

Caregiver Compensation Surveys Report

Executive Summary:

In 2022, Division of Services for People with Disabilities (DSPD) developed two surveys to provide data on the caregiver compensation (CC) program to the Utah Legislature and inform future decision making within DSPD moving forward. One survey, the Caregiver Quality of Life survey, was sent to all caregivers of individuals with disabilities who use self-administered services (SAS) through DSPD to gather input on how CC has impacted the quality of life for them and their families. Another survey, the Support Coordinator Survey on Caregiver Compensation, was sent to all support coordinators (SCEs) and their corresponding companies to gather input on how CC has impacted individuals on their caseloads and their families. All current caregivers and SCEs were emailed on July 6th, 2022 and asked to voluntarily participate in the survey. Due to the response rates (approximately 44% for caregivers and 35% for SCEs), we are confident that the survey results are representative of both groups. Notable results are summarized below.

Caregiver Quality of Life Survey Results Summary

Caregivers who received caregiver compensation:

- Approximately 77% of survey respondents reported that they received CC.
- Most caregivers represented have reportedly had more time to spend with their partner, other children, daily responsibilities, personal health, and themselves because of the program.
- An overwhelming majority of caregivers represented have reportedly felt much more secure in their housing, bills, food, and transportation situations because of the program.
- Eighty-eight percent of caregivers represented indicated that they were either very or somewhat satisfied with their overall quality of life.
 - Ninety-four percent of caregivers represented said that their quality of life has improved since starting caregiver compensation services.
 - Ninety-seven percent of caregivers represented said that the quality of life of their family member with a disability who received CC services improved.
- Caregiver compensation overwhelmingly had a positive impact on the represented caregivers' financial situations. Ninety-seven percent reported a positive overall impact on their financial well-being, 81% reported a positive impact on their ability

to save money, and 95% reported that their stress levels were either “significantly” or “somewhat” reduced.

Responses (n): 280 Caregivers who received caregiver compensation

Caregivers who did not receive caregiver compensation:

- Approximately 23% of survey respondents reported that they did not receive caregiver compensation.
- Most caregivers who did not participate in CC services reported either not having enough time or sometimes having enough time to spend with their partner, other children, daily responsibilities, personal health, and themselves.
- Fifty-five percent of caregivers not receiving CC reported that they were either “very” or “somewhat” satisfied with their overall quality of life, compared to 88% of caregivers receiving CC in the survey.
 - Thirty-seven percent of non-CC caregivers said that their quality of life is either good or very good.
 - Forty-nine percent of non-CC caregivers said that the quality of life of their family member with a disability is either good or very good.
- Sixty-four percent of caregivers who did not participate in CC services reported having to quit a job in order to care for their family member with a disability.
- Eighty-eight percent of caregivers who did participate in CC services reported having to reduce their work hours to care for their family member with a disability
- Fifty-eight percent of non-CC caregivers disclosed being unable to save enough money for future expenses and 70% said they feel either very stressed or somewhat stressed about their current financial situation.

Responses (n): 83 Caregivers who did not receive caregiver compensation

Support Coordinator Survey on Caregiver Compensation Services Results Summary

- Ninety-six percent of SCEs reported having individuals on their caseloads currently receiving caregiver compensation.
- Approximately half of SCEs reported having less than 20% of their caseloads receiving CC support.
- The majority of SCEs represented (54%) reported having 5 to 18 families participating in CC services.

- The most common disabilities of those receiving CC, disclosed by SCEs represented in the survey, are intellectual or developmental disabilities (96%), autism (82%), and physical disabilities (57%).
- Support coordinators reported that the overall quality of life for most individuals with disabilities and their caregivers increased due to receiving CC services.
 - Eighty-two percent of individuals with disabilities' overall quality of life either "significantly" or "somewhat" increased.
 - Sixty-five percent of caregivers' overall quality of life either "significantly" or "somewhat" increased.
- Support coordinators reported that stress levels for most individuals with disabilities and their caregivers decreased due to receiving CC services.
 - Sixty-eight percent of individuals with disabilities' stress levels either "significantly" or "somewhat" decreased.
 - Seventy-two percent of caregivers' stress levels either "significantly" or "somewhat" decreased.
- According to SCEs, the primary reasons individuals did not participate in CC services included people being happy with the current services they had at the time (59%), family members did not feel like they needed to be compensated for caring for the individuals with disabilities, and CC was not being in the best interest of individuals (44%).
- Sixty-eight percent of respondents reported that CC had either "significantly" or "somewhat" relieved some of the stress of the workforce shortage.

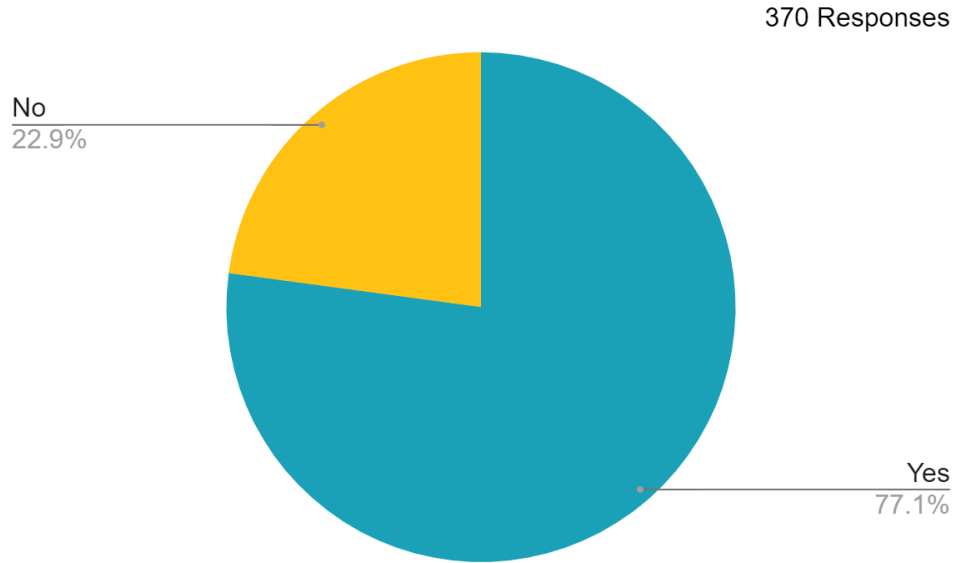
Responses (n): 75 support coordinators

Limitations: Much of the Support Coordinator Survey on Caregiver Compensation Services asks SCEs about caregivers' and individuals with disabilities' experiences with CC and may not accurately reflect the true experiences and thoughts of them.

Caregiver Quality of Life Survey

The Caregiver Quality of Life survey was sent to all mothers, fathers and legal guardians of individuals who use SAS through DSPD. This amounted to 831 distinct email addresses. Of those, DSPD received 370 responses for a response rate of 44.5%. Of those, 98.1% of respondents were classified as the primary caregiver of the individual in services and were able to move forward with the survey. Of the primary caregivers represented, 77.1% reported that their family member received CC services and 22.9% of individuals chose not to participate (see Figure 1).

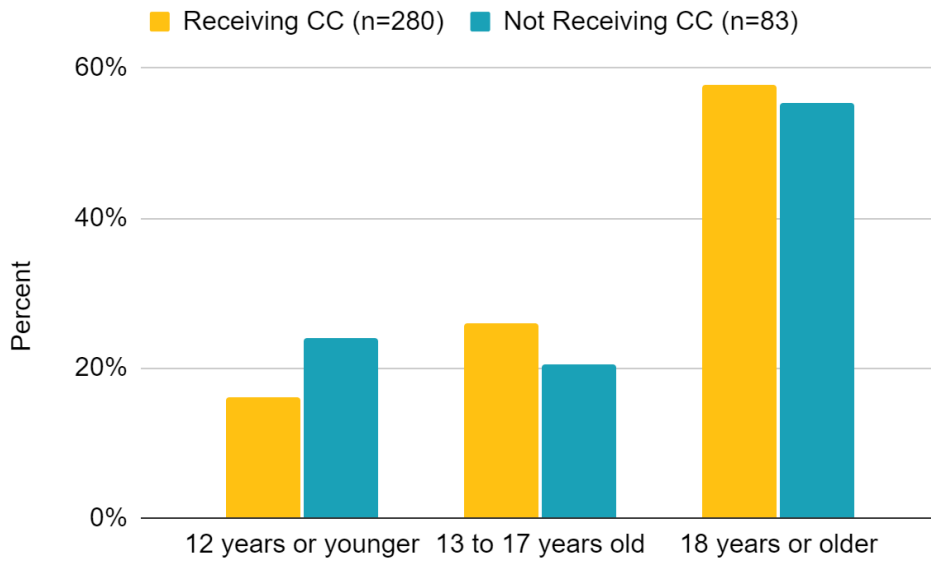
Figure 1. Respondents whose family member receives caregiver compensation services



Demographics

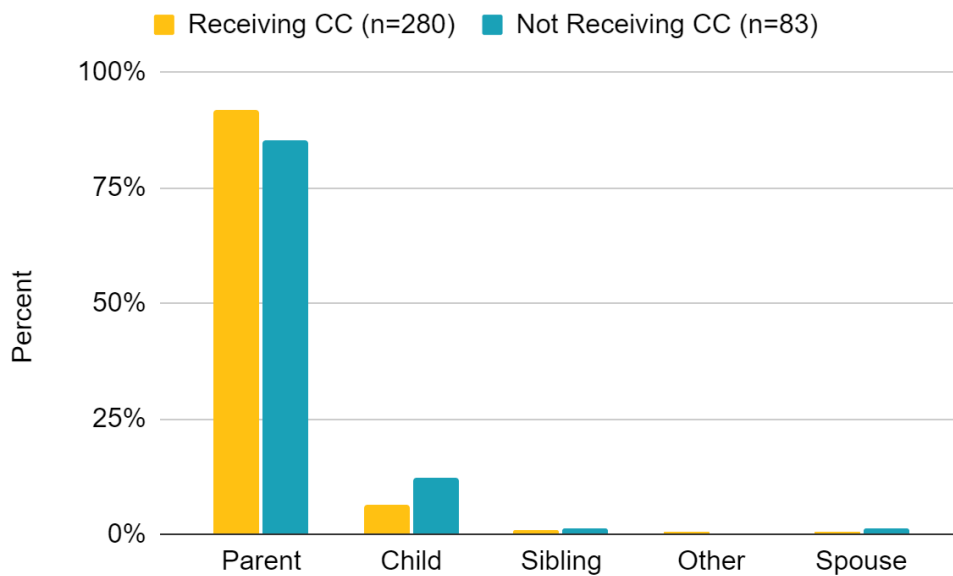
This section focuses on the demographic characteristics of respondents and their family members with disabilities, particularly age ranges, relationships, and disability types. As shown in Figure 2 below, respondents who received CC services, and those who did not, reported that most individuals that they cared for were above the age of 18, 58% and 55%, respectively.

