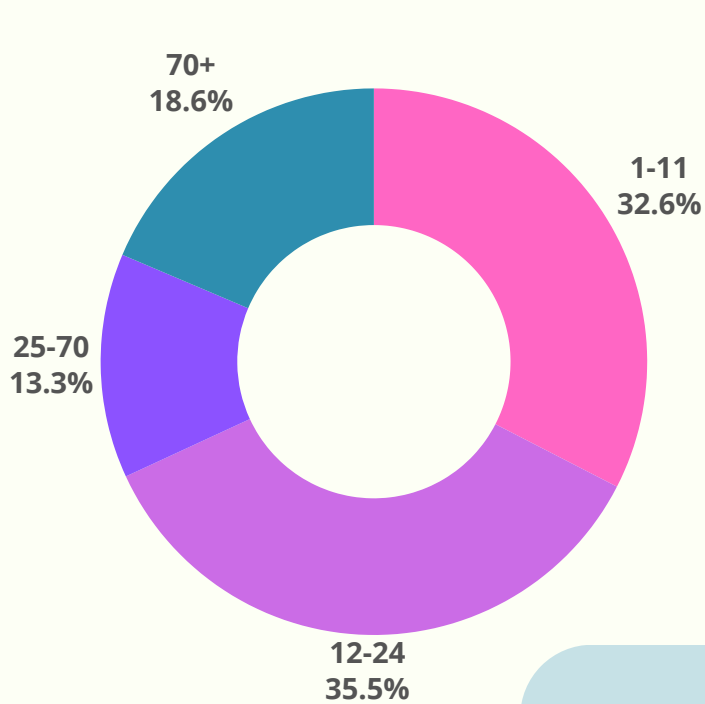
Additional Requested Services



Do you know what services are available?



