



NEBRASKA CAREGIVER SURVEY REPORT

July 1, 2024 - June 30, 2025



RESPITE EMPLOYER ENGAGEMENT
MUNROE MEYER INSTITUTE



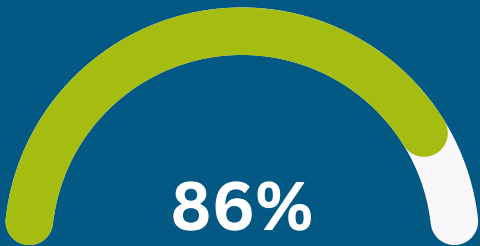
OBJECTIVE

This survey is designed to showcase the needs and demographics of individuals and caregivers across the state of Nebraska. Full details of the survey are listed below.

OVERVIEW

The average Nebraska resident is a woman over the age of 40 who is a primary caregiver for a parent/in-law and/or child with special needs. She provides at least 20 hours of care per week outside of her full-time job. The person in need of care lives with her and has been receiving her care for 3-5 years. She receives a daily break from caregiving with the help of a family member.

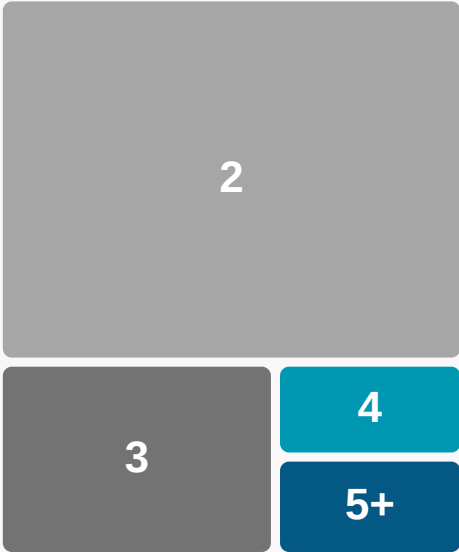
Over 80% of survey participants are caring for a loved one with a chronic health condition, disability, or limitation due to aging (n=129).



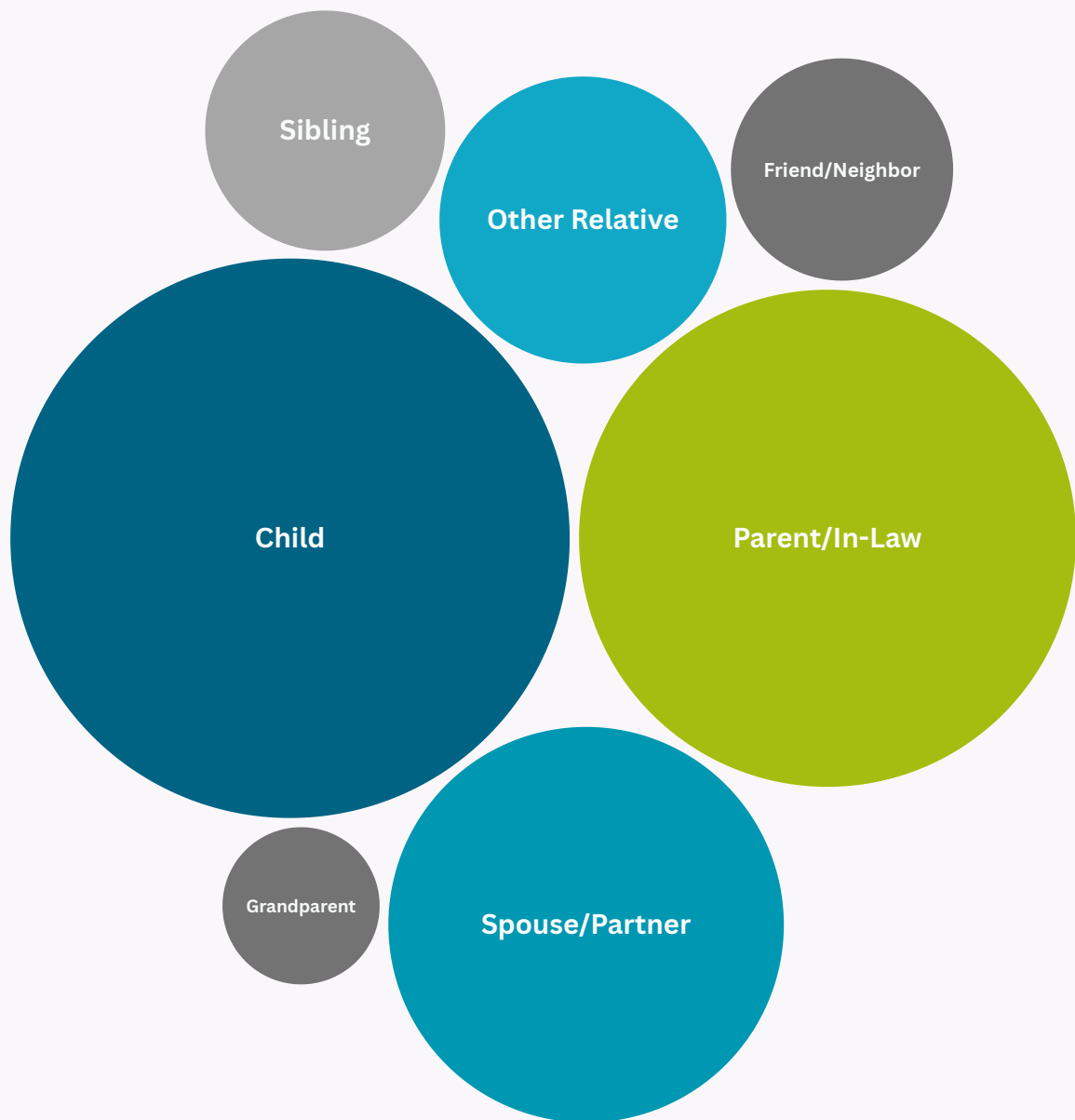
The majority are primary caregivers (n=100).

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Most care for 1 individual who is disabled, chronically ill, or aged (n=99).



Most are caring for a parent/in-law or child with special needs(n=102).



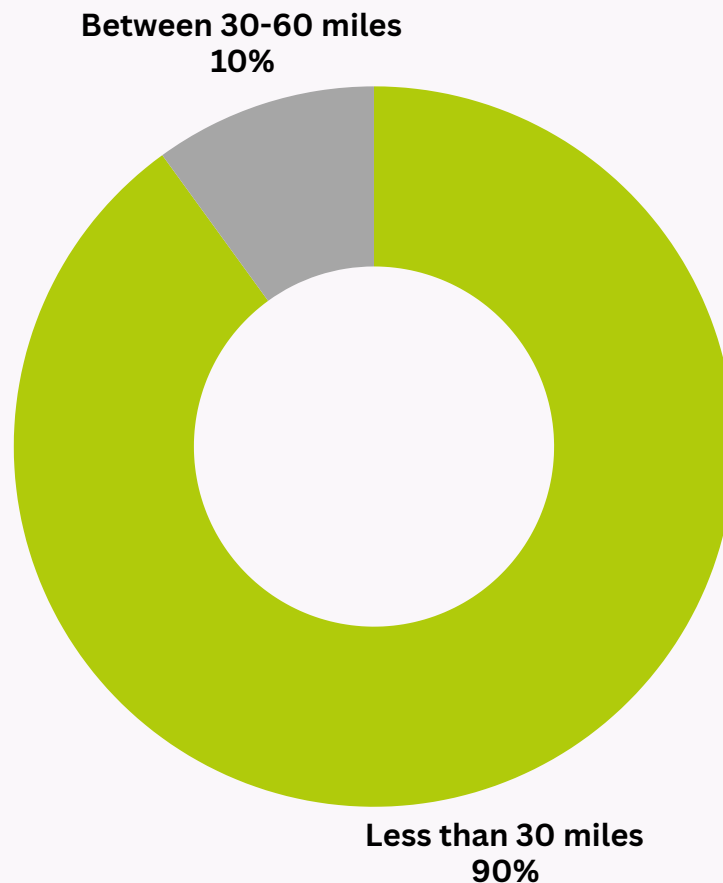
The majority of caregivers live with the individual(s) in need of care (n=98).



Only 10% of caregivers support a loved one in an assisted living facility (n=30).



Nearly all respondents care for an individual that lives less than 30 miles away (n=30).