Figure 2. Age ranges of individuals with disabilities receiving and not receiving caregiver compensation



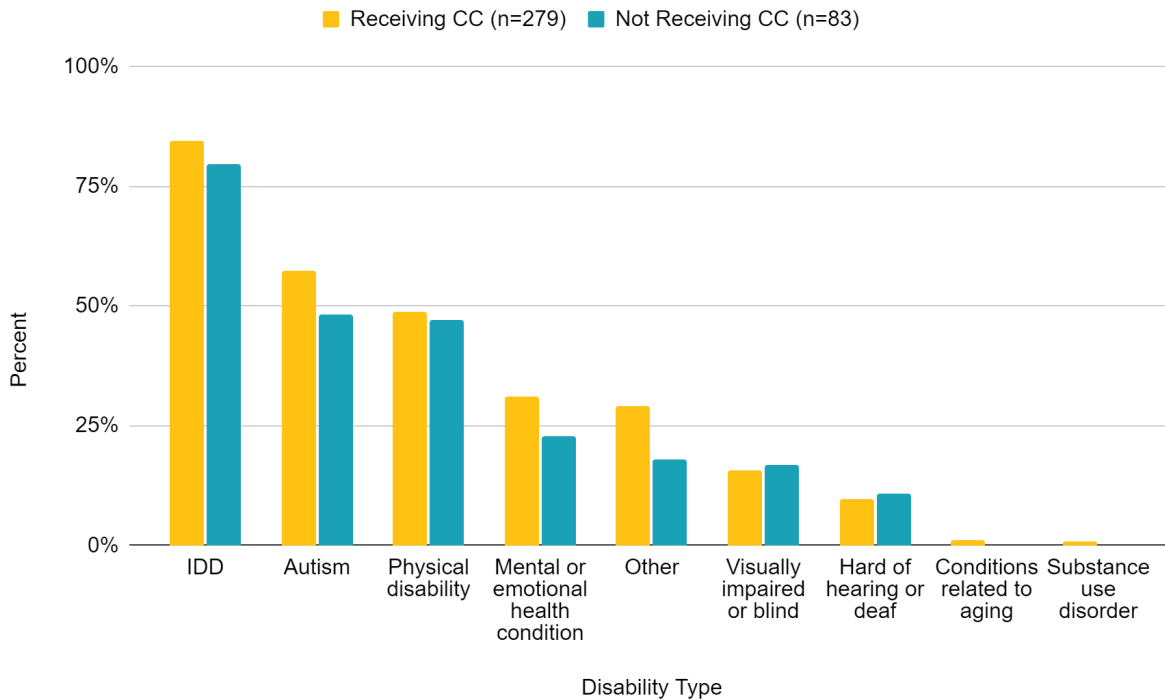
Respondents were also asked what their relationship is to the person receiving CC services. As shown in Figure 3, The vast majority of respondents who received CC and those who did not were the parent or legal guardian of the individual with a disability (92% and 85%, respectively).

Figure 3. Respondent relationship to family member with disability



Disability types were also similar among both groups of respondents. The most common types of disabilities disclosed were intellectual or developmental disabilities (IDDs), autism, and physical disabilities. Figure 4 breaks down the responses.

Figure 4. Disability types among individuals



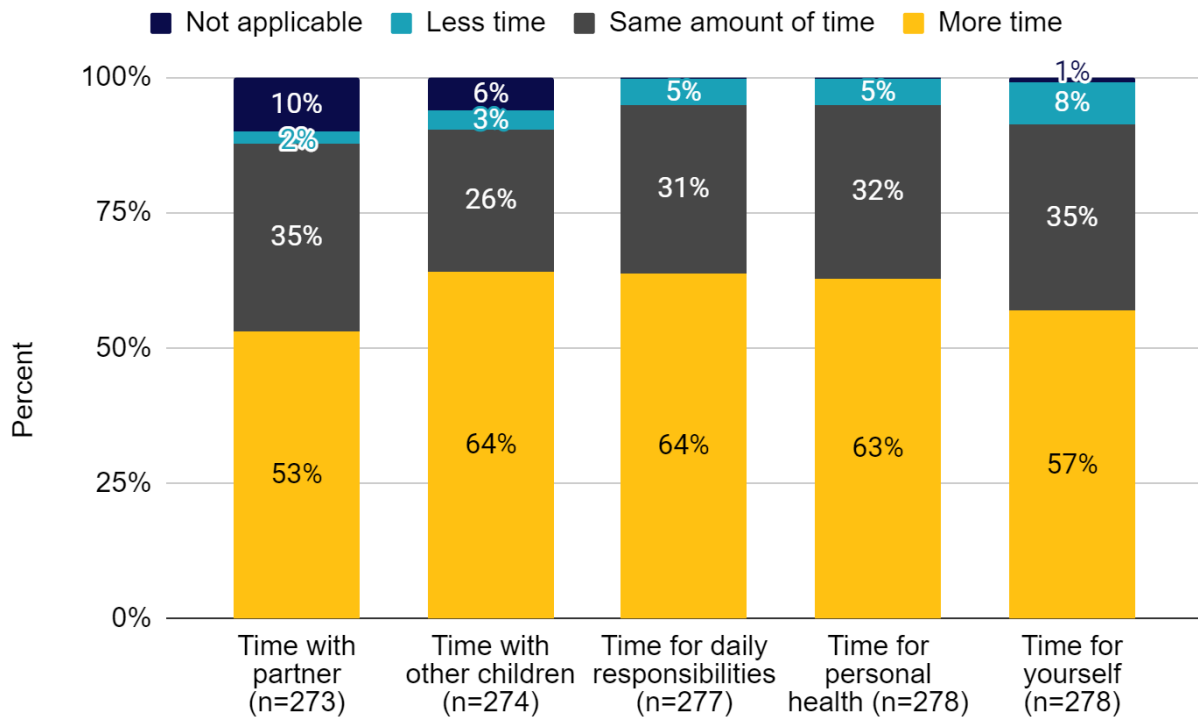
* Respondents were allowed multiple responses resulting in a summation greater than 100%.

Quality of Life

This section focuses on the quality of life of respondents in relation to having received CC services. It also focuses on the quality of life of respondents who chose not to receive CC services. At times, this section compares results of both groups to highlight the positive impact CC services had on caregivers of individuals with disabilities.

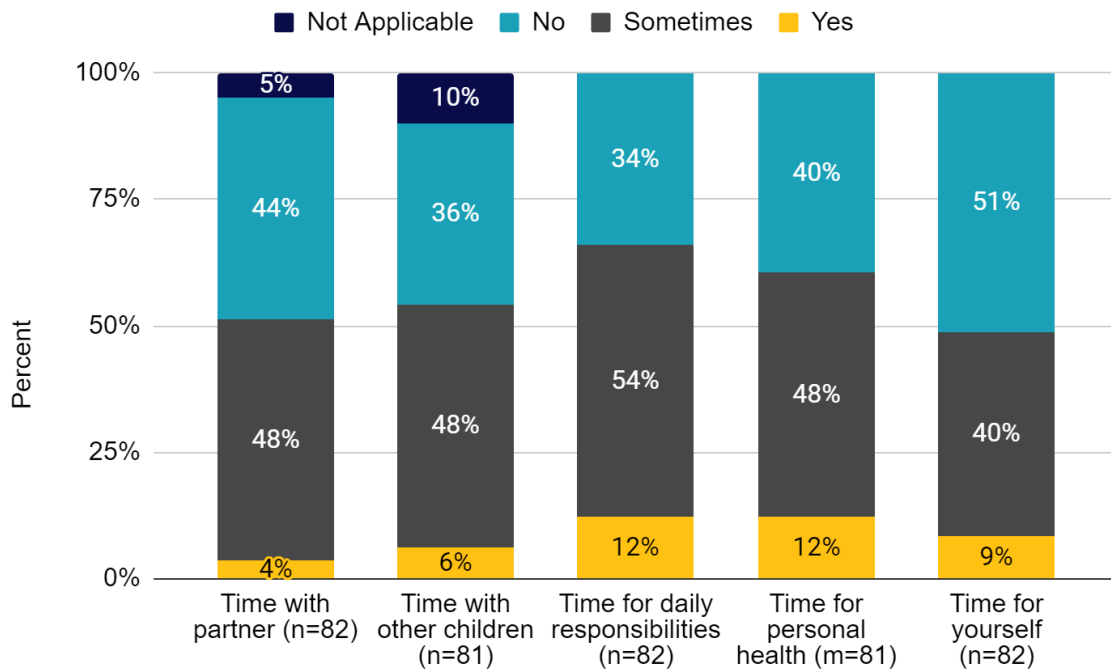
Respondents who received CC were asked whether CC impacted the time they have for things in life such as their partner, children, daily responsibilities, personal health, and themselves. After receiving CC, over half of respondents said they had more time to spend on the aforementioned categories. Figure 5 illustrates the responses.

