

## Purpose:

The goal of this Division of Services for People with Disabilities (DSPD) study is to understand the impact that short-term and long-term services have on quality of life for individuals and caregivers who are waiting for ongoing services.

## Study Population & Type:

This is a longitudinal study of people/caregivers currently on the the DSPD wait list or people/caregivers recently moved into DSPD services. This means that DSPD will email this survey to eligible individuals/caregivers at regular intervals to understand how answers change over time.

## Colors:

Question responses are color coded by the group who answered the question(s). Individuals' with disabilities responses are displayed in **Blue-Teal** colors and caregivers' of individuals with disabilities responses are displayed in **Orange-Red** colors.

## Key Findings:

A total of 5544 email invitations were sent out and 1655 surveys were completed between March 30-April 12, 2022 (29.85% response rate). Five percent (n=91) of the surveys were completed by people with disabilities (PwD) on the DSPD waiting list and 95% (n=1564) of the surveys were completed by caregivers of a person on the DSPD waiting list. The median time to complete the survey was 3.35 minutes for PwD and 6.13 minutes for caregivers. The disabilities most represented in this survey were: 1) intellectual or developmental disabilities; 2) autism; and 3) physical disabilities. An overwhelming majority of primary-caregiver survey respondents were a parent of a PwD.

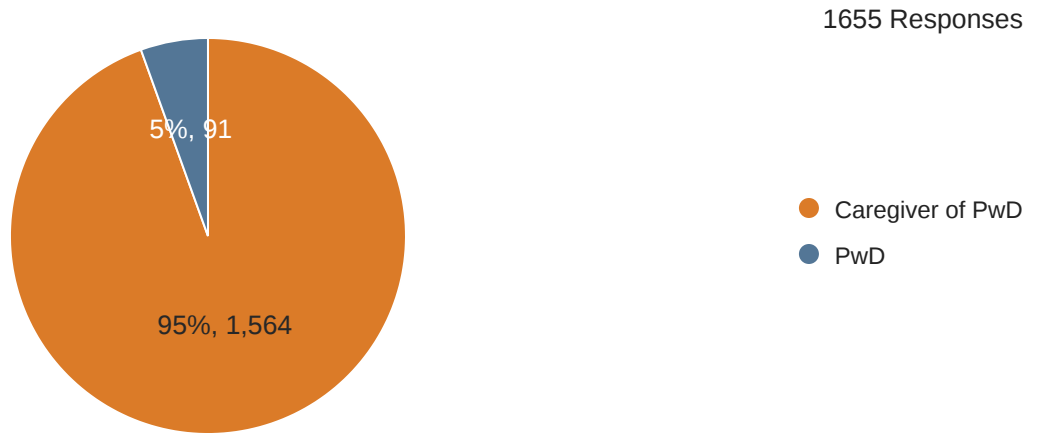
### *People with Disabilities*

Only 22.99% of PwD reported that they get to do things in the community as much as they want. While 26% of those surveyed reported having a job in the community and no one reported disliking their job. Of those without a job, 74% reported that they would like a job or aren't sure if they would like a job. The most common barriers reported for not having a job were help needed finding the right job, transportation difficulties, and support needed for developing occupational and social skills.

### *Caregivers*

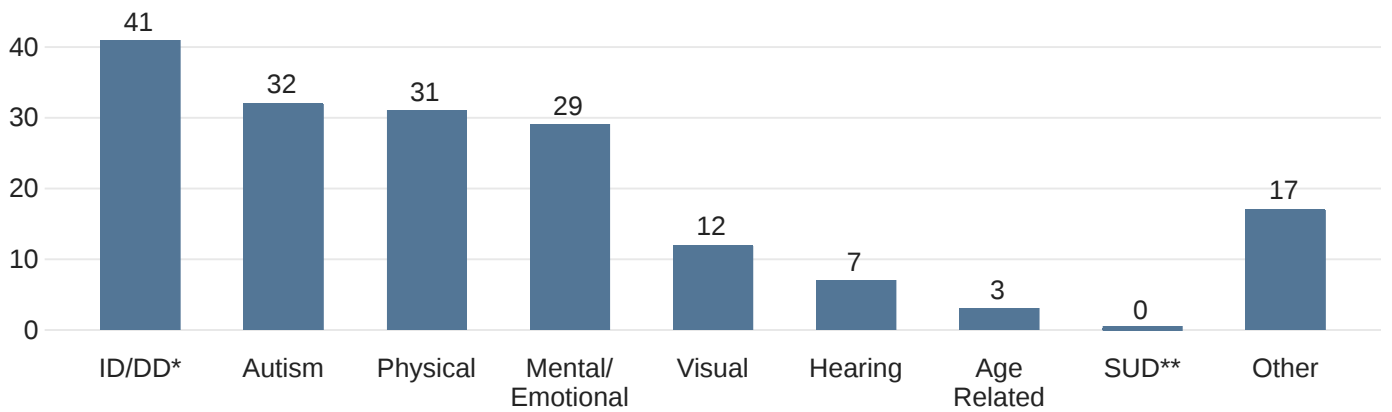
Only about a fourth (25.91%) of primary caregivers (PCs) reported being satisfied with their quality of life and only 4% reported not feeling stressed about caring for their family member with a disability. Over a third (37.76%) of PCs reported that they have had to quit a job and 62.75% of PCs have had to reduce work hours to care for their family member with a disability. PCs ranked the most beneficial services for their families and loved ones with disabilities as respite services, including summer programming and weekend respite, and day program services. When asked what PCs would do if they were compensated for caring for their loved one with disabilities (i.e. caregiver compensation), most reported that they would reduce their work hours (37.15%) and only 16.39% reported that they would quit their jobs. Eighty-five percent of PCs believed caregiver compensation would have a positive impact on their financial well-being, 12% believed it would have no impact, and 3% believed it would have a negative impact.

Who is responding to this survey?