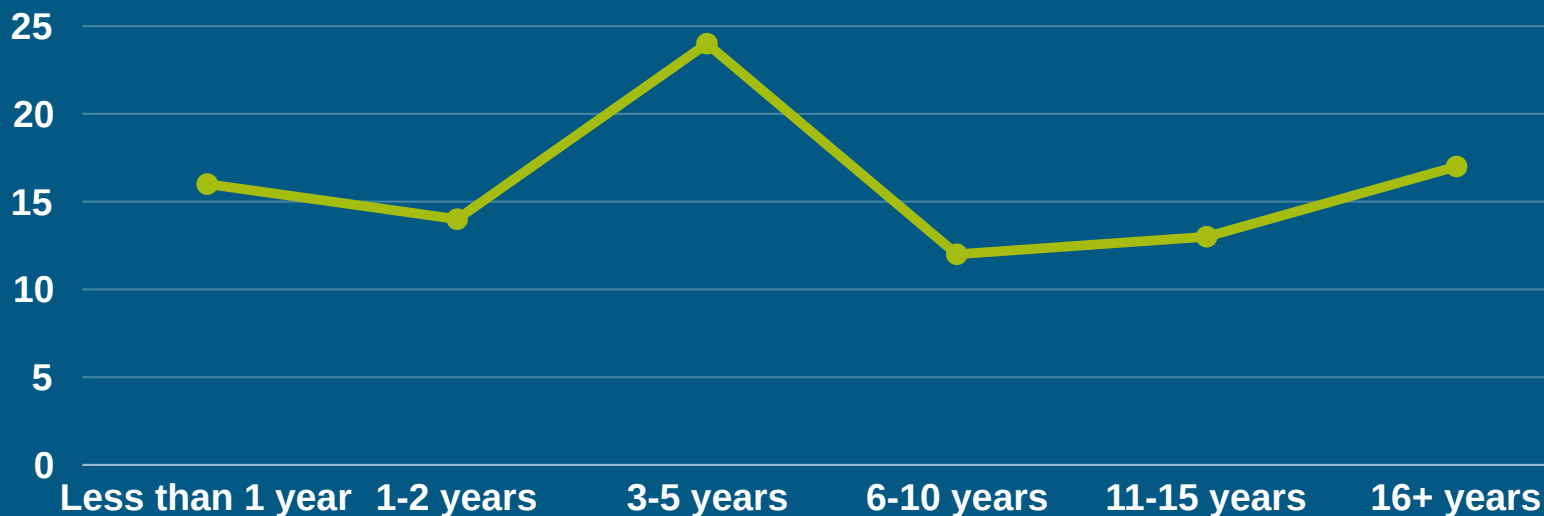


Most respondents provide care on a daily basis (n=96).



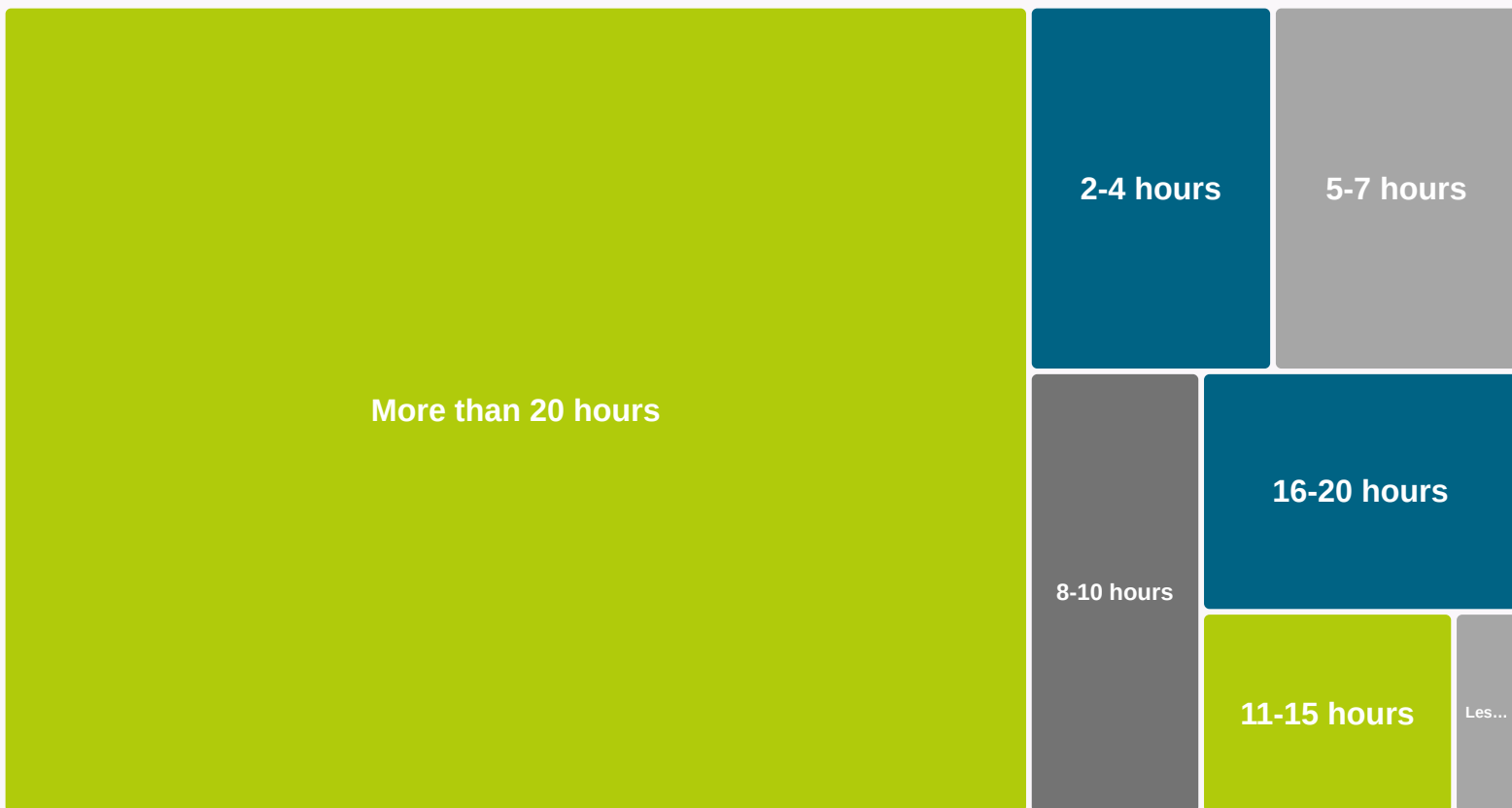
YEARS SPENT CAREGIVING

Most respondents have been providing care for 3-5 years (n=96).



HOURS PER WEEK

Most are providing more than 20 hours of care per week (n=96).



Everyone reported that caregiving requires a variety of tasks (n=96).



BREAKS

Most caregivers get a daily break from caregiving, but **23%** never get a break (n=94).

Daily

Once a Week

Every 1-6 Months

Monthly

Never

2-6 Times per Week

Once Every Other We...

Ever...

RESPITE

Most caregivers rely on relatives and/or significant others for Respite (n=83).

Other Relative

Spouse/Partner

Other

Respite Provider

Childcare Provider

School



Half of respondents have no one to call to fill in as caregiver if they are not able to provide care due to an emergency (n=96).



A quarter of caregivers have a health condition of their own that affects their caregiving abilities (n=92).



The majority of caregivers have experienced emotional and/or physical stress from caregiving (n=92).



Most respondents care for someone with memory care needs, long-term health conditions, and/or developmental disabilities (n=97).

Developmental Disability

Long-Term Health Condit...