Figure 5. How receiving CC has impacted the time caregivers have for things in life



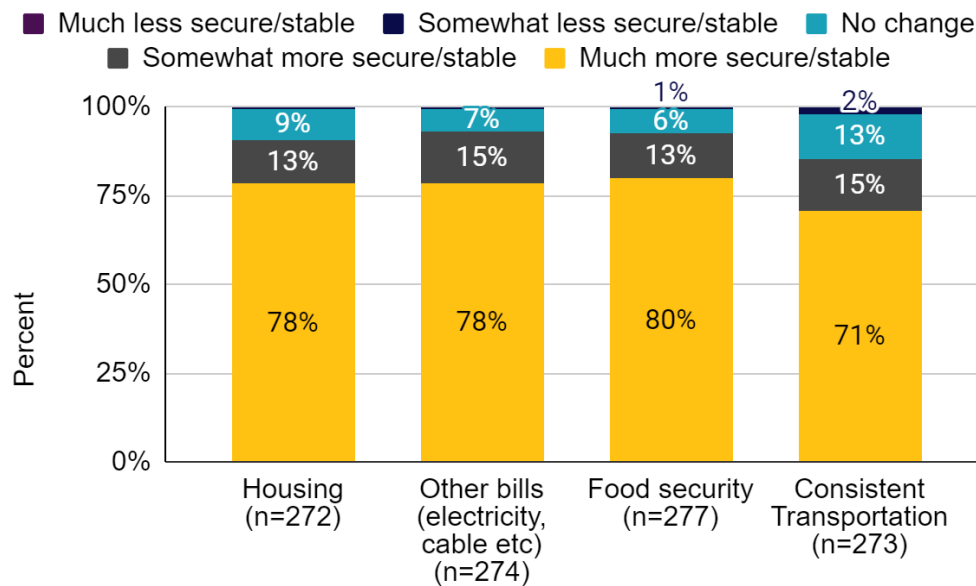
Similarly, respondents who received SAS through DSPD and chose not to receive CC were asked if they had enough time to spend with their partners, their children, on their daily responsibilities, their personal health, and themselves (see Figure 6 below). Their responses indicate that they did not have much time to spend with important people and responsibilities in their lives.

Figure 6. Do caregivers not receiving CC have enough time for important people and responsibilities in life?



Financially, respondents who received CC felt more secure in the areas of housing, bills, food, and transportation. Shown in Figure 7 below, an overwhelming majority felt much more secure in all areas after receiving CC.

Figure 7. How receiving CC has impacted the security and stability of life essentials



Furthermore, caregivers were asked how satisfied they are with their overall quality of life (Figure 8 below). A much larger proportion of respondents who received CC reported being

“very satisfied” with their overall quality of life than those who did not receive CC, suggesting that CC services had a positive impact on caregivers’ lives. This is further illustrated in Figure 9. Seventy-five percent of respondents and 76% of their family members with disabilities who received CC felt that their overall quality of life became much better after receiving services.

Figure 8. Caregiver overall quality of life

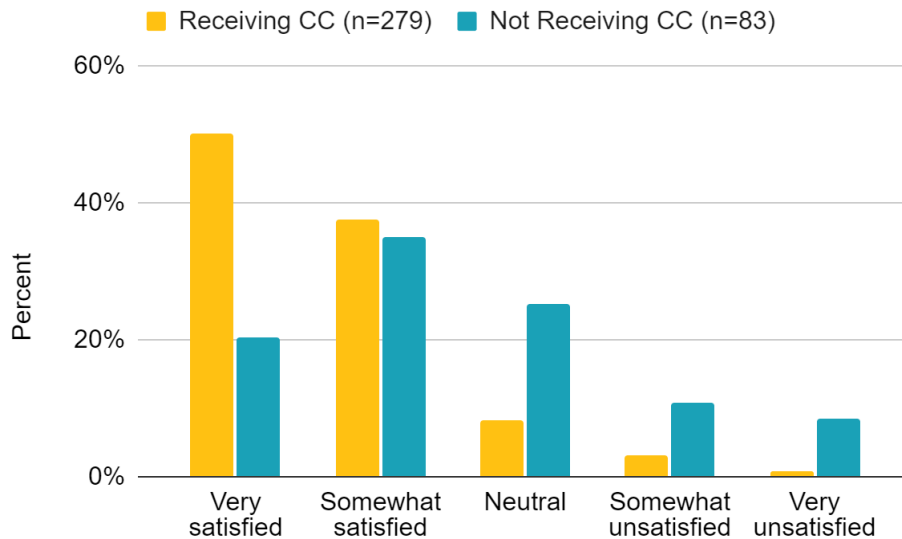
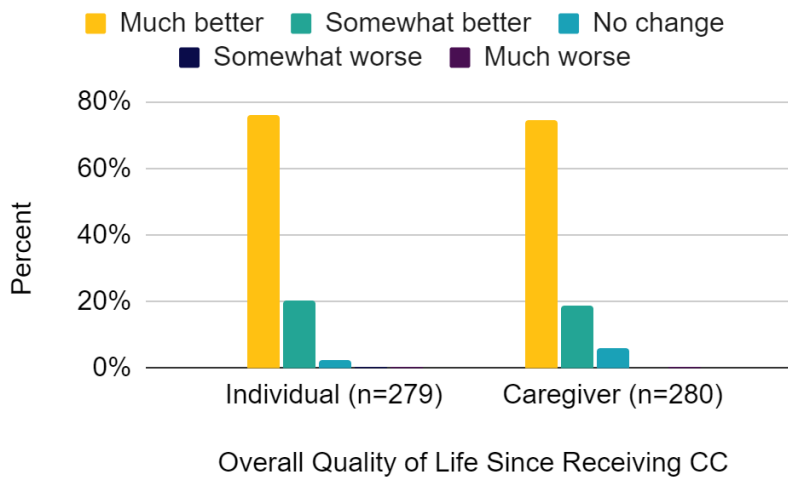


Figure 9. Caregiver and individual with disability overall quality of life since receiving CC

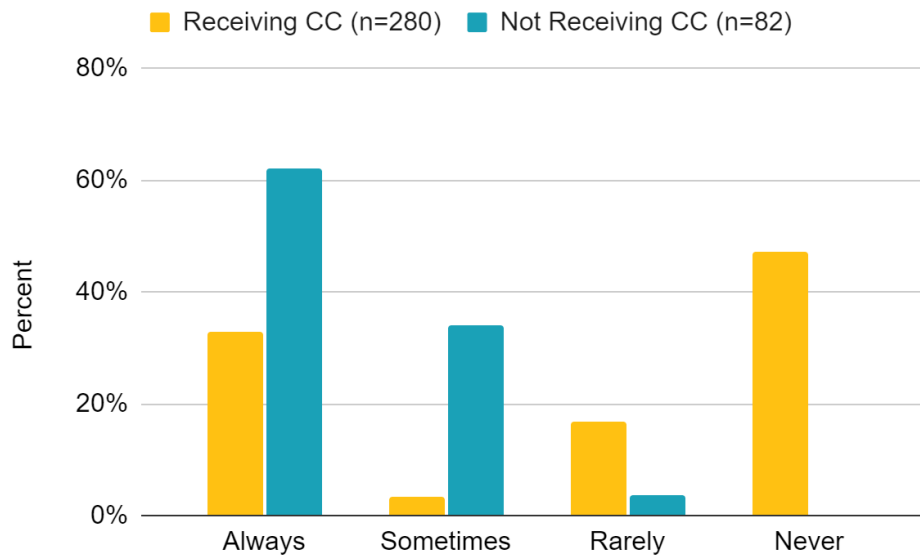


Note: response options were on a 1 to 5 scale with 1 being “much worse” and 5 being “much better.” For better readability, DSPD re-coded 2 as “somewhat worse,” 3 as “no change,” and 4 as “somewhat better.”

Caretaking for individuals with disabilities can be a stressful job. The survey asked caregivers how frequently they felt stress over caring for their family member with

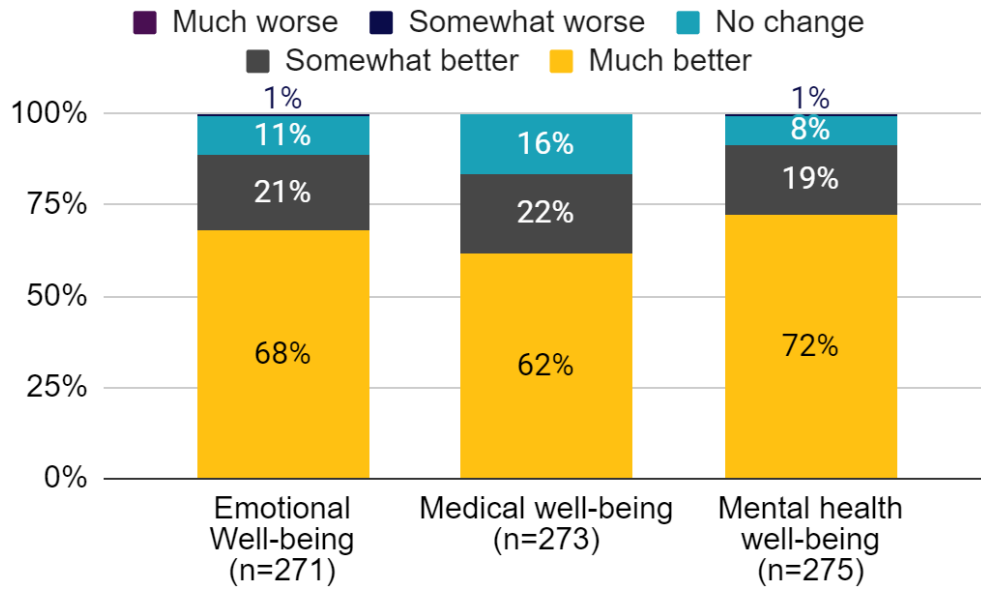
disabilities to see if there were any differences in attitudes between caregivers who received CC and those who did not. As seen in Figure 10 below, there is a stark difference in stress levels between the two groups. Forty-seven percent of respondents who received CC reported never feeling stress when caring for their family member as compared to 0% of respondents who did not receive CC.