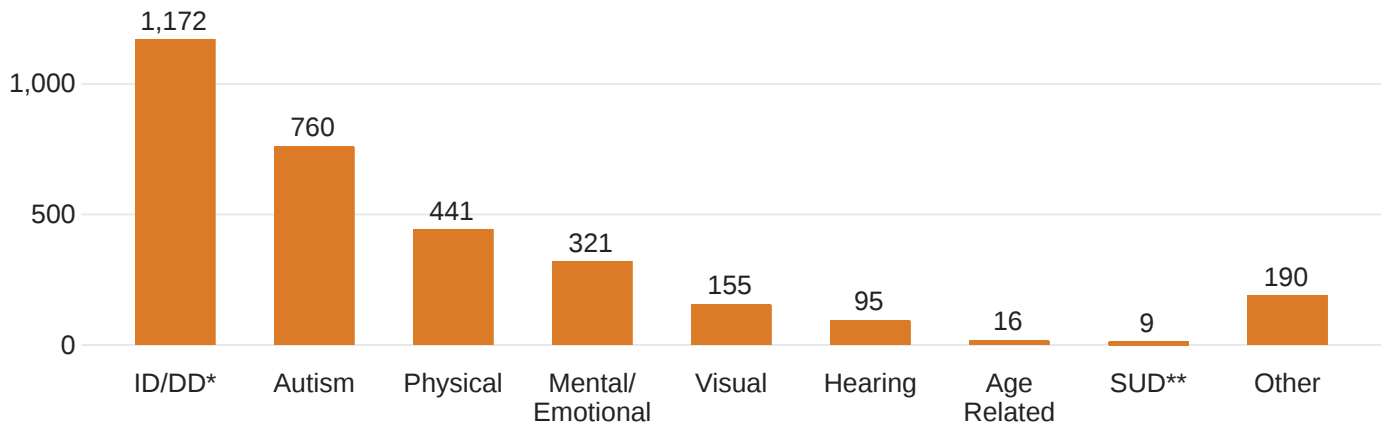
What type of disability do you, as a **person with a disability**, have? (check all that apply)

88 Responses



What type of disability does **your family member** have? (check all that apply)

1556 Responses



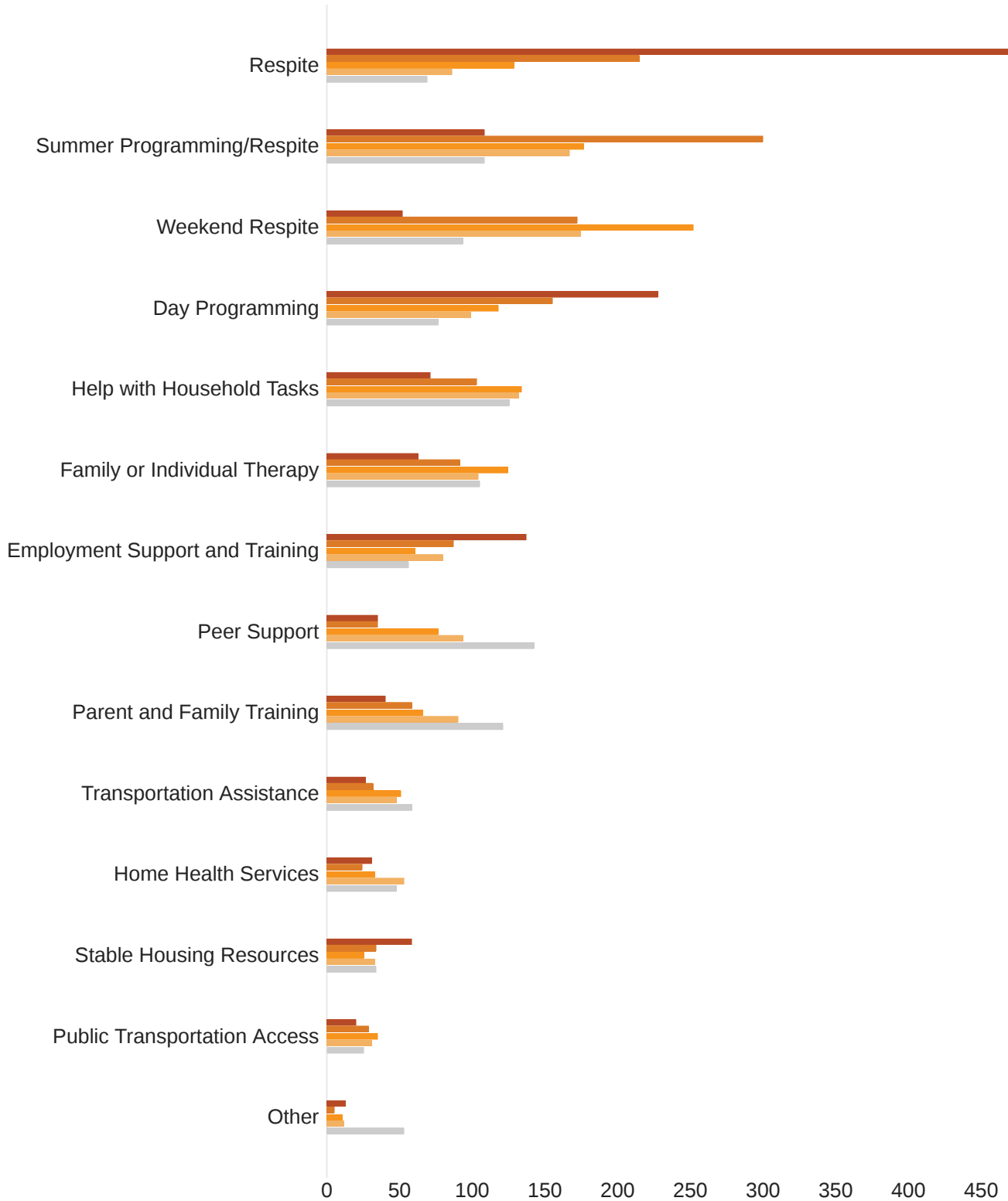
\* ID/DD=Intellectual Disability/Developmental Disability; \*\* SUD=Substance Use Disorder

Do you feel that your child or family could benefit from any of the following services:

(Rank 1-5, 1=most beneficial)