Hours per Week // Days per Week

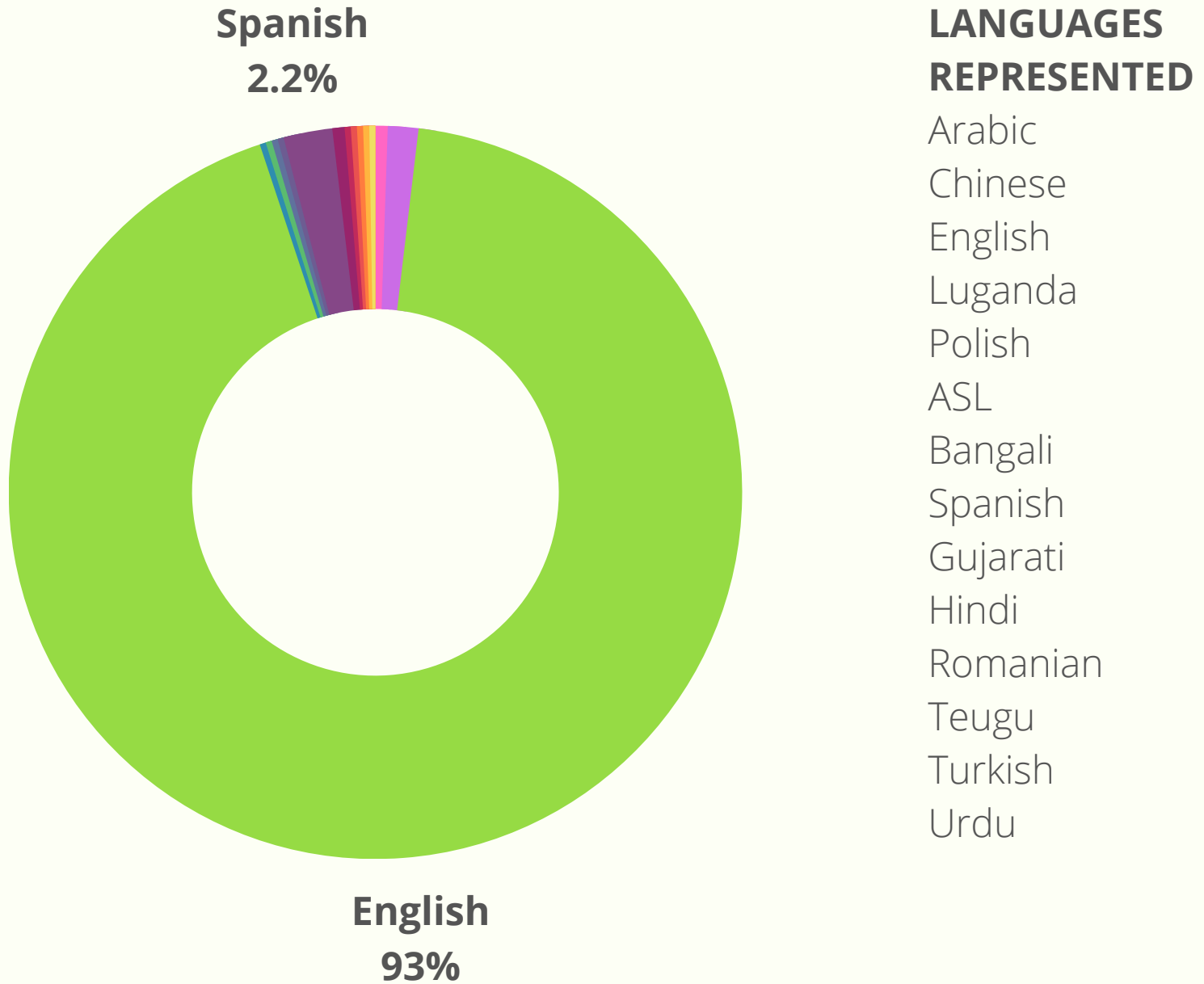


Please note:
 Based on how these two responses seem to contradict themselves, look to the “days per week” responses more closely than the “hours per week” category. Through analyzing the results, it