Figure 10. Frequency of stress over caring for individuals with disabilities among caretakers



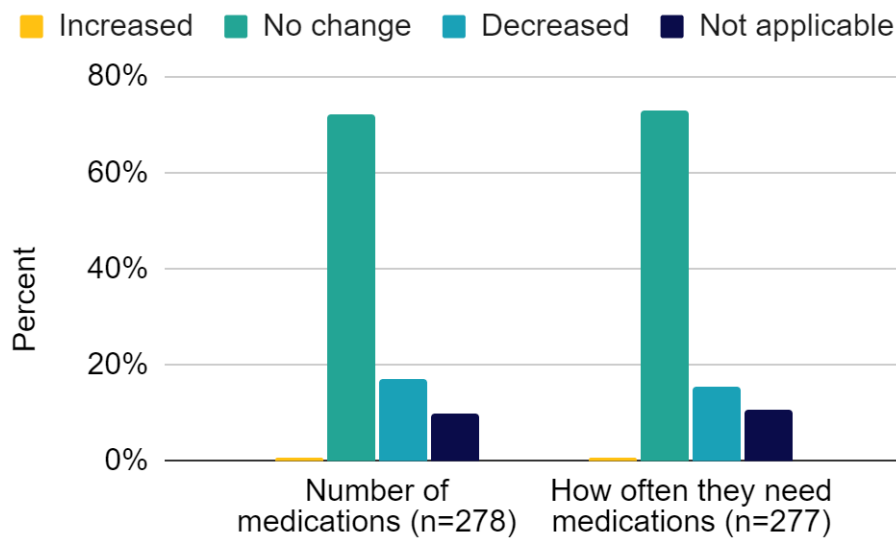
With regard to the individuals with disabilities being cared for, the survey asked caregivers specific questions on how having received CC impacted their family members' well-being and whether their family member had been able to get out into the community as much as they would like. The majority of respondents reported that their family member's emotional, medical, and mental health well-being became "much better" after having received CC services (see Figure 11 below).

Figure 11. CC impact on individuals with disabilities' well-being



The survey also asked caregivers whether the number of medications and the frequency of taking medications changed for individuals with disabilities as a result of CC. Seventy-two percent of respondents reported no change in the number of medications being administered and 73% reported no change in how often individuals with disabilities needed medications; however, 17% and 16%, respectively, saw a decrease in the number of medications and frequency of taking them. Figure 12 illustrates the responses.

Figure 12. Caregiver Compensation impact on individuals' medications



Lastly, caregivers were asked whether their family member with disabilities was able to get out into the community as much as they would like since receiving CC services. Seventy-five percent of represented caregivers responded “yes” (see Figure 13 below). Similarly, those who receive SAS but chose not to receive CC were asked if their family member with disabilities was able to get into the as much as they would like. Only 17% responded “yes” and 49% responded “no” (see Figure 14)

Figure 13. Individuals with disabilities’ ability to get out into the community since receiving CC

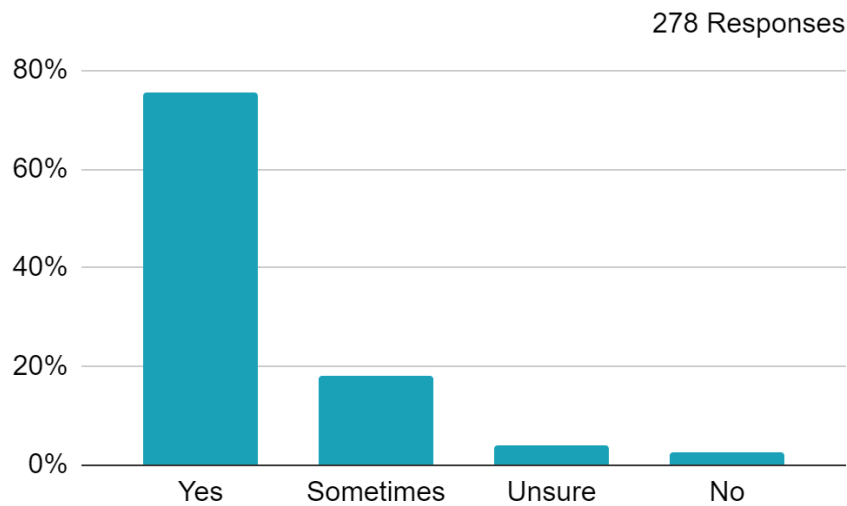
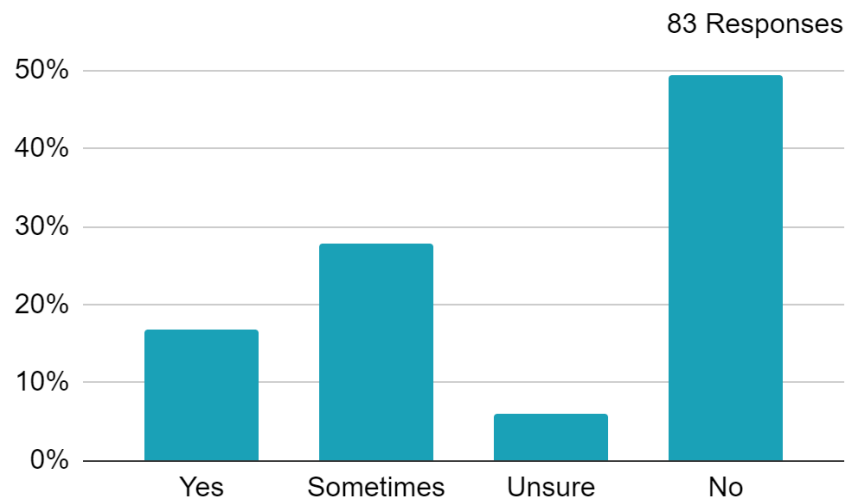


Figure 14. Individuals with disabilities’ ability to get into the community who did not receive CC

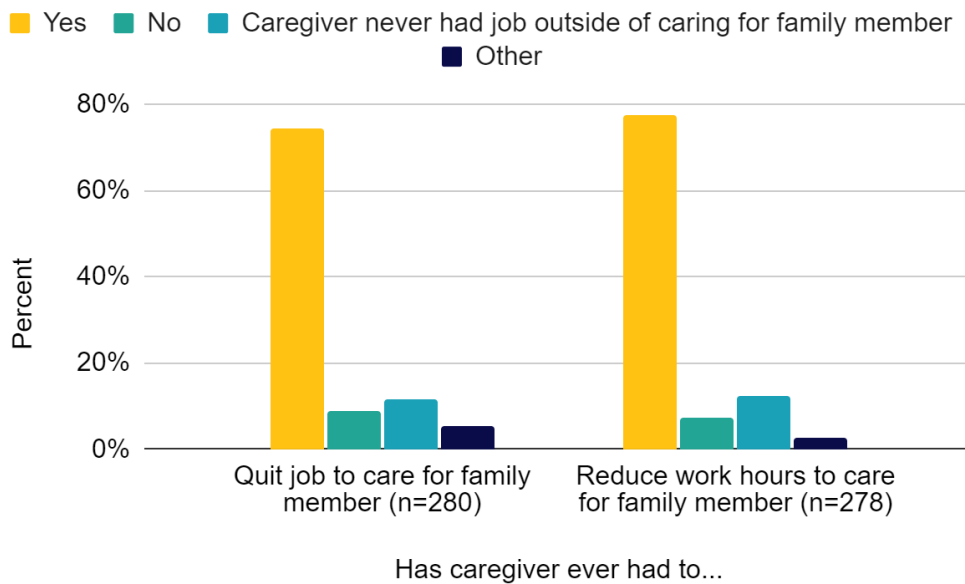


Employment and Financial Stability

This section focuses on economic and financial conditions of caretaking for family members with disabilities such as the effect on employment and CC impact on financial

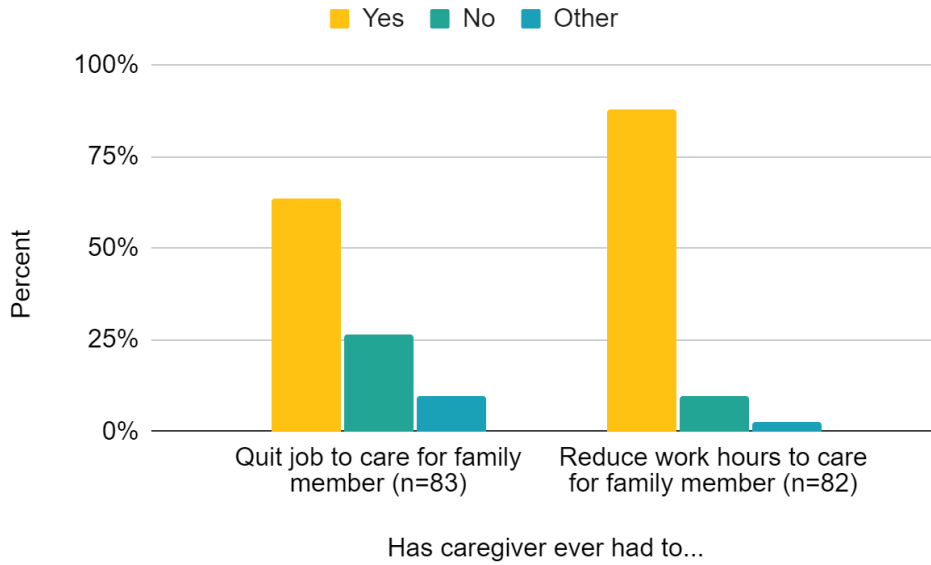
well-being. Respondents were asked whether they have ever had to leave a job, or reduce work hours, in order to care for family members with disabilities. Seventy-four percent reported having had to quit a job in the past and 78% had to reduce work hours, as shown in Figure 15 below.