1365 Responses

● 1 ● 2 ● 3 ● 4 ● 5

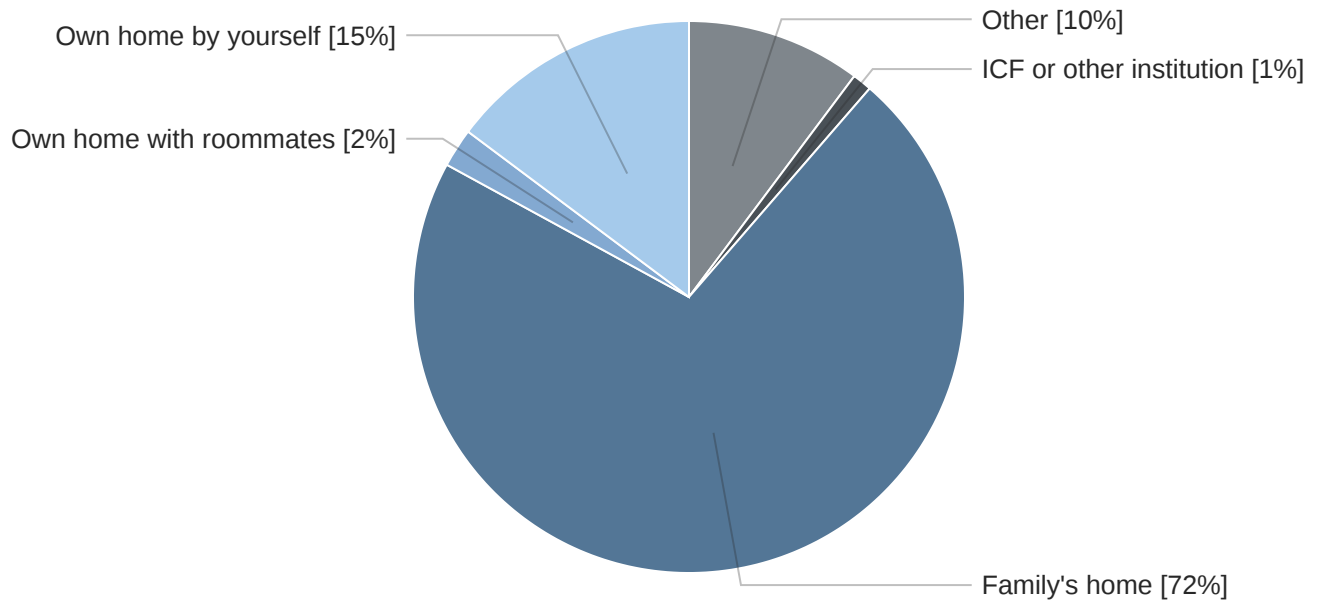


## Individuals : Choice Questions

Where do you live?\*

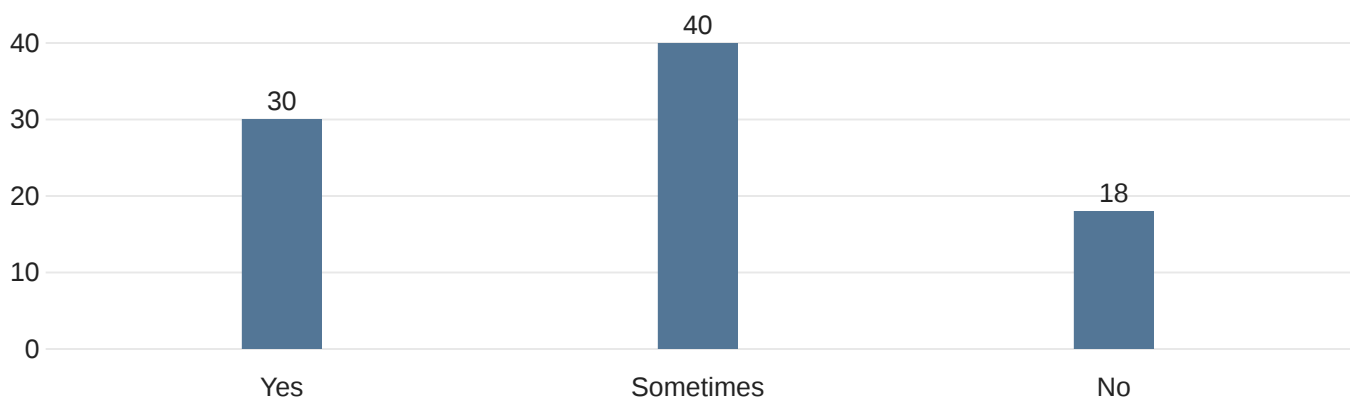
\*Group home [0%]

88 Responses



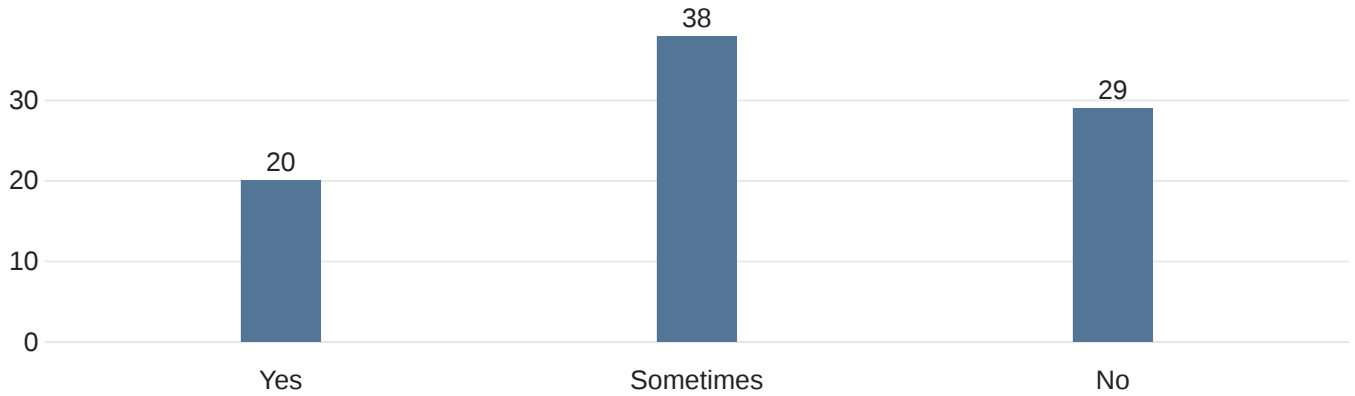
Do you feel like you have enough choice in your daily schedule?

88 Responses



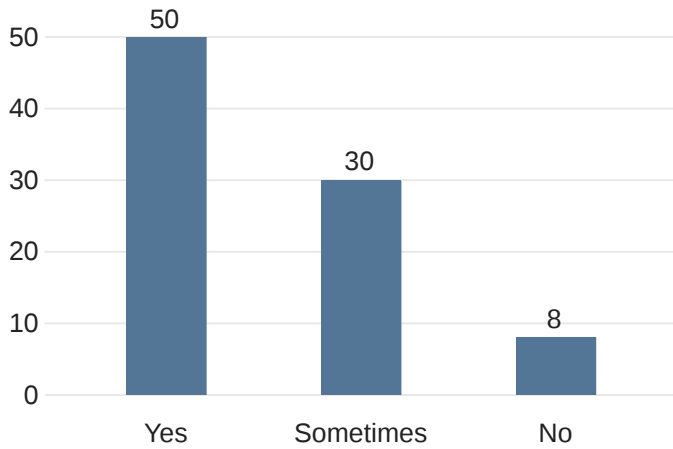
Do you get to do things in the community as much as you want?