appears that many caregivers read hours per week as hours per day, skewing these answers. We anticipate editing this question in the next survey iteration for better results.

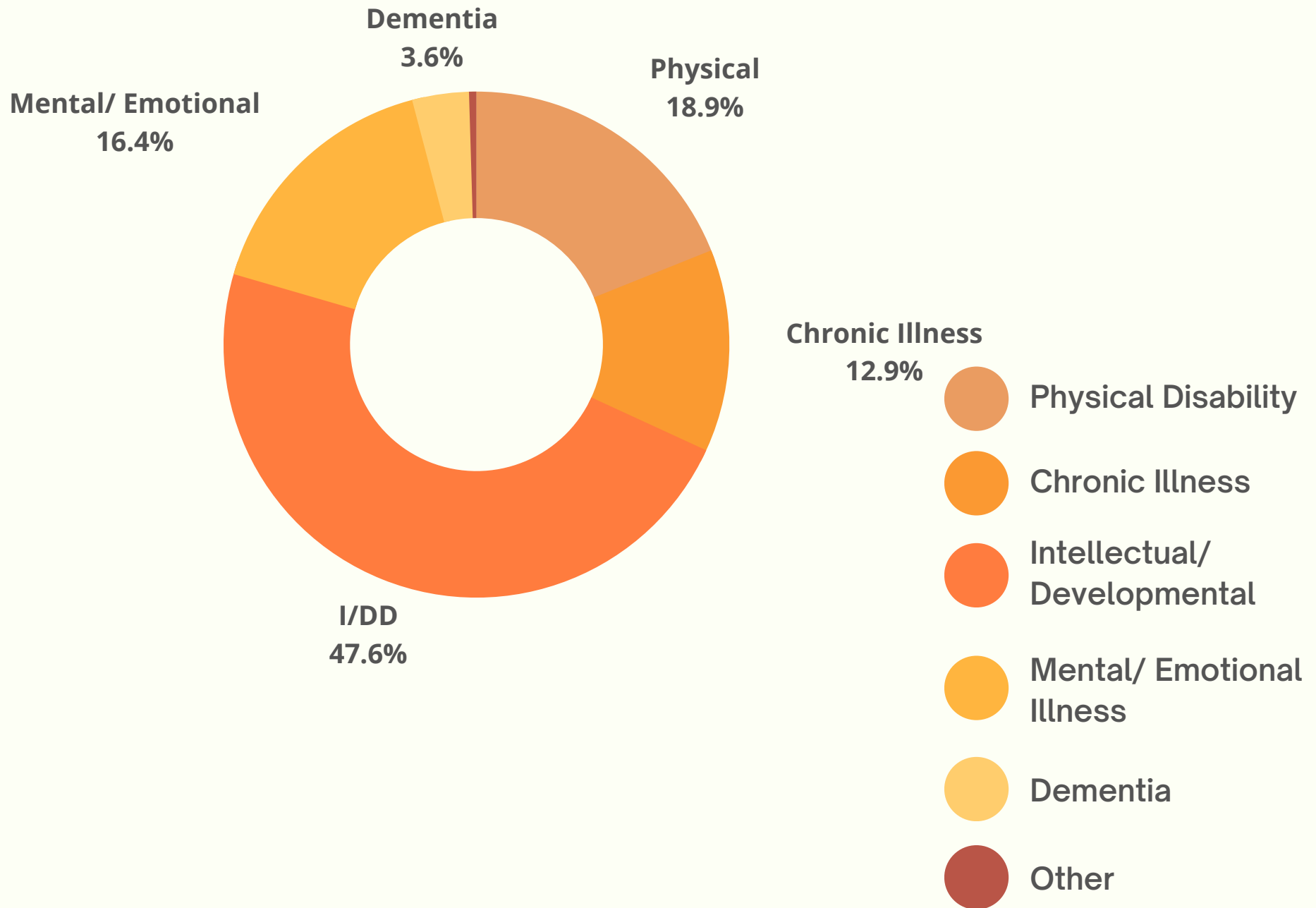
- 1-11 hours
- 12-24 hours
- 25-70 hours
- 70 + hours