Figure 15. Caregiving impact on employment for those who received CC



The same question was asked to caregivers who chose not to receive CC. For that group, 64% reported having had to quit a job in the past and 88% had to reduce work hours (see Figure 16 below).

Figure 16. Caregiving impact on employment for those who did not receive CC



As a result of receiving CC, nearly half of respondents reported quitting their job or reducing work hours so they could spend more time taking care of their family member with disabilities and receive compensation for it (Figure 17 below). Further, having received CC, respondents reported that it overwhelmingly had a positive impact on their financial well-being (97%) and ability to save money (81%), which is illustrated in Figure 18 below.

Figure 17. Change in caregiver employment status since receiving CC

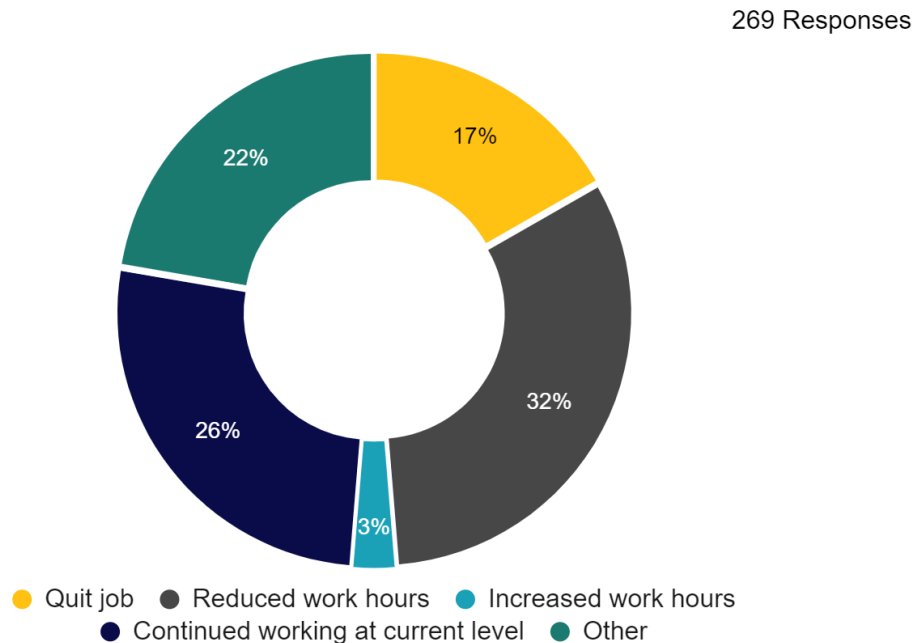
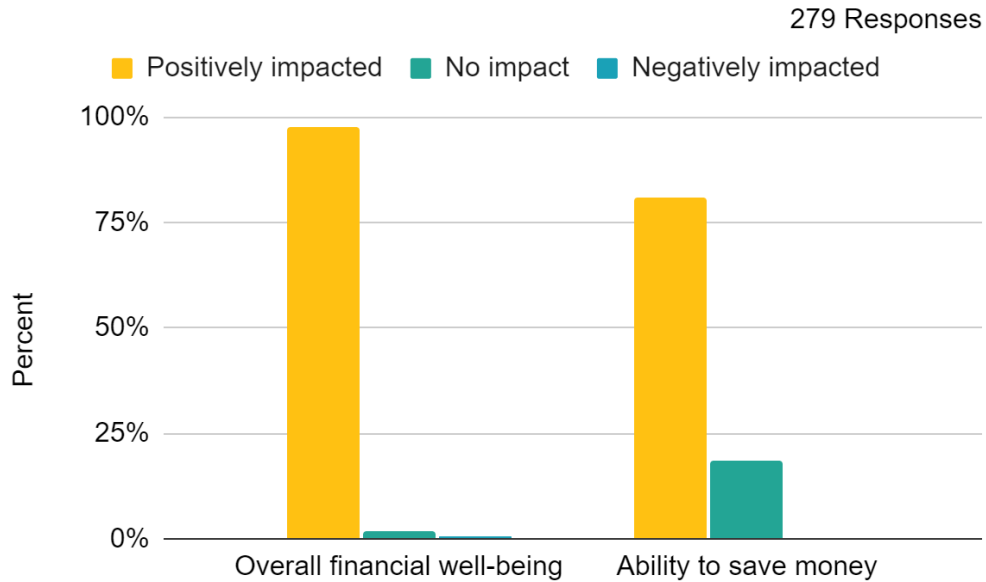
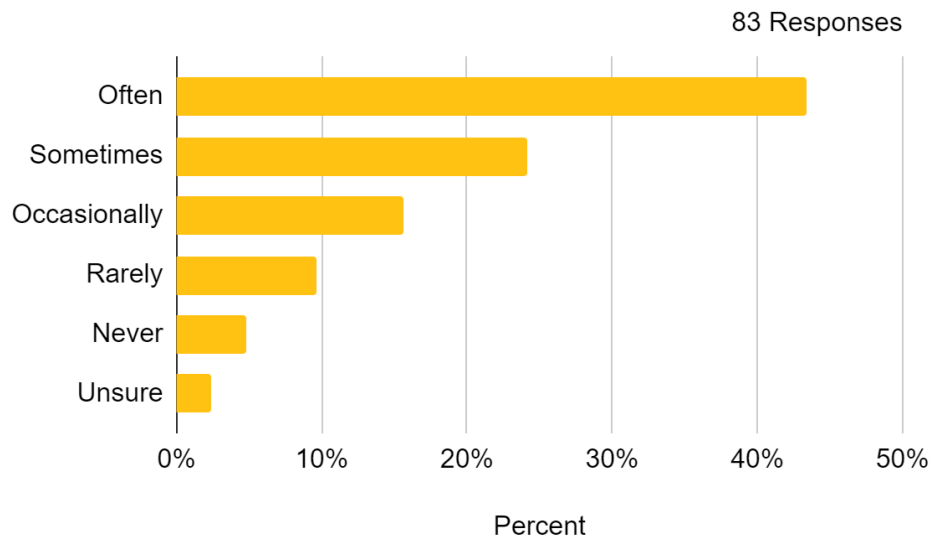


Figure 18. Caregiver compensation impact on family financial conditions



Caregivers who did not receive CC services were asked whether they had to change their spending habits within the past 6 months to meet the needs of their family members with disabilities. Forty-three percent of respondents reported that they “often” had to change spending habits and 24% reported that they “sometimes” had to. Only 5% percent said they “never” had to change spending habits (see Figure 19).

Figure 19. How often non-CC caregivers had to change spending habits, within the past 6 months, to care for their family member with disabilities



In addition, caregivers who received CC were asked how stress about their financial situation had changed as a result of receiving CC services. Figure 20 below clearly shows that the vast majority of respondents (95%) had their stress “significantly” or “somewhat” decrease since beginning CC services. Similarly, caregivers who were eligible for CC services and chose not to receive them were asked what their stress level is over their financial well-being. Seventy percent of respondents reported either being “very” or “somewhat” stressed (see Figure 21 below)

Figure 20. Caregiver financial stress level after receiving CC services

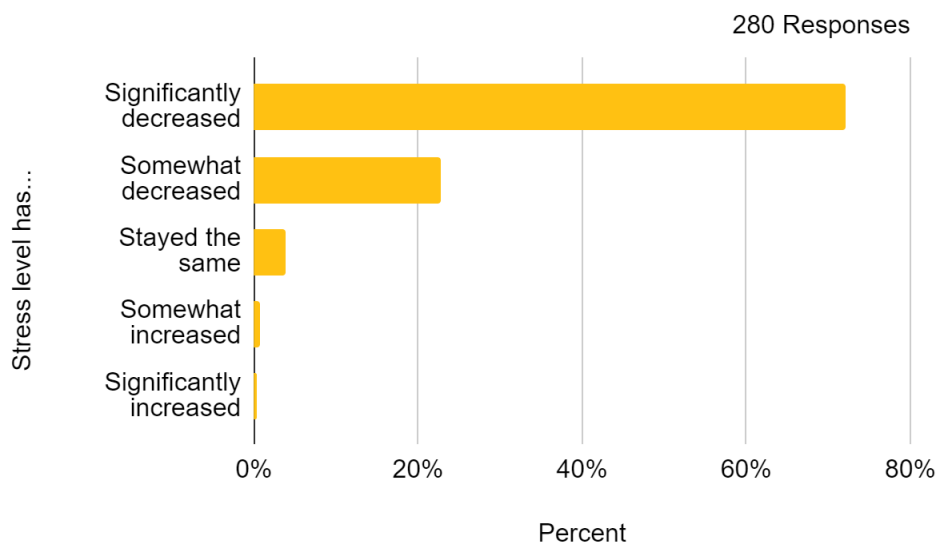
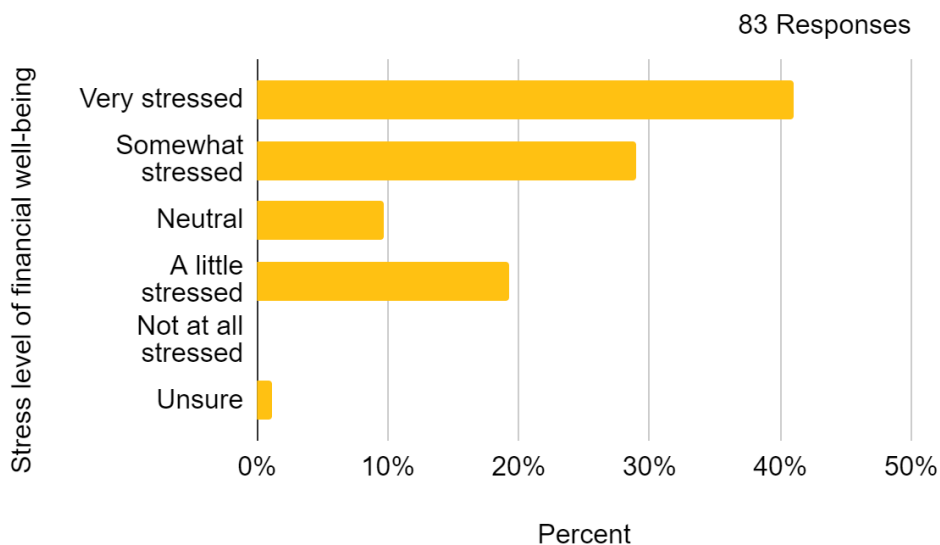