87 Responses



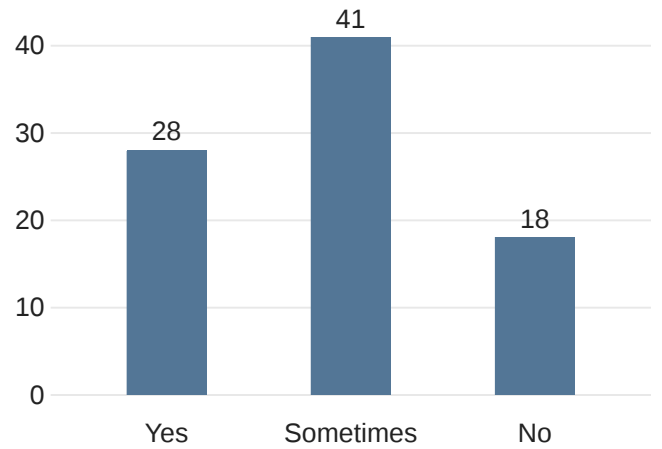
Do you get to choose how to spend your free time?

88 Responses



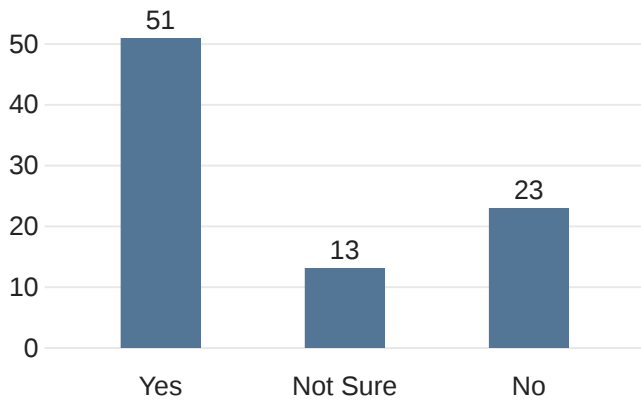
Do you have enough activities you like to do when you are home?

87 Responses



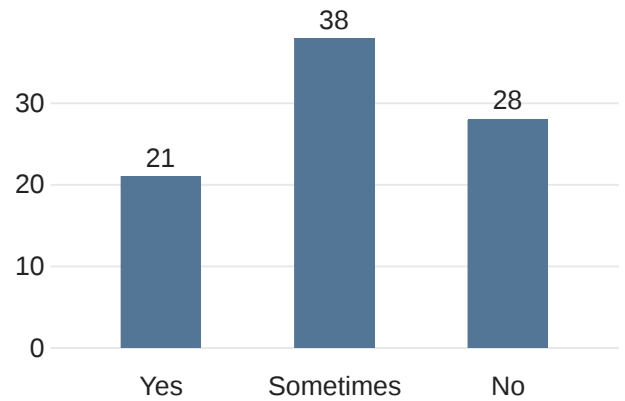
Do you have friends outside of your family members?

87 Responses



Are you able to meet up with friends and family when you want?

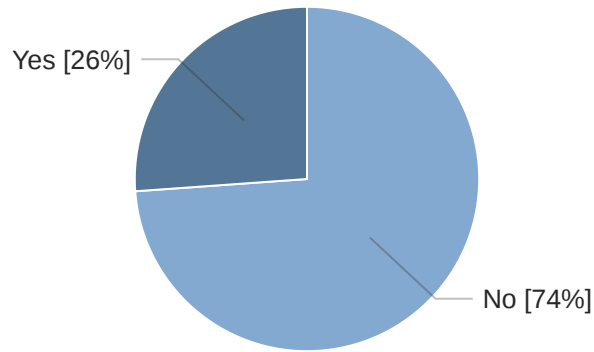
87 Responses



# Individuals : Employment Questions

Do you have a job in your community?