- 1-3 days
- 4-5 days
- 6 days
- 7 days

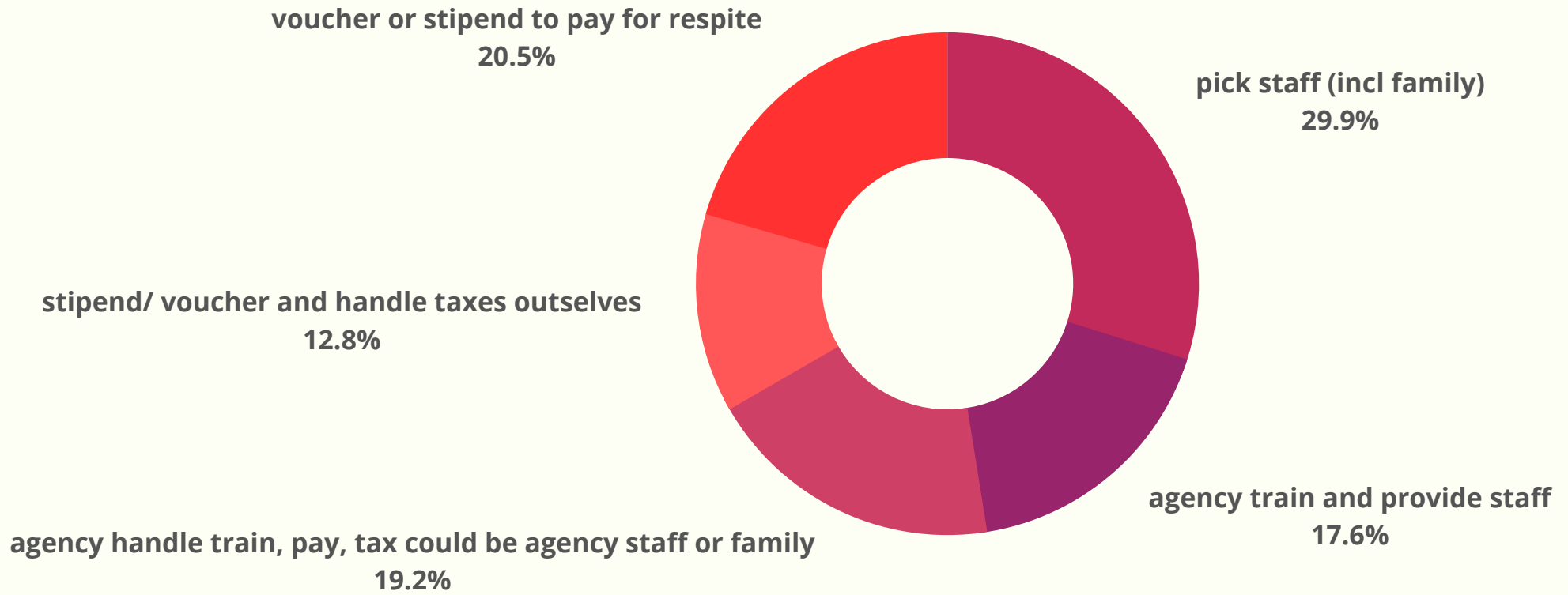
Primary Language



Types of Disabilities



Choice for Staff Payment/ Training



Impact on Employment

“It is difficult to work on little to no sleep. I enjoy working, but often get overwhelmed at the needs of loved one and the need to earn enough to support our family. Paperwork required to advocate for our loved one can be time consuming.”

“My husband and I have been fortunate enough to find flexible mostly work from home jobs and we are self employed. It would be very difficult to maintain employment outside the home.”

“Lower wages, hourly job due to needing to be available to son, sick days are used up every year and usually have to take unpaid time off, can't work in my chosen profession because work hours would not coincide with caregiving needs.”

“What employment? This is the hardest job I've ever had. In my premom life I worked as a RN on the floor of a local hospital- before that 8 years in skilled nursing facilities... well the day I had my daughter I clocked in for a shift that has never ended.”

Impacts on Friends and Family

“Not many friends left; they just quit coming around.”

“We cannot always do events or social commitments on the account of caregiving - if we do we pick wisely and when we do it often ends up being a blow-out of a situation, which leaves us wondering why we decided to try to participate. We have had to forfeit plans last minute, wasting money and impacting our relationships. Things that other families enjoy (like going to the swimming pool in summer) can be extra stressful and challenging for us to participate in. I have had to take mental breaks before going to work, after caregiving, because of how challenging/stressful the moments leading into work were/are. We cannot travel on planes, and we hesitate to travel far by car, so the ability to take trips and visit friends is very limiting with our child, but then it's equally as challenging to travel without our child because we have to find someone to care for him while we are gone and to have someone equipped to do that for overnights is near impossible. Our child is still in diapers and the world is not equipped to deal with a larger child in diapers, so that limits our ability to run errands and go to social events (where are we supposed to change him if he needs a diaper change)?”

“Most of my family is out of state or in later age to take care of him. I stopped asking some people because it feels like a burden to them, I don't have many friends because I can't go out when they can.”

Positive Impacts of Caregiving

“She had taught me a lot, she had made me understand our world better. She helps us slow down and enjoy the small things, she teaches us to not complain so much.”

“Fulfilling a promise to my late mother.
Helping my Dad.”

“My son is so full of joy, it has made me prioritize what’s important, I have confidence in how to take care of him, I can help others who are in similar situation, I’ve learned so much about Down syndrome.”

“Hugs, smiles, cherish time together, enjoy exploring together, seeing their growth, observing how they try new experiences, perceive life's experiences, problem solve, etc. Watching them glow when enjoying activities they like n they are beaming when he/she is around peers enjoying same thing. New things they think of and new stages and phases.”

“Sharing his joy of life. Our son loves his job. He is very active in Special Olympics. He has friends who are delightful. He is loving of his extended family. He cares for the poor and homeless. He is accepting of everyone.”

What would You like Us to know about caring for a Loved One?

“It’s extremely hard on our bodies in every area. We also worry more than most people. Respite is vital to the longevity of our lives.”

“It is one of the most rewarding and heart wrenching experiences I've ever had. It's a lifelong commitment for an entire family to support their special needs person. For the parents but also for the siblings. I'm trying to get by day by day but also planning for the day I am gone if my special needs child outlives me. I need to make sure she is supported and I need to make sure her brother don't have the weight of the world on him to care for her. Having funds to help her live her life now is so important to us. The small amount of respite care we do get means a lot to our family.”

“It is a great and loving honor that we have, and that we know we will face for the rest of our lives, unlike other parents whose children will eventually fly the nest and have their own lives. Even as we hope and plan for a CILA placement, we also know that our son does not advocate for himself and is the perfect potential victim. This is a heartbreaking reality.”

“Very stressful on the family. Cannot do anything together like going to dinner, movies, sports events, etc. Someone always has to be home with my son. I've missed out on my other children's sports events for years.”