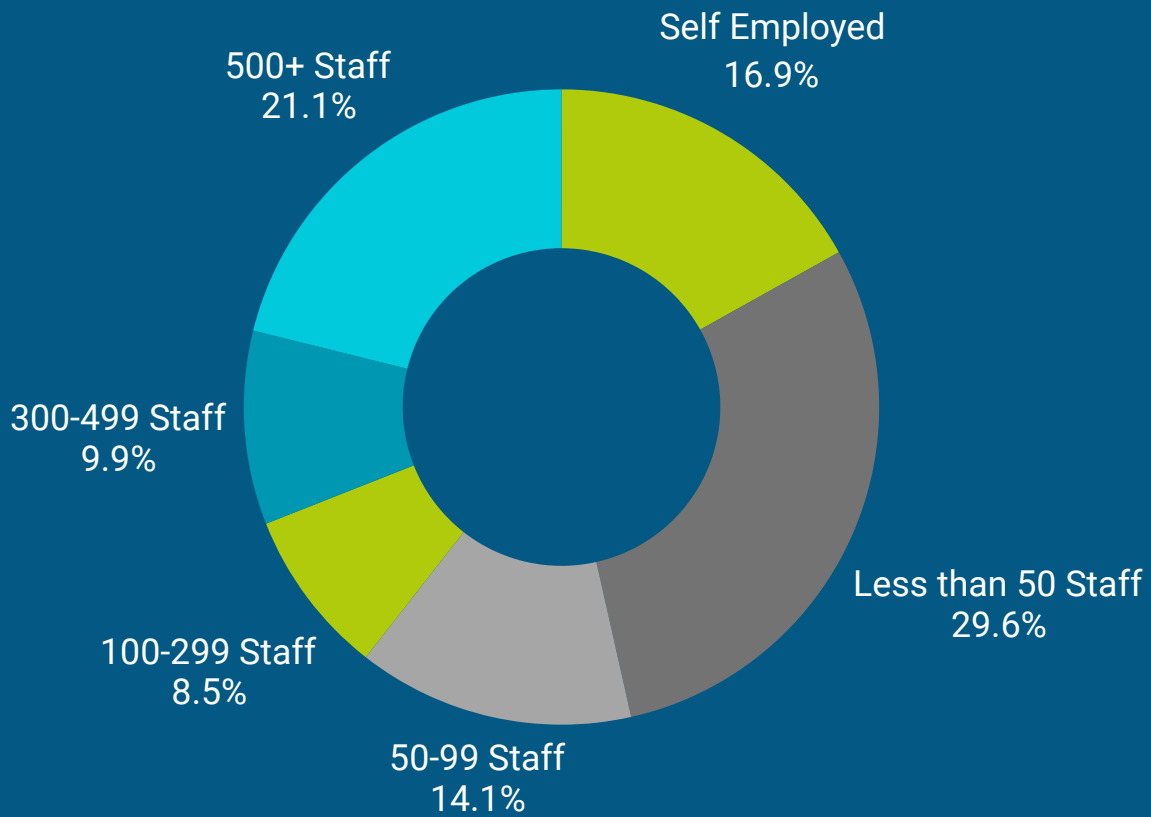
Dementia/Alzheimer's

Age-Related Condition

Mental Health

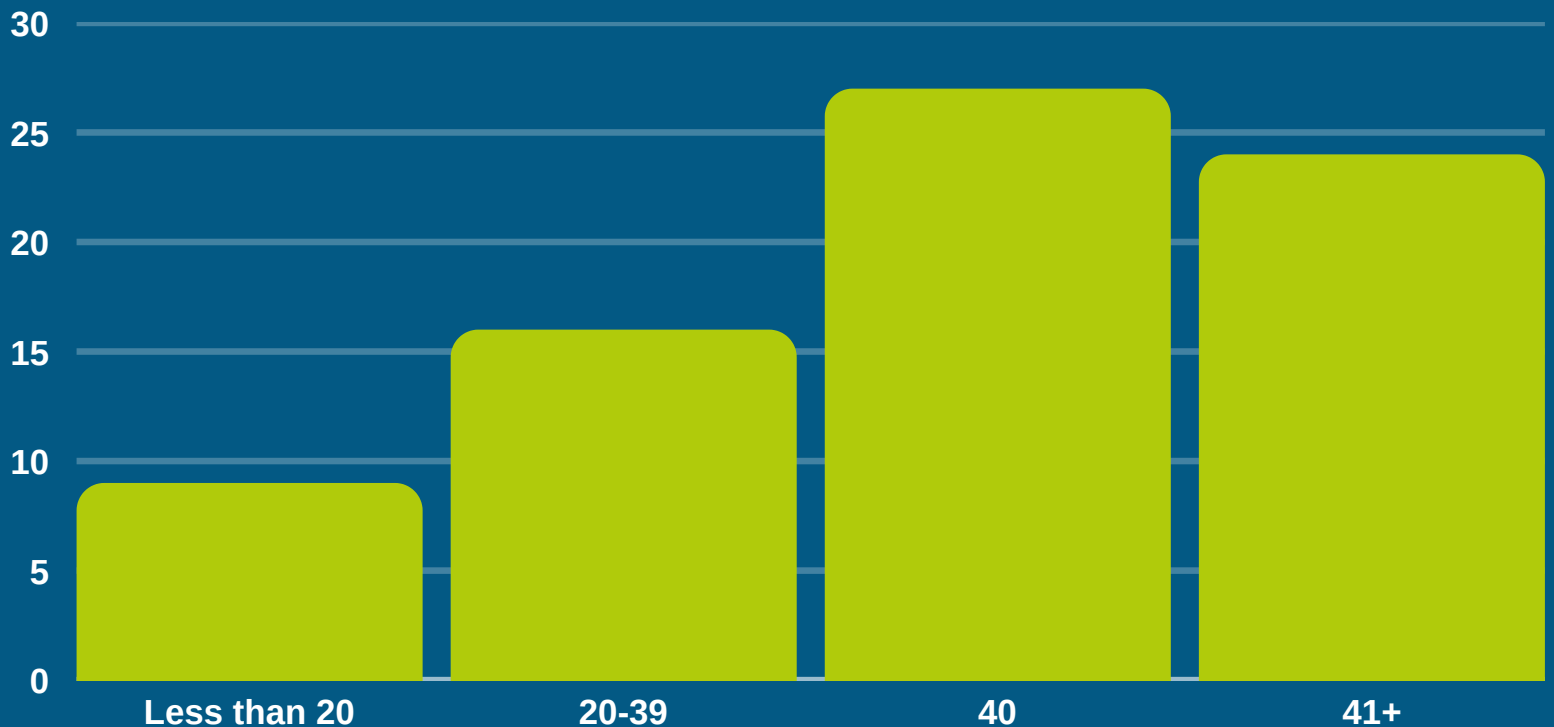
Short-Term...

Caregivers work for employers of all sizes
(n=71).



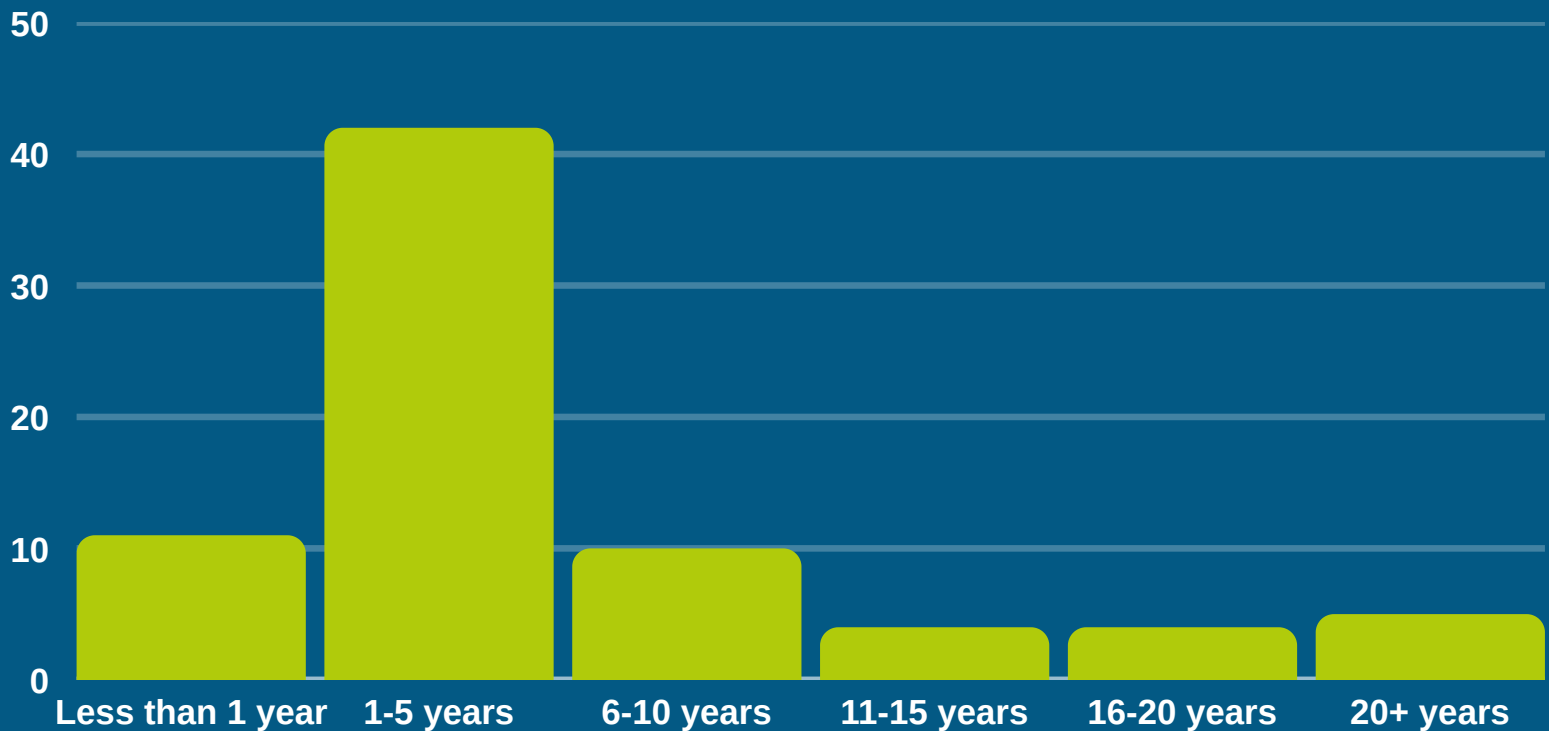
HOURS PER WEEK AT WORK

Most respondents work full time
(n=76).



DURATION OF EMPLOYMENT

Most respondents have been with their current employer for 1-5 years (n=76).



The majority of respondents are currently employed (n=116).



Half of caregivers have experienced financial stress due to caregiving (n=92).