88 Responses



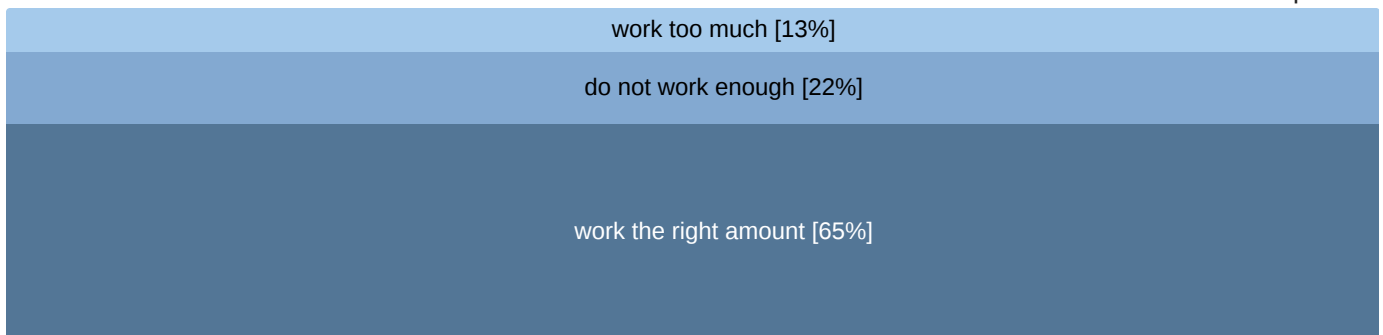
## Enjoyment

23 Responses



## Time: I feel like I...

23 Responses



## Compensation: I feel like I...

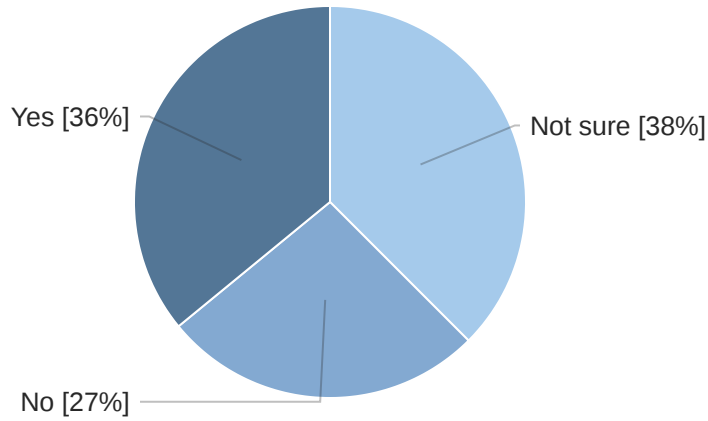
23 Responses



### Those who do not have a job were asked...

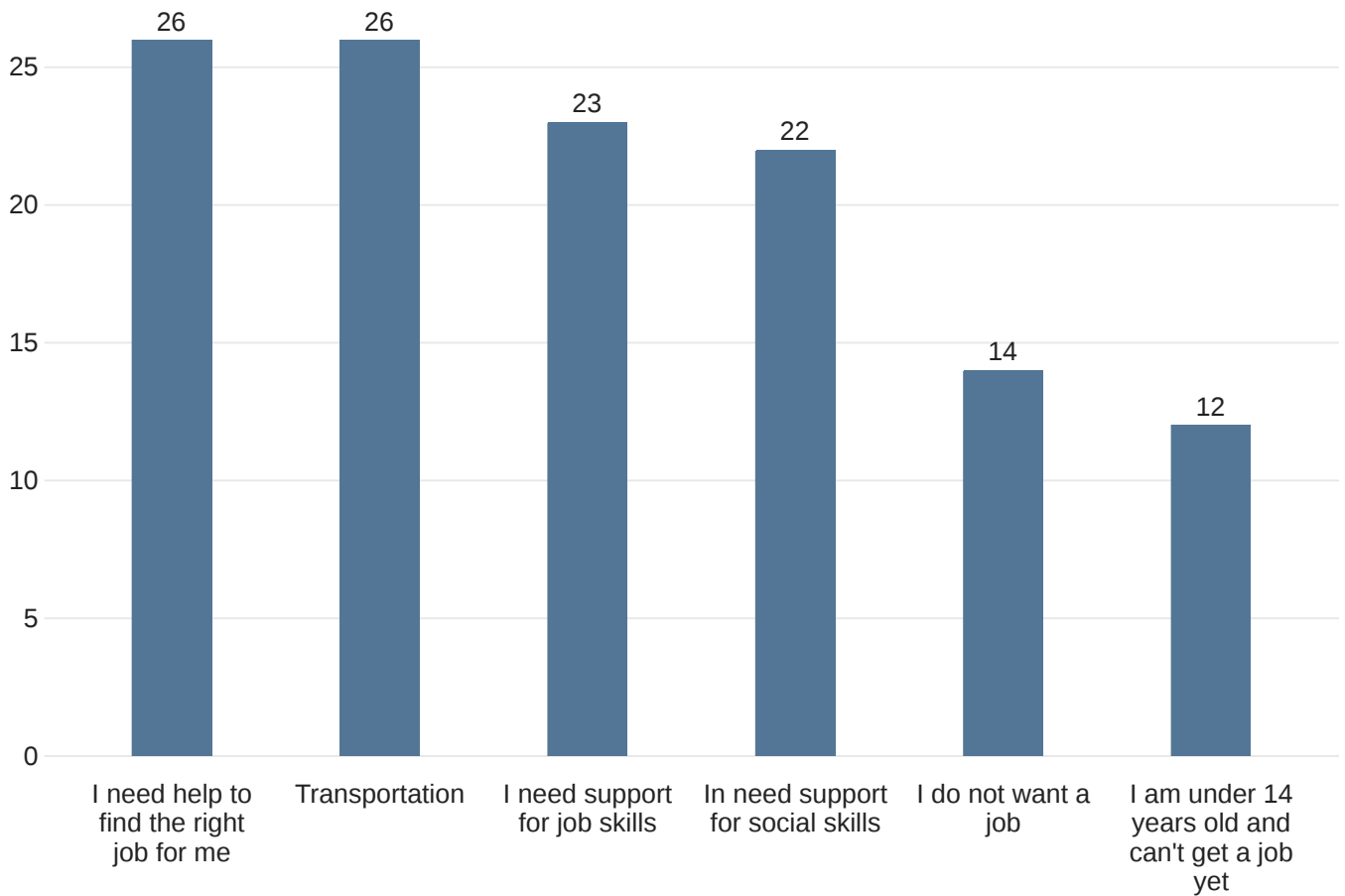
Would you like a job in the community?

64 Responses



If you would like a job, what barriers do you have to getting one? (check all that apply)