Figure 21. Level of financial stress of caregivers not participating in CC services



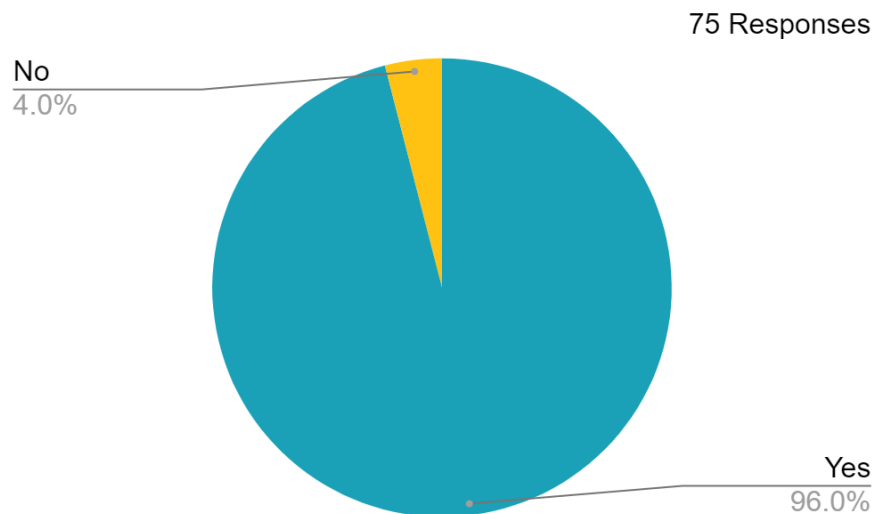
Reasons Caregivers Chose Not to Receive Caregiver Compensation

The survey asked caregivers who did not participate in CC services whether their family member’s support coordinator discussed CC services with them. Forty-five percent of respondents said their SCEs did. Most respondents reported the information given to them about CC services to be either “very” or “somewhat” accurate, and if it were in the best interest of their family members, 85% said they would participate. The main reasons respondents chose not to participate in CC services were the risk of the program not having ongoing funding, not feeling like they needed to be compensated for caring for their family members, and some individuals with disabilities being happy with their current services at the time.

Support Coordinator Survey on Caregiver Compensation Services

The Support Coordinator Survey on Caregiver Compensation was sent to all DSPD SCEs and their corresponding companies. This amounted to 215 distinct email addresses. Of those, DSPD received 75 responses for a response rate of 34.9%. Of the SCEs, 96% reported having individuals on their caseloads who were receiving CC and 4% reported not having any (see Figure 22).

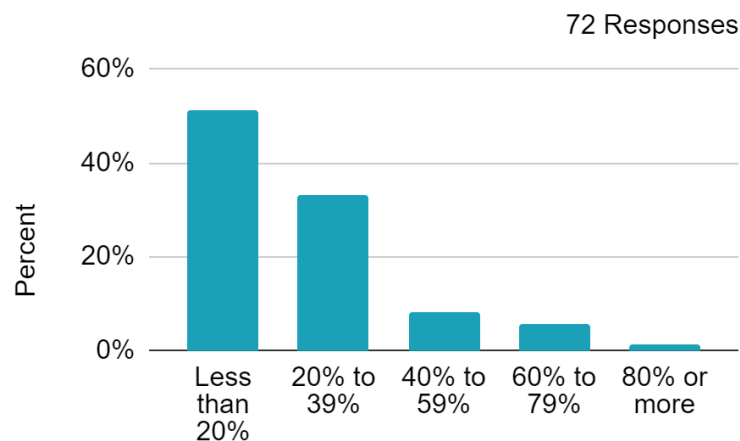
Figure 22. Support Coordinators represented who have recipients of CC on their caseloads



Caseloads and Demographics

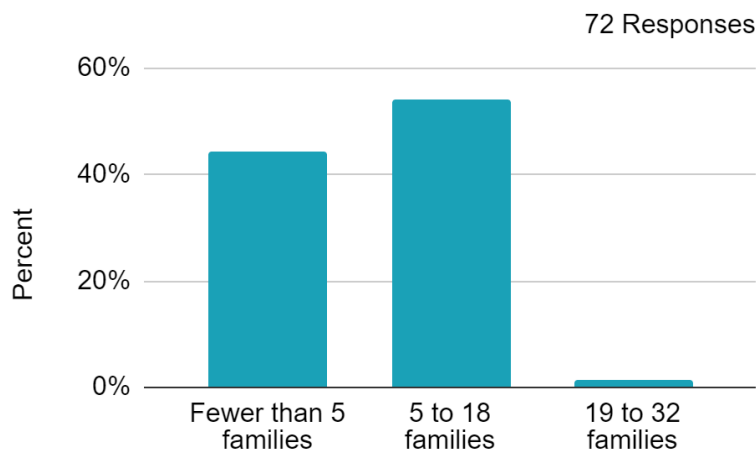
This section focuses on the SCEs' caseloads in relation to caregivers who received CC services as well as demographic characteristics of caregivers who received CC according to SCEs. Regarding the SCEs' who had one or more recipients of CC on their caseloads, just over half (51%) reported having less than 20% of their entire caseloads receiving CC support, with another 33% making up 20-39% of SCEs' caseloads. Figure 23 breaks down the responses.

Figure 23. Proportion of SCE caseloads who are CC recipients



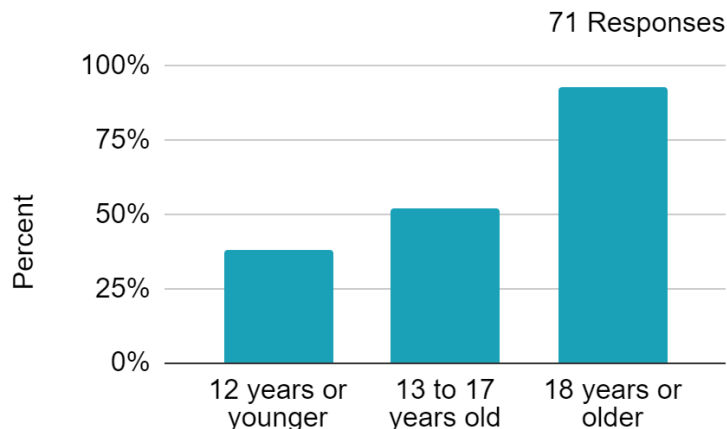
In addition, most SCEs represented (54%) said that they had approximately 5 to 18 families on their caseloads, followed by another 44% being fewer than 5 families. Only 1% of respondents had over 19 families on their caseloads receiving CC (see Figure 24 below).

Figure 24. Amount of families receiving CC on SCEs caseloads



The age ranges and disability types among individuals served, according to the SCEs represented, varied. Ninety-three percent of respondents reported having at least one individual who received CC on their caseload being over the age of 18, with another 52% reportedly having individuals 13 to 17 years old, and 38% reporting individuals 12 or younger (see Figure 25 below).

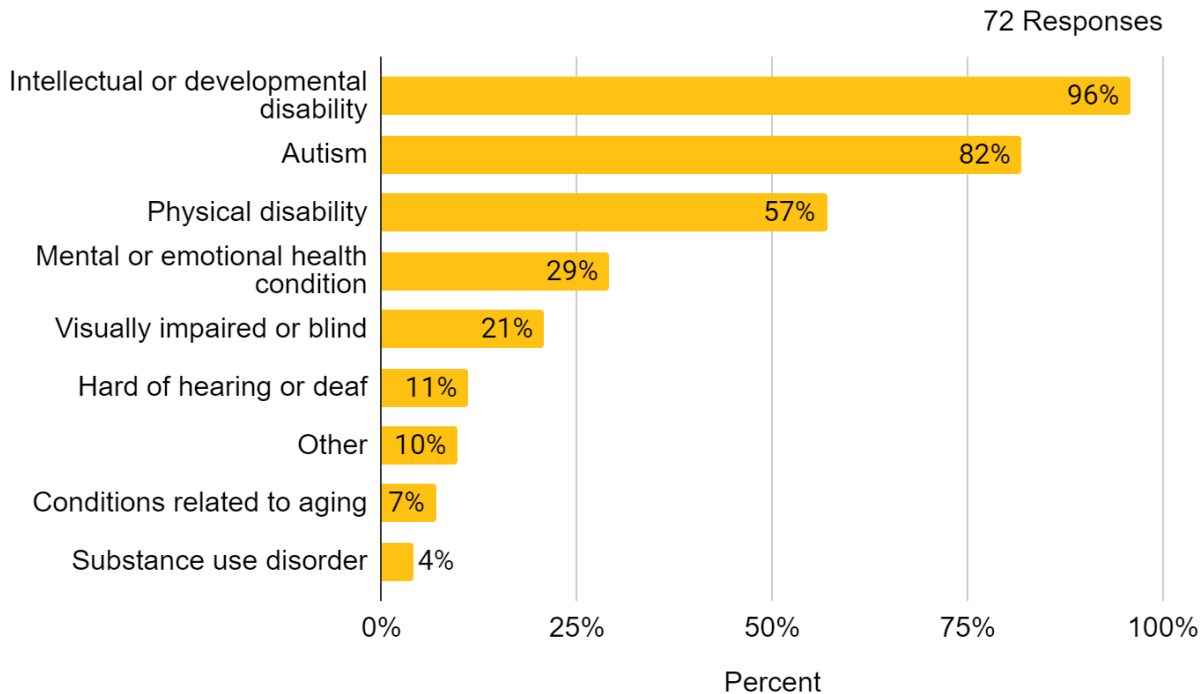
Figure 25. Proportion of age ranges on SCEs' caseloads



* Respondents were allowed multiple responses resulting in a summation greater than 100%.