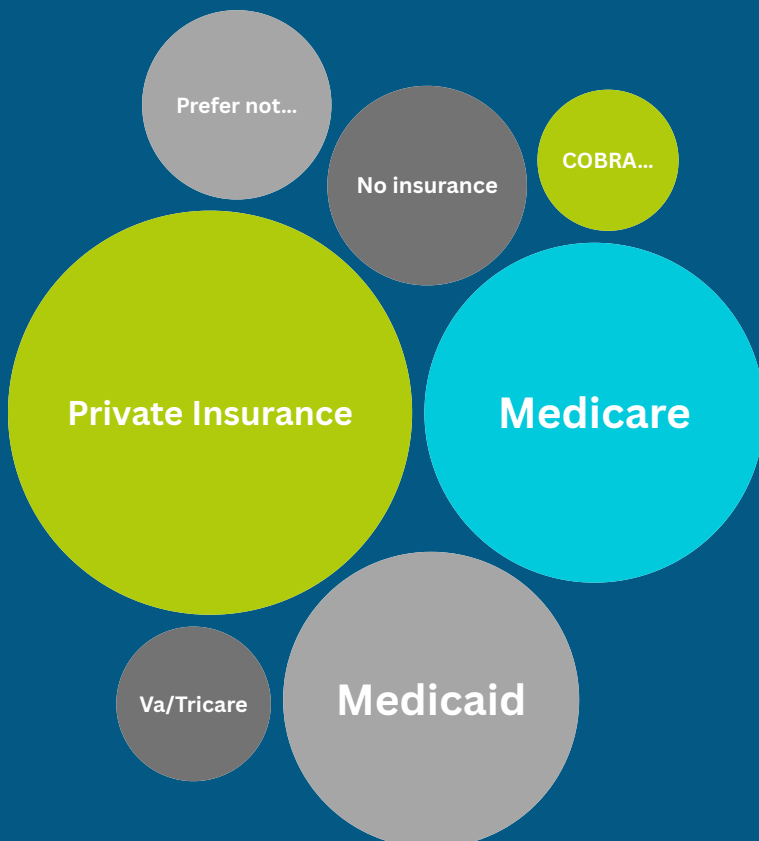
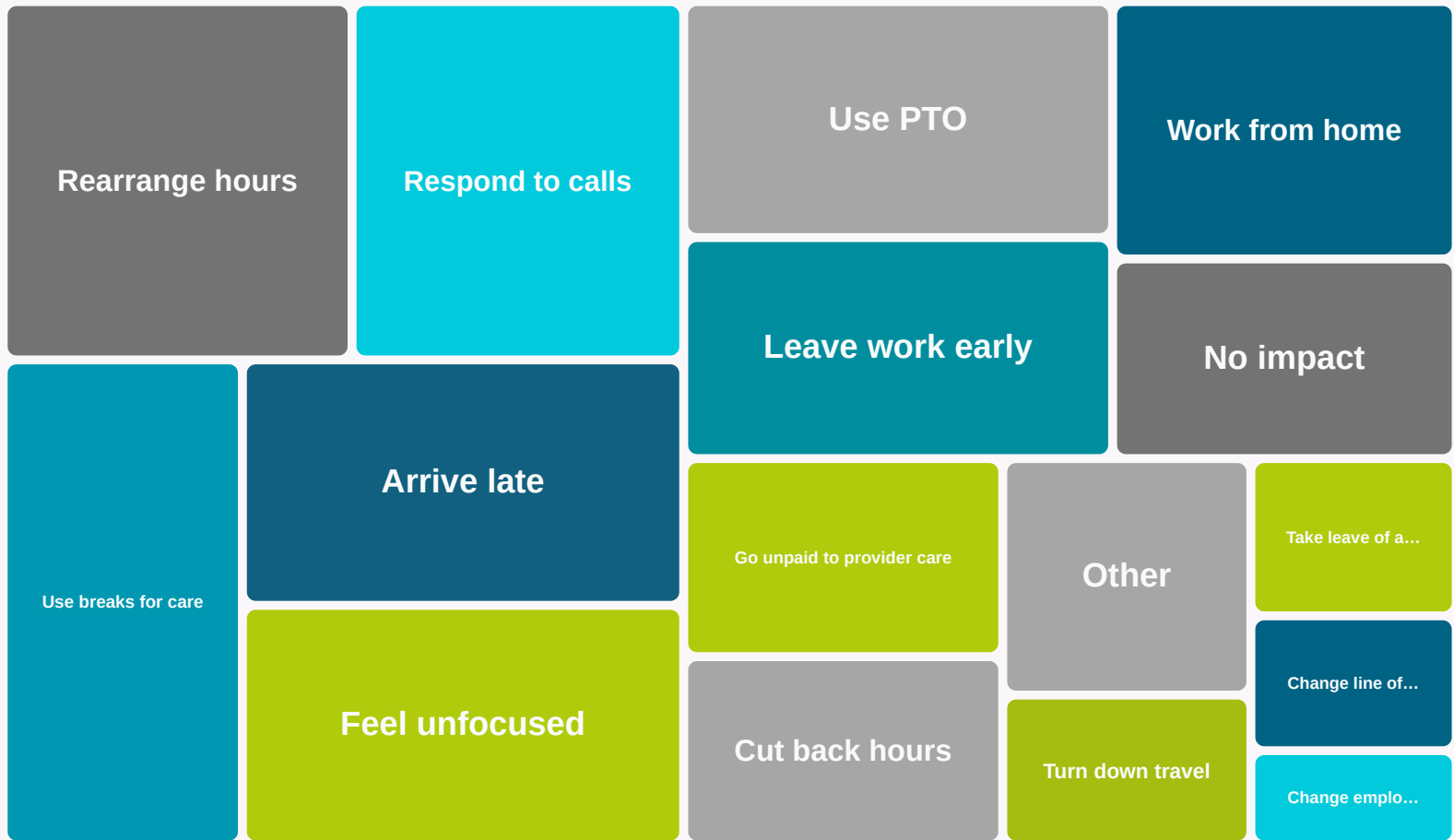


Over a quarter of respondents say that caregiving responsibilities have prevented them from being employed (n=105).



IMPACT

Everyone reported caregiving has impacted their job in many ways.



INSURANCE

Most respondents have private health insurance or Medicare/Medicaid (n=105).

Nearly 10% do **NOT** have health insurance.



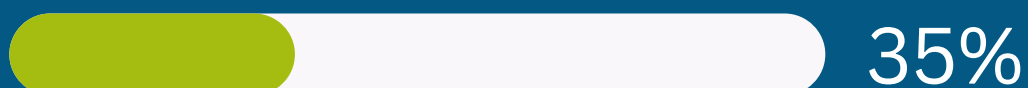
Nearly half of respondents do not have paid time off through their employer (n=77).



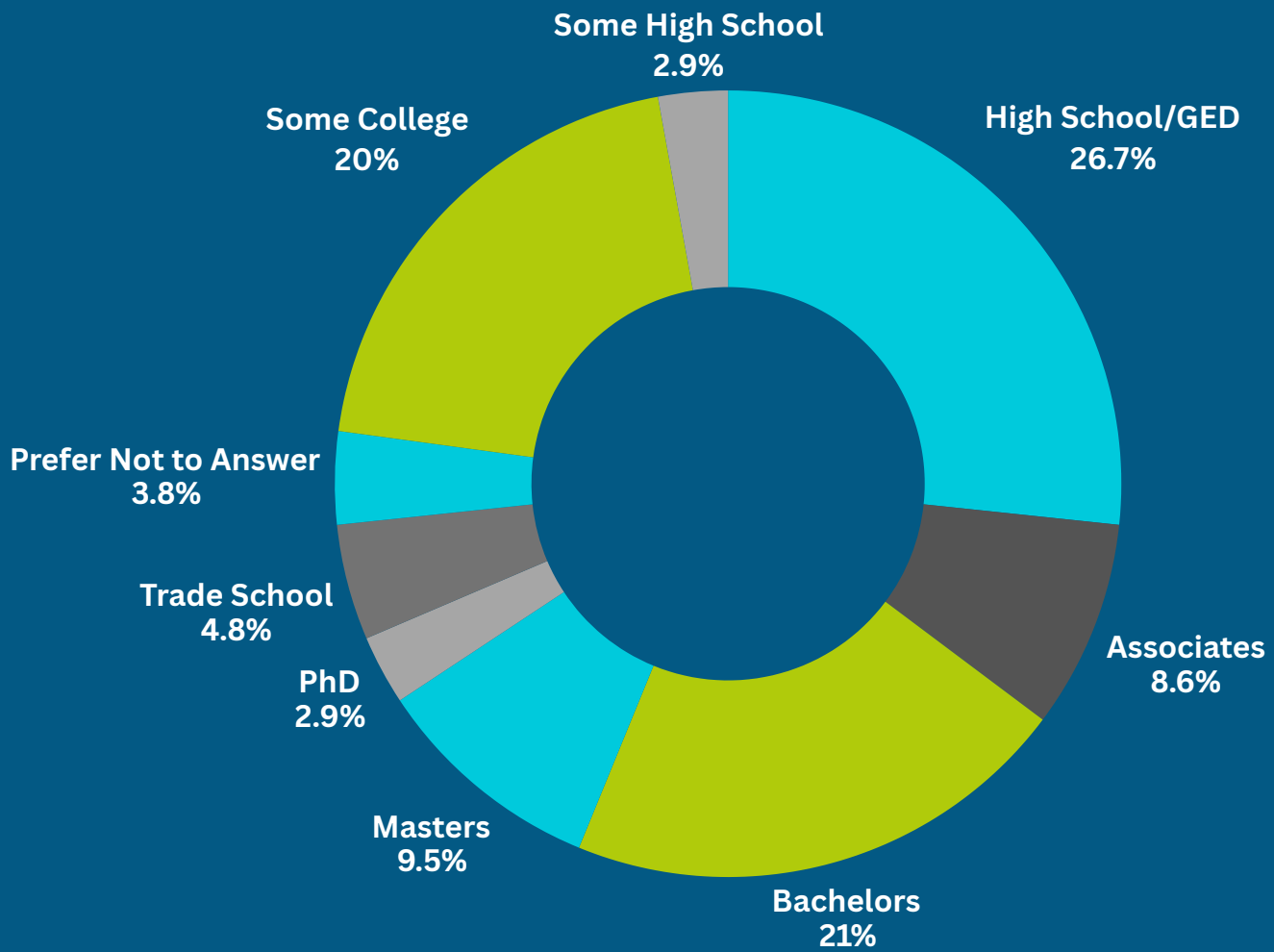
Only 12% of respondents have used Family Medical Leave Act (FMLA) for leave of absence due to caregiving (n=24).