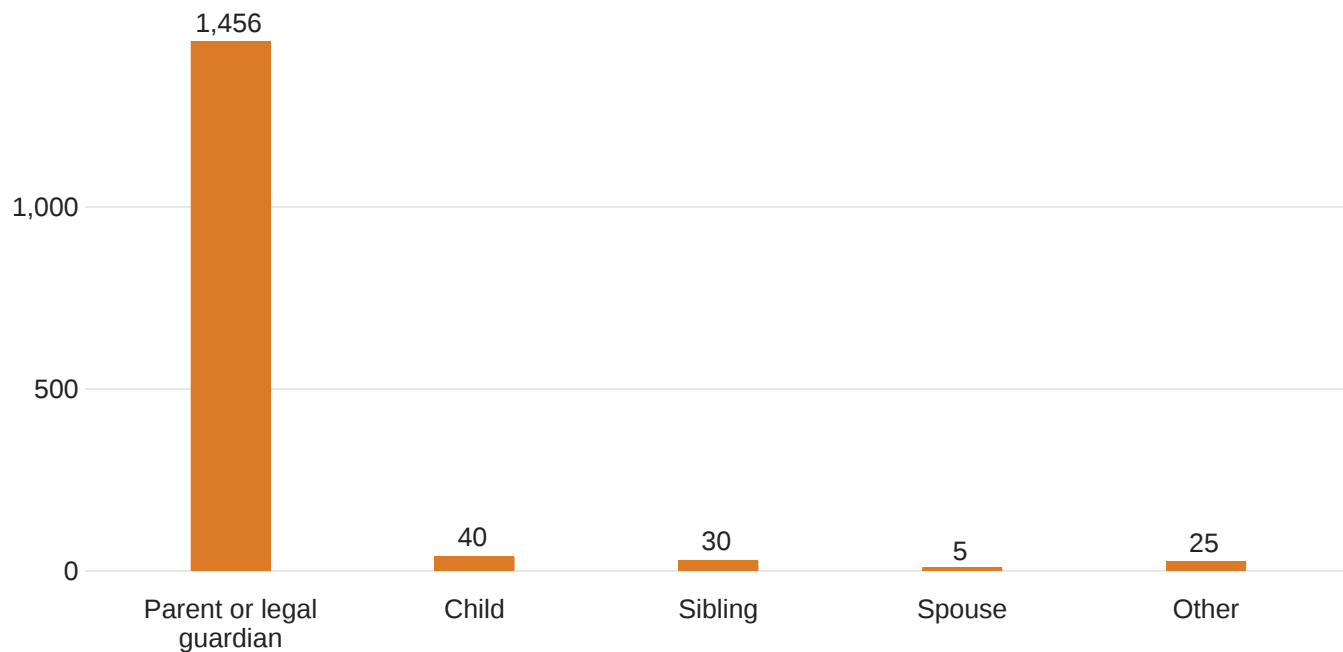
60 Responses



## Caregiver : General Questions

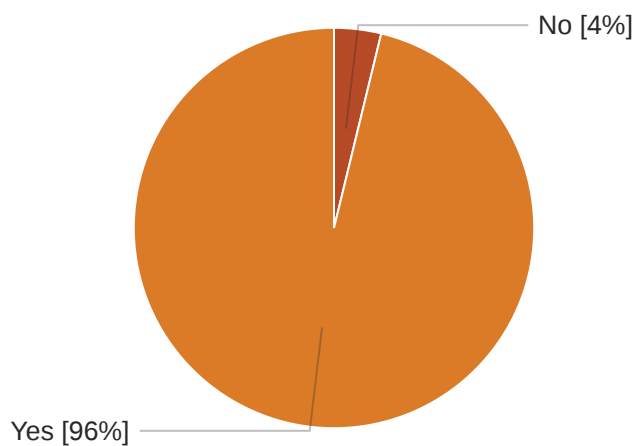
What is your relationship to the person on the waiting list?

1556 Responses



Are you the primary caregiver for the person on the waiting list?\*

1554 Responses



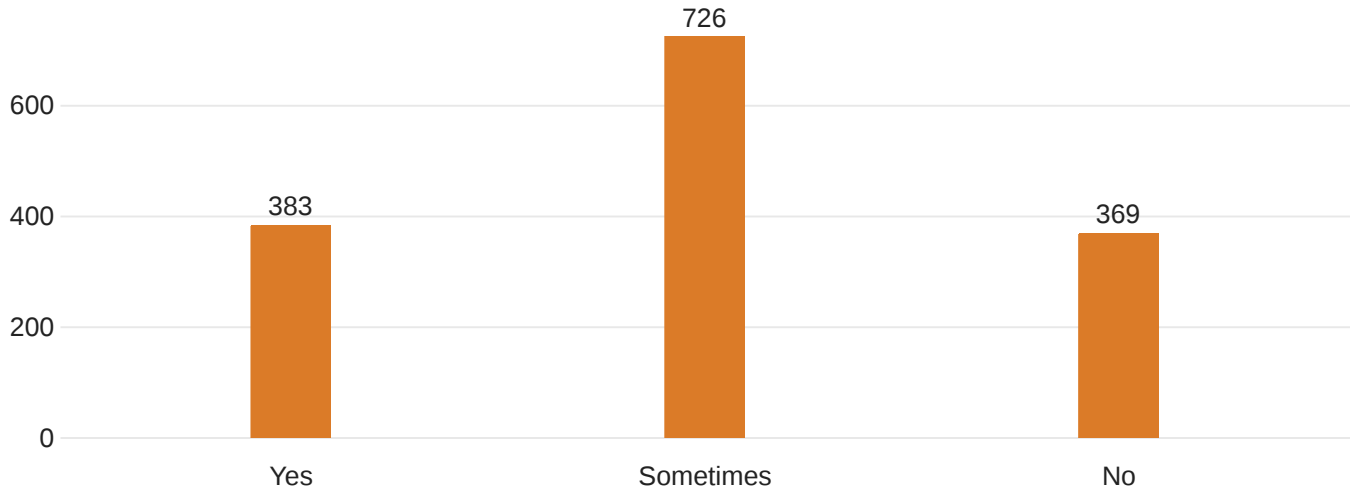
\*Only those answering "Yes", they are the primary caregiver, were asked the remaining questions.



## Caregiver : Quality of Life Questions

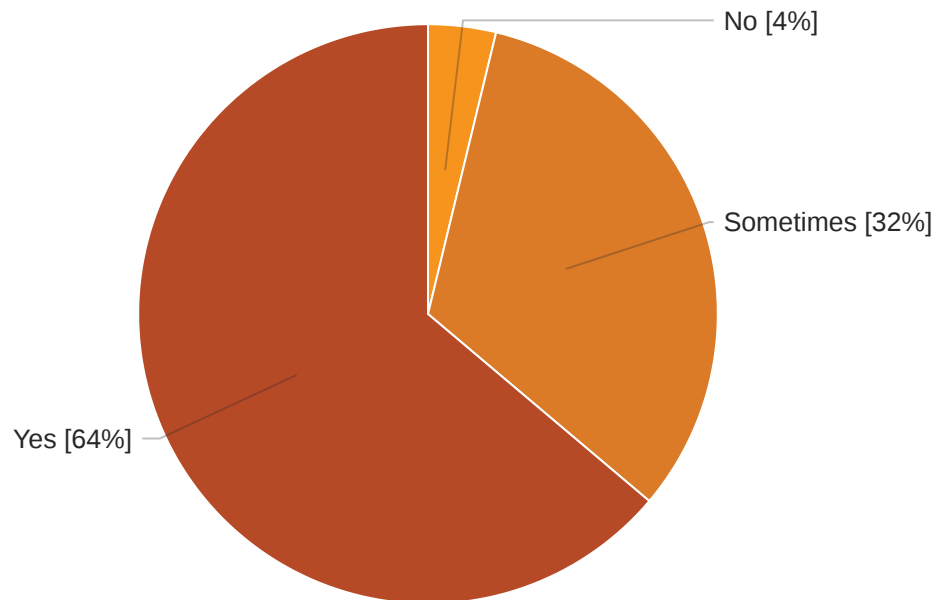
Are you satisfied with your overall quality of life?