Support coordinators were also asked about the disability types among individuals who received CC support. Similar to the results of the Caregiver Quality of Life survey, the most common disability types, according to SCEs, were intellectual or developmental disabilities (96%), autism (82%), and physical disabilities (57%). Figure 26 breaks down the responses.

Figure 26. Disability types among individuals receiving CC



* Respondents were allowed multiple responses resulting in a summation greater than 100%.

Caregiver Compensation Participants' Quality of Life

This section focuses on various conditions regarding the quality of life of individuals and caregivers who received CC, as reported by the SCEs represented in the survey. Topics in this section include the impact CC had on individuals' and caregivers' overall quality of life and stress levels, and the individuals' ability to get out into the community.

The majority of SCEs who responded to the survey agreed that CC support has "significantly" or "somewhat" increased the overall quality of life for caregivers (82%) and their family members with disabilities (65%) (see Figure 27 below). Furthermore, a majority of respondents also agreed that individuals with disabilities and caregivers also had their stress levels "significantly" or "somewhat" reduced as a result of receiving CC services. Figure 28 breaks down the responses.

Figure 27. Support coordinator quality of life of individuals and caregivers who received CC

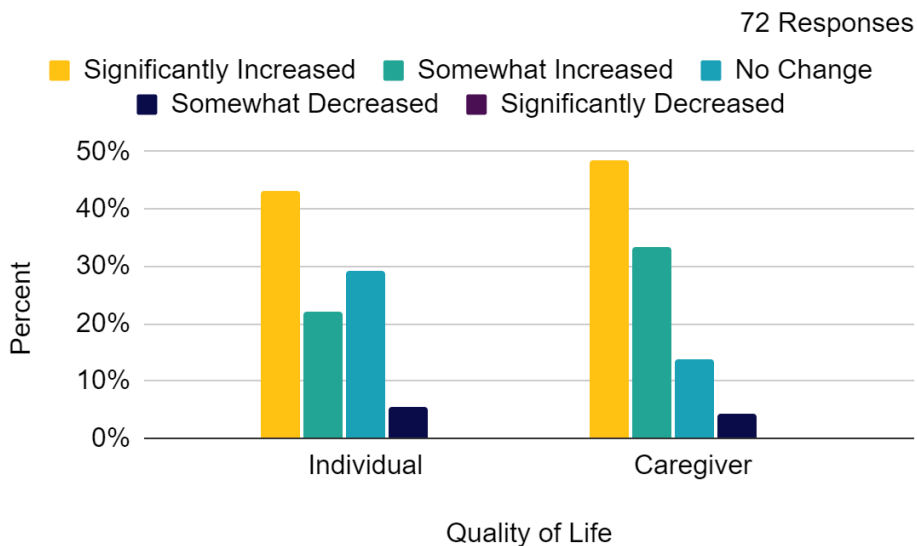
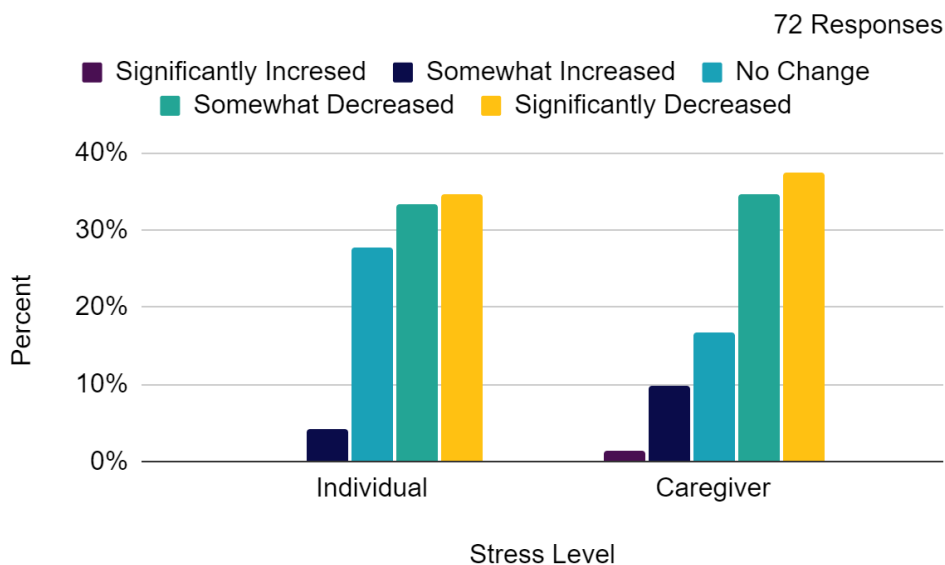
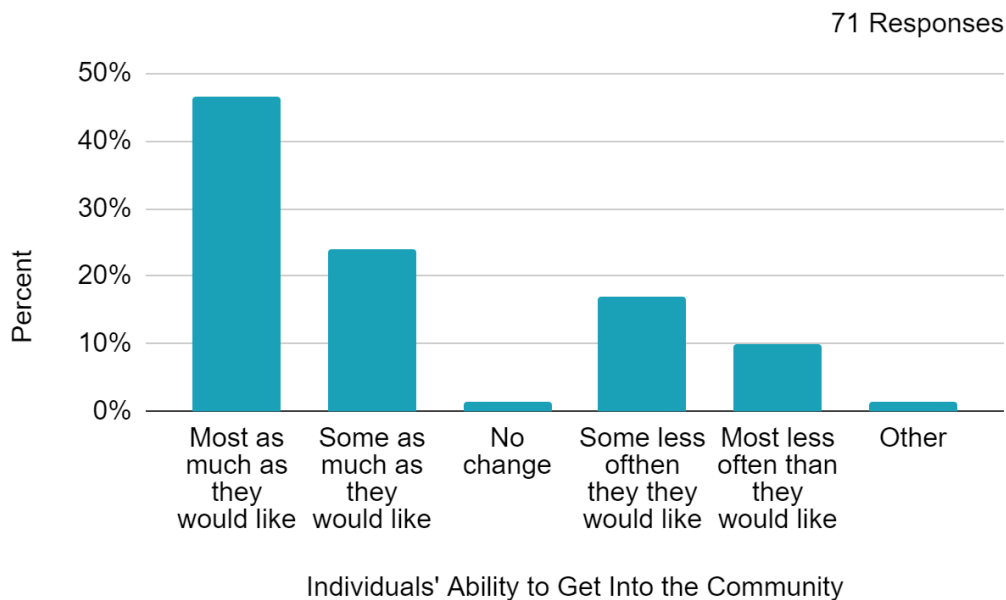


Figure 28. Support coordinator stress level rating of individuals and caregivers who received CC



Support coordinators were also asked whether they thought CC impacted the individuals with disabilities' ability to get into the community. Forty-six percent of respondents believed that most individuals were able to get into the community as much as they would like and 24% believed that some individuals were able to (see Figure 29 below).

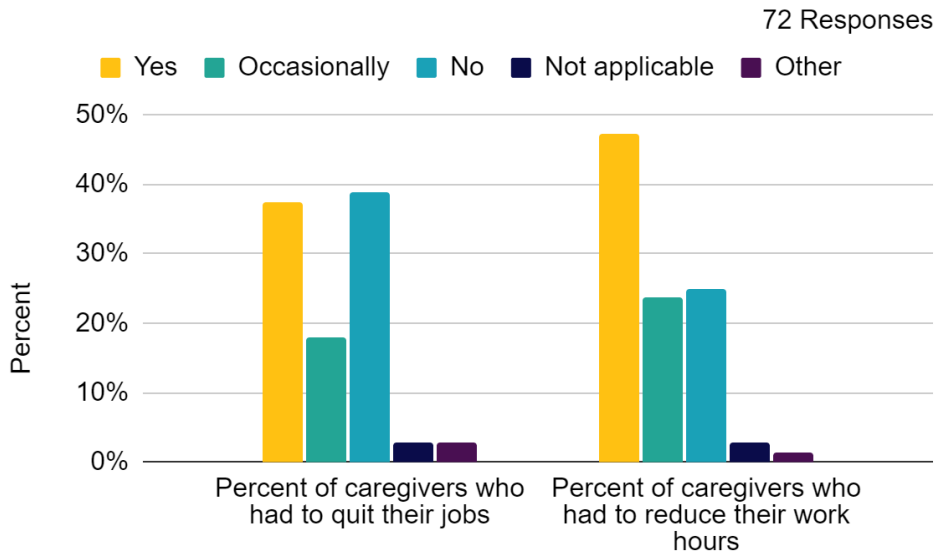
Figure 29. Support coordinator perception of individuals with disabilities' ability to get out into the community as a result of having received CC services