Many respondents do not know if their employer offers FMLA (n=77).

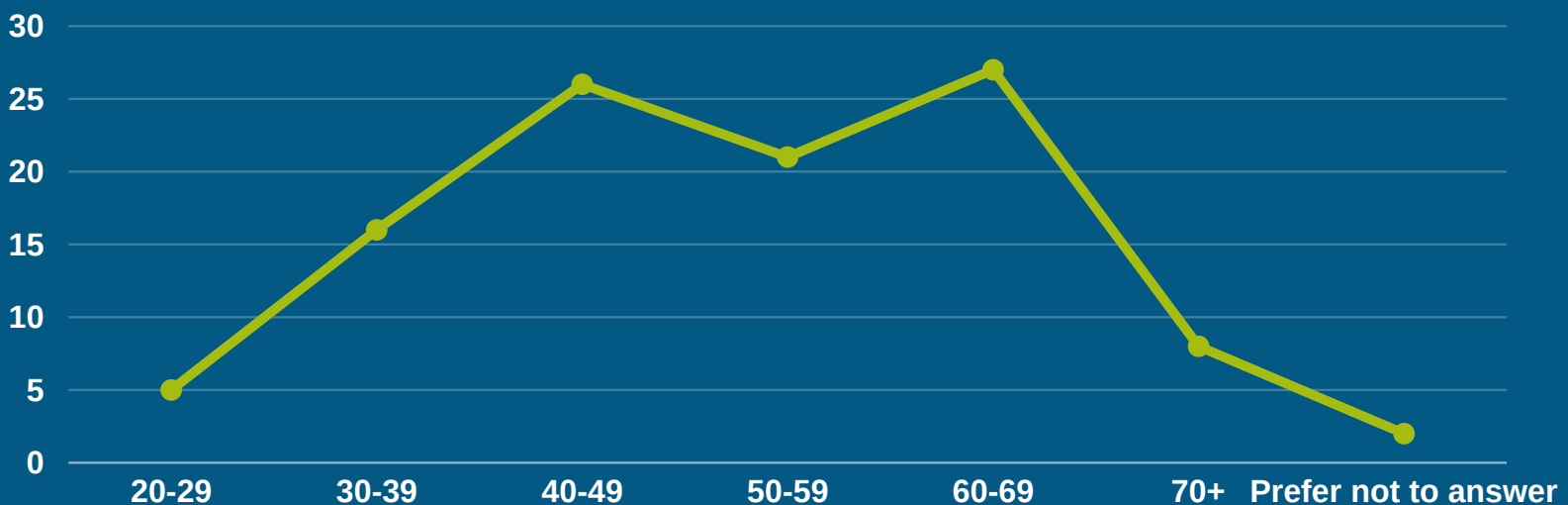


Caregivers have an array of education (n=105).



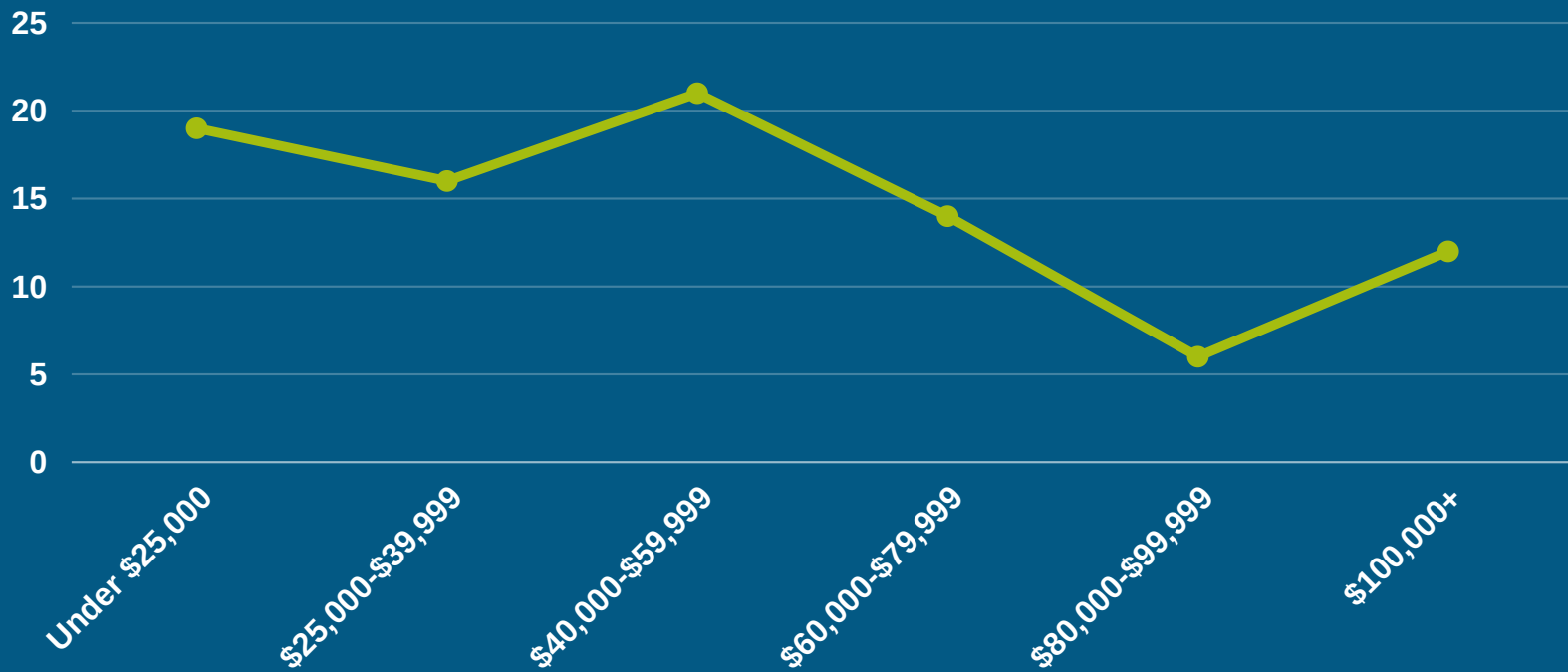
AGE

The majority of respondents are between the ages of 40-69 (n=105).