1478 Responses



Do you feel stress over caring for your family member with a disability?

1482 Responses



Legend: **Yes** **Sometimes** **No** N/A

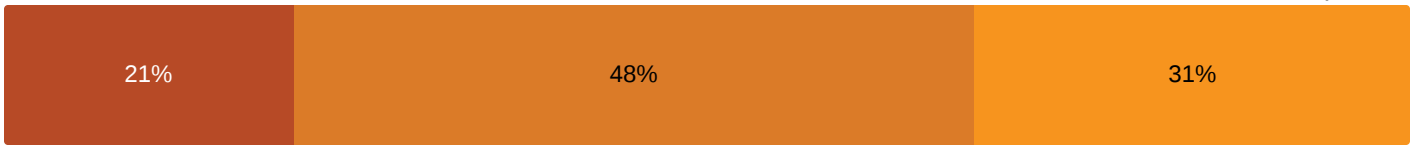
Do you have enough time to yourself?

1481 Responses



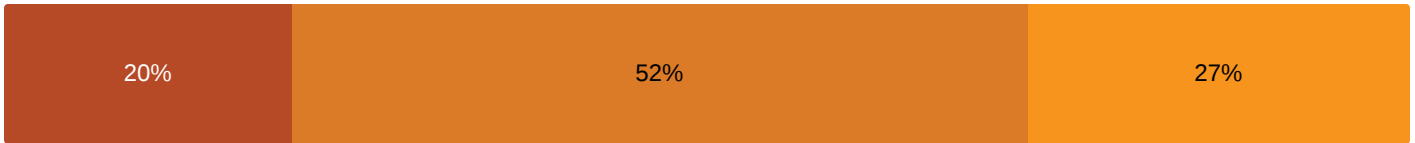
Do you have enough time to take care of your personal health?

1483 Responses



Do you have enough time your daily responsibilities?

1481 Responses



Do you have enough time to spend with your partner/spouse?

1481 Responses



Do you have enough time to spend with your children?

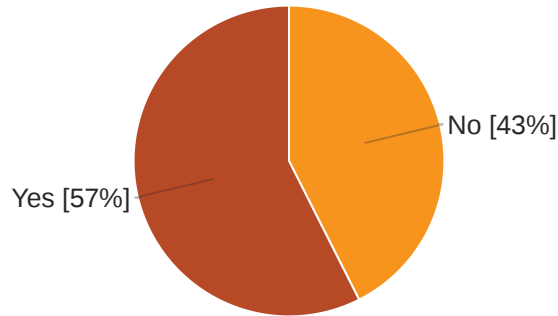
1480 Responses



## Caregivers : Employment Questions

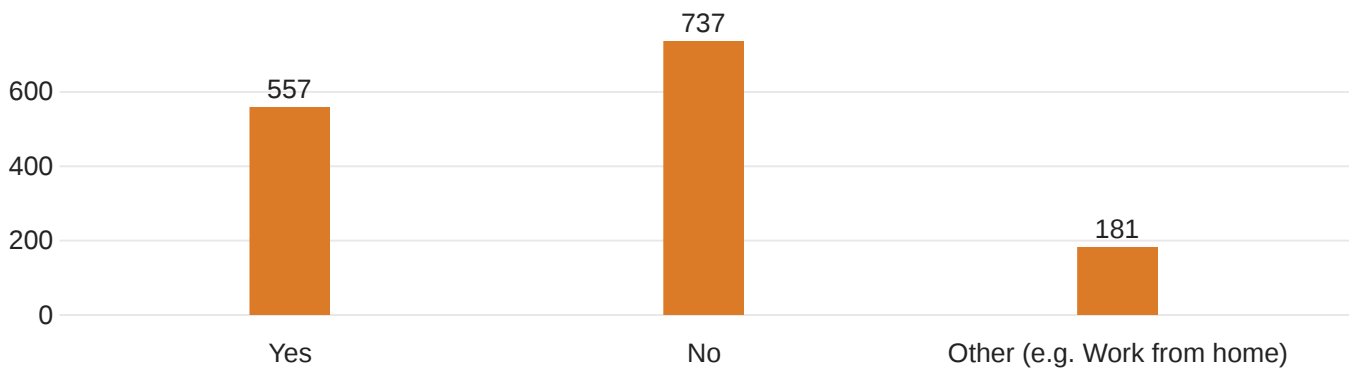
Are you, or have you been, employed in the past three months?

1476 Responses



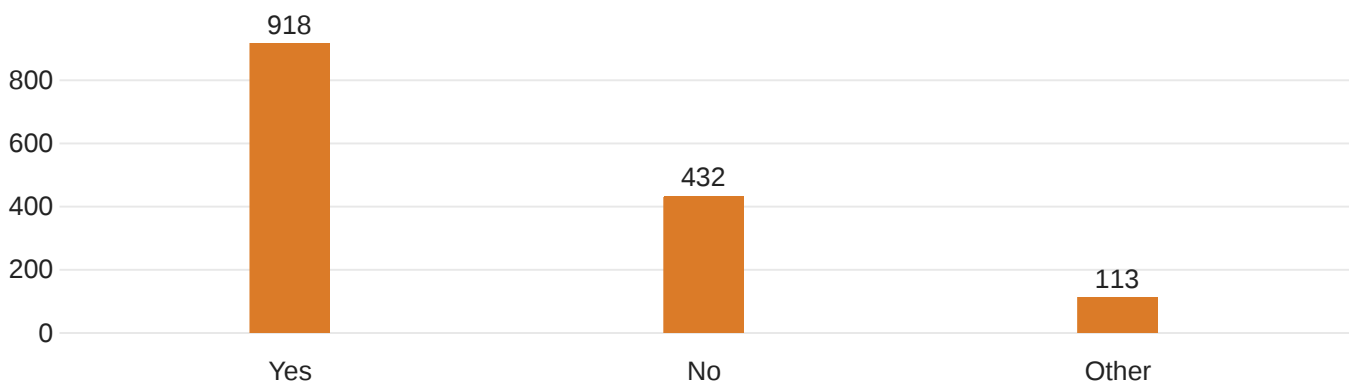
Have you ever had to quit a job in order to care for your family member with a disability?