Caregiver Employment

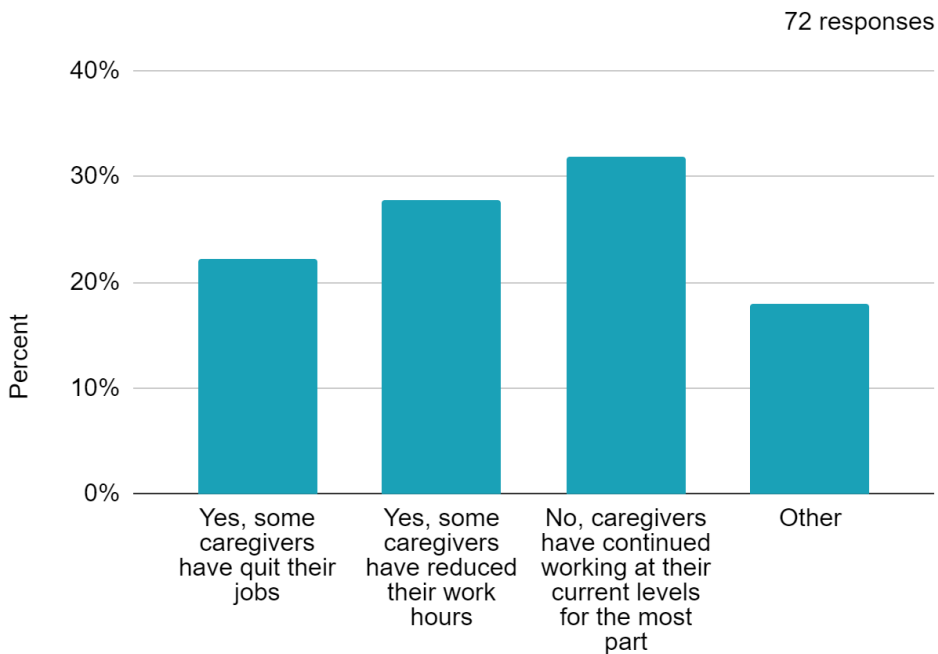
This section focuses on the impact CC had on caregivers' employment according to SCEs' observations. From the perspective of the SCEs, CC did not have as large of an impact on caregiver employment as seen from the Caregiver Quality of Life survey results. Thirty-nine percent of respondents reported that they had not had individuals on their caseloads have to quit their jobs in order to take care of their family member with disabilities, and 39% said they did, followed by 18% reporting "occasionally." When it comes to having to reduce work hours to care for someone, 47% of SCEs represented said that they have had caregivers have to reduce hours, and 25% said that they have not had any (see Figure 30 below).

Figure 30. Caregiving impact on employment according to SCEs



On a similar note, SCEs were asked whether they noticed any changes in caregivers' employment status since beginning participation in CC. Their responses were similar to those above. Thirty-two percent said caregivers had continued working at their current levels, 28% said some had to reduce work hours, and 22% said some had to quit their jobs. Responses are illustrated in Figure 31 below.

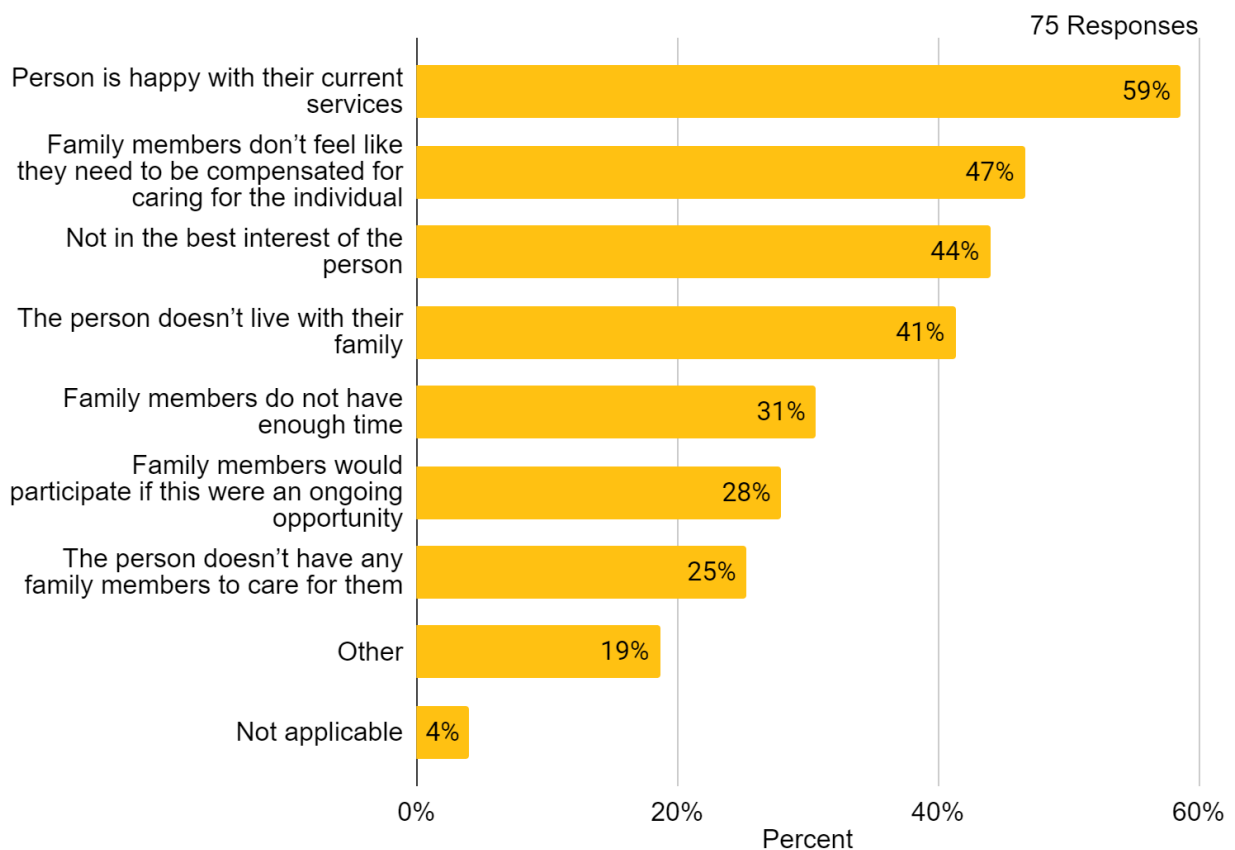
Figure 31. Caregiving impact on employment after having received CC services



Additional Information

In addition to understanding the impact CC had on individuals with disabilities and their caregivers, DSPD wanted to know why individuals chose not to participate. According to respondents, the most common reasons why were that individuals were already happy with their current services at the time (59%), families did not feel like they needed to be compensated for caring for the individual (47%), and it was not in the best interest of the person (44%). Figure 32 breaks down the responses.

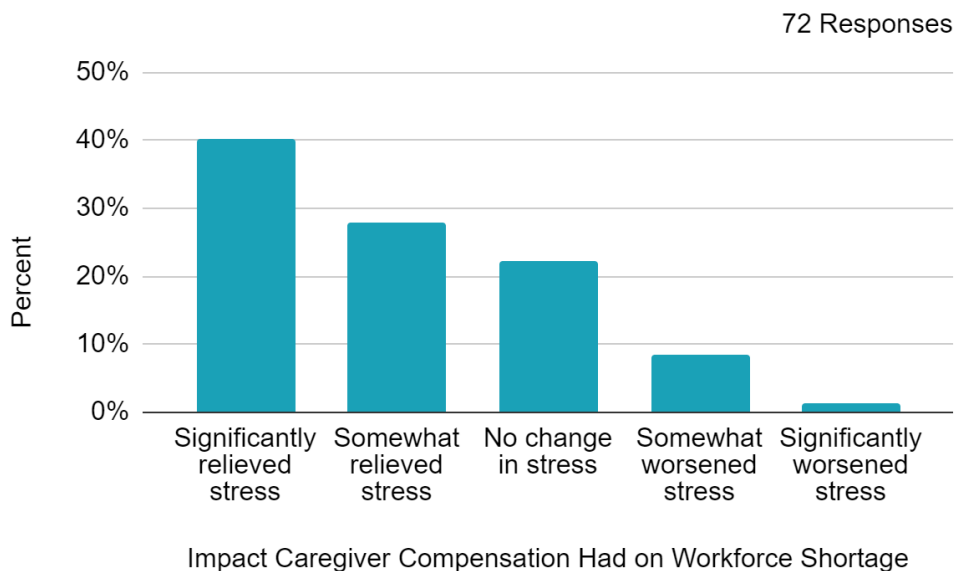
Figure 32. Reasons why people chose not to participate in CC services according to SCEs



* Respondents were allowed multiple responses resulting in a summation greater than 100%.

DSPD also wanted to better understand what impact the program had on the workforce shortage. Most respondents (68%) reported that CC services had either “significantly” or “somewhat” helped relieve some of the stress of the workforce shortage (see Figure 33 below).

Figure 33. Caregiver compensation impact on workforce shortage



Lastly, SCEs were asked what positive outcomes they noticed in the disability system through the addition of CC. Division of Services for People with Disabilities used qualitative coding methods to highlight common themes raised in respondents' open-ended responses. As shown in the word bubble below (Figure 34), respondents most commonly mentioned outcomes generally referring to improved access to care, financial support, and reduced stress as positive outcomes of CC services. The more positive outcomes were mentioned, the larger the text.

Figure 34. Most common positive outcomes of CC services observed by SCEs