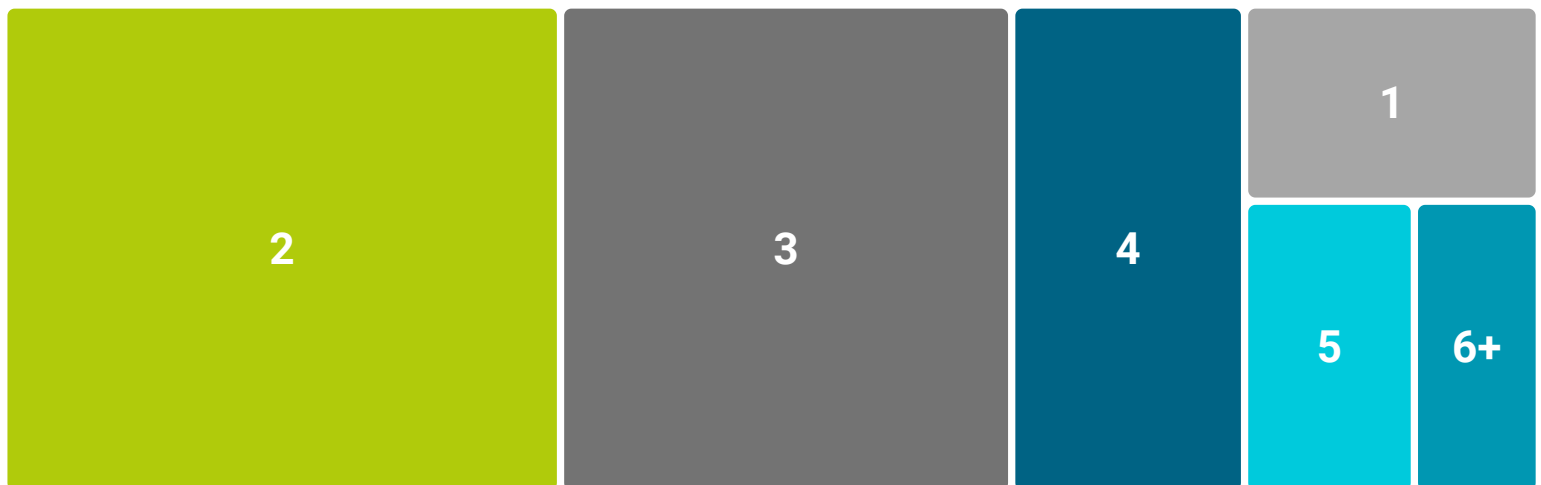


INCOME

The majority of respondents have an annual household income less than \$40,000 (n=98).

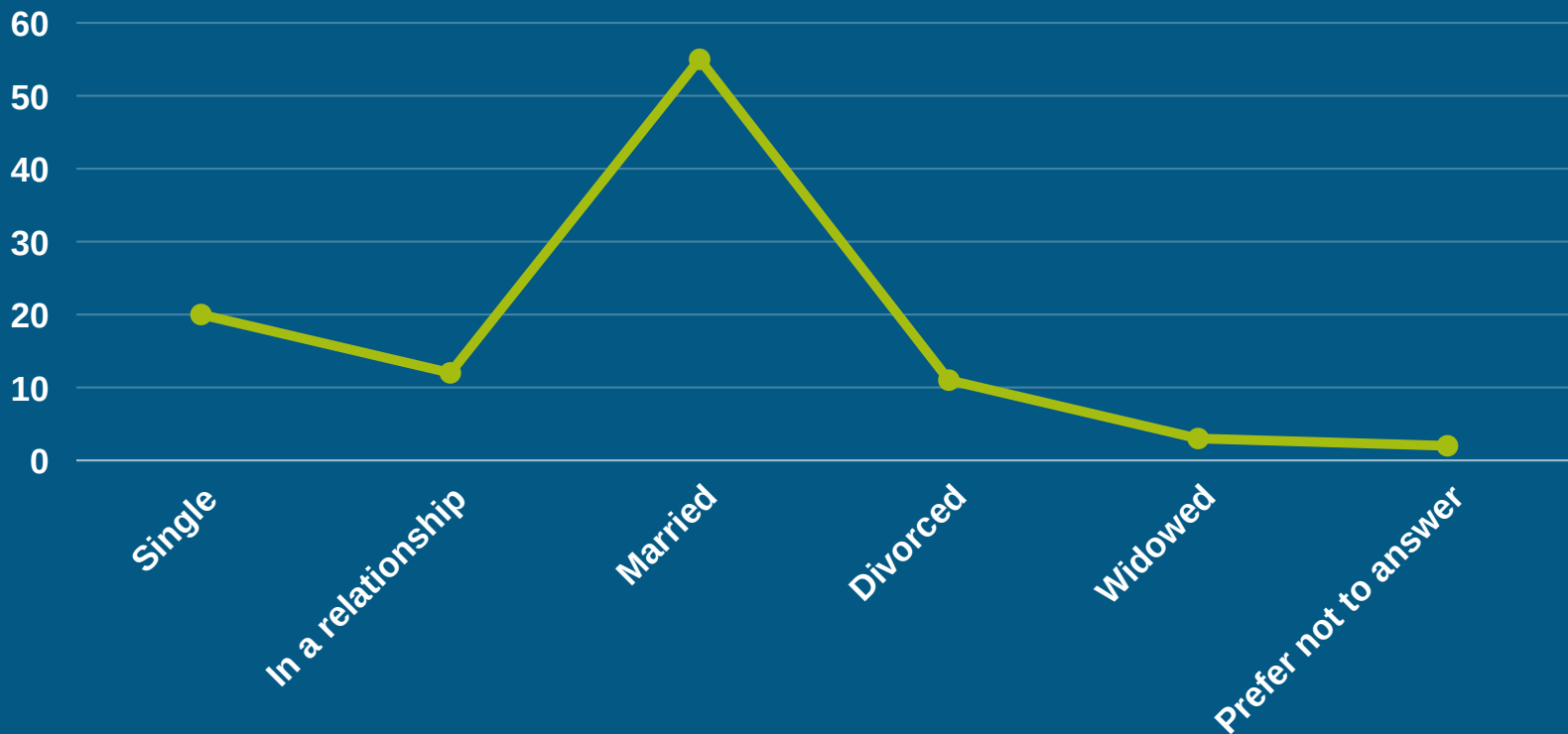


The average household size is 2-3 people (n=105).



MARITAL STATUS

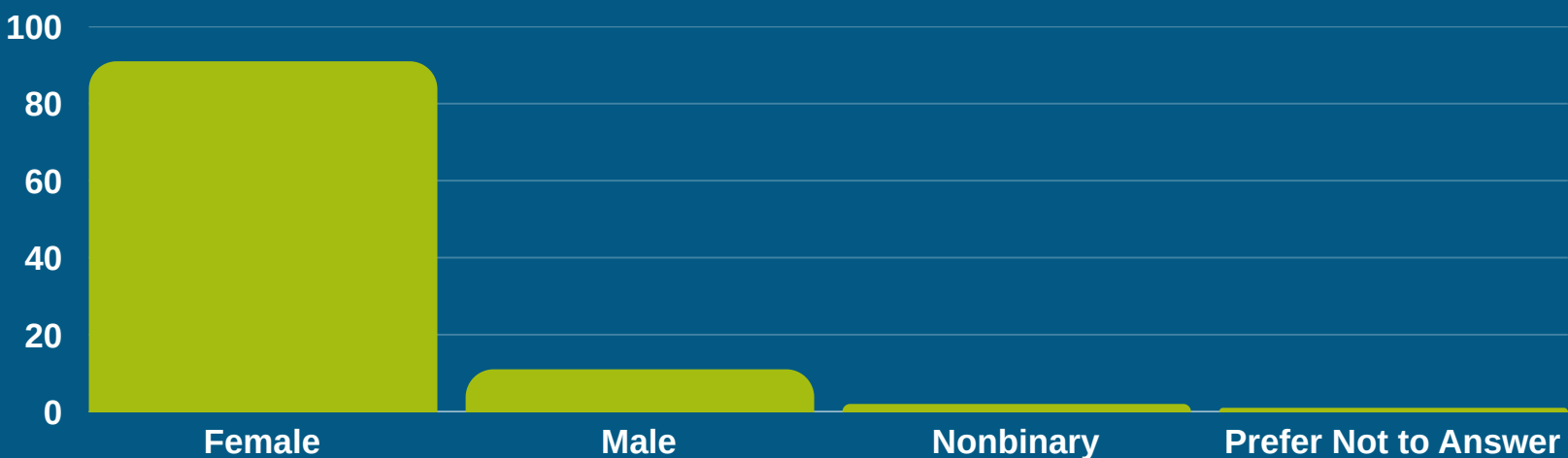
The majority of respondents are married (n=105).



Most respondents do **NOT** have children under the age of 18 in their home (n=105). They are not the 'sandwich generation'.