1475 Responses



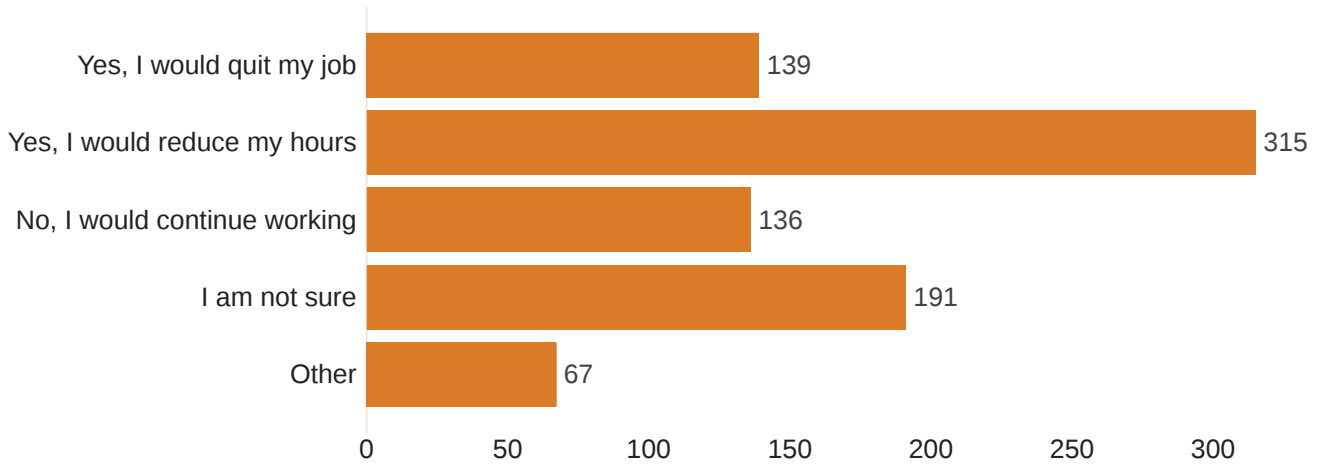
Have you ever had to reduce your work hours to care for your family member with a disability?

1463 Responses



If you were given the option to be compensated for caring for your family member with a disability, would you change your employment decisions or commitments?

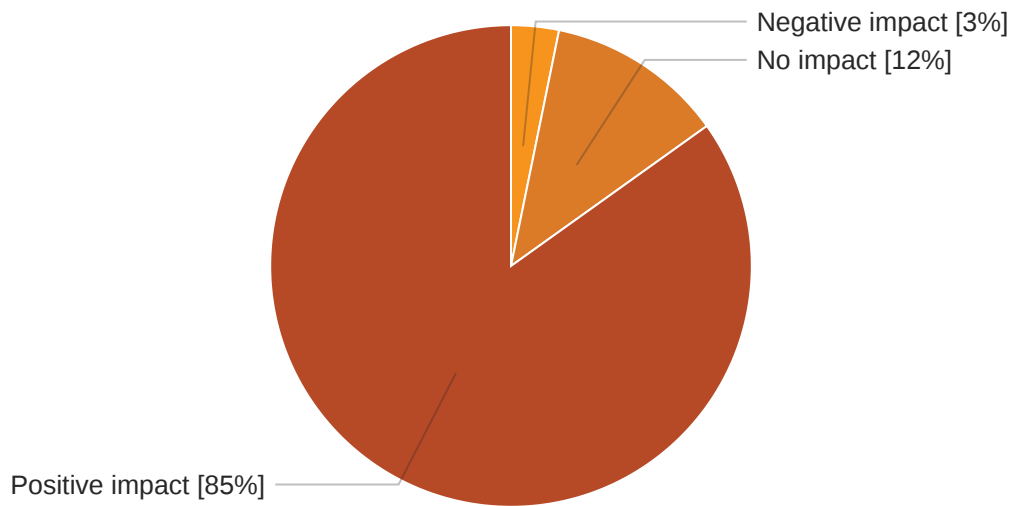
848 Responses



### Caregivers : Financial/Caregiver Compensation Questions

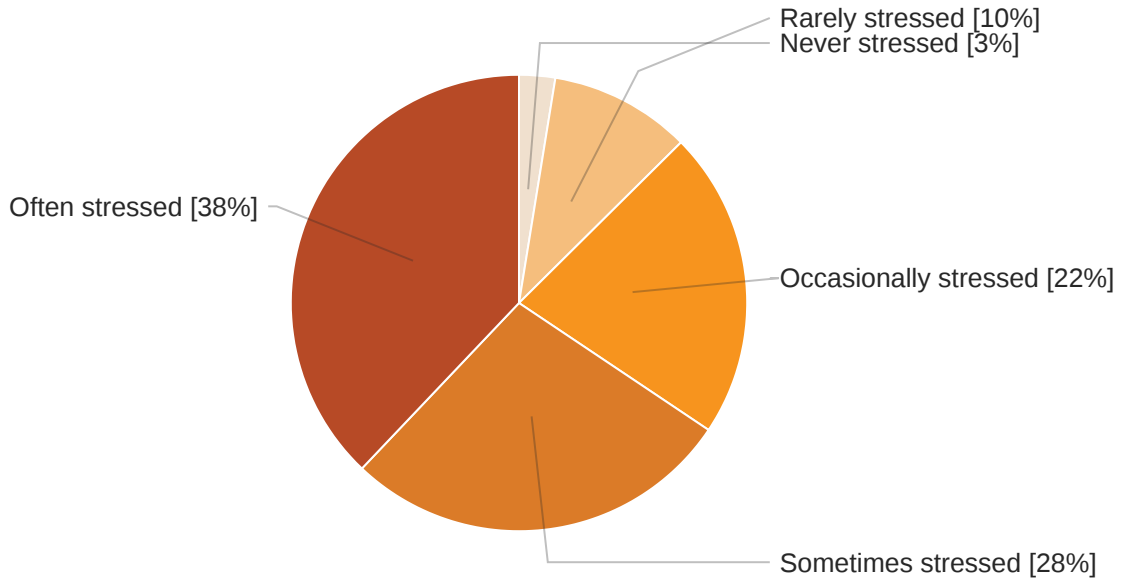
How do you think being paid to provide care for your family member with a disability would impact your overall financial well-being?

1435 Responses



How do you feel about your current financial situation?

1448 Responses



Are you currently able to save enough money for future expenses?

1448 Responses



In the past six months, have you had to change your spending habits to meet the needs of your family member with a disability?

1445 Responses