GENDER

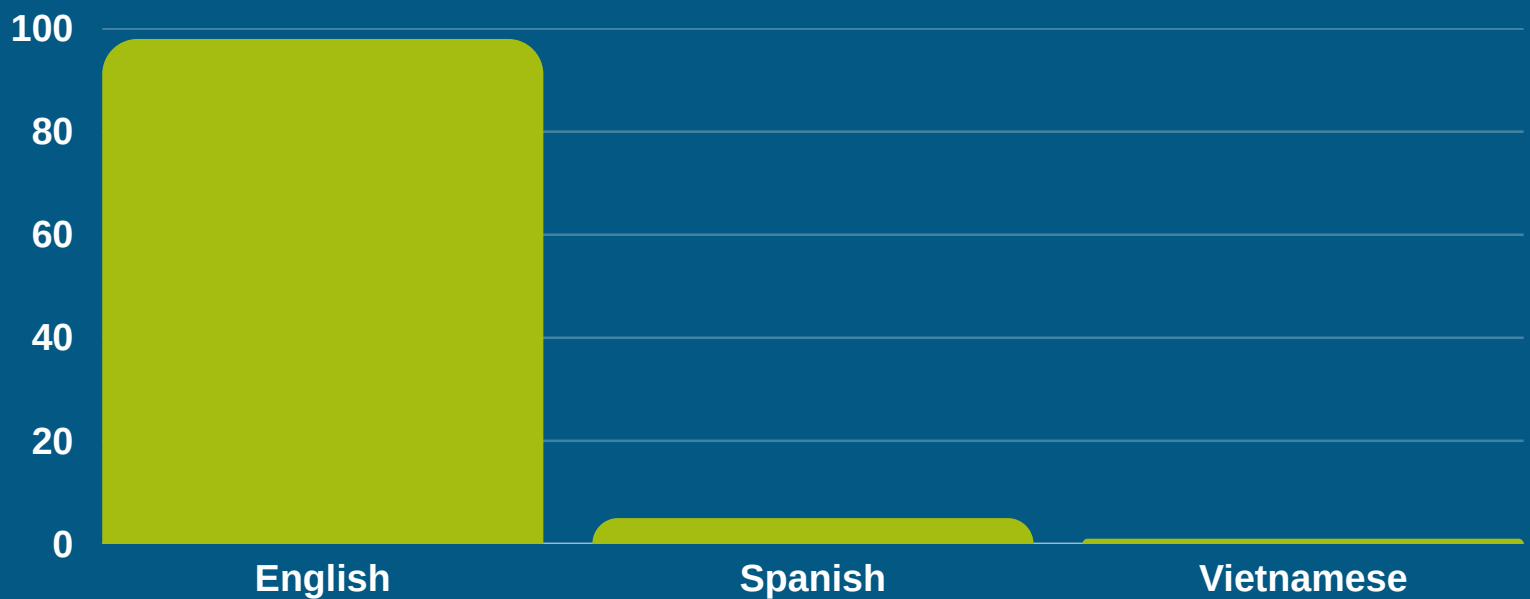
Most respondents identify as female (n=105).



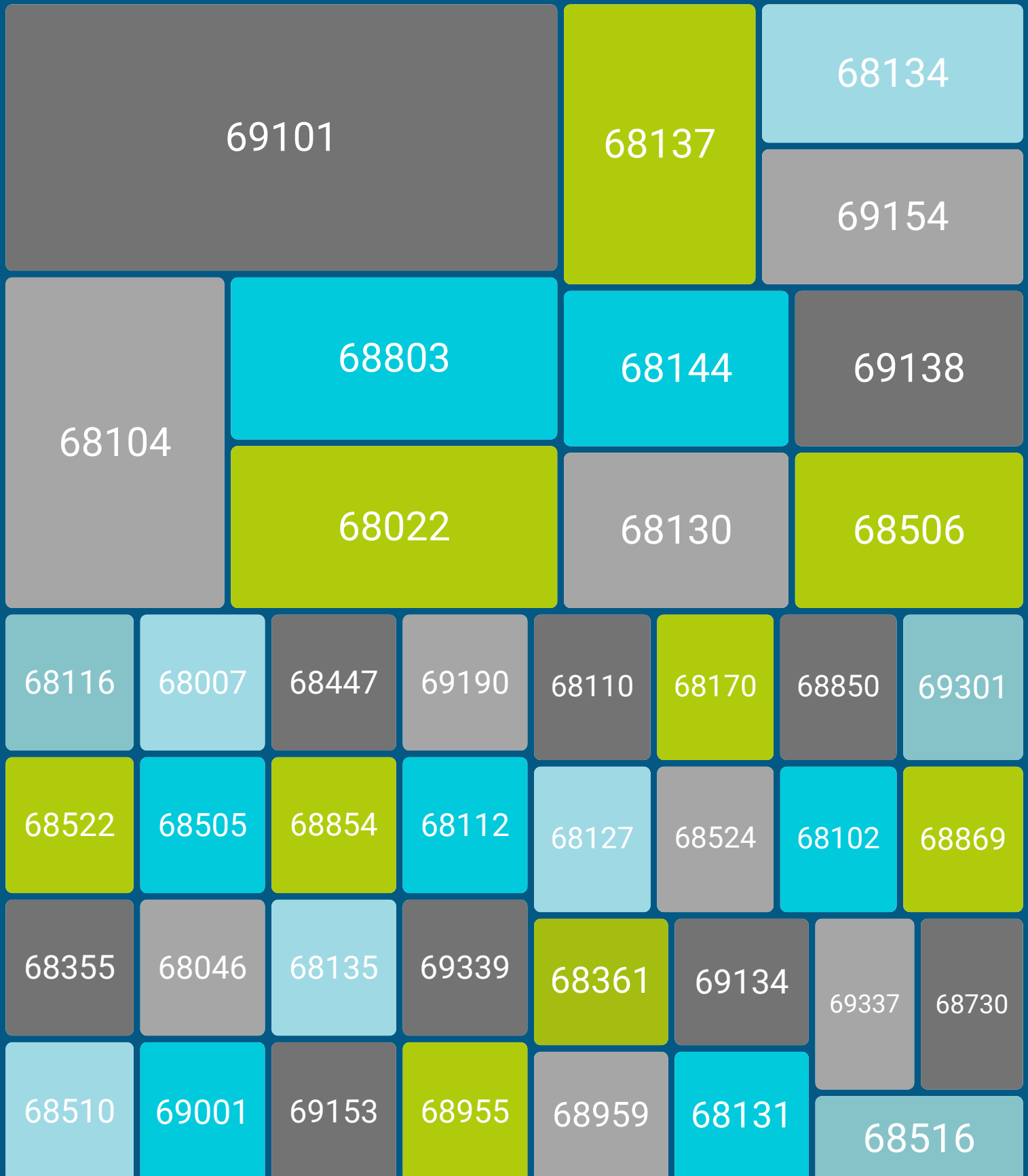
The majority of respondents are White or Caucasian (n=105).



The majority of respondents primarily speak English (n=104).



Caregivers live in many Nebraska Zip Codes (n=150).



Comments from Caregivers:

“I DEPLOY 1-2 TIMES PER YEAR FOR UP TO 3 MONTHS AT A TIME, LEAVING MY WIFE WITH THE FULL TIME RESPONSIBILITY OF TAKING CARE OF OUR SON. I WORRY FOR HER PHYSICAL, EMOTIONAL, AND MENTAL HEALTH A LOT WHEN I AM DEPLOYED.”

“THERE IS NO PROGRAM IN THE INTERIM TO HELP CAREGIVERS FIND THE SUPPORT THEY NEED WHEN THEY HAVE TO LEAVE FOR MEDICAL RELATED PURPOSES. NEBRASKA STATE PROGRAMS TAKE A REALLY LONG TIME TO PROCESS ANY APPLICATIONS EVEN IF THE RECIPIENT IS MOST LIKELY TO GET APPROVED FOR IT. THERE IS NOT ENOUGH ‘PAS’ CAREGIVERS AVAILABLE TO HELP OUT EVEN IF APPROVED FOR THOSE UNDER CRITICAL CIRCUMSTANCES SUCH AS GOING THROUGH CANCER TREATMENT THAT HAS BEN DIBILITAING. THERE IS BARELY ANY PROGRAMS TO SUPPORT CAREGIVERS WHILE TRANSITIONING FROM HOSPITAL TO HOME AND NOTHING COULD BE EXPEDITED. NO FACILITY WOULD ACCEPT HIM AS A PATIENT TO HELP GO THROUGH CANCER TREATMENT AND GET WHAT HE NEEDS TO RECOVER. HE ONLY HAS HOME HEALTHCARE SERVICES AND THEY DON’T OFFER ANY CAREGIVER SUPPORT EITHER. ITS BEEN AN EXHAUSTING PROCESS.”

“MY SIGNIFICANT OTHER HAS HEALTH ISSUES AS WELL BUT CAN MAINLY CARE FOR HIMSELF. WE HAVE A LOCAL GIRL HELPING WEEKLY BUT WOULD APPRECIATE ANY HELP.”

“I AM ON ANTIDEPRESSANTS AND ANXIETY PILLS AND HIGH STRESS AND THE SADNESS OF ALZHEIMER’S REALLY AFFECTS ME.”

“I WANT TO WORK AND MAKE PROGRESS AT MY CAREER, BUT MANAGING CARE FOR A DISABLED INDIVIDUAL IS ALMOST A FULL TIME JOB ON ITS OWN.”

“WHAT HAPPENS IS THAT I AM THE CHILD’S MOTHER AND I CANNOT WORK BECAUSE I TAKE HIM TO SCHOOL, I PICK HIM UP, I COOK FOR HIM, THAT’S WHY I CANNOT WORK BECAUSE HE DEPENDS ON ME. HE DOESN’T KNOW HOW TO SERVE HIS FOOD, HE DOESN’T KNOW HOW TO WASH HIS PLATE, AND THE TRUTH IS I WANT HELP, PLEASE. I TAKE HIM TO HIS APPOINTMENTS, OR RATHER, EVERYTHING.”

“HOUSING IS A MAJOR ISSUE, AS IS AFFORDABLE TRANSPORTATION. UNTIL BOTH ARE SORTED OUT PROPERLY, INCLUDING RETROFITTING SAID VEHICLE WITH A RAMP AND/OR LIFT, WE CANNOT ACCESS MOBILITY AIDS WE BOTH NEED. AFTER ALL, WHY GET A WHEELCHAIR IF YOU CAN’T GET IT IN THE CAR? WHY GET A WHEELCHAIR WHEN THE KIND WE NEED CAN’T FIT THROUGH THE FRONT DOOR?”

“I’M EXHAUSTED.”

Comments from Caregivers:

“MAKE CHANGING THE WORK SCHEDULE TO FIT WHAT IS HAPPENING EASIER IF IT’S NEEDED. SUCH AS WHEN APPOINTMENTS SCHEDULED WITH A DOCTOR ARE OUTSIDE OF THE WORK HOURS.”

“I WISH I DIDNT FEEL THAT IF I TAKE TOO MUCH TIME OFF TO ATTEND TO CAREGIVING NEEDS THAT MY ABILITY TO ADVANCE OR GET A RAISE AT WORK WOULDNT BE AFFECTED, BUT I DO. THERE IS STILL A CULTURE OF ‘WORK WHEN YOU ARE SICK’ AND COWORKERS/EMPLOYERS MAY LOOK DOWN ON EMPLOYEES THAT HAVE TO TAKE EXTRA TIME TO CARE FOR INDIVIDUALS WITH DISABILITIES.”

“MY EMPLOYER DOES A GREAT JOB, I THINK. WHAT I NEED IS HELP OCCASIONALLY IF DAD IS RECOVERING FROM A PROCEDURE AND HAS ISSUES FOR A TIME AND I'D NEED TO GO TO WORK. FOR INSTANCE, THIS WEEK WE WENT TO THE ER BECAUSE DAD BECAME DEHYDRATED AND WAS STILL WONKY. MY BOSS IS OUT OF TOWN SO I HAD A LOT MORE UNALTERABLE WORK DUTIES THIS WEEK. “

“I DID NOT GET A RAISE LAST YEAR DUE TO FINANCIAL CONSTRAINTS AT WORK, WHICH MAKES THINGS HARD TO AFFORD.”

“I WISH I WAS ABLE TO AFFORD A PART-TIME CAREGIVER.”

“MY IMMEDIATE AND HIGHER LEVEL SUPERVISORS HAVE BEEN VERY SUPPORTIVE AS MUCH AS THEY ARE ABLE TO.”

“MAKING NECESSARY APPOINTMENTS FOR MYSELF BECOMES HARD SOMETIMES BECAUSE MY HOURS REVOLVE AROUND MY CLIENTS.”

“CAREGIVING IS MY JOB.”



Comments from Caregivers:

“MY HUSBAND HAS ADVANCED PARKINSONS DISEASE AND I HAVE SEVERE OSTEOARTHRITIS. MEDICAL CARE (A NURSING HOME) HAS BEEN UNCOOPERATIVE WITH HIS CARE.”

“I DO EVERYTHING FOR MY MOM WHO I AM A CAREGIVER FOR AND HAVE BEEN TRYING TO GET IT APPROVED THROUGH THE STATE TO BE HER CAREGIVER SO I CAN GET PAID. IT HAS BEEN SINCE MAY AND IT'S STILL NOT APPROVED. I HAVE TO MAKE SOME TYPE OF MONEY BEFORE I GET KICKED OUT OF MY HOUSE BECAUSE I CAN'T AFFORD ANY BILLS. I HAVE A 2 STORY HOUSE WITH THE BEDROOMS AND BATHROOM ON THE TOP FLOOR SO MY MOM CANNOT GO DOWNSTAIRS AT ALL BECAUSE SHE CAN'T GET UP AND DOWN. HOUSING IS REFUSING TO PUT ME ON A WAIT LIST FOR A ONE STORY SO I'M TO THE MAX WITH STRESS.”

“I ENJOY BEING ABLE TO TAKE CARE OF MY LOVED ONE. THIS WAY SHE CAN BE IN HER OWN HOME AND HAVE SOME INDEPENDENCE OF HER OWN.”

“OMAHA IS UNDER PREPARED TO OFFER ASSISTANCE AND ASSISTED LIVING FOR BOOMERS WHO HAVE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES WHO WERE ALSO EMPLOYED. THEY FALL THROUGH THE CRACKS FOR MOST PROGRAMS BECAUSE THEY ARE TOO RICH OR TOO POOR, TOO HEALTHY OR TOO SICK, TOO ABLE OR TOO DISABLED. AS THEIR ADULT CHILDREN AND CAREGIVERS WE HAVE FEW OPTIONS FOR THEIR SAFE AND HEALTHY FUTURES, AND WE ARE ILL EQUIPPED WITH RESOURCES. NEBRASKA, IT'S REALLY NOT FOR EVERYONE.”

“I WOULD JUST LIKE TO KNOW OF RESOURCES AND GET THEM MOVING SO WE CAN GET SOME HELP, MOSTLY FINANCIALLY.”

“DO NOT HAVE HELP TO CARE FOR MY SON FOR MORE THAN A FEW HOURS AT A TIME AND VERY RARELY.”

“I NEED HELP SO I CAN LEAVE FOR A FEW DAYS.”

“I HAD A STROKE IN APRIL 2024. MY OWN RECOVERY IS COMPROMISED BY CAREGIVING SINCE MOM BROKE HER HIP IN MAY 2024. RESPITE WOULD BE NICE. “

“I HAVE THE PASSION FOR HELPING OTHERS AND I WOULD LIKE TO MAKE A CAREER PATH IN THAT.”

“MY HUSBAND REQUIRES A LOT OF CARE AS HE IS PARALYZED ON HIS RIGHT SIDE AND CANNOT WALK OR TRANSFER BY HIMSELF.”

“MY SON IS NON VERBAL AND AUTISTIC AND 8 YEARS OLD. WE WANT TO MAKE SURE HE IS SAFE AT ALL TIMES.”

Comments from Caregivers:

“I HAVE TRIED TO GET SUPPORTS WITH CARING FOR THE CHILDREN, BUT IT SEEMS THAT THE SUPPORTS THAT SHOULD BE THERE FOR THEM ARE NOT THERE OR UNAVAILABLE. CURRENTLY THE CHILDREN ARE IN NEED OF CHILDCARE ASSISTANCE/RESPIRE, AND I HAVE NOT BEEN ABLE TO GET ANY ASSISTANCE WHATSOEVER WHICH IMPACTS THE CARE THAT I CAN GIVE.”

“THE PERSON I CARE FOR GETS CARE AT THE VA...THE VA IS VERY DIFFICULT TO NAVIGATE. I WISH THERE WAS MORE SUPPORT FOR CAREGIVERS THROUGH THE VA.”

“IT IS A VERY SATISFYING REWARD TO HELP SOMEONE BUT IT CAN ALSO BE MENTALLY VERY DRAINING.”

“THERE ARE NOT ENOUGH SERVICES PROVIDED FOR HELPING KEEP SENIOR CITIZENS IN THEIR HOMES AS LONG AS POSSIBLE. I DON'T QUALIFY FOR RESPIRE CARE OR ASSISTANCE BECAUSE I DON'T RESIDE WITH MY DAD. BUT I AM STILL AM AT HIS RESIDENCE 2-3 TIMES PER DAY, 7 DAYS A WEEK.”

“SOMETIMES I GET VERY STRESSED. OTHER THAN MY HUSBAND, I HAVE NO OTHER FAMILY IN THE AREA, SO NO ONE ELSE IS AROUND WHO CAN RELIEVE ME AT ALL. MY HUSBAND AND I CAN'T EVEN GO OUT TO EAT ALONE. I DON'T THINK PEOPLE REALIZE THE STRESS I'M UNDER ALL OF THE TIME.”

“IF NOT FOR MY FATHER FINANCIALLY TAKING CARE OF ALL MY DISABLED MOTHER'S NEEDS I WOULD HAVE GONE BROKE TAKING CARE OF HER. MY FATHER WAS NOT ABLE TO RETIRE, AS MY MOTHER WAS DIAGNOSED THE SAME YEAR THEY WERE BOTH SET TO RETIRE (7 YEARS AGO). UNFORTUNATELY, WE WILL HAVE TO KEEP WORKING (IN ADDITION TO THE 24/7 HANDS-ON CARE WE PROVIDE HER) UNTIL SOMETHING VERY TRAGIC HAPPENS TO ONE OF MY PARENTS.”

“MY HUSBAND HAS ADVANCED PARKINSONS DISEASE AND I HAVE SEVERE OSTEOARTHRITIS. MEDICAL CARE (A NURSING HOME) HAS BEEN UNCOOPERATIVE WITH HIS CARE.